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Australian Mental Health Consumer Network Inc: Platform for Change

**Submission to the Senate Select Committee on Mental Health
May 2005**

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Introduction

The following recommendations represent concerns and definitive action steps to increase consumer involvement and expand peer support services; reduce discrimination and stigma; increase opportunities for a consumer-driven system; protect and enhance consumer's rights; and ensure that disparities in mental health care are eliminated. This submission is articulated solely from a consumer perspective. These recommendations are the result of dialogue with the Australian Mental Health Consumer Network (AMHCN) members, in particular Merinda Epstein, Desley Casey, Pauline Miles, Gwen Scotman, David Webb, Cath Roper, Evan Bichara and Helen Connor, to identify major areas of consensus and action.

Over the past 30 years, the consumer movement has made remarkable strides resulting in reduced stigma and discrimination, increased peer support services, and enhanced rights for persons with mental illnesses. Deeply embedded in the tenets of the consumer movement is the absolute right for consumers to self-direct or determine their own care and treatment.

The field is in the midst of a sea of change with the consumer movement serving as a beacon to consumers seeking hope, recovery, and empowerment. We are caregivers, grassroots advocates, providers, policymakers, researchers, leaders, and trailblazers. Moreover, we are the final arbiters of our own care and in many instances, our own caregiver or that of a family member. We are all part of the Australian community.

The following recommendations are thoughtfully crafted and based on comprehensive discussion and dialogue. Current budget challenges are acknowledged. However, there is a call to action requiring financial consideration from national leaders and others. The AMHCN Platform for Change believes that in order to make progress, public financial resources must follow these recommendations. Thus, the implementation of these recommendations should be a top priority for the Australian Government as the government determines how to use its resources. The Australian Government should ensure that block grant funds or other discretionary program funding will be deployed on a priority basis to enable jurisdictions to initiate programs that reflect these recommendations. In addition, to make the National Mental Health Plan 2003-2008¹ "...new models of service delivery and improved interventions that are more responsive to diversity of need should be developed and evaluated for their effectiveness and cost-effectiveness", a reality, there is an urgent need for increased funding for non-government organisations providing services to mental health consumers. That increase should include an allocation, in an amount equal to at least 20% of the mental health grant, dedicated to implementing the recommendations set forth in this paper.

In keeping with the responsibility of the Australian Government to provide innovation and leadership, we urge that mental health programs in every State and Territory be required to fund consumer-run services. In addition, any Australian Government funded initiatives must be coupled with a comprehensive evaluation and research component.

We will now address several of the Terms of Reference in turn and make recommendations. These recommendations are to be taken seriously, coming as they do from the national representative mental health consumer organisation, the AMHCN.

¹ Australian Health Ministers. National Mental Health Plan 2003-2008. Canberra: Australian Government, 2003, Page 12.

BUT firstly and most importantly....ensure mental health care is consumer driven.

Involve consumers fully in orienting the mental health system toward recovery.

Peer-run services - recovery-oriented services that are administered and operated by self-disclosing consumers of mental health services.

In order to involve consumer fully in orienting the mental health system toward recovery, the AMHCN recommends the following:

- i. Make peer-run services a mandate. As a condition of continued eligibility for Commonwealth Mental Health funding, every jurisdiction must develop, as part of the state mental health plan, a demonstration project to explore innovative strategies and mechanisms to ensure all consumers of mental health services have the choice to access services and supports offered by consumer operated programs. These plans may include, but are not dependent on, accessing Australian Government funds. However, the AMHCN recognizes there will be different funding mechanisms developed on a state by state basis, since each state plan is dependent on jurisdiction-specific factors.

Access to consumer operated programs offering a comprehensive range of services and supports must be developed and supported as part of the array of options for mental health consumers, regardless of funding source. Ideally, and as a means of establishing a benchmark, the AMHCN recommends a minimum of a 25% increase in consumer operated program capacity for each state by 2008. This recommendation is not intended to imply or require that consumers receive a particular type of service from a particular type of provider (i.e. - consumer operated programs versus traditional mental health service providers).

Additionally, work force development efforts should focus on achieving at least a 25% increase, by 2008, in the number of self-identified persons living with mental illness working as direct providers of mental health services, supports, and treatments. The Australian Government must provide jurisdictions with technical assistance to facilitate that process.

Services delivered by peers should include, but not be limited to, mentoring, housing, supported education and supported employment services (e.g. - model United States peer specialists programs). Peers providing services should be adequately paid.

- ii. Regarding research, the Australian Government must fund dissemination of currently available research findings on evidence-based and other effective practices (practice based evidence) of consumer-operated services.
- iii. Allocate funding for research on peer-run programs to further the emerging evidence base; these research findings must be funded for publication and dissemination.
- iv. Financial resources should be provided for the operation of state mental health planning councils in order to support the voice of consumers in planning, providing, and evaluating mental health services, from concept to design to implementation.
- v. Require an independent consumer entity (i.e. – State Consumer Liaison) act as liaison with each state mental health authority for coordination of state-wide activities and efforts. This entity should have input into funding decisions, and should not be limited to state offices of consumer and family affairs. Such entities must be staffed by self-identified consumers/family members. Support both internal

- (within state government) and external (within peer-run organizations) offices and mutual collaboration.
- vi. Support a national initiative to identify, state by state, examples of consumer voices being represented and the menu of activities in each jurisdiction.
 - vii. Expansion of piloting of models of consumer self-determination strategies; fund a person, not a system.
 - viii. Fund at least one consumer/consumer-supporter technical assistance centre for each jurisdiction.
 - ix. Re-evaluate and re-construct authorisation protocols of reimbursement streams to encourage and support peer-run services.

Finally, a disclaimer ... or two ...

- the limited time – and resources – available to prepare this submission means that detailed citation of relevant references in support of this submission has not been possible, though could be prepared and made available to the Select Committee if time and resources permitted it some time in the future;
- another weakness in this submission – again due to limited time and resources – is that it would undoubtedly have been strengthened by more extensive consultation and review by more consumers than has been possible;
- it needs to be pointed out that these weaknesses in this submission arise directly from the current inadequate resourcing of genuine mental health consumer organisations such as the AMHCN as highlighted in this submission; and
- all the work done in preparing the AMHCN submission has been done by consumers in an entirely voluntary capacity, in stark contrast with some other organisations with the staff and other resources to do the more thorough submission preparation that we would have liked to have done ourselves ... and would be keen to do if resources became available.

RECOMMENDATIONS

The information supporting these recommendations can be found in more detail under the relevant Terms of Reference in the text of this submission.

Recommendations TOR b

1. That funding should flow to those interventions that clinicians and consumers jointly recognize as the most important and the least destructive.
2. That consumer knowledge and understanding about the lived experience of their own illness is respected within all services from the acute end right through to respite delivery.
3. That the variety and scope of available services no longer be limited by institutional traditions or medical model understandings of what constitutes a health intervention.
4. That all practices that promote institutionalisation and/or an escalation of symptoms be terminated or minimized.
5. That clinicians be made aware of the aspects of their own practice and the development of service structures which demote autonomy and self reliance or promote crisis.
6. That all services be encouraged to seek '*real*', generously funded and untokenistic partnerships between consumers who use the service and clinicians who provide them so that innovations can be explored, joint projects can be developed, ongoing evaluation and priority setting can happen cooperatively and consumer participation can be grounded in the everyday experiences of grass roots consumers and clinical staff.
7. That the call for '*more acute beds*' be understood in relation to the lack of alternative modes of service delivery.
8. That government takes seriously the consumer warning that some acute experiences leave people psychologically scarred, sicker and more dependent in the long term.
9. That emergency departments of mainstream hospitals be a focus for ongoing consumer/clinician/management exploration and creative problem solving around issues of staff training, discrimination, dignity and efficiency.
10. That alternatives to medical model provision of crisis interventions (including consumer - operated opportunities) be explored and that funding be made available to trial some of these initiatives.

Recommendations TOR c:

More information about these TOR recommendations can be found in the text.

- 11 That implementation of the National Standards for Mental Health Services is made part of Australian Government legislation.
- 12 That services are required to show evidence in how they have responded to Mental Health Consumers Perceptions and Experiences of Services.
- 13 That consumer surveyors be on Accreditation Teams be mandatory.
- 14 That funding of Mental Health is commensurate with that of other developed countries.
- 15 That there needs to be less autonomy on how mental health '*care*' is delivered from the state down to the local level. Mental health departments and services **must** be accountable to its shareholders, the taxpayers.

- 16 Health Service staff should be gazetted Public Servants and Health Services be accountable to the community not just to their line manager.
- 17 That governments adequately fund consumer networks and advocacy agencies.

Recommendations TOR f:

More information about these TOR recommendations can be found in the text.

- 18 Disparities in Mental Health Services are eliminated
- 19 Improve access to quality care that is culturally competent.
- 20 Even more compelling, few people have any conceptualization of what a “qualified mental health interpreter” is. To address these concerns, the AMHCN has several specific action items:
 - Recruit and train clinicians from minority and linguistic groups and cultures, in particular, from Aboriginal and Torres Strait Islander populations
 - When interpreters must be used, interpreters must be qualified mental health interpreters
 - Clinicians working with interpreters must be trained to work with interpreters
 - Ensure that providers who work cross-culturally have sufficient training to be competent, not merely aware.
- 21 Support the development of peer provided supports and services that are reflective of particular cultural and linguistic considerations, and assertively integrate these supports and services into the mental health system at all levels.
- 22 Fund an initiative to collect information, by jurisdiction, regarding current programs and models of providing peer supports and services which are specifically responsive to particular cultural and linguistic community’s needs. These include, but are not limited to, the following (alphabetically):
 - Age;
 - Disability;
 - Ethnicity;
 - Gender identity and expression;
 - Geography;
 - Language/linguistic preferences;
 - Race;
 - Religion; and
 - Sexuality.

Recommendations TOR i

More information about these TOR recommendations can be found in the text.

- 23 That a scoping study be immediately be funded to progress the idea of developing a Centre of Excellence for Consumer Perspective Studies in a tertiary institution, service, or attached to a pre existing consumer organization or interest group.

- 24 That two (or more)² consumer researchers be funded to travel overseas and collect state of the art information about:
- consumer run services;
 - consumer designed step up and step down services,
 - centres of excellence for other disempowered groups that could be used as a model for mental health consumers in Australia; and
 - information about the roles and working condition for consumer educators, consumer consultants, peer workers, consumer advocates and other paid consumer roles and positions in the mental health field.
- 25 That two (or more) consumer researchers are funded to travel around Australia speaking to consumer workers (consultants, advocates, peer support workers etc.), consumer organizations, providers and services about all initiatives that have been tested in relation to developing the consumer workforce in mental health in Australia and:
- a report be produced that identifies not only differences in working conditions and support but also in wages, hours worked each week, potential problems advantages, locum services, training etc;
 - they collect examples of job descriptions and other pertinent documentation; and
 - on completion such a report (including recommendations) is made widely available to all consumers, consumer organizations and services that are developing consumer participation policies.
- 26 That the Australian Government reverts to a model of policy promotion, which tags Australian Government funds to encourage States to spend 'real' money on consumer participation initiatives as a matter of urgency.

Recommendations TOR j

Governments must act decisively to improve mental health services in Australian prisons. An ongoing concern should be reducing the population of prisoners who have mental illnesses. Secondly, governments must develop standards, provide oversight mechanisms, and mobilise resources to ensure effective, quality mental health care in prisons. More information about these TOR recommendations can be found in the text.

- 27 Reduce the incarceration of persons with mental illness.
- 28 Set high standards for prison mental health services.
- 29 Improve conditions of confinement.
- 30 Establish effective performance reviews using independent experts.
- 31 Establish comprehensive internal quality review mechanisms for each prison system and prison.
- 32 Solicit and heed prisoners' concerns.
- 33 Provide mental health training for correctional staff.
- 34 Ensure mental health input and impact in disciplinary proceedings.
- 35 Exclude prisoners with mental illness from segregated confinement.

² Because of differences in assumed and real power between consumers and other players in the mental health industry the AMHCN policy is that consumers should always work together in at least pairs.

- 36 Support funding for appropriate prison mental health services.
- 37 Ensure that the National Principles for Forensic Mental Health Care are endorsed and implemented.

Recommendations TOR k

- 38 Protect and enhance the rights of people with mental illness
 - 39 Protect against rights violations through effective monitoring, enforcement, and litigation.
 - 40 Continue to ensure all States and Territories have legislation and service provision that protects the rights of consumers and the community³.
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- 41 Enhance rights through effective education, advocacy, and policy change.
Specifically:
 - i. Initiate a comprehensive national mental health consumer rights education and awareness project.
 - ii. Review the adequacy of existing complaints systems⁴.
 - iii. Initiate a state protection and advocacy entity structure to be consumer and family controlled (75% of Board of Directors primary consumers).
 - iv. Pass federal legislation requiring recognition of advance directives and health care attorneys.
 - v. Address discrimination in insurance (travel and income protection).
 - vi. Pass federal legislation banning ECT on persons under the age of 18 by 2008.
 - 42 Pass federal regulations banning seclusion and restraint by 2008.
Specifically:
 - i. Promote adoption by jurisdictions of the United States NASMHPD/NTAC Restraint & Seclusion Curriculum, or similar curricula.
 - ii. Make available to the public, while respecting confidentiality, all restraint and seclusion events until restraint and seclusion are outlawed.
 - iii. Develop a publicly accessible, free database of relevant case law and court decisions regarding rights of persons with mental illness and children with serious emotional disturbances.
 - iv. Continue work towards the elimination of force, coercion, and violence in the mental health system, and in those social programs providing housing, employment, and education for persons with mental health problems and mental illness and children with serious emotional disturbances.

³ Australian Health Ministers. National Mental Health Plan 2003-2008. Canberra: Australian Government 2003. page 24. Outcome 24.

⁴ Australian Health Ministers. National Mental Health Plan 2003-2008. Canberra: Australian Government 2003. page 24. Key direction 24.3.

Recommendations TOR I

- 43 Advance and implement a national campaign to reduce discrimination and stigma associated with seeking care.
- 44 That the key message of such a campaign promotes the concept of recovery and wellness. This includes a focus on:
 - i. Community integration and accessing services
 - ii. Mental health recovery education
 - iii. Myths including those about violence
 - iv. You are not alone
 - v. Normalisation and individuality
 - vi. Including a range of mental health problems such as eating disorders, addictions, abuse, and trauma
- 45 That one-on-one contact approaches must be the primary strategy for this campaign. These should be: consumer developed and implemented; strength based; culturally developed and implemented; focus on putting a face on mental health; and emphasizing positive visibility. Specific recommendations include:
 - i. Grants to state consumer groups at the minimum of \$75,000 to support and evaluate anti-discrimination/anti-stigma efforts
 - ii. Media outreach focus on getting our story out
 - iii. Creative strategies including art shows
 - iv. A standardized PowerPoint presentation for speaker bureaus
 - v. Letter writing templates
 - vi. Use of mainstream and non-traditional media
 - vii. Legislative education
 - viii. Developing an anti-stigma toolkit
- 46 That this campaign should build on and expand existing anti-discrimination/anti-stigma activities including, but not limited to:
 - i. Mental Illness Education Australia which includes public speaking to high school and college students, publications targeted toward youth, teacher lesson planning, and media partnerships such as MTV;
 - ii. Syndicated radio program on public health issues and also available on the Internet
 - iii. Consumer/self-help technical assistance centres activities including newsletters, websites, media outreach, and speaking bureaus as well as supporting community based peer operated services
 - iv. Activities of many other groups including: AMHCN, MHCA, beyondblue, SANE and state/local organisations
 - v. Annual activities including Mental Health Week, World Mental Health Day, Schizophrenia Awareness Week, and other events
 - vi. Creative arts & recovery programs, e.g. REMIX project in Brisbane

Recommendations TOR n

The AMHCN strongly believes that current mental health research stigmatises and discriminates from the consumer perspective. The current mental health research agenda contributes to and perpetuates the pervasive stigma, discrimination and human rights abuses against mental health consumers. Further exploration of this theme and additional recommendations are to be found in the text under TOR n.

- 47 That a national network of genuine consumer organisations be established and funded
- 48 That a holistic, genuinely consumer-oriented research agenda be established and funded with:
 - a) A whole of person approach to mental health research encompassing:
 1. The phenomenology (lived experience) of mental health consumers
 2. Nutrition, exercise, sleep, play and relaxation for mental health
 3. Complementary (alternative) therapies
 4. Indigenous ways of understanding mental health
 5. Spirituality
 - b) A whole-of-community approach to mental health research
 1. Cultural, social and historical contexts of 'psychosocial distress'
 2. Cultural, social and historical healing of 'psychosocial distress'
 3. Peer support
 4. Consumer-run services
 5. Prevention
- 49 That a 'Centre of Excellence of Consumer Studies' be established and funded
- 50 That research be conducted into consumer-led services
- 51 That human rights research be established and funded
- 52 That adequate and sustainable funding approximately equivalent to that which has been made available to beyondblue be made available as a matter of urgency to:
 - establish a strong 'network of networks' across Australia of genuine, mental health consumer organisations to promote greater consumer participation in all aspects of the mental health system in Australia; and
 - establish a Centre of Excellence fo Consumer Studies to further develop and pursue the research agenda as outlined above.

Recommendations TOR p:

- 53 That consumers be funded to develop and drive the recovery training for mental health staff, break down the processes in order to assist the mental health service system and providers to understand the respect the language of consumers and the AMHCN.
- 54 That consumer run recovery centres, activities, consumer networks/groups and consumer run service delivery programmes attract serious and adequate funding and support.

- 55 That enhancement of consumer employment opportunities within the mental health services including consumers as members of existing mental health teams (However these employees have consumer line managers to existing consumer run teams in the area and/or independent line management outside the mental health service entirely in order to retain independence.)
- 56 That consumer advocates remain independent of the mental health service's system however are funded via the mental health service at adequate levels in order to provide genuine consumer advocacy to consumers they see.
- 57 That further development of existing consumer run teams within mental health services with innovative support structures which ensure and protect the consumers within these teams from taking on a MHS service provider perspective and actions.
- 58 That the National Standards for Mental Health Services are legislated as commonwealth legislation in order for their full implementation by Australian mental health services.
- 59 That consumer driven education of mental health services on responding to consumers when the mental health services and systems are in CRISIS.
- 60 That a National Taskforce to develop Practice Standards for Consumer Employment, including addressing all Human Resource Issues & Practice be established.
- 61 That a National Taskforce to establish partnership linkages with all Australian States that has the power to fund and address the development and establishment of innovative consumer run services, including the non-government sector, develop prevention and promotion activities which are consumer run and/or consumer focused be established.
- 62 That the mental health services to come to the table and be prepared to do things 'our' way for a change rather than simply doing everything 'their' way. To really listen and hear consumers and support their ideas, suggestions and concerns. If mental health services were genuine about consumer participation and partnership they would be able to innovatively and seriously address and institute consumer sensitive services and the HR issues of mental health staff in the process.

TOR 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.

Early intervention and prevention is at best ad hoc or non-existent in many mental health services in Australia. The rhetoric is in black and white in many glossy documents written by mental health services; stating that it is vital to a person's ability to stay in the community; that community care is a vital component to enabling the consumer to stay in the community in spite of having an ongoing mental illness. It is not only cost-effective in monetary terms but also the human cost. Supporting people to live with an illness in their own environment is vital to the recovery process not only for the individual but the wider community as a whole. There are many examples of consumers leading very productive lives in the community where their support needs are met, usually by non-government organisations. Non-government organisations are in the best position to deliver services in the community because they are less restricted in policy directives and institutional bureaucracy. They are able to respond to different situations more readily because of the flexibility and nature of their management styles. Rather than having to write numerous letters to the powers to be, the non-government organisations are able to make more autonomous decisions when the need arises, therefore consumers are able to have their needs met before there is an escalation in symptoms and subsequently hospitalisation.

The particular aspects of this TOR will now be addressed.

Prevention:

1. The AMHCN hears frequently from members with histories of child abuse and neglect. Many consumers come from childhood backgrounds that were psychologically dangerous and damaging. This calls not only on interventions to protect children but also on supporting psychotherapeutic interventions early – before harmful adult mental health patterns are fully established. At the present time there is almost no psychotherapy available in public mental health systems in this country. Since the First National Mental Health Plan 1993-1998 pushed priorities away from 'talking therapies' there has been no investment in developing the capacity of mental health services to respond to people with abuse and neglect histories.
2. Many of our members believe very strongly that their experiences of mental distress are closely linked to life experiences. Poverty, physical illness, immigration detention, racism, family violence, breakdown of adult relationships, losing substantial amounts of money, gambling etc. etc. lead to mental illness. Over the past decade it has been fashionable to attempt to understand mental illness as some sort of a biochemical abnormality acting in isolation from the rest of people's lives. This has meant that the focus has come off searching for ways of preventing the social and cultural inequities and traumas that many consumers believe precedes the development of signs of mental illness.
3. We need far more services in the community that enable consumers to have an occupation. I use the word occupation in this submission to mean engagement in the community in an activity or group of the consumer's choice. For example:
 - The Freight Gallery and Studio in Fremantle WA, is just one example of an enterprise where people with a persistent psychiatric illness are provided with the environment and resources to enable them to participate as any Australian Citizen in the social and cultural life in the community. From this creative space the benefits have been enormous both from a community and individual perspective. For more information about this enterprise you can contact the Gallery on Email gallery@dadaa.asn.au

4. The AMHCN believes that the community and government need to look beyond the institutional constructed view on mental illness. Governments need to seek more communication with consumer and carer bodies who are the experts in the response needed by services that are or are not readily available.

Early Intervention:

1. The AMHCN is anxious about the attempts that have been made to intervene early in people's lives. We are not convinced that giving people medical diagnoses (labels) when they are young does anything to help their self esteem and generate the strengths that are necessary to deal with the sort of real life issues that are mentioned above. We recognize that psychiatric diagnoses can be a mixed blessing. Some consumers do report that it was a relief to get a diagnosis as it offered them some social standing in our community which, despite the discrimination against people with mental illness, still privileges illness over mere "uselessness", a social failure, a drop-out or just a 'loser' which are the other sorts of labels which consumers report receiving (and, unfortunately, giving themselves) before obtaining a diagnosis.

Certain diagnoses seem to have greater and lesser status in the community and in mental health systems. This status is often contradictory. It seems that "proper mental illness" (psychosis) brings some status within mental health systems but is perhaps most vilified in the community. Alternatively, 'nasty behaviour traits' (e.g., Borderline Personality Disorder) does not carry the same burden as Schizophrenia in society but is a dreaded diagnosis within mental health services and often leads to clinical neglect and gross and unfair judgments by many clinicians. However, consumers wish to point out that they know that diagnosis goes hand in hand with a medical model understanding of mental distress. Consumers know that making a diagnosis is an essential first step that is demanded in Western medicine. Not giving people their diagnosis in an attempt to protect them from the social reality of their diagnosis doesn't work. People prefer to be told the truth. The challenge, which as yet has not been adequately met, is how to support young people without settling for a labelling medical model understanding of their distress. The best way to do this is to provide resources for young people to determine how it should be done.

2. The other aspect of early intervention that is important to consumers is early intervention in relation to episodes of illness. Consumers are quick to point out that nobody knows their illnesses as well as they do. After all they are the ones that have to live with it. As consumers we are sick of trying to get treatment in the public mental health system only to be told that we need to go away and get worse before anyone will take any notice of us. This also escalates symptoms. As consumers most of us have learnt how to '*work the system*' when we know we are getting distressed. 'Newbys' are disadvantaged and will learn eventually from those of us who have been around the system longer. We know that to get noticed in the public system you often have to be seen to be a risk to yourself or to others and some consumers are convinced that things have got so bad that , '*being suicidal is no longer sufficient and to get noticed it is often now necessary to be talking about homicide*'⁵. We know off by heart the questions we will be asked about suicide if we declare we have intentions. 'Do you have a definite plan?' Have you got the means? Etc. etc. If we need to be taken seriously we will try and skew our responses around in an effort to get help. This has absolutely nothing to do with 'manipulation' or 'attention seeking' or any other thing the system might want to throw at us. It has to do with intelligence and, thankfully, the fact that we are still empowered enough to be proactive about getting the help that we need. Consumers have also learnt the ironic truth that once you know you are getting

⁵ "True comment by a consumer at a public meeting in Melbourne in 2003

unwell this insight' will be sufficient to convince service gatekeepers that you are sufficiently insightful to be arbitrarily dismissed.

Acute Care:

A quote from a nurse working in an acute setting:

"I think that nurses where they have to deal with situations where there is violence, where the violence has occurred because of them (and by that I mean – because of the way they speak to people) their whole attitude can frequently spark aggression ... the nurses don't know that this is happening for people. There are signs that people are getting out of control... And so the nurses feel they have to take control and it's sort of a mechanical thing you're instructed to hold the limb and that limb this way and down on the floor... the debriefing doesn't happen. [If it does] it's just about "that went well" or "no, that didn't go well". If it went well they usually just mean no one was injured [physically], it was fairly easy, the patient was restrained and they became compliant, we stuck the needle in and locked the door basically... That sort of outcome nurses will say is good, and they'll say its bad if someone gets injured... there's never any talk about how they felt... Most nurses feel pretty awful about it..."⁶

It is the opinion of the AMHCN that consumers are divided about the efficacy of acute care. Many consumers argue that acute psychiatric hospital "care" (particularly if it is involuntary) is often cruel, destructive and permanently psychologically damaging. There are others who find some time in an acute setting is useful to settle scary symptoms of their illness. Both of these truths need to be considered.

The fact that many consumers find acute psychiatric hospital "care" to be psychologically damaging is frightening. It is also a factor that needs to be seriously considered when certain lobby groups within mental health are calling for more acute beds, more acute beds, more acute beds as the answer to the present malaise in the mental health system. Several things need to be considered in relation to this:

- a) Is it possible to change acute facilities and culture to make them more like places of healing rather than places of fear and loathing?
- b) Is it even possible to make these places psychologically safe given the reality that we have Mental Health Acts in all States and Territories which allow for people to be locked up against their will and forcibly treated?
- c) What is it about the history and culture of acute settings that lead so many of them to become dangerous places for people?
- d) What are the gender issues for patients in acute psychiatric hospital units? What about people with histories of child abuse and neglect?
- e) What are the ironically contradictory realities of the roles played by power and compliance in acute settings?

The only way to really understand what an acute unit does to people is to ask the people who use the unit. This seems really obvious but time after time after time it does not happen. In some States consumers are being employed (and paid) to be enablers of consumer feedback to the hospital. This is one of the best things to have come out of the policy directions of the First National Mental Health Plan 1993-1998. However, in most services these jobs have become mere tokens of the intent of inclusion of consumers in hospital decision-making. Many consumers who work in acute services are treated badly. They are employed part time

⁶ VMIAC, Understanding and involvement (U&I) Consumer Evaluation of Acute Psychiatric Hospital Practice – "A Project's Beginnings...: 1994 p 71

(for insufficient hours) to enact change that they desperately see as being needed. They are paid appallingly and expected to undertake the extremely stressful job of being institutional change agents in a system that does not want to change. Many of them have tertiary qualifications as well as important life experiences but they are treated like minions simply because their expertise is not yet adequately understood nor valued within acute services. This is part of the 'sick' culture of many acute settings. Ironically many psychiatric hospitals have done little work on the needs of employees with disabilities and episodic illness. It would seem that these places should be at the cutting edge in relation to this and yet this is far from the reality.

Many consumers argue that forced treatment is incompatible with the maintenance of a healthy ward culture. If most of the people who are there as patients don't want to be there and people are continuing to be thrown to the ground and injected against their will, obtaining and sustaining a healthy work-place/hospital-place culture is very difficult. Some consumers argue that it is totally incompatible and that there should be no Mental Health Acts or involuntary treatment. Others argue that there are ways of talking people 'down' and developing plans with them about how best to look after them when they are very agitated and distressed. The AMHCN believes that involuntary treatment is used too often and this is too often out of system laziness, a prison type (or detention centre type) culture, or lack of staff skills and initiative. Some of these cultural problems will only go away when acute institutions are re conceptualized. Overseas consumers and visionaries have developed and tested models of providing help in times of crisis that involve looking towards other consumers as the holders of knowledge rather than the medical profession and less use of drugs. In these situations crisis intervention is seen as a small interlude in a holistic journey towards recovery. At the present time in Australia acute units are too often seen as nothing more than institutionalised holding bays and drug pumping stations.

1. *Acute psychiatric hospital practice has a long, dark history.* This history informs present practice. The AMHCN is adamant that present hospital practice must be understood in relation to the past. If you re-create history you run the risk of yearning for a past reality that never existed. The AMHCN is concerned that there is an element of this creeping into some of the present thinking about mental health services. This is not to say that we too don't yearn for some aspects of the old bins – namely the trees! However, painting a unit in bright colours and putting flowers in the lobby (etc) does not necessarily mean that the essential life of the institution is that much different. Pretending that places of penitentiary and forced treatment are really all acceptable now because the walls are pink and the plastic eating utensils have pictures on them only leads some consumers to feel more angry and more unheard and disempowered. The meaning the acute institution has to the consumer is the only meaning that is important. The idea that de-institutionalisation is somehow all done now that we have people out of the 'bins' is nonsense. Human rights and other abuses still happen far too frequently in such settings. . The AMHCN hears constantly from consumers whose human rights have been violated. Secretive place where all the power is in the hands of staff and almost nothing in the hands of consumers will always be potentially dangerous places.
2. *Women are still getting raped and molested in acute psychiatric hospital units.* The AMHCN believes that mixed units of really distressed people is unacceptable and is particularly wrong when it is a High Dependency Unit where the most distressed people are placed and where there are frequently ratios of up to five potentially violent men to only one woman (for example). There seems no good reason for this situation not to be rectified. It is only sustained because it is the cheaper option as it allows for admission flexibility. However this argument is totally unconvincing when balanced with the potential damage such gender pre-figurations can have on consumers. Obviously the situation is even worse for the many women with either childhood sexual abuse histories and/or adult sexual assault experiences. As many consumers fit into this

category we believe that dealing with the dangers of missed acute units must be seen as a priority. Our experience is that this problem escalates with the present trend for acute units to admit more and more young men with acute drug induced psychoses.

3. *Acute units are also dangerous places because they are places of such powerlessness.* Fundamental to the AMHCN understanding of mental health is the idea of the regaining of health as the regaining of personal autonomy and power. Whilst we (consumers) remain disempowered our recovery journey will be stunted. Much of the responsibility for making sure that this doesn't happen lies in our own hands but not all. Acute unit experiences, especially if they drag on for too long, continue to institutionalize us. It does not take long to re-learn dependency and dependent behaviour comes easily in many acute units because it is rewarded. Compliant patients are seen as 'good' patients by institutions. Many consumers aspire to be seen as 'good' and therefore give up their fight for the very autonomy and self-realisation that will lead to health.
4. *Many consumers have sought and obtained their medical records through Freedom of Information Legislation.* One consumer said about the records that were kept over many admissions to acute units that she was relieved to read her file because, "*I was right. They had been writing disgusting things about me!*" Consumers are very aware that part of being in an acute setting is that you will be monitored to within an inch of your life. This is paranoia provoking but it also leads to people very realistically knowing that every single staff member they come in contact with will have read that they are 'uncooperative', 'attention seeking', 'acting out' 'dangerous' and so on. They know that the way they are being treated comes directly in part from the often unaccountable descriptions that are not only committed to paper but are often repeated and repeated as lazy recorders follow the string started by someone else in a previous shift, a previous admission, a previous life. The keeping of records that are pernicious is another dangerous part of acute mental health care. These dreadful, words and judgements do not appear so readily in the files of people with physical illness (although they are not unknown). The AMHCN supports the idea of "*open charting*" where consumers have free access to their files and can add to them and co-write them.

The AMHCN acknowledges that there are some brilliant clinicians who work in acute units and we marvel at their capacity to continue to see us as whole people rather than diagnostic categories. Because so many of us are forced into hospital these units often breed anger and discontent in consumers. They tend not to be places where clinicians receive accolades from grateful patients: roses and chocolates. *However it is not consumers' responsibility to look after the self-esteem of clinicians.* As much as some staff might see the need for reciprocity in the caring that takes place, the hard truth is that they are paid to "care" for us and we are not paid to care for them. This is important. However, some consumers still do double back flips to try and help staff they see as struggling because of inadequate experience, a shortage of staff or because they are covering for others who are just plain incompetent, incompetent and senior or insufficiently briefed agency staff. The support of clinicians working in the acute setting is the responsibility of the sector, senior clinicians and management. All of these players need to be educated by well-paid and senior consumer educators who understand ward culture from the perspective of the patient. The other aspect that the AMHCN is keen to promote is that clinicians rotate around different positions in acute and community settings. Constantly seeing and being with consumers experiencing the worst of their distress leads to wrong conclusions about the degree of disability and potential for autonomy of everyone labelled as mentally ill.

Community Care:

There is a problem with clinical care in the community. The mere fact that other lobby groups (particularly carers) seem to be calling for "more beds", "more beds", "and more beds" would

directly indicate that consumers are not getting what they need from community settings. As mentioned above the AMHCN is keen that this inquiry hears a more sophisticated response than just clamouring for either re-institutionalisation or more beds. We know that these things make people sicker in the long term. From the perspective of the AMHCN there are several issues that we need to put on the table in relation to clinical care in the community. These include: more money needed for prescribed consumer positions in community services; calling a halt to diagnostic prejudice and the vilification of certain groups within psychiatric services; the urgent re-engagement of clinicians with psychotherapy and counselling backgrounds; sufficient staff to enable people to be seen regularly enough to maintain wellness; a change in culture which leads to case managers taking it seriously when consumers say they are becoming unwell; a change in culture which enables case managers and doctors to speak with other parties designated by the consumer about aspects of the consumers life that is worrying; and the need for ongoing professional training for clinicians provided by well supported and well paid consumer educators.

1. NSW, Victoria, Queensland and the ACT have now had over ten year's experience of consumers with prescribed consumer perspective positions working in community clinical services. These positions have now become indispensable in many services. Slowly the culture is changing and consumers are being seen as more than just a diagnosis. In other services it has been a wobbly start as change is being resisted however the hubbub around the predictable issues of confidentiality and '*what'll we do if s/he gets sick at work?*' have now died to a flicker in the States that pioneered these important new positions. The AMHCN argues that such positions urgently need to be established in the States and Territories that have been slow off the mark. However this must be done by taking on board the lessons already learnt. At the same time, more is needed. If consumer consultants/advocates are going to perform to the potential of the positions they need to be supported with:

- supervision (preferably with experienced consumers paid by the service),
- a decent budget especially to pay for the involvement of other consumers on an ad hoc basis and to employ locum consumer consultants when people get 'sick' or need to take a break to prevent a crisis;
- education from experienced and well paid consumer educators;
- sufficient hours on a weekly basis to make the positions viable; and
- discretionary funds available to enabled them to go to conferences, mix with other consumer workers, run workshops themselves for other consumers, give papers and talk about their role etc. etc.

These are important initiatives that need to be funded urgently. When not funded properly these positions don't just become tokenistic, there is also the possibility of them becoming treacherous because the clinical service sector can act like a giant suction cup pulling people back into their sickness identity. In the consumer literature this is called re-triggering⁷ and it is perfectly normal, predictable and does not indicate that there is something wrong with the consumer. However it can cause enormous damage if it is not understood and prevented by putting in place sufficient structures for de-briefing, support and flexibility. From the perspective of the AMHCN the frustrating reality is that consumers are demanding so little money compared to the claim on funds that comes from the "old order" demands that are rarely questioned. Despite this, squeezing any money out of Area/District level budgets is like pulling teeth for so many of us. The service paranoia is that they might lose clinical staff (or a .5 of one clinical staff member) to enable consumer participation to take place. The AMHCN believes

⁷ See U&I

that irrespective of such fears investment in consumer workers is an essential service asset for the future.

2. The triage arrangements not only around who gets to be an inpatient but also who gets ongoing clinical support from a case manager needs to be questioned. Triage will always be fraught. The AMHCN understands and accepts this. However, following the huge (and now generally acknowledged) mistake of using the undefined term of “*Serious Mental Illness*” (SMI) in the First National Mental Health Plan⁸ there has been ongoing debate about how ‘seriousness’ should be defined and by whom. Unfortunately, the initial response in the early 1990s which was supported and propagated by lobby groups interested in psychotic illness was to define serious by virtue of diagnosis. That is, if you have Schizophrenia, for example, this is serious but if you have Depression this is, by definition, not serious. When spelt out like this the obvious limitation of such an approach to establishing seriousness become immediately obvious. The AMHCN argues that diagnosis should never be the primary qualification of seriousness. There are other criteria like level of distress and level of disability and possibility of receiving services outside the public sector that are much more important and fair. One of the areas where there has been overtly neglected is in the area of Borderline Personality Disorder. Because this is so often deemed to be ‘*just behavioural*’ many seriously distressed people (over 70% women with histories of childhood sexual abuse) have literally been thrown on to the streets. What makes it worse in this situation is that the most common way in to get a case manager is initially through a crisis, then the obtaining of an inpatient bed and then follow up “*in the community*”.

It has been known for many years now that inpatient settings are terrible places for people with who have Borderline Personality Disorders. Many get “*re-triggered*” into *reliving their abuse experiences and sometimes self harm as a consequence.*” More than any other category of patient these women (usually) do really badly in hospital. Because of this most services now have a system where people with Borderline Personality Disorder are told they will only be admitted very briefly (no more than four days) and only once every two months for example. However, the triage system is often too clumsy to pick up people who have not been hospitalized with psychotic illness as being needy of case management. Unfortunately many people with this Borderline diagnosis (for example) lead a terrible life on the streets, cutting themselves regularly, perhaps picked up for a few days in an acute setting, told that what is happening to them isn’t serious and sent out to deal with their lives themselves. This happens even when it is demonstrably shown that they can’t do this on their own. This was shown graphically during the ABC Four Corners program about Cornelia Rau. Whilst the services (prison, detention centres and psychiatrists) believed she had ‘*just a personality disorder*’ the way she was treated was deemed acceptable and the outrage only came when it was found out she had schizophrenia. From a consumer perspective this is bizarre and unacceptable. All forms of mental distress should be treated as serious and all people regardless of how they are presenting or how the medical establishment wishes to label them should be treated with compassion and dignity.

3. Unfortunately since the First National Mental Health Plan in the early 1990s we have lost a whole generation of psychotherapists. Psychotherapy is out of fashion and these fashions are spuriously justified by cries from some quarters for evidence-based practice. The AMHCN supports consumers who claim, “*i am the evidence*”. Pharmaceutical company funded and psychology department funded research leads to evidence that supports the sorts of clinical interventions that the proponents of the

⁸ Australian Health Ministers, First National Mental Health Plan 1993-1998

medical model want supported. It is not only psychotherapy that consumers are calling for. They are also calling for grief counselling and well-funded peer counselling initiatives. These are very relevant to people with awful experiences in the past that need re-casting in their lives (a long, strenuous and complex task for both the consumer and the therapist and therefore one that does not lend itself to simplistic understandings of evidence-based practice).

However, counselling services are also needed for people who have been diagnosed with more simple organic illnesses like schizophrenia. Put yourself into the position of someone⁹ who has just finished her engineering degree and has her first episode of schizophrenia. She recovers from the crisis and then relapses ever time she tries to push herself to do anything beyond the simple acts of day by day survival in the community. The grief she needs to work through to come to terms with her life and the expectations that have had to be abandoned must be obvious to everyone. This woman does not just need anti-psychotic medication and three month reviews. Nor does she need to be patronized by a case manager who might ask her what she is doing to fill in her days. She needs expert guidance to re-invent herself and this is a complex task that will probably needs the ongoing support of her friends (if there are any left after her first episode) and skilled counselling (either by professional counsellors or by peers).

4. More money does need to flow into clinical services in the community sector. The AMHCN supports this but not at the expense of the development of consumer-initiated and operated projects, peer services, the non-government sector and so on. It is preferable that clinical services and the consumers that use them get together to explore better ways to provide clinical services that consumers really want in the community rather than pour good money after bad to maintain the status quo. The AMHCN believes that movement of public money into unexamined community clinical services will be just as wasteful as a deluge of money into the funding of more acute beds. Things have to be done differently.
5. Amongst what is needed in relation to increased funding is the capacity for case managers and others to positively react when consumers are detecting the early signs of an episode. This requires manageable caseloads. However, it is not just an issue of caseloads. It is also (and just as importantly) a change in attitude from one of believing that the professional is the expert to one, which recognizes that the consumer is the expert in his or her own illness. This requires a move away from the present situation where far too many consumers detect that the community clinical services are bursting at the seams and try, often in vain, to protect their case managers from a greater impost by denying their increasingly worrying symptoms and moving instead steadily into crisis.
6. Mental health services are not very good at listening to people designated by consumers as their allies and friends. The excuse of confidentiality is sometimes misused by services to cover up poor practice. This is not a general carte blanche for services to collude with carers. Rather, it is about re-training clinicians (from a consumer perspective) to understand the idea of confidentiality in a more subtle and sophisticated way. Consumers often say that around services, "*confidentiality means confidential from no one except you!*" That is, consumers are confused as to why clinicians seem to be able to swap personal information about the consumer as much as they want however when the consumer wants to know what they are saying or the consumer wants someone they know and trust to be able to feed into the clinical decision making this is nearly always deemed to be impossible. Good communication

⁹ This is a true story

is essential to good mental health practice. Excusing bad communication and justifying so doing by sighting confidentiality is unacceptable.

7. Clinicians working in any capacity in community settings have, unfortunately, had very limited opportunity¹⁰ to be exposed to consumer educators in their undergraduate training. This makes a huge hole in their medical preparation. Hopefully this will start to change as consumer perspective studies becomes more sophisticated and more widely offered¹¹ In the meantime consumer education initiatives must be funded, respected and promoted as part of in-service education opportunities.

After-hours crisis services

After hours crisis services do need attention however the AMHCN is opposed to separate facilities being built in public emergency departments to '*house the mad people*' and protect the sensitivities of a discriminating general health workforce and the 'ordinary' public. If new parallel emergency services are built it will take no time at all before they are stigmatized and people with mental illness will be embarrassed and ashamed to be seen going into them. The issue of discrimination in emergency departments, as it is everywhere, is a huge whole-of-society problem.

One of the things that need to be achieved quickly is the re-education¹² of emergency department staff in relation to mental illness. This needs to be undertaken by consumer educators with consumer perspective learning tools and case examples of the dreadful things that have happened to people with mental illness in emergency departments. The AMHCN often hears stories from members who have been treated dreadfully in emergency departments. Recently one consumer described having her handbag searched in front of all the people waiting in emergency and then her clothes confiscated. After waiting all night with no clothes her husband (who had been instrumental in provoking the crisis in the first place) was called and told to drive her from the emergency department to the psychiatric unit at a different hospital. The couple had a Land Rover with a large step to get in. The woman's clothes were not returned and her husband was given custody of them and instructed to give them to staff on arrive at the psychiatric unit. All of this took place as the woman was still groggy and barely coherent after a serious overdose. She was for all this time covered in black tar (that they give you to vomit up the drugs that had been swallowed) and no one had offered to help her remove it before she was instructed to publicly leave the emergency department with only a hospital gown (which didn't do up at the back) to cover her. The woman explained how all she wanted to do was to apologise to the staff but no one would listen to her. She was very distressed that she was unable to say 'sorry'.

Both the above responses are based on an assumption that we are stuck with a model of dealing with distress that is based primarily on medical intervention. This assumption is not necessarily useful. Overseas, consumers¹³ have had some really surprising and pleasing experiences of providing support for distressed people in services that are consumer-run or community-run. When we get very distressed we need different things regardless of our

¹⁰ At present it is mostly offered in an inadequate and ad hoc way as consumers are invited into classes and asked to share their stories.

¹¹ There is great potential for this. Leading the way is the Melbourne University Centre for Psychiatric Nursing Research and Practice with the appointment (now into its third year) of a designated consumer academic.

¹² Perhaps it might be better to say 'de-education' because many of the problems that are faced by consumers in emergency departments arise from the dreadful way those undergraduate clinicians are trained in relation to psychiatric illness. Perhaps this is magnified by the 'type of person' who seems to be attracted to the cut and thrust of emergency work.

¹³ Sometimes referred to as survivors, service users, users etc.

medical diagnosis. Some people know that they need medical drugs; some people know that they need containment to stay safe, others of us know that we need someone to talk to and others need to cut themselves to deal with the build up of pressure within them. Crisis services need to be far more creatively perceived and funded. Emergency Departments are one alternative that might work for some and not for others. CATT Teams that are not using up all their energy reserve trying to deal with triage impossibilities because of the inadequacy of funding are another option that might be useful for some. Funded safe houses (24 hour crisis respite, alternative to hospital¹⁴) run by consumers are another perfectly practical alternative that has been tried overseas. Another creative alternative is to fund consumer run "sub acute" 'peaceful places' where people can go and be cared for and which then frees up CATT time for more overtly critical matters and acts as a circuit breaker to stop everyone's symptoms escalating as they move towards achieving what they need in terms of intervention by proving they are suicidal or homicidal. (*This is not a criticism of consumers and has nothing to do with attention seeking. The search for recognition of one's pain and the desperate need to be taken seriously are real and the consequent escalation of symptoms is not a sign of individual 'badness' but rather is symptomatic of a mental health system malfunction that costs lives.*) In New Zealand the Mental Health Commission has trialled introducing consumer-run 'warm lines' that are available for consumers to ring where they know they do not have to prove they are desperate in order to have a conversation with someone they regard highly and who is wise about mental health issues because they have experienced them first hand. This is designed to take pressure of case workers and others and divert crisis.

Recommendations TOR b

1. That funding should flow to those interventions that clinicians and consumers jointly recognize as the most important and the least destructive.
2. That consumer knowledge and understanding about the lived experience of their own illness is respected within all services from the acute end right through to respite delivery.
3. That the variety and scope of available services no longer be limited by institutional traditions or medical model understandings of what constitutes a health intervention.
4. That all practices that promote institutionalization and/or an escalation of symptoms be terminated or minimized.
5. That clinicians be made aware of the aspects of their own practice and the development of service structures which demote autonomy and self reliance or promote crisis.
6. That all services be encouraged to seek 'real', generously funded and untokenistic partnerships between consumers who use the service and clinicians who provide them so that innovations can be explored, joint projects can be developed, ongoing evaluation and priority setting can happen cooperatively and consumer participation can be grounded in the everyday experiences of grass roots consumers and clinical staff.
7. That the call for '*more acute beds*' be understood in relation to the lack of alternative modes of service delivery.
8. That government takes seriously the consumer warning that some acute experiences leave people psychologically scarred, sicker and more dependent in the long term.

¹⁴ Connor H. Consumer-Operated Services Discussion Paper. Presented at the AHMAC National Mental Health Working Group, Auckland 7 March 2005 (unpublished).

9. That emergency departments of mainstream hospitals be a focus for ongoing consumer/clinician/management exploration and creative problem solving around issues of staff training, discrimination, dignity and efficiency.
10. That alternatives to medical model provision of crisis interventions (including consumer-operated opportunities) be explored and that funding be made available to trial some of these initiatives.

TOR 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

The National Mental Health Plan 2003-2008 states¹⁵ in Key direction 4.2: *Increase the capacity of consumers to take charge of their own care, through self-help resources, culturally appropriate training packages, networks and advocacy agencies.*

Consumers of mental health services are overrepresented in the chronic and complex disease group and life spans are reported to be at least 10 years shorter than the national average.

State/Federal split in responsibilities enables each to blame each other for the poor state of mental health services. The Australian Government says the States aren't passing the funding on, States say the Australian Government isn't funding sufficiently. In 2002, total spending on mental health services was \$3.1 billion, a 65% increase in real terms since 1993. As a proportion of overall health expenditure, this is similar to mental health expenditure in other developed countries. In terms of a service-costing approach, specialised mental health services accounted for 6.4% of Australia's recurrent health expenditure in 2001–02. Using an alternative disease-costing approach, the Australian Institute of Health and Welfare (AIHW) estimated that Australia spent 6.2% of recurrent health expenditure on mental health care in 1993–94. This is comparable to 6.6% in the Netherlands and 7.3% in the United States, although comparison between countries is difficult because of the differing ways expenditure and services are counted. The AIHW analysis also shows that the proportion of health expenditure for mental health rises to 9.6% if substance abuse and dementia are included. It has been argued that, as mental disorders and substance abuse contribute 13% of Australia's disease burden, 9.6% of health expenditure is insufficient. There have been claims to the contrary, but, in fact, there are no reliable international benchmarks by which to judge Australia's relative investment in mental health¹⁶.

Both state and federal governments have bureaucratic structures that do not allow for the differences that come with a psychiatric disability.

Whole of community: An 'episode of care' is mostly in the community and the community and community organizations, government and non-government. Do not see the responsibility they hold. Consumers are discriminated against by many organizations by an 'unwritten' gate-keeping.

A basic principle of health promotion is that health outcomes are better when consumers are involved in their own care. For there to be '*appropriate and comprehensive care*' it is necessary to ask the consumer '*what do you need*' but consumer participation is pretence and not partnership.

Some examples:

The AMHCN is aware of at least two instances where it was necessary for a consumer and/or family to contact the Minister for Health's office to get seen by a medical registrar, for very poor physical health, whilst hospitalised in an acute inpatient mental health unit. This was not due to a lack of trying by mental health staff.

¹⁵ Australian Health Ministers. National Mental Health Plan 2003-2008. Canberra: Australian Government, 2003, Key Direction 4.2. page 17

¹⁶ Whiteford, H. & Buckingham W. *Ten years of mental health service reform in Australia: are we getting it right?* Medical Journal of Australia: Volume 182 Number 8 • 18 April 2005 p 396-400

It is not unusual for consumers to have come through Emergency Department (ED) and get to the mental health unit without the physical wounds they have, through self harm or other means, being tended. If a known consumer attends ED the mental health service will be contacted and told one of yours is here, irrespective of the reason for their attendance at the Emergency Department. In one instance a consumer required admission to hospital for adjustment of her diabetic medication, there was an expectation by the broader health sector that she would be admitted to the mental health unit despite the fact that there was not evidence that she was mentally ill or disordered.

Centrelink assessment tools for both DSP and the Carer pension are appropriate for physical, sensory and developmental disabilities but not for psychiatric. Review assessment tools are not in line with evidence based practice as required to be used by mental health services under the National MH Information Strategy. Reasonable adjustment for work has not been appropriately explored for psychiatric disabilities except by specialist mental health employment agencies which are all too few.

In one area of some 500,000 people there is 1 psychiatric disability officer for 10 TAFE's.

Mental Health Unit staff profiles do not reflect a whole of person approach but a "manage and containment approach" to mental health care. Numbers of social workers, diversional and occupational therapists, welfare workers and consumer workers are very low and thus reinforce the 'management' process. Members of these disciplines (except consumer workers) working in the community find themselves doing general 'case management', whatever that means, and rarely using their discipline specific skills. Not only they not encouraged to further develop discipline specific skills but are in danger of losing those they do have due to lack of use.

Best practice states that recovery is defined by consumers and one tool that can be useful is an Individual Care Plan. In a recent service file audit of care plans for 5% of active 'clients' (21), 5 had care plans, none were signed by the consumer. Each had one goals identified, one of these had a consumer identified goal, 3 had '**compliance** with medication' and the 5th had 'compliance with CTO' (community treatment order). Under the segment marked responsibility, the service had no responsibility.

Recommendations TOR c:

- 11 Legislation of the National Standards for Mental Health Services
- 12 Services be required to show evidence in how they have responded to Mental Health Consumers Perceptions and Experiences of Services.
- 13 Consumer Surveyors on Accreditation Teams be mandatory.
- 14 Funding of Mental Health be commensurate with that of other developed countries.
- 15 There needs to be less autonomy on how mental health 'care' is delivered from the state down to the local level. Mental health departments and services **must** be accountable to it's shareholders, the taxpayers.
- 16 Health Service staff should be gazetted Public Servants and Health Services accountable to the Public not only to their line manager.
- 17 Adequately fund consumer networks and advocacy agencies

TOR 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.

Disparities in mental health care are eliminated

The vastly sized group of people, being those from culturally and linguistically diverse (CALD) communities have not been highlighted, nor mentioned, at all in the entire Inquiry. It therefore stands to reason to claim unfairness in marginalising or even fading out this active and highly productive group of people who have contributed enormously to the growth of our nation over the many decades of economic, social and political advancement.

It is important to improve adequacy by additional contribution towards the ethnic consumers and their families in the mental healthy stream I am not asking for more money, however overseeing from the top and its many variations of practices that are implemented should somehow cast improvements for our ethnic communities.

More projects should be designed to create attitudinal change among ethnic communities to address their concerns more openly, more confidently and with a degree of enthusiasm to improve themselves, as well as the system. How do we expect this to occur if Mental Health is being reviewed at the top level by this Inquiry, and no mention of expression to examine the ethnic communities relating to mental health issues?

The AMHCN asks, on behalf of our many ethnic mental health consumers and their families throughout the nation: that more or at least equal weight be placed on the nation to look at our many culturally and linguistically diverse people of Australia. Look at the practicalities of Mental Health Services made available to this vast section of the population. Offer funding to create innovation in the system to cultivate more user friendly services, benefiting those that have earned to be looked after within the mental health system nationally.

Improve access to quality care that is culturally competent.

"Cultural Competence" goes far beyond just learning a few stereotypical anecdotes about a group of people. It means having a thorough understanding of the mores, values, beliefs, and language and how these affect the perception of mental health and mental illness. It means recognizing that each cultural or ethnic group is actually a collection of many different groups.

Additionally, the suggests that the term *"culturally competent"* itself needs to be permanently expanded to distinctly identify and include *linguistic* competencies as well (visit the National Association of the Deaf website at www.nad.org), i.e., "(cross) cultural and linguistic competence."

Recommendations

- 18 Disparities in mental health services is eliminated
- 19 Improve access to quality care that is culturally competent
 - First, a distinction must be consistently made between cultural competence (services provided by individuals who have both cultural knowledge and linguistic skills) and cross-cultural competence (services provided by mental health professionals using qualified accommodations, approved by the consumer or family member, such as qualified interpreters). The need for this distinction is evidenced by separate systems of care that have evolved in many geographic areas throughout the country and consumers and family members should have a choice about how and where they receive services.

- Furthermore, there are many distinct populations of people in Australia, beyond those ethnic and cultural groups usually identified, who have experienced enormous disparity in the supports and services they have received or not received, for example: People who are deaf, hard of hearing, late deafened or deaf-blind; people from sexual minority and gender identity and expression communities; people who are older.
 - Each of these groups has a diverse membership and our society needs to respect and support indigenous forms of mental health support, treatment, prevention, and care (e.g. those found in many Aboriginal and Torres Strait Islander cultures.) We need to acknowledge that seeking and receiving formal mental health services may run counter to prevailing norms.
 - These groups need to be acknowledged, respected, and supported for and in their efforts to create and coordinate (cross) cultural and linguistic competent systems of care for their members. Training and recruiting competent providers must include cross-training in mental health and/or culture and/or language. This applies across multiple systems (e.g. mental health, substance abuse, HIV/AIDS, law enforcement & criminal justice, housing); therefore, cross-systems training is necessary.
 - Second, there needs to be some standardisation in what is meant by “cultural and linguistic competence.” To many people, this simply means taking a cultural “sensitivity” workshop. While the AMHCN by no means disparages the value of these efforts as an introductory training, it must be understood that being culturally (or cross-culturally) and linguistically competent involves much more. To be meaningful, training has to be thorough, in depth, and backed by real world experiences and hands on activity. Further, there is no consistent agreement on what constitutes a “bi-lingual provider.” Clearly mental health service requires a level of fluency far greater than a couple of semesters studying of a particular language as part of a liberal arts requirement.
- 20 Even more compelling, few people have any conceptualization of what a “qualified mental health interpreter” is. To address these concerns, the AMHCN has several specific action items:
- Recruit and train clinicians from minority and linguistic groups and cultures, in particular, from Aboriginal and Torres Strait Islander populations
 - When interpreters must be used, interpreters must be qualified mental health interpreters
 - Clinicians working with interpreters must be trained to work with interpreters
 - Ensure that providers who work cross-culturally have sufficient training to be competent, not merely aware.

Finally, each of these distinct populations may be considered a "rural population" given that individuals or communities with similar needs and their available resources for services may be spread out over extremely large geographic areas. The availability and use of tele-psychiatry health technology may greatly enhance the delivery of (cross) cultural and linguistic competent mental health care in the future. Funding must be made available for purchasing infrastructure technology and policies governing funding streams need to be changed to recognise services provided through these approaches.

- 21 Support the development of peer provided supports and services that are reflective of particular cultural and linguistic considerations, and assertively integrate these supports and services into the mental health system at all levels.
- 22 Fund an initiative to collect information, by jurisdiction, regarding current programs and models of providing peer supports and services which are specifically responsive to particular cultural and linguistic community's needs. These include, but are not limited to, the following (alphabetically):
 - Age
 - Disability
 - Ethnicity
 - Gender identity and expression
 - Geography
 - Language/linguistic preferences
 - Race
 - Religion
 - Sexuality

TOR 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

Iatrogenesis

Definition: *An iatrogenic disorder is a condition caused by medical personnel or procedures or through exposure to the environment of a health-care facility*¹⁷.

The AMHCN hears regularly from members whose experiences of mental health services have been so bad that it has left them with permanent scars. Here is a quote from one consumer:

*“...so many consumers say to me, “I was in hospital for such a short time but it is the central experience... I now feel I have to get over the trauma of that as well as the trauma of my original problems”*¹⁸

When watching the Four Corners program on Cornelia Rau the first and most obvious thing we noticed was that she ran away from an acute unit in Sydney. Why did she run away? And why didn't the program probe why she ran away? Consumers who have had to cope with conditions in public mental health acute units were not at all surprised that she was a refugee from mental health services. What we were surprised about was that nobody except us seemed to be asking the pivotal questions about how we make such units safer, less damaging and tolerable for people so that we are encouraged to stick around and get some assistance rather than run away to places where we believe we can regain our autonomy and our dignity both of which are too often stripped from us when we are admitted to mental illness hospitals.

There was outrage that Cornelia Rau had been subject to prison and detention centres. We acknowledge and support this outrage but it is imperative from the perspective of the AMHCN that Senators understand that too often acute psychiatric hospital facilities behave and feel just like prisons: The media painted a picture that would suggest that the bad treatment of 'Cornelia' ended by admitting her to a High Dependency Unit (H.D) at Glenside. Those of us who have been incarcerated in Glenside (especially in H.D) or any other H.D. unit of a public psychiatric hospital do not believe this. As one consumer put it:

“And I remember often thinking, when I was by myself, I used to sort of think, I'm so frightened but there's no one to tell you're frightened. You can't tell the nurse; “I'm frightened.” I mean, you couldn't- and then I couldn't walk up to a nurse- and one day I was crying. The nurse said, “It's a little bit too late to cry.” It was like – I mean, it was like you were just in prison... [and] you'd actually committed your crime”.¹⁹

Consumer researchers²⁰ have spent time exploring some of the ways that mental health facilities take on the characteristics of penitentiaries even in this time of supposed deinstitutionalization..²¹

¹⁷ In The Mosby Medical Encyclopaedia, 10/1/1996

¹⁸ Victorian Mental Illness Awareness Council, Understanding and Involvement (U&I) Consumer Evaluation of Acute Psychiatric Hospital practice, Melbourne 1994 p.73

¹⁹ IBID p. 72

²⁰ Victorian Mental Illness Awareness Council, Understanding and Involvement (U&I) – consumer evaluation of acute psychiatric hospital practice, 1996

²¹ In some ways this has been made worse rather than better now that there are no longer the grounds and huggable trees which existed in some of the old 'bins'. One of the not so trivial and interesting factors is the role of cigarettes. Many consumers smoke. The percentage of

Institutionalisation is another way that consumers can be maintained by the mental health system in a dependent sick role. Powerlessness feeds mental illness. Consumers find themselves having to be 'sick' in order to live out who they have come to believe they are. Forced treatment, detention in hospitals against your will forcing us to have regular injections also against our will in the community and Community Treatment Orders which are a bit like 'prison in the home' are all ways that the health system acts to make us construct ourselves as 'sick'²². One consumer thinker and writer²³ coined the term '*playing dead*' to describe ways in which consumers are too often rewarded for being powerless and 'pathetic'.

Where consumers are insisting that the health-making concept of 'recovery' needs to be the guiding principle of every single intervention too many services (particularly but not only acute services), some carers and carer organisations, some clinicians and others use the language of compliance to maintain control over people with mental illness. So-called compliance is too often antithetical to our driving ideas of recovery and self-actualisation. Self-actualisation is the embodiment of mental health. Consumers are adamant that forced treatment and detention has the potential to make people sick. One of the challenges is to think of radically new ways to both protect people and society from the adverse effects of our 'madness' without putting us through hospital and community 'health' regimes that leave us naked, terrified, angry and hopeless. Consumers overseas have told us that in other countries²⁴ truly innovative ways of supporting people through 'madness' have been trialled and found very useful. Many of these are run by consumers themselves. There is an urgent need for consumer researchers to be funded to travel overseas and collect as much information as they can about how to do things very, very differently. Funding for more and more of the same sort of services that are funded at the moment will only continue to make people sick.

The AMHCN is extremely worried about institutionalisation, revictimisation²⁵ and iatrogenesis in relation to some private hospitals as well. The issues might be slightly different but some of the results are equally as negative. This is particularly worrying in situations where consumers are kept hospitalized for long periods of time and where there is not the necessity to move

consumers who smoke is much higher than the general population. In acute units most people smoke even more because they are caged up and agitated, many pacing the perimeter of the locked unit. Many consumers find themselves losing power over every aspect of their life after they are admitted. Cigarettes become currency in such situations. Often, people's cigarettes are confiscated and people are only given permission to knock on the door of the nurse's station and ask for one every hour. Just imagine what this does to your self esteem: grown men and women having to beg reluctant clinicians to give them a cigarette, which belongs to them in the first place. They are also used as punishment (cigarettes confiscated) and bribes ("if you stop asking for your **** (drug name) you can have a cigarette.") They are also currency in the exchanges between patients. People with cigarettes often have status and sometimes staff who smoke are also seen differently.

²² A serious situation which is unfortunately aided and abetted by some of the anti discrimination programs that seems to have been designed by everyone except consumers. This is the exact opposite of what has happened in New Zealand where such campaigns have come from the grass roots up.

²³ Ross Findlay

²⁴ Netherlands for example

²⁵ For people with childhood abuse and trauma experiences psychiatric hospitals can be very dangerous places indeed. Often they are places where you are not trusted, punished in front of other patients, ridiculed, and spoken to in a patronising way and where you are too often treated like a child. Unfortunately for people with abuse histories this can trigger them into reliving the abuse. Similarly, psychiatric hospitals (regardless of whether they are private or public) can be places of male violence and disinhibition as a symptom of certain mental illnesses. These are not safe surroundings for women with histories of rape or anyone with a history of sexual abuse.

people through as rapidly. These institutions do not have the same checks and balances as public services. Few of them employ consumers and they are not the domain of community visitors or other watchdog organisations and advocacy services. In this submission we want to warn Senators about the potential hazards of long stays in psychiatric hospitals.

Recovery Focus

The most remarkable change that has taken place over the past decade has been the introduction and then the growth of consumer participation in mental health planning and delivery. This has accompanied new ways of thinking about and conceptualising people's trajectory (career) as patients through mental health services. Consumers have adamantly claimed that mental illness must never again be seen as a life sentence to half citizenship. Increasingly the term, recovery, is being used and believed. This has been an incredibly big change in emphasis and has largely been driven by consumers. It brings hope and health instead of hopelessness. The AMHCN cannot emphasise this enough.

Consumer Participation

A recovery focus has called for not only new and different sorts of services but also new ways of seeing old services and new ways of understanding who and which groups should make up the mental health workforce. In Victoria, New South Wales and Queensland consumers have been employed in mental health services for over a decade. This followed the First National Mental Health Strategy in the early 1990s and the Burdekin Report which came out at about the same time. Up until this time the only model of being a consumer that service staff were able to access was consumers being 'really unwell'. Now, thankfully (in some States and Territories), consumers play many different roles in service provision and evaluation. The National Mental Health Service Standards and the National Mental Health Practice Standards were both developed with considerable consumer input. This would have been seen as a ridiculous idea fifteen years ago. Consumers are now working in services as consultants (Victoria) or as advocates (New South Wales). Consumers have also been trained to fulfil essential roles as key people in every team of assessors responsible for auditing mental health facilities for the Australian Council of Healthcare Standards (ACHS). These audits are big news for every mental health facility. The consumer presence on audit teams, the consumer perspective questions that are now routinely asked and the surety that the service will have to have met (on paper at least) its responsibilities for consumer participation in accord with the National Mental Health Practice Standards are all extremely important initiatives that have developed in the past fifteen years.

However this is not enough to reverse the tendency towards iatrogenic services. Most of the consumer initiatives survive perilously. They are seen by insightful clinicians and consumers as absolutely central to help overhaul services that have a tendency to cause harm. However in the larger scheme of things they are often terribly under funded. Consumers are being asked to work as culture change agents in services which are often steadfastly resisting change²⁶. Many consumers burn out and the attrition rate is high. This is not just because of illness (although many of these roles are extremely stressful and surprisingly perhaps some mental health services are extremely bad employers of people with episodic and stress-related disabilities). Some services continue to see consumer advocates/consultants as luxury add-ons which can be dispensed with at the first sign of budget tightening. Many still talk about their consumer participation activity needing to be budget neutral, which is, of course, impossible and self-defeating. Many consumer participation activities are driven by a small number of inspired staff but they are not built in²⁷ to the service so that when these staff leaves

²⁶ Pinches, Allan Pathfinders" <http://www.alphalink.com.au/~alpin/>

²⁷ Wadsworth, Y. The Essential U&I, Victorian Health Promotion Foundation
<http://www.vichealth.vic.gov.au/default.asp?artid=325&tmid=407&level=3>

there is no corporate intelligence about consumer participation initiatives and everything dies, Therefore future attempts are forced to start again from scratch. Re-inventing the wheel is a major problem for consumer participation endeavours around Australia. Consumers who have been active in the pursuit of a sustainable consumer workforce, better conditions and co-ordinated knowledge sharing are very frustrated by this. With each new generation of consumers the history gets lost and the capacity to stem the tide of hurtful relationships with staff and iatrogenic experiences of hospital gets lost.

Although we now have (in Victoria, New South Wales and Queensland) an established consumer workforce and general agreement that we could not and must not ever lose this again an existing national project funded under the National Mental Health Strategy to look at the education needs of the mental health workforce²⁸ does not include consumer workers as part of the workforce. There are very few training opportunities for consumers working in services. This is diabolical. Consumers bring to the service culture the lived experience of being labelled and treated as mentally ill. This is a unique knowledge set that should but is not always valued highly. However they also need many other skills; knowledge of the consumer movement and consumer political history, education skills and many others. It is imperative that they get regular and high quality access to consumer-run education initiatives.

Consumers as educators of the mental health workforce

It now seems so obvious but fifteen years ago no one would have even imagined the major role that some consumer educators are playing in training clinicians. Perhaps the most interesting position is that occupied by Cath Roper who has a position at Melbourne University Centre for Psychiatric Nursing Research and Training. She is a designated consumer academic and her role is to help psychiatric nurses understand consumer perspective and encourage them to reflect on their own professional behaviour and witness it through consumer eyes. Even though Cath's position is only part time she does have some time to write consumer perspective syllabi and start to develop a discipline of consumer perspective studies. The AMHCN is excited about these initiatives but there are far too few positions equivalent to Cath's in Australia. To really make the sorts of changes to practice culture that are necessary consumer educators need to be actively involved right across the board and not just with nurses but with every professional group that works with people who have a mental illness.

The AMHCN is keen to point out to Senators that the old model (if anything took place at all) for consumer participation in education and training of clinicians was to invite consumers to come in and tell their story to groups of students. This cost little and demanded very little of students. It was popular because it didn't really challenge the students at all. Students went away saying, "*wasn't that awful the way she was treated by them (those other clinicians in the story)*" and then they went back to practicing in the same damaging ways they had always practiced before. From a consumer perspective it was too often like taking all your clothes off and exposing yourself in a very public way and many of us later felt awful and realized we had somehow been seduced into something. This model might be relatively cheap but that isn't sufficient reason to keep doing it against the evidence and advice coming from consumer educators. We have now developed more interactive ways of educating clinicians but these are more expensive and often require in-house consumer educators as part of service education teams. This is not just about a nice idea to hear from consumers. Consumer educators need paid time to write articles not only for the grey literature²⁹ (which is where we have traditionally been published) but also in the refereed journals which intimidate many of us. We need help to learn the skills that will enable us to bring consumer perspective to the places where professionals and academics gain their knowledge. Consumers subsisting on

²⁸ Mental Health Practice Standards Project - Chaired by Professor Bruce Singh

²⁹ Informal unpublished consumer magazines, newsletters and papers etc.

the Disability Support Pension cannot afford to do all these things for nothing. This is urgent. Iatrogenic practices must be challenged at their very base and this is in the minds and hearts and everyday practices of clinicians. This costs real money.

As part of the Australia wide mental health workforce clinical standards project³⁰ that is presently being funded, consumer educators have put forward strong arguments for funding a model Consumer Studies Centre (similar to the idea of a Aboriginal Studies Centre) which would provide the opportunity for a critical mass of consumer thinkers, writers and educators to get together to develop and share curricula, disseminate consumer articles, organise conferences and support consumers doing undergraduate and/or postgraduate studies in areas directly related to the mental health sector thinking or practice. A paper will be produced as part of this project that will, hopefully be made publicly available some time towards the end of the year.

Peer Support

There are so many ways that consumers can not only support each other but also take some of the heat off professionally run services. In New Zealand the Mental Health Commission³¹ has trialled a 'warm line' which is a peer support telephone service run by trained consumers which is available 24 hours a day and which can take the pressure off Crisis and Assessment (CAT) Teams and other institutionalised crisis services. Consumers are encouraged to ring the warm line if they need to talk or are frightened or just need the opinion of another consumer. CAT teams can refer people to the warm line. This is just one example of a really important initiative that is consumer run.

Throughout Australia there are some (but too few) examples of formal ways that consumers support each other to avoid crises and provide purpose in people's lives. There is a need for an Australian-wide directory of peer support and consumer run services. Because mental health services are the responsibility of States and Territories there has been far too little attention paid to collecting and disseminating information about consumer initiatives through the different States and Territories. Again, this leads to disjunction, confusion and replication of ideas and effort.

In the 1990s the Commonwealth Mental Health Branch funded several projects (Innovative Grants Project) that encouraged consumers (and providers) to try new ideas. A significant number of consumer projects were funded. Two that stand out were the two undertaken by the Victorian Mental Illness Awareness Council (VMIAC) which is the peak body for consumers in Victoria.³² These were the Lemon Tree Learning Project which was interested in exploring different ways that consumer educators could be involved in the education of clinicians and Vincent's Peer Support Centre³³ which was a big old house in inner suburban Melbourne where consumers developed training for other consumers who wanted to be employed as peer counsellors. The Commonwealth published a listing of all the innovative projects that were funded through this project. This was a really useful document however it is now dated. Other peer initiatives have been funded in Sydney, rural Australia and elsewhere

³⁰ Mental Health Practice Standards Project - Chaired by Professor Bruce Singh

³¹ Which is a model for what consumers would like to see in Australian States and Territories. It has a role to play as a watchdog organisation and one out of the three Commissioners in a consumer.

³² Victoria is the only State or Territory that has a consumer peak body. This is probably because Victoria has a longer history of funding non-government services.

³³ The VMIAC thought this project was an amazing success. Various evaluations testified to this. However, despite all efforts they failed to attract ongoing funding and the whole thing floundered eighteen months after its official opening.

but because these have all been funded as local and State projects³⁴ there has never again been the incentive to produce another directory, which would enable consumers in one State to speak to and learn from others who are further down the path towards successfully operating peer initiatives.

Recommendations TOR i

- 23 That a scoping study be immediately be funded to progress the idea of developing a Centre of Excellence for Consumer Perspective Studies in a tertiary institution, service, or attached to a pre existing consumer organization or interest group.
- 24 That two (or more)³⁵ consumer researchers be funded to travel overseas and collect state of the art information about:
 - consumer run services;
 - consumer designed step up and step down services,
 - centres of excellence for other disempowered groups that could be used as a model for mental health consumers in Australia, and
 - information about the roles and working condition for consumer educators, consumer consultants, peer workers, consumer advocates and other paid consumer roles and positions in the mental health field.
- 25 That two (or more) consumer researchers are funded to travel around Australia speaking to consumer workers (consultants, advocates, peer support workers etc.), consumer organizations, providers and services about all initiatives that have been tested in relation to developing the consumer workforce in mental health in Australia and:
 - That a report be produced that identifies not only differences in working conditions and support but also in wages, hours worked each week, potential problems advantages, locum services, training etc;
 - That they collect examples of job descriptions and other pertinent documentation;
 - That on completion such a report (including recommendations) is made widely available to all consumers, consumer organizations and services that are developing consumer participation policies;
- 26 That the Australian Government reverts to a model of policy promotion, which tags commonwealth funds to encourage States to spend 'real' money on consumer participation initiatives as a matter of urgency.

³⁴ Wonderfully, some have ongoing program funding at last.

³⁵ Because of differences in assumed and real power between consumers and other players in the mental health industry the AMHCN policy is that consumers should always work together in at least pairs.

TOR j the overrepresentation of people with a mental illness in the criminal justice system and in detention, 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

"It is deplorable and outrageous that this state's prisons appear to have become a repository for a great number of its mentally ill citizens. Persons, who, with psychiatric care, could fit well into society, are instead locked away, to become wards of the state's penal system. Then, in a tragically ironic twist, they may be confined in conditions that nurture, rather than abate, their psychoses."
(Judge William Wayne Justice, Ruiz v. Johnson, 37 F. Supp.2d 855 (S.D. Texas, 1999).

The AMHCN believes apart from any relationship that may, or may not, exist between offending and mental illness; it is clear that people with mental illness are currently to be found in the criminal justice system. They, like any person with an illness, require appropriate care and treatment. Equally, irrespective of putative associations between mental illness and offending, the law regards aspects of mental illness, in some circumstances, as mitigating, or even exculpatory, and makes disposals dependent on the provision of appropriate mental health services. In short the criminal justice system and the mental health services inevitably interact and share an interest in some of the same people.

There are enormous gaps in our knowledge when it comes to the mental health needs of those offenders in the criminal justice system in detention, on various community orders, and on those offenders diverted into the mental health system, informally, or on court orders. The problem with studies of offending behaviours among people with mental illness is that they usually focus exclusively on violent behaviours and they incorporate a wide range of behaviours, which though potentially open to prosecution in practice, rarely lead to charges, convictions and court determinations.

The close approximation between the 'best Australian' estimate and the UK provides a degree of confidence in asserting that up to 8% of male and 14% of females in our prisons have a major mental illness with psychotic features.

Those with mental illnesses have been assumed from ancient times to be more prone to criminal, and in particular violent, behaviours than their fellow citizens. The presence of a disproportionate number of people with mental illnesses among those who populated prisons and workhouses was repeatedly noted over the last two centuries. More recently claims have been advanced that the numbers in prison with severe mental illness, notably the schizophrenias, are rapidly escalating (Torrey, 1997)³⁶. This supposed increase in the proportion of severely mentally ill coming in contact with the criminal justice system and ending up in prison is frequently attributed to the closure of the old asylums and the move to systems of community based care. In short part of the increasing numbers being imprisoned not only in Australia but through most of the western world is attributed to failures in mental health services (Torrey, 1997). Or more generously, that improvements in mental health care could reduce the rates of offending and subsequent incarceration among the seriously mentally ill (Mullen, Burgess, Wallace, Palmer, Ruschena, 2000)³⁷.

³⁶ Torrey, E. F. (1997). *Out of the shadows: Confronting America's mental illness crisis*. New York: Wiley.

³⁷ Mullen P. E., Burgess, P., Wallace, C., Palmer, S., Ruschena, D. (2000). Community Care and Criminal Offending in Schizophrenia. *The Lancet*, 355, 614-617

These arguments are based on a series of assumptions namely:

1. That having a mental illness, or at least some types of mental illnesses, is associated with increased rates of offending.
2. That people with mental illness are over-represented among those in the criminal justice system either as prisoners or on various forms of community orders.
3. That the proportion of those with mental illness among offenders, and in particular prisoners is increasing.
4. That the presence of a disproportionate number of people with mental illness in the criminal justice system is either related to prior failures of care and management by mental health services, or could be improved by better systems of mental health care and management.

Doing time in prison is hard for everyone. Prisons are tense and overcrowded facilities in which all prisoners struggle to maintain their self-respect and emotional equilibrium despite violence, exploitation, extortion, and lack of privacy; stark limitations on family and community contacts; and a paucity of opportunities for meaningful education, work, or other productive activities. But doing time in prison is particularly difficult for prisoners with mental illness that impairs their thinking, emotional responses, and ability to cope. They have unique needs for special programs, facilities, and extensive and varied health services. Compared to other prisoners, moreover, prisoners with mental illness also are more likely to be exploited and victimized by other inmates.

Mental illness impairs prisoners' ability to cope with the extraordinary stresses of prison and to follow the rules of a regimented life predicated on obedience and punishment for infractions. These prisoners are less likely to be able to follow correctional rules. Their misconduct is punished - regardless of whether it results from their mental illness. Even their acts of self-mutilation and suicide attempts are too often seen as "*malingering*" and punished as rule violations. As a result, prisoners with mental illness can accumulate extensive disciplinary histories.

"...very little mental health care. I was devastated. I hated it there. I saw the psychiatrist every three months and a counsellor once in a while. There was nobody to talk to. They told me to go to church - that that would help me.... I remember trying so hard to remain in contact with reality before they put me back on Haldol. It took a week to see the psychiatrist and get put back on Haldol. They said "you'll just have to wait till he gets around to you."

(Woman ex-prisoner – information given to writer)

According to the 2002 report of the Criminal Justice/Mental Health Consensus Project in the United States:

The professionals in the [mental health] system know much about how to meet the needs of the people it is meant to serve. The problem comes, however, in the ability of the system's intended clientele to access its services and, often, in the system's ability to make these services accessible. The existing mental health system bypasses, overlooks, or turns away far too many potential clients. Many people the system might serve are too disabled, fearful, or deluded to make and keep appointments at mental health centres. Others simply never make contact and are camped under highway overpasses, huddled on heating grates, or shuffling with grocery carts on city streets.³⁸

³⁸ Council of State Governments, *Criminal Justice/Mental Health Consensus Project* (Council of State Governments, New York, June 2002). The report reflects two years of collaborative work between over one hundred lawmakers, police chiefs, sheriffs, District Attorneys, public defenders, judges, mental health advocates, victim advocates, correctional officials, substance abuse experts, and clinicians on the topic of the mentally ill and criminal justice.

This also applies to conditions in Australia.

The mental health “*system’s failings lead to unnecessary and costly disability, homelessness, school failure, and incarceration.*” Every state has its own experience with the “criminalisation of people with mental illness.” For example:

Community mental health services, though very good, are, due to lack of resources, inadequate to meet the needs of persons with mental illness. This has resulted in some persons with mental illness falling through the treatment services net and into the criminal justice system. The lack of community mental health resources also impairs the ability of law enforcement, courts and corrections facilities to divert persons with mental illness away from the criminal justice system and into more appropriate treatment settings.

(Mental health carer – as told to writer)

Police

Police are generally the first on the scene when a person with mental illness creates a disturbance or commits a crime. To some extent they have the discretion to determine the subsequent course of events – arrest, hospitalisation or informal referral – depending on their view of the severity of the disturbance, the behaviour of the offender, and the resource options available to them.

In most jurisdictions, the police can initiate emergency hospitalisations for people who are either a danger to themselves or others. In practice, however, this discretionary power is significantly restricted by the stringent legal criteria surrounding involuntary commitment, the unavailability of community-based treatment slots, the unwillingness of mental health facilities or emergency rooms to accept patients who are perceived as intoxicated or recalcitrant, and the time and bureaucratic procedures required for admission.

The appropriate use of discretion also requires police officers to understand the problem they are faced with and how best to react. Police agencies should provide in-service training to enable officers to recognise the signs and symptoms of serious mental illness.

Reintegration and community-based issues

These clear service gaps focus on reintegration matters and community-based issues:

1. The AMHCN is concerned that there is a strong need for step-down services into the community for released prisoners with mental health problems. At the current time, the feeling is that appropriate services are not being provided. However, no useful and relevant data are being collected to establish this need. Data in this area are urgently needed to guide service provision. This is seen to be a particularly important matter, given the interface between justice, community mental health services, and forensic services (as available) for prisoners with mental health problems returning to the community.
2. Beyond concerns regarding integration matters, we believe that there is the need to establish forensic community mental health services for those offenders with mental illnesses who are being supervised by community corrections and/or who have been diverted from court programs. This is an area of great importance as the community mental health services generally do not see that they have the expertise to deal with these clients, and they typically express concerns about the level of risk for harm to others that the offenders present.
3. Although there is obviously some degree of variability across the states, appropriate services for those on community corrections orders are currently not being delivered and there exists no comprehensive forensic community mental health database to guide service provision. Indeed, virtually all of the data collected both in Australia and internationally concerning the prevalence of mental illness among offenders has come

from prisoners. As such, surprisingly little is known about the general mental health problems of community-based offenders.

Recommendations TOR j

Governments must act decisively to improve mental health services in Australian prisons. An ongoing concern should be reducing the population of prisoners who have severe mental illnesses. Secondly, governments must develop standards, provide oversight mechanisms, and mobilise resources to ensure effective, quality mental health care in prisons.

- 27 Reduce the incarceration of persons with mental illness.

Steps should be taken at the national and state levels to reduce the unnecessary and counterproductive incarceration of low-level non-violent offenders with mental illness. Mandatory minimum sentencing laws should be revised to ensure prison is reserved for the most serious offenders (whether or not mentally ill) and prison sentences are not disproportionately harsh.

Mental health courts, pre-trial diversion, and other efforts should be supported which will divert mentally ill offenders from prison and into community based mental health treatment programs. Reducing the numbers of offenders with mental illness sent to prison will also free up prison resources to ensure appropriate mental health treatment for those men and women with mental illness who must, in fact, be incarcerated for reasons of public safety.

- 28 Set high standards for prison mental health services.

Government must not accept low quality mental health services for prisoners with mental illness. International human rights standards require officials to ensure the highest attainable standard of mental health, including accessible, acceptable, and appropriate and good quality mental health services, provided by trained professionals. Officials should not tolerate the misery and pain of prisoners whose mental illness is left untreated or under treated. Quality mental health services in prison will not only help prisoners, but will improve safety within prisons, benefiting others prisoners and staff. Good correctional mental health services will also increase the likelihood that prisoners will be able to return successfully to their communities following release.

- 29 Improve conditions of confinement.

Governments must ensure that all prisoners are confined in conditions consistent with their human dignity. No prisoner should be confined in overcrowded, dangerous, filthy, vermin- or bug-ridden, or unbearably hot cells. Such conditions violate the rights of all prisoners, but they have an especially detrimental effect on prisoners with mental illness.

- 30 Establish effective performance reviews using independent experts.

Governments cannot exercise their obligation to ensure appropriate mental health services for prisoners if they do not have objective information provided by independent and qualified experts. Correctional officials often do not have an adequate understanding of the limitations on mental health services provided in their prisons, and other elected officials often have even less understanding. Expert reports presented during litigation are often the only way light is shed on prison conditions. Governments should not wait, however, until an inmate or family member brings a lawsuit. Existing prison accreditation mechanisms focus primarily on the existence of appropriate policies; they do not assess their implementation or the quality of services actually provided. Experience reveals that implementation often lags far behind even the best of policies.

- 31 Establish comprehensive internal quality review mechanisms for each prison system and prison.

Quality controls for mental health services are often rudimentary, ineffective, or nonexistent. Mental health staff often lacks an effective opportunity to engage in candid self-criticism, gather data, identify and discuss shared problems, and work with senior corrections officials to develop solutions to problems in the delivery of mental health services. Establishment of internal quality review procedures and the commitment of prison officials and mental health staff to effectively implement those procedures will provide a vital and ongoing complement to external quality assurance audits.

- 32 Solicit and heed prisoners' concerns.

As consumers of mental health services, prisoners are singularly without power to protest poor treatment. They cannot switch to another provider, and their legitimate complaints and concerns are rarely acknowledged, much less responded to by corrections officials. Prisons should establish at an institutional as well as departmental level procedures by which prisoner perspectives about mental health services (indeed all medical services) are solicited and heeded. Prisoner views should be incorporated into the outside as well as internal quality review mechanisms recommended above.

- 33 Provide mental health training for correctional staff.

It is counterproductive and dangerous for correctional staff that has little or no training in mental illness to work in housing units, on the yards, and elsewhere in prison with prisoners who have serious mental illnesses. Effective training should be provided to all new officers in such areas as: signs of mental illness; different treatments for mental illnesses; side-effects of medications used for the treatment of mental illnesses; effective interaction with mentally ill prisoners; defusing potentially escalating situations; recognition of the signs of possible suicide attempts; and training on the safe use of physical and mechanical restraints for offenders with mental illness. Additional information pertinent to working with prisoners with mental illness should be provided during in-service training.

- 34 Ensure mental health input and impact in disciplinary proceedings.

Prisoners with mental illness can have unique difficulties complying with prison rules and may engage in bizarre or disruptive behaviour because of their illness. Punitive responses to such conduct do little to reduce or deter it. When prisoners who are on the mental health caseload violate rules, disciplinary procedures should require mental health input to the disciplinary officers regarding whether the prisoner's behaviour was connected to or caused by mental illness, and regarding what sanctions might be appropriate. In specialised units housing only mentally ill prisoners, corrections officials should work with mental health staff to determine whether the normal prison disciplinary system should be suspended, and mental health staff should determine appropriate responses to prisoner misconduct consistent with his or her mental diagnosis and treatment plan.

- 35 Exclude prisoners with mental illness from segregated confinement

The AMHCN opposes the prolonged and unnecessary incarceration of any prisoner in isolated segregation or security units. Prisoners with serious mental illnesses, even if they are currently stabilised or asymptomatic, should never be confined for prolonged periods in the harsh isolation conditions typical of segregation. There is an unacceptably high risk that the isolation, reduced mental stimulus, lack of structured activities, and the absence of social interaction will provoke a deterioration of their symptoms and increased suffering. We recognize

there are some prisoners with mental illness who require extreme security precautions even when under mental health treatment. For these individuals, prisons should provide specialised secure units that ensure human interaction and purposeful activities in addition to mental health services.

- 36 Support funding for appropriate prison mental health services.

It is difficult to secure adequate funding for services and programs for prisoners. Improvements in mental health services in prison are, unfortunately, heavily dependent on financial resources. Qualified, competent staff cannot be hired and retained in sufficient numbers without appropriate funding. Governments must support adequate funding levels for mental health services and permit corrections officials and mental health staff to argue forcefully, extensively, and publicly on behalf of such funding. They must present candid analyses to the public of existing problems with correctional mental health treatment, the consequences of those problems and the need for resources to address them. They should encourage legislators to reduce prison populations, by lowering unnecessarily harsh mandatory sentencing laws and by supporting alternatives to incarceration for low-level non-violent offenders, rather than by cutting indispensable services for those prisoners who must be incarcerated.

- 37 Ensure that the National Principles for Forensic Mental Health Care are endorsed and implemented.

TOR 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 minimizing treatment refusal and coercion.

The Universal Declaration of Human Rights (UDHR) and Principles for the Protection of Persons with Mental Illness require that treatment be “based on an individually prescribed plan,”³⁹ and they require that “the treatment of every patient shall be directed towards preserving and enhancing personal autonomy.”

A basic principle of health promotion is that health outcomes are better when consumers are involved in their own care. This is supported by National Mental Health Plan 2003-2008⁴⁰: *Increase the capacity of consumers to take charge of their own care, through self-help resources, culturally appropriate training packages, networks and advocacy agencies.*

The ‘practice of detention and seclusion within mental health facilities’ is not in accordance with these tenets. There is an imbalance in how the ‘rules’ for detention are applied; it is often driven by a clinicians judgement or a diagnosis. For example:

A consumer was given day leave 12 hours after being transferred from a high dependency unit to an open ward, he was still talking about hurting his wife, the doctor told him to ‘stay away from his wife’ (thinking that sufficient care), he went on day leave and murdered his wife in front of his children. Another consumer was discharged because he was no longer mentally disordered, despite his pleas to stay in hospital. He went home and hung himself from the clothesline, his mum found him.

AND

During an inspection of an acute inpatient unit a Health Minister requested to be locked in a seclusion room ‘to get a feel of the place’. The Consumer Worker accompanying the Inspection Team encouraged service providers to check on him every 30 seconds to imitate the usual routine. His words on his release were ‘How is that supposed to make people get better?’ His appearance was distressed and he had dishevelled his hair greatly.

Culturally and Linguistically Diverse (CALD) consumers are over represented in forced detention and are routinely admitted to hospital via police transportation and the use of force. When acutely unwell they often lose English as a second language and revert to their language of origin. Interpreters are only used for medical interviews and magistrate hearings and thus people are **unable** to be ‘compliant’ with nursing instructions and frequently end up experiencing seclusion. For CALD consumers who have emigrated from an experience of a police state or experienced torture and trauma the mental health admission is a reliving of what they thought they had escaped from.

The routine practice of using security guards, dressed in uniforms that imitate police uniforms, in high dependency wards; as gatekeepers to mental health units in which the consumers are supposedly voluntary; for people spending time in emergency departments and for involuntary consumers who need to be in general hospital wards, either for medical reasons or because of no acute mental health beds. The mental health units where the ward is locked and photos of ‘voluntary’ consumers are kept at the reception desk and ‘buzzed’ in and out. This is

³⁹ The Universal Declaration of Human Rights (UDHR) and Principles for the Protection of Persons with Mental Illness

⁴⁰ Australian Health Ministers. National Mental Health Plan 2003-2008. Canberra: Australian Government 2003, Key Direction 4.2

contravention of 'Mental health care law: ten basic principles (World Health Organization, 1996b)⁴¹ - Provision of the least restrictive type of mental health care.

The regular practice of consumers being 'voluntary' until they wish to leave, maybe having found that an acute inpatient unit is not helpful to recovery, or until they ask for leave to take care of essentials of living eg housing, income, and if insistent they are scheduled. How often consumers have said 'oh yes, I'm voluntary, but if I try to leave they will make me involuntary'. What is voluntary about being threatened with scheduling if you try to leave? If you are admitted as involuntary you will be informed of your rights under the Mental Health Act but when you are voluntary there is no obligation to inform you of your rights. In the involuntary status services are legally obliged to inform you of your rights, as one nurse has quoted '*It's the CARE principle – cover ass, retain employment*'

I have lost count of the times nurses have been heard to say 'if you don't come here, do this, do that etc you will be put in seclusion/given an injection'. When threats are being used how can there be "proven practice in promoting engagement"? When people are powerless over their own lives, as has been evidenced above, often the only choice left is to say no.

Rights

The rights of people with mental health problems and mental illness should be guaranteed and protected throughout the lifespan and at all times throughout the course of illness and recovery in accordance with the Mental Health Statement of Rights and Responsibilities⁴² and national and international conventions⁴³.

When does coercion beget anything but anger, learned helplessness or surface compliance? When does violence teach anything but passivity or more violence? How congruent is "recovery" with forced isolation or immobility?
(Quote from consumer)

Restraint and seclusion, currently accepted methods for the management of psychiatric patients in this country, meet the DSM IV definition of human-induced traumatic stressors. (Quote from mental health worker)

If we could all (service providers in particular) just recognize and acknowledge that the ordeal of seclusion and restraint is harmful, it would be a wonderful beginning for creating a mental health system that is truly about recovery, wellness, and helping the whole person.

In order to protect and enhance the rights of people with mental health problems and mental illness and children with serious emotional disturbances, the AMHCN recommends the following:

- 38 Protect and enhance the rights of people with mental illness
- 39 Protect against rights violations through effective monitoring, enforcement, and litigation.
- 40 Continue to ensure all States and Territories have legislation and service provision that protects the rights of consumers and the community⁴⁴.
- 41 Enhance rights through effective education, advocacy, and policy change.

⁴¹ Mental Health Legislation & Human Rights – World Health Organization, 2003

⁴² Australian Health Ministers. Mental Health Statement of Rights and Responsibilities. Canberra: Australian Government Publishing Service, 1999.

⁴³ Australian Health Ministers. National Mental Health Plan 2003-2008. Canberra: Australian Government 2003. page 24.

⁴⁴ Australian Health Ministers. National Mental Health Plan 2003-2008. Canberra: Australian Government 2003. page 24. Outcome 24.

Specifically:

- Initiate a comprehensive national mental health consumer rights education and awareness project.
 - Review the adequacy of existing complaints systems⁴⁵.
 - Initiate a state protection and advocacy entity structure to be consumer and family controlled (75% of Board of Directors primary consumers).
 - Pass federal legislation requiring recognition of advance directives and health care attorneys.
 - Address discrimination in insurance (travel and income protection).
 - Pass federal legislation banning ECT on persons under the age of 18 by 2008.
- 42 Pass federal regulations banning seclusion and restraint by 2008.

The techniques normally don't leave any permanent physical scars, but if the practitioners could see the psychological damage done they would know that the treatment causes more harm than good. It is like amputating someone's leg to deal with a broken ankle. The mental condition that you leave with shouldn't be worse than the one you arrived with, but when a human being is treated like a nonhuman, that insult and injury is added on to the diagnosis that you already have. However, it is not acknowledged by anyone but the person who experienced it.

(Quote for a mental health consumer to)

Specifically:

- Promote adoption by jurisdictions of the United States NASMHPD/NTAC Restraint & Seclusion Curriculum, or similar curricula.
- Make available to the public, while respecting confidentiality, all restraint and seclusion events until restraint and seclusion are outlawed.
- Develop a publicly accessible, free database of relevant case law and court decisions regarding rights of persons with mental illness and children with serious emotional disturbances.
- Continue work towards the elimination of force, coercion, and violence in the mental health system, and in those social programs providing housing, employment, and education for persons with mental health problems and mental illness and children with serious emotional disturbances.

⁴⁵ Australian Health Ministers. National Mental Health Plan 2003-2008. Canberra: Australian Government 2003. page 24. Key direction 24.3.

TOR I 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.

Statement:

Discrimination and stigma continue to seriously restrict opportunities for mental health consumers to live, work, socialize, and learn in communities of their choice. To overcome these barriers and fulfil the promise of Outcome 3⁴⁶ of the National Mental Health Plan, 2003-2008, the AMHCN recommends the following:

A. Messages

The key message of such a campaign promotes the concept of recovery and wellness. This includes a focus on:

- vii. Community integration and accessing services
- viii. Mental health recovery education
- ix. Myths including violence
- x. You are not alone
- xi. Normalisation and individuality
- xii. Including a range of mental health problems such as eating disorders, addictions, abuse, and trauma

B. Methods

One on one contact approaches must be the primary strategy for this campaign. These should be: consumer/student developed and implemented; strength based; culturally developed and implemented; focus on putting a face on mental health; and emphasizing positive visibility. Specific recommendations include:

- ix. Grants to state consumer groups at the minimum of \$75,000 to support and evaluate anti-discrimination/anti-stigma efforts
- x. Media outreach focus on getting our story out
- xi. Creative strategies including art shows
- xii. A standardized PowerPoint presentation for speaker bureaus
- xiii. Letter writing templates
- xiv. Use of mainstream and non-traditional media
- xv. Legislative education
- xvi. Developing an anti-stigma toolkit

C. Mediums

Messages and approaches should be transmitted within diverse groups including (alphabetically):

- Consumers, including addressing self-stigma
- Criminal justice system

⁴⁶ Outcome 3: *Increased levels of mental health literacy in the general community and in particular settings, and decreased levels of stigma experienced by people with mental health problems and mental illness.* Australian Health Ministers. National Mental Health Plan 2003-2008. Canberra: Australian Government, 2003.

- Educators
- Employers
- Ethnic communities
- Faith communities
- Gender identity & expression communities
- General public
- Government officials
- Housing authorities
- Local government
- Media
- Members of Parliament (Federal & State)
- Mental health system
- Older adults
- Rural communities
- Sexual minority communities
- Students (primary school, high school, TAFE and university)

D. Modalities

This campaign should build on and expand existing anti-discrimination/anti-stigma activities including, but not limited to:

- i. Mental Illness Education Australia which includes public speaking to high school and college students, publications targeted toward youth, teacher lesson planning, and media partnerships such as MTV;
- ii. Syndicated radio program on public health issues and also available on the Internet
- iii. Consumer/self-help technical assistance centres activities including newsletters, websites, media outreach, and speaking bureaus as well as supporting community based peer operated services
- iv. Activities of many other groups including: MHCA, beyondblue, SANE and state/local organisations
- v. Annual activities including Mental Health Week, World Mental Health Day, Schizophrenia Awareness Week, and other events
- vi. Creative arts & recovery programs

Recommendations

- 42 Advance and implement a national campaign to reduce discrimination and stigma associated with seeking care
- 43 The key message of such a campaign promotes the concept of recovery and wellness. This includes a focus on:
 - Community integration and accessing services

- Mental health recovery education
- Myths including violence
- “You are not alone”
- Normalisation and individuality
- Including a range of mental health problems such as eating disorders, addictions, abuse, and trauma

TOR n the current state of mental health research, the adequacy of its funding and the extent to which best practice is disseminated.

A. Current problems in mental health research

1. Current mental health research stigmatises and discriminates:

- from the consumer perspective, the current mental health research agenda contributes to and perpetuates the pervasive stigma, discrimination and human rights abuses against mental health consumers
- knowledge of the lived experience of consumers, who know about mental health difficulties ‘from the inside’ and are the only source for this unique expertise, should be a vital component of mental health research but our experience, knowledge and voices are currently systematically excluded
- in academic terminology, the lived experience of some phenomenon is known as phenomenology, which recognises the vital importance of the first-person data – and first-person research methods – for a comprehensive understanding of the phenomenon under question, but little of this research is found in mental health research
- this active and deliberate discrimination in current mental health research can be easily demonstrated, and is a major contributor to the widespread stigma and discrimination against consumers in the wider community

2. Medical biases in research are the ideological source of this discrimination:

- current mental health research is dominated by medical research – to see this just ‘follow the money’ and see where it is spent relative to the non-medical research that consumers and many others are crying out for
- but medical science by itself is incapable of researching the first-person data of the lived experience of mental health problems – perhaps the single most neglected area of current mental health research
- the lived experience (first-person data) is recognised as vital in all other human sciences research (e.g. teaching and learning, parenting, gender studies etc) but, curiously, virtually not at all in mental health research
- nor is medical science capable of researching ‘holistic’ approaches to mental health (see below), for which there is great demand from the consumer community, but also from the wider public concerned about mental health promotion and ‘illness’ prevention
- this failure to engage with and research the consumer experience and holistic approaches to mental health is based more on the ideological prejudices of medicine than on good science – prejudices which are dogmatically blind to anything other than the narrow, limited and obsolete notion that only objective, empirical ‘evidence’ is valid evidence(see below)
- these criticisms in no way diminish the importance of good, medical science and research – the problem is how these prejudices, in conjunction with the political power and influence of the medical profession, serve to exclude other vitally important research from the research agenda – and from research budgets
- this situation represents the systematic and deliberate discrimination against some essential research questions, which in turn represents a stigmatising discrimination against the consumer experience and a fundamental failure of current mental health research in Australia

3. 'Evidence based' research is the mechanism of this discrimination:

- 'evidence based' research (and practice) is the current catchcry to justify research proposals – and the funding of them
- the criteria used, however, for what constitutes valid evidence in research are narrowly based on the established criteria defined for medical research, which are inappropriate and inadequate for the vitally important research that is currently neglected, as alluded to above
- for instance, the 'gold standard' for medical research is the randomised control trial (RCT), which is an appropriate standard for testing potentially dangerous new drugs, but utterly inappropriate for researching the lived experience and holistic approaches to mental health – i.e. for researching the two most critical gaps in current mental health research
- that is, the 'evidence based' arguments, as currently defined by medicine, actually serve to narrow the research agenda to the exclusion of other, equally important research for which, as noted, there is a great demand from consumers and from the wider community
- to emphasise this another way, the current 'evidence based' arguments are actually more to do with medical public relations – and winning research funding grants – than they are about establishing the comprehensive research agenda required in mental health
- it is unfortunate that governments and politicians, their bureaucracies in mental health, as well as other funding agencies, have by and large accepted uncritically the narrow, medical 'evidence based' public relations

4. Medical colonisation of the psyche is a consequence of this discrimination:

- medical scientific prejudices, with narrow criteria of what constitutes valid evidence, represent a colonisation of the human experience – of the human psyche (or soul) – that reduces us to our biology and diminishes us all
- it must be noted that such extreme medical prejudices against the subjective, lived experience, against holistic approaches, and against the social cultural and historical contexts of mental health, do not exercise anywhere near as much influence in other human and health sciences as they do in mental health
- teaching and learning, parenting, and gender studies have already been mentioned as examples of where the lived experience and holistic approaches have long had a recognised place in research, but in the last decade or so even physical medicine has a come to recognise the need for research in these areas more than we currently find in mental health research – this is decidedly odd given that mental health difficulties almost always touch our deepest sense of self
- of particular relevance to this inquiry is the relationship between the narrow medical approach to mental health compared with the current 'best practice' approaches, here and around the world, found in fields related to but still largely distinct from mental health – such as drug and alcohol (substance) abuse, victims of torture and trauma, domestic violence and child abuse, to mention just a few
- current best practice in these fields is not medical practice – or, more accurately, is not exclusively medical – but more psychosocial or, once again more accurately, biopsychosocial
- consumer and workers alike in these fields are concerned, and some are quite alarmed, at recent moves to medicalise these very human difficulties – in

substance abuse, even the terminology of 'dual diagnosis' is an indication of the increasing colonisation of our psychic health by medicine

5. Exclusion of the consumer voice is a consequence of this discrimination:

- the medical exclusion of the lived experience, or phenomenology, of mental health difficulties effectively excludes the consumer voice from research, in blatant contradiction to the rhetoric we hear about the need for greater consumer participation in all aspects of mental health – including research
- this exclusion of the consumer voice arises directly from the prevailing research paradigm in medical research, as outlined above, with obvious flow-on discrimination against consumers in mental health services and in the wider community

6. Human rights abuses are a consequence of this discrimination:

- human rights is the single most pressing issue in mental health, especially for consumers but also for many others, such as carers and many in the wider community – and an issue that will feature in many of the other terms of reference of this inquiry
- fundamental human rights that are correctly taken for granted by everyone else in Australian society are currently regularly and routinely denied to mental health consumers
- for consumers, the most significant of these human rights violations is the excessive reliance in the existing mental health system on the use of forced 'treatment' – drugs, electroshock, restraints, seclusion etc
- these forced treatments, or human rights violations, are justified as part of a consumer's treatment plan based on the rationale of the medical model and the judgments of medical practitioners
- all the arguments for forced treatment boil down to it being "for their own good", which is precisely the same argument used to justify the Stolen Generation of aboriginal children and comes from precisely the same patronising and discriminatory attitudes and suffers precisely the same weaknesses
- in Australia in the 21st century, it is not acceptable for fundamental human rights to be denied to citizens by such flimsy arguments
- this and other human rights issues are currently neglected in mental health research but requires urgent and critical attention that cannot be left solely to the medical profession but must include experts in human rights, in law and ethics, as well as mental health consumers and, indeed, the whole community
- the biomedical approach to mental health represents the primary source of many of the most harmful human rights violations in our current mental health system

Recommendations TOR n

44 That a national network of genuine consumer organisations be established and funded

- i. effective consumer participation in mental health research, so neglected but so desperately needed, requires strong consumer organisations at both state and national levels
- ii. there are many other reasons why the mental health consumer community needs these organisations, including (but not limited to)

consumer advocacy, information and education and, perhaps most important of all, for a mutually supportive environment amongst our peers against the current stigma and discrimination against consumers

- iii. these organisations are also required for the essential 'capacity building' of the consumer community so that we can develop the discourse – that is, to find and give voice – in our own spaces in our own language, on the experience of living with mental health difficulties
- iv. this is no different to many other communities in Australian society that have recognised the need, and fought for, their own organisations to advance their basic human rights – examples here include human rights organisations fighting for the rights of women, people with (physical) disabilities, indigenous people, and gay and lesbian people
- v. the mental health consumer community in Australia currently does not have a 'critical mass' of consumer-oriented and consumer-run organisations and this represents one of the greatest weaknesses in our current mental health system
- vi. until we have these organisations, the consumer voice and consumer participation in mental health will continue to be weak and vulnerable to either tokenism, which is commonplace today, or even worse, the also common practice of 'political puppets' who are carefully selected to 'represent' us by those in power who seek to control and silence us
- vii. it needs to be noted that the current pathetic funding for the Australian Mental Health Consumers Network (AMHCN), the genuine consumer organisation that is the national voice for consumers, needs to be seen as part of the continuing and deliberate discrimination against consumers that is a scandal and a national disgrace
- viii. these are harsh words, but they need to be seen in the light of the exorbitant funding in comparison that is received by medical mental health research centres such as the Mental Health Research Institute in Victoria which, for instance, received \$45 million for yet another machine to take even more photos of consumer's brains
- ix. another example is the staggering public funding of 'beyondblue', now approaching \$100 million, which has the temerity to boast about its appalling track record on consumer participation, and is an excellent example of the stigmatising and discriminatory effects of the medical model of mental health as outlined above
- x. these are just two of many examples that illustrate the enormous public investment in promoting a medical model of mental health that actually contributes to the stigma and discrimination against consumer, in contrast to the shameful neglect of any real support for genuine consumer organisations – as noted above, if you want to find the real source of discrimination against consumers, 'follow the money'

45 That a holistic, genuinely consumer-oriented research agenda be established and funded

Given the limited time and space – and resources – to spell out in more detail here what a genuine consumer-oriented research agenda would include, the recommendations here are outlined under the following two headings:

- a) a whole-of-person approach to mental health research; and
- b) a whole-of-community approach to mental health research

Combined, these two categories represent a more holistic approach to understanding and responding to (or ‘treatment’ of, to use the medical jargon) mental health difficulties.

Please note that these recommendations are not proposed instead of but rather as well as the current medical research. Furthermore, these proposals would best be pursued in a spirit of collaboration with current medical research, for a truly holistic approach must be inclusive of all valid contributions, rather than the currently exclusive medical approach. They are emphasised here because mental health consumers regard these issues as vitally important but currently grossly neglected in our existing mental health system, including research.

Also note that this outline is far from exhaustive but is only illustrative of the kinds of research that is currently most neglected and most desperately needed. As indicated in the Recommendation 1 above, in order to flesh out – not to mention prioritise – a more comprehensive research agenda will require much more (genuine) consumer participation, including the strong consumer organisations to enable us to participate more effectively.

46 A whole-of-person approach to mental health research

A whole-of-person approach recognises all aspects of an individual's experience of personal wellbeing – body, mind and spirit. In some ways it is artificial to itemise the elements of this separately as the holistic approach assumes an integrated, balanced harmony of all these elements. As mentioned, the list here is only to indicate what is currently most neglected. There are also some obvious overlaps between the items listed here.

- i. The phenomenology (lived experience) of mental health consumers
 - first and foremost, this requires research into the phenomenology, or lived experience, of mental health difficulties, as alluded to above
 - this requires a genuine appreciation of, and skills with, the first-person data and first-person methods, such as narrative methods, for working with this data
 - this in turn requires genuine participation of consumers in the research process, not just as the objects of research as is typically the case currently, but as major participants in defining the research questions, designing and implementing the studies, and interpreting and communicating the results of the research – that is, consumers are necessary here as co-researchers and principle researchers
- ii. Nutrition, exercise, sleep, play and relaxation for mental health
 - although there is some minimal research into the non-medical biology of mental health, much more can be done – and is being done overseas – to understand the role of nutrition and diet, exercise and sleep, and rest, relaxation and play
- iii. Complementary (alternative) therapies

- there is much demand among consumers for more and better information on, as well as access to, complementary or alternative therapies for both healing and also preventing mental health difficulties
- again, there is some significant research in these areas occurring overseas but we hear little about it and, besides, we need to be doing our own research into these
- a short, initial list of these therapies would include acupuncture and shiatsu, herbs and dietary supplements, homeopathy, kinesiology, massage and other 'bodywork' therapies, yoga and meditation (note the overlap here with the previous item) and many others about which consumers regularly report significant benefits
- in Australia we have many skilled and experienced complementary health practitioners and services, including accredited university courses for some therapies, but as yet they have little presence, and even less specialisation, in the mental health sector

iv. Indigenous ways of understanding mental health

- the wisdom of traditional ways of understanding 'mental health' in indigenous cultures is massively neglected in Australian society – again, this can be largely attributed to the dominance of the medical model
- consumers in other countries, such as New Zealand, report of many significant benefits for all consumers, not just for indigenous populations, through a meaningful engagement with traditional, indigenous wisdom

v. Spirituality

- there is a recognised 'spirituality gap' in mental health where many consumers speak of their struggles in spiritual terms but those we seek help from are professionally unable to engage with us in dialogue about spiritual values and needs
- this connects with the lived experience of mental health struggles and how they often relate to our deepest sense of self – another topic that is central to the consumer experience that medical research is blind to and fails to research
- sensitive spiritual counselling is not religious preaching – it needs to be seen in a similar light to the good work done in recent years around culturally sensitive research, education and practice (although this is another area that requires further development and greater participation of culturally and linguistically diverse (CALD) consumers)

47 A whole-of-community approach to mental health research

As with the whole-of-person approach, the following represents only an initial list of items requiring immediate and urgent attention in both the practice and research into mental health. And once again, overlaps occur between items and indeed with some of the items in the whole-of-person category. For instance, indigenous wisdom and spirituality should also be included here. Similarly, the cultural, social

and historical contexts of our mental health (or otherwise) are personal, individual contexts as well as the community context for consumers. Also, although the issues raised here are addressed to some extent by existing psychosocial services, these services, including research, are also grossly neglected in the existing mental health system for the same reasons – and with the same complaints – that we find from consumers. That is, the biggest obstacle to more and better psychosocial services, including more and better psychosocial research, is the dominance of the medical model and its insatiable appetite for resources.

i. Cultural, social and historical contexts of ‘psychosocial distress’

- this includes a much greater recognition than is currently the case (under the medical model) of the social, cultural and historical origins – as opposed to simply biological explanations – of mental health difficulties, which might more reasonably be called ‘psychosocial distress’ if viewed from the perspective of these contexts
- it therefore requires a better understanding of how a life history that includes things like childhood abuse, domestic violence, trauma and torture, social isolation, poverty and homelessness – it’s a very long list – can impact on our sense of personal wellbeing and trigger feelings and behaviour that are labelled as mental health problems, or even worse under the medical model, as ‘mental illness’

ii. Cultural, social and historical healing of ‘psychosocial distress’

- following directly from understandings arising from the previous item, many effective and much sought after psychosocial approaches offer ways of healing, recovery or rehabilitation (rather than medical notions of treatment or cure) for psychosocial distress
- as with psychosocial services, research into psychosocial approaches to healing, recovery or rehabilitation is very much the ‘poor cousin’ of mental health research – again, medical prejudices and medical power and influence as discrimination

iii. Peer support

- for many consumers, peer support in its many guises is one of the most important and beneficial means for coming to terms with, understanding, accepting, coping with, managing, healing, and/or recovering from mental health difficulties
- the intersubjective space of peer support occasions is well known for its many benefits, but where is the research that examines this and looks for ways to create and facilitate these much sought after opportunities?

iv. Consumer-run services

- a separate recommendation below calls for research into, as well as the implementation of, consumer-run services which are sadly missing from the mental health system here in Australia – but is included here as a vital component of a whole-of-community research agenda

v. Prevention

- there is remarkably little discussion in mental health branches of government bureaucracies, one of the key centres of power for the medical domination of mental health (and mental health research), about the promotion of mental health and wellbeing and the prevention of mental health difficulties
- to some extent, other government and semi-government agencies, such as VicHealth in Victoria and others in 'community development' that seek to address these issues – but their interaction with mental health departments seems to be minimal and limited by very different approaches to understanding mental health
- the nearest mental health bureaucracies seem to get to health promotion and 'illness' prevention strategies are the medically oriented 'early intervention' strategies that are now being quite widely pursued and researched
- research is required to bridge the gaps in our understanding and in the discourse around promotion, prevention, early intervention and recovery
- some guiding principles here have to be the recognition that prevention is much more cost effective than expensive interventions and that prevention is a whole-of-community enterprise

48 That a 'Centre of Excellence of Consumer Studies' be established and funded

In the light of the preceding (incomplete) discussion, there is an identifiable need for a Centre of Excellence, or equivalent, for the research, development, education and training for greater consumer participation in mental health research.

This centre could and should be more than 'just' a research centre, important though research is – it can and should be a centre for the development of the discourse around consumer participation in the mental health system at all levels. The centre would be based on a partnership between genuine mental health consumer organisations (properly resourced ones, that is), state and federal mental health agencies (including promotion and prevention agencies), one or more universities (preferably with a TAFE college), and perhaps with some other non-government or semi-government mental health research centres.

It is essential that within this structure, control of the vision, mission, strategies, projects and activities must always rest with mental health consumers – in particular, situating the centre as a division within an existing mental health research centre that is controlled by proponents of the medical model would completely defeat the purpose of the proposed centre.

49 That research be conducted into consumer-led services

There are quite a few exciting initiatives overseas of consumer-led mental health services, including some that now have a decade or more experience in providing these services and others that have considerable research showing their benefits. These services are much sought after by consumers, especially those looking for non-medical (or less medical) approaches to dealing with their mental health difficulties.

Despite this, there are virtually no consumer-led services in Australia other than a few precious but limited 'drop-in' groups that primarily provide valuable social contact and peer support for consumers. Similarly, there is virtually no significant research in Australia into consumer-led services – but would be addressed as a priority by the Centre of Excellence proposed in the previous recommendation.

50 That human rights research be established and funded

As indicated in the discussion above, given the widespread and systemic human rights violations in the current mental health system, there is an urgent and critical need for appropriate and relevant research into the principles of the basic human rights of mental health consumers. In particular, this research must be conducted not by medical practitioners but by experts in human rights, ethics and the law and must engage fully with mental health consumers and the wider community in this research.

This research must, as a priority, look into the most serious human rights violations that are the use of forced treatment (assault and torture) and forced and arbitrary detention of consumers under the pretence of medical treatment.

This research (which could perhaps best be undertaken in conjunction with the national inquiry into mental health human rights abuses that many consumers are also calling for) also needs to consider many other human rights abuses, whether through neglect, ignorance, incompetence or deliberate abuse, and also ways for monitoring, reporting, responding to them to ensure such abuses are minimised and hopefully eliminated from Australia's mental health system.

51 That funding approximately equivalent to that which has been made available to 'beyondblue' be made available as a matter of urgency

Finally, funding for these recommendations must be mentioned. There is widespread acceptance by everyone involved in mental health in Australia that funding for mental health is grossly inadequate but funding for these recommendations is not only about – and should not be dependent on – major increases in mental health budgets in the immediate future.

As mentioned above, mental health consumers have observed what for us seems staggering public funding for mental health research organisations (such as the MHRI in Victoria) and 'beyondblue', which from the consumer perspective offer few benefits to consumers and little in the way of genuine consumer participation in research – and in the case of 'beyondblue' particularly, considerable public monies are being spent to actually make the stigma and discrimination against consumers worse.

Even without doing the detailed planning and costings – again, consumer organisations lack the resources to even bid effectively for resources – it is clear that all the above recommendations could be commenced and pursued with vigour with the sort of funding that was somehow 'miraculously' discovered for 'beyondblue'.

There can be no doubt that the implementation of these recommendations would be certain to offer more benefits not only to mental health consumers but to the mental health system in general and, indeed, the whole community, than the questionable benefits (not to mention harm) of the failed 'beyondblue' experiment. The final recommendation therefore is that funding approximately equivalent to that which has been made available to 'beyondblue' be made available as a matter of urgency in order to:

- establish a strong 'network of networks' across Australia of genuine, mental health consumer organisations to promote greater consumer participation in all aspects of the mental health system in Australia
- establish a Centre of Excellence for Consumer Studies to further develop and pursue the research agenda as outlined above

TOR p the potential for new modes of delivery of mental health care, including e-technology.

The National Mental Health Plan 2003-2008 is guided by 4 priority themes⁴⁷. These being:

- Promoting mental health and preventing mental health problems and mental illness;
- Increasing service responsiveness;
- Strengthening quality; and
- Fostering research, innovation and sustainability.

These four priority areas, are all areas where if genuine consumer involvement and participation, consumer employment, adequate funding of consumer run services and independent consumer networks took place, will identify a range of potential new modes of delivering mental health care to people with a mental illness (consumers). The potential to encourage, enable and support a range of innovative services organised and run by mental health consumers. Consumers are in many respects currently only included as after thoughts for mental health services, participate only in order for mental health services to tick a box to state they have consumer participation and are often ignored in respect to the vast array of expertise, ideas, suggestions and concerns they hold. For example:

- The “lived” experience of living with a mental illness and receiving mental health services. This is an expertise in itself which is commonly and blatantly ignored by mental health service providers, including management.
- Consumers very sound knowledge, based on genuine consumer participation and partnership principles & philosophies, upholding consumers’ rights including international human rights instruments, consumer advocacy and recovery plus a wide range of knowledge and skills or core precepts, principles, philosophies and concepts which underpin the mental health consumer movement in Australia and Internationally.
- Some mental health consumers have become “experts” in their own right on a vast range of topics and issues. For example:
 - Churchill⁴⁸ Fellows researching consumer advocacy and consumer run services, forensic issues, recovery core principles and philosophies, National Standards for MHS and Policy issues, Research, Surveyors of Health Care Systems and the list goes on.
- The mental health consumer community is not a homogenous group, therefore many consumers hold a diverse range of University degrees, diplomas, certificates, including professional degrees required by mental health service providers, for example: Social Workers, Nurses, Doctors, Psychologists, Researchers, Computer Analysts & Programmers to name but a few.

Consumers have the very real huge potential to not only develop innovative and new modes of delivery of mental health care, including e-technology but also have the real potential to be providing on the ground, feedback, advocacy, representation, service provision and participating as equal members of research teams. Consumers are largely an untapped resource within mental health services, health systems and governments. They are often

⁴⁷ Australian Health Ministers. National Mental Health Plan 2003-2008. Canberra: Australian Government 2003. page 13

⁴⁸ A Churchill Fellowship is the award of an opportunity, through provision of financial support, to enable Australian citizens from all walks of life to travel overseas to undertake an analysis, study or investigation of a project or issue that cannot be readily undertaken in Australia

overlooked as supposedly being “too sick” to: contribute, to have a voice or give a real opinion or even know what they’re actually talking about.

Not only is there potential to develop a range of innovate consumer run mental health services, but also to participate as equal team members of existing mental health service clinical teams is overlooked.

Their feedback to committees and working parties is often ignored and/or the consumer is politely told “we understand” and absolutely nothing is done to implement anything the consumer puts forward. Quite often consumer representatives and consumer advocates and employees have the “simple” solutions which doesn’t take any funding whatsoever however mental health service providers either ignore their ideas and suggestions, create every barrier including quite often a range of legislations or simply don’t ask them in the first place.

The current employment of mental health consumers is so tokenistic it’s an absolute joke. For example, the majority of consumer employees are employed for part time hours; many for example between 4 – 18 hours per week. In one consumer run team the combined total of 4 consumer employee’s hours is 38 hours per week. Not even equivalent to a full time position. Yet this team is expected to perform a range of managerial tasks, advocacy, support services and continually develop new and innovative ways to encourage and enable consumers to participate. However, as soon as the co-ordinator of this team puts forward an idea, the directors request brief after brief be written which usually doesn’t get read and no feedback is provided even as a beginning discussion point. Every idea to develop and enhance consumers opportunities are simply ignored, even if the funding is actually less than \$1,000 for full implementation. Try and obtain more work hours and the mental health service clams up even further.

Examples:

Recovery

- *Pitane Recovery Centre* is the only consumer run recovery centre for consumers in metropolitan Sydney. This centre has no funding whatsoever from mental health services and relies on small community grants, membership fees and fundraising efforts of consumers. Yet this centre is gaining an international reputation due to providing a unique range of recovery activities which consumers not only enjoy but have given very positive feedback. Consumers don’t always want to talk about their mental illness. They want to participate in a wide range of activities which not only socially connects them to their community but test out options they might like to include into their recovery journeys and lifestyles of choice.
- There is enormous scope for governments and mental health services to fund, support and enable consumers and consumer groups to establish recovery centres and develop and host a wide range of recovery activities, develop recovery training for mental health staff (which is based on consumers’ concepts of recovery and doesn’t medicalise recovery which is currently happening within mental health services due to service providers trying to own recovery and understand from a clinical perspective); provide information, self discovery series, education and training to consumers on a wide range of topics including rights, successfully negotiating for the service which meets the individual needs of consumers; breaking out of the welfare and poverty cycle; developing innovative training tools in the process.
- There is also opportunity within such consumer run recovery centres the capacity to employ non-clinical mental health staff as in the Brook Recovery, Empowerment & Development Centre in Brisbane. This centre has non-clinical staff from the community to participate, assist consumers to organise, host and participate in a wide range of recovery activities. This also ensures that recovery does not become a ‘clinical’ concept and create further access to a wide range of information, skills and knowledge

which is community based rather than clinically or even mental health service provision based.

- WRAP⁴⁹ (Wellness Recovery Action Plan) developed by Mary Ellen Copeland from America at present is only being offered by 3 consumer groups within Australia. These being in Perth, Brisbane and Sydney. The experience of the Sydney project is that consumers right across metropolitan Sydney are literally screaming out for such information and to be able to participate. The group successfully sought alternate funding to host a 3rd WRAP group and now has started a waiting list for consumers in order to try and seek funding for a 4th WRAP group. All within the space of 4th months of the project.
- Boston University has developed a range of recovery workbooks which consumers can easily facilitate if given the opportunity. Also the National Empowerment Centre in America.
- There is also scope for mental health consumers to establish support groups for a variety of consumer population groups in order to assist consumers on their recovery journeys. For example, anxiety support groups, beating the blues support groups, handling emotions, consumers with a dual diagnosis and the list is endless.
- A group of consumers deciding not to rely on only the recurrent funding allocated by the mental health service to organise and host a range of activities, started fundraising and have been reasonably successful in obtain small community grants to be able to host a range of activities for other consumers. The directors of the Mental Health Service now expect and have told the consumer group to fundraise for everything, including addressing OH&S issues on the health owned premises that consumers have control of.

Promotion:

- Consumers have a wide range of ideas, knowledge and skills in order to assist and/or develop innovative prevention and promotion activities and services for not only other consumers, mental health services but also the community at large.
- Currently five separate consumer groups in five Australian States are planning and organising "*The Well of Life – Mental Health Parade*" to be hosted simultaneously on the same day in October, 2005. This being to promote positive mental health messages, decrease stigma for people with a mental illness and focus on ability rather than disability.
- Some consumer groups have produced a wide range of innovative training and promotional materials for wide distribution either within the Australian Mental Health Consumer Movement or within their Sector & Area Mental Health Services.
- Consumers have a vastly different approach to mental health promotion to the general community. This approach being primarily focused on promoting positive messages, working wherever possible with journalists and the media, developing a wide range of activities for consumers and the general community to participate in.

Increasing Service Responsiveness:

Responsiveness or the lack thereof is of major concern and interest to mental health consumers. If consumers cannot receive a service when they require a service, they know their mental health wellbeing is placed at serious risk.

⁴⁹ Wellness Recovery Action Planning, Mary Ellen Copeland www.mentalhealthrecovery.com

- Consumers have unique opportunities to establish and develop activities and services to enhance consumers' experiences of receiving a responsive mental health service. These being:
 - Consumer representation at all levels of mental health service committees to provide consumer feedback and input into the delivery of mental health services. For example members of Mental Health Executives, Clinical Practice Improvement Projects, Benchmarking Working Parties, Quality Committees and so forth. More often it is about the consumer representative having to accept what the MHS wants to do rather than the MHS incorporating the consumers' perspective.
 - Consumer advocacy to consumers in inpatient units, community, supported accommodation and rehabilitation services (including long stay psychiatric hospitals). However, the funding for such participation is severely limited and in some areas totally non-existent. Yet, again consumers report if they are employees of the health system they are caught between conflict of interest issues, how to effectively seek the MHS to respond to the situations consumers raise eg. Advocating for consumers to be admitted to more appropriate inpatient units rather than remaining in a seclusion room for seven days. Many MHS and consumer groups have a debate in respect to whether consumer advocates should be independent or employees of the health system in order to effectively carry out their role.
 - Consumer groups and networks have developed a broad range of feedback surveys, currently developing a valid satisfaction tool (MH-COPES) and one network has developed a consumers' issues database which records all issues consumers raise that can be tracked and trended and supplied to the mental health service in reports, which the MHS can begin to address for overall best practice.
 - Some MHS do invite consumer feedback and input into the various ideas being proposed the service would like to implement – however even though consumer participation & partnership has been embedded in national mental health policy for 14 years, consumers and consumer groups across Australia report this is still very adhoc and tokenistic.
- Consumers have a very unique perspective to bring to the table, however, in many instances their perspectives are ignored, the practicality of the strategies for enhanced responsiveness by the MHS are considered often times “too practical and too basic” to actually implement and if they are listened to it is on the ‘rare occasion’.
- For example, one consumer advocate talked about how a group of consumers in an inpatient unit were plotting and scheming to create trouble in the unit and the consumer was informed the reasons being “when the staff, treat us with respect, we will treat the staff with respect”. The MHS were in a total spin, organising for security guards, bringing in extra staff to work the night shift to deal with the ‘crisis’. The consumer advocate reported this all to the Consumer Coordinator who spoke to the Service Director that all the consumers wanted was for the staff to sit down and talk to them, listen to them and treat them with dignity and respect. The Service Director spent time with the consumers on the unit and listened to what they had to say and calm was restored.
- As in the above example, in many respects, consumers state “it’s not about pouring more money into clinical services (especially inpatient beds and inpatient units), it’s more about staff ‘practice’ and ‘attitudes’ and staff need to get back to good clinical practice rather than simply throw their hands up in the air and say “it’s all too hard” or what currently happens bring in the ‘heavies’ – the security guards. They don’t seem

to see that whilst they expect consumers to give respect they in turn have to give respect. *“Respect is a 2 way street not simply a one way, dead end and consumers must follow regardless”*.

- Consumers can be (and in one MHS was) employed to be members of crisis team services or actually run a crisis service for consumers. One consumer run service runs a “phone connections” service for consumers in their area and simply touch base with consumers by phone to see how they’re going and have a chat.
- Consumers have started services such as “home connections” to visit very isolated consumers however MHS staff simply don’t refer consumers to the service. This being despite the fact one of the major issues and dilemmas for a majority of consumers living in the community is they feel very isolated.
- Consumers can be funded to run after hours and weekend activities for consumers and to assist community care co-ordinators.
- Some consumers are employed directly in MHS community teams to visit and talk to consumers alongside the care co-ordinator. However these consumers report they’re expected in many respects to take on the team ‘culture’ and one has to be a very strong consumer employee indeed to ensure the consumers’ perspective/s are upheld within the team.
- MHS staff, regularly report that the cost of funding a clinical person is simply not available, however MHS management do not talk to consumers or seek to work with consumers to develop creative and innovative solutions, for example, employ consumers to work in any of the above, undertake shopping for consumers who have just been discharged from an inpatient unit and so forth. Whilst consumers need to be paid for a fair days work like any other person, the cost is much less than a psychiatrist or a psychologist position.
- In many respects consumer employees are being totally abused by the MHS system. The MHS system is far ‘sicker’ than any consumer will ever be and this is never more apparent than how the system treats consumer employees currently working within the system in Australia. Consumer employees are expected to simply take on the ‘language’ of the service provider and the MHS and deny the language of the consumer movement. They have demands and expectations placed on them which due to the total inflexibility and absolute ‘you have to assimilate’ to our language, our practices and our types of service provision, this eventually results for the consumer employee in simply having to make a choice for which population group they ultimately ‘owe their allegiance’ to. Woe betide the consumer employee who decides the population group happens to be consumers!

Strengthening Quality:

People talk about quality as if it is something new and from another planet. Yet, just like having a recovery focused service, all it is really all about is ‘good clinical practice’. Treat the consumer with dignity and respect, as an adult and a human being, talk to the consumer and ask them what they want to do and work with them rather than controlling them. Then you will have a quality mental health service!! It’s not rocket science, it’s simply basic human courtesy!!

Consumers have a very unique and important role to participate in with respects to assisting MHS to deliver services which are best practice and of high quality. Yet, again consumers report that even if they are included in Quality committees and activities, it is more about the MHS ticking the box to be able to say they have consumer participation and there is a consumer on the committee rather than really taking on board quality improvement issues for consumers.

- The MHS system and its culture is the dominant culture and the supposed participation and partnership with consumers is a farce, rhetoric and extremely tokenistic. In many respects what consumers in the Australian Consumer Movement has been asking is for the MHS system is to respect and listen to the culture and language of the consumers and the consumer movement. Not adopt our language as its own without any understanding of the core precepts, principles and philosophies which underpin the language of the consumer movement thereby medicalising or making it an academic exercise that service providers must go through in order to say they have participation and partnership. Consumers constantly report how MHS inform them how much consumers 'need' them rather than a 2 way street.
- Consumers regularly report that to put any consumer viewpoint it has to be on the terms and ways of the MHS rather than MHS being willing to meet consumers and talk to consumers in any genuine way which allows for consumers and the consumer movement to put forward the consumers' perspectives which will in fact enhance quality and delivery of MHS to consumers receiving a service. Even when consumers do put forward viewpoints every possible barrier is then instituted as to why this viewpoint will not be listened to and incorporated.
 - One consumer group developed a consumers' issues database primarily utilising the computer programme Access, which records all issues raised by consumers in receiving services from the various MHS teams. This initial project was so successful, the MHS included in Area MHS policies for this database and the tracking and trending of all consumers' issues to be available across the Area.
 - Whilst initial support was given by the MHS to further develop the database to be able to do this, the MHS has subsequently informed the group the consumer employee must pay for her own tuition at a college (out of her work hours) to learn the required skills of the Access computer programme to finish the development. No MHS service provider is expected to pay for their own tuition (even though she has said she simply cannot afford this or for that matter the actual time) to be able to utilise a computer programme to develop a database which an Area MHS policy requires in order to record clinical data, for eg. MH-OAT or even develop the actual database the MHS requires clinicians to provide data on! Yet, this is exactly what this consumer and the consumer group is expected to do.
 - Hence even when consumers contribute and develop innovative activities, projects to strengthen the quality of service delivery, the MHS simply throws up barrier after barrier in order to not to fully implement the activity.
- A number of consumers within Australia are trained Consumer Surveyors for Accreditation Organisations. However, the sticking point for a lot of MHS is that in order to have a consumer surveyor as part of the Accreditation Team, the cost of the consumer surveyor is extra. More like the consumer surveyor is an add on. The extra sticking point is the training and the cost of regular ongoing training provided to consumer surveyors.
- Many consumers say, if you want to strengthen the quality of the MHS in Australia then legislate the National Standards for MHS as this is the only way that MHS will actually take these Standards seriously and actually implement them in their entirety. As with the Disability Service Standards which are legislated, disability organisation virtually improved their service delivery overnight. Yet, in mental health the opposite is true.
- Many consumers who have roles within Mental Health Service (MHS) for 10 years plus constantly state: "*MHS are worse now than what they were when they started 10 years ago*". This is a terrible indictment for MHS and service delivery. Services are too quick

to blame lack of funding, rather than look at how they deliver a quality MHS. “They’re too busy talking about what their ‘core’ business is supposed to be than actually providing a core business”.

- Attend a quality meeting and the meeting is usually about anything but ‘quality’. MHS throw around their facts and figures and have their little graphs; however they tend to have to be constantly reminded that there are human beings behind those facts and figures and the graphs. They talk about Continuum of Care but do nothing in ‘real’ terms to ensure there is continuity of care for consumers.
- We’re tired of *‘you have to be patient and accept a shoddy service whilst we soften up the staff’*. Will there ever be a time for staff to hear, do it the right way, treat consumers with dignity and respect, listen and care ‘with’ them or there is the door – go find yourself another job where you don’t do harm to anybody??

Consumers are TIRED of the RHETORIC. WE NEED MORE REALITY AND WANT ACTION.

Recommendations

- 52 Consumers to be funded to develop and drive the recovery training for mental health staff, break down the processes in order to assist the mental health service system and providers to understand the respect the language of consumers and the AMHCN.
- 53 Consumer run recovery centres, activities, consumer networks/groups and consumer run service delivery programmes attract serious and adequate funding and support.
- 54 Enhancement of consumer employment opportunities within the mental health services including consumers as members of existing mental health teams (However these employees have consumer line managers to existing consumer run teams in the area and/or independent line management outside the mental health service entirely in order to retain independence.)
- 55 Consumer advocates remain independent of the mental health service’s system however are funded via the mental health service at adequate levels in order to provide genuine consumer advocacy to consumers they see.
- 56 Further development of existing consumer run teams within mental health services with innovative support structures which ensure and protect the consumers within these teams from taking on a MHS service provider perspective and actions.
- 57 The National Standards for Mental Health Services are legislated as commonwealth legislation in order for their full implementation by Australian mental health services.
- 58 Consumer driven education of mental health services on responding to consumers when the mental health services and systems are in CRISIS.
- 59 Establishment of a National Taskforce to develop Practice Standards for Consumer Employment, including addressing all Human Resource Issues & Practice.
- 60 Establishment of a National Taskforce to establish partnership linkages with all Australian States that has the power to fund and address the development and establishment of innovative consumer run services, including the Non-Government Sector, develop prevention and promotion activities which are consumer run and/or consumer focused.
- 61 For the mental health services to come to the table and be prepared to do things ‘our’ way for a change rather than simply doing everything ‘their’ way. To really listen and hear consumers and support their ideas, suggestions and concerns. If

mental health services were genuine about consumer participation and partnership they would be able to innovatively and seriously address and institute consumer sensitive services and the HR issues of mental health service's staff in the process!!

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