Northern Beaches Mental Health Consumer Network

P.O. Box 1655, Manly NSW 2095 **Ph. 9976 9602 or Fax 9976 9663**
Email : dcasey@doh.health.nsw.gov.au **Mobile 0417 502 178**

Submission to the Federal Senate Inquiry into Mental Health

April, 2005.

Introduction:

The Northern Beaches Mental Health Consumer Network is a group of consumers (people with a mental illness) who are funding to influence mental health service delivery at all levels of the health service. As such the Consumer Network undertook a consumer feedback survey based on the inquiry's terms of reference to all consumers on the 2 mailing lists held by the Network and the following is the collated responses.

Term of Reference : A

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

Why:

"All people in need of mental health care should have access to timely and effective services irrespective of where they live" (National Mental Health Plan, p.10, 2003-2008)

- Funding of mental health services and its subsequent resources is a combined responsibility of both federal and state governments, including policy directions and the addressing of barriers that address the inadequacies of such progress.
- Australia has some of the best mental health policies anywhere in the world, however, the implementation of its policies is where the sticking point really is at. From a consumers' perspective, consumers quote policies left, right and centre to advocate for improved mental health service provision. From a service providers' perspective the policies developed usually do not come with funding attached to actually implement such policies, therefore, service providers who do decide to read the national and state policies and its directions simply do not implement at the grass roots level in a genuine and effective manner, thereby enhancing opportunities for growth, innovative service provision and actually attempting to meet the 'real' needs of consumers.
- Consumers have a lot to contribute to the decisions and service delivery of mental health services, however, in many instances consumer networks, consumer run teams within mental health services are simply add ons to the specific mental health service in order for these services to 'tick the box' they have consumer participation. In doing so mental health services and in fact consumers lose out in the process. This being due to consumers having been there and done that have the 'lived experience' and as such can provide an genuine and valuable role in assisting other mental health consumers on their journeys of recovery, providing consumer advocacy in order that consumers are informed of their rights and support consumers in their attempts of self advocacy in order to receive a service which meets their individual needs.
- Consumers in the feedback survey, the Consumer Network undertook, stated that funding should be provided by both federal and state governments and that the commonwealth needs to allocate more funding to states in order for the above to happen. They gave their reasons for this as follows:

Examples:

- "Because mental health services are appalling – closure of beds, hardly any outpatient services, underpaid and overworked doctors and nurses".
- Consumers feel it is far more "economical in the long run to care for consumers in the community".

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- Consumers feel it is very important for people who are mentally ill to be able to benefit from health services which assist them to becoming well again and able to take up their lives of living in the community and contributing to the wealth of Australian society.
- It is commonly known that the federal government has a surplus, however, also known that the federal government is being extremely tight with this surplus whilst 'real' mental health services on the ground are suffering in the process.
- "The CSDA" agreement needs to reflect the 'real' costs of providing a range of mental health services and supporting mental health consumers in the community"
- Another reason to provide an increased flow through effect between commonwealth and state governments is for the provision of funding to enhance the mental health workforce in order that high quality and sensitive mental health clinicians who understand the national policies and the national directions are employed and actually provide consumer sensitive services to the mental health consumer community.
- State governments are notorious at dealing out 'old money' rather than actually enhancing mental health budgets. Consumers have become extremely cynical of governments (both commonwealth and state) who simply promote how they're increasing funding and when you really get to the centre of what the politicians are saying, it's all recycled funding which was promised a year or two ago, which they trot out when the media circus highlights the inadequacies of the funding regimes for mental health services.
- The biggest mistake of governments is in handing out money hand over fist to simply prop up an ailing mental health system, which is far sicker than any mental health consumer will ever be, and in doing so, simply focuses on inpatient beds.

Recommendations:

- Implement the current policies that have been written and distributed with attached funding to mental health services who do implement these policies in such a way as to provide consumer sensitive services to consumers.
- Undertake a genuine needs and costs analysis of community mental health care and how mental health services can assist consumers to be supported in the community, including providing access to a range of services, i.e. crisis care, community care co-ordination, recovery services, long stay rehabilitation, short stay crisis services in the community (not hospital based), consumer run support services, establishment of support groups for consumers with a variety of mental illnesses and disorders, family care and so forth.

Term of Reference : B

the adequacy of various modes of care for people with a mental illness; in particular prevention, early intervention, acute care, community care, after hours crisis services and respite care

Why:

"For as much as 25 years, we have been talking about continuity of care, but there appears to be little evidence that it happens. Both within service delivery units and between service delivery units, there seem to be a lot of difficulties – particularly between hospitals and clinics and with referrals from hospitals to community clinics. If psychiatric hospitals service one area, and community mental health clinics service another area, people fall in between. Continuity of care is vital to maintaining the human rights of mentally ill people so that they don't fall between services and so that they are not tossed from one unit to the other" (Human Rights & Mental Illness, Report of the National Inquiry into the Human Rights of People with a Mental Illness, 1993, p.302)

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- The Northern Beaches Mental Health Consumer Network in October 2003 hosted a 2 days Consumers' Issues Conference on the Northern Beaches of Sydney. This is what consumers at the conference, literally 10 years on from the HREOC inquiry had to say:

  - The public system is only geared for acute. $$$$. There is a gap between what people expect and what is on offer.
  - Access is a huge issue for consumers, access to community services, access to community crisis services, access to recovery services, access to supported accommodation services, access to rehabilitation services and also access to inpatient services.
  - Call link services to people in hospital when there.
  - Every person needs a care plan.
  - Barriers to access – the squeaky wheel gets the oil. Being articulate, controlled, educated miss out. "Serious" mental illness don't support "wellness" – maintain. Having a carers. Fear of the unknown in services. Lack of private & $. Lack of communications between service providers. $$$$
  - Consumers want flexibility with an individualized service delivery, rather than a delivery model which consumers have to fit into in order to receive a service. They want service providers to listen to them, work to develop opportunities to change and manage mental health wellbeing, increased opportunities to speak to care co-ordinators and assistances to access the relevant services to obtain the support they require which is practical and non-dogmatic.
  - Facilitate access to the life people deserve/have a right to.

- In 2005, consumers responding to the feedback survey for the submission for this inquiry stated the following:
  - Early intervention services which is across the life span and mental illnesses.
  - Prevention services which incorporate services for consumers with a dual diagnosis who can obtain education and prevention services, suicide prevention services which include crisis teams, care – co-ordination, continuity of care, being regarded as a person "seeking attention" rather than "attention seeking" behaviours.
  - Consumer run recovery services, which incorporates consumers accessing information on self esteem, living with a mental illness, weekly support groups.
  - GP's who understand and have knowledge of mental health consumers who are a patient of theirs and actually notice them as human beings. Education and early intervention.

- Hence one can clearly ascertain that in 12 years very little, if anything has changed for mental health consumers living with a mental illness. They are still requesting the same basic access to mental health services that they were requesting 12 years ago. The promise of 12 years ago has never been fully delivered. In fact, consumers expectations were set up only to be summarily dashed because of the failure of governments and health bureaucracies to actually put their money where their mouth is and fund mental health services adequately.

- Consumers constantly talk about continuity of care, follow up and requiring assistance and support to access the most basic of basic services in order to enhance their quality of life and having a lifestyle of choice in order to manage their mental health wellbeing.

- When are governments and health bureaucracies going to deliver on their promise all of those years ago. Consumer employees and consumers in formal consumer representation and consumer advocacy roles constantly talk about how mental health services are worse now than they were 10-12 years ago. However, these consumers are constantly ignored, considered as not knowing what they're talking about and in effect having their voices silenced in order for the status quo to continue.

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- Consumers feel that very little is working at present in respect to mental health services as services 'rock from one crisis to another."

Examples:
Acute Services:

- "It's important that a mentally ill person be treated straight away. They will benefit and everyone concerned will benefit".
- "Extended hours team has times when they say they will ring you back. You could have killed yourself by the time they see you"
- The overwhelming majority of consumers want access to 24 hours crisis services, which will see crisis services coming to the consumers' home in order to assist the consumer in crisis. Consumers cannot revolve their acute phases of illness around existing crisis and extended hours teams operating hours eg. 8am – 10pm.
- An Area Director of one Area Mental Health Service wrote to the local newspaper printed in a sector of his health service, disputing that there was not 24 hours extended care for consumers and families in the sector. He based his 'considerable lack of knowledge' (in consumers' eyes) on the aspect that consumers could contact the sector inpatient unit after the extended hours team had clocked off for the night or make the trip to the emergency department. He quoted that there was no need to enhance the hours of this crisis team because there were few crisis calls made to the inpatient unit. This Area Director failed to understand the following:
  - Consumers refuse to contact the inpatient unit as the staff are either too busy (looking after the consumers in the unit), too bored to really talk, are not skilled in community crisis work and constantly tell consumers to make the trip eg. at 2am to the emergency department of the hospital (when there is little or no public transport to do so).
  - Due to the above consumers ring the local Life Line call centre in order for this organisation's counselors to assist them with their crisis. Because at least the counselor will try and listen to the consumer and what the consumer is actually going through.
- Consumers want a range of options in order to assist them when in crisis. For example: respite care (which consumers know is a 'dirty word' in the health bureaucratic machines); 24 hour crisis services to assist them to remain at home in their own environment as long as possible, consumer run crisis and respite services; consumers as integral members of crisis teams as consumers can relate far quicker and easier to other consumers when in a crisis as well as immediate access to an inpatient bed when required.

Community Services:

- Consumers want consumer run recovery centres which can offer employment opportunities to other consumers in order for all to assist each other on their recovery journeys.
- Consumer participation, accommodation and counseling rather than simply just the medical model of 'observation and review' which currently happens in community health services. Many consumers want to talk to clinicians about what is happening for them and obtain assistance and support to be able to deal with a whole range of life events and situations. Instead what happens is consumers are either simply observed and the only 'small talk' is about the medication the consumer is on and if the consumer is lucky the actual side effects the consumer may or may not be experiencing.
- Consumers suggest a range of 'therapy' groups in the community to assist them and for care co-ordinators and/or the doctor to undertake a home visit when things are too tough for the consumer to make the trek to the community health centre.
- "The funding of (consumer run) recovery services, such as Pitane (Recovery Centre,) at Manly Hospital is important to someone in remission".

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- The current federal government discussions and plans for the DSP & Welfare Reform in order to increase workforce participation by people with a disability (including mental health consumers) it is imperative that the enhancement of community services and consumer run recovery services are funded adequately to support any proposed changes to assist consumers to enter and retain employment in the community.
- Consumers would like consumers providing a range of services, especially after discharge from hospital, for example, assistance with cleaning and shopping, support groups, educational evenings, assistance in the home (especially for parents with a mental illness who have custody of young children).
- Isolation is a very key issue for many consumers. Consumer employees undertaking home visits to consumers especially those who are very isolated within the community; consumer advocacy visits to consumers in order to ensure consumers rights are upheld and encourage and support consumers in their attempts of self advocacy.
- In general mental health services and clinicians tend to ignore consumer run services even if such consumer run services have aspects which will enhance the overall support provided by the mental health service.

Recommendations:

- Reconfiguration of existing community mental health services to reflect the needs of consumers accessing services, which allows for continuity of care for individual consumers.
- Enhancement of consumer run services including consumer run recovery services provided by consumers which assist these services to work in a more effective partnership with traditional mental health services provided.
- Early intervention, prevention and promotion, including access to community services prior to becoming acutely unwell, innovative crisis care services to maintain consumers in their own homes for as long as possible, including community homes for consumers to be able to obtain more informal acute care prior to any admission to an inpatient unit be developed and implemented.
- Crisis teams be funded to operate 24 hours, 7 days per week and have adequate staffing levels in order for this to operate successfully for consumers and the mental health service.
- Early intervention services for consumers across the life span and across all mental illnesses.
- Consumers as educators and trainers to assist in the training of mental health service providers (including Directors) of recovery focus services, how to provide consumer sensitive services and also to influence and promote consumer participation and partnerships from the individual treatment and recovery levels to all levels of the health service.
- Consumer participation and partnership be reflected as genuine culture change agents, which acknowledge the core precepts, principles and philosophies of the Australian Mental Health Consumer Movement within existing mental health services and service provision. This participation be more on “consumers’ terms” rather than bureaucrats terms who lack the knowledge and understanding that genuine consumer participation will in fact assist them to enhance staff morale, staff participation and in fact staff service delivery.
- In other words – it’s about time, bureaucrats and service providers actually acknowledge consumers’ expertise (whose participatory culture enhances genuine participation and involvement which incorporates a wholistic approach) and came to the table as a genuine partner rather than as the ‘dominant force’ insisting on imposing a very sick culture on consumer participation and involvement.

Term of Reference : C

opportunities for improving co-ordination and delivery of funding and services at all levels of government to ensure appropriate and comprehensive care is provided throughout the episode of care

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Why:

"Mental health care should be responsive to the continuing and differing needs of consumers, families and carers, and communities" (National Mental Health Plan, 2003-2008, p.11)

- Please see response to terms of reference B.

- One of the biggest sticking points for mental health services including community non-government organisations, is that the co-ordination of funding between commonwealth and state governments via the CSDA agreement is an absolute bureaucratic nightmare, full of gaps, centers more on "let's try and short change this government or that health service provider" than actually adequate funding in 'real' terms the 'real' costs of mental health service delivery that meets the needs of people with a mental illness.
- There requires to be more of a streamlined effect that mental health budgets are not only enhanced via the consumer price index and population health basis in relation to the cost of services but budgets are enhanced also via an acknowledgement of the actual needs of the community trying to access services. This being that communities are not disadvantaged simply because their population base may not be staggeringly different to years gone by, but by the needs of the population residing in these communities.
- Hence, mental health services are adequately funded to 'meet the needs' of the community and mental health consumers residing in the community rather than deny access to the most basic mental health care due to the increased demand placed upon services and clinicians who simply don't have the resources to meet the ever increasing demand.
- The continual discussions on what exactly is the 'core business' of a mental health service is simply another way to create a barrier for mental health consumers to access services which meets their continual and possibly even ongoing needs. This discussion needs to be taken out of the hands of clinicians and bureaucrats and placed into the hands of the consumers with all coming to the table to brainstorm, develop and implement creative solutions to enhance the delivery of streamlined services which enhances continuity of care for consumers.
    - Consumers talk about consumer run recovery services, including consumer advocacy services, and services which provide assistance and activities in order to re-enter the workforce. They also talk about care co-ordination and access to acute services (as required).

Examples:

- What consumers feel currently works well is:
    - Early intervention services for young people (however would like to see this across the life span).
    - Pitane Recovery Centre (a consumer run recovery centre based on the grounds of Manly Hospital) and Pioneer Clubhouse (a non-government organisation whose primary focus is as an specialist employment mental health organisation).
    - At times the sector inpatient unit (East Wing), the Clopine Clinic and for the most part the Extended Hours Team (crisis team) and a community health centre at Queenscliff.
    - Having good access to community care co-ordinators (when assigned one).
    - Consumer advocacy visits to consumers in their own homes, or supported accommodation homes.
    - The Consumer Network whose primary focus is influencing service delivery.
    - Consumer Participation Service which is the consumer run team within the Northern Beaches MHS (who has primary responsibility for Pitane Recovery Centre, undertakes phone connections, home connections and a small range of social activities, as well as provides consumer advocacy to consumers residing in the supported accommodation homes.
    - "Encouragement to the patient such as Pitane at Manly Hospital".

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- "There is very little cohesive care co-ordination and follow up. Mental health service ignores consumer run services".

- What consumers feel doesn't work well for them is:
  - Being isolated.
  - Lack of privacy in the aged care inpatient unit.
  - "Communication between doctors, patients/consumers and family and carers. Because family members are usually the winners rather than the patient".
  - Services not be funded well enough in order to be readily accessible.
  - Doctors and nurses who are overworked and underpaid.

- The lack of enhanced continuity of care leads to consumers obtaining the perception from mental health providers that they are 'no hopers'.
- Consumers on the Northern Beaches throughout the feedback survey for this submission commented on Pitane Recovery Centre (which is a consumer run recovery centre) and how everyone is doing well at Pitane.
- Consumers state "Services (are) not funded well enough to be readily accessible".
- Maybe if services stopped looking at providing consumers a service as an "episode of care" and rather views providing consumers a service as a journey in the consumers' life, maybe then governments, bureaucrats and clinicians will enhance their delivery of service.
- This being they would fit the service around the 'needs of the consumer' rather than insist the consumer fit their needs around the service.
- Consumers are not always in 'crisis' however funding is really only for when consumers are in such a crisis they require hospitalization.

Recommendations:
- "Recognise unique role consumers can bring because of lived experience".
- Fund Pitane Recovery Centre to be able to employ (job share) a full time non-clinical support worker and provide an enhanced co-ordination and liaison roles.
- Clarify role for 'care co-ordination' and change name to 'assist'/'support worker' (explore models already out there).
- Work with health/educational institutions to develop a training package suitable for the role." (Consumers, 2 Days Consumers' Issues Conference Report, October, p.17, 2003)
- Exploration of a range of care co-ordination options which actually enhance consumers' recovery journeys and these options be fully funded rather than an add on to what currently exists (or lack there of).
- Continuity of care be such that there is more support for consumers in the home upon discharge from an acute inpatient unit.
- Primary focus of government funding be based on community continuity of care and including fully funding consumer run services and consumer run recovery services.
- Mental health services required to stop talking about what their 'core business' is and actually begin talking about how they can best serve the needs of community in which their service is to be provided, including addresses access and attitudinal barriers consumers experience in order to receive a service.

Term of Reference : D
the appropriate role of the private and non-government sectors.

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Why:

- Generally the role of the non-government sector in the matter of mental health service provision does have a unique role in which to provide a range of community services to consumers living in the community. This being so, the inquiry might like to investigate further the CSDA agreement and how the funding under this agreement creates huge barriers for non-government organisations to obtain the relevant funding in order to provide mental health services to consumers.
- The role of private mental health services is such that unless mental health consumers have a private income, have employment which affords them paying for private health care, then the private mental health services are simply way out of the reach of mental health consumers. Private psychiatrists now do not either 'bulk bill' or allow for Medicare funding to be paid prior to the consumer paying the gap between the scheduled fee and the psychiatrist's rate.
- Another aspect of the role of the non-government sector is because both commonwealth and state governments have squeezed the mental health funding dollar so tightly, state governments have decided to shift the burden of care and the burden of costs to the non-government sector rather than fully fund public mental health care. In doing so, due to the non-government sector being adequately funded to cope with the burden of care, some non-government organisations are providing sub standard mental health care in the process or again moving along the lines of the public mental health system and deciding what is their 'core business' and who will or who will not receive a service.
- Inadequate training of staff, who in the main are not clinicians, is also an issue in the non-government sector. Staff are even more poorly paid than their public service counterparts (even if they do hold the same or similar professional degrees).
- There is a real niche for non-government organisations – mental health focused who provide a range of recovery services for mental health consumers.

Examples:

- Non-government organisations such as PRA (Psychiatric Rehabilitation Association) and Pioneer Clubhouse provide a range of services to support and encourage consumers on their recovery pathways.
- Recovery is about action and non-government services tend to be more 'action' focused than their public mental health service counterparts who appear to all intents and purposes more focused on 'clinical' care rather than providing a range of options for consumers to participate and become involved in.
- .
- Non-government organisations continually talk about the lack of access by public mental health services they can access for the consumers accessing their organisation.
- Other issues such as the lack of memorandums of understanding which clearly sets out the roles and responsibilities of non-government organisations and public mental health services confuse all – consumers, service providers and the community organisations in question as to what services are provided and how consumers can access the services which meets their individual needs.

Recommendations:

- The Medicare rebate to be reviewed to lessen the gap between public and private mental health services, with the private psychiatrists being more accessible to consumers on the DSP.
- Private psychiatrists, psychologists, counselors be funded to work part time hours in public mental health services in order to increase and enhance access for consumers who cannot afford private health insurance and the gap between the scheduled fee and the fee of the private clinician.

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- Memorandums of Understanding which clearly articulates the roles and responsibilities of the non-government organisation and the public mental health service in the local community.
- Clarification of the role of non-government organisations and what they can provide which meets the individual needs of consumers and not have consumers as the pawns (or meats in the sandwich) having to access inappropriate community services due to the lack of available services which meets their individual needs or stages on their recovery journeys.
- Pubic mental health services adequately fund community organisations if they are not going to provide a specific service required by the community.
- CSDA agreement be streamlined that there is adequate funding with safeguards to ensure that community organisations do meet the needs of the consumers in the community they are operating in which enhances the range and delivery of a wide range of services.

Term of Reference : E
the extent to which unmet need in supported accommodation, employment, family and social support services, is a barrier to better mental health outcomes

Why:

"Mental health warrants a resource base that reflects the impacts of mental health problems and mental illness on individuals, their families and carers, and the community. Resources are necessary to support the reduction of these impacts, and should be related to defined need. Resources should be directed at services and interventions – across the spectrum from mental health promotion and mental illness prevention to recovery and relapse prevention ….." (National Mental Health Plan, 2003 – 2008, p.12)..

Please refer to all terms of references above:

Accommodation Issues including supported accommodation:

- An area where is there is a very heavy emphasis in NSW is shifting supported accommodation services to the non-government sector, where there are quite a few non-government organisations (please contact to be given the names and details of these organisations) who literally refuse to maintain and upkeep properties, furniture and equipment and so forth – even though the residents pay their rent. Subsequently consumers are virtually living in sub standard accommodation and in some instances actual squalor not of their own doing, but because the organisation refuses to continually maintain the properties to a decent and/or high standard.

Consumers at the 2 Days Consumers' Issues Conference discussed a range of barriers for accommodation including supported accommodation and consumers residing in Dept. of Housing complexes. These issues are summarized as follow:

- "Department of Housing evicting consumers whilst they are demolishing houses and not rebuilding.
- Discrimination issues.
- Consumers from culturally & linguistically diverse backgrounds have major issues with discrimination & poverty.
- Lack of resources.
- Need for more supported accommodation homes.
- Accessibility from service providers is much easier than a consumer.
- Range of combination styles of housing required" (October 2003, p.7)

(The) 2 Main Issues (being):

- Discrimination for people with a mental disorder and also from a culturally & linguistically diverse background.

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o Lack of resources" (October 2003, p.7).

- Consumers talk about a range of accommodation options in order to reside in the community as full and equal participants in Australian society. These options range from:
  - a range of community dwellings, eg. living alone to sharing with another, in units and terrace homes.
  - to a range of small supported accommodation dwellings (no more than 2-3 people) which consumers 'invite' staff to enter and assist them with their attempts of successful community living
  - to a range of transitional accommodation in order to obtain some of the most basic skills however have the capacity to move to more permanent accommodation when ready and
  - to a range of community acute or crisis accommodation prior to admission to an inpatient unit and post discharge if required.
- Consumers really do not talk about living in 'hostel' or 'half way houses' type of accommodation. Consumers like everybody else want to live beside the ordinary person in community and have access to a range of community activities like every other person in the community. This being that in many instances, consumers whilst they like the support of other consumers, prefer to live in accommodation which sees them mixing with a broad cross spectrum of Australian society rather than simply living with a group of people with a mental illness.
- More often than not, it is service providers or families who decide that consumers require '24 hour' supported accommodation rather than consumers. In many instances if the community support was available, including access to a 24 hour phone connection service (not crisis or therapeutic service) and provided in a manner which not only meets the needs of the individual consumer but also is sensitive to the consumer's lifestyle and based on consumers' choices, then 24 hour support would in fact not be required.
- Many supported accommodation services provided focus on the handling of medication rather than the recovery journey for the consumer. In fact, the staff tend to rock in and rock out dishing out the medication to the consumer (even if the consumer is living in their own home) rather than taking the time to talk to consumers and encouraging and supporting consumers to create and live a lifestyle of their choice which assists their mental health wellbeing and manage their mental illness.

Employment issues, including supported employment:

- The role of the non-government sector is best seen in the provision of employment programmes for people with a mental illness. For example, Clubhouses and other supported employment organisations. However in saying this, the current trend of the federal government with job network is to fund large multi faceted community organisations for mental health consumers to access rather than specialist mental health organisations. The danger, which is already being experienced in the mental health community, is that these large organisations have no understanding of mental illness, mental health consumers and refuse to train their staff in how to support and assist a mental health consumer to obtain and retain open employment.

Support Services:

- There is a real niche for consumer run organisations to run a range of consumer services to people with a mental illness, which incorporate aspects such as:
  - Phone connections – to touch base with consumers via a friendly phone call
  - Home connections – to visit very isolated consumers and support and tap these consumers into a community activity of their choice.
  - Social activities including after hours and weekend activities.
  - Recovery activities, for example, gentle connections, creative writing, self discovery series, WRAP Groups (Wellness Recovery Action Plan),

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- Consumer advocacy services who primary focus is to uphold the rights of the consumer to receive a service.
- Organising and hosting a range of information and education series for consumers, staff and service providers on consumer participation, partnership and involvement at the individual treatment and recovery levels.

Examples:

Accommodation:

- Supported accommodation options tend to revolve around the needs of the organisation rather than around the needs of the consumers, including the lack of ongoing maintenance of properties.
- Property management, which some might argue should not be in the hands of clinicians in public mental health services, tends to ensure the accommodation is of higher standard due to the rent money continually being utilised for upkeep and maintenance of properties. However, in stating this, there appears to be a real need for public mental health service supported accommodation to employ a specific person (non-clinical) who has a co-ordination role in ensuring that all the needs of the consumers residing in the property (to do with property maintenance, upkeep) are met.

Employment:

- Job Network contacts are now being awarded by the commonwealth to large non-government institutions rather than to specialist mental health service providers in the non-government sector.
- This being public mental health services are inappropriately referring consumers to employment organisations when these consumers require other types of community and social supports and are simply not ready to even begin the necessary steps required to obtain support to obtain employment.

Support Services:

- Issues such as the lack of drop in centers or centers for consumers to access rather than supported employment organisations is becoming even more of an issue as time goes on. Instead what appears to be happening is existing community organisations are becoming the 'dumping ground' for a cost shift and to hide the lack of available public mental health services and the consumers get caught up in the middle.

- This being public mental health services are inappropriately referring consumers to employment organisations when these consumers require other types of community and social supports and are simply not ready to even begin the necessary steps required to obtain support to obtain employment.

Recommendations:

Accommodation:

2 Main Recommendations from the Conference Delegates were:

- "Education and training for all parties (service providers, consumers) on discrimination, advocacy and access issues. Tenancy rights should be upheld.
- Monitoring and evaluating and reporting of same". (October 2003, p.7)

- Employment of property managers/co-ordinators in public mental health service accommodation services.

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Employment:

- Job Network contracts for people with a mental illness remain with specialists non-government mental health organisations.

Support Services

- Consumer run recovery centre (eg. Pitane) and consumer run services to be funded to develop and provide a range of recovery activities and innovative services for mental health consumers.
- Consumers be given the skills and information on establishing such centres and also the processes and provided with support to incorporate such centres if required.
- The funding of community drop in centres which people with a mental illness can also access.

Term of Reference : F

the special needs of groups such as children, adolescents, the aged, Indigenous Australians, the socially and geographically isolated and of people with complex and co-morbid conditions and drug and alcohol dependence.

Why:

"Attention needs to be given to people with specific problems such as (dual diagnosis). There need to be specific services for people (with mental illness and chemical addiction) – with staff who are trained adequately to deal with people who have those dual problems. At present such patients fall between services with the mental health services saying, 'well, look, really they have got an alcohol problem: it is not fur us, it is more for you; and the alcohol services saying 'it is really a mental health problem, not their alcohol'. I think there ought to be a designated service … attached to the mental health services (with staff who are) specially trained to deal with the unique problems of that particular group" (Human Rights Inquiry & People with Mental Illness, Report of the National Inquiry into the Human Rights of People with Mental Illness, 1993, p.664-665).

- This report went further to state that one of the major problems for people with a dual diagnosis is the '… lack of communication between mental health and drug and alcohol fields …." (opcit.)
- Consumers ask what has really changed in 12 years? Very little, if anything whatsoever. Consumers with a dual diagnosis continue to fall through the cracks (gaps) in the system, thereby are denied relevant service provision to meet their needs.
- Mental health and Drug & Alcohol services appear to be starting to try and communicate with each other via developing "pathways to care" for consumers with a dual diagnosis, however the reality is that these pathways currently still remain all bar non-existent.

Examples:

- The consumer most at risk of being evicted from Department of Housing complexes is the consumer with a dual diagnosis, who simply does not have the required supports which meets their individual needs in order to retain successful tenancies. Hence, accommodation becomes a huge factor for consumers with a dual diagnosis.
- A consumer can identify more easily with other consumers, therefore consumer run support services for consumers with a dual diagnosis can increase access and enhance consumers on their recovery journeys, including being able to effectively maintain their mental health wellbeing and manage living with a dual disorder.

Consumers reported at the 2 Days Consumers' Issues Conference which the Northern Beaches Mental Health Consumer Network hosted in October 2003 the main issues for consumers with a dual diagnosis are as follows:

P.O. Box 1655, Manly NSW 2095 **Ph. 9976 9602 or Fax 9976 9663**
Email : dcasey@doh.health.nsw.gov.au **Mobile 0417 502 178**

- "Not much into anywhere – eg. mental health, drug & alcohol, community, internet.
- Lack of information re long term use of substances on health, mental health in the elderly.
- People tend to be passed from service to service.
- Limited dual diagnosis units/services – GROW, John Fletcher Hospital.
- National comorbidity taskforce – to improve quality of life of people affected by mental health and substance use.
- Different practices, funding, reporting, education, communication between the two services.
- Lack of consumer focus.
- Mental health and Drug & Alcohol services very separate – difficult to address problems so inter-related.
- Self medication – reasons for.
- Lack of support, understanding from mental health services.
- People are only "half treated".
- Easy access to drugs on wards.
- Various substance use – cause of result of illness?
- What is the real reason for psychosis?
- People prioritizing drug use over basic needs eg. food, housing.
- Lack of information in community about substances use of impact on mental health" (p.25-25)

Recommendations:

- Via the feedback survey for this inquiry consumers called for enhanced accessibility to a range of 12 step programmes, including gamblers anonymous for consumers with a gambling problem;
- Specialized centres with relevant qualified staff for consumers with a dual diagnosis to be able to access.
- A specialized care co-ordination team specifically for consumers with a dual diagnosis with consumer support workers working with this team.
- Consumer run support groups for consumers with a dual diagnosis which attracts relevant funding in order to continue.
- Recommendations by consumers at the Consumers' Issues Conference were:
  - "More training for staff in mental health and drug & alcohol. Need to have a consumer focus – "comorbidity". More services. Service delivery planned in joint fashion – mental health, drug & alcohol, non-government organisations.
  - More education information. More services. Ask Consumers what do you need? Nothing About Us Without Us" (October, 2003, p. 26).

Term of Reference : G

the role and adequacy of training and support for primary carers in the treatment, recovery and support of people with a mental illness

Why:

- Whilst this terms of reference primarily is for carers in the mental health community to respond to, the Consumer Network asked in its feedback survey how consumers perceive what the role of carers is in regards to participating in the consumer who is the family member individual treatment and recovery as well as what education needs to be provided to carers in order to encourage and support the consumer.

P.O. Box 1655, Manly NSW 2095 **Ph. 9976 9602 or Fax 9976 9663**
Email : dcasey@doh.health.nsw.gov.au **Mobile 0417 502 178**

Examples:

- Consumers stated that mental health services either can give no information or the wrong information to carers and this makes it difficult for the consumers to live and manage their mental health wellbeing.
- "It's important for a carer, family member or other to be informed, not only to help the consumer, but to educate themselves".
- Another reason stated is due to "communication breakdowns" and there is a "lack of commitment, money, energy and creativity".
- Many carers treat the family member who is a consumer as if they have suddenly lost their adult status as like other siblings and tend to "over protect" the consumer, treat the consumer as if still a child and operate more from feelings of guilt of having brought into this world a person who has developed a mental illness rather than a human being who is capable of anything s/he puts their minds to despite the fact of living with a disability.
- Many consumers like their carers to be involved, however, want to reserve the right to not have their carers involved in every aspect of their treatment and recovery, however carers and mental health service providers tend to totally step on such boundary issues and ignore the consumer's wishes of when s/he would like to have their carer involved and when s/he would prefer not to.
- Carers talk about their rights as being a carer of a person with a mental illness, however, in many instances they are really confused on where the boundaries lie in respect to their rights and the actual rights of the consumer they are a carer for. For example, some carers consider they have a right to attend in person every appointment with the consumer accessing their doctor or care co-ordinator, expect mental health service providers to give them every piece of information about the consumer and his/her life without due respect and acknowledgement, that the consumer also has a right to not only be treated as an adult but the right to privacy.
- Carers are insisting they're incorporated into State mental health legislation, however, currently they are adequately provided for in such legislation. The difficulties are that there is a lack of education of consumers, carers and service providers on how and when carers can be involved, who provides the consent for such involvement and where the actual boundaries lie in respect to upholding consumers' rights in the process.
- Many aging carers are extremely worried what will happen to their son or daughter however nobody has been able to assist these carers to understand that the majority of the problem is that the carers refuse to 'bow out' of the consumer's life and living with a mental illness in order to allow the consumer to get on with their life independently of the carer and other family members, however retain the support of their family in the process. These carers not only do the consumers a huge disservice but also themselves and their families.

Recommendations:

- Education to be provided to carers, family members and significant others on the following:
  - The effects of living with a mental illness, the stigma, the debilitation, the lack of opportunity i.e. accommodation, employment.
  - Information on a range of various types of mental illness including post traumatic stress and trauma induced psychosis and medication issues.
  - Consumers are in fact adults and treated as such who are able to make their own decisions and lead their own lives. For carers to "support and encouraging the consumer and not tell the consumer what they can't do. Grief counseling".
  - To assist carers to be "patient and understand pressuring us does not help. Saying things like 'get a life' is unhelpful".
- Support groups for carers, family members and significant others where they can obtain the "best information".
- "Help in the home so everyone can get on with their life".

P.O. Box 1655, Manly NSW 2095 **Ph. 9976 9602 or Fax 9976 9663**
Email : dcasey@doh.health.nsw.gov.au **Mobile 0417 502 178**

- Retain current mental health legislation in respect to carers involvement, however provide a range of education and training to consumers, carers and service providers in respect to how carers can be involved, the right of the consumer not to consent to carer involvement, and the actual boundaries of how carers can be involved which maintains the dignity and worth of the adult consumer to participate in their own care, treatment and recovery without over emphasis placed on carer involvement.
- Carers receive relevant support, grief counseling and so forth in order to assist them to view the consumer to be able to live their own lives as fully functioning adults within Australian society who have ability rather than focusing on disability.

Term of Reference : H
the role of primary health care in promotion, prevention, early detection and chronic care management

Why:
"Mental health promotion aims to protect, support and sustain the emotional and social wellbeing of the population, from the earliest years through adult life to old age. It should address people who are currently well, those at risk of developing a mental health problem, and those experiencing mental health problems or mental illness" (National Mental Health Plan, 2003-2008, p.16)

- Mental illness and living with a mental illness is still very isolating and consumers incur a lot of stigma, discrimination and down right lack of empathy from all sections of society, including mental health service providers. They can be treated tokenistically, informed they have no expertise and are incapable of living a quality lifestyle of their choice, have their right to make choices and their own decisions taken from them and the right to have affordable accommodation, employment and the financial acumen to access a wide range of community activities which are offered to the general community.
- Mental health services quite often utilise the argument that if they heavily promote what is available and mental illness then there will be an increased demand placed upon their services by people in the community. Therefore, don't promote, don't try and really de-stigmatise mental illness and don't try and provide a service to people in the community prior to the person becoming so acutely unwell that they subsequently require more intensive interventions and possibly even for a longer period!
- Population health promotion whilst promoting positive mental health wellbeing, can subsequently deny the reality that some people actually do have a mental illness and require early intervention, prevention and recovery services to assist these consumers to have a quality lifestyle of choice.
- General health promotion is more about utilising a 'softening' approach and describing mental illness as social and emotional wellbeing thereby denying that mental health wellbeing is also part of the whole for a human being. This is especially worrying as general health promotion is gaining wider acceptance, including in mental health services, as the approach to utilise which can in effect turn the clock back more than 30 years for mental health consumers, re-stigmatise and increasingly marginalize those who live with a mental illness and socially and emotionally isolating mental health consumers from the general community. By the way "nerves actually don't break".
- The other aspect of this is if mental illness is based on social and emotional wellbeing, there is a huge danger of regarding any person with a mental illness as having a 'behaviour' problem thereby denying the most relevant care and support to the consumer. A classic and extreme example of this is the Cornelia Rau affair who was denied treatment and care for more than 12 months due to a range of government departments viewing her mental illness symptoms as a 'behaviour problem' rather than a woman who was very seriously acutely unwell.

P.O. Box 1655, Manly NSW 2095 **Ph. 9976 9602 or Fax 9976 9663**
Email : dcasey@doh.health.nsw.gov.au **Mobile 0417 502 178**

Examples:

- The overwhelming majority of consumers who responded to the feedback survey for this submission responded that mental health services has a role in promoting to the community positive messages about people with a mental illness. Respondents gave a range of promotions they would like to see governments and mental health services undertake. These being:
  - Media campaigns, including television and radio, advertising promoting positive mental health messages. (Please note under the first National Mental Health Strategy there was a highly regarded by consumers media campaign promoting positive mental health messages of consumers having ability and contributing in the community, which was subsequently withdrawn by government. Many consumers still talk about this media campaign as it de-stigmatised mental illness and have since its withdrawal advocated for this campaign to be reinstituted.)
  - Talks and presentations given to school children, the business community, organisations within the community about mental illness, mental health wellbeing and living with a mental illness.
  - Articles, for example, “On A Wing & A Prayer” which is written by print media journalists which highlight mental illness, service provision or lack thereof, in order to raise community awareness.
  - More interaction between doctors and consumers in a public environment.
  - A range of innovative promotional community activities including Expos, positive news stories, the range of mental health services provided and community discussion and debate on mental illness and living with a mental illness in order to reduce stigma and discrimination.
- Consumers via the feedback survey gave a range of ideas and actions consumers can undertake to promote and support consumers in mental health service and promote recovery for consumers. These being:
  - Consumer advocacy and also a consumer run accommodation service for consumers with a dual diagnosis.
  - Support groups and discussion groups.
  - Networking, education, training and self discovery series of information provision.
  - More activities run by consumers for consumers including self discovery series
  - Consumers talking about and giving examples of recovery journeys to consumers who are not as well.
  - “Talk about their illness without shame but not make it so serious. Try and learn from each other”.
  - “Such groups such as Pitane give patients (consumers) the opportunity to share their feelings”.

Recommendations:

- Consumers be involved in developing innovative media campaigns which not only promote positive mental health messages but also promote acceptance of people with a mental illness within the Australian community as full contributors to the fabric of Australian society and the communities in which they reside in.
- Health promotion incorporate social, emotional and mental health wellbeing approach in order to promote positive wellbeing to the general community.
- Acceptance by mental health services, which incorporates consumer participation, involvement and input, that they actively promote and can assist in early intervention, prevention and lessen the period of consumers requiring acute and/or long term assistance in order to maintain mental health wellbeing.

P.O. Box 1655, Manly NSW 2095 **Ph. 9976 9602 or Fax 9976 9663**
Email : dcasey@doh.health.nsw.gov.au **Mobile 0417 502 178**

Term of Reference : I
opportunities for reducing the effects of iatrogenesis and promoting recovery-focussed care through consumer involvement, peer support and education of the mental health workforce, and for services to be consumer-operated

Why:
Our understanding of this term of reference is that mental health services and clinicians are to "Do No Harm" to the consumer who accesses the service and enhance the consumer's journey of wellness and recovery. This being so, there surely can be no argument that in many instances the reverse is quite often the experience of mental health consumers.

Definition of Partnership:
"Essentially,
Consumer involvement is about the ways and means of creating partnership:
Of consumers being actively involved.
- In decision making about service provision, and, more completely ….
- In decision making about choices which affect their lives.

There are several cricitcal elements involved in the *creating of partnership.* These include:
- The need to organize
- The overcoming of discrimination
- The identification of attitudinal barriers
- Shaking off the bogey of tokenism" (Janet Meagher, Partnership or Pretence, 1993, p.18)

- Some consumers get well 'despite the mental health services provided and/or the lack thereof".

- Others, take many years to actually undertake any steps on their journeys of recovery and mental health wellbeing due in the main to the fact that mental health service provision does the most harm, can be considered, more in the lines of placing a pseudo power and control mechanisms upon the consumer and totally ignore consumers' choices, decisions and are quite disrespectful of consumers' lives.

Examples:
- It is not uncommon that consumers accessing a consumer group have low self esteem, lack the basic knowledge of their rights and how to negotiate for their individual needs to be met, have great difficulties in many respects the ability to think for themselves and access a range of network opportunities with a wide range of consumers in order to enhance their own thinking on a range of consumers' issues, core precepts, principles & philosophies of the Australian mental health consumer movement and how these sit with them as individuals and as participants of a wider consumer movement.
- It is not uncommon for mental health consumers to simply 'give up' and take the path of 'least resistance' due to being worn down and often time worn out by mental health services who impose their ideas, concepts, decisions and power on the consumer in order to control not only the so called 'chemical imbalance' but to ensure consumers are 'compliant' little consumers who simply 'don't' rock the boat'.
- It is not uncommon due to all these types of experiences that service providers who genuinely want to encourage and support individual consumers to participate have so much difficulty due to the history the consumers hold of having 'no power', no say of the decisions being made and no encouragement to have and maintain independent thought processes as human beings who simply live with a mental illness.

P.O. Box 1655, Manly NSW 2095 **Ph. 9976 9602 or Fax 9976 9663**
Email : dcasey@doh.health.nsw.gov.au **Mobile 0417 502 178**

- Consumer run services constantly are challenged to encourage and support consumers to actively participate in their care, treatment and own recovery, which acknowledges the consumers' rights to maintain their own self power and self worth, think for themselves and make their own decisions and maintain a control of their lives and mental health wellbeing.
- Mental health services, in many respects, have become even more tokenistic and intolerant in respects consumer participation, involvement and consumer perspectives than what was apparent over 10 years ago. Thereby, consumers who participate who insist on maintaining their consumer perspectives and consumer identities are usually more often than not ignored, regarded as the 'problem consumer representative', 'antagonistic', 'hostile', having no expertise whatsoever and definitely not willing to maintain the 'status quo' thereby, try everything to ensure the consumers' voices are silenced and not heard in any genuine shape or form.
- Community consumers are heavily 'systemised' (a community form of institutionalization) and have great difficulties thinking through perspectives which doesn't see mental health services doing 'more harm' to the general consumer population that services are being provided for. They're more often than not told what they can't do rather than what they can do, what their individual goals and achievements will be rather than allowing consumers to talk about their hopes and dreams and acquiring the support and encouragement to bring these hopes and dreams to a reality; how they should think, behave and are often ignored or even denied services if they think or behave differently to what service providers are either used to, demand or simply want the status quo to remain.
- Consumers have many practical ideas on how mental health services can be improved, which either cost absolutely nothing in the way of funding and more to do with actual staff practice, or very little, eg. up to $1000. More often than night they're told every reason under the sun why their ideas cannot be implemented.
- Many staff who genuinely try to 'do no harm' and creatively and effectively encourage and support consumers to genuine participate and have control over their own lives can in many instances be literally 'hounded' out of the mental health services in order for the dominant culture and poor staff practice to be maintained. These staff quite often experience high burn out, increased stress levels and in order to protect their own sanity and mental health wellbeing literally resign from the mental health service 'team' or get out of practicing as a mental health clinician altogether.
- Many consumer run teams and consumer groups are simply regarded as add ons to the mental health services in order for these services to 'tick the box' that they have consumer participation. This being so, many consumer groups and consumers are silenced in being able to genuinely participate and provide a range of creative and practical solutions which will enhance the delivery of services to the consumer population group.
- Mental health services, bureaucracies and governments have simply stamped their dominant culture on consumer groups, consumer participation and involvement, expecting consumers to perform and undertake the roles of bureaucrats and understand all the time why the mental health system should not be changed, accept shoddy mental health service delivery as afterall 'health workers do have the best interests of consumers at heart' - that many consumer groups either have great difficulties maintaining a genuine consumers' perspective, have become quasi mental health service providers, experience high burn out, or the group simply folds up and get out of consumer participation activities altogether.
- Consumer peer support groups have yet to fully be developed in Australia and many services think consumers are totally incapable of facilitating and running such support groups without a heavy influence from mental health service providers.
- The difficulty is when consumers design and try to implement education and training programmes (which are made mandatory for staff to attend) or activities such as 'chew and chat' sessions which bring consumers and staff together informally, such activities are poorly attended by service

P.O. Box 1655, Manly NSW 2095 **Ph. 9976 9602 or Fax 9976 9663**
Email : dcasey@doh.health.nsw.gov.au **Mobile 0417 502 178**

providers who consider they 'know it all about consumer participation' and surely consumers must realise staff are busy 'delivering a service' (even if it is a shoddy one at best!)

- In the Northern Beaches Consumer Network experience, consumers in formal roles such as consumer representation and consumer advocacy and participatory activities have far more ongoing education and training on a wide range of topics and issues relevant to the successful undertaking of such roles than the staff ever encounter or even actually know exists. For example, consumer representatives are more highly skilled in representation than staff who sit around the committee table. Staff believe their simply there to 'represent' their own views, whereas consumer representatives are there to represent the views of the consumer group and the wider group of consumers they come into contact with almost on a daily basis.

Recommendations:

- "CARE – Compassion, Acknowledgement, Respect, Enabling – Listen to the Consumer.
- Education, education, education.
- Employ adequate numbers of doctors and nurses and re-educate them sufficiently so that are able to be empathetic individuals – are attracted"
- "As before – be positive. Try to make things not too serious. Try not to make consumers feel they are different to them (health workers".
- Educate and train mental health clinicians, including doctors, they are not the ones in control of the individual consumer's life.
- The consumer to retain and maintain this control throughout all interactions, care and support.
- Clinicians coming to the realization they're not in fact "God" and making all their pronouncements as they if they're coming from a God like space who deigns to talk to the consumer (when s/he has the time that is) and expect consumers to obey their every command and decision.
- Consumer run services including recovery services and self advocacy consumer groups be more supported financially to undertake a valued role within the mental health consumer community however work in partnership with mental health services and service providers.
- Top down, bottom up approach – where there is a major 'culture shift' which incorporates genuine consumer input and participation at all levels.
- Service Directors and/or managers not accepting poor staff practice and start emphasising, poor practice will not be tolerated and if staff do want to continually undertake poor clinical practice then show them the door.
- Recognition by Service Directors that the underlying principles of consumer participation and involvement can also be translated to staff participation and involvement which will increase and enhance staff morale and staff education, training and supervision to bring about positive, innovative and creative service delivery provided to consumers.
- Recovery focused mental health services is not in fact 'rocket science'. It is about action and this being good clinical practice which is based upon: Listening to the consumer. Respect and courtesy being given to the consumer. Meeting the consumer on an equal and mutual basis which respects that consumers also have an expertise to bring to the table – the lived experience.
- Genuine funding, support and encouragement for consumer groups, consumer run activities, consumer participation and consumer groups who are encouraged and supported to maintain their independence of the mental health system however work in genuine partnership with service providers and mental health services.

Term of Reference : 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

P.O. Box 1655, Manly NSW 2095 **Ph. 9976 9602 or Fax 9976 9663**
Email : dcasey@doh.health.nsw.gov.au **Mobile 0417 502 178**

Why:
"Certain groups in the community encounter specific access challenges due to cultural, linguistic and geographical barriers, and service gaps. These groups include Aboriginal and Torres Strait Islander people, people from culturally and linguistically diverse backgrounds, people using forensic services and people living in rural and remote areas. In additions, those with complex needs are not optimally served" (National Mental Health Plan, 2003-2008, p.19).

- The long and short answer is the Northern Beaches Mental Health Consumer Network believes, consumers are overrepresented in the criminal justice system simply because they are denied basic access to a range of quality mental health services which meets the consumer's individual needs and support them effectively in the community.
- The Manly District Court now has a Court Liaison Officer to assist with streamlining and obtaining the mental health services required for mental health consumers who become part of the criminal justice system. This is a step in the right direction, however there does need to be enhanced liaison between the court and the sector mental health services in order to address the needs of the consumers.

Examples:
- There are many debates re whether consumers are 'mad' or 'bad'. Many consumers are denied access to services due to assessments which decide they're more 'bad' than 'mad' hence, are caught up in the prison system, which in itself increases the risk of any human being becoming mentally ill, in order to 'punish' them rather than 'care and support them'.
- Many consumers who end up in the criminal justice system have been 'diagnosed' as having 'behaviour' problems rather than a 'treatable' mental illness.
- Many other consumers due to the fact they are homeless subsequently end up in prisons, simply in order to obtain 3 square meals a day and have a roof over their head. This being that mental health service provision for mentally ill homeless people simply is not provided which meets the needs of the homeless consumer rather, yet again, services expecting the homeless consumer to fit into the model of care provided by services.
- Yet again, consumers are still talking about poor access and overrepresentation of consumers in the criminal justice system as reported during the Human Rights Inquiry into Mental Illness in 1993. Hence, very little, if anything has changed in more than 12 years for consumers who come in contact with the criminal justice system.
- In NSW for example, the prison act overrides the mental health act, thereby, another avenue to deny mental health consumers in the prison system access to basic mental health care and treatment.
- At the October, 2003, 2 Days Consumers' Issues Conference, delegates listed the issues for forensic consumers as being:
  - "Target group – diagnostic groups left to each jurisdiction – dangerous.
  - Forensic consumers very restricted hospital access.
  - Some States – there is no set time period of detention.
  - NSW Governor's pleasure.
  - Support services – housing, MHS.
  - Being held in wrong facilities.
  - Ordinary police do not have the training to work with consumers.
  - Move to privatization of correction services.
  - All correction officers – juvenile justice, jailors, probation need training on working with consumers & consume perspectives.
  - High representation of Aboriginal & Torres Strait Islanders & consumers from culturally & linguistically diverse backgrounds.

P.O. Box 1655, Manly NSW 2095 **Ph. 9976 9602 or Fax 9976 9663**
Email : dcasey@doh.health.nsw.gov.au **Mobile 0417 502 178**

- High suicide rates for forensic consumers.
- Aboriginal & Torres Strait Islander lore is not law.
- Access to drugs really easy.
- Large amount of self mutilation by women – harsh punishment by corrections but not care.
- Poor entry assessment.
- Training mainstream mental health workers on forensic consumer issues" (page 12).

Recommendations:
Consumers in the feedback survey for this inquiry responded via the giving of the following recommendations:

- The Mental Health Act to either override the Prison Act or at least be on an equal standing ground in order that consumers in the criminal justice system have equitable access to care and treatment.
- Different parts in jails for forensic consumers which allow more freedom of movement, space and unit design which is less of a prison atmosphere and isn't controlled by the prison guard mentality of waking up prisoners eg. at 2am in the morning to search their 'cells and their belongings', which subsequently places the heavily medicated consumer at risk of being further punished by punitive measures simply due to the heavy handiness of a prison system who treats them more as 'criminals' rather than a person with a mental illness who sadly committed a crime due to their mental illness.
- Mental health services – including community forensic mental health services should be involved in providing 'adequate, timely and periodical care, rehabilitation and prevention".
- The ensure that recent medications are available to consumers in the criminal justice system rather than old psychotropic medications which heavily sedate and have wide reaching side effects.
- "Court liaison, consumer run support services, for example, individual support – in care support group.
- Close observation of consumers and respect to consumers.
- "Provide more court liaison officers. Ensure adequate mental health care if in custody. Educate police officers about mental illness.
- Education sessions for prison officers, magistrates & judges, parole officers with consumers participating in these education sessions, about mental illness and the positive role these personnel can undertake when dealing with a consumer in the criminal justice system".
- "All corrections officers (juvenile justice, gaolers, and probation) need training on working with consumers & consumer perspectives.
- Training mainstream mental health workers on forensic consumer issues" (2 Days Consumers' Issues Conference Report, 2003, p. 12).

Term of Reference : K
the practice of detention and seclusion within mental health facilities and the extent to which it is compatible with human rights instruments, humane treatment and care standards, and proven practice in promoting engagement and minimizing treatment refusal and coercion.

Why:

Consumers responded to these questions in the feedback survey as follows:

- "We need to eradicate any measure or system which reflects more on a punitive and/or continually views the consumer as a criminal simply for having a mental illness."
- "I think, whilst mental health services are able to legally detain or put a person in a seclusion room, the staff, the community and carers will not develop other more sensitive and caring options to provide to assist consumers who are very ill, a possible danger to themselves or another. For example, providing more intensive support with highly skills and trained staff in a more open

P.O. Box 1655, Manly NSW 2095 **Ph. 9976 9602 or Fax 9976 9663**
Email : dcasey@doh.health.nsw.gov.au **Mobile 0417 502 178**

environment; enhanced crisis support services; providing community services a long time prior to consumers becoming so ill they require inpatient care; recovery services".

- "There is simply so many gaps in the system – all people want to do is lock up the consumer and throw away the key in one form or another so they don't have to deal with these gaps and provide 'real' services to consumers. Detainment and seclusion are simply 2 ways of the community continuing to think and be afraid of people with a mental illness regardless of how well the consumer manages the illness and has successful lifestyles and contribute to society in general"
- "We are talking about detainment and seclusion, however every consumer in East Wing is literally detained by the mere fact the outer doors to East Wing and many inpatient units are locked. Whatever happened to the least restrictive environment????? The r4eality doesn't match the rhetoric!"
- "It's pretty brutal being put into seclusion but sometimes it's the only alternative to some in the midst of mania of psychosis destroying and damaging everything and everyone in their path. Eventually they calm down".

Examples:

- People in general health who refuse treatment, even life saving treatment are not considered too ill to make such choices and decisions and are not locked up for refusing such care and treatment and forced to have treatment against their will. They're considered of 'sound' mind to have made such choices and decisions, however, one can justifiably question, exactly how sound is a person's mind in acute and many times ongoing and chronic pain and distress, undergoing major side effects to invasive treatments and procedures to be making such choices and decisions?
- Some consumers consider the use of detainment (forced treatment) and seclusion as having no validity whatsoever and that mental health services need to become more creative in being able to effectively deal with consumers who are acutely unwell, rather than detainment and the use of seclusion being the first options of choice.
- Due to the lack of available care and treatment options in the community, the lack of funding for creative community mental health services, lack of community options to care for consumers prior to or when progressing to an acute phase of illness, governments, bureaucrats and mental health services have denied consumers their most basic human rights, denied genuine capacity and capability of accessing a range of creative mental health service delivery which assists them to remain out of inpatient units, thereby also avoiding the fact of having to be detained and in many respects placed into a seclusion room – thereby denying consumers the most basic and fundamental human right to be access mental health care which meets their individual needs, maintain freedom and their basic human dignity and self worth is severely tested if not downright abused.
- There are many consumers in the mental health community who have literally been 'forced' to accept that to receive any service whatsoever, then they have to accept the complete denial and abuse of their most fundamental human rights, i.e. accept detainment and seclusion, simply to be able to access a piddling amount of mental health care in order to become well and be able to get on with their lives. In many instances, these consumers either totally reject all mental health care due to its punitive nature and criminalization of mental illness via the denial of their fundamental human rights or become so 'compliant' and dare not even question whether mental health service delivery and its provision in case they receive no service whatsoever.
- Consumers responding to the feedback survey were nearly split down the middle as to whether mental health services should be able to legally detail a person which acutely unwell or not. Some reasons given were as follows:
  - As previously stated the community is not detained when they're actually physically unwell and refuse medical treatment.
  - "When consumers may be a danger to themselves or another.

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Email : dcasey@doh.health.nsw.gov.au **Mobile 0417 502 178**

  - They might have murdered someone.
  - For their safety or the safety of others, including other patients.
  - It's a worry to detain, could be the benefit of the very ill."
- Consumers responding to the feedback survey in respect to the use of seclusion tended to be more positive on the use of seclusion, however, some respondents were critically opposed to the use of seclusion. Their reasons being:
  - "Seclusion is a punitive measure and inhibits mental health service staff from talking and being with the consumer.
  - It has helped me.
  - They might harm nurses, other patients or themselves.
  - Only in dire circumstances when all else fails to protect themselves, staff or other patients,
  - So patient can have time out.
  - Sometimes there is no option but it's pretty prehistoric".

Recommendations:

- Creatively address the current gaps in the mental health system and provide adequate support, funding and training to mental health service providers, consumers and carers and we will be able to do away with such 'prehistoric' and 'punitive' measures.
- Human Rights Instruments to be legislated that they override any mental health act legislation in any Australian State.
- Review current mental health act legislation and delete the 'power' to detain and seclude a person with a mental illness, however ensure through this process that relevant structures, supports are in place to effectively care for people with a mental illness prior and during an acute phase of illness. Give the 'power' to the consumer rather than to the service provider.
- Educate, educate, educate mental health staff to 'talk and listen' to consumers. When (and if) they ever finally get this very simple and most basic message, mental health staff will be able to effectively care for a mental health consumer without having to resort to punitive options such as detainment and seclusion.
- Broad cross spectrum community education and awareness that mental illness is not a criminal offence and should not be treated as such. The majority of mental health consumers are less dangerous than the general population.

Term of Reference : L

the adequacy of education in de-stigmatising mental illness and disorders and in providing support service information to people affected by mental illness and their families and carers.

Why:

The long and short answer the Consumer Network would like to put forward is that currently there is a huge inadequacy of education to the community, consumers and cares which de-stigmatise mental health consumers, mental illness and disorders and assist consumers to obtain the relevant support from services including the provision of accurate and easy to understand information about living with a mental illness and having a positive lifestyle of choice and contributing in the community.

- Whilst some attempts have been made in this area, there is simply so much to do and so many aspects and population groups in the community to reach and inform, the task can border on being so overwhelming that it simply becomes impossible to even take the initial steps to promote positive mental health messages to the community.
- The Consumer Network on the Northern Beaches is currently caught up in a bureaucratic maze in order to obtain permission to host "The Well of Life – Mental Health Celebration Parade" which is currently caught between a health department and a local council. Hence, even when consumers

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Email : dcasey@doh.health.nsw.gov.au **Mobile 0417 502 178**

do develop innovative and creative activities to promote positive mental health message and assist to decrease stigma, the barriers to implement such strategies become an absolute bureaucratic nightmare in themselves, that people simply stop being creative, stop their efforts and say 'to hell with it all'.

- The sad thing is that this parade has now become a national initiative with 4 other consumer groups in 4 other Australian States planning and organising to host the same parade simultaneously in their respective States on the same day. Yet, the originators of the activity have as yet to obtain the relevant permission to be able to further develop and plan to host the parade in NSW.
- Consumers are rarely invited and or asked to be involved in developing promotional events which assist to de-stigmatise mental illness within the community, with service providers and with school age children and adolescents.
- Consumers want a range of self discovery courses to assist them to break out of the poverty and welfare cycle, live with a mental illness whilst maintaining a positive lifestyle, however these courses organized by consumers for consumers.
- WRAP (Wellness Recovery Action Plan) developed by Ms Mary Ellen Copeland in America and used worldwide by mental health consumers to assist them on their recovery journeys, has been making a huge impact for consumers in metropolitan Sydney. Pitane Recovery Centre (based at Manly Hospital) which is consumer run is only 1 of 3 centres in Australia facilitating WRAP Groups and the only centre in NSW. This is having an enormous impact on de-stigmatising a whole raft of issues which assist the consumer to participate in their own recovery and this recovery journey is one of their choosing.

Recommendations:

Services:

- A range of information and education provided to school age children & adolescents including people in the community, TAFE & University students.
- Informing and educating the business community on how to support people with a mental illness in the workforce. Also to provide information and education to mental health consumers on how to access and maintain work in employment.
- "Ongoing education for the consumer through their case worker or health professional. To be able to put plans in place for early intervention".
- More funding i.e. more qualified staff contact – written material for families and consumers.
- Counseling, a forum where recovery is introduced into the system

Consumers:

- Living with a mental illness. Breaking the Welfare & Poverty cycle, confidence, self esteem, getting on with your life, recovery information & education eg. WRAP, Recovery Workbook, PACE
- 2 pack containing brochures, contact numbers, stories etc.
- Pitane is a good example – more groups like it.
- Just being a friend and sharing experiences.
- Consumer run information and education including knowing your rights.

Governments:

- "Media in a positive light
- Interview people on t.v. who are on their road to recovery. Interview on radio also. Support "The Well of Life" Parade 2005.
- Members attend functions organized by consumers.
- Go on television. Doctor explain we are not crazy, we just have an illness like cancer or diabetes. We are not in the dark ages.

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- Show how consumers lead productive lives – mental illness is not catching.
- Re-institute the media campaign promoting people with a mental illness to the community.
- Put more money into mental health so that people getting discharged don't flounder.
- Grants for people de-stigmatising and educating public eg. Anne Deveson.
- It can happen to anyone, that's why it should not be a stigma".
- More funding for consumer run activities, recovery centres and initiatives undertaken by consumer groups, which cut through the red tape and literally ensure these activities can take place and are successful in the process.

Term of Reference : M

the proficiency and accountability of agencies, such as housing, employment, law enforcement and general health services, in dealing appropriately with people affected by mental illness

Why:

Key directions in the National Mental Health Plan, 2003 – 2008 are as follows:

"Key direction 19.2: Develop service eligibility criteria that are based on consumer needs, rather than service structure.

Key direction 19.3: Explore the development of standards assessment processes and shared assessment and outcome tools for use within and across service sectors.

Key direction 19.4: Improve linkages between the specialist mental health sector and the primary care sector, and between the public mental health sector and the private mental health sector.

Key direction 22.1: Enhance cooperation between the mental health sector and other sectors in terms of service provision, with better articulation of roles and responsibilities" (p.23).

These 4 key directions in the National Mental Health Plan clearly articulate the need for mental health services, housing, employment, law enforcement and general health services to work together, with clear lines of accountability and 'articulation of roles and responsibilities' which assist people living with a mental illness.

- Mental health consumers on the Northern Beaches responded to this term of reference as follows:
  - "Streamline their service to meet the needs of people with a mental illness, for example, flexibility, and access, break down rules & regulations, promote positive measures and not become punitive.
  - Provide info on their services in East Wing and community health centres.
  - Inform consumers on discharge from hospital what services are available and follow it pu with a case manager who is informed and competent".

Whilst there is a Memorandum of Understanding in NSW between Health and the Police Department in many instances this memorandum falls down in the practical implementation. Consumers report being asleep in bed and having police barge in and cart them off in the paddy wagon to hospital; police who lack empathy and understanding when dealing with a mental health consumer who is unwell and who subsequently shows a range of bruises to arms, legs as a result of being physically manhandled by police.

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- A consumer reported calling the police for a domestic violence dispute eg. between her daughter and her partner and subsequently being grilled for more than 2 hours by police for them to ascertain whether the she (the consumer) is the one who should be taken away and hospitalized, even though not mentally unwell, rather than the police dealing with the reason for the call in the first place – the domestic violence dispute between the daughter and the daughter's partner.
- Crisis teams who simply inform carers to ring the police rather than actually attending and assessing whether police assistance is really required.

Department of Housing is another government department which is so full of rules and regulations that it borders nigh on the impossible for the mental health consumer to successfully negotiate. Whilst there is in NSW a Joint Guarantee of Service between Health and Housing, many consumers throughout NSW have reported this Joint Guarantee of Service does very little if anything to assist consumers to maintain success Dept. of Housing tenancies and is another form of controlling consumers and placing another 'punitive' measure in place for consumers residing in the community.

- There is currently no formal consent form which consumers can give their informed consent to have both mental health services and the Dept. of Housing involved in case conferencing to assist their tenancies.
- By the time a consumer's situation is referred for such case conferencing the consumer is virtually on the last stages of being evicted from their homes.
- Dept. of Housing are now, due to this Joint Guarantee of Service, discriminating against people with a mental illness, via insisting that to apply for housing they have to have mental health documentation which states they can effectively live and manage by themselves living in Dept. of Housing Complexes. (To the Consumer Network's knowledge no other population group accessing Dept. of Housing complexes are forced to produce such documentation.)

Employment agencies:
Centrelink has a very dire reputation with mental health consumers as is clearly evident in the focus groups with consumers held in preparation for the national consultation hosted by Dept. of Employment & Workplace Training.

- The rules and regulations are such they severely discriminate against people with a mental illness. They have impossible systems which simply make it incredibly difficult for any mental health consumer, especially a person acutely unwell, to comply with. Eg. waiting for hours on end to report income via the phone or face having benefits or the disability support pension reduced as a result.
- Many consumers consider this department to be one of the most punitive departments in the government system, which is closely followed by the mental health system, then the prison system. This being that consumers' livelihoods and incomes are drastically affected by Centrelink and for that matter Dept. of Housing to a huge degree and non-acceptance of every Centrelink rule and regulation can meet with absolutely disastrous consequences for the mental health consumer – eg. loss of income, loss of accommodation and in fact create homelessness.
- Centrelink provide little if any up to date relevant information on the range of benefits and entitlements which can assist mental health consumers to make informed decisions and choices in respect to employment opportunities.
- Three (3) government departments take a slice of the gross income that consumers earn if in employment. These being: Australian Taxation Office, reduced Centrelink benefit and increased rent if living in Department of Housing – all three based on the gross income rather than the latter 2 departments basing their deductions or increases on the nett income. Then governments wonder why some consumers prefer not to seek employment!!!!

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Email : dcasey@doh.health.nsw.gov.au **Mobile 0417 502 178**

Recommendations:

- Education, education, education and this education developed and provided by mental health consumers.
- Media ads which highlight positive mental health messages to employees of these departments.
- Continually updated, accurate and relevant information on their services in inpatient units and community health centres be provided.
- Genuinely liaise with consumer groups and organisations to ensure consumers' perspectives are incorporated into their organisations and how they deliver their services to mental health consumers.
- Centrelink to "try to understand some of us can't work and not make us feel like bludgers".
- A complete overhaul of the Centrelink system and Dept of Housing system and increase and enhance 'genuine' consumer participation to be part of the decision making processes of these systems in order to ensure more friendly service provision, flexibility in respect to rules and regulations.
- Police be fully educated on mental illness and how to effectively negotiate with a person with a mental illness when in an acute phase of illness.
- Mental Health services develop genuine service delivery options which assist consumers and their families prior to having to call in the police in crisis situations.
- Mental Health Crisis services co-attend emergencies with police and assist with negotiations with the consumer.
- Consumers not be transported in a police paddy wagon – this criminalizes the illness.

Term of Reference : N
the current state of mental health research, the adequacy of its funding and the extent to which best practice is disseminated.

Why:

- Whilst Rotary International has made huge inroads into the mental health research arena, there is very little, if any acknowledgement of consumer research and consumers participating in the participatory research arena.

- Mental Health research is still way too clinically focused on medications, and brain mapping exercises to incorporate participatory research which will also benefit mental health service delivery and genuine consumer participation and involvement.

The long and short of things is as follows: Mental health consumers in the Australian Mental Health Consumer Movement report mental Health Services, bureaucrats and especially psychiatrists totally medicalise, colonise and totally bastardise literally every core precept, principle and philosophy underpinning the Australian mental health consumer movement, key concepts developed by consumers internationally and then try and place a rigid 'academic and therapeutic' diagnostic approach to same. This then can be seen how they very tokenistically regard and treat, impose their medicalised and bastardized understandings and perceptions on consumers at the grass roots levels in so many ways that this submission simply doesn't have the word space to totally describe!

Examples:

- In many respects Australian mental health consumers who write papers for wider dissemination, papers for conferences, presentations and talks on a wide range of issues, including developing and providing education to a range of government, health, community and mental health organisations are often informed they are 'ill informed' and making 'unjustifiable assumptions' – especially by mental health clinicians.

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- Mental health clinicians have adopted and 'colonised' consumers' language, core precepts, principles and philosophies and medicalised and created and perpetuated as an academic exercise in the process with any genuine attempt at understanding exactly what they're adopting and the language of consumers is vastly different and has very different meanings, ethics and integrity.

- Mental health clinicians, particularly psychiatrists and bureaucrats have taken internationally acknowledged consumer research undertaken by overseas mental health consumers and actually 'bastardised' the concepts, principles, precepts and philosophies in the process. One wonders whether their intent is to destroy thereby stating 'see we told you this can't work' syndrome.

- Many consumers in the Australian mental health consumer movement report, the dominance of the government and bureaucratic health culture towards consumer participation and involvement, the increasing view by mental health services that independent consumer groups are teams of the mental health service, thereby trying to create quasi service providers out of consumers, annihilate independent consumer voice and silence the consumer voice in the process – thereby literally providing the death knell to consumer groups establish to influence service delivery rather than undertake service provision.

- The medicalisation which is being increasingly witnessed by mental health consumers by mental health services in respect to 'recovery' and its core precepts, principles and philosophies. This same medicalisation is now also being applied to consumer advocacy which is underpinned by social justice principles and self advocacy and try and now state it's a form of 'therapy' and a 'therapeutic intervention'.

- Health bureaucrats are trying to rewrite the history of the Australian Mental Health Consumer Movement for their own ends, thereby denying the mental health consumer community its right to retain and perpetuate its own history, culture, core precepts, principles and philosophies to other consumers and consumer groups.

- The dominance of the mental health culture exhibited in these respects and many other ways and insisted upon domination local consumer groups is so blatant that this dominance of pseudo power play can be likened to the dominance of western culture on the Australian Indigenous Community. The parallels are sadly and very frightening very, very similar.

Recommendations:

- Only members of the Australian Mental Health Consumer Movement be able to write their history, their core precepts, principles and philosophies inherent in this movement. In other words – psychiatrists and health bureaucrats totally 'butt out".
- Governments, bureaucrats and mental health service providers take 3 steps back and actually invite consumers to inform and educate them on the core precepts, principles and philosophies of consumers' language, concepts, partnership and participation.
- Academia and mental health service providers recognise 'consumers' writings' , papers, articles as valid perceptions and experiences of mental health consumers without the need to 'sanitize such writings!
- Consumers develop ongoing participatory research opportunities which attract adequate funding and resources to further develop key understandings and approaches of consumers' concepts, and participatory frameworks that can be utilised by mental health services to create 'consumer sensitive' service delivery for grass roots consumers accessing a service.

Northern Beaches Mental Health Consumer Network

P.O. Box 1655, Manly NSW 2095 **Ph. 9976 9602 or Fax 9976 9663**
Email : dcasey@doh.health.nsw.gov.au **Mobile 0417 502 178**

Term of Reference : O
the adequacy of data collection, outcome measures and quality control for monitoring and evaluating mental health services at all levels of government and opportunities to link funding with compliance with national standards

Why:

"High-quality mental health services will be facilitated through continual review of performance, assessment and accreditation. The mental health quality agenda needs to be broadened from its current emphasis on service inputs and structure to service impacts and outcomes. This can be achieved through the development of a culture of measurement and establishment of consumer – and clinician – rated measurement systems, national benchmarking of mental health services, and agreement on, and establishment of appropriate levels and mix of services" (National Mental Health Plan, 2003 – 2008, p.25)

Examples:
- The majority of respondents to the feedback survey for this submission believe that governments should link funding and quality improvement of mental health services together.

- The majority also believe that this link could be best undertaken by leglislating the National Standards for Mental Health Services just like the Disability Standards are now leglislation.

- Quality improvement should simply not be left up to mental health services to undertake in an adhoc manner or simply when accreditation agencies are due to front up on their doorstep.

- The majority of consumers responding to the survey consider that mental health services do need to be accountable to consumers and to the consumers who access their services. The measures they suggest are as follows:
  - "Regular accreditation
  - Education information, availability
  - Better communications.
  - Community laws answerable for themselves and each others
  - Funding linked to the 'quality' improvement, which reflects 'genuine' consumer participation".

- One of the consumers in the Northern Beaches Mental Health Consumer Network has participated at all levels, including State and National levels in respects to implementing the National Standards for MHS. Due to this, this consumer constantly heard why mental health services couldn't implement these Standards rather than discussions on how mental health services can implement these standards which enhances the quality and delivery of services to consumers.
- Recognised accreditation agencies, whilst incorporating the National Standards for MHS, into their accreditation standards, don't have the power to insist that mental health services focus on quality rather than simply ticking a box to state they have this piece of document to show the surveyors at accreditation time!
- Currently consumer surveyors for recognised accreditation bodies are an extra cost to be included on the accreditation survey team for mental health services to pay for.

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- Consumers in the Northern Beaches Consumer Network in partnership with the Northern Beaches Consumer Participation Service (CPS) developed the Consumers' Issues Database in which to record, track and trend the vast range of issues consumers raise and how these issues are addressed by consumer advocates and the sector mental health service.
- This database is currently being further developed to go Area-wide (across 4 sector mental health services and a stand alone psychiatric hospital) and has now been incorporated into Area Mental Health Service policy.
- Consumer advocacy as Janet Meagher describes in her book "Partnership or Pretence" is a 'quality control' tool for services (p.43). However, currently some mental health services providers view consumer advocacy from a clinical reference point rather than from its origins in social justice and self advocacy principles.
- The Northern Beaches Mental Health Consumer Network has had a strong consumer advocacy focus, not only as an independent consumer group, but also in the sector inpatient unit (East Wing) since 1995. As such the partnership which has developed between the Consumer Network and the Northern Beaches Mental Health Service, whilst has its hiccups and ups and downs, in the main has a positive and mutual partnership to enhance the delivery of inpatient care to consumers accessing this unit. Education is undertaken by the Co-Ordinator for inpatient staff in order to assist staff understanding of the role of the consumer advocates, the Consumer Network, CPS and Pitane Recovery Centre.
- The Network also has a strong focus on education and training for consumers in consumer representation and consumer roles and many of the programmes developed have been utilised by consumer groups throughout Australia. Currently the Network is broadening its education and training focus to incorporate a range a self funded participants participating in a range of self discovery courses, however will maintain its leadership in the areas of education and training for consumer representation and consumer advocacy.

Recommendations:

- The National Standards for Mental Health Services become leglislation in its own right with funding attached for the implementation of these standards by mental health services.
- Enhanced funding opportunities for mental health consumers to undertake consumer advocacy roles as independents of mental health services.
- Quality measures incorporate the human being rather than simply statistics on a piece of paper that mental health services view providing quality is all about.
- Consumer surveyors for accreditation agencies be fully funded and incorporated as part of the team rather than simply an add on cost for mental health services to pay in order to have a consumer surveyor accredit their mental health services.

Term of Reference : P

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

The National Mental Health Plan 2003-2008 identifies 4 priority themes. These being:

- "Promoting mental health and preventing mental health problems and mental illness.
- Increasing service responsiveness
- Strengthening quality.
- Fostering research, innovation and sustainability" (p.13).

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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), create consumer sensitive service delivery by mental health clinicians, promote positive mental health wellbeing to the community and provide a range of opportunities for consumers to enhance their journeys of recovery, journeys of discovery and journeys of hope..

There is great potential to encourage, enable and support a range of innovative services organised and run by mental health consumers including recovery centres and recovery activities. 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.

However, if genuinely incorporated have a vast range of ideas and practical suggestions which can and will create innovative and consumer sensitive service delivery. Consumers want:

- "Adequate and compassionate inpatient services adequately resources and staffed. Adequate and committed outpatient (community) services interested in recovery of the individual rather than medicated oblivion and isolation.
- Liaison and linkage service for homeless consumers.
- Funding for innovative programmes; early intervention across the lifespan; grief counseling service for consumers.
- Proper treatment – caring nursing staff – nursing not just in hospital but after things like accommodations.
- Follow up after a time in hospital.
- A bigger, better, more available 24 hour team.
- Provide en-suites to all inpatient rooms – to provide privacy and safety.
- Access to counselors/psychologists for each consumer – so they can confide in a professional other than their psychiatrist (which can be too short a visit and not enough).
- Workshops,
- Consumer run recovery centres and more recovery activities at Pitane Recovery Centre.
- Consumer run development of education to assist mental health clinicians in what a recovery focused mental health service is really all about.
- Opportunities to employ a range of consumer support workers who can assist the consumer from discharge from hospital to getting back on their feet.

The Northern Beaches MHS Consumer Participation Service provides the following consumer run support for consumers:

- Phone connections – touching base by phone to those who want a friendly phone call.
- Home connections – to visit very isolated consumers in our community and tap them into a community activity of their choice (and not necessarily one provided by a mental health team).
- Social activities such as bi-monthly women's coffee club and lunch at a local Thai restaurant.
- A small consumer advocacy service to residents in the supported accommodation homes.

CPS has primary responsibility for Pitane Recovery Centre in partnership with the Northern Beaches Mental Health Consumer Network, however Pitane receive no recurrent mental health funding – all activities provided are either provided on a voluntary basis or due to obtaining community grants or other fundraising efforts by the Consumer Network. Pitane is the only consumer run recovery centre in metropolitan Sydney.

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Pitane provides a range of recovery activities such as:

- Creative writing
- Break Out – for young people aged 18 – 30 years (totally run in the community)
- Gentle connections which connects people with a mental illness and people with cancer to come together for a gentle, non-intrusive massage and sharing of a meal together.
- Pop In for consumers to meet and greet each other (on a weekly basis only)
- Education and training including now providing a broader self discovery series courses.
- WRAP (Wellness Recovery Action Plan) Groups
- Monthly women's discussion group
- Monthly morning teas where consumers and the directors of the sector mental health service get together to have a friendly cuppa and a chat.
- Saturday Soapbox – based on the principles of soapbox in the parks.
- Live Poet's Society.

The Network (primary function is to influence mental health service delivery), CPS (primary focus is consumer run service provision) and Pitane (primary focus on recovery activities) also undertake a range of other activities. For example:

- Organising "The Well of Life Mental Health Celebration Parade"
- Hosting a Pitane Recovery Centre Fundraising Concert to highlight the talented consumers in our area.
- Organising a second 2 Days Consumers' Issues Mental Health For Young & Old Conference (May 2006).
- Special one off outings in the community, for example; Visiting the Opera House, Harbour Cruise and so forth.
- Fundraise for the majority of funding required for consumers to facilitate the recovery activities hosted at Pitane Recovery Centre.

- In many respects, what consumers tend to consider 'innovative' is actually mental health services and clinicians delivering services on the CARE principle: Compassion, Acknowledgement, Respect, Empathy & Enablement.

- Why should consumers have to consider this to be 'innovative' service provision by mental health clinicians when in reality it is simply good clinical practice????

- Consumers want services which meets their individual needs as they access services throughout their journeys of recovery and incorporating a recovery pathway.

Recommendations:

- Funding access for consumer run services including recovery centres, consumer run teams which include consumer support workers**,** provision of after hours and weekend consumer run services and activities.
- More training for doctors and nurses on consumer participation, involvement and recovery concepts which is developed and delivered by consumers.
- "It is in the government's own interest to adequately fund and resource mental health services. The mentally ill are the most isolated, marginalized and disregarded sector of the community equal with the plight of Aboriginals!"
- Task force to establish and develop an award structure for consumer employees within mental health services, address human resources and the many other and varied issues of consumers

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Email : dcasey@doh.health.nsw.gov.au **Mobile 0417 502 178**

employees who are often isolated, marginalized and ignored by mental health services clinicians and teams.

- Taskforce established to administer grant funding (including recurrent) funding for consumer run services, consumer groups involved in self advocacy and promote genuine consumer participation and partnership within mental health services.

In conclusion:

Many inquiries simply write a report, which sits on the bookshelves and nothing changes. Consumers WANT ACTION not more inquiries and more talkfests.

Respondents in the feedback survey, all the way through spoke about the value of Pitane Recovery Centre and having this resource, how Pitane should be financially supported. In the words of one respondent "What is happening with Pitane is wonderful at Manly Hospital".

The Northern Beaches Mental Health Consumer Network, undertook to organize a feedback survey in order to provide as broad consumer input as possible into the various terms of reference in this inquiry.

The Network requests that the inquiry does listen to the consumer voice, and develop recommendations and strategies and options which ensure that innovative and creative consumer sensitive services are eventually delivered to consumers.

The Human Rights & Equal Opportunities Commission Inquiry into the Human Rights of People with a Mental Illness delivered much promise in 1993, however many consumers across the nation state that services are no better or more to the point even worse than what consumers reported to this inquiry.

There is an old adage: the more things change, the more things stay the same.

Consumers understand this old adage very well. They see clinicians come and go, bureaucrats come and go, governments make promises which are usually in the main never delivered or really acted upon; less access provided to consumers to access mental health services which meets their individual needs.

Consumers have for many, many years been saying: "fund community services so we can access support and assistance well before our mental illness becomes an absolute crisis and you will decrease the demand on inpatient beds".

Because governments and health bureaucracies have continually ignored this very important consumer voice and message, particularly in NSW, the mental health system in NSW is literally imploding upon itself and is far sicker than any consumer will ever be. Thereby dragging down, dedicated health professionals and clinicians, and denying the very basic human right of consumers to access care and support to assist them with their mental health wellbeing.

In many respects the consumers' voice has been ignored, silenced, dominated by clinicians who think they know and understand consumers and the Australian mental health consumer movement, taken over our language and subsumed our culture.

Will you, the members of this current inquiry, really listen and hear the consumer voice?

Desley Casey,
Collator of this submission on behalf of
The Northern Beaches Mental Health Consumer Network