The Most Important Issues
Affecting People with a Mental Illness or Disorder

The most devastating issues were discussed with **23 issues** being identified as a priority

Solutions to all these issues have been developed

Over 200 people experiencing a mental illness came together from across Australia and New Zealand to develop these solutions at the largest Mental Health Services Conference (TheMHS) in Australia and New Zealand.

The process was facilitated through The Consumer Forum at (TheMHS) held on Monday 28th of August 2000, Adelaide Convention Centre.

The Consumer Organising Committee would like to thank all 200 plus mental health consumers who helped develop this document.

The solutions exist   . The task is to turn them into reality.

Index: 23 Big Issues Facing Consumers

The 23 big issues are not in any particular order, all issues are important!

1. Transporting people with a mental illness to hospital by police.
2. People experiencing a mental illness being strip-searched and put in seclusion rooms when detained in psychiatric facilities
3. Mental health consumers having little or no choice of prescribed medication and the side-effects that result
4. Lack of choice, safety and support regarding accommodation for people with a mental illness
5. Lack of employment opportunities for those experiencing a mental illness
6. People with a mental illness having to be really unwell to access help
7. Continuity of care in the community and hospitals for people with a mental illness
8. Lack of choice in type of therapist ie Alternative, Psychologist, OT, Peer Worker
9. Lack of worthwhile and appropriate rehabilitation.
10. Unfair and inappropriate Detention, Treatment and Administrative Orders to force treatment such as Electro-Convulsive Treatment (ECT).
11. Amount of unpaid work done by people with a mental illness
12. Stigma from the family, community, workplace, police force, mental health service providers
13. Lack of information given to consumers about their illness and legal rights
14. Lack of legislation protecting mental health consumers
15. Lack of true partnership in service delivery and tokenistic representation.
16. Lack of empowerment for mental health consumers
17. Lack of mental health services in rural and remote areas.
18. Little or no involvement in management plans
19. Little support from hospital to home for people with a mental illness
20. Lack of suitable access to psychiatrists
21. Children of parents with a mental illness
22. Unique problems facing young people with a mental illness
23. Culturally and Linguistically diverse people experiencing a mental illness

NB: We are not claiming that these are all the issues that affect people with a mental illness. Although these are the most common issues raised and experienced

Creating Solutions Exercise
23 Big Issues Confronting Mental Health Consumers

Getting Started
Everyone pick **one issue** they would like to develop solutions to.
We are not going to be discussing our experiences but instead **developing solutions** to these common and ongoing issues.

Doing it
- We will break into small groups
- Each group will look at **one issue**.
- They will develop solutions to this issue.
- The size of the group will be around 10 to 15 people.
- The group will have **35 minutes** to develop solutions to one issue

Facilitators
- Each group will have a trained consumer facilitator.

Role of Facilitators
- **To guide the group into developing solutions and "keeping on track"**
  - To make sure all members of the group have a fair say
  - To feedback the groups' solutions to the consumer forum.
  - There will be two to three minutes to do this per group.

Support people
- A group of friendly service providers have been selected by the consumer organising committee to assist.
  - There role will include:
  Finding appropriate places for groups to work
  Being a scribe (only if asked by consumer facilitator)
  Any other odds and ends we require.

The next step
The Solutions:
- Will be presented to everyone at TheMHS on Wednesday afternoon during consumer and carer feedback session.
  - Will be sent to the Mental Health Council of Australia.
  - Will be sent to Consumer Advisory Groups around Australia.
  - Will be given to The Australian Mental Health Consumer Network
  - Will be given to relevant places in New Zealand.
- Will be presented to the Australian Federal Government during October as part of the National Youth Round Table findings.

Issue (1)
Transporting people with a mental illness to hospital by police

BACKGROUND
This practice has too many adverse affects on people with a mental illness, their family, friends and the community as a whole. Police officers (through no fault of their own) have extremely limited training in this area, and find themselves deficient in the necessary skills to adequately mange these delicate and difficult situations. This often results in total mismanagement, the worst results hitting our news headlines with sickening regularity. Currently in South Australia there is a case before the courts where a person with a mental illness was shot and killed in their own house by a police officer.

This practice criminalizes mental illness causing untold psychological stress and community stigmatization as neighbors see the person with a mental illness 'dragged' from their homes by police.

It is also a shocking waste of police time as two police officers have to accompany the person with a mental illness to a psychiatric facility and wait until they have been seen by a doctor.

SOLUTIONS
- • **Legislation needs to be changed to enable mental health service providers to legally transport people with a mental illness to hospital**
- • **Use unmarked (non-police) vehicles when transporting all people to hospital**
- • **Education for police facilitated by mental health consumers**
- • **Lobby politicians to stop the practice and change the policy**
- • **Use of trained consumers in crisis and intervention mental health teams**

Issue (2)
People experiencing a mental illness being strip-searched and put in seclusion rooms when detained in psychiatric facilities

BACKGROUND
This practice further criminalizes mental illness, strip-searching and seclusion is comparable to punishment. Consumers feel violated throughout this whole process. Although it is acknowledged seclusion may sometimes be necessary, it is a last resort not a convenient way to deal with a problem, in an under resourced facility

SOLUTIONS
- Seclusion rooms to be used as a last resort
- Constant re-evaluation of a person in seclusion room
- Constant re-assuring and communicating with people in seclusion rooms
- The seclusion room should be a safe and appropriate place, used only for original intentions, ie treatment not punishment
- Empathy de-briefing to work through the issues and feelings caused by seclusion
- Provide empathy and support from a consumer advocate during and after the seclusion

Issue (3)
Mental health consumers having little or no choice of prescribed medication and the side-effects that result

BACKGROUND
Consumers feel they do not get enough information to allow them to make an informed choice about medication and are often expected to put up with unacceptable side-effects. The term "side-effect" diminishes what people who take the medication experience. They are unwanted, distressing and often more debilitating than the mental illness.

SOLUTIONS
- Consumer advocates at point of prescription
- More focus on therapies which involve discussing issues
- Information and explanation about side-effects which may occur every time a prescription is administered
- Doctors to be made more aware of drug reactions and interactions
- Information provided on alternative therapies

Issue (4)
Lack of choice, safety and support regarding ACCOMMODATION for people with a mental illness

BACKGROUND
There is a lack of appropriate housing at both State and local service level. A safe affordable and supportive living environment is a right, yet rarely considered as an essential part of service provision. Admission to hospital can cause consumers to lose their accommodation placements. This often leads to consumers being discharged to accommodation outside of their established community network. This leads to further isolation and alienation for consumers. Consumers experiencing high levels of symptoms and an ongoing disability are all too frequently discharged from inpatient units to what's available, not what's appropriate due to lack of "hospital bed's" and lack of resources within the community. The quick and unmanaged shift often results in readmission to an inpatient unit when the problem stems not from the individual, but their environment.

SOLUTIONS
- **Develop housing plans for all mental health consumers**
- **Develop a variety of living situations, address important factors such as age and disability**
- **Provide intensive supported accommodation in the community for those who require it**
- **Improve existing conditions and mandate standards to ensure continuity of services**

Issue (5)
Lack of EMPLOYMENT opportunities for those experiencing a mental illness

<u>BACKGROUND</u>
Feeling productive and doing meaningful work is a goal of most mental health consumers. Clinical services often do not understand the importance and value of this to consumers. They also tend to expect consumer input to service design and evaluation without just payment for that consultation. Potential employers need to be educated about mental illness and subsidies and supports offered. In the longer term these are very cost-effective strategies.

SOLUTIONS
- **Develop training and support programs to assist consumers in obtaining ongoing employment**
- **Publicise and improve government subsidies to the wider community of employers**
- **Support consumers in developing worker co-ops**
- **Education of employers about mental illness**
- **Legislate standards for payment of consumers within mental health services, ie classification of positions and amount of payment**

Issue (6)
People with a mental illness having to be really unwell to access help

<u>BACKGROUND</u>
Most mental health consumers would be able to tell you a graphic story of how they tried to receive a service because they knew they where becoming unwell, but where told they where not 'unwell' enough to qualify for a service. When consumers eventually do 'qualify' as being unwell their hospital stay is lengthy and their illness is server. Consumers are experts on their own illness they understand their own *'early warning signs'* and know when they need early intervention to stop the onset of a server episode which usually requires lengthy hospitalisation.

SOLUTIONS
- • **Listen to people with a mental illness, when they state they are becoming unwell**
- • **Adequately resource services so that consumers don't have to be extremely unwell to receive some service**
- • **Stop the practice of discharging mental health consumers from community care teams because they are "too well"**
- • **Increase range of options available to access before crisis**
- • **Improved follow up post discharge**
- • **Home based support - respite**

Issue (7)
Continuity of care in the community and hospitals for people with a mental illness

BACKGROUND
Many consumers lack discharge plans, or if one does exist they have had no input into its design. People felt that they were discharged too soon (if there was a lot of demand for inpatient beds) and sometimes not soon enough. Many consumers are basically abandoned upon discharge and there is no preparation or information given to them. Communication between different parts of mental health services is poor. A discharge plan which involves the consumer, mental health and other workers who are or will be providing a service is a requirement of the National Standards for Mental Health Services and is the right of every consumer, but in reality this very rarely occurs.

SOLUTIONS
- **Discharge planning involving Consumer, Carer, Key Worker, etc**
- **Provide discharge package (range of services and contacts)**
- **Increase community supports in:**
  - **Supported accommodation**
  - **In home**
  - **Drop in centres**
  - **24 hour help lines**
- **Well trained and informed GPs**

Issue (8)
Lack of choice in type of therapist ie: Alternative, psychologist, OT, and Peer Worker

BACKGROUND
The "Side-effects" from prescribed medications are often harder to deal with than the mental illness. Some medications have long term irreversible affects that are unacceptable.
The Medical model of service provision is overpowered by prescribed medications, consumers know that the 10 to 30 minutes with their doctor will be spend discussing medication. The social, psychological and environmental stress of the illness is far to often ignored which greatly hinders recovery.

SOLUTIONS
- **Medicare rebates to include alternative treatments**
- **Conduct research to prove effectiveness of alternative treatments**
- **Educate consumers about their options**
- **Lobby**
  - **Power brokers**
  - **Public mental health policy makers**
  - **Politicians**

Issue (9)
Lack of worthwhile and appropriate rehabilitation

BACKGROUND

Consumers believe that rehabilitation has been downgraded over the past few years and that very few resources are devoted towards it. There are models that show the positive results consumers can achieve when providing rehabilitation services. If government funded mental health services are unwilling to commit to adequate rehabilitation then the resources should be shifted towards consumers to facilitate it.

Some drop-in services and skill training groups run by self-help, voluntary and non-government organisations are very necessary and enthusiastically supported by consumers although we feel that rehabilitation provided by many mental health services just "occupies people's time" so they don't become a problem to others or the community. Successful models exist which have positive outcomes such as {AMIGOS (SA) and EPPIC (VIC), and others involving consumer ownership} these need to be developed in all areas.

SOLUTIONS
- **Funding for consumers to run training and workshops**
- **Identify what consumers see as rehabilitation and improve system accordingly**
- **Educate service providers and funding bodies in a consumer focus**
- **Provide adequate resources to facilitate meaningful rehabilitation**
- **Increase empowerment of consumers within services to increase confidence etc.**

Issue (10)
Unfair and inappropriate Detention, Treatment and Administrative Orders
to force treatment such as Electro-Convulsive Treatment (ECT)

BACKGROUND

A system of advocacy needs to be implemented, adequately resourced and respected. Consumers can be alienated from services forever by inadequate consultation and explanation. A number of people with a mental illness feel coerced into having treatments they do not want. Suitable standards in the area of involuntary treatment and detention need to be established.

SOLUTIONS for ECT:
- **Two of Three Doctors to approve use**
- **Benchmarking of standards**
- **Consumer Advocate on Guardianship board**
- **Abolition**

SOLUTIONS for Administrative orders:
- **More flexibility**
- **Support from Advocates**
  - • **Work like a bank or credit union**

Issue (11)
Amount of unpaid work done by people with a mental illness

BACKGROUND

We are the experts! Services need our expertise! We should be considered in a similar way as computer technicians are. They have knowledge, experience and skills which few people have, and receive payment accordingly. Our experience cannot be learned through formal education, it needs to be lived. Without consumers shaping the future and providing education and support the current services would not function as they do. Precedents need to be set and in-forced if services are to improve!

SOLUTIONS
- **Legislate which type of work consumers will be paid for**
- **Create and agree upon suitable standards and rates of pay**
- **Create a consumer union to protect consumer workers**
- **Dedicate funding within budgets towards consumer wages**

Issue (12)
Stigma from the: Family, Community, Workplace, Police force and Mental Health Workers

BACKGROUND

People with a mental illness experience stigma on a daily basis.
Pervious efforts have been seen as useful but too little and for too short a period of time.

SOLUTIONS
- **Education at all levels utilizing consumers experience, skills and knowledge**
- **Mandatory training for professionals such as teachers, youth workers, GPs, etc**
- **Education for the media, ie more promotion of media kit entitled "Achieving the Balance"**
- **Main streaming of health service**
- **Enacting national and state mental health policies and plans**
- **Compulsory education in secondary and tertiary learning centres**

Issue (13)
Lack of information given to consumers about their illness and legal rights

BACKGROUND

The quality and content of information given to consumers is generally poor and not standardized. The National Standards for Mental Health Services requires consumers be appropriately informed about their illness. Services must be held accountable for the information they provide to consumers. It is a consumer right to be informed about their illness, not a need.

SOLUTIONS
- **Standardized information provided by all services**
- **Legislation and protocols to assure documents are received**
- **Consumer advocates to monitor quality of information given**
- **Increase availability of interpreters for all languages**

Issue (14)
Lack of legislation protecting mental health consumers

BACKGROUND

South Australia is the only state not to include mental illness in its Equal Opportunity Act (EEO Act). Currently the Attorney Generals Department is proposing changes to the (EEO Act) to include mental illness.

SOLUTIONS
- **To ensure changes are enacted within legislation to align with the rest of Australia**

Issue (15)
Lack of true partnership in service delivery and tokenistic representation

BACKGROUND

Services seem willing to involve consumers in "talk" but not in designing and implementing substantive change. True partnerships between service providers and consumers is very rare (one of the goals of the 2nd National Mental Health Plan). For true partnerships to exist the power structure needs to be horizontal not vertical as presently exists. Consumers need to be represented at every level of the service. For public mental health services, this means from the board level down.

SOLUTIONS
- **Legislation to enforce consumer power**
- **Service providers need to share power**
- **Payment and classification of consumer positions to enhance partnership**

Issue (16)
Lack of empowerment for mental health consumers

BACKGROUND

Historically consumers have been kept in the "dark" about their illness, their rights and excluded from policy making and service provision. This still occurs in a majority of mental health services around Australia.

SOLUTIONS
- Payment and classification of consumer positions to create equality
- National unification of state consumer groups
- Legislation to enforce consumer involvement
- Enforce service providers to share power
- Ensure mental health consumers have representation on all boards and interview panels

Issue (17)
Lack of services in rural and remote areas

BACKGROUND

Under resourcing of rural and remote areas is an historical and chronic problem. These problems still persist today.

SOLUTIONS
- Provide mental health services within rural and remote areas
- Better incentives for mental health professionals to "go rural"
- Increase information about resources available
- Resource social interaction. Consumers networks enable gathering for crisis intervention, prevention and friendship
- Explore and improve "Best Practice" models, adapt these to rural

environments

Issue (18)
Little or no say in management plans

BACKGROUND

Case management plans (individual service plans or some other term) are not in routine use everywhere and consumers felt alienated from them because they were rarely involved in their development when they were used. This is despite this being a requirement of the National Standards for Mental Health Services.

The rhetoric about "consumer empowerment" is just that until consumers are consciously, deeply and consistently involved in determining what they need from service providers and their preferred ways for those needs to be met.

SOLUTIONS
- Develop a consumer care path to well being, with active consumer involvement
- Use consumer peer workers / Consultants to ensure it occurs
- Greater cooperation and coordination by service providers
- Increase consumer input and education of service providers

Issue (19)

Little support from hospital to home

BACKGROUND

Many consumers are discharged from hospital to no services, sometimes not even appropriate accommodation. The isolation can often manifest into another episode and result in a re-admission, this re-enforces the "revolving door" syndrome. Not only do constant re-admissions damage and affect consumers in so many ways it also places a drain on resources already under pressure

SOLUTIONS

- **The development of a management plan for every mental health consumer**
- **Community based "Key Workers" or "Case Managers" to meet and visit all consumers in hospital.**
- **Home support such as community service workers to be provided where necessary**

Issue (20)

Lack of suitable access to Psychiatrists

BACKGROUND

A lack of availability of psychiatrist has been an ongoing problem but seems to be more acute now. Travelling is a problem for many consumers and adequate support and reimbursement needs to be established. A lot of money seems to have been spent on technology (Tele-medicine etc.) but are the dollars worth the outcomes? Some Consumers find using it an alienating experience and it does not replace face to face contact for some people.

SOLUTIONS

- **Proper outreach programs for all, including forensic clients**
- **Tele-medicine is OK but does not replace face to face contact. Amount of time allocated to each consultation, needs to be extended**
- **Increase resources, to eliminate lengthy waiting lists**
- **Supports needed to decrease travel burden**

Issue (21)
Children of parents with a mental illness

BACKGROUND

Consumers who are also parents have great fears and worries for their children especially when they are unwell. Their detention can result in children being "home alone" without supervision or support. Children often take on the role as "carer" or the parenting roles at a very young age (under 10 years old is not uncommon). Children of consumers face stigma and aren't provided with education and knowledge of their parents illness. There are many more problems surrounding this delicate issue and it needs to become one of the focuses of our mental health systems

SOLUTIONS
- **Supply support and supervision for children when parents are unwell**
- **Increase services and support for children, not just when Parents are in crisis**
- **Support and education for children to understand parents illness, to reduce confusion and depression**
- **Specialised service, with trained workers to assist entire family**
- **COMIC (Children of Mental Illness Consumers) support groups are slowly developing, these groups need to become a standard part of youth and adult mental health systems**

Issue (22)
Unique problems facing young people with a mental illness

BACKGROUND

Youth issues are an area of particular concern and despite the effectiveness of early intervention and prevention programs there does not seem to be the same commitment of resources in South Australia as in a number of other states. Young people often feel alienated by current mental health services. Services provided to young people the aged 18 years and above are grouped together with all adult clients. This results in hospital and community group sessions containing people as young as 18 and as old as 65. Young people feel alienated and start to think they will be unwell for their entire life.

SOLUTIONS
- Provide peer support including age, experience and gender
- Increase recognition, resources and support for youth
- Implement mental health / illness education in all school syllabuses
- Education covering mental illness to be component of primary and secondary school teachers Education / University degree
- Increase community awareness about mental illness and prevention actions
- Improve specialised youth services and knowledge of available services
- Increase empowerment of young people
- Provide adequate and appropriate activities
- Incorporate mental health services for young people within general youth health services to reduce stigma and increase acceptability of youth to access the service ie feeling comfortable

Issue (23)

Culturally, sexuality and linguistically diverse people experiencing a mental illness.

Issues covered by this group included

- Lesbians & Gays, Bisexuals and Transgender
- (NESB) Non- English speaking backgrounds
- Indigenous issues Aboriginal, and Torres Straight Islanders
  - Spirituality
  - Creativity

(All 22 issues listed above affect culturally and linguistically diverse people, in many cases more severally than the wider community)

<u>BACKGROUND</u>

A minority within a minority! Culturally, sexuality and linguistically diverse people are often misunderstood by the wider community and have a separate stigma to live with on a daily basis. Adding the trauma of mental illness provides the uneducated community with more ability to discriminate. Cultural beliefs are sometimes taken by mental health professionals as delusions and to "be part of the illness" without realising it is a common and standard belief for their community or culture.

SOLUTIONS

- Uphold United Nations principals (Resolution 41)
- Educate the community to understand individuality and diversity
- Amend the diagnostic and assessment tools to include specific aspects for diverse people within the DSM 4
- Provide mental health workers with knowledge to gain understanding of sensitive cultural beliefs and practices
- Involve relevant community members in treatment programs