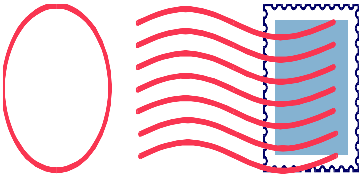

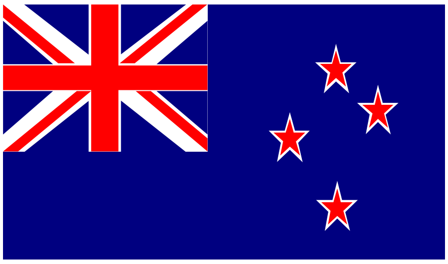

MENTAL HEALTH
CONSUMER PARTICIPATION :
A NEW ZEALAND PERSPECTIVE

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Disclaimer:
The views expressed in this document are those of the Author. MidCentral Health has not expressed any views in respect of this document, nor has the Author sought them.

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PART 1

INTRODUCTION AND BACKGROUND

This paper discusses:

(1) Background to Consumer Participation
(2) The Vertical Integration of the New Zealand Consumer movement
(3) The need to expand consumer participation in the HHS
(4) Linear integration of the HHS and bridging the gap
(5) Computerisation of the integration
(6) Conclusion

"Challenge the old, champion the new…..change your thinking!"
(Telecom NZ ad……1999)

Consumer Participation Introduction

"People affected by mental illness are amongst the most vulnerable and disadvantaged in our community. They suffer widespread, systematic discrimination and are consistently denied the rights and services to which they are entitled.

The level of ignorance and discrimination associated with mental illness in the 1990s is completely unacceptable and must be addressed." **(1)**

Historically mental health consumers have been powerless and vulnerable. They have had few opportunities to develop expertise that would enable them to make decisions for themselves or to control their lives. However, they often have significant practical expertise in the area of mental health.

One of the visions of the World Health Organisation in primary health is that, "the people have the right and duty to participate individually and collectively in the planning and implementations of their health care". **(2)**

Over the last 5 years the involvement of consumers in mental health services has undergone radical change. All consumers look to the new millennium for a greater improvement to our right to ***'quality care',*** as detailed in Right 5, Consumers' Code of Rights.

Real improvements in mental health need to be implemented by governments, working with a national strategy addressing consumer concerns such as economic, social, educational and cultural factors which impact mental health. **(3)**

Government must show leadership in improving mental health in New Zealand.

With the recent change in government to Labour/Alliance, the consumer movement looks forward to those promises made in *"Addressing the Gaps in Mental Health"*, released by Labour New Zealand 2000, 15th October, 1999.

A hostile media is counter-productive to good health and Mental Health Services (Hospital and Health Service [**HHS**], Non-Government Organisation [**NGO**], Iwi); themselves need radical change in their philosophies of service delivery, with a greater need of consumer focused solutions and activity.

The assaults on the clinicians in the numerous National Enquiries into the care and treatment of consumers has left a defence mechanism in the services which is entrenched. Mental Health staff still experience shellshock from the side-effects of these enquiries and have been shown little enticement to venture from the 'fortress'.

Stigma exists for them as much as it does for consumers.

Recruitment of mental health staff needs to reflect employment of staff that share the vision and values of consumer partnership, consumer empowerment and the recovery model. Pay scales of staff should reward the attempt for betterment in the service of the 'recovery model'. They should also be attractive to win back the 'brain drain' of talented clinicians practising overseas. Bonuses should be paid for those who are instrumental in 'change mechanisms', which are consumer focused. Policy making and Service delivery must be tailored to suit local needs.

Greater emphasis must be made to win back our cream of educated clinicians to the fold.

Community facilities which are linked into the HHS should be expanded, to divert traffic away from acute settings. More consumer focused attention needs to be devoted to facilities that create a two way bridge with the HHS from the Community to secondary services. This should include the provision of consumer driven awareness raising through education.

In New Zealand we do not have a national consumer collective body to give input into the statutory bodies of government or to determine a national consumer participation policy. This paper discusses a suggested solution to the problem of how best to attend to a National strategy of a workable N.Z. plan.

The foundations of interaction are formulating at the base level of consumer activity, albeit somewhat slowly. The majority of the ground work is being done by local groups, carers, independent advocates and consumer advisors/consultants; although well meaning construction of participation is by no means to a identifiable architectural plan.

Consumer Participation

The word **"participation"** means to take a part or share (in). Consumer participation has arrived. Clinicians use a variety of terminology to categorise the consumer. Some will opt for "user", some still persist with "patient", whilst others will use "client" or even "customer". Considering much information and statutory writings simplifying it to "consumer", it would be helpful using the terminology 'consumer' to aid standardisation. How the clinician refers to their consumer in a private session of consultation or between peers is a matter of individual choice, but when one enters the realm of official writing and policies then people should adopt a more international terminology, of 'consumers' of mental health services.

The definition of Consumer Participation is a " process to improve the quality of service delivery and increase the level of consumer satisfaction with mental health services. Consumer participation in the mental health field means that the service providers ensure consumers have the opportunity to influence decision-making processes in the areas of service delivery, service planning and development, training and evaluation." **(4)**

Increasing consumer participation through increasing use of consumers as service advisors is a fundamental strategy to improve the quality and responsiveness of mental health services, and is a key objective of the national mental health strategy.

Expectations of consumer participation can occasionally be excessive. In some areas this is going to be a long and slow process.

The advantages of health consumer involvement in writing health care guidelines have been well canvassed.

Greater consumer involvement in decision making about quality improvement is supported by the fact that clinical outcomes improve when health consumers are actively involved in managing their own health - shifting emphasis from curing illness to promoting health - and by a growing awareness of the contribution the community can make to the health of individuals. **(5)**

What is Quality Improvement ?

It is important for all of us to remember the six principles of quality improvement programmes:

1. Quality is determined by consumer needs and expectations,
2. Building quality into organisational processes reduces variation in a system,
3. For continuous improvement reliable and valid process and outcome measures are required,
4. Most quality deficiencies result from system problems rather than problems with individuals,
5. Commitment from leadership to provide tangible resources such as funding, training, personnel, and computing services determines quality,

6. Empowered teams made up of personnel responsible for different functions in a process are better to understand problems and to devise feasible solutions. (Hence the need to involve consumer input). **(6)**

Successful quality improvement requires a supportive organisation; culture that emphasises empowerment, flexibility, and teamwork, rather than a culture reflecting a hierarchical and bureaucratic management structure.

Not paying adequate attention to consumers and to culture factors necessary to support quality improvement initiatives will result in failure. The obvious question is how to foster development of such a culture.

There is a need for the service to become more responsive to the needs of all its consumers. To be able to do that the service will have to redefine itself, and build alliances with consumers and significant others, (community agencies, other mental health providers), in the local area and most definitely with its own staff.

It is for the leaders to ensure this transformation is constructive for consumers and staff.

Barriers to Consumer Participation

Implementing consumer participation is not an easy process. This is largely because historically, mental health services have only in a limited way organisationally and culturally involved consumers in policy making and service planning and development and finally quality improvement.

Barriers to participation are generally major issues among consumers, who feel them quite passionately.

Many consumers believe the Medical Model is too narrow and can be disempowering. The promotion of consumer led recovery, a scope for alternative approaches to service delivery and a proactive use of services by consumers needs to be put into place.

There is a lack of a clear, cohesive and integrated national policy on consumer participation. A lucid consumer national participation policy, promulgated by the Ministry of Health must be instituted, which is:

- Current;
- Financially directive for the HFA (or service purchaser) to implement, without favour;
- HHS and community (local) orientated linking into the vertical integration of the consumer movement;
- Formulated in partnership with consumers (possibly by a Committee of the national Consumer Forum -see Part 2);

Overcoming the Barriers

Effective ways that can be utilised in overcoming the barriers are:

- Working towards changing the culture of the services. The services are available to provide an environment in which the consumer can recover but finally it is the consumer who does all the leg work. The Government funded services are but a small part. The issues to be concerned about in service delivery are:
    - concerns by consumers about medication. Insufficient information about medication, side-effects, limited choices, restricted access to new medications, and unnecessary changes in medication;
    - lack of respect from mental health staff, including not being listened to
    - communication difficulties with staff, compounded by frequent turnover of psychiatrists and short appointment times;
    - lack of information about rights and lack of communication in these rights
    - unsatisfactory treatment in acute units, particularly use and abuse of restraint and seclusion;
    - poor discharge procedures and poor access to supported accommodation of good quality. **(7)**
- The service has to have a willingness to change and to implement change, based on consumer input. This has to be created with a 'change agent", as found in globalised corporations.
- Education for service provider staff, to enhance respect and taking more consumer-empowering approaches in dealing with consumers. These processes should involve consumers, in partnership with the HHS - Consumer Educator. (see Part 3).
- Participation needs to be a mixture of approaches – not just committees, and it should be happening on all levels, ranging from consumers having a say in their Integrated Treatment Plans through to service planning and development; characterised by collaboration and partnerships.
- Recognition that consumers are the major stakeholders in the service and thus should hold an entitlement to significant input to the service through their wealth of knowledge from personal experience.
- Financial remuneration. This needs to be realistic and in line with commercial practice. Many consumers live on poverty incomes. Extras, like a drink with the Group, are not "incidental" on a welfare allowance.
- Ownership of the key stakeholders' share: (Adaptation of Sherry Arnstein's ladder of citizen participation) **(8)**

8	**Consumer Control**	**Degrees of Consumer Power**
7	**Delegated Authority**	
6	**Partnership**	
5	**Conciliation**	**Degrees of tokenism**
4	**Consultation**	
3	**Informing**	
2	**Therapy**	**Non Participation**
1	**Manipulation**	

Partnership

The Mental Health Commission's *Review of Progress 1994-1999* for New Zealand's National Mental Health Strategy reported that "there is a growing recognition that services need to value and empower service users as genuine and respected partners in all aspects of policy development, planning, service delivery and evaluation. Recovery is enhanced and long term dependence on services reduced when true partnership occurs at all levels of the mental health sector."

Increasing recovery depends on true consumer partnership being achieved at all levels of the mental health sector. **(7)**

Partnership means a 50/50 working relationship consumer/service provider. It also means a meaningful relationship of consumers with the Ministry of Health and the Health Funding Authority.

Partnership among different members of the community can be demonstrated and strengthened by joint projects. For example, consumers and professionals, consumers and family/whanau members, consumers and community leaders have teamed to make educational presentations and working groups for consumer/service needs.

Code of Conduct (Consumer on consumer)

The requirement in being able to participate to form a partnership means that the consumer needs to adopt a responsible approach in respect of the meaning of the two words. Sometimes, possibly as a result of their illnesses, consumers can be their own 'worst enemy' and this can be reflected in their relationship with a fellow consumer/s.

The Health and Disability's Code of Rights should also encompass Responsibilities of the Consumer as well as Rights which should include respecting fellow consumers.

The writer has observed a passion by some consumers for ownership (of facilitation), and indeed some cases of paternalism in interplay in consumer groups. Sometimes non-observance of basic human qualities such as good manners, respect of another person's illness or side effect to their medication, often is disregarded. These issues are surely 'bait' for non-consumers to help underwrite the delivery of consumer input and participation.

Michael Kendrick, a Canadian with 30 years experience, gives the following tips for consumers:

- See the good that is already here – great strengths, passion and goodwill
- Learn from and accept our mistakes
- Show goodwill to ourselves and our colleagues
- Celebrate the small victories
- Try to do good and be good to each other **(8)**

When is Consumer Participation Appropriate?

Consumer participation is appropriate in the following areas:

- Staff interviewing and selection
- Policy and procedure development
- Changes to consumers' environment
- Consumer Advocacy
- Psycho-education
- Planning and needs assessment
- Recovery
- Purchasing/fund allocation decisions
- Decision making

Rehabilitation services
Residential service assessment
Quality Assurance and system review
Mental Health Promotion
Job Descriptions
Research projects
Maori and cultural programmes
Consumer surveys
Key-stakeholders' ownership

WHAT DO THE STATUTORY BODIES HAVE TO SAY?

Ministry of Health (MOH)

The function of the Ministry of Health, in part is to:

- Develop policy. This is often undertaken by projects. These involve basic research, fact-finding and consultation.. Some of the targets in the National Mental Health Plan are derived from the Ministry's projects. The Guideline
- Advise the government on priorities
- Assist the government in setting expectations on the funding/purchasing body
- Monitoring of the purchasing body
- Reviews the national strategy
- Sets national targets **(9)**

The MOH contracts consumers to provide a perspective into specific projects and guidelines development. Consumers have been involved in the appointment processes for District Inspectors.

The involvement of consumer participation in the Ministry does not currently meet targets set in the National Mental Health Standards.

The Ministry's contract with the Mental Health Advocacy Coalition requires that a consumer's perspective informs any of their recommendations or advice to the Ministry.

Health & Disability Commissioner Act (1994)

The Health and Disability Commissioner Act 1994 is a key element in the new environment of consumer-focused and consumer-accountable health and disability services and has become a primary vehicle for dealing with complaints about any service provider in New Zealand.

The consumers rights are laid down by law in the Code of Health and Disability Consumer's Rights (1996).

Lack of participation in this area is a need for a Code of Consumer's Responsibilities to add an equal balance to the 'partnership'. Responsibilities could include:

- Respect of other people's rights;
- The need to respect various Acts (e.g. the Smoke Free Environment Act 1990);
- To actively participate in individual's recovery;
- To respect facilities of service providers;
- To participate in the principles of the Treaty of Waitangi.

The problem with this office is that consumer complaints take a lengthy time for resolve and it is doubtful whether the investigating officers really have a sufficient understanding of service delivery and consumer issues.

Health Funding Authority

The role of the Health Funding Authority, in part is to be the government's official purchaser and of health services **(9)**. It also:

- Monitors contracts with service providers;
- Prepares regional plans;
- Translates the national targets into specific services that meet regional needs;
- Reviews and updates regional plans.

While it is unlikely that any single service provider would provide the full range of adult mental health services, the HFA requires that providers will work collaboratively and co-operatively together to ensure that the full range of services funded are provided in an effective and complementary manner which focuses on consumer needs. **(10)**

"Consumers will also:

1) Participate in the planning, delivery and review of their own care.
2) Consumers will also participate in the planning, delivery and review of the service or sets of services as a whole.

The HHS will:

3) ensure that staff attitudes reflect that provision of high quality service is a priority, and that people accessing the service are welcomed accordingly.
4) comply with the National Mental Health Standards (Ministry of Health 1997) (NMHS) by 1 July 2000.
5) comply with *"Guidelines for effective Consumer Participation in Mental Health Services (1995)".*
6) ensure staff training having a consumer focus when they provide services.

The HFA wishes to fund a full range of consumer focused, responsible services:

- Consumer advisory services

- Consumer run support service (advocacy/peer support)
- Consumer run support services (Adult Service), (A&D), (CAF), (Forensic), (Older People).
- Family/whanau support services (Adult Services), (A&D), (CAF), (Forensic), (Older People) " **(11)**

The HFA will continue to use a variety of mechanisms to involve consumers in planning and evaluation. This will include employment on Health Funding Authority teams, consumer advisor contracts, consumer consultation, contracts with consumer groups, and involvement in audit and monitoring projects. **(12)**

Whilst there are some consumer participation processes in place the Health Funding Authority also does not currently meet the required targets in the National Mental Health Strategy.

The HFA would benefit greatly from implementing a nationally consistent approach to funding of mental health consumer participation in HHSs in a way which provides funding clarity to the HHS but allows for flexibility of approach at the local level.

The HFA needs to recognise the value of working collaboratively with contracted providers. "Trapped in a suspicious view of the 'community' the agencies of the state will remain reluctant to place all "cards" on the table. (This also includes the stance taken by WINZ on beneficiary rights). A truly collaborative approach would redress the power imbalance presently found in the contract mentality, one in which the state largely defines all the rules." **(13)**

Mental Health Commission (MHC)

The Mental Health Commission has a responsibility to monitor and report on implementation of the National Mental Health Strategy. The requirements for consumer participation are outlined in Standard 9 of the national Mental Health Standards, 'Consumers are involved in the planning, implementation and evaluation of the mental health service', which is also reflected in Target 3 of *Moving Forward*. As part of its monitoring and reporting responsibilities the Commissions intends to review consumer participation across a range of health agencies. **(14)**

The Commission also has, in part, the following functions:

- Evaluates the extent to which the Ministry has exercised leadership;
- Evaluates the degree to which other governmental agencies are fulfilling their role in respect of mental health;
- Evaluates the robustness of accountability systems for mental health funding;
- Looks into any other matter that the Commission and the Ministry considers needs particular attention. **(9)**

At present the 'life' of the Mental Health Commission (MHC) is until year 2001. The MHC is responsible to ensure that the *Blueprint for Mental Health Services in New Zealand*, developed by the MHC is implemented and a far wider coverage involving housing, employment, income, and education, needs to be considered.

There is a need to extend the tenure of the MHC for the *Blueprint* to be further developed and implemented.

PART 2

THE VERTICAL INTEGRATION OF THE CONSUMER MOVEMENT

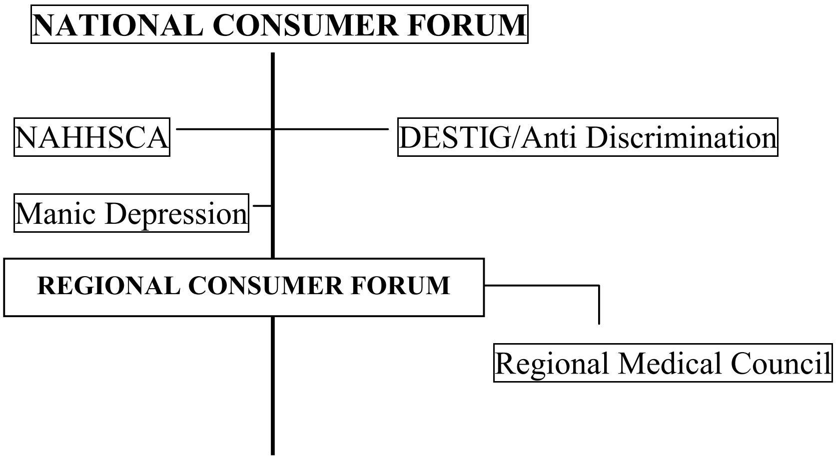
National Consumer Network

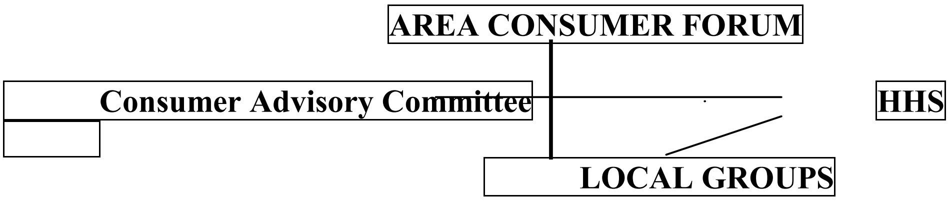
Some attempts by government bodies have been investigating the principle of Consumer Vertical Integration, without much luck, or fully understanding a ‘growth’ mechanism. Their tactical approach seems to be utilisation of Consumer consultants, on a “mission”, in search of some “instant” solution to what is indeed a very complex issue; that of a workable National Consumer Participation Plan. Various questionnaires and surveys also have attempted to find answers, and nothing seems forthcoming from these bodies.

New Zealand lends itself ideally to a consumer network maintained by vertical integration. The Unitary system of Government makes it less complicated and more likely to succeed than, say, the American or Australian model of consumer involvement, which involves Federalism and the ensuing “disempowering” of different State Laws.

The ladder of Consumerism starts at the bottom, with strong foundations at the local level, with proper funding by the HFA into the Area Consumer Forum (ACF) and its steering committee; the Area Consumer Advisory Committee (CAC). This tree of growth is further strengthened in the trunk by linear integration into the HHS. (See Part 3 of this paper).

The diagram shows the proposed linkage:





Author's note: The working model this paper is centred on is MidCentral Health Limited.

Guidelines for the Establishment and Operation of Consumer Groups

a. Members should be primary mental health consumers only and should be capable of representing the interests and concerns of their consumer interests.
b. Membership should encompass both genders, Maori, Pacific Islanders and non-speaking English speaking backgrounds.(In line with EEO principles)

PRIMARY LEVEL

Local Groups

The consumers' first line of involvement after discharge from an Acute Mental health unit or being assigned a keyworker in the community and accessing the service is at the Primary level of integration. "Access to Mental Health services is from any referral source, including self-referral. Emphasis is on early access to the services on a voluntary basis." **(11)**

Local issues vary extensively throughout New Zealand. For instance the issues in Tauranga would certainly be diametrically opposed to Wellington where they would tend to be more mainstream.

Local issues mean exactly that; satisfy them with local solutions. The local groups in one's area could include:

Schizophrenia Fellowship
Women's Health Collective
Gay & Lesbian Group *
AA
Manline
Rape Crisis
Activities Centre
Housing Advice Centre
Bipolar Group
Like Minds Destig

* a success story has been the Lesbian, Gay, Bisexual and Transgendered (LGBT) Youth Vocational Mentoring project in Christchurch. **(14)**

The "HFA Schedule on purchasing" **(11)** details that the range of services provided will include:

- Consumer run support service (advocacy/peer) - Adult
- Family/whanau service - Adult
- A&D consumer run support service
- A&D family/whanau support service
- CAF consumer run support service

- Forensic service consumer run support service
- Forensic family/whanau support service

It should be noted that in many areas through-out new Zealand there are none/ or minimal mental health consumer run services existing in the community.

Area Consumer Forum (Consumer Advisory Group)

This group has membership of all consumers in the local HHS's environs. The MidCentral's Area Consumer Forum (ACF) was officially founded on 7 October 1999. Reports filter in of the existence and formation of CAGs which are similar in nature to ACFs.

The role of the forum is to provide a community meeting place where consumers have input into local issues. These roles include:

a. Political interactivity,
b. Social interaction,
c. community education,
d. community communication,
e. consumer employment,
f. consumer accommodation,
g. Computer website maintenance,
h. Identifying sources of financial support.

It is important to use creative thinking and approaches which facilitate real two-way communication, as with any political process. The Forum must facilitate political and social lobbying by the consumer movement, at a local level, liasing with city and district councils on issues that impact on consumers.

As an example the MidCentral area problems centre around accommodation, the current configuration of Government funded MH Services and consumer employment issues. The forum has asked the Area Consumer Advisory Committee to:

a. seek funding from local and statutory bodies for legal status of the Forum;
b. define vision, mission, rules and responsibilities;
c. develop a business plan.

This has since been sent to a sub-committee, while the question of funding is resolved.

Area Consumer Advisory Committee

The membership of this group in Manawatu has been limited to five consumers. The actual number on this committee would depend, of course, on the size of the area in question.

A committee was duly elected by the ACF with a Chair and Vice-Chair and Secretary being appointed.

So far, there have been three fully funded meetings of this Committee (funded by MidCentral Health).

Although in its infancy the Committee has highlighted the following consumer issues to develop:

- **Consumer Accommodation**. Possibly working with your local supported housing (HFA purchased), to devise a plan for some sort of consumer run accommodation and also consumer run support services, as per "HFA's guidelines" **(7).** The Ministry of Health also mentions that consumer participation could also allow some consumers to set up or become involved in consumer-run and consumer-managed enterprises.**(15)**

- **Consumer Research/Projects**. To link in with the HFA, Polytechs and Universities to attract funding for this niche of consumer participation. Publishing projects, making videos or multi-media presentations with consumers telling their "stories" and sharing perspectives. A particular project could be linked in with *In Our Hands- New Zealand Youth Suicide Prevention Strategy.*

- **Consumer Community Education**. Utilise presently funded consumer bodies, such as, "Like Minds" to present workshops and Roadshows for Community education, especially destigmatisation. Linking in with the service to collaborate to develop psychoeducation and social courses for consumers, with a focus on recovery.

  There needs to be more emphasis placed on the wellbeing of all young people and promotion of seeking help in times of need.

- **Consumer Community Communication**. The possible establishment of the following:

  - a community Radio network
  - an 0800 warm line, staffed by consumers offering advocacy and referral (A current HFA project in the South Island)
  - a consumer website for "chat room" and "Dear Doctor" access. Linking up with other consumers on a chat line. The 'Dear Doctor' facility could actually be linked into the local HHS's.

- **Consumer Employment**. Concentrating on the establishment of paid work for:

  - Consumer advocates within the community and HHS; training provided by the HHS and monitoring of the advocate by clinicians for consumer safety issues.
  - Peer support workers for the "Cell Module" idea for the HHS .
  - Direct Care in "specialling" consumers, especially in Emergency Department of the HHS, and some supported accommodation needs. Appropriately qualified ex-consumers should not be barred from direct care roles.

Encouraging participation in and opening up training for nursing, social work, psychology, occupational therapy and disability support work to ex-consumers (Similar to the Alcohol and Drug Counselling Course).

- Membership of certain Hospital/Ethics Committees' consumer positions, as arise.
- Consumer youth liaison officers for programmes such as school-based. destig programmes, peer support for students, health promotion on avoidance of drugs and alcohol. **(16)** (this at present could be championed by HHS-Public Health but some youth consumer input is vital).

The advantage of consumer employment is that expectations are realistic and the job usually involves an agreed relationship with health professionals. Other areas of employment could be outside the health sector, with gardening co-operatives, farm and orchard work and manual labour. The consumer with office skills could band together to offer a pooling of clerical and secretarial skills for community work, similar to what the university students do.

This idea is being utilised in the Italian model in Trieste. The co-operatives can be divided into 2 groups:

a. Co-operatives that are commercial in nature;
b. Co-operatives that provide services to other users.

These commercial co-operatives provide a variety of services such as cleaning and farming to operating coffee bars (drop in centres), restaurants and hair salons. The number of workers in these co-operatives in Trieste exceed 500. Many other co-operatives in other parts of Italy provide services such as case management and residential care.

Also in Canada, Mary Graham successfully created S.A.F.E.(Self Abuse Finally Ends) and employs fellow consumers for peer support work in group situations.

Utilisation of work schemes such as Workbridge , Phoenix, etc, should also be implemented by the consumer movement.

Consideration needs to be made of the fact that not all consumers can initially take on full time work, with part-time or casual work, being the preferred option. This would enable some consumers to cope with their degree of 'disability' and that 'recovery' is not a cure; rather a process.

- **Watchdog of Consumer Rights.** Working closely with consumer advocates, the independent consumer advocates and the District Inspector attached to the HHS champion Consumer Rights, especially in the community (e.g. support housing, conduct of police and prison officials)

Membership of the CAC

As discussed earlier, the actual numbers will vary according to the actual size of the Area we are talking about, however a maximum number of 15 is suggested.

Membership should cover Rural consumers, gender, Maori and Pacific Island interests and special interest groups with the balance of metropolitan consumers.

The members of this group are elected into positions by the ACF and the tenure of their position should last for two years to maintain some continuity.

Advertisements for nominations should be placed in local newspapers seeking expression of interest . All relevant consumer and carer groups and NGO's should be advised of membership vacancies or public meetings of the ACF should be held to solicit nominations. Background information on the structure of the CAC should be prepared for distribution of interested parties, together with a nomination form.

The Chairperson and Deputy Chair, must be duly elected by members of the CAC.
If a member resigns from the CAC, then they should be replaced. The new member should be selected from the ACF, by the CAC, to give fair representation of the local groups of the ACF.

Conduct of the CAC

The following points are a suggestion only as to the protocol necessary for the CAC to operate:

- The CAC should be legalised as a charitable trust;
- CAC members should accurately represent the views of their local consumers. In order to achieve this close liaison is required:
  - with ongoing discussions with as many consumers as possible,
  - reporting back to their constituents, the issues discussed at the CAC meetings;
- all members should treat each other and visitors with courtesy and respect. If issues arise at meetings, these should be resolved by negotiation between members;
- time management must be utilised for economies of scale and where possible meetings should have an agenda. Issues requiring more time should be delegated to sub-committees;
- Minutes of meetings should be kept and later disseminated to local groups including HHS and NGO's. This also includes meetings of sub-committees;
- A CAC quorum should be at least two-third's of members;
- Meetings should be monthly, in the initial stages of development;
- Decisions should be passed by simple majority;
- Action taken on behalf of the CAC by the Chair/Deputy, should reported on at the next CAC meeting;
- The CAC should allow visitors attending CAC meetings to give information sharing;
- The CAC should nominate one of their members as the Media spokesperson and media watchdog.

Professional Conduct of Members

- where a two-third's majority of members consider another member's conduct not to be in the representative interest of the Group and specifically
    - has persistently refused or neglected to comply with the operational guidelines of the CAC, or
    - has brought the CAC into disrepute through misrepresentation in formal or informal discussions with parties outside the CAC, or
    - has repeatedly conducted him/herself in a manner which other members of the CAC find intimidating, oppressive or disempowering

  then the Group may decide to suspend the particular member for a specific period, or consider the replacement of the member.

Remuneration for the CAC

The members should be paid an hourly rate for meetings including any hours spent researching for meetings. Travel allowance must also be included together with refreshments being made available, when the committee meets. Ideally rooms should be sought in the community setting, but initially the HHS might help with resources.

SECONDARY LEVEL

Regional Consumer Forum

Membership of this group would be elected from the ACF. This group would function more like a steering committee, rearranging finances and resources for the various areas within the Region.

They would also have a representative on the Regional Medical Council, which has been recently established.

The regional forum's creation is in the HFA's 5 year plan. The intention here by the HFA is confusing, as it is like building the second storey of a building with no foundation but the creation of this secondary level is necessary due to levels of accountability. The role would be more like organising submissions from area forums, collating and disseminating on a regional level and forwarding on outcomes to the tertiary level; similarly forwarding regional concerns back into the ACF for their considerations.

This forum should be elected from members of the Area Consumer Advisory Committee. Delegates should be representative of the area concerns and numbers should not exceed 6 people.

TERTIARY LEVEL

National Consumer Forum

Perhaps we should take time out to explore the Australian model of a National Forum. Consumer participation in health care services, policy and research is extensive in Australia by international comparison. **(17)** Indeed, it is difficult to find an example of such a far-reaching consumer movement anywhere else. Certainly, seeking community input into the development of health services began earlier in Australia than in many other places. The first documented community consultation by government on a health care issue that I have identified occurred in 1944, a long time before such consultation became a phenomenon elsewhere. **(18)**

A key factor in the evolution of health consumer advocacy in Australia has been the support of successive national governments for a consumer-initiated body representative of health care consumers, the Consumers' Health Forum of Australia ("the Forum"). **(19)**

The Consumers' Health Forum is a national coalition of consumer and community groups with an interest in health that provides and supports consumer representations on more than 100 national committees at any time. Soon after its establishment in 1987, the Forum produced guidelines for consumers representatives, now in its fourth edition. The Forum has held training workshops for consumers on a variety of topics: consumer representation, participating in research, developing consumers' research, writing grant applications and understanding research. The Forum develops policy and provides consumer perspectives on a broad range of issues. Its achievements include the development of consumer participation in the pharmaceutical evaluation process in Australia and in reforms to general practise. It has developed valuable materials about consumers' views of quality in general practice and a tool for measuring consumers' views of quality. The Forum has successfully extended consumers' rights to be informed in health care and has put informed financial consent onto the agenda in Australia. **(19)**

Perhaps the Australia model could be modified for New Zealand.

ANOPS

Aotearoa Network of Psychiatric Survivors governed as an incorporated society from 1988 and stopped operating on 7 April 1998.

ANOP'S role included reporting on service quality to the MOH and policy advice into the MOH's mental health guidelines documents.

In the early years, ANOPS provided a collective national voice for consumers. It worked well. **(20)**

ANOPS were also instrumental in developing a successful Maori network and in later years attempted to develop a Pacific Nations consumer network in Auckland.

The demise of ANOPS left a large gap both in national networking and independent leadership. The consumer movement, today, is desperately in need of strong and effective leadership. The leadership needs to have vision and clarity of thought and expression. It needs ' movers and shakers'; negotiators. More especially it needs Clinicians who are ex-consumers to 'out' (identify) themselves and join the consumer movement.

The emergence and maintenance of a lasting national forum is only a matter of time. How it is formed is a matter for both government agencies and consumers working in partnership.

Whatever form it takes, a more business like approach is necessary for its survival and also for the protection of consumer members.

The consumer movement itself is becoming more complex. It is not obvious whether this is caused unintentionally by the government agencies in commissioning different approaches or agencies themselves veering off course. The risk here of course, is self destruction through power struggles, etc.

A new national consumer body needs to manage this complexity so that the widest range of consumer voices can be heard.

The role of the New Zealand National Consumer Forum should include the following:

a. political lobbying on clinical issues such as:
    - use of seclusion
    - use of ECT
    - medications, especially interaction with PHARMAC. They should also contact other drugs companies for clinical trials of psychotic drugs and the money being re-invested in the consumer movement.
b. membership on National committees with an advisory issue on consumer affairs including Ethics Committees.
c. Consumer rights and privacy issues. Working closely with the Health and Disability Commissioner's and the Privacy Commissioner's departments.
d. Developing and maintaining a National Consumer Participation Policy
e. Participation in Consumer research. The Universities and polytechs would have to seek the permission of the consumer movement and its collaboration.
f. Maintenance of a National Consumer website. Initially this could be done with the help of the MHC's website.
g. To "globalise" the consumer movement, talking to other countries' consumer movements and the United Nations Human Rights department.
h. To develop and arbitrate on cultural issues maintaining the bi-cultural composition of the Treaty of Waitangi. To invite Maori to set up a Maori network in partnership with the forum.
i. The official consumer "linchpin" to the Ministry of Health and to have active membership, internally, in the Ministry of Health.
j. Quality assurance of service delivery issues and national policy formulation, working with Standards N.Z., MOH and the MHC.

PART 3

THE HHS:THE NEED TO EXPAND CONSUMER PARTICIPATION IN THE HHS

Introduction

Requirements for the HHS's in the national mental health strategy, have necessitated some fast tracking to cover consumer participation. In some cases the MHS has been caught out either by paying lip service or non-compliance to the *Guidelines on Consumer Participation (Ministry of Health) 1995*, *Moving Forward* and the NMHSs.

In any case the need for accreditation by the HHS will necessitate a major rethink and increased level of participation. It will also necessitate a revisit to the Vision and Mission of the mental health service in the HHS.

The consumer representative's positions nationally in the HHS is slowly gaining some momentum with a current level of 17 out of 22 HHSs employing some form of consumer representation.

The HFA's purchasing contract makes provision for Consumer Advisors within the HHS. **(11)** It also states that any shortfalls should be discussed with the HFA. So far only some South Island HHSs have received this funding. The purchasing by the HFA of Consumer Advisors, seems to have a haphazard approach to it. At the last meeting of the National Association of Hospital and Health Consumer Advisors, the group wrote to the HFA, asking for them to seriously address this issue.

Slowly with identification of consumer participation as being a valuable tool for quality improvement, some consumer representatives are at level 6 of the Arnstein's Ladder, whilst others are treading water at level 4.

Critical factors for Consumer Participation in the HHS

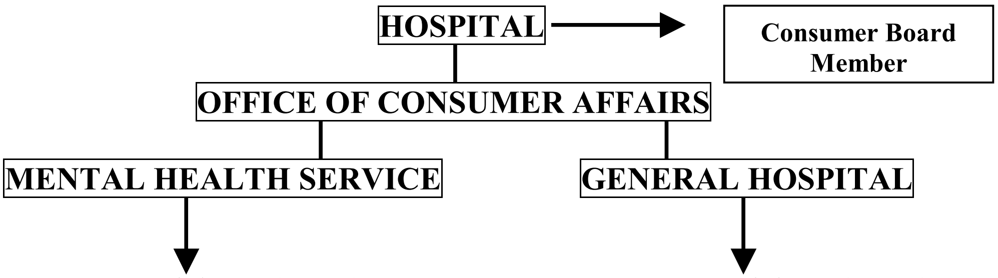
Consumer participation in the HHS needs to cover the following:

- An organisational consumer participation philosophy
- Stated goals and objectives
- A policy which supports participation
- A realistic timeframe for implementation
- Specific components of the strategy identified
- Resources made available

- Adequate funding and proper purchasing by the HFA
- Flexibility and the ability to refocus on local issues and needs
- Training
- An employment focus
- Job descriptions which values the consumer's experience
- Support, Supervision, Assessment, and monitoring

The actual recommended consumer participation within the HHS is best viewed in the following diagram:

A Suggested Organisation of Consumer Representation-HHS



Line	Consumer Advisor (1FTE)	Consumer Advisor (1FTE)
	Consumer Educator (1FTE)	Consumer Educator (1FTE)
	Cultural Advisor (0.5)	Cultural Advisor (0.5)
	Consumer Auditor (0.5)	Consumer Auditor (0.5)
	Consumer Complaints (0.25)*	Consumer Complaints (0.75)*

* This position probably exists as the Customer Relations co-ordinator and also takes on board the role of a Privacy Officer within the HHS.

Office of Consumer Affairs

As with most things, an American modernisation of doing it "big" would suit the consumer movement with the establishment in the HHS's of the Office of Consumer Affairs. This forward thinking is necessary for the future growth of the consumerism within the HHS. Although this paper only deals with mental health services, the neglect of consumer rights in the General side of the service is quite apparent. Some of the consumer positions I have recommended are line share between mental health and general services; a situation most HHS's could well afford and in partnership with the purchaser of services, be resolved to fully protect the consumer rights under the Health and Disability Code.

Consumer Board Member

The transition to a Consumer being on the HHS board should be logical progression for the future.

The current Labour platform envisages a district health board, with elections for board members to be held in conjunction with the 2001 local elections. **(3)**

Consumer Advisor (CA)

As a Mental Health worker employed specifically to represent the consumer, the CA holds the mandate to ensure that they explore a greater range of choices that are likely to be acceptable to consumers. The CA's guiding principles provide for an informed and collaborative approach to consumer services.

In partnership with the service, the CA is the strategic organiser of consumer participation in service delivery and policy making within the HHS.

The CA also provides consumer focused direction and leadership for all mental health staff and teams; responsible for overall establishment of consumer participation processes and systems, giving appropriate professional input and advice to the services and the monitoring of these.

For service development, the CA must have skills on promoting clinical quality improvement within the HHS and that consumer involvement/consultation is ensured in policy, procedure and process development.

The CA is also a salesperson/marketer, promoting and managing successful relationships with teams and individuals in the HHS.

To maintain a level of awareness, the CA needs internet access and an e-mail account. They should help design, or have input into the HHS website on the intra/internet. They should also have input into information systems on development of supports to the Patient Line, especially the consumer safety aspect of computerisation of clinical files.

The CA's abilities must include the following criteria:

- Knowledge and understanding of bi-cultural issues,
- Knowledge and understanding of a commercial environment,
- The ability to create a vision for the long-term development of the service,
- Be able to step outside their own area of expertise and profession to achieve a wider service experience,
- Have courage and be willing and able to challenge the status quo and take calculated risks that deliver the most effective long-term outcomes
- The ability to facilitate and collaborate with a wide range of consumers at various stages of wellness/unwellness; to take on board opinions to the contrary and, where possible, obtain satisfaction for these for the particular consumer.

To be involved exclusively within in the HHS plunges the CA into professional interactions without balancing involvement in the wider community. There is a danger that they come to share the perspective of the HHS only. The pioneering of consumer participation is not an easy manifest, as the CA learns to deal constantly with 'the wheels falling off'.

I talk further on about the need for the CA to bridge the HHS with the Vertical Integration of the Consumer at the Area level, to give participation a rock solid foundation at the most active level of consumer movements between the service and the community. This pathway needs a 'eight lane' bridge to allow fast and easy access, either way between the HHS and the community.

Membership of HHS Committees/Groups

For consumers, particular problems also arise in HHS structures where they are systematically placed in a minority position. If there is a disheartening load on one individual, effective participation is severely compromised.

Membership by the CA or another HHS consumer representative, together with consumer members of the Area Consumer Forum should be nominated for the following committees/groups within the HHS:

Service or Quality Improvement Committee
Process and/or Policy Improvement Team
Incident Review Committee
Health & Safety Committee
Methods of Restraint Authorising Committee
A & D consumer group
CAF consumer and carers group
Recruitment Panels

Of course all of the above would also include the Cultural Advisor – Mental Health Services.

There is also a need for the consumer representatives to meet with the Chief Executive Officer at least monthly, to give updated reports on the level of consumer effectiveness.

National Association of Hospital and Health Consumer Advisors (NAHHSC)

The Consumer Advisor or other agreed consumer representatives, employed by the HHS have membership to this national body. The association meets twice a year. Already considerably ground work has been achieved by this body in information sharing about consumer issues, specific to their local HHSs. This group had their first meeting in March 1999 and success has been achieved in networking with fellow CAs.

Within the HHS

The CA should also interact with team members of the Public Health Unit, who are responsible for public awareness of Stigma issues and who work closely with destigmatisation movements in the community. This linking of Public Health and the

CA has promoted events such as Mental Health Awareness Week, both in the Community and HHS setting. The CA must also ensure that if a separate service for the Elderly exists within the HHS, they manage to bridge into that department, as well.

If the CA's position in the HHS is the only consumer representative, then this can be a huge problem to effective consumer input. The goals are ambitious but the environment can be like a fortress. The CA is outnumbered, and can occupy the least influential position in terms of the HHS structure.. The CA in this vulnerable position, would indeed need extraordinary skills to survive. Being a consumer, the person is still maintaining their level of recovery and could be exposed to periods of unwellness taking some of the clinical culture to heart. If the CA does get ill, then provisions should be made for paid respite or access to another service within the Region.

There is an old saying "safety in numbers", and indeed in MidCentral Health with the addition of a Consumer Educator, the drive forward of "consumer lead recovery" has been significant, with staff showing a welcomed level of involvement in the 'partnership'.

Guiding Principles for Consumer Advisors:

Consumer Advisors have to take into consideration, the following:

- Partnership and collaboration are key to the function of the consumer representatives. "You win some, you lose some" is a philosophy that a CA should take on board. Banging heads on walls, only hurts; diplomacy must be developed,
- Actively encourage individual consumer participation. The ability to listen, accept and represent consumer ideas, even though they may or may not be personal held views, needs to be nurtured,
- Valuing consumer representation. It is indeed a privilege to share some other person's innermost and private thoughts. The CA must be able to fully accept and understand their fellow consumer's illness,
- Working towards quality and fairness for each consumer. The aspect of cultural safety needs to be learnt and exemplified,
- Accountability for establishing and maintaining consumer participation. The CA needs to frequently move into the community, actively seeking, where appropriate, membership of community groups,
- Putting forward consumer input on issues that influence their care. Involving as many voices possible in the development of service delivery and policy making/ review,
- To ensure consumer rights are vigorously upheld (See *The Code of Health and Disability Services Consumers' Rights*)

Consumer Educator (CE)

This is a forward thinking idea in MidCentral Health as a crucial part of consumer input into the service. The role of the Consumer Advisor is in some part divorced from that of the CE, who predominately concentrates on psychoeducation, psychosocial education of the consumer, carer/family/whanau and staff.

Consumers, service providers and disability support services need to collaborate to develop psychoeducation courses for consumers, with a focus on empowerment, self-help, coping skills and recovery. The employment of an additional consumer in the HHS; viz. a CE, would satisfy this venture. The CE at MidCentral Health having been in the job for 6 months has made substantial inroads into psychoeducation.

The CE should possess some teaching or research skills as vocabulary and content expression are important.

The CE also has an important link to the local GPs through consumer education.

Critical Success Factors for Consumer Education

The CE must be able to achieve the following:

- Implement a consumer oriented staff development programme that is seen as integral to consumer participation;
- Identify the learning needs of particular groups;
- Plan programmes that will meet their special needs and the development of formal skills. This includes training modules for consumers to take part in training activities normally reserved for staff, e.g. Legislative Compliance, Cultural Safety, Recruitment and Selection, Mental Health (Compulsory Assessment and Treatment) Act 1992,etc.
- Integrate competency-based and educationally-based programmes in order to cover individual learning needs. For example tasks can adequately be demonstrated through training. Education requires reflection and discussion.
- Selectively introduce programmes that extend the knowledge of participants.
- Implement educational programmes that meet learning, teaching and evaluation standards.
- Select speakers who are knowledgeable on the topic.
- To identify teaching opportunities that moves consumer participation forward, including:

    - New staff orientation to consumer issues, involving members from the Area Consumer Forum. The education should focus on consumer rights, family rights, consumer issues related to the duties of the Duly Authorised Officer, Consumer safety (as opposed to Cultural safety).
    - Working with the Mental Health Service Trainer/ DAMHS/CNS
    - Accessing GPs and School Counsellors
    - Consumer education regarding early intervention.
    - Psychoeducation for family and carers, linked in with the Day Services, clinical community rehabilitation centres and local NGOs

- Psychosocial factors need to be addressed through consumer education include;

    - interpersonal skills, such as managing social situations, reluctance to interact with others, etc
    - personal skills like drug and alcohol use/abuse, personal care

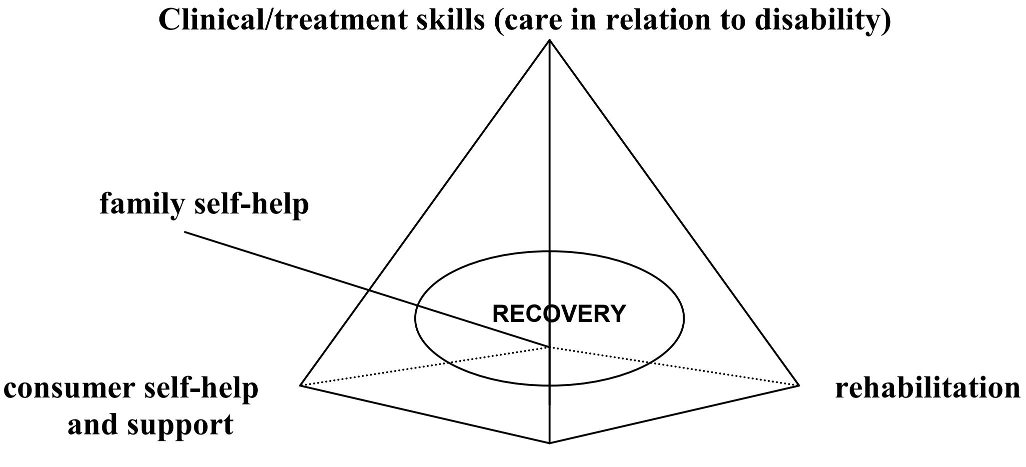
- financial; managing the budget especially in the case of those experie3ncing addiction(s)
- risk factors. These could perhaps be the focus of a mini-Mary Graham workshop on self abuse.
- Rehabilitation program being designed for the Day Services, community clinical rehabilitation centres and inpatient/ rehabilitation units in co-operation with specialist community teaching/learning establishments.
- Working closely with the Public Health unit for education into destig programs, both internally and externally.

A recent proposal by the CE at MidCentral Health is for a ***lifeskills development programme*** to be provided by MidCentral Health as a vehicle for moving medium and long-term consumers of the mental health service from a position of seeing themselves as people with mental disabilities to a position of seeing themselves as valued members of society. Participants are likely to be individuals in Subacute inpatient (Rehabilitation unit) services, Day Services programmes and community groups or individuals moving towards wellness.

Recovery in relation to a life-skills programme

Rehabilitation and recovery are terms that are often used in the context of mental health services. How far-reaching the understanding of the words and the practices that go along with them are, has yet to be demonstrated.

The developers of the programme have concluded (in consultation with consumers) that as quality improvement for assisting medium and long-term consumers of the mental health service towards a new meaning and purpose in their lives, the paradigm of rehabilitation/recovery would serve consumers well. Resources have tended to build up around the organisations which have the longest history of service and it is not surprising therefore to see the treatment model having the dominant influence over other models. Laurie Curtis' Recovery process is new and recognises the importance of four models based on a three point triangle:



Recovery is a person-centred approach which builds upon an individual's sense of control and responsibility in the process of getting well. The recovery perspective supports the development of a range of services assisting consumers to develop relationships within a wide range of communities. It also helps provide access to information so that the consumer is better positioned to make choices for himself. Collaborative working arrangements provide consumers with more creative thoughts, behaviours and relationships and these small successes give rise to larger more substantial achievements.

The role of the multidisciplinary team is to enable the consumer to move beyond disability to health and independence. Enabling is to give another strength, resources, tools, conviction, authority to achieve a desired purpose. It also provides the consumer with hope that at some point the mental disability will take second place to independence.

Recovery is a process not an event. It is about recovering what was lost; rights, roles, responsibilities, decision making, potential and support. It is not about symptom elimination, but about what an individual consumer needs, how he/she can obtain it, and how others can assist/support the consumer to reach their goals. Recovery involves people having a personal vision of the life they want, seeing and changing patterns, discovering symptoms so that a management regimen can be implemented. Recovery is about reclaiming the healthy person.

Rehabilitation can be summed up as attending to the consequences of an illness; impairment, dysfunction, disability and disadvantage and integrates into the process of recovery. The mission of rehabilitation is to help consumers with serious psychiatric disabilities function with success and satisfaction with the least amount of professional intervention possible.

The Lifeskill Programme takes account of the concepts of rehabilitation and recovery. The programme outcomes are based on the evaluation of the Lifeskills programme run at a New Zealand Polytechnic two years ago.

This is but one of many projects being undertaken in the CE's realm of education.

Cultural Advisor (CuA)

The Treaty Of Waitangi is a founding document; the Cultural Advisor to mental health services has a gazetted place within the HHS setting. The absolute requirement for cultural input into the service delivery and policy making, is a must for the HHS and this needs to purchased nationally within the HHS. The Cultural Advisor would work in concert with the CA and CE.

The guidelines for Maori needs are highlighted in the Mental Health Commission's *Blueprint for Mental Health Services*, page 12.

The roles of the **CuA c**ould cover:

- Cultural advice/ consultation on the requirements for Maori ;

- Introducing Maori language into the service;
- Liaison with Iwi/Hapu;
- Liaison with Maori Health Units in HHS's;
- Membership of various HHS committees/groups with the CA;

(It is recognised that Maori need to decide for Maori what is required and these suggestions are discussion points only)

Consumer Auditor (Cau)

Once again another new position to be created within the HHS, involving Standards, Quality Assurance, Audits and consumer surveys. The HFA has stated an intention to involve consumers in audits of mental health service quality.

Standards

The NMHSs were published by the Ministry of Health in June 1997 with the stated aim to "upgrade the quality of our mental health services". The Minister of Health expected these standards would gain "immediate implementation in CHE services", and be included in contractual arrangements between service providers and the Health Funding Authority.. It is also expected these standards will compliment existing standards and that they would be useful in informing "consumers, their families and the New Zealand community what to expect from a mental health service".

These standards "aim to improve continuous quality improvement of mental health services in New Zealand through participation of consumers, families, carers, purchasers and providers", and are intended to apply to all mental health service providers in New Zealand with the understanding that providers may adopt the standards to meet their local circumstances.

The CAu would be responsible at a National level, through the National Consumer Forum for participation in development of competencies of mental health staff through their professional bodies.

On a local level the CAu would measure the performance of staff in relation to consumer focus in line with Mental Health Standards in liaison with the Team leader or Manager. The performance measure would be that these competencies would be available for all staff.

The CAu would work alongside the Team Leader/ Manager to ensure follow up occurs for specific training or learning needs for staff and/ or performance issues and that a system is developed and implemented and works effectively.

The development of Integrated Clinical Pathways, professional standards of practise and protocols need also to have input from the CAu.

The CAu would therefore work within this directive to ensure that audits are carried out within the Quality Assurance team of MHS against the NHMS's standards.

Quality Assurance

For quality improvement to take place, reliable and valid information should be available and compiled. Without information on consumer surveys, consumer expectations and outcomes, it is not possible to determine sources of instability in the system. With little or no data Continuous Quality Improvement initiatives may not be targeted appropriately.

The process of examining consumer complaints and incident reports is the current way for many of the MHS to get feedback from consumers. Incident reports highlight individual incidents but do little to highlight a whole system approach that may have contributed to this problem. The system can tend to defend itself and administrators do not have access to adequate information for corrective action. Participation by the **CAu** in this area would definitely enhance quality assurance

Audits

Regular "in-house" reviews of MHS should be encouraged, working as a team with Risk Management and Infection Control, together with the Quality Assurance member for MHS, applying the National Mental Health Standards' audit tool.

The idea of an independent audit would allow a sense of objectivity to be reached. Input of staff and consumers should be encouraged to ensure quality of information necessary for quality improvement. These reports should be sent back to management, especially Service Improvement/ Quality Committees.

Consumer Surveys

There needs to be a variety of face to face interviews, small groups pooling views on particular topics, postal questionnaires, feedback sheets to fill in and collection of consumer views of service delivery or issues of importance.

It is also recommended the consumer auditor is involved at time of discharge planning, by having a final interview with the consumer prior to discharge. The purpose of this is for feedback on their hospital stay, ensuring that they and their carer/family/whanau (where permission is granted by the consumer) have a copy of their discharge plan.

Consumer Complaints (CC)

This position is normally found in HROD within the HHS, devoting part of their time to mental health services but mostly to the General Hospital side.

The complaints policy is standard within HHSs. No new change to this function is deemed necessary, other than the timely satisfaction of complaints. It is suggest that the MHS becomes accountable to scrutiny of incidents in service delivery or of wrong workings of policy. The establishment of a Complaints Tribunal separate from the MHS but still in-house is strongly recommended. This tribunal could be composed of Health and Safety, Infection Control, Risk Management and consumer and cultural representatives. This is not meant to be an inquisition but to ensure objectivity in the investigation of serious complaints.

The CC should also involve themselves in Privacy issues regarding the consumer, especially with the age of Information technology. The uplifting of MHS clinical notes, identification tags (NHI and DOB) and also physical notes onto computers need a greater degree of protection. Who should access what information, including the General Hospital, (when a consumer needs physical attention), is an area exposed to possible abuse at the moment.
Audits on consumer needs assessment/ analysis involving third and fourth parties in compilation of consumer details are well documented. What is alarming is the Ethics Committees allowing the extraction of such personal information, without involving the consumer in making choices about their information. The invasion of consumer records and information, without their approval and the future impending computerisation of consumer information should be an issue that the National Forum of Consumers addresses in concert with the Privacy and Health and Disability Departments.

Consumer Participation Policy - HHS

Designing services according to perceived needs does not mean the MHS has to ask its consumers how to provide care. It is the task of the MHS management to see development of innovative models of care and delivery. The role of the consumer is to provide oversight and possibly regulation. The models of care should be based on perceived needs of consumers and the consumers should be able to provide feedback so that the process can be improved. This should be done with the HHS's Consumer Participation Policy.

This policy needs to be written by the HHS consumer and cultural representatives in partnership with the service. A realistic timeframe of objectives should be targeted.

The Policy needs to cover:

- Purpose
- Scope
- Roles and Responsibilities
- Prerequisites
- Actual Policy
- Health and Safety
- Definitions, References, related documents, appendices and keywords

ACCESSING THE HHS

This is where the 'revolving door' is situated. The initial interaction by the service of the first time consumer will make a lasting impression on the consumer. Admitting staff play a vital role in the consumers involvement with the Service . The admitting staff member need vigilance, compassion and to observe the following:

- The rights of the consumer in relation to:
  - ❖ Access to treatment
  - ❖ Transportation to hospital
  - ❖ Dignity being accorded to consumers by mental health professionals
  - ❖ Consumer and carer input in treatment plans; and

  - Ease of access to complaints mechanisms and adequate redress of concerns.
- The need to understand past history as a means to avert further trauma (this includes actions taken by general hospital staff in other departments).
- The close involvement of family/whanau and the protection of their rights;
- a possible ‘cooling down’ period;
- The correct application of the *Mental Health Act (Compulsory Assessment and Treatment) Act 1992;*
- a spiritual assessment on entry to the service;
- The attendance by a consumer advocate as part of the MH admitting Team particularly in times of consumer crisis at any access point throughout the HHS (including Community and General Hospital).

The need to take control

Chairman Lee, Samsung Corporation 1993 ………… ***“Change begins with you”***

The consumer should be encouraged to take control at the very earliest opportunity when their symptoms subside.

This control must be assisted with education; arming the consumer with their rights and also their responsibilities. I have had several clinicians complaining that an attachment to the *Consumers Code of Rights* should be the Consumers Responsibilities, as discussed earlier.

In a ward setting the consumer does have certain responsibilities that include:

- Considering other consumers’ rights, treating them with respect and courtesy. This includes respect for their culture, beliefs, values as well as their personal privacy.
- Treat the HHS facilities and equipment with care and to assist in retaining a pleasant, healthy and safe environment,
- Observe certain rules (e.g. the No Smoking Policy)

It also needs to include that as a consumer of mental health services:

- Will not use any alcohol or illicit substances in ward settings
- that there is a willingness to participate in each Integrated Treatment Plan

Some inpatient units around the country have been likened by consumers to ‘hotels’; as a convenient form of accommodation. The criteria for admission, if this was true, must also be revisited and training implemented for staff to avert this. The impact of national inquiries and defensive practice as mentioned earlier in this document and the negative media coverage also to contribute to the ‘hotel’ mindset.

Acute Unit Consumer Participation

“Services will have an orientation toward recovery and will focus on ensuring best possible outcomes. Services will also identify and build upon individual strengths, and will generally promote the mental health for whom services are provided” **(11).**

Integrated Recovery Plan (IRP)

The consumer needs to be a partner with the service in devising their recovery plan. The main clinical participant must be the **keyworker** working in concert with other clinicians. The recovery plan must match the consumer's needs with the appropriate staff, fellow consumers and other resources, within a co-ordinated framework.

The IRP must also actively involve the carer/family/whanau, with the consumer's consent. It is recommended that the terminology 'treatment plan' be changed to 'recovery plan' through-out the sector in line with the National Mental Health strategy's focus on recovery.

Clinical services should trial consumer involvement in writing or viewing clinical notes in the Integrated Recovery Plan. Some Consumer Advocates suggest this method aids recovery, partly by fostering a sense of "belonging" and empowerment for the consumer. This participation is already part of operating procedures in some HHSs. This should be "a collaborative approach to the recording of notes is not uncommon and is relatively uncontroversial. The clinician can record what he/she regards as necessary factual information and the consumer can tell their 'story'. Seeing mental illness as a country one visits has its merits as a way of describing the experience. If the story is about the consumer's journey it seems reasonable for the consumer to write it, albeit in collaboration with the clinician, and since the consumer is the author it follows much have some authority over it.

A counter argument to this might be to claim the clinicians write the notes, so they may have a valid claim to authority over them. This ignores collaborative note writing, which is based in part on the idea that the process is consistent with the *partnership* and consumer focus that is necessary for recovery." **(21)**

Therapeutic Ward Group Programs

Many consumers become bored at times during their stay in Acute, Subacute and rehabilitation units if ward programmes are insufficient.

With the mixture of illnesses and levels of unwellness in an Acute unit coupled with the boredom and a modified loss of privacy and rights, the equation points to a festering situation that can enhance aggression, reaction and increased trauma.
There needs to be an urgent restoration of consumer participation in the ward which involves a fivefold approach:

- **Restoration of therapeutic ward programmes** – encouraging in consumers a pro-active approach to treatment – together with promoting a support-enhanced and more needs-targeted programme structure.
- Some innovative **re-structuring of programme forms and content**, drawing on current and high quality information and advice from various disciplines. This could include talks from the Clinical Trainer/DAMHS/CNS and District Inspector on Consumer Rights especially under the Mental Health Act. Further consideration could be given to external/ internal presenters including:
    - Community services/ supported housing;

    - Keyworkers presenting community Mental health services
    - Public Health Services;
    - Nutrition;
    - Medication talk by the Pharmacist;
    - Cultural and spiritual groups.
- The prescence of a **multidisciplinary team** in areas of key consumer needs.
- The development of **cell modules** within ward meetings, bringing together “like” illnesses. Thus if there were groups of 2 to 5 consumers with drug and alcohol issues, or “voices” or depression issues, then they would be able to work through activities in group programme modules specifically activated for them. Individual and peer support could be purchased from the Area Consumer Forum, with “role models” participating in therapy sessions, showing the way to recovery. At all times this must be clinically led, as in S.A.F.E sessions of Mary Graham’s Canadian organisation.
- Consumers to be employed as **peer support workers** in the system, and self help support groups. Appropriately qualified past consumers (including past clinician/consumers), should not be barred from direct care roles. Encouraging participation in and accessing training for nursing, social work, psychology, occupational therapy and disability work to past consumers. A possible area of consumer involvement could be in the local NGO (supported housing/ accommodation)

Clinician to Consumer

Clinicians need to ensure they have:

- Good communications skills;
- Empower the consumers;
- Recognise that consumers have a legitimate right to be involved in all aspects of care;
- Have substantial knowledge of community care and available resources;
- Keep up to date with recent changes in mental health care service delivery; and
- Know how to establish the effective links with other organisations which are necessary to support people in their every-day lives.

The services need to be delivered in a consumer friendly environment with consumer friendly staff. Clinicians need to recognise the importance of an accurate diagnosis and the prescribing of medication (if required) as factors contributing to the ‘partnership’ between consumer and clinician. The utilisation of a multi-skilled workforce to deliver the service to the consumer may decrease incidents of so called ‘treatment failure’.

Leadership, together with new ideas and an option of choices for the consumer must be ever present in a ward setting. Consumers, especially women, are extremely vulnerable, in this setting. "It has been felt by some consumers that mental health professionals were seen as the single most important source of discrimination and discriminatory practice"**.(1)**

The family/carer/whanau must also be suitably armed to help during the IRP and the ensuing convalescent stage into the community. Details of diagnosis, medication and its side effects and anticipated behaviour patterns to look for must be passed onto them. The family must also be looked at being a source of history to enable a proper diagnosis to be arrived at.

The consumer needs an accurate diagnosis, as a target for recovery.

Not only is the diagnosis relevant but also to diagnosis in the context of impact on life circumstances. This includes accurate assessment of problems associated with:

- Child abuse;
- Sexual assault;
- Domestic violence;
- Loss and grief;
- Torture and trauma

The clinician needs to make available to the consumer:

- Absolute honesty and respect;
- Treatment options;
- Choice to a second opinion;
- Using language the consumer can understand
- Interpreter services as required;
- Conversing with respect and in partnership with the consumer towards a recovery plan.
- The primary nurse befriending the consumer and assimilating as much information about the prognosis and the needs of the consumer as possible. They must also interact with the carer/family/whanau during IRPs and visiting hours;
- Advocacy support must be offered;
- Ensuring Consumers know their Rights. (eg: Section 16 appeal)

“One possible way to monitor ‘consumer’ friendly clinicians is for:
- The Royal Australian and New Zealand College of Psychiatrists review its training programme to ensure that graduates treat consumers and carers with dignity and respect, and
- That mechanisms be developed for ongoing monitoring of the practise of all mental health professionals and their re-registration.” **(1)**

Consumer Advocates

Public participation should be as wide as possible.

The role of the advocate is to assist consumers to make sure that their rights are respected. This service is free to mental health consumers. Advocacy services must operate independently of government agencies, the Health and Disability’s Commissioner and providers and funders of MHS.

Advocates are not investigators and do not make decisions on whether there has been a breach of the Code. Nor are they mediators. Rather, their role is to support consumers in reaching clear decisions and taking action as a result of those decisions with the aim of resolving complaints. Advocates work using the empowerment model, where consumers are supported and encouraged to take action to resolve their concerns with providers. Where necessary, they will act for the consumer on his or her instructions.

The involvement of Consumer Advocates (separate from an Independent Advocate Network under the Health & Disability Act 1994), should come from the ACF and be specifically trained by the HHS. Mention must be made of the myriad of 'well intentioned' community advocates, who are not consumers. Funding of this group can be from various sources including HFA backing, religious input or community trust grants. Some consumers prefer not to deal with them as sometimes paternalistic attitudes tend to be adopted in advocacy or not having a complete understanding on consumer empathy.

The ACF should actively seek funding from the HFA for funding of consumer advocates, as they would meet the criteria of " consumer run" **(11)**

Safe and effective Advocacy is where you have consumer for consumer. (23)

Inpatient and Rehabilitation Units-Consumer Participation

The primary concern here is that as the consumer needs a further stay in hospital while awaiting extended care/ intensive rehabilitation , supported accommodation, support for independent living or to arrange suitable community accommodation. An overstay in the inappropriate level of care is counter-therapeutic to the consumers needs. Nationally there appears to be problems with the configuration of levels and bed numbers available in various levels of care.

Additional problems may range from lack of service co-ordination, keyworker or clinical interventions, or just a lack of fundable resources.

The **CA** along with the **CAu** must keep a watchful eye on developments or lack of them in the sector . As highlighted earlier, the CE has a major role in psychoeducation and social topics, with an emphasis on rehabilitation being an integral part of recovery.

The consumer representative also has time to develop a closer relationship with the long stay consumer, ensuring that their reassimilation into the community is aided with living skills, and basically the service is trying their best for this resettlement.

There could be the need for introduction of a multi-modal psychological model, as trialled by the Buchanan Rehabilitation Centre **(22).** This model concentrates on :

- Psychoeducation
- Cognitive behaviour therapy
- Interpersonal activities
- Supportive means
- Spiritual needs

The programme instituted by Dr Patte Randal was designed specifically for ‘treatment resistant’ consumers.

PART 4:

LINEAR INTEGRATION OF THE HHS: BRIDGING THE GAP

“There is a need to promote co-ordination among all agencies associated with mental health services and to ensure that clear lines of accountability exist”. **(9)**

For this to happen in the HHS, there needs to be the ability, internally, to move around opening as many doors of participation as possible.

Externally there is a requirement for a greater degree of stakeholders’ participation with the HHS. More information sharing needs to be adopted, a community ‘users’ manual’ needs to be created, circulated and maintained. This manual must contain easy reference for the consumer, carer/family/whanau and enable them easy access to both HHS and community mental health services in a crisis situation. They could be placed in GP rooms, Police Stations, Community Health Centres, etc.

I have talked about the MHS’s need to link in with Public Health on awareness issues. There also needs to be involvement of the general health staff; to understand the problems in mental health itself. There needs to be a greater acceptance by all staff in general wards, emergency department staff to respect consumer rights and needs. Hospital and community chaplains also have a role to play in meeting the spiritual needs for holistic recovery. They too should participate in the needs essential for the recovery model to be promoted; by promoting a safe environment in which the consumer can recover.

This particular area could be addressed during staff orientation day. The CA/CE would be a valuable contributor for induction.

The consumer representatives within the HHS need to be able to easily bridge into the community, at the same time moving horizontally, between teams in the HHS. In the community, they need to develop:

- Closer relations with the ACF and the CAC;
- A personal understanding of local issues by way of membership of local community consumer agencies;
- Relationships with Iwi/Hapu;
- Relationships with ethnic groups;
- A consumer focus on recovery with GPs;
- New stakeholders or work on projects to merge duplicate, multiple stakeholders;
- A working relationship with police and forensic services;
- A carers’ consultation dialogue;
- A dialogue with local and district councils;

- An understanding of local youth issues.

Community Participation

"In general, the savings resulting from de-institutionalisation have not been redirected to mental health services in the community. These remain seriously under-funded, as do non-government organisations which struggle to support consumers and their carers. While the movement towards mainstreaming mental health services may alleviate the stigma with psychiatric care, there is a serious risk it will not receive the resources it desperately deserves." **(1)**

There needs to be greater interaction by the HHS and the community, per se. Regular stakeholders' meetings should be held by the service as part of bridging the gap. Invited groups should cover the following areas:

- HHS Emergency department
- HHS Public Health
- Schizophrenia Fellowship
- Samaritans
- Youthline
- Barnados NZ
- Manline
- Womens' Health Co-operative
- Student Counselling Services
- Police
- CYPFS
- Iwi Enterprises
- Area Consumer Forum
- HHS Services for the Elderly
- HHS MHS
- Salvation Army
- Stroke Foundation
- Gayline
- Plunkett Society
- Community A&D services
- Rape Crisis
- Independent Advocacy Services
- Local & District Council
- Housing Trusts
- Prison and Probation Services
- Specialist Disability organisations

The Destig Programme

An example of a project working in the community with the HFA, HHS and consumers is the discrimination project. Consumer participation in this project differs from participation in personal mental health services.

Consumers are the main beneficiaries and the main recipients of MHS. While they are also the main beneficiaries of the anti-discrimination project, they are not its main recipients; being the people who discriminate against people with mental illness. This means that others, such as recipients, public relations, public health and community development experts may have a good understanding of effective ways to deliver the project as consumers do.

Consumers still need to be involved in delivery of the project and we need to remind ourselves, that we as consumers, do not fit into the shoes of the recipients of the project.

The primary purpose of the project is to reduce discrimination against consumers. A well developed and co-ordinated local consumer movement is crucial to the success of the project.

Other Community Projects

The working model of the Taylor Centre, a community mental health service in Auckland, is a newer model of the community interacting with mental health services with an adaptation of primary care. Ultimately the CMHT will relocate into a Community village taking with it the Crisis team and more specialist needs teams.

A more holistic approach to MHS will see the involvement of GP’s in this village as is happening with the Newtown Union in Wellington. Consumer advocacy and involvement on the Village board will need to be nurtured, maintaining a strong link with the ACF via the CAC.

The Maudsley model was put forward by David Goldberg and Kevin Gournay of the institute of London, who argue the case for a radical re-appraisal of the mental health work undertaken by both primary care and community mental health teams; with CPNs carrying out less supportive work and more cognitive behavioural, the interaction of the GP and computerised self care treatments.

PART 5:

COMPUTERISATION OF CONSUMER PARTICIPATION

Computerisation of the Consumer Participation

The future has arrived!

Even primary school children now have a PC on their desk, or at least in their classroom; for chat rooms or as a library of information. Some kids now do their homework on them. For those of you on affordable incomes, the risk of your children shanghaiing your phone-line in your home after dinner is a reality. Even if they have not crashed your ability to communicate with the outside world, they are indeed locked in their rooms; play-stationing some inner galactic catasprophe, obliviously ticking over the power bill.

Such is the pace of our society, with more electronic developments on the horizon.

In the mental health field, knowledge really does equate with power to a large extent, and consumer empowerment efforts are thus most strongly linked to information-base processes.

In the Information Age, we as a society are becoming aware of the high social costs borne by groups who are among the so-called “information poor”. Many consumer fall into this category, and are disempowered as a result. **(4)**

The positive potential of electronic communication is indeed great. For those who are on the Internet, sending messages and information barrelling down the information superhighway is cheaper than any other form of communication (for now at least). Chat room therapy has its crisis intervention merits.

However the cost of getting there is prohibitive for the average consumer.

The main user of this network would be community groups, who, as a group, would have greater access to funding. The benefit for this group would be tremendous and the opportunity of using this should not be discarded.

It is very important the ACF has access to the Internet and the ability to establish and maintain a website.

Access to the Internet can be online as follows:

- Individual access - Accounts with Internet service providers (ISP)

- Public Access – Information from a community electronic network e.g. Libraries, Community Colleges, Adult Evening Classes, Non-profit community agencies.

Computer equipment can be obtained through:

- Individual purchase
- Community computer recycling programs (e.g. Telecom)
- Donations from business
- Government assistance

Training can be provided by:

- Public Libraries
- Non-profit Community agencies
- Utilisation of IT within the HHS, as part of the HHS's commitment to providing resources

Once on line the consumer needs a basic e-mail account to communicate and benefit from electronic communication. If an Internet account is purchased from an ISP an e-mail account is included. Additional e-mail addresses/accounts can usually be purchased from an ISP for a nominal monthly cost. There are also free e-mail accounts to be found with:

- Hotmail http://www.hotmail.com
- Juno http://www.juno.com
- FreeMail http://www.freemail.co.za
- Yahoo mail accounts http://www.yahoo.com
- Others – utilise search engines to investigate other sources of free e-mail accounts.

Access and Subsidy

We do not have universal community access to the Internet for large numbers of people in our society. The benefits of all health services communicating with each other in treatment programmes would be immensely helpful to the consumer movement.

If consumers are going to gain access, then it all comes down to who is going to bear the cost. From a treatment perspective utilising the Internet would aid psychosocial rehabilitation programmes.

Consumer Use of the Internet

The consumer has a very wide range of services available with 24 hour coverage.

- Advocacy (24 hour);
- Cultural advice (access to mental health publications in foreign languages);
- Legislative Updates;
- Access to Privacy and Health & Disability Commissioners;
- Self-help (Education);
- Support Groups;

- Individual Support, especially for “rural” consumers;
- Information & Referral;
- Crisis Intervention through chat rooms and Advocacy;
- Community building/organising efforts;
- Technical assistance;
- Publicity and online publishing.

Benefits of the Internet for Consumers

- The internet as a community tool to help end loneliness and isolation by giving the consumer access to interaction with people of similar interests.
- It allows empowerment of the consumer and enables the consumer to have control on how much information they wish to pursue with and the rate that they wish to disseminate.
- Promotes self sufficiency by providing education about individual conditions, diagnosis and treatment.
- Reduced visits and access to service would eventually lead to reduced direct service costs.
- Education.
- Development of job skills from online experiences.
- Development of future life skills in communication.

CONCLUSION

The consumer movement is alive and kicking in New Zealand. The next 3 years will highlight whether we return to the old days or launch into the millennium with futuristic strategies which include:

- A national consumer participation policy;
- An updated and consumer focused National Mental Health Standards;
- The education of people about the Treaty of Waitangi and it’s meaning for the consumer movement, service delivery and policy;
- The creation of the vertical integration of the consumer movement, properly financed by government and non-government organisations, independent of the HHS;
- The linear bridging of this movement into the HHS;
- The expansion of consumer participation in the HHS;
- A purchaser that works collaboratively and in partnerships with the service provider, the consumer movement, the consumer and the wider local community;
- Greater consumer participation in government agencies;
- A more community focused service allowing consumers early intervention and access; more community models to be developed according to local needs;
- More information technology available to the consumer movement;
- A shift from the ‘medical’ model culture to the ‘recovery’ model;
- For all professionals, an updating and monitoring of ‘consumer friendly’ skills.

For this success it is up to the team - the partnership, the collaborators, the politicians, the public officials; more importantly the clinicians, the consumers, carers/ family and whanau and the community at large.

LET'S DO IT NEW ZEALAND !

"Change begins with you".

Palmerston North 7 December 1999

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