

**Discrimination Against People
with
Experiences of Mental Illness**

**Discussion Paper for the
Mental Health Commission
July 1997**

Discrimination

*Please strip away the veil,
Look behind the mask,
For you see my face,
As it pleases you.*

*See my beauty not your fear,
Look upon my joys and not despair,
For I am no beast but human,
And I truly wish to be no burden.*

*Can you see I strive to be just like you.
Grant me some happiness,
Between my madness,
(For that is not me)
Give me hope that I may succeed.*

*Look at our hearts.
I have eyes. Can you see,
That I am like you,
and you like me?*

Robert S. Allan, Ground Zero

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The Mental Health Commission

The Mental Health Commission was established in September 1996 as a result of an Inquiry into Mental Health led by Judge Ken Mason. The Commission has been given a limited term of five years and within this time it is expected that a fully developed range of mental health services appropriate to the needs of those with mental disorders will be developed.

The priorities of the Mental Health Commission, as set by Government, are to ensure that:

1. the Government's Mental Health Strategy is implemented;
2. discrimination and prejudice against those with mental illness is reduced; and
3. the mental health workforce is strengthened.

The role of the Commission in these areas is to monitor the mental health sector, provide advice to the Minister of Health and provide leadership in the sector. The Commission also seeks to support and work collaboratively with the range of other agencies, both government and non-government, which have responsibilities and are active in the mental health sector. The Commission works in close collaboration with the Ministry of Health and the regional health authorities to achieve its objectives.

This report was commissioned to assist the Commission to identify areas in which it could work to achieve one of its three priorities, that is reducing discrimination and prejudice. Thus, the purpose of this report is to enhance the Commission's understanding of discrimination against mental health consumers and to provide guidance on how such discrimination can be reduced.

Foreword

Discrimination against other people is what we use as a way of keeping ourselves safe - from uncomfortable questions, facing reality, and challenges to ourselves. But it is a belittling and dangerous technique. It marginalises other people and in the end, when we discriminate as a society, it causes pain, distress, and long-term damage. It also damages us as a society because it limits our world and impoverishes our understanding.

People who have experience of mental illness almost always also have experience of discrimination. They may be denied jobs, accommodation, relationships, social dignity, and of course adequate services. Their families, and the people who work to try to help them may also experience discrimination, because it spreads like a sickness.

It is sometimes hard to explain what we mean by discrimination. It is one of those abstract words which cuts us off from the human impact. But this report starts to give some illustrations of what it means for people. And more importantly, this report begins to examine what causes us to discriminate against others. It looks for parallels and differences in other kinds of discrimination - on the basis of gender, sexuality, age, culture, religion, colour, victimisation, physical disabilities, and size.

Sometimes people offer very simplistic solutions to the problem of discrimination. 'Just change attitudes'. 'Tighten up the law'. 'Get people to stand up for themselves'. For every complex problem there is a simple solution. And it is wrong. Complex problems usually mean complex solutions. Discrimination is not a 'tame' problem. It is a 'wicked' one. So the solution involves a combination of approaches, as this report explains. We also need to be aware that the problem of discrimination will itself change as we try to change it and so it may need to be resolved time and again.

The Mental Health Commission is committed to getting rid of discrimination against people with mental illness. It knows that there is no quick solution, because it involves refusing, as a society, to accept any longer the myths about mental illness. It means learning how to distinguish between the person and the illness and understanding the effect of the illness on the person. And most importantly it means being willing to open our hearts to the experience of other people and show compassion and not be afraid of that experience.

I hope you will help the Commission in its work, and at a personal level (because that's where social change begins) start to question your own prejudices about mental illness and be alert to what you observe around you.

Julie Leibrich
Commissioner

Preface

It was immediately obvious to us that we could only ‘scratch the surface’ of this huge topic. This was partly because of the limited time available but also because, despite all the reports on mental health services and all the research into negative public attitudes, there has been little focus on practical measures to eliminate discrimination or even to recognise that discrimination occurs. Nor much recognition that discrimination is a health issue as well as a rights issue for consumers.

We have sought to:

- accurately reflect the relevant experiences and ideas of the people we spoke to or whose papers we read;
- compare the experience of mental health consumers with the experience of other groups who have suffered discrimination;
- develop a conceptual framework for strategic planning of anti-discrimination and health promotion projects; and
- recommend specific actions which will make a difference to consumers.

As we came to the end of our study we received a paper from Sylvia Bell of the Human Rights Commission, a stalwart supporter of the rights of mental health consumers. The conclusion of her paper sums up the position we had reached by another route.

‘Just as other members of society, mentally ill (sic) people have a right to have rights. The reality of their existence is daunting enough without their being further disenfranchised by retrograde moves to remove the rights they do have. Ironically enough, what detractors of patients’ rights may not realise is that they are drawing attention to the need for more wide ranging rights. To date the focus has been on civil liberties. What is needed now is a range of social rights that address the various facets of the day to day existence of people living with a mental illness.’¹

We are a mother and daughter team, mother, a senior legal and policy adviser in government, and daughter with varied work experience, particularly research, writing and design. We have no professional background in the health sector but as a family, like most families, we have had encounters with mental health services including both positive and negative experiences. We hope that Mary O’Hagan’s comments on her effectiveness as a Winston Churchill Fellow can be seen to apply to our undertaking: *‘Outsiders looking in, no matter how briefly, can sometimes see with more clarity than the people who are immersed in their particular organisation.’²*

We have found the opportunity to write this paper both stimulating and humbling. We regret that we were not able to connect with all the people who are working effectively to reduce discrimination nor to adequately reflect their experience. For this, we apologise. We want to thank all those with whom we did talk for their generosity and inspiration.

Margaret Thompson, BA (Hons), LLB (Hons)

Tessa Thompson, BA, BDes

¹ Bell, S. *Whose Rights Are They Anyway?*

² O’Hagan, M. *Stopovers On My Way Home from Mars.*

PART ONE - Discrimination Within the Mental Health Context

1. What is Discrimination?

Introduction

It is the standpoint of this paper that the discrimination experienced by mental health consumers has a great deal in common with discrimination experienced by other groups, sometimes historically and in some cases still today.

In order to identify effective ways to reduce discrimination, a comparison has been made with other areas of discrimination where significant social change has been sought, such as discrimination on the basis of gender, sexual identity, race, culture, physical disability. This comparison of strategies to reduce discrimination provides useful insight for mental health consumers. It is also most striking to realise how rapidly and how recently public attitudes have changed in some of these areas.

The comparative study confirms that effective change has principally come about from the assertion of rights, political activism and positive discrimination. In addition, the individuals discriminated against and other members of the community must interact positively to get to know each other and understand their differences.

Broadly, discrimination:

- permeates all levels of society, from Parliament to the corner shop, and both inside and outside professional services;
- promotes an 'outsider' syndrome and people become dehumanised. This effect is increased where there has also been visual distinction or physical separation;
- encourages stereotyped views of people discriminated against which is perpetuated in myths and by the media; and
- leads to some form of enforced segregation or restricted access within society for the discrimination victims.

Despite radical changes in the treatment of mental illness over the last few years, negative public attitudes towards people living with mental illness remain relatively unchanged. Innumerable studies have documented community antipathy towards people with a mental illness and there is no indication that discrimination against people with mental illness is abating. A 1987 study³ concluded that attitudes towards people with mental illness had not significantly changed in 22 years.

The last few years have seen a confluence of powerful forces for change in the mental health system which make the *Discrimination Against Mental Health Consumers* report very timely: rapid restructuring of health services, developments in medication accompanied by a community-based approach to treatment, influence of international 'rights' movements and

³ Green et al. 'Community Attitudes to Mental Illness in New Zealand Twenty-Two Years On'

underfunding and fragmentation of mental health services, accompanied by increased public anxiety.

Although many other Western countries are tackling similar issues, there is little guidance from overseas on practical measures to eliminate discrimination towards mental health consumers.

However, the necessity for change is undisputable. As one consumer activist states: *'For too long mental patients have been faceless, voiceless people. We have been thought of, at worst, as subhuman monsters, or, at best as pathetic cripples, who might be able to hold down menial jobs and eke out meagre existences, given constant professional support. Not only have others thought of us in this stereotyped way, we have believed it of ourselves. It is only with the emergence and growth of the mental patients' liberation movement, that we as ex-patients have begun to see ourselves for what we are - a diverse group of people, with strengths and weaknesses, abilities and needs, and ideas of our own.'*⁴

Report focus

For the purposes of this report, the term 'mental health consumers'⁵ is used to include all people who experience or have experienced a mental illness.

There are two focuses of this paper:

1. Discrimination facing mental health consumers directly, rather than 'secondary' discrimination faced by supporting family and friends.

It is acknowledged that 'secondary' discrimination - discrimination by association - is experienced by family and friends and often causes very similar distress. However, the focus in this report is on consumers because prejudice against them is at the core of the problems experienced by others. Reduction of discrimination against consumers should also improve the situation of others. We acknowledge that separate discrimination issues do arise for supportive family and friends which are not explored in this report but which are an important part of the total discrimination picture.

2. Discrimination faced by mental health consumers in the community, rather than those within institutions.

Legal protection for the civil rights of consumers in institutions is possibly more advanced than for consumers living in the community because of statutory requirements such as complaints procedures, visiting inspectors and reviews. The challenge of achieving an appropriate balance of rights where people are compulsorily detained has generally been treated very seriously in law and by professionals. However, the rapid expansion of community-based mental health services has not led to a similar awareness of the rights of consumers as members of the community. The approach taken in this paper could add new perceptions about the everyday

⁴ Chamberlin, J. *On our own: Patient Controlled Alternatives to the Mental Health System.*

⁵ The terms 'mental health consumer', 'psychiatric survivor' and 'mental health service user' are used interchangeably in this document.

living environment for consumers in and out of institutions and the attitudes of professionals which may unintentionally lead to discrimination.

Experiences of discrimination

Relentless and degrading discrimination experienced by mental health consumers in almost all areas of social interaction is the starting point for this paper.

Describing the extent of discrimination suffered by mental health consumers was not the task of this report, but we note that there is a dearth of such material in contrast to the wealth of research into the attitudes of others to consumers. This report draws on the considerable international literature on public attitudes to mental illness and the stigma attached to people with mental illness⁶, supplemented by talking to consumers and others about the subject. There is little research literature on the specific discrimination experienced by New Zealand mental health consumers, although published reports do document some of those experiences.⁷

The following examples were provided by a variety of people and are also included in Appendix II of this document.

Stories of discrimination

Housing

A mental health consumer signed up for rented accommodation on two occasions within 24 hours of the publishing of newspaper articles where she was photographed. Both these times she was subsequently told that 'we (the landlord/ agent) have made a mistake and the house had in fact already been let'.

On a third occasion this occurred after leaving a contact phone number of the community health agency. The agent asked if the person concerned was staff or patient. When told, 'patient', the agent said, 'sorry we made a mistake the flat was already let'.

Many residential care homes have strict rules, such as couples are not allowed to share a room. The kitchens are locked, sometimes even the bedrooms are locked during the day.

Employment

A psychiatric survivor was employed as a community support worker. However, she found that the salary was set at \$10,000 less than other community workers who were no more qualified.

One person was offered a job and then had the offer retracted when an employee of the firm revealed to the employer that the person had spent a short time in a psychiatric ward. The employer said that dishonesty would not be tolerated and that an interview would not have been granted if disclosure had been made.

Family and custody issues

⁶ See bibliography for list of relevant published papers on public attitudes to mental illness.

⁷ For example, *The Mason Report* and the 1992 report *Public Attitudes to Mental Health* by Dean Patten. Both contain personal accounts of discrimination against people with mental illness.

Legal representation which highlights a parent's mental illness has led to adverse decisions where custody has been lost for the parent. This has happened to both fathers and mothers despite the fact that often the illness has been a one off episode.

Children are often not allowed to visit their parents in residential care as the environment - shared by other people with mental illness - is not considered appropriate for children, despite the fact that it is the home of their parents.

Health Services

The mental health services often play 'ping pong' with people who are difficult to manage. The services 'pass people around', hoping that another service will pick them up. A mental health professional said that a 'difficult' person's file may be passed around a meeting until a decision is made, sometimes to leave the person with the crisis team. This usually results in consumers remaining unwell.

On many acute wards mental health consumers are not offered counselling, occupational therapy or speech and language therapy, which are services available on most other hospital wards and seemingly appropriate in a psychiatric ward.

Children with a psychiatric diagnosis are often put on an adult ward, despite the fact that for any other illness or injury they would be in the children's ward.

Goods and services

Many stores will not make hire purchase agreements with people who have psychiatric histories.

A medical insurance company recently increased its cover for all medical specialties without imposing any restrictions. However 'psychiatry' was singled out as the only medical specialty in which restrictions were imposed to an unrealistic degree. Some companies do not allow psychiatric claims.⁸

Some people have been refused life insurance on the grounds of a previous history of mental illness, in one case the history consisted of a one time episode of post-natal depression.

Discrimination related to services

Despite the commitment of the wide range of groups working in the sector, the effectiveness of mental health services continues to be questioned by mental health consumers, mental health workers and the public. Acute dissatisfaction with the process of institution closure combined with a perceived inadequacy of the delivery of community based services has given mental health a high political profile.

The low status of services provided for mental health consumers is itself a manifestation of discrimination against people with experiences of mental illness. Specific problems identified by interviewees, as arising in the present structure, reflect the findings of the Mason Report and no doubt also mirror the findings of the Commissioners on their travels.

⁸ This information was provided by 'Auckland Private Psychiatrists'.

Specific issues raised include:

- **Insufficient time allowed for client/professional contact on mental health issues**
- **Difficulty in accessing appropriate services in a crisis**
- **Inadequate early intervention arrangements** - Early intervention skills are lacking in some staff and this in turn discourages self management by consumers. Even when consumers do seek help in a crisis situation there is sometimes nowhere appropriate to refer them. Even when consumers do seek help in a crisis situation, there is sometimes nowhere appropriate to refer them and, it is alleged, consumers are sometimes callously given a label or diagnosis which does not carry an entitlement for ongoing care.
 These criticisms of the lack of early intervention services raise very serious concerns because it is thought that every serious episode of mental illness is likely to set eventual recovery or adjustment further back. Arguably, it is an infringement of the rights of consumers under the new Code of Consumer Rights to services of an appropriate standard. Achieving early intervention is a discrimination issue as it *'requires increasing community understanding of these disorders through raising awareness of early signs and decreasing the stigma which can sometimes delay people from seeking help'*.⁹
- **Inadequate community based services where there are people with long term therapeutic and support needs**
- **Insufficient child and adolescent services** - Another area of concern is the apparent dearth of mental health services available to children. It is suggested in the Mason Report that this is due to a large number of factors such as: 'ignorance and antagonism', 'lack of clear prescriptive direction from the Ministry of Health (MOH) to Health Funding Authority (HFA) and from HFA to Health and Hospital Service (HHS)', 'lack of trained staff', 'boundary problems between health, education and welfare' and 'adultcentrism of management'.¹⁰
- **Current services not designed to meet the needs of Maori or Pacific people** - It is clear that Maori mental health consumers experience another set of discrimination difficulties over and above the general populace of mental health consumers. These are outlined in a report by the Ministry of Maori Development. *'Trends in Maori Mental Health 1984 - 1993'*¹¹ This report provides a thorough set of recommendations and information on the subject of Maori mental health and appears to comprehensively deal with issues of discrimination that are specific for Maori people. We have therefore taken recommendations directly from the report, including a suggestion that there is a follow up meeting with the writers of the report about discrimination.
 There is not (to our knowledge) a similar report available on the subject of Pacific peoples' mental health concerns. This can be seen as a form of discrimination in itself given the significant number of Pacific Nations consumers. It is suggested that a report along similar lines to the Ministry of Maori Development's report would be a productive way to begin and identify specific discrimination concerns for Pacific Island people.
 Lack of recognition of the validity of other cultures' approaches in dealing with mental illness raises wider issues of discrimination against non-Western cultures which can have serious consequences for mental health consumers.

⁹ P145 Mason Report

¹⁰ Mason Report, pp131-136.

¹¹ *Nga Ia O Te Oranga Hinengaro Māori: Trends in Maori Mental Health 1984-1993*, Ministry of Maori Development, (Te Puni Kōkiri) in association with the Mental Health Foundation 1996

- **Discrimination in drug availability** - It has been claimed by some that mental health consumers do not receive equal treatment in terms of the supply of drugs or consideration of their side effects.
- **Overemphasis on drug treatments and lack of availability of free counselling and psychotherapy services.**
- **Lack of training for all mental health workers** - A major concern of interviewees is that both professional and untrained staff who support and assist consumers to live in the community are sometimes deficient in recognising individual consumer support needs and clinical risks.
- **Demoralised mental health professionals** - Many professionals are struggling to do the very best they can in difficult and demoralising circumstances. Staff feel that they are working in 'siege' conditions but continue to do so because they are dedicated to their work. At the same time, the high public profile of mental health makes staff understandably anxious about the complex judgment calls they must make.

Understanding discrimination

'To discriminate' means to distinguish between two options, according to the dictionary. Discrimination can be a neutral, not pejorative, word carrying the implication of rational choice.

People exercise discrimination many times a day when making informed choices, however, the exercise of discrimination also implies an interest in the kind of outcome desired, that is, to discriminate is to be either for or against one of the options. If the effect of the distinction is favourable it is seen as positive discrimination; if it is restrictive it can be described as negative discrimination. In general use the word carries negative overtones and 'discrimination' implies that a choice is made on an unfair basis.

Common usage of the term discrimination to describe unfair or negative behavior has probably arisen with the development of human rights legislation which emphasises the illegality of such discrimination. Overriding our freedom to discriminate negatively is the cultural, legal and democratic framework of society. Our human rights legislation lists prohibited grounds for negative discrimination and makes it illegal to discriminate, and so unreasonably restrict or deny a person's ability to participate in society, on the basis of certain personal attributes.

Discrimination can be seen as the converse side of the coin from recognition of rights because it usually results in denial of rights. However, it is important to note that not all rights popularly claimed have a basis in law. For example, an underlying view of most people in our democratic society is that all individuals should at least have equal opportunities to lead the 'best' life possible for them. This is seen as a right of individuals, although it is not enshrined in our legislation.¹²

¹² Domestic law does not provide equal rights to basic services such as food, shelter, education etc. On the other hand, constitutional lawyers would argue that an unwritten rule of law, including such norms, is the foundation of our constitution and legal system.

*'The idea that people ought to have an equal opportunity to lead the best life for them, is one of the cornerstones of recent liberal notions of justice.'*¹³

This view underlies the frequent claim that the respect and treatment accorded to dependent members of society is an important measure of the quality of civilisation. As the Wellington Branch of the Schizophrenia Fellowship submitted to the Mason Report:

'People who suffer such cruel and at times debilitating disorders must be fully supported and adequately resourced so that life for them can be the best it can possibly be. Can a society, which places value on human rights and democracy, do anything less than fully support and value its most vulnerable.'

The situation of disadvantaged groups in society may call for the exercise of positive discrimination in order to ensure that they have equality of access to goods or services. This is possible under our law. It should perhaps be acknowledged that where positive discrimination is successful in redressing inequalities, it would eventually be no longer needed.¹⁴

Human Rights Act 1990

The starting point of the Human Rights Act 1990 is that discrimination on certain grounds is prohibited. However, the Act also recognises that not all rights are absolute and allows specific exclusions which the person seeking to discriminate must demonstrate. For example, there are situations where an individual mental health consumer is unsuited to an activity or work, just as a deaf person is unlikely to make a good music instructor. The point is that there can be no generalisations - what about Beethoven?

The diagnostic name of an illness or disability does not necessarily describe a person's capabilities, for example, one individual with a bi-polar disorder may not be able to function in the community while another could effectively run the country, just as the capabilities of two people with diabetes can be very different. Moreover, mental health consumers, just like other individuals, may have particular needs and preferences, for example, to work in a quiet place. Mental illness can also occur with varying degrees of severity and one individual is likely to experience different depths at different times. Under the Human Rights Act 1993, discrimination can only be justified after consideration of the individual case.

Health and Disability Commissioner Act 1994

The Health and Disability Commissioner Act 1994 attempts to provide a legal framework whereby the rights of people to the best health care possible can be established and protected. Thus an investigation into an alleged breach of the Code of Consumers' Rights is likely to examine the basis for choice - the exercise of discrimination - by professionals. A breach of the

¹³ Noted by John McMillan, assistant lecturer at the Bioethics Research Centre, Otago. He also noted that, 'John Rawls in *A Theory of Justice* argues that this sort of notion of justice ought to be the first virtue of our social institutions', and that Norman Daniels' book *Just Health Care* voices a similar sentiment.

¹⁴ It is noted that the state of California has now limited the scope of positive discrimination, seemingly in response to a public perception that some ethnic groups were receiving unfair advantages. This may yet be struck down as being unconstitutional.

Code could, however, occur because of reasons other than the deliberate exercise of negative discrimination, such as ignorance or misinterpretation of the Code.

Discrimination and mental illness

Discrimination is only just beginning to be recognised as an issue for mental health consumers in the community. Historically, 'stigma' has been more commonly used.

Although the difference between stigma and discrimination may seem to be purely semantic, we suggest it can lead to a difference in how problems are tackled. Years of research into public attitudes and stigma has not led to the development of effective models for change, whereas the introduction of community care has applied pressure for change.

Whereas stigma attaches to the consumer, discrimination results from actions of others. If placed in a human rights framework, there is clear evidence that widespread discrimination is exercised against people with mental illness. More importantly, that framework also offers a well tested methodology for identifying and resolving discriminatory practices. It is argued in a recent paper that '*The Human Rights Commission rather than, or as well as, the Mental Health Commission should have a role, in both addressing specific discrimination, and as an instrument of social change in reducing stigma and the discrimination which results*'.¹⁵

We also note here our observation, drawn from comparing the experiences of discrimination victims, that mental illness has to some extent been a scapegoat for other groups attempting to reduce discrimination who have been labelled as 'mad'.¹⁶ In other words, many discrimination victims have found it useful to claim, 'hey, it's not fair to treat us like mad people, we are more deserving'.¹⁷

This approach can only reinforce the public attitudes described earlier and the belief that it is justifiable to discriminate against those who are seen as 'mad'. They are legitimate outcasts, perhaps more similar to criminals than to other members of society. An implicit meaning of words such as 'mad', 'insane' is as labels to identify people who are 'beyond the pale', to borrow from a different experience of discrimination.

Strategies to reduce discrimination against mental health consumers must therefore develop effective counters to these deeply held feelings that such discrimination is legitimate and justifiable. It is also important that a similar approach of scapegoating other groups is not taken in countering discrimination within the mental health arena.¹⁸

¹⁵ Bell, S. 'The Mental Health Commission', in *Mental Health and The Law*

¹⁶ For example, one of the tactics to reduce discrimination of intellectually disabled people or those with cerebral palsy was to point out that these people have impairments quite different than mental illness and, perhaps, more 'deserving'. Religious sects or those with distinctive cultures had to clarify that they had different ways of seeing the world rather than suffering from madness. Homosexuals had to claim that their way of life was not a sickness of the mind.

¹⁷ S O Davis' article, 'We're Not All Crazy' in *The Australian Women's Weekly*, Nov 1996

¹⁸ 'Patients with schizophrenia, for example, may be labelled as personality disordered, not because of conceptual similarities, but when they are about to be rejected because of their unpleasant behaviour.' 'Personality disorders are an ill-defined, yet substantial group of diseases which are the concern of all branches of psychiatry. . . . Patients with personality disorders are likely to be unpopular. . . . At times the term 'personality disorder' is part of the language of rejection.' The Mason Report, p150.

Consequences of discrimination

Negative attitudes and discriminatory treatment impact seriously on mental health consumers. The consequences can be categorised under headings such as those that follow.

Degradation

Overt and covert derogatory comment on mental illness at all levels, from conversation to parliamentary debate, is generally socially acceptable. *'Negative publicity commonly leads to a breach of clients' rights in that they are discriminated against (often not intentionally) due to the anxiety provoked within the public.'*¹⁹

Scapegoating

Mental illness is often falsely associated with violent crime. The chairman of the Council of Licensed Firearms lobby makes the following assumption about mental health consumers in arguing against tough gun legislation: *'Such misfocused and useless laws which seem to be based on the premise that because a mentally deranged person kills with firearms the sane and responsible cannot be trusted to have them.'*²⁰

Mystification

The language of diagnosis and treatment is often mystifying allowing the possibility for discrimination and exploitation of consumers by mental health professionals. *'The helping professions are the most effective agents of social conformity and isolation. In playing this political role they undergird the entire political structure, yet they are largely spared from self criticism, even from political observation, through a special symbolic language.'*²¹

Shame

Shame means that many consumers and their families do not wish to admit to their association with mental illness. *'My younger brother was told I was in jail. Jail wasn't seen to be as bad as a psychiatric hospital. I've never been to jail.'*²²

De-humanisation

Ordinary physical, emotional and social needs are often not considered as important for people who have a mental illness. This can result in a denial of basic human skills, dignity, pleasures and needs, during treatment or by the community. A dog-loving consumer made this analogy: *'If you don't want your dog to piss on the floor you could treat it like "an animal" and beat it, or you could help it learn what to do. Mental health consumers do not always seem to be given "human" status.'*²³

Denial of access to goods and services

Underpinning all of this and probably of the greatest practical significance in daily life is the common denial of mental health consumers' access to accommodation, education, employment, information and special need services - basic civil rights. *'Discrimination results*

¹⁹ *The Mason Report*, p163

²⁰ Beltowski, L. *Sunday Star Times*, Feb 23, 1997

²¹ Edelman, M. 'Political Language and the Helping Professions', in *Political Language That Succeed Policies that Fail*.

²² 'Survivors View', Ministry of Health

²³ A verbal quote from a Mental Health Consumer.

*in alienation from mainstream community life, the creation of barriers to recovery and integration, and problems in finding housing and work.*²⁴

Inadequate health care

Although everyone has mental health needs these tend to be neglected in general medicine, despite the fact that mind and body are both of concern to the pursuit of good health. The training of health professionals in general practice, such as GPs and Plunket nurses, appears to have been less than adequate in relation to mental health according to the mental health professionals with whom we spoke. Moreover, it seems that patients with a history of mental illness have more difficulty in accessing general health care because their 'stories' about their symptoms are not always taken seriously.

Invisibility

Attitudes in society generally reflect a lack of general awareness of the need to care for one's mental health. An employee cannot comfortably say to the boss, *'I need a day off as I am stressed and may become depressed if I am not careful'*. Nor is an employee likely to admit visiting a counsellor or psychiatrist, although a visit to the GP or even hospital is without shame. These inhibitions weigh most heavily on people who have been institutionalised, or even more so, on people who show visible signs of mental illness. If they admit to mental health treatment, they have a radically reduced chance of getting a job or even participating in society in an ordinary way, such as finding accommodation, membership in a sports club or just gaining friends.

Professional status

Workers in the mental health services also experience discrimination in the form of low status among their peers, which is also reflected in resource allocation and priorities at all levels. Negative discrimination against mental health has been seen as a byproduct of the conceptual separation between mental and physical health in western medicine.²⁵

Media/community attitudes

Although media attitudes towards mental illness are to some extent a gauge of public attitudes, the media is clearly also a source a public information about mental illness. In fact, research has shown that the media have a substantial impact on community attitudes. *'It is clear the inclusion of violent offenders among the mentally ill and the publicity about them through the media influenced the attitudes [research] group members expressed about mentally ill people generally.'*²⁶

A plethora of surveys on public attitudes to 'the mentally ill'²⁷ broadly confirm that the public does indeed see mental health consumers as both dangerous and incapable,²⁸ a constant theme

²⁴ Bell, S. *Whose Rights Are They Anyway?*

²⁵ There has been a growing trend towards a more holistic approach in medicine in recent years, in contrast to the conceptual dichotomy between mind and body prevalent in most western thinking, from religious texts to scientific discussions.

²⁶ Patten, D. *Public Attitudes to Mental Illness*

²⁷ Unfortunately many of these surveys use the phrase, 'the mentally ill', in their titles or text, rather than according the status of people who have, or have had, a mental illness.

²⁸ See bibliography for list of some of these surveys. Three useful NZ papers are: Patten, D. *Ibid*

of the media. A clear illustration of this is shown in public comment on the release of 'psychiatric inmates' into the community which implies that this is dangerous for 'us' and quite inappropriate for 'them'. Indeed, some comment seems analogous to the likely uproar if lions were released from the zoo to live among us.

As expressed by Erin Kennedy in *The Dominion* (Feb 25, 1997): '*The commonly held view is that people with mental disorders are dangerously unbalanced and violent people.*'

Two pervasive and false generalisations - danger and incompetence - strongly influence employers and others to deny opportunities to mental health consumers, as we have seen. Yet statistically, '*Jo Bloggs is as likely to be an axe wielding maniac as an ex-psychiatric patient.*'²⁹ A survey of firearm homicide in New Zealand between 1992 - 1994 showed that '*none of the perpetrators had a history of mental illness.*'³⁰ At risk of labouring this point, it was noted in *The Dominion* that '*not more than 1 in 2000 "schizophrenics" will commit a violent crime*' and that '*a high proportion of violent crimes are related to young men aged 17 - 25. Of course no one is suggesting we lock up all young men.*'³¹

An example of how the media misrepresent facts and excite fear on the issue of mental illness is the way the 1996 Port Arthur tragedy in Tasmania was handled. At the time of the incident there was wide speculation in the press about the mental health of the perpetrator. However, when he was actually assessed by a psychiatrist (Professor Mullen) who found that he did not have a mental illness, this fact did not receive similar media coverage.

Even without a dramatic tragedy involving a person with mental illness, informal surveys of the media find that coverage chooses angles which reinforce negative community perceptions. For example, common approaches to a range of mental health related stories are:

1. deinstitutionalisation - how it is not working, that it is under-resourced, that the workforce needs training and support, and that the community cannot 'shoulder the responsibility'
2. the weaknesses and inadequacy of the legislation, in particular a perceived inability to ensure adequate services are available to those with mental illness.

Furthermore, these stories are commonly laced with stigmatising language, such as 'schizophrenic', or 'committed psychiatric patient'.

These attitudes result in discrimination which manifests on many different levels. The forms of discrimination are interrelated and operate in overlapping, vicious circles, for example, stigma results in secrecy and lack of interest which can cause a lack of funding, which in turn exacerbates the dearth of factual information and leads to overt discrimination.

Romans, SE. 'A Community's Attitudes towards the Mentally Ill', *New Zealand Medical Journal*

Barwick, H. *Positively influencing Public Attitudes to people with a Psychiatric Disability; A Review of the Literature*

²⁹National Institute of Mental Health. 'What do we know about mental disorder and violence?'

³⁰ According to Alpers, '73% of the killers are known to have no previous history of mental illness' (Alpers, P, *A Decade of mass gun killings in Australia and New Zealand 1986-1996*) (*Firearm Homicide in New Zealand: Victims, Perpetrators and Their Weapons 1992-94*)

³¹ Erin Kennedy, 'Sorting out a delusive disorder', *The Dominion*, Feb 25, 1997

Consumer/professional dynamics

Some mental health consumers see elimination of discrimination by health professionals as the highest priority. They ask, how can public attitudes change if the professionals reinforce stereotypical views of mental health consumers or are silent in the face of publicly accepted discrimination? Such attitudes by 'those who know' must be enormously influential.

Many consumers also feel that the approach to them on a personal level taken by professionals does not respect their status as unique individuals, or even as people.³² At the same time, consumers are conscious of their dependence on the good will and skills of professionals and the, literally, extra-ordinary power that professionals wield over their lives.

Work conditions for professionals

As discussed earlier, it is clear that many professionals are struggling to do the very best they can in difficult and demoralising circumstances. As was stated strongly in submissions to the Mason Report, many staff feel that they work under 'siege' conditions of declining quality, but they continue to do so because they are dedicated to their work. At the same time, the high public profile of mental health issues means staff are anxious about the complex judgment calls they must make in their work every day.

It is acknowledged by some professionals that the high frustration and stress levels of staff mean that some individual patients receive less than their due in terms of professional standards. One professional (not listed among the interviewees) said, *'I can't allow myself to think of the patients as like me or I am overwhelmed by their tragedy and the inadequacy and unfairness of the services I can bring. I have to think of them in terms of their illness so I can keep going'*. Yet this person is empathetic and provides additional services to dual diagnosis patients beyond the strict terms of responsibility.

Consumer/professional working relationship

This volatile mixture of lack of respect by some professionals and resentment on the part of some consumers can inhibit useful dialogue with professionals. It is a unique situation to work with mental health workers whom you may be associated with users of services and this raises quite different issues than those for consumers in other work places. It was suggested that in such situations consumers need special support, for example, the supervision model provided for social workers but with supervisors who understand the issues, or other support networks

Mary O'Hagan describes some of the difficulties and requirements of consumers working in with mental health professionals: *'When mental health professionals are challenged by the survivor movement, they are being asked to change their relationship from one of paternalism to partnership. Many professionals find it difficult to see us as their teachers. When they get over this hurdle they sometimes deny that we are different by relating to us as ordinary colleagues.'*

There should be room for agreement between professionals and consumers on the need for mutual understanding and work together to eliminate the kind of stress discrimination described above. As Mary O'Hagan also acknowledges: *'My righteousness is always tempered*

³² For example, we noticed some workers referring to people as 'my head-cases' or 'my fruit-loops'.

*by the sobering knowledge that if I had been a mental health worker instead of a survivor I would probably be all, or some of the things I criticise them for*³³

It is more difficult for professionals and consumers to find common ground in relation to more radical views of discrimination, which attribute discrimination to the denial by some professionals of the validity of consumer experience and consumers' views of the world, denial even of their right to hold views. Some consumers feel that professionals do not sufficiently acknowledge consumers' strengths and skills in functioning within their own reality.

It is quite beyond the brief of this report to explore these opinions but it is relevant to note that some consumers and professionals see community based services as an opportunity to develop more co-operative and creative services tailored to meet individuals' needs. For such a future to evolve, the knowledge base of some professionals may be questioned as inherently discriminatory.

Anti-discrimination measures

Elimination of discrimination stems first from an acknowledgment that discrimination exists. In the case of consumers under compulsory treatment orders, such recognition is problematic as the civil rights of consumers are often subsumed by the provisions of the Mental Health (Compulsory Assessment and Treatment) Act 1992. This means that mental health professionals are used to thinking of their decisions and behaviour towards consumers in terms of specialist knowledge of illness and the treatment required, rather than in the framework of human rights.

Although we conclude that it is essential to include mental health professionals in any work to eliminate discrimination, the situation is very different than with other groups. The primary need here seems to be for further exploration of the experience of discrimination by consumers in an environment which supports them speaking out and also supports professionals who feel that they are doing their best. There needs to be dialogue between the professionals and consumers and an identification of common objectives. It is also important that a systematic analysis of the legislation is undertaken within an anti-discrimination framework.

To implement change it is important that the professional groups themselves see the need for improvement, are committed to change and can create opportunities to effect change despite their exacting clinical responsibilities.

³³ O'Hagan, M *Stopovers on My Way Home from Mars*

2. The legal rights of mental health consumers

Introduction

Two separate international movements for social change are shaping re-examination of the approach taken by government, health professionals and the community to mental health consumers:

1. the human rights movement, with leadership from the United Nations,³⁴ has required national governments to provide and implement legal recognition of individual human rights, including people with mental illness
2. clinical developments which contributed to the closure of institutions and the promotion of community based mental health services.

Together, these movements are raising awareness of the fact that people with mental illness have the same individual rights, although interpreted within a particular legal framework, as anyone else. This is a very different basis for the provision of mental health services than the traditional model, whereby people with mental illness were segregated from the community and not regarded as entitled to the same individual rights.³⁵

From the public's point of view it is probably true to say that even where goodwill is present, there is complete bewilderment about how the individual rights of a person with mental illness can be appropriately recognised in the community. Without goodwill, the negative public attitudes described earlier create a barrier to the successful implementation of community based mental health services.

There is a need now to look closely at how 'treatment' and 'rights' intersect and to specify what the rights movement means for the provision of community-based mental health services and how the 'best' treatment models can be delivered within an individual rights framework.

Legislative change has coincided with a maelstrom of restructuring in the health sector over the last five years. However, the new structure of mental health services does not seem to have adequately complemented the new legal framework. Although the legislation is enlightened in regard to recognition of individual rights and the need for community care, the actual delivery of community and crisis services for mental health consumers is the subject of severe criticism.

³⁴ International Covenant on Civil and Political Rights 1966, UN Principles for the Protection of Persons with Mental Illness and for the Improvement of Mental Health Care 1991

³⁵ 'The Mental Health Act 1969 was drafted from a paternalistic perspective and aimed at providing care and protection. In contrast the present Act is based on the concept of patient autonomy.' Bell, S. 'The Mental Health Commission', in *Mental Health and the Law*.

Legal framework

International context

*'Today it is unfashionable, indeed almost unthinkable, to believe that common sense and benevolence are sufficient safeguards when society intervenes in the lives of its citizens.'*³⁶

International human rights law has had a profound impact on our legislation. Much of that law emanates from the United Nations and includes a variety of international legal norms, standards, processes and institutions primarily developed to protect the rights of individuals and minority groups.

Although not always adopted by New Zealand, this international law has underpinned the drafting of our human rights legislation and its interpretation by the Court, and also offered guidelines about appropriate standards for health care and services to mental health consumers.

The **UN International Covenant on Civil and Political Rights 1966** sets out fundamental rights such as the rights to be free of cruel inhuman or degrading treatment or punishment, to be treated with respect and dignity and with humanity if deprived of liberty, to freedom of movement and choice of residence, equality before the law and by the law. The principles of the Covenant are incorporated into the New Zealand Bill of Rights 1990 which outlines the standards to be considered when interpreting other legislation.

The **UN Principles for the Protection of Persons with Mental Illness and for the Improvement of Mental Health Care 1991** specifies the rights of mental health consumers. 'The Principles provide a benchmark for the protection of and treatment of people with a mental illness and reiterate a number of fundamental freedoms and basic rights, as well as outlining the standards for treatment that can be expected from a mental health system.'³⁷ These principles are further complemented by the *Standard Rules on the Equalisation of Opportunities for Persons with Disabilities* adopted by the UN in 1993. The Rules uphold the principle of equality and claim, *inter alia*, that the use of resources must be planned so that every individual has the opportunity to participate equally.

New Zealand Context

Treaty of Waitangi 1840

In the last decade New Zealand law has undergone a major shift in respect of the Treaty of Waitangi and indigenous rights, largely as a result of statutory recognition and some landmark Court of Appeal decisions. General principles interpreting the Treaty are now well established in common law. These have been specifically applied in some public sector areas but we are unaware of any work of this kind in the mental health sector, although people are entitled to treatment that is culturally appropriate under the mental health legislation.

³⁶ Amer, G. 'Mental Disorder: "Serious Danger" A Minor Faux Pas or a Serious Mistake?' in *Mental Health and the Law*.

³⁷ Bell S. 'The Mental Health Commission', in *Mental Health and the Law*.

New Zealand Bill of Rights 1990

The principles of the International Covenant on Civil and Political Rights 1966 are incorporated into the New Zealand Bill of Rights 1990 which outlines the standards to be taken into account when interpreting other legislation. However, specific legislation relating to mental health consumers may override the provisions of the Bill of Rights, eg the right to refuse medical treatment does not apply where this is specifically dealt with in the Mental Health Act. Nevertheless the Court has emphasised that in exercising a relevant statutory discretion ‘*a weather eye to the internationally recognised norms for the human rights*’ should be maintained.³⁸

The Bill of Rights also protects the rights of consumers who appear as offenders in the criminal justice system. However, an increasing number of mental health consumers are appearing in the criminal courts, perhaps as a result of inadequate support in the community and anecdotal evidence suggests that some have neither adequate legal representation nor receive appropriate sentences.

Human Rights Act 1993

The basis of the New Zealand Human Rights Act 1993 is that discrimination on certain grounds is prohibited. ‘Disability’ is one of the prohibited grounds of discrimination³⁹ and this includes:

- (iii) Psychiatric illness,
- (iv) Intellectual or psychological disability or impairment,
- (v) Any other loss or abnormality of psychological, or anatomical structure or function

As we have seen, the Act also recognises that not all rights are absolute and allows specific exclusions which the person seeking to discriminate must demonstrate.

While mental illness should be treated the same way as any other of the prohibited grounds of discrimination, there is probably less general awareness and understanding of what this really means. Consequently many people with a mental illness would not think of the Human Rights Act 1993 to pursue complaints.

On the other hand, an enormous amount of energy has been put into some of the other areas of discrimination in the last few years, for example, sexual identity or gender. This can be seen as an advantage for mental health consumers because they can distill lessons about how best to effect change from others’ experience. In any case, people with experience of mental illness frequently feel so disempowered that they find it difficult to pursue a complaint.

Mental Health (Compulsory Assessment and Treatment) Act 1992

The long title of the Mental Health (Compulsory Assessment and Treatment) Act 1992 states that this is an Act ‘*to redefine the circumstances in which and the conditions under which persons may be subjected to compulsory psychiatric assessment and treatment, to define the rights of such persons and to provide better protection for those rights, and generally to*

³⁸ *Police v M* (no 5), unreported DC Henderson 24/4/96, discussed in Brookbanks, W, ‘Keeping a Weather Eye on Fitness to Plead and International Obligations’, in *Mental Health and The Law*

³⁹ S21(1)

reform and consolidate the law relating to the assessment and treatment of persons suffering from mental disorder.’.

The Act defines the general entitlements of patients such as entitlement to information, consultation, legal representation and also entitlements relating to their particular situation such as to communicate and to have company. Only the entitlement to information is mandatory but many of the entitlements are replicated in other legislation.

The Act has various provisions that enable mental health consumers to pursue grievances. Administration of the Act includes the appointment of independent District Inspectors with power to conduct inquiries and official visitors. Consumers can take complaints of breaches of their rights to the District Inspector. Consumers also have specific rights in relation to review of their clinical condition by their responsible clinician and on appeal to a Review Tribunal. The Minister has authority to establish Review Tribunals as may be required, with the powers of a Commission of Inquiry ‘to consider the condition of a patient who has applied for such a review, or in respect of whom an application for such a review has been made’.⁴⁰

Discrimination within the Act

The Act provides a legislative framework for largely community-based mental health services but these are only available for those who fall within the definition of ‘mental disorder’. The Act applies only to those whose behaviour derives ‘from themselves’ (that is, not from substance abuse or criminal intention), and to those who can be treated, (that is, not intellectual disability). However, the Act can also be applied to others who have a mental illness if it is considered that this presents a danger.

It could be argued that the Act furthers negative stereotyping by referring to ‘serious danger’⁴¹ in defining mental disorder. *‘What is becoming clear from the emerging case law is that a person will only be considered to be mentally disordered in those cases where both requirements of the definition are satisfied. This means that people whose behaviour is socially unacceptable cannot be detained if they are not sufficiently dangerous or not likely to benefit from the treatment offered.’*⁴²

In practice the narrow interpretation of ‘mental disorder’ has led to discrimination against some mental health consumers because services are not provided for them elsewhere, and to boundary disputes among professionals about who is responsible for whom. Mental health consumers affected by this include those suffering from dual diagnosis, aged dementia, stroke/head injury, personality disorders, alcohol and drug disorders.⁴³

Health and Disability Services Act 1993

The stated purpose of the Health and Disability Services Act 1993, is to reform the public funding and provision of health and disability services in order to provide the best health care or support for those in need and ‘the greatest independence for people with disabilities that is reasonably achievable within the amount of funding provided’. The Act establishes the present

⁴⁰ S102

⁴¹ Amer, G. ‘Mental Disorder: “Serious Danger” A Minor Faux Pas or a Serious Mistake?’ in *Mental Health and The Law*.

⁴² Bell, S. *Whose Rights Are They Anyway?*

⁴³ Ibid

structure of the health services with a funder/purchaser/provider split and describes the objectives and functions of RHAs and CHEs.

Health and Disability Commissioner Act 1994

The stated purpose of the Health and Disability Commissioner Act 1994 is to promote and protect the rights of consumers by:

- the appointment of a Commissioner to investigate complaints;
- the establishment of consumer advocacy services; and
- the promulgation of a Code of Health and Disability Services Consumers' Rights.

The first task of the Commissioner was to develop and publicise the Code, which was published in July 1996. The Code describes the rights of health consumers in terms of broad principles which should govern the delivery of services. What the Code will mean for individual consumers in the mental health area is not clear but will be developed by the Advocates appointed under the Act and the Commissioner over time, according to staff in the Commissioner's Office. It is pertinent that resource constraints are valid circumstances which can reduce provider's responsibility to give effect to the Code.

Privacy Act 1994

Finally, the Privacy Act 1994 has implications for mental health consumers as it does for everyone else. There have been difficulties in applying the principles of the Act to people under compulsory treatment orders, but it is hoped that most of the issues which have arisen can be sorted out by the adoption of the Act.⁴⁴ It should ensure that consumers' rights to privacy are protected but balanced by health promotion needs such as support from family and friends.

Coordination of legislation

A look at how discrimination issues are dealt with in the new legal framework is timely. It is suggested that there is a need for a coordinated presentation of the rights provided in current legislation to uncover any gaps, overlaps and conflicts between the various pieces of legislation or in existing procedures applying the legislation.

While the preceding description covers the main statutes with relevance to mental health consumers, it is not intended to be a complete list. We note in particular that there may need to be specific work done in relation to children with mental illness and the interaction of the Mental Health (Compulsory Assessment and Treatment) Act, the Guardianship Act, and the Children, Young Persons and their Families Acts.

The Health and Disability Commissioner and other people charged with similar responsibilities in the mental health arena, such as District Inspectors and the Human Rights Commissioner, have not yet developed protocols for working together where their responsibilities overlap. Broad distinctions can be seen, that is, District Inspectors have specific responsibilities in relation to compulsory treatment orders, the Code of Rights applies to all health services and the Human Rights Commission tends to investigate discrimination complaints arising in the wider community.

⁴⁴ *Private Word*. Newsletter of the Privacy Commissioner. No 6 June, 1996

However, there is a need to explicitly fit the legislation together and to identify clearly the rights and entitlements of mental health consumers. The Mental Health Commission, the Ministry of Health, the Health and Disability Commissioner, the Human Rights Commissioner, and the Privacy Commissioner can all be seen to have an interest in such a project. It should be coordinated with the review of the Mental Health (Compulsory Assessment and Treatment) Act 1992 which has been scheduled by the Ministry of Health.⁴⁵

The following examples of gaps and overlaps were given to us.

Example 1

The Mental Health Act assumes that every patient will have a principal caregiver and places specific responsibilities on medical advisers in relation to that person. Yet some adults patients do not in fact have such a person and object to the medical adviser contacting a relative or friend who has no real link with them.

Example 2

Another possible breach of privacy is the requirement for a copy of the preliminary assessment forms to be sent to the person who applied for assessment, even if that person *is* a total stranger, such as a police officer. Another breach is the requirement to send the assessments to anyone, prior to the result of review if one is sought.

Example 3

An example of a questionable procedure is the application of rules on acute wards about such matters as visitors, telephone contact, choice of activity or food is sometimes discriminatory. The rules are usually justified under the provisions of the Mental Health Act 1992 as being in the 'best interests of the patients' but it is questionable whether individual best interests can be assessed and applied to all equally, or even which best interest is being met.

⁴⁵ Project 10, Mental Health Projects 1996/97, Ministry of Health. Also see Action Plan Relating to Objective 9 - Ongoing Review of Mental Health Legislation and Guidelines

PART TWO - Comparative Study and Anti-Discrimination Objectives

3. A Comparative Study

Introduction

Our hypothesis was that a comparative study of general discrimination and the strategies adopted to reduce it would reveal a knowledge base for analysis of the specific experience of discrimination by those with mental illness.

A comparison has been made with other areas of discrimination where significant social change has been achieved, such as discrimination on the basis of age, gender, sexual identity, race, culture, physical disability. This comparison provides useful insight for mental health consumers. It is also most striking to realise how rapidly and how recently public attitudes have changed in some of these areas.

The following summary gives an overview of the comparative study. It sets out the similarities and differences as compared with the mental health area, together with the strategies adopted to reduce discrimination. Although this is simply a cursory comparison, the method used has proved fruitful as an overview of discrimination issues and as a source of ideas. In the comparison, the experiences of the wider mental health consumer group were considered, including all who have assistance from mental health services, whatever the clinical diagnosis. While this clearly includes those subject to compulsory treatment orders, the consumer group is far wider than that.

Table One: Comparison of the discrimination experienced by mental health consumers and that of other groups

| BASIS FOR DISCRIMINATION | SIMILARITIES WITH DISCRIMINATION AGAINST PEOPLE WITH MENTAL ILLNESS | DIFFERENCES | STRATEGIES TO ADDRESS THE DISCRIMINATION |
|--------------------------|--|---|---|
| Gender | <p>The discrimination is embedded in our language, both professional and everyday language</p> <p>(Self) acceptance and perpetuation of discrimination</p> | <p>Now a strong political issue</p> <p>Non minority issue</p> | <p>The women’s rights movement, for example, particular campaigns around equal pay and reproductive autonomy</p> <p>The rise of ‘politically correct’ language</p> <p>The advent of EEO authorities</p> |
| Sexuality | <p>Secrecy - historically gay individuals and society have hidden homosexuality</p> <p>Fear - the media spreads fear and prejudice. The HIV / AIDS or paedophile threat are popular media subjects as much as violence committed by a person with mental illness</p> <p>Shame - an historic connection with evil (Sodom), homosexual people are therefore seen as undeserving. Similarly, a common view sees madness as caused by possession by the devil. There is an enormous amount of shame and even blame attached to ‘losing your mind’. This leads to secrecy and unwillingness to seek help early on</p> <p>Discouraged from ‘openly’ being gay</p> | <p>Powerful group</p> | <p>Legislation</p> <p>‘Out of the closet’</p> <p>Public parades and parties</p> <p>Gay pride</p> <p>Information campaigns eg about AIDS</p> <p>Secularisation and reinterpretation of the bible</p> |
| Children | <p>Dependent</p> <p>Powerless</p> <p>Cannot always effectively speak for themselves, or even comprehend what they need and what their rights should / could be.</p> | <p>Considered innocent / worthy</p> <p>Dependent for a predictable period of time</p> | <p>Clear responsibility of government</p> <p>United Nations charter of children rights. Definition of special rights</p> <p>Commissioner for Children</p> <p>Support services available</p> |

| BASIS FOR DISCRIMINATION | SIMILARITIES WITH DISCRIMINATION AGAINST PEOPLE WITH MENTAL ILLNESS | DIFFERENCES | STRATEGIES TO ADDRESS THE DISCRIMINATION |
|---------------------------------------|---|--|--|
| Elderly | Dependent Considered incurable Blurred boundaries with other illnesses Exhibit visible signs / behaviour Institutionalised Can lose rights | Considered innocent / worthy Personal identification Can be planned and prepared for | Adequate support services Popular charity cause Rights protected by legislation |
| Minority / Culture or Religion | Stereotypes create a fear of 'other' members of society Society's institutional communication paths were often inflexible about other languages/methods of communication, eg in the courts or education facilities. Community fear - 'not in my back yard' - because of different or unfamiliar behaviours Exhibit visible behaviour differences | In built, inherent support networks | The eclectic nature of 'post modern' culture encourages acceptance and celebration of difference. Diversity expressed through mass media. Modification of some behaviour Dispute resolution processes established, for example the Treaty of Waitangi. Provision of interpreters in courts Positive discrimination |
| Colour | Fear / myths / stereotypes Instantly visible Historical segregation | Visibility | Affirmation No forced segregation Legislation |
| Victims of Offences | Historically invisible Small percentage of society from all ages and levels Recognised as suffering emotional/psychological trauma | Seen as innocent Effective lobby group Powerful personalities | International movement Support groups established by Victims Task Force Funding support from Police / Community Funding Agency |
| Physical Disabilities | Dependent (special assistance required) Services mainly based in the health system Require a holistic view of their lives. It is not inherently a powerful lobby group | Recognised Regarded as innocent Easy to empathise with Became effective lobby group | Community assistance Politically correct language legislation (building codes) Disability liaison officers Public education |

| BASIS FOR DISCRIMINATION | SIMILARITIES WITH DISCRIMINATION AGAINST PEOPLE WITH MENTAL ILLNESS | DIFFERENCES | STRATEGIES TO ADDRESS THE DISCRIMINATION |
|--|---|---|---|
| Size⁴⁶ (Larger people) | Stereotypes (lazy, greedy) creates contempt Considered unworthy Discriminatory language issues Considered a health issue Media a major culprit Health problems associated with 'treatment' | Big dollar business Not considered dangerous | Media images are challenged Education and health promotion programmes Fat Acceptance Lobby Groups Links with feminist groups |

The study confirms that effective change has principally come about from the assertion of rights, political activism and positive discrimination. In addition, the individuals discriminated against and other members of the community need to interact positively to get to know each other and understand their differences.

The conclusions from Table One were then analysed further, based on a broad understanding of the significant issues behind discrimination generally, as well as the particular myths and emotions attached to mental illness.

⁴⁶ Adzoxornu, Isaacus, *Discrimination Against Fat People. Part 1: It Is Not Over Till The Fat Person Sings*. This offers an interesting analysis of a discrimination issue which has not yet been effectively dealt with.

Table Two: Characteristics which mental health consumers share with other groups and the strategies adopted

| CHARACTERISTIC | GROUP DISCRIMINATED AGAINST | STRATEGIES ADOPTED |
|-------------------|--|--|
| Dependency | Elderly Physically/intellectually disabled Children | <p>State provided assistance from several agencies including health services, education sector, social welfare, ACC, also from some local bodies eg housing</p> <p>Assistance from well established community organisations such as church groups, consumer groups, iwi.</p> <p>Specific responsibilities allocated by Government or in legislation, eg building codes, complaints procedures, some rights defined (Children, Young Persons and their Families Act 1989, Protection of Personal and Property Rights Act 1988)</p> <p>Some coordination of services and support for patients and families, eg ACC and information brochures</p> |
| Language | Women Disabled Non-mainstream cultures Non-white races Larger people | <p>Activists and academics have promoted an awareness of the power of language.</p> <p>Invention of new useful terms such as ‘herstory’, ‘psychiatric survivors’, ‘ms’, and ‘challenged’ have come quickly into widespread use. Even if initially resisted, they stimulate new insight to issues which are otherwise not understood.</p> <p>Concept of politically correct language adopted by teachers and editors and the subject of claims to Human Rights and Race Relations Offices. Some words illegal, eg nigger, ‘girl’ for woman, cripple. (Words such as loony and mad could be treated similarly.)</p> |
| Shame | Gay people Larger people | <p>Gay pride parades, ‘coming out’</p> <p>Dispelling myths through information, media campaigns.</p> <p>Identification with leading personalities</p> <p>Self acceptance</p> <p>Smart Fashion options</p> <p>Fat Acceptance (US development)</p> |

| CHARACTERISTIC | GROUP DISCRIMINATED AGAINST | STRATEGIES ADOPTED |
|---|--|---|
| 'Different' behaviour and appearance | Some physical disabilities Ethnic/religious minorities Larger people | Promotion and information campaigns increase the acceptance of people with unusual behaviour and appearance Encouragement of self acceptance and pride. 'I am eccentric, what of it, I am a paraplegic / Fijian / Islamic and proud of it, I have a disability but it is not who I am'. The Human Rights Act 1993 |
| Stereotyping | Non white races Gay people Women Larger people | Education, propaganda and myths dispelled through media, eg The Cosby Show 'Mainstreaming' certain groups previously separated, eg black people, deaf people, people with intellectual disabilities Positive discrimination |

Issues which only, or more strongly, affect mental health consumers

Next, we identified those characteristics which only, or more strongly, affect mental health consumers and for which the model cannot provide examples of reduction strategies.

- **Compulsory treatment orders** are, potentially the most powerful infringement of consumers' basic human rights. These provisions of the Mental Health (Compulsory Assessment and Treatment) Act and their administration warrant independent scrutiny and consumers must have access to fair review.
- The **dearth of general information** and education about mental illness for consumers/families/health professionals and public, not only encourages misinformation but also inhibits people of goodwill from feeling able to be positive or respond usefully. (This lack of knowledge was previously a problem for other forms of discrimination).
- There is an exaggerated **community distrust** and fear of 'mentally ill people roaming our streets' because of major service failures and media hype. The public tend to wonder whether the de-institutionalisation process was motivated by government cost cutting needs rather than a real concern for mental health consumers and the general community.
- **Professional 'capture' of mental health 'care'**. Mental illness is regarded as the sole concern of the mental health professions rather than of us all, and particularly other service providers, such as police, education sector, criminal justice system, social welfare, other health services, employers/landlords etc. This has inhibited awareness of the basic rights and needs of mental health consumers (this may have parallels in the way some people with disabilities were previously treated).
- **The nature of an individual's mental illness changes constantly** because the degree of illness changes unpredictably, sometimes very rapidly. This requires a flexible system, for

example, a case manager may have to spend lot of time with a consumer who normally requires little attention, and is therefore not available to other consumers.

- **Lack of culturally safe services for Māori and Pacific people.** Different cultures have different views on the causes, symptoms and treatment of mental illness, and these views have not been fully validated in the provision of services and devolution of resources.
- **Limited mental health services for children young people with psychiatric disabilities.** Despite the fact that ‘psychiatric disorder in childhood is relatively common’⁴⁷ and that the risk factors are well identified, very few children or adolescents access mental health services. Other services often do not refer potential young patients to mental health services resulting in missed opportunities for early intervention.
- **Lack of everyday language to describe mental illness** which is not abusive, discriminatory, implying that the person is the illness, or implying that all people with mental illness are ‘the same’. We need neutral, simple language to usefully describe the illness and its effects to employers, family, doctors and even to the patients themselves. In addition the language of professionals often has underlying political connotations whilst pertaining to be merely descriptive. When reading becomes ‘bibliotherapy’ it establishes a superior and subordinate role around a common activity.⁴⁸

⁴⁷ ‘What is Mental Illness’, Department of Health.

⁴⁸ Edelman, M. ‘Political Language of the Helping Professions’ in *Political Language that Succeed Policies that Fail*

4. General principles about how to reduce discrimination

Some general principles for reducing discrimination have emerged through the comparison of the issues facing and strategies used by other anti-discrimination groups. These were tested in further discussion with the Commission, consumers and health professionals.

1. An enforceable and accessible legal framework.
2. Consumer involvement in development of ideas, and policy development.
3. Simple ways consumer groups can assert their rights, such as liaison officers, complaints procedures, interpreters etc.
4. Any special requirements should be defined, promulgated and adopted by relevant agencies to ensure the particular group is treated equitably in the community.
5. Positive discrimination may be necessary to ensure access to goods and services by both Government (policy and funding) and providers.
6. Political activism by the group (engaging influential personalities, media stories about unfairness, targeting MPs/Ministers both favourably and unfavourably, engagement with relevant government departments, link to international movements etc).
7. Increased visibility in society, positive experiences of consumers by all factions of society, overcoming shame.

Testing the principles against an existing model

As an anti-discrimination model developed, we thought it was very important to test the emerging concepts with informed people from an area where such strategies had been successful. The New Zealand AIDS Foundation was an obvious choice because it has conducted a very successful health promotion and anti-discrimination campaign over the last decade, adapted to New Zealand circumstances. The analogy should not be taken to imply that the two groups include the same people but there are some powerful similarities in the extremes of fear and ignorance behind public attitudes and because discrimination in both cases can inhibit health promotion.

A successful anti-discrimination strategy

The AIDS Foundation was established in March 1985 with the support of the Department of Health. The disease is most closely associated with gay men who are historically a stigmatised group enduring serious discrimination, including legal sanctions against homosexuality.

In order for the Foundation to achieve its objectives to 'keep positive people well', it was necessary to address the discrimination issues. The first hurdle was to achieve homosexual law

reform so that the target group was de-criminalised and could be reached with health promotion campaigns.

The discrimination issues the Foundation faces are similar to the issues surrounding discrimination against mental health consumers. In particular, the problems of low self esteem, arising from discrimination, are a fundamental health concern. As long as people do not wish to identify themselves as part of the group, due to fear of discrimination, it is very difficult to provide health services. This is one of the primary reasons for eliminating discrimination.

The change that has occurred in the last decade for gay men's status in society is inspirational for those who aim to effect similar change for mental health consumers. Moreover, New Zealand now has the longest sustained decline in AIDS cases in the western world.

The Ottawa Charter

To achieve their goals the Foundation adopted the health promotion principles of the Ottawa Charter. The Charter provides five health promotion action guidelines which can be applied to assist mental health consumers. It presents discrimination as a health promotion issue and provides a framework which could serve to empower mental health consumers.

Guideline headings

1. **Building healthy public policy:** The objectives of health promotion must be supported by a complementary legal and policy framework. For mental health consumers it may also mean a radical change in the way health professionals define their role and a close look at the 'medical model'.
2. **Creating supportive environments:** In order to provide a supportive social environment, public attitudes have to be addressed.
3. **Strengthening community action:** Promoting community action means allowing, encouraging and facilitating consumers to take the reins of their own health care and their place in the community.
4. **Developing personal life skills:** This is crucial to enable consumers to participate in society in the best way they choose.
5. **Re-orienting health services:** Initially we felt that the health services may be beyond the brief of this discrimination report, but the experience of the AIDS Foundation is that in order to combat discrimination it is necessary to look carefully at existing institutions. It is not possible to make changes in public attitudes if these are undermined by professionals.

5. Anti-discrimination objectives

A priority of the Mental Health Commission, as set by Government, is to reduce discrimination and prejudice against those with mental illness. The objectives contained in this section are proposed to assist the Commission in this task. They are drawn from the comparative study summarised in Sections 3 and 4.

The proposed objectives are based on two principal assumptions:

1. that we already have a legal and policy framework which upholds the rights of consumers and outlaws discrimination, albeit with room for improvement;
2. that provision of a framework alone is not sufficient to prevent discrimination. There are a variety of reasons for this failure but it is clear that there is a lack of commitment and knowledge about the legal rights of mental health consumers at all levels of government and in society generally.

A critical lesson from the comparative analysis is that those who suffer discrimination also have the passion and energy to devise effective strategies to reduce it. Anti-discrimination is an area where strong consumer leadership and participation are essential.

It is suggested that the following criteria should underpin the initial selection of initiatives. Clearly, initiatives aimed at reducing discrimination will have to be carried out across the broad spectrum of society and over a long time, will require a collaborative framework and a strategic overview. The following criteria should underpin the initial selection of initiatives:

- direct benefit for consumers and supported by consumers
- linkages with other Mental Health Commission projects
- minimal start-up time
- likely to fit with a strategic plan for reducing discrimination
- link with other government agency initiatives.

Proposed objectives

The objectives are categorised according to whether they relate to core business of the Commission or whether they are to be undertaken separately.

Core anti-discrimination work of the Mental Health Commission

1. Ensure that issues of discrimination are recognised in the core work of the Commission.
2. Encourage an ongoing working partnership between mental health consumers and the Mental Health Commission in preventing discrimination.
3. Encourage the elimination of gaps in service delivery which discriminate against some people who need mental health services
4. Address serious deficiencies in service delivery by promoting the adoption of positive discrimination for mental health services, by government
5. Establish and publicise best practice standards for early intervention by support services, caregivers and for self referral

6. Encourage the establishment of financial incentives to enable GPs/early intervention professionals to spend more time on diagnosis and to undertake more training for this function
7. Address the issue of the availability to all consumers of assistance to access services and goods in the community, or liaison on their behalf.
8. Address the issue of appropriate training for support persons and trust managers.

Anti-discrimination objectives to be progressed separately

Ensure that:

1. positive discrimination measures to ensure the voice of mental health consumers are adopted at all levels of government policy and service delivery
2. clear information is available about the existing legal rights of mental health consumers and that these rights are upheld
3. consumers can access legal advice in relation to discrimination issues
4. consumer groups can become more active in promoting their interests
5. the recommendations of the report by the Ministry of Maori Development, '*Trends in Maori Mental Health 1984-1993*' are progressed
6. goods and service providers are aware of the special needs of mental health consumers, and of their responsibility to put in place measures to meet these needs
7. the human dignity and civil rights of mental health consumers are recognised by mental health professionals, and reflected in treatment option and consumer choice
8. health promotion strategies for mental health consumers are developed and based on the principles of the Ottawa Charter
9. public knowledge and understanding of mental health and consumer issues is increased
10. useful and appropriate information is provided to the media to counter discriminatory publicity
11. non-discriminatory lay persons language is used in relation to mental illness.

ADAPT

An interim anti-discrimination action plan team (ADAPT) has been established to develop a strategic plan for the Commission based on this Discussion Paper. The team, consisting of a sector adviser, a consumer representative, and a legal adviser who work part-time, and a full time advisory officer, is also undertaking seven projects immediately.

- Media Watch
- Legal Rights of Mental Health Consumers
- Mental Health Sector Statistics
- Consumer Participation in Mental Health Services
- Discrimination Against Consumers by the Mental Health System
- Existing Anti-Discrimination Initiatives
- Stories of Recovery

Appendix I - List of Interviewees

Consumers

| | |
|---------------------|---|
| Vicki Burnett | Inside Out |
| Jim Crowe | Schizophrenic Fellowship |
| Maxine Gay | Advisory Board for Mental Health Commission |
| Anne Goslin | Editor of <i>New Moon</i> |
| Pauline Hinds | Advisory Board for Mental Health Commission |
| John Ferguson-Smith | Wellington Mental Health Consumers Union |
| Sue Tawhai | ANOPS |

Mental Health Professionals

| | |
|------------------|--|
| Erina | Psychotherapist |
| Dr Noel Fernando | Director of Area Mental Health Service, Tairāwhiti |
| Dr Van der Sluis | Director of Area Mental Health Service, Tokanui |
| Vivienne | Psychiatric Nurse |

Government Agencies

| | |
|-----------------------------|-----------------------------------|
| Sylvia Bell | Human Rights Commission |
| Annie Fraser | Health and Disability Commission |
| Janet | Human Rights Commission |
| Rowena Millow | Ministry of Health |
| Ron Patterson | Ministry of Health |
| Mike Sukolski | Central Regional Health Authority |
| Mental Health Commissioners | |

Other

| | |
|--------------|--------------------------|
| Tony Hughes | The NZ AIDS Foundation |
| Erin Kennedy | The Dominion, Wellington |

Appendix II - Stories of Discrimination

Family and custody issues

Legal representation which highlights a parent's mental illness has led to adverse decisions where custody has been lost for this parent. This has happened to both fathers and mothers despite the fact that often the illness has been a one off episode.

Children are often not allowed to visit their parents in residential care as the environment - shared by other people with mental illness - is not considered appropriate for children, despite the fact that it is the home of their parents.

A couple living in residential care whose children were in foster care found that if they broke any of the rules of the home they were staying in they would lose access to their children. If, for example, they went to the pub and had one drink, they were not allowed to visit their children that week. Control of access was used as a punishment system.

Housing

A mental health consumer signed up for rented accommodation on two occasions within 24 hours of the publishing of newspaper articles where she was photographed. Both these times she was subsequently told that 'we (the landlord/ agent) have made a mistake and the house had in fact already been let'.

On a third occasion this occurred after leaving a contact phone number of the community health agency. The agent asked if the person concerned was staff or patient. When told, 'patient', the agent said, 'sorry we made a mistake the flat was already let'.

Many residential care homes have strict rules, such as couples are not allowed to share a room. The kitchens are locked, sometimes even the bedrooms are locked during the day.

Within many residential care homes there are rules such as tenants not being able to have relationships, and couples not being allowed to share rooms. The kitchens are locked, sometimes even the bedrooms are locked during the day. In contrast, a house in Auckland 'Rangimarie' recently came under new management and unlocked all the doors etc. They found that there is no problem with thieving and that the consumers have responded very well to having responsibility for the kitchen and more.

Although theoretically consumers are meant to be able to choose their accommodation, in many cases there are minimal beds available and they have to stay in an environment run by a privately owned group who may be, for example, a religious group. As a result, consumers can be forced to conform to the beliefs of that particular environment when they would really prefer not to do so.

A consumer was admitted to an acute ward for the first time and while she was in hospital she lost her state house. When she came out of hospital she was told she will never again qualify for a state house.

A city council believe that a trust group will need resource consent in order to lease a house to psychiatric survivors.

There are very few if any suitable rural places for consumers to live. In some cases people who have to leave an institution after many years, have been used to a rural setting all their lives and it is a risk to their health if they are forced to move to a city.

Some consumers point out that many residential homes are based on a nuclear family type model but that many people (not just consumers but the members of the general population) would prefer to live in an extended family or hostel type situation.

Employment

A psychiatric survivor was employed as a community support worker. However, she found that the salary was set at \$10,000 less than other community workers who were no more qualified.

One person was offered a job and then had the offer retracted when an employee of the firm revealed to the employer that the person had spent a short time in a psychiatric ward. The employer said that dishonesty would not be tolerated and that an interview would not have been granted if disclosure had been made.

Consumer advocates employed by health services are often employed on a minimal wage, for example, \$60, so as not to effect their invalid benefits. They are often not given the same rights as 'other' or perhaps 'actual' employees. They feel that there is an element of tokenism in their contracts and that they are not taken seriously nor is their experience recognised as a valid qualification to speak on many mental health services.

Housing monitoring teams have at least one consumer representative, however these employees are only allowed to monitor consumers and nor give an overall evaluation of the service.

Many job application forms ask whether there is a history of mental illness.

Health Services

The mental health services often play 'ping pong' with people who are difficult to manage. The services 'pass people around', hoping that another service will pick them up. A mental health professional said that a 'difficult' person's file may be passed around a meeting until a decision is made, sometimes to leave the person with the crisis team. This usually results in consumers remaining unwell.

On many acute wards mental health consumers are not offered counselling, occupational therapy or speech and language therapy, which are services available on most other hospital wards and seemingly appropriate in a psychiatric ward.

Children with a psychiatric diagnosis are often put on an adult ward, despite the fact that for any other illness or injury they would be in the children's ward.

One consumer was left with a crisis team for two years, having crisis intervention twice a day. Nobody was willing to take this person on.

In most hospitals the psychiatric ward is the only ward that does not offer a choice of menu and individual trays. Also, the nurses on these wards can say who is, and who is not allowed to visit, in a more restrictive manner than is practiced on other wards.

While on an orthopaedic ward for a broken leg, a consumer was visited by her psychiatrist and a domiciliary nurse. A fellow patient complained to the medical superintendent that she objected being in a room with a psychiatric patient. The psychiatrist then asked what the consumer had done to upset this other patient. It was in fact the presence of the psychiatrist that scared the other patient.

Goods and services

A medical insurance company recently increased its cover for all medical specialties without imposing any restrictions. However 'psychiatry' was singled out as the only medical specialty in which restrictions were imposed to an unrealistic degree. Some companies do not allow psychiatric claims.

Some people have been refused life insurance on the grounds of a previous history of mental illness, in one case the history consisted of a one time episode of post-natal depression.

A consumer took a medical and life insurance policy out 10 years ago. Since then he has been treated with anti-depressants and has seen a psychiatrist on a number of occasions. When he attempted to have the policy upgraded he found he could not get the same cover and the new premiums were 'extremely high'.

Two mental health consumers (known to the hotel management) were asked to share a room when it was found that the hotel was over-booked. In contrast, businessmen in the same situation were offered wine and free taxis to other hotel accommodation in the city. When the consumers refused to share they were told that there was nothing more the hotel would do.

Some (up market) shops do not allow known consumers on their premises.

Individuals have been banned from large supermarkets after they 'lost' it while in the shop because the shop was so busy. This can mean they can not buy food at the cheaper prices available in large stores.

Many stores will not make hire purchase agreements with people who have psychiatric histories.

Unfortunately one store which does make hire purchase agreements has used them to exploit mental health consumers. An electrical goods store has a policy which provides easy access to hire purchase agreements for 'psych' people. This results in the eventual repossession of the items which they then resell through their second hand department. The business signs up excessive dollar deals which are impossible to meet off a benefit and consumers are easy target victims

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