# Let THE SUNSHINE IN

Planning and evaluating work to counter stigma and discrimination against people with mental illness or distress.

#### From a presentation by Mary O'Hagan, Mental; Health Commissioner.

his metaphor seeks to provide an understandable and userfriendly framework for planning and evaluating antidiscrimination work, largely based on the work of Liz Sayce from England and Hamish McKenzie from New Zealand.

The sun represents the ideal of equality rights and respect. The clouds and rain represent the problems of stigma and discrimination. The rainbow and the neighbourhoods, avenues and vehicles in the city represent the solutions to stigma and discrimination; they stand for the most important issues that need to be taken into consideration when planning, evaluating and generally thinking about anti-discrimination work.

#### Looking up to the sky

Imagine you are flying directly above a small city in changeable weather with clouds, rain, a peep of sun and a rainbow. This whole scene is a metaphor for stigma and discrimination and our work to reduce stigma and discrimination against people who experience mental illness or distress. Now, look at what is happening in the sky.

### The Ideal

#### The sun - equality, rights and respect

The sun represents equality, rights and respect for people with mental illness or distress – it is the absence of stigma and discrimination. As the sun's light crosses the sky and shines on the city, it ensures that people with mental illness are free from stigma and discrimination.

### **The Problems**

### Clouds and rain -the stages of stigma and discrimination

The clouds and the rain are stigma and discrimination. Just as there are degrees of bad weather there are degrees or stages of stigma and discrimination:

**Partly cloudy – the perception of difference.** This weather means that there is a perception that people with mental illness or distress are different from other people in a value-neutral way, this is sometimes called labelling or stereotyping.

**Totally cloudy – the judgement that diffe rence is negative.** This weather is the judgement that the differences associated with people with mental illness or distress is negative; this is sometimes called stigma.

**Intermittent showers – the justification for excluding people.** This means that people believe they have justification for excluding or separating people with mental distress; the user/survivor movement has sometimes referred to this as 'mentalism'.

**Constant rain – the act of excluding people.** This means an act or a failure to act has led to the exclusion or loss of status of people with mental illness or distress; this is often called discrimination.

Work to reduce stigma and discrimination can address any or all of these stages or degrees of stigma and discrimination at the individual, group and systemic levels. Understanding the degree or stage of stigma or discrimination you are tacking, should enable you to develop better targeted solutions.



### **The Solution**

### The rainbow – why we are doing anti-discrimination work?

When the sun comes out again at the end of the bad weather it strikes the droplets of rain still in the sky. The sun's white light of equality, rights and respect splits and refracts into a rainbow of seven colours. These colours represent the different philosophies or assumptions about the nature, aspirations or social context of people with mental distress that underlie efforts to reduce stigma and discrimination.

**Red** – **Medical model.** The red light represents the medical model view that people with mental illness should not be stigmatised or discriminated against because they are blameless victims of their own psychopathology. Many anti-discrimination campaigns have used this assumption to justify their work, such as the NAMI campaign in the USA and the SANE campaign in Australia. The major outcome they seek is to reduce the stigma that acts as a barrier to people seeking help from mental health services. However, the medical model rationale may inadvertently increase stigma and discrimination because it views the experience of mental illness as having no value and people with mental illness as having lost their competence.

**Orange** – **Common humanity.** The orange part of the rainbow represents the common humanity view that people with mental illness are not all that different from others because we all share a common humanity; this includes our experiences of distress and mental health problems, which differ only in degree. An example of this approach is the Like Minds, Like Mine television adverts which feature famous and successful people with mental illness and end with the slogan that one in five people experience mental illness at some time in their lives. The common humanity view has been criticised because in its attempt to minimise the difference between people with mental illness and others, it may inadvertently increase stigma and discrimination against people who are most severely affected by their mental illness or distress who are often perceived as being the most different.

Yellow – Human rights. The yellow part of the rainbow is the human rights view that all citizens have the same civil, political, social, economic and cultural rights. These rights are universal. Included in this are people's rights to autonomy or self-determination, which are often denied to people with mental distress. People with mental illness should be treated as autonomous human beings – even if they make mistakes or decisions that no-one else agrees with. Lobbying to give people with mental illness the vote or the right to live where they choose as well as campaigns to end forced treatment are based on this assumption.

**Green** – **Disability inclusion.** The green part of the rainbow represents the social model of disability that asserts it is society that disables people, not the impairment carried by the individual. Disabled people may be different because of their impairment but their right to be included is equal to non-disabled people. Therefore society has a responsibility to remove any barriers experienced by disabled people to participate and be included. An example of this approach is the New Zealand Disability Strategy.

**Blue** – Journey of recovery. The blue part of the rainbow is the recovery process of individuals with mental distress. People with mental illness have the capacity to recover and live well and they should not be prevented from doing so by people and systems that have no hope or



belief in them. The individual recovery approach needs to be supported by some of the more society-oriented or collective assumptions such as human rights and disability inclusion. An example of work using this approach is 'Kia Mauri Tau' – a research report on 40 peoples' experiences of recovery.

Indigo – Whanaungatanga. The violet part of the rainbow is whanaungatanga or collectivism. Whanaungatanga is a Maori term meaning 'relationship' or 'kinship'. Stigma and discrimination don't just hurt the individual – they hurt the whole group because the individual is subsumed in the group they belong to; the 'I' is 'we'. This is often an important assumption for people from non-western cultures. An example of work promoting whanungatanga would be to reduce discrimination among Maori and extended families so that Maori with mental illness who have lost their roots can become a part of them.

**Violet** – other assumptions or philosophies. There is a seventh colour to the rainbow – violet. This leaves a space for assumptions and philosophies that haven't been thought of yet.

The colours of the rainbow tend to blend into each other and efforts to counter stigma and discrimination often draw on more than one of these assumptions or philosophies. Some fit well together while others can clash. The assumptions or philosophies you choose will probably be determined by your own world view, but you could make the choice to appeal to your audience, such as using the medical model approach with psychiatrists.

The rainbow helps us define WHY we are doing anti-discrimination work.

#### Looking down to the city

Imagine you are still flying and that you start to look down at the city instead of up to the sky. The city represents society. It cannot function well for all its disabled, distressed and disadvantaged citizens without direct sunlight. The city is circular and is made up of neighbourhoods, avenues, and vehicles. These all converge at the city centre, making it the hub of equality rights and respect – the place where people with mental illness want to be able to get to.

## The neighbourhoods in the city – what we need to change in the lives of people who are discriminated against

The city is divided up into nine neighbourhoods, like the segments



of a cake. These neighbourhoods represent the aspects of people's lives that may be adversely affected by stigma and discrimination.

The neighbourhood of education includes education at all stages of life and all stages of advancement.

The neighbourhood of work includes paid work, voluntary work and domestic work in one's own household

**The neighbourhood of money** includes the money a person earns or receives and the opportunities they have to spend, save or invest their money and to take out loans or insurance.

**The neighbourhood of housing** includes the physical state and location of housing as well as the opportunities to choose independent housing, home ownership and who if anyone a person lives with.

**The neighbourhood of health** includes both physical and mental health and the opportunities people have to maintain and restore their health.

The neighbourhood of liberty includes personal freedom, autonomy

and the rights of people to freedom of thought, freedom of speech and to refuse treatment.

**The neighbourhood of safety** includes the right to be protected from avoidable danger and from all forms of abuse and neglect.

The neighbourhood of citizen participation includes the opportunities to take part in politics, legal processes, the culture of one's choice, the services people use, arts, recreation, sport, philanthropy and religion.

**The neighbourhood of family life** includes the rights and opportunity for people to have partners, to bear children and care for them, and to define who their family is.

The neighbourhoods help us define WHAT we need to change in the lives of people adversely affected by stigma and discrimination.

### The avenues into the city – what we need to change in the people and systems that discriminate

Leading from the edge to the centre of the city are three major avenues.

The avenue of hearts and minds concerns the internal thoughts and feelings experienced by individuals who perpetrate stigma or discrimination. Examples of work directed at hearts and minds are the stories of people's own mental illness or a play that gives positive messages about people with mental illness or the Like Minds, Like Mine television adverts.



The avenue of words and deeds concerns the outward language and other behaviour of individuals or groups who perpetrate stigma or discrimination. Work directed at changing words and deeds could be a campaign to discourage the use of degrading language, antidiscrimination training for employers, or a manager's insistence that mental health workers must involve service users as equals in their recovery planning.

**The avenue of rules and regulations** concerns the policies, regulations and legislation created by the groups or systems that discriminate. Work directed at changing rules and regulations might include a project to identify and change discriminatory policies in government departments or streamlining vocational services funding so that people with mental illness have better access to these services. It could also be anti-discrimination law, an Act that empowers people to see their clinical files or a law that gives boarders the same rights as tenants.

The avenues help us define WHAT we need to change in the people, groups and systems that perpetrate stigma and discrimination.

### The vehicles on the avenues – how we need to bring about change

A number of solar powered vehicles are driven, or at least navigated, by people with mental illness or distress on the avenues that lead to the centre of the city. These vehicles indicate the different methods or ways of doing anti-discrimination work.

**The vehicle of advocacy** – such as 'no force' demonstration or a coalition to fight discriminatory housing by-laws.



**The vehicle of education** – such as awareness-raising workshops in schools or producing a kit for employers on the types of work

conditions people with mental illness might need.

**The vehicle of legal reform** – such as the legal banning of ECT or the introduction of anti-discrimination law.

**The vehicle of policy development** – such as deinstitutionalisation policy, or a government-funded project to reduce discriminatory policy in government agencies, or a government standard that mental health services must work to reduce discrimination.

**The vehicle of service development** – such as an affirmative action protocol to encourage people with mental illness to work in mental health services, a checklist for social services staff to identify their own stigma and discrimination against clients with mental illness, or entering a partnership with service users for the planning and evaluation of services.

**The vehicle of community development** – such as working with a neighbourhood to reduce their fears and enable them to accept people with mental illness living on their street or supporting a group of service users to develop an advocacy organisation.

**The vehicle of arts and media** – such as the Like Minds Like Mine television adverts, or a Mad Pride concert put on by people with experience of mental distress.

**The vehicle of research** such as a survey of the discrimination experiences faced by people with mental illness, or an evaluation of a mental health services standard for reducing discrimination, or a participatory action research project involving people with mental illness to explore discrimination and ways of reducing it.

The vehicles on the avenues help us define HOW we need to bring about change.

### Some suggestions for applying the metaphor to your work

The categories within the bad weather, rainbow, neighbourhoods, avenues and vehicles should be viewed as malleable. For instance, some people may prefer to separate arts from media and create another vehicle or they may wish to add a totally new vehicle, such as 'local government by-law reform'.

A lot of anti-discrimination work is based on more than one of the categories. For instance the Like Minds, Like Mine television adverts are based primarily on the common humanity assumption in the rainbow. But there are also some aspects of the medical model and journey of recovery reflected in parts of the adverts. They are not specifically targeted to any of the neighbourhoods. The adverts seek to change hearts and minds, but they could change some words and deeds as well. They fit into the arts and media vehicle but they also fulfil an education function.

This framework can be used for individual projects or for systemic overviews of anti-

discrimination work. Its main benefits for individual projects will be to give them some internal consistency and clarity. In systemic overviews of anti-discrimination work the framework will help to identify duplications, gaps and inconsistencies between different projects and activities.

This is a work in progress. The Mental Health Commission is developing a template out of this metaphor for people to plan and evaluate anti-discrimination efforts.

### **SUBMISSIONS on Like Minds National Plan** Support Stronger Human Rights Focus

Almost forty individuals and groups have made submissions to the Ministry of Health giving their views on the draft National Plan 2003-5 for the Like Minds project.

It's great to have received comment on all aspects of the project, with many in support of its stronger human rights and anti-

discrimination focus,' says Gerard Vaughan, national project manager for the Like Minds project.

'I'm especially pleased by the number of individuals who took the time to read the plan, and send in their comments,"' he said. 'Their comments represent the very grass roots of the project, and indicate that the project's future direction matters deeply.'

Gerard says there have been some excellent submissions from community organisations also. 'CCS have a strong understanding of the connections between discrimination and the way society disables people, and it has been valuable to get such a thoughtful submission from them.'

'People obviously have a very wide range of beliefs about what the project is really about,' says Helen Gilbert, a senior policy advisor who is analysing the submissions. 'Some people are very clear that Like Minds should be about challenging discrimination, and using the techniques that have proven to be effective in doing that. Other people have the idea that the main purpose of the project is to improve the mental health of specific populations. But that is the responsibility of a wider range of organisations, and not directly in line with the project's purpose.'

Support for growing the leadership of people with experience of mental



illness has been very strong, according to Helen. 'One group made the point that that support needs to be for our consumer-run organisations, so that we can build our community and organisational capability, rather than just for individual consumers.'

Some aspects of the new plan got the thumbsup from some people and the opposite response from others, so that needs to be taken into account too, says Helen. She also noted that only two of the country's thirty-four DHBs made submissions, 'which suggests that, despite years of work, Like Minds is way below their radar'.

When the submissions have been analysed and summarised, the draft plan will be modified, and made final.

A summary of the submissions will be available on the Like Minds website at www.likeminds.govt.nz.