The Project to Counter Stigma and Discrimination associated with Mental Illness

NATIONAL PLAN

May 1999

Mā te ora o te tangata kotahi ka ora ai te whānau.

Towards creating a nation that values and includes people with mental illness

Prepared by
Health Funding Authority
The Health Funding Authority would like to thank Janet Peters, the members of the Consumer Advisory Group, the Project Advisory Group and the Stakeholder Group for all their efforts in helping to develop this National Plan.
Table of Contents

<table>
<thead>
<tr>
<th>Section</th>
<th>Page Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.0 Executive Summary</td>
<td>5</td>
</tr>
<tr>
<td>2.0 Introduction</td>
<td>7</td>
</tr>
<tr>
<td>3.0 Vision and Objectives</td>
<td>8</td>
</tr>
<tr>
<td>3.1 The Vision</td>
<td>8</td>
</tr>
<tr>
<td>3.2 The Aims and Objectives</td>
<td>8</td>
</tr>
<tr>
<td>3.3 The Guiding Principles</td>
<td>8</td>
</tr>
<tr>
<td>4.0 Background</td>
<td>9</td>
</tr>
<tr>
<td>4.1 The Problem</td>
<td>9</td>
</tr>
<tr>
<td>4.2 Addressing Stigma and Discrimination - A History from 1996</td>
<td>10</td>
</tr>
<tr>
<td>5.0 Project Structure and Linkages</td>
<td>12</td>
</tr>
<tr>
<td>5.1 Project Structure</td>
<td>12</td>
</tr>
<tr>
<td>5.2 Māori Mental Health</td>
<td>12</td>
</tr>
<tr>
<td>5.3 Consumer/Tangata Whaiora Involvement</td>
<td>13</td>
</tr>
<tr>
<td>5.4 Linkages</td>
<td>14</td>
</tr>
<tr>
<td>Figure 1: Current Project Structure</td>
<td>16</td>
</tr>
<tr>
<td>6.0 The Funding Strategy</td>
<td>17</td>
</tr>
<tr>
<td>6.1 A National Framework</td>
<td>17</td>
</tr>
<tr>
<td>6.2 The key audiences</td>
<td>18</td>
</tr>
<tr>
<td>6.3 Where are we now?</td>
<td>18</td>
</tr>
<tr>
<td>Figure 2: The Project Funding Strategy - A Diagram</td>
<td>19</td>
</tr>
<tr>
<td>Table 1: Financial Projections</td>
<td>20</td>
</tr>
<tr>
<td>7.0 Achievements to Date</td>
<td>22</td>
</tr>
<tr>
<td>7.1 Achievements on a national level</td>
<td>22</td>
</tr>
<tr>
<td>7.2 Achievements on a local level</td>
<td>23</td>
</tr>
<tr>
<td>7.3 Contracts in place locally</td>
<td>24</td>
</tr>
<tr>
<td>8.0 Strategic Objectives and National Workplan 1998/99 - 2000/01</td>
<td>28</td>
</tr>
<tr>
<td>8.1 Strategic Objective: To continue to fund “Project and Sector Development” services</td>
<td>28</td>
</tr>
<tr>
<td>8.2 Strategic Objective: To change attitudes and behaviour in the broader field</td>
<td>29</td>
</tr>
<tr>
<td>8.3 Strategic Objective: To change public attitudes and behaviour through mass media, public relations and health promotion</td>
<td>29</td>
</tr>
<tr>
<td>8.4 Evaluation</td>
<td>30</td>
</tr>
</tbody>
</table>

The Project to Counter Stigma and Discrimination Associated with Mental Illness
National Plan
May 1999
9.0 Strategic Objectives and Local Workplans 1998/99 - 2000/01

9.1 Strategic Objectives: To develop infrastructure and networks to empower consumers/tangata whaioa and increase consumer/tangata whaioa involvement

9.2 Strategic Objective: To change attitudes and behaviour in the mental health sector

9.3 Strategic Objective: To change and behaviour in the broader field

9.4 Strategic Objective: To change public attitudes and behaviour through mass media, public relations and health promotion

9.5 Evaluation

10.0 Working towards the vision: What will success look like in the long-term?

10.1 For consumers/tangata whaioa

10.2 For those involved in the Project

10.3 For target groups

10.4 For the general public

10.5 For the media

10.6 The main achievements

11.0 The Risks

11.1 Managing different expectations

11.2 Media reporting of isolated events

11.3 Creating more demand on services

11.4 Gaining stakeholder input on messages effective for attitudinal changes in the wider public

Appendices

Appendix 1: The Environment

Appendix 2: Research Evidence: New Zealand and Overseas

Appendix 3: “Anti-Discrimination and Destigmatisation” - An excerpt from the Health Funding Authority National Mental Health Funding Plan 1998-2002

Appendix 4: Findings of Business Research Centre research

Appendix 5: “Destigmatisation Project: Community Attitudes Towards People with Mental Illness Stage 1 - Pre-Research with Māori”

Appendix 6: “Community Attitudes Towards People with Mental Illness: An Interpretation of Māori Results of the Benchmark”

References and Extra Reading
1.0 Executive Summary

In 1996, the Inquiry under Section 47 of the Health and Disability Services Act 1993 in Respect of certain Mental Health Services, known as the Mason Report, reviewed mental health services in New Zealand.

It identified negative public attitudes towards those with experience of mental illness as a barrier to developing good mental health services and accessing services at an early stage.

The Report recommended that funding be allocated to a national public awareness campaign to reduce the stigma associated with mental illness.

The following document represents the Health Funding Authority’s national response to recommendation for a public awareness campaign. It is the National Plan for the “Project to Counter Stigma and Discrimination Associated with Mental Illness”.

The National Plan presents the vision and objectives for the Project, a strategic framework for the Project, local activities and a workplan for national and local activities.

The funding strategy of the Project has two components – firstly, developing programmes and networks at a community level for the mental health sector; and secondly, supporting these community initiatives with a national programme of policy development, media and public relations activities.

Services will be funded on both a national and a local basis – two-thirds locally; one-third nationally. Local programmes will be funded that reflect the national framework; services will be funded nationally only when they support and add value to those services in the localities.

The first component, “Project and Sector Development”, lays essential groundwork by establishing the infrastructure, the networks, and a common sense of purpose amongst a diverse range of groups and organisations. There are three key strategic objectives:

- to develop infrastructure and networks;
- to empower consumers/tangata whaiora and to encourage consumer/tangata whaiora involvement; and

1 Referred to in this document as “The Project”.

The Project to Counter Stigma and Discrimination Associated with Mental Illness
National Plan
May 1999
to change attitudes and behaviour in the mental health sector.

With a more supportive environment in the mental health sector and at the community level, a second component brings the messages to a wider audience. The “Public Awareness” component builds on the work developed in the community, but uses the public health tools of health promotion and education through mass media. There are three key strategic objectives in the “Public Awareness” component:

- to continue to fund “Project and Sector Development” services at a local level;
- to change attitudes and behaviour in the broader field, i.e., government agencies, through policy development with the agencies involved; and
- to change public attitudes and behaviour through mass media, public relations and health promotion.

We are currently in the third year of the project which runs to 2001.

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2 “Consumer/tangata whaiaora” refers to those people who have experience of serious mental illness and have used mental health services.

3 Tangata whaiaora refers to persons in pursuit of wellbeing/wellness. In the context of this document, this term is used to acknowledge Māori who utilise mental health services.

4 The Health Funding Authority regards consumer involvement in the Project as pivotal. A structure to ensure ongoing consumer involvement is in place. However, a longer term solution to involving consumers at all levels of planning for and delivering mental health services will be consulted on over the coming months. See page 12.

5 See Page 22 for “Achievements to Date”.

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2.0 Introduction

The Project to Counter Stigma & Discrimination ("the Project") associated with Mental Illness is a five-year project to reduce the stigma of mental illness and the discrimination encountered by people with experience of mental illness. The Project was initiated under the Ministry of Health in 1996, with local programmes managed by the then four Regional Health Authorities. It was then transferred to the Health Funding Authority in 1998.

This document outlines the rationale for the Project, how the Health Funding Authority has structured the project after transferral from the Ministry, and the strategic direction that the Health Funding Authority is taking. The Project ends in 2001.
3.0 Vision and Objectives
The Project is based on the following vision, objectives and principles, which guide the work of the Project.

3.1 The Vision
The vision for the Project is:

*Working towards creating a nation that values and includes people with mental illness.*

3.2 The Aims and Objectives
To reduce the stigma associated with mental illness and reduce discrimination experienced by people with mental illness by:

- empowering individual consumers/tangata whaiora to gain equality, respect and rights;
- putting mental health on people’s personal agendas;
- educating people about what mental illness is;
- promoting greater understanding of, acceptance of and support for people with mental illness;
- changing public and private sector policy to reflect the above; and
- communicating the above effectively with all key groups in New Zealand, including consumers/tangata whaiora, statutory agencies, GPs, health agencies, other governmental agencies such as Housing New Zealand, and people with other disabilities.

3.3 The Guiding Principles
The work of the Project will be guided by the following nine principles:

1. Acknowledge and build on the good work already done by individuals and groups in this area.
2. Ensure the Project activities are driven by the focus of reducing stigma and discrimination for consumers/tangata whaiora who suffer from serious mental illness and where possible that consumers/tangata whaiora will be employed and remunerated for their skill and contribution.
3. Ensure Māori perception and experience of stigma and discrimination are acknowledged and valued throughout the Project. This requires Māori participation at all levels in accordance with the Treaty of Waitangi (see page 12, 5.2, Māori Mental Health).
4. Ensure Pacific Islands peoples’ perceptions and experience of stigma and discrimination are acknowledged, included and valued throughout the Project.
5. Ensure that people who are actively working within the Project model the attitudes and behaviours that we wish to encourage in others. In other words, that we practice what we preach in valuing others.
6. Ensure families/whānau are involved and their contribution is valued.
7. Work with the Mental Health Commission to fulfil the Statement of Intent (see page 15).
8. Ensure that local programmes are consistent with the National Plan.
9. Ensure that national activities support and enhance local activities.
4.0 Background

4.1 The Problem

In New Zealand, figures show that:

- 1 in 3 people will experience a mental illness in their lifetime
- 1 in 5 people will experience a mental illness in any one year
- 3% of the population will experience serious and ongoing mental illness

*Note: These figures relate to rates of mental illness in European New Zealanders. Most epidemiological studies in New Zealand do not have sufficient numbers of Māori or Pacific Island people in the samples to tell us whether Māori and Pacific Island peoples experience the same levels of mental illness.*

The Mason Report of 1996 identified that mental health services are rendered less effective if they are delivered in a hostile environment.

*It is painfully apparent that even if treatments are successful, gains will be minimal if the person lives in a hostile and uninformed community. Therefore, efforts to reduce stigma and discrimination must be given the priority that other treatment modalities demand.*

The issue of stigma associated with mental illness and discrimination against those who have a mental illness has implications for the person who has the illness, their family/whānau, mental health services, all other services that work with people who have a mental illness and the community in general. For the 3% of the population experiencing serious, ongoing mental illness, this stigma and discrimination is most acute. Public perceptions, often shaped by reports in the media, are that people with mental illness are more violent, dangerous, and/or unpredictable. The media is found to have a substantial impact on the community’s opinions of people with mental illness.

*There needs to be a specific community education and media education programme. Mental Health stories sell papers (because of) the way the media currently handle the topic. They also intensify the stigma and hinder the development of good services. There needs to be a deliberate strategy to address this and to ensure that the general public will not prevent a person obtaining accommodation or a job because they have a psychiatric disability. A greater willingness to seek help early in the onset of an illness is important and is not helped by current media reporting.*

There are also other groups, particularly Māori and Pacific Island peoples who experience discrimination based on their ethnicity as well as mental illness. Addressing discrimination

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6 See Appendix 1 for a fuller report on the environment which has lead to The Project to Counter Stigma and Discrimination Associated with Mental Illness.


against those with mental illness must be accompanied by strategies to deal with the added effects of racially based discrimination.10

4.2 Addressing Stigma and Discrimination - a History from 1996

In 1996 the Mason Report reviewed mental health services in New Zealand. As a result of this report, $10.4 million (GST exclusive) was allocated for a five year project to reduce the stigma of mental illness and the discrimination experienced by people with mental illness, with particular emphasis on the 3% of the population who will experience serious and ongoing mental illness. The project is known as “The Project to Counter Stigma and Discrimination Associated with Mental Illness” (the Project). The funds were allocated over a five-year period from 1 July 1996.

We support a public awareness campaign - it is a must. It is fundamentally wrong that a vulnerable group in our society should be continually subjected to the comments and actions of those who possess an outcast mentality. ... We are optimistic enough to believe that a well-informed New Zealand public will then realise that [people with a mental illness] are people whom we should nurture and value.11

July 1996 - August 1997

Initially, the funds were allocated to the Public Health section of the Ministry of Health to develop a public awareness campaign and to the four Regional Health Authorities to develop local programmes.

The Ministry of Health developed the initial strategy for a national public campaign. The main tools were mass media and public relations. Local programmes were developed separately.

Three main national contracts were let for advertising (Colenso), public relations (Huia Communications) and market research (Business Research Centre).

After seeking advice, the Minister of Health took the decision in March 1997 to delay the advertising campaign and concentrate on health sector developments. Subsequent activities focused on local community-based programmes.

August 1997 - December 1998

In August 1997, the Government transferred the management of the Project to the then four Regional Health Authorities, with responsibility lying jointly with Mental Health and Public Health. Funding transferred in May 1998.

In January 1998, the four Regional Health Authorities were combined to create one national funder of health and disability support services - the Health Funding Authority. The Health Funding Authority recognised that the key challenge was to first unite the health sector. It needed to establish a structure that ensured a strong national and local foundation for the

10 There is research evidence to show that Māori are twice as likely to be secluded within health services as non-Māori (Edmonds et al 1998). Whilst the reasons behind this are not yet known, it is possible that some form of ‘stigma’ against those who are Māori may contribute to this.

Project and, most importantly, to work to ensure that consumers/tangata whaiora were an integral part of all these processes.

In 1998 The Health Funding Authority organised a national hui of stakeholders, including consumers/tangata whaiora, providers and people from Public Health and Mental Health to discuss stigma and discrimination. As a result of the hui, a national vision for the project was established (see Page 23).

It is important to note that local programmes, initially the responsibility of four separate Regional Health Authorities, were developed independently. Thus the approach locally is slightly different across the country and each region is at different stages of development.

The Project is now managed jointly by the Public Health and Mental Health sections of the Health Funding Authority (HFA).

With additional funding from the Public Health Operating Group the total budget for the Project is now $12.64 million (GST excl). Of this $1.2 million (GST excl) awaits budget confirmation.

The Project is currently in the third year of the five-year project.
5.0 Project Structure and Linkages

5.1 Project Structure
The Project is jointly managed by the Public Health and Mental Health Operating Groups of the Health Funding Authority (see figure 1, page 16) by the Senior Locality Managers. Both are based on the South Island. A Project Manager reports through the above.

Four HFA Public Health Portfolio Managers based in the offices below manage the local funding of services:

- HFA Auckland office which covers Auckland & Northland
- HFA Hamilton office which covers Waikato, Bay of Plenty and Taranaki
- HFA Wellington office which covers Wellington/Wairarapa, Manawatu/Wanganui, Tairawhiti/Hawkes Bay
- HFA Dunedin office which covers the South Island

The Project is consistent with the Māori Health Strategy (see below).

Consumer/tangata whaiora have a pivotal role to play in the Project, providing considerable insight and expertise into discrimination from a personal perspective. A Consumer Advisory Group has provided ongoing advice to the Project and will continue on an interim basis until a more broad-based consumer network is established (see below, “Consumer/Tangata Whaiora Involvement”).

A National Stakeholder Group and a National Project Advisory Group have ensured that consumer/tangata whaiora, family/whānau, Māori and Pacific Island perspectives are considered and addressed.

A national public relations company, Huia Communications, has been a consistent thread throughout the life of the Project, providing coordination and public relations support.

5.2 Māori Mental Health
The Project is to be based on Treaty relationships at all stages of development, implementation and evaluation. The HFA has approved a Māori Health Strategy and a set of Māori health gain priorities. These have become the framework that is used by the Public Health Group in addressing the principles of partnership with the Māori Health Operating Group and the Mental Health Operating Group who co-fund this Project. It should also be noted that in Auckland office, an additional feature of the Treaty relationship includes the MAPO, the co-funders for Māori health within Auckland and Northland.

Accordingly, the Project has been developed with Māori input at the regional and national levels. This has included both internal and external participation. A key feature of the external participation has been the involvement of Māori consumers. This approach has ensured that Māori community needs and views have been considered, and incorporated within resource availability during the planning, design and implementation stage. This Project recognises and acknowledges the different requirements to meet Māori needs within the context of their social reality.
Most of the Project funding has now been allocated to community-based initiatives. The HFA has dedicated funding to Māori for Māori initiatives as well as mainstream initiatives.

The media campaign provides another example where the HFA plans to address Māori needs as well as the general public over the next three years. Therefore, the media campaign evaluation will need to assess the cultural appropriateness and the effectiveness of the campaign for Māori.

Ko Tāu Raurau
Ko Tāku Raurau
Ka Ora Te Iwi

5.3 Consumer/Tangata Whaiora Involvement
Consumer involvement has evolved during the life of the project, particularly since the hui in Rotorua in 1998.

Consumer involvement now takes place at a variety of levels and there are several roles for consumers/tangata whaiora. These include consumers as beneficiaries of the Project (monitoring and feedback); consumers as advisors, and consumers as recipients of the Project in the sense that some consumers/tangata whaiora will receive training to be providers of projects and training to deal with discrimination and stigma themselves. All these levels of involvement occur throughout local and national aspects of the Project. This has been deliberate at the request of consumers.

Although consumers of mental health services are the ultimate beneficiaries of a successful project that reduces discrimination, the target group of the Project is the general public.

Research has suggested that one of the most effective ways to raise awareness and reduce discriminatory views is for the general public to get to know a person who has or has had a mental illness (Business Research Centre: Public Knowledge of and Attitudes to Mental Health and Mental Illness – December 1997). In addition, of course, consumers/tangata whaiora bring a unique perspective to the development of any project such as this one.

To help achieve consumer/tangata whaiora advice and feedback, the Project has endorsed the resourcing and development of consumer/tangata whaiora networking at both the local and national levels. In particular, a Consumer Advisory Group has been established at a national level. This is still developing, however, and needs to increase the input from both Māori and Pacific Island consumer networking.

This input from both local and national levels has proved invaluable to the project.

Alongside this, discussions have been taking place within the Mental Health Operating Group about how best to gain broad based consumer input and involvement for all mental health services - not just for the Project. The Operating Group is committed to getting such input, involvement and advice about all aspects of planning and delivery of mental health services in New Zealand.
In its National Mental Health Funding Plan 1998-2002, the HFA stated that mental health services would be improved by incorporating consumer advice into decision making for mental health services at different levels.

These are:
- at the individual level, by having input into the treatment and services that consumers use as individuals;
- at the organisational level, by having input into provider agencies and funding organisations;
- at the policy level, by contributing to the development of policy within funding agencies; and
- in the auditing and monitoring of services.

The Mental Health Operating Group proposes that it will achieve this by:
- having contracts with providers that specify they must be responsive to the needs of consumers;
- purchasing specific consumer advisor positions, in particular within the Hospital and Health Services;
- establishing a national structure to ensure ongoing consumer input to the HFA at both the organisational and policy level – this would have local, regional (where appropriate) and national components; and
- establishing auditing and monitoring activities as part of its Quality Improvement Strategy.

At each level specific discussion needs to take place about how best to achieve this for Māori and Pacific Island peoples.

There are processes in place to achieve some of this, however the key gap is the national structure. The intention would be to develop local and regional structures first, which will be consulted upon with consumers. Once these were well established we would discuss with consumers/tangata whaiora what kind of national structure would be best and how they would like it developed.

At that stage, any agreement over a national network for Mental Health may affect the existing Consumer Advisory Group to the project. However, this will be fully discussed with the Consumer Advisory Group before any decisions are made.

Establishing local and regional structures is likely to take some time and in the meantime no changes are proposed to the existing consumer/tangata whaiora processes for the Project.

5.4 Linkages
The success of the Project will partly depend on effective linkages with other agencies and groups who have a role in mental health.

National and Local Programmes
Activities take place at both a national and local level. A national project manager ensures that local programmes are coordinated with national activities.

The Ministry of Health
In its national mental health plan of 1997, *Moving Forward*, the Ministry of Health stated as one of its objectives:

*To increase public knowledge and awareness of mental health issues in order to: create a more supportive environment for people living with a mental illness; and help remove the barrier of discrimination and stigma that stops people seeking early assistance and help.*

The Ministry of Health has a role to monitor the Project.

**The Mental Health Commission**

As a result of the Mason Report, both the Mental Health Commission and the Health Funding Authority have responsibility to work towards reducing discrimination associated with mental illness.

Both parties signed a “Statement of Intent” in September 1998. The agreement describes how the organisations will work collaboratively to maximise the benefits for mental health service users. In particular, the HFA and the Commission work together to advocate for changes to discriminatory policies of statutory and other agencies.

The Mental Health Commission also has a role to monitor the Project.

**Other national agencies**

Several national agencies, including the Schizophrenia Fellowship, the Australian & NZ College of Psychiatrists, the Mental Health Advocacy Coalition and the Mental Health Foundation have pledged support for and assistance to the Project. Ongoing communication and collaboration is essential to ensure consistent messages and efforts.

**Consumers/tangata whaiora**

Consumer representatives have been incorporated into the overall structure of the Project to ensure and facilitate ongoing advice. The Consumer Advisory Group provides ongoing advice to the Project Coordinator; there is a consumer representative on the Project Advisory Group; and four consumer representatives on the larger national Stakeholder Group.

Each locality must demonstrate the involvement of consumers/tangata whaiora in their programmes.

**Māori**

In accordance with the Crown’s Treaty of Waitangi obligations, Māori participation is included at all levels of the project.

Nationally, there is Māori representation on the Project Advisory Group and the national Stakeholder Group. There is also Māori representation on the Consumer Advisory Group.

Each locality must also demonstrate the involvement of Māori in their programmes.

**Pacific Island Peoples**

The Project involves Pacific Island peoples at all levels. Nationally, there is a Pacific Island Peoples’ representation on the Project Advisory Group and the national Stakeholder Group. There is also Pacific Island representation on the Consumer Advisory Group.

Each locality must also demonstrate how Pacific Island perspectives and issues are considered and addressed.
6.0 The Funding Strategy

6.1 A National Framework

The funding strategy of the Project consists of two components – firstly, developing a project infrastructure and programmes for the mental health sector at a community level; and secondly, supporting these community initiatives with a national programme of policy development, media and public relations activities (see figure 2, page 19). This reflects the recommendations in literature on programmes that have sought to change public attitudes, in particular a campaign conducted in Australia.\[12\]

The Funding Strategy is consistent with the Health Funding Authority National Mental Health Funding Plan 1998-2002 and the Māori Health Strategic Plan.

Services will be funded both nationally and locally\[13\] - two-thirds in the localities; one-third nationally. Local programmes will be funded that reflect the national framework; services will be funded nationally only when they support and add value to those services at the local level.

The first component, “Project and Sector Development”, lays essential groundwork by establishing the infrastructure, the networks, and a common sense of purpose amongst a diverse range of groups and organisations. There are three key strategic objectives:

- to develop infrastructure and networks;
- to empower consumers/tangata whaiora and to encourage consumer involvement; and
- to change attitudes and behaviour in the mental health sector.

With a more supportive environment in the mental health sector and at the community level, a second component brings the messages to a wider audience. The “Public Awareness” component builds on the work developed in the community, but uses the public health tools of health promotion and education through mass media. There are three key strategic objectives in the “Public Awareness” component:

- to continue to fund “Project and Sector Development” services at a local level;
- to change attitudes and behaviour in the broader field, ie government agencies, through policy development with the agencies involved; and
- to change public attitudes and behaviour through mass media, public relations and health promotion.

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12 A literature search on programmes seeking to change public attitudes showed that the most effective approaches have included three main elements: mass media, educational materials and community activities. For a full summary of the literature search, see Appendix 2.

13 The financial tables on page 20 indicate the projected year end 30 June 1999 position (including roll over from 1996/97 and 1997/98) and the projected expenditure by locality office and nationally for the next 2 years to 30 June 2001.
6.2 The Key Audiences

First component

The “Project and Sector Development” component initially targets people involved in the project and the mental health sector. Activities focus on ensuring consumer/tangata whaiora involvement and making consumers more visible and comfortable to participate on the Project.

Local providers are given media training so that they can build relationships with their local media to promote their local programmes positively.

Awareness workshops describing discrimination and its effects are run for people working in the mental health sector. These include *Hearing Voices that are Distressing* and *Discrimination Awareness* workshops.

Second Component

The “Public Awareness” component targets a wider audience. This will include other health professionals, health professionals in training, governmental and non-governmental agencies using workshops, advocacy and policy development initiatives.

Finally, the messages will be brought to the wider New Zealand public through mass media and public relations initiatives.

6.3 Where are we at now?

We are currently in the third year of the five-year project.

Much of the work in the “Project and Sector Development” component has been consolidated. These programmes, described in more detail below, are ongoing and reflected in the local funding contracts.

Work is beginning on the “Public Awareness” component.
The Project to Counter Stigma and Discrimination Associated with Mental Illness

Objective: To reduce stigma and discrimination

Component One – Project & Sector Development

- to develop infrastructure & networks
  - appoint a project manager
  - establish and maintain local and national advisory groups
  - develop and publish a national stakeholder newsletter
  - purchase technical advice
  - conduct research

- to empower consumers and increase consumer involvement
  - incorporate consumer advice into project
  - make available advocacy kits
  - work with families of consumers
  - organise local consumer hui
  - develop consumer networks for the project

- to change attitudes in mental health sector
  - deliver Discrimination Awareness workshops
  - deliver Hearing Voices that are Distressing workshops
  - deliver workforce development workshops
  - develop provider resources, including newsletters and video

Component Two – Public Awareness Campaign

- continue and enhance project and sector development (Component One)
  - services will be delivered locally

- to change attitudes and behaviour in broader field
  - develop organisational standards for adoption by government and other national agencies
  - produce training programmes for organisations
  - fund advocacy services, i.e. submissions and select committee activity
  - contribute to curriculum of wider health sector

- to change public attitudes and behaviour through mass media, public relations and health promotion
  - develop and implement a paid media component
  - develop national media awards
  - publish media handbook to assist journalists reporting on mental illness
  - develop media response team
  - develop logo and branding
  - organise activities for Mental Health Awareness week
  - establish and maintaining links with key audiences, i.e. MPs
  - develop merchandising materials
  - research and publish health education resources to support public campaign
  - develop and maintain web site
  - organise national PR activities
### Multi-Locality Programmes - Financial Projections

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### National Programmes - Financial Projections

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**This expenditure is represented by**

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<th>1999/00</th>
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</table>
Notes to the Financial Projections

1. All figures are GST exclusive.

2. An adjustment to revenue and expenditure has been made for years 1999/00 and 2000/01 to reflect the re-defining of the HFA locality boundaries. Specifically, Tairawhiti locality is now the responsibility of the Wellington office and Nelson/Marlborough locality is the responsibility of the Dunedin office.

3. The allocation as a result of the Mason report was $10.4m. With additional funding from the Public Health Operating Group the total budget for the Project is now $12.64 million (GST excl). Of this $1.2 million (GST excl) awaits budget confirmation.

4. In years 1996/97 and 1997/98 expenditure by the Ministry of Health is included.
7.0 Achievements to Date

Much of the work to date has focused on the first component of the project: “Project and Sector Development”.

At a local level, providers are now in place and, in many cases delivering services in the community. Nationally, work has focused on developing the infrastructure and networks.

7.1 Achievements on a national level

Strategic Objective: To develop infrastructure & networks

- In 1996 the Business Research Centre conducted attitudinal research. While the response rate was low, it did provide some initial data about public knowledge and attitudes. This research included pre-research with Māori.

- A public relations company, Huia Communications, has been contracted to provide national coordination and public relations support. Huia produces a regular Project newsletter. The main aim of the newsletter is to link a wide range of groups involved in the project. It also aims to raise the positive profile of consumers/tangata whaiora, act as a tool for information sharing and raise awareness generally about mental illness.

- A national provider hui was held in 1998 in Rotorua. This was the first opportunity for consumers/tangata whaiora and people from both Public Health and Mental Health to raise issues around stigma and discrimination.

- A national hui of Māori stakeholders was held in June 1998. This hui brought together Māori providers that had been contracted to the project to date along with Māori consumers and other stakeholders. Important outcomes of the hui were a proposed purchasing/funding framework for Māori tangata whaiora services, and Māori slogans for the project, one of which has been adopted.

- A national hui of Pacific Island stakeholders was held in June 1998. This hui brought together Pacific Island providers, consumers and other stakeholders. The hui identified key Pacific Island groups to target and networks to use, and reinforced the idea that services for Pacific Island peoples must be delivered by Pacific Island peoples.

- A national project structure was developed at a national project development workshop. The structure is now in place and allows for advice from a wide range of interests (see Figure 1, page 16). A National Consumer Advisory Group gives advice to the project manager from a consumer perspective. A Project Advisory Group ensures input from Māori, Pacific Island, family/whānau and consumer representatives. A National Stakeholder Group has provided a wider range of expertise to support the Project.

- As a result of the national project development workshop, a national vision was established:

> To create a nation that values and includes people with mental illness.

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14 A full summary of the findings of this research can be found in Appendix 4.
• The Health Funding Authority and the Mental Health Commission have signed a Statement of Intent which formalises cooperation to achieve the goals of the project (see page 15).

• Several national agencies have pledged support for and assistance to the Project (see page 15).

**Strategic objective - To empower consumers/tangata whaiora and increase consumer involvement**

• Huia Communications worked with the Mental Health Commission and the Mental Health Foundation to develop a training programme for people working on the Project. The aim is to teach media skills. Nine training sessions throughout the country have been completed. This workshop has been adapted for Māori audiences.

• Huia Communications has also provided coordination support with consumers/tangata whaiora, other agencies and other groups involved in the Project.

**Strategic objective - To change attitudes and behaviour in the mental health sector**

• The Ministry produced a leaflet, Everyday People with Mental Illness, which described four mental illnesses: depression and anxiety, schizophrenia and bi-polar disorder (manic depression). The leaflet was made available from Public Health Units.

• A presentation on the Project has been given to the Hospital and Health Services Mental Health Managers and Clinical Directors.

7.2 **Achievements on a local level**

Two-thirds of the services are funded at the local level by the local Public Health offices of the Health Funding Authority. Each locality office will be responsible for involving consumers/tangata whaiora, families/whānau, Māori and Pacific Islands peoples in their programmes. The locality offices are also responsible for ongoing evaluation of local services.

As the Project started under four separate Regional Health Authorities, each locality office has taken a slightly different approach to funding services.

After an initial planning and developmental period, contracts are now in place in each of the localities and will include:

**Strategic Objective: To develop infrastructure and networks**

• establish and work with community networks

**Strategic Objective: To empower consumers and increase consumer involvement**

• train consumers/tangata whaiora to tell their stories and facilitate networks

• work with family/whānau

**Strategic Objective: To change attitudes and behaviour in the mental health sector**

• work with local Mental Health services staff to raise awareness of the issues around stigma and discrimination
• deliver consumer-led workshops, such as the *Hearing Voices that are Distressing* and *Discrimination Awareness*

**Strategic Objective: To Change public attitudes and behaviour through media, public relations and health promotion**

• work with local media
• purchase activities to support Mental Health Awareness Week

**Strategic Objective: To change attitudes and behaviour in the broader field**

• work with key local organisations to ensure policies create a safe and respectful environment for consumers/tangata whaiora
• work with local governmental agencies who have direct contact with consumers/tangata whaiora of mental health services to offer education and training to increase staff knowledge of the issues around mental illness
• develop modules dealing with issues of discrimination and stigma for inclusion in core curriculum of health professionals and related sectors, i.e. social workers and teachers.

### 7.3 Contracts in place locally

**Northern localities**

The Auckland locality office has signed contracts with six providers – each for a 38-month period beginning 1 May 1998.

The providers are:

• **The Mental Health Foundation**: The contract includes the development of core training and awareness workshops for mental health providers and related sectors; development of resources to be used to support the Project including resources for media activity, and policy work. The Mental Health Foundation also holds a separate contract to coordinate, train and support consumer participation in the Project and to maintain consumer networks in relation to the Project.

• **Framework Trust**: This contract covers projects which are undertaken in partnership with the community, awareness workshops for families and training for consumers to run workshops in the community. Framework Trust is also developing a drama production for Mental Health Awareness Week in October 1999.

• **Hapai Te Hauora Tapui Limited**: This provider has responsibility for delivering the Project to Māori in the Auckland locality. It includes regular hui and panui, the development and implementation of training and educational packages for delivery at marae-based communities, and policy work.

• **Te Hau Ora O Te Tai Tokerau**: This contract covers a full range of programmes in the Northland locality, both Māori and mainstream. It includes workforce development for health and related sectors and consumers, projects that are undertaken in partnership with the community, family/whānau education, and policy work.

• **Pacificare Trust**: This provider has responsibility for delivering the Project to Pacific Island peoples in the Auckland locality. The contract covers training of Pacific Island
consumers and mental health workers; development of resources, implementation of workshops for families and consumers, projects which are undertaken in partnership with the community, and policy work.

- Phoenix Research Limited. This provider has the responsibility for formative, process and outcome evaluation of all Project activities in the area covered by the Auckland Office.

Midland localities
This locality office currently has six providers, three Māori and three mainstream (includes Pacific Island people), and are based in three geographical areas: Taranaki, Waikato and Bay of Plenty. All providers will be contracted to the year 2001.

The providers are:
- Taranaki Mental Health Association: covers services for mainstream, facilitating training workshops, and working with local media in developing reporting protocols. It has also initiated a Consumer Advisory Group (CAG).
- Tui Ora Ltd, Māori Integrated Service Organisation (MISO): this organisation has recently taken over contracting responsibilities, however the provision of this service remains with Te Atiawa Hauora Ltd. Their main focus is on families and key Māori opinion leaders in the Taranaki area.
- New Progress Enterprises: covers services for mainstream, facilitating workshops focusing on workers in the mental health field as well as with consumers.
- Raukura Hauora o Tainui: this provider has established networks with the different iwi affiliations throughout the wider Waikato locality. Raukura Hauora o Tainui has encouraged these affiliations to develop activities that will raise stigma and discrimination as an issue, with a strong emphasis on reaching families and marae settings, who have experience with whānau/hapū/iwi members with a mental illness.
- Serious Fun’n Mind Charitable Trust: this is a newly established Trust whose mission statement is “to achieve sustained respect for people who suffer from mental illness”. They provide a mainstream focus in the Bay of Plenty area. In terms of changing attitudes, it will focus particularly on health services, government agencies, employers, Territorial Local Authorities, media, and other agencies that have an impact on the day-to-day lives of people who experience mental illness.
- Poutiri Trust: a MISO organisation, it will facilitate education hui targeting whānau/hapū/iwi, provide training to the wide range of Māori providers under its wing, and provide advice and advocacy to public and private sector agencies, and encourage Māori opinion leaders and media to change the climate of public beliefs.
Central localities
The Central locality office has 12 contracts in place covering five areas: mainstream services; Māori and Pacific Island funding; and provider workshops. One future contract will be in place for evaluation of services.

The following provide mainstream services, including initiatives for addressing negative attitudes and behaviour, developing linkages with consumers, “training the trainers” programmes, public relations activities to support Mental Health Awareness Week, advocacy services and newsletters.

- Nelson/Marlborough Health
- Hutt Valley Health
- Healthcare Hawkes Bay
- MidCentral Health
- Good Health Wanganui
- Pacific Island Community Health Services (PACH) is responsible for services focusing on the Pacific Island community. These will include training consumers to facilitate workshops and delivering workshops for the identified priority audiences - family, churches and mental health workers.

Four geographically based Māori providers are responsible for services focusing on Māori communities. Services will include conducting consultation with Māori, establishing advisory groups with consumer representation; delivering awareness workshops to priority audiences (whānau and mental health workers), and training consumers to participate in the Project. The providers are:

- Te Rāpua O Te Waiharakeke (Nelson/Marlborough)
- Te Roopu Pokai Taniwhaniwha (Wellington)
- Te Oranganui Trust (Wanganui/Manganuku)
- Te Taiwhenua O Heretaunga (Hawkes Bay)
- A joint venture in Tairawhiti, (involving the Public Health Unit and Mental Health service providers of Tairawhiti Healthcare Ltd, Turanga Health, Ngati Porou Hauora, Vanessa Lowndes Centre and consumer representatives) focuses on community education, consumer networks and training, and media awareness.
- The Mental Health Foundation provides support to providers involved in the Project.

Southern localities
The Southern locality office has identified four providers: one for mainstream services as well as three separate providers for Māori services, Pacific Island services and evaluation. All contracts will run to 30 June 2001.

The providers are:
• The Mental Health Foundation: Responsible for the provision of information and training, educational activities, development of resources, employment of consumers to work on the Project, local networking and coordination. It also provides a central point of contact for five district advisory groups.

• Nona Milburn Mediator and Consultant: Provides formative, process and outcome evaluation for the local activities, using both qualitative and quantitative methods.

• Te Awa O te Ora: To promote greater understanding of, acceptance of and support for tangata whaiora/Māori consumers; develop information and resources; develop and maintain networks and linkages locally and nationally; and further develop skills of tangata whaiora through training and education. This contract covers Canterbury and Christchurch. It will, over time, cover additional areas across the South Island.

• Crown Public Health for Pacific Island component: To develop and support Pacific Island consumer group, inform and educate consumers’ families and communities about mental illness, stigma and discrimination; develop and distribute resources; and provide education sessions.
8.0 Strategic Objectives and National Workplan
1998/99 - 2000/01

The final two and a half years of the Project will see a continuation of the “Project and Sector Development” activities covered by the local contracts. This will continue to account for approximately two-thirds of the total spending on the Project.

Supporting the “Project and Sector Development” activities, the HFA will develop national tools to achieve the three strategic objectives of the “Public Awareness” component:

1. to continue to fund “Project and Sector Development” services at a local level;
2. to change attitudes and behaviour in the broader field, ie government agencies, through policy development with the agencies involved; and
3. to change public attitudes and behaviour through mass media, public relations and health promotion.

To achieve these strategic objectives, the HFA will fund services to:

- develop and advocate for guidelines for use by governmental and other national agencies to create supportive environments for consumers/tangata whaiora and to educate those who come into direct contact with consumers/tangata whaiora;
- develop a national mass media component;
- undertake national public relations activities;
- develop workforce training programmes to be included in training curriculum for health professionals; and
- develop health education and health promotion resources.

A detailed national workplan to achieve the strategic objectives of the “Public Awareness” component follows. Details about local workplans and activities follow on page 31.

8.1 Strategic objective: To continue to fund “Project and Sector Development” services at a locality and national level.

<table>
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<tr>
<th>Activity</th>
<th>Completed by</th>
</tr>
</thead>
<tbody>
<tr>
<td>Formalise mechanism for incorporating consumer advice into Project and maintain linkages with consumer groups</td>
<td>Work to be undertaken by Mental Health Operating Group</td>
</tr>
<tr>
<td>Organise national hui and networks for consumers/tangata whaiora, Pacific Island Peoples and providers</td>
<td>Scheduled between Oct-Dec 1999</td>
</tr>
<tr>
<td>Fund M aori initiatives, including adaptation of workshops for M aori and activities to support Mental Health Awareness Week</td>
<td>By Oct 1999 and Oct 2000</td>
</tr>
<tr>
<td>Fund Pacific Island activities, including adaptation of workshops for Pacific Island peoples and activities to support Mental Health Awareness Week</td>
<td>By Oct 1999 and Oct 2000</td>
</tr>
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</table>
Organise activities for family/whānau to coincide with Mental Health Awareness Week  

Fund project support and coordination, including national coordination of workshops and production of national newsletter  

<table>
<thead>
<tr>
<th>Activity</th>
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<tr>
<td>Fund development of a set of generic organisational guidelines and service quality guidelines for the purpose of addressing stigma and discrimination in statutory agencies and non-governmental agencies</td>
<td>Provider selected and contracts agreed by Sep 1999</td>
</tr>
<tr>
<td>Fund coordination of input into the training of psychiatrists, psychologists, nurses, occupational therapists, social workers and community support workers</td>
<td>Provider selected and contracts agreed by Sep 1999</td>
</tr>
<tr>
<td>Agree a joint plan with the Mental Health Commission to develop a programme to inform Members of Parliament of the issues around mental illness, stigma and discrimination</td>
<td>By Oct 1999</td>
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</table>

8.2 Strategic objective: To change attitudes and behaviour in the broader field, i.e. government agencies, through policy development with the agencies involved. Through direct contact and advocacy, the HFA will aim to raise awareness of discrimination with key audiences. These will include politicians, medical training schools, and governmental and non-governmental agencies, i.e. housing and welfare. National tools will be developed for use locally.

8.3 Strategic objective: To change public attitudes and behaviour through mass media, public relations and health promotion.

<table>
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<td>Mass Media Campaign</td>
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<tr>
<td>Fund a mass media campaign, which includes television, radio and print advertising.</td>
<td>Contract to be in place July 1, 1999.</td>
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<tr>
<td>Public Relations Activities</td>
<td></td>
</tr>
<tr>
<td>Fund public relations support for media campaign, targeting mainstream, Māori and Pacific Island media</td>
<td>Contract signed Apr 1999</td>
</tr>
<tr>
<td>Fund organisation of marketing activities including development of website</td>
<td>Contract signed Apr 1999</td>
</tr>
<tr>
<td>Fund the organisation of and participation in Mental Health Media Awards</td>
<td>Apr 1999</td>
</tr>
<tr>
<td>Fund development of merchandising material to support Mental Health Awareness Week</td>
<td>May 1999</td>
</tr>
</tbody>
</table>
Develop Project logo and fund the development of branding guidelines

| Logo developed Feb 1999; Guidelines developed Apr 1999 |

Fund the implementation of multi-locality response team for media activity

By Oct 1999

Fund the development of media handbook for media education and training

Mar 1999

Health promotion and education activities

Fund development of fact sheets for mainstream, Māori and Pacific Island providers to distribute at workshops

By Nov 1999

8.4 Evaluation

The national activities will be subject to ongoing evaluation. This will comprise a mix of formative, process, impact and outcome measures. National activities will be evaluated to measure effectiveness of programmes for Māori.

It is important to note, however, that evaluation will have its limitations.

- The project aims to change attitudes and behaviour. This is a complex area to measure and there is very limited international experience.
- Even if we could measure such change, it would be difficult to attribute such change purely to this Project.

As the basis for improving the programme, evaluation will therefore need to be realistic as to its parameters and focus on practical measures, such as awareness of the Project, what activities occur, etc. and capture the development, success and problems that have been happened during this journey.
9.0 Strategic Objectives and Local Workplans
The following is a workplan outlining local activities required to achieve the Strategic Objectives.

9.1 Strategic Objectives: To develop infrastructure and networks and to empower consumers and increase consumer involvement

<table>
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<tr>
<th>Activity</th>
<th>Completed by</th>
</tr>
</thead>
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<tr>
<td><strong>Northern localities</strong></td>
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</tr>
<tr>
<td>Develop consumer networks to provide ongoing advice to the Project</td>
<td>Networks in place</td>
</tr>
<tr>
<td>Establish links with Māori and Pacific Island consumers</td>
<td>Networks in place</td>
</tr>
<tr>
<td>Hold regular meetings of providers for the purpose of maintaining linkages</td>
<td>Ongoing</td>
</tr>
<tr>
<td>Establish process to train and support consumers to participate in the Project</td>
<td>“Walk in our Shoes” training ongoing</td>
</tr>
<tr>
<td>Establish a “Speakers Bureau” of consumers who are trained and supported to tell their stories.</td>
<td>June 99</td>
</tr>
<tr>
<td><strong>Midland localities</strong></td>
<td></td>
</tr>
<tr>
<td>Hold a provider hui to discuss activities in the localities, share ideas and solidify plans</td>
<td>June 1999</td>
</tr>
<tr>
<td>Establish consumer groups to provide ongoing advice to the Project. (For Māori, the Project uses Māori networks already in place for other services.)</td>
<td>Completed except for Waikato where process has been initiated</td>
</tr>
<tr>
<td><strong>Central localities</strong></td>
<td></td>
</tr>
<tr>
<td>The HHS Public Health Units have set up advisory groups with consumer representatives to provide ongoing advice and support to the local projects in their areas.</td>
<td>completed</td>
</tr>
<tr>
<td>The four Māori providers and Pacific Island provider are required to set up advisory groups with consumer/tangata whaiora representatives to provide advice to local projects.</td>
<td>Jul 1999</td>
</tr>
<tr>
<td>Training programme provided for Pacific Island and Māori consumers by Pacific Island and Māori providers.</td>
<td>ongoing</td>
</tr>
<tr>
<td>Fund providers to establish “Speakers Bureau” of consumers who are trained and supported to tell their stories.</td>
<td>phased in from July 1999</td>
</tr>
<tr>
<td><strong>Southern localities</strong></td>
<td></td>
</tr>
<tr>
<td>Establish five geographically-based District Advisory Groups (DAGs) to ensure ongoing consumer, Māori, Pacific Island and other stakeholder advice to the Project</td>
<td>completed</td>
</tr>
<tr>
<td>Develop orientation packages for those participating on DAGs</td>
<td>completed</td>
</tr>
<tr>
<td>Organise regional workshop (including training element) for District Advisory Groups, including training for Māori.</td>
<td>completed</td>
</tr>
</tbody>
</table>
9.2 Strategic Objective: To change attitudes and behaviour in the mental health sector

<table>
<thead>
<tr>
<th>Activity</th>
<th>Completed by</th>
</tr>
</thead>
<tbody>
<tr>
<td>Northern localities</td>
<td></td>
</tr>
<tr>
<td>Deliver awareness workshops to staff of mental health providers and related sectors</td>
<td>ongoing</td>
</tr>
<tr>
<td>Deliver awareness workshops for Māori and Pacific Island audiences</td>
<td>ongoing</td>
</tr>
<tr>
<td>Deliver marae-based workshops</td>
<td>ongoing</td>
</tr>
</tbody>
</table>

| Midland localities |              |
| Deliver awareness workshops for staff of mental health providers | workshops developed July 1999, delivery ongoing from July 1999 |

| Central localities |              |
| Deliver awareness workshops for staff of mental health providers | ongoing |
| Incorporate mental health providers in advisory groups for an integrated approach to planning activities and information sharing. | completed |

| Southern localities |              |
| Deliver awareness workshops for staff of mental health providers | ongoing |
| Participate in mental health services training opportunities | Commenced, training ongoing |
| Develop “by Māori for Māori” training and resources | ongoing from Nov 1999 |
| Produce “Consumer Perspective” document to educate mental health sector about how to interact with consumers | May 1999 |

9.3 Strategic Objective: To change attitudes and behaviour in the broader field

<table>
<thead>
<tr>
<th>Activity</th>
<th>Completed by</th>
</tr>
</thead>
<tbody>
<tr>
<td>Northern localities</td>
<td></td>
</tr>
<tr>
<td>Deliver awareness workshops to government agencies whose staff come into direct contact with consumers, including workshops developed for Māori and Pacific Island staff</td>
<td>ongoing</td>
</tr>
</tbody>
</table>

<p>| Deliver awareness workshops to community groups, including Māori and Pacific Island groups | ongoing |
| Deliver awareness education for family/whānau | ongoing |
| Develop a travelling creative arts production involving consumers to educate students and other community groups | production developed by Dec 99 |</p>
<table>
<thead>
<tr>
<th>Activity</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>Develop a drama production for Mental Health Awareness Week targeting mental health service providers and members of the public</td>
<td>Oct 1999</td>
</tr>
<tr>
<td>Establish process by which community initiatives to change attitudes and behaviour are identified and offered funding</td>
<td>process established</td>
</tr>
<tr>
<td>Develop generic organisational standards for use by governmental and non-governmental agencies to ensure their policies are safe for consumers</td>
<td>standards developed Dec 1999; advocacy from Jan 2000</td>
</tr>
<tr>
<td>Develop core modules for inclusion in curriculum of health sector and related sectors to address stigma and discrimination</td>
<td>standards developed Jan 2000, delivery ongoing from Jan 2000</td>
</tr>
<tr>
<td><strong>Midland localities</strong></td>
<td></td>
</tr>
<tr>
<td>Deliver awareness workshops for staff of government agencies who come into direct contact with consumers</td>
<td>workshops developed Jul 1999; delivery ongoing from Jul 1999</td>
</tr>
<tr>
<td>Deliver awareness workshops to hapū/iwi/whānau</td>
<td>ongoing</td>
</tr>
<tr>
<td>Hold hui for family/whānau to develop strategy to address issues of stigma and discrimination</td>
<td>Oct 1999</td>
</tr>
<tr>
<td>Advocate for generic organisational standards, developed nationally, with local statutory agencies and non-governmental agencies</td>
<td>From Jan 2000</td>
</tr>
<tr>
<td>Advocate for inclusion of modules dealing with issues of stigma and discrimination in local curriculum of health and related sectors' training programmes</td>
<td>From Jan 2000</td>
</tr>
<tr>
<td><strong>Central localities</strong></td>
<td></td>
</tr>
<tr>
<td>Fund a “Train the Trainers” programme to deliver workshops to community organisations, schools and social services agencies</td>
<td>ongoing</td>
</tr>
<tr>
<td>Fund advocacy component to service</td>
<td>ongoing</td>
</tr>
<tr>
<td>Advocate for generic organisational standards, developed nationally, with local statutory agencies and non-governmental agencies</td>
<td>From Jan 2000</td>
</tr>
<tr>
<td>Advocate for inclusion of modules dealing with issues of stigma and discrimination in local curriculum of health and related sectors' training programmes</td>
<td>From Jan 2000</td>
</tr>
<tr>
<td><strong>Southern localities</strong></td>
<td></td>
</tr>
<tr>
<td>Fund process to work collaboratively with government agencies, local authorities, social service agencies and community groups to influence attitudes and behaviour</td>
<td>Process established</td>
</tr>
<tr>
<td>Advocate for generic organisational standards, developed nationally, with local statutory agencies and non-governmental agencies</td>
<td>From Jan 2000</td>
</tr>
<tr>
<td>Fund relevant submissions on legislation or policy issues that affect tangata whaiora/whānau.</td>
<td>Ongoing from May 1999</td>
</tr>
<tr>
<td>Advocate for inclusion of modules dealing with issues of stigma and discrimination in local curriculum of health and related sectors' training programmes</td>
<td>From Jan 2000</td>
</tr>
</tbody>
</table>
### 9.4 Strategic Objective: To change public attitudes and behaviour through mass media, public relations and health promotion

<table>
<thead>
<tr>
<th>Activity</th>
<th>Completed by</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Northern localities</strong></td>
<td></td>
</tr>
<tr>
<td>Fund providers’ proactive media plans to promote positive stories in media and to establish links with media</td>
<td>ongoing</td>
</tr>
<tr>
<td>Provide media training to providers</td>
<td>ongoing</td>
</tr>
<tr>
<td>Fund providers to plan activities and events to support Mental Health Awareness Week</td>
<td>Oct 1999</td>
</tr>
<tr>
<td>Develop a resource development plan</td>
<td>completed</td>
</tr>
<tr>
<td><strong>Midland localities</strong></td>
<td></td>
</tr>
<tr>
<td>Each provider to develop communications strategies to promote their services positively</td>
<td>By Aug 1999</td>
</tr>
<tr>
<td>Provide media training for providers</td>
<td>May 1999</td>
</tr>
<tr>
<td><strong>Central localities</strong></td>
<td></td>
</tr>
<tr>
<td>Fund providers to implement proactive media strategies to promote their services</td>
<td>ongoing</td>
</tr>
<tr>
<td>Fund media response component for services to ensure appropriate and accurate reporting</td>
<td>ongoing</td>
</tr>
<tr>
<td>Fund public relations activities to support Mental Health Awareness Week</td>
<td>Oct 1999</td>
</tr>
<tr>
<td><strong>Southern localities</strong></td>
<td></td>
</tr>
<tr>
<td>Fund providers to establish and maintain links with media and to promote positive stories and attitudes, targeting mainstream, Māori and Pacific Island media</td>
<td>ongoing</td>
</tr>
<tr>
<td>Provide media training to those involved in the DAG</td>
<td>ongoing</td>
</tr>
<tr>
<td>Establish the feasibility of video production promoting positive attitudes using local issues e.g. NZ Broadcasting School and regional access networks</td>
<td>By Oct 1999</td>
</tr>
<tr>
<td>Establish media response process for registering concerns/complaints and accuracy reporting</td>
<td>Template established by April 1999</td>
</tr>
<tr>
<td>Establish a clearing house of health promotion material available</td>
<td>established</td>
</tr>
<tr>
<td>Ensure health promotion material is appropriate and available for whānau/hapu/iwi to challenge myths, legends and stereotypes.</td>
<td>Ongoing from May 1999</td>
</tr>
</tbody>
</table>

### 9.5 Evaluation

Evaluation of local services is the responsibility of the four locality offices of the HFA. Each office will have contracts in place, which will comprise a mix of formative, process, impact and outcome measures for the local activities.
10.0 Working towards the vision: What will success look like in the long-term?

The Project to Counter Stigma and Discrimination Associated with Mental Illness is a project that seeks to make a contribution towards changing public attitudes and behaviour. Such social change does not happen overnight but over a long period of time and almost imperceptibly. What will the world look like once we have succeeded in realising the vision?

10.1 How will the lives of consumers/tangata whaiora have changed?
Consumers/tangata whaiora involved in the Project:
- will feel more able to speak of their experiences of mental illness and recovery;
- will be more able to support other consumers/tangata whaiora;
- will have, in conjunction with mental health-funded networks, stronger consumer links and networks; and
- will have been employed and paid for their skills.

Consumers/tangata whaiora in general:
- will see an improvement in their quality of life;
- will have seen other consumers/tangata whaiora in this Project more able to speak publicly about their illness;
- will feel they are treated with more respect by Mental Health services staff;
- will have greater opportunity to access consumer networks if they wish.

10.2 What will we — people directly involved in the Project (consumers/tangata whaiora, families/whänau, Māori, Pacific Islands peoples, the HFA, providers and other key stakeholders) — be saying and doing that is different than what we do today?
- we will be able to clearly articulate the problems of stigma and discrimination associated with mental illness;
- we will have an understanding that the impact of stigma and discrimination may vary between groups and that this understanding is reflected in our activity in this area;
- we will have changed our own attitudes and behaviour as a result of being involved in this Project;
- we will practice what we preach in terms of ‘valuing and including people with mental illness’;
- we will be actively involved in education and training concerned with consumer safety and payment, and that training will be built into the contracts and policies of the agencies we work for; and
- the infrastructure already in place for this Project will support the continuation of its work when funding has ceased.

10.3 What will specific target groups (such as mental health services staff, Work and Income NZ, MPs, police) be saying and doing that is different?
- they will have had the opportunity to be trained by people who have had experience of mental illness and by educators who address issues of language, attitudes and behaviour as it relates to stigma and discrimination against consumers/tangata whaiora;
• they will have access to resource materials (fact sheets) on mental illness;
• they will be more aware of appropriate language to use when speaking of mental illness;
• they will be more aware of appropriate (respectful) behaviour as specified by consumers/tangata whaiora (so that staff attitudes are different); and
• all of the above will be built into their respective services’ contracts/policies.

10.4 What will the general public think and do that is different?
• they will be more aware of their own attitudes and behaviour towards people with mental illness and more likely to exhibit positive behaviours towards people with mental illness;
• they will have access to fact sheets; and
• they will be aware that there is a Project to Counter Stigma and Discrimination Associated with Mental Illness and why this is important for NZ.

10.5 How will the media report mental illness differently?
• the media will be more aware of discrimination against people with mental illness and be less prone to using stigmatising language and reinforcing negative stereotypes;
• subjects and stories will be reported within an appropriate context;
• they will have access to named mental health spokespeople for this Project.

10.6 What will have been the main achievements of reform in this area?
• consumers/tangata whaiora and providers: upskilling.
• target groups: attitudes challenged and awareness raised.
• public: more awareness of discrimination associated with mental illness.
• media: appropriate reporting and use of language.
11.0 The Risks

11.1 Managing Different Expectations
There is a range of groups with different expectations of the project. The mental health sector is one with a wide range of perspectives (consumer, family/whānau, Māori, Pacific Islands peoples, stakeholders, clinicians and providers). Developing strong and ongoing linkages with consumers, community and government agencies, and mental health providers will help to manage some of these expectations by involving a range of opinions.

Ongoing communications with the above groups will also clarify what the Project can and cannot achieve. Strong communications links will also clarify other funding initiatives of the Mental Health Operating Group.

11.2 Media Reporting of Isolated Events
Sensational reporting by the media of isolated events has the potential of derailing the Project and undoing good work achieved to date. A priority for the Project will be to continue to work closely with key media to educate them in the longer term.

Timely response to media coverage of events will be important. The Project will establish community-based media response teams who will respond to unbalanced media coverage and add balance.

The Mental Health Operating Group will respond to issues of treatment; a joint response with the Public Health Operating Group will be more appropriate when it is an issue of the Project or wider societal attitudes towards mental health issues.

It is important to note that it is inevitable that these isolated events will occur.

11.3 Coping With More Demand on Services
Evidence elsewhere, notably Australia and the USA, suggests that there can be an increase in demand for services, particularly early intervention services, immediately following a mass media campaign.

The Mental Health Operating Group, in its National Mental Health Funding Plan 1998-2002, has increased funding for community-based services and early intervention services.

Ongoing discussions between the Mental Health Operating Group and the Health & Hospital Services nationally, will focus on estimating any potential increase in demand and putting in place strategies to cope with this.

11.4 Gaining Stakeholder Input on Messages Effective for Attitudinal Changes in the Wider Public

The target audience for this Project is initially the health sector. In later stages the audience is widened to include related sectors such as Education and Housing and then ultimately will include the public.
The Project will have processes in place to ensure a range of perspectives at critical stages of developing the media campaign, for example, when developing key messages. Campaign materials will need to be relevant to a range of different groups. Advertising and health promotion materials will be pre-tested.

To ensure the public awareness component of the campaign is able to reach a wide audience, funding for the media component has been increased by $1.8m over three years, of which $1.2m still awaits budget confirmation.
Appendices

Appendix 1    The Environment
Appendix 2    Research Evidence: New Zealand and Overseas
Appendix 3    “Anti-discrimination and Destigmatisation”, an excerpt from the Health Funding Authority National Mental Health Funding Plan 1998-2002
Appendix 4    Findings of Business Research Centre Research
Appendix 5    Destigmatisation Project: Community Attitudes Towards People with Mental Illness Stage 1 – Pre-Research with Māori
Appendix 6    Community Attitudes Towards People with Mental Illness: An Interpretation of Māori Results of the Benchmark
Appendix 1: The Environment

The following is a review of the environment in which the Project was conceived and will operate.

Consumer Views in New Zealand

NZ Government policy makers started moves towards more and better community-based mental health services in the late 1980s. During this process the consumer voice was recognised and finally granted authority through two Churchill Fellowship reports. These reports brought the issues of stigma and discrimination to the attention of the government. The first, Outside Chance by Julie Leibrich, was published in 1988 and states that:

*Any move to community based care needs to be accompanied by strategies to educate the public eye, to change the image of mental illness and to improve the status of the people concerned.*

The second report, by Mary O’Hagan, was “Stopover on the way home from Mars”. Both reports were also influential in bringing the issues of stigma and discrimination to the mental health sector.

The first time consumer participation and input was actively sought for policy making was in the national mental health consortium. This was set up, at the request of the Ministers of Health and Social Welfare in 1989, to establish national objectives and priorities. The resulting report clearly describes the need for the government to work towards reducing stigma and discrimination.

Strong calls for change in this area have come from people like Mary O’Hagan, Iwa Natana and Pauline Hinds, who have had the courage to publicly speak out about their personal experiences of mental illness. Mary formed the Aotearoa Network of Psychiatric Survivors (ANOPS), the first national consumer movement in New Zealand. Since that initial leadership provided by ANOPS, and other consumer organisations in New Zealand, the consumer voice has strengthened. Currently, ANOPS has ceased trading and the HFA Mental Health division is undertaking a review of consumers/tangata whaiora needs for a national consumer organisation.

Public Perceptions and the Media in New Zealand

Barbara Disley (former head of the Mental Health Foundation and currently one of three Mental Health Commissioners) was one of the first to write and speak in the media of the need for public education and training on the areas of stigma and discrimination.

New Zealand studies of public attitudes towards mental illness demonstrate that there is little knowledge about mental illness and confusion about what constitutes mental illness. For example, intellectual disability is often seen as a mental illness (Ng et al, 1995; Patten, 1992; Green et al, 1987). Ng et al (1995) showed that those surveyed had a perception that people with mental illness were more violent, dangerous, and/or unpredictable. There was unease about how to relate to people with mental illness, which seemed to stem from a lack of
understanding rather than fear or non-acceptance. The media was found to have a substantial impact on the community’s opinions of people with mental illness.

On the positive side, these studies suggest that people need and welcome information about mental illness. Organisations such as the former ANOPS, the Schizophrenia Fellowship and the Mental Health Foundation have done much to pave the way in this area. The Fellowship, in particular, has effectively used the media to inform and raise awareness of schizophrenia.

**Stigma and Discrimination in Health Service Structures**

Surveys in the UK in 1996 (conducted by MIND), and the US in 1997 (NAMI) found that most consumers/tangata whaiora’ experiences of stigma came from general health and mental health professionals.

Collings and Ellis (1997) note that health professionals are not immune from the process of discrimination. Mental health professionals may devalue their client group or particular subgroups of people, such as those who have a long-term illness. In addition, people who have a history of mental illness are often not taken seriously by general health care providers (Collings & Myers 1992), with physical symptoms being seen as psychosomatic rather than somatic (Pulice et al 1995), and consequent neglect of physical problems.

It has also been suggested that mental health services staff themselves are marginalised from the mainstream (‘real’) general health services that deal with ‘real’ (read physical) illness (Collings & Ellis, 1997). For example, a psychiatrist may be viewed as a ‘failed physician’ by other medical specialists.

Collings and Ellis (1997) argue that prejudice against people with mental illness operates at a structural level in society, influencing the allocation of resources. In New Zealand, the private medical insurance system is one such example. The authors cite Tommasini (1994) who states that currently, people are not able to anticipate and make provision for the possibility of mental illness at some time in the future in the way that they insure against the risk of physical illness.

**Influencers of Public Attitudes**

Barwick (1995) found that there is not a large body of literature on the subject of positively influencing public attitudes towards people who have a mental illness. The research falls into three main categories. Programmes (in order of proven effectiveness) attempt to influence attitudes by:

- direct contact with, or exposure to, people with a mental illness;
- indirect exposure (via the media) to people with a mental illness; and
- information and persuasion.

Most research in this area focuses on the role of the media. The role of the media has generally been described as selecting the news, reporting information, serving as a channel of communication, presenting views and opinions, and legitimising the issues (Marcos, 1989).
Collings and Ellis (1997) suggest that the media reflects and perpetuates the stereotypical view of people with a mental illness as violent, unpredictable, dangerous and to be feared. They note that perceived dangerousness has been said to be the single most important factor contributing to the stigma of mental illness. People who have had little contact with people who have a mental illness are most influenced by media stereotypes, however their beliefs are revised when there is direct contact (Link & Cullen, 1986; Read & Law; and Read & Harre, submitted for publication).

An interesting view is put forward by Bowler (1994), who suggests that it may not only be the journalists’ fault that they react negatively to stories on mental illness – it may also be the failure of mental health interest groups to agree among themselves on any consensus approach to the issues.

One avenue of positive influence is self-help agencies. Segal et al (1993) suggest that the structure of such organisations often gives people access to roles that permit them to take responsibility for, and exercise control over, policies affecting them directly (reported by Collings & Ellis, 1997). Thus, the structure and internal processes of such agencies may do much to counter the disempowering effect of stigma and discrimination, in ways that consumer involvement in professionally run services may not. This finding points to the importance of having well-funded, strong consumer networks – to benefit this Project and to enhance Mental Health Service delivery.

The Social and Economic Environment
Over the last three decades, and for very good reasons, the process of the de-institutionalisation of mental health services has been occurring – and is discussed in numerous publications.

Following the 1993 health reforms, NZ has experienced the relocation of many health services from a hospital to a community setting. There has been fast growth in the number of service providers, more diversity in methods of service delivery and promotion of initially a competitive (more recently a collaborative) environment. The resulting political and public debate around these reforms has at times, left the public distrustful of the motivation for changes to services for people with mental illness, and such debate has sometimes been a venue for discriminatory and stigmatising comment.

Recent Health Structures
In the last two years, we have seen the establishment of the Mental Health Commission, which has developed the Mental Health Services Blueprint and the Map of the Journeys.

There have been three changes in the structure and name of the now Health Funding Authority.

Crown Health Enterprises have been renamed Hospital and Health Services. The Ministry of Health has reoriented into a more strategic policy and monitoring agency.

We have seen a refocusing of the Mental Health Foundation.

ANOPS has ceased trading.
Socio-economic Structures
Disley (1997) states that studies of the impact of the wider socio-economic environment tell us that:

- social isolation contributes to poor mental health;
- poverty and poor housing worsen mental health; and
- in the future, there may be changes in the policies of other statutory agencies (such as changes to benefits, housing, unemployment or education) which may directly affect people who have mental illness, and therefore affect this Project.

Cultural Issues
1. Māori
Dyall (1997) says that when Māori present to the health system, they come with their own world-view and cultural concepts and values. A person may feel they are unwell because they have breached certain cultural protocols. Words used to describe their sickness may be mate Māori, or mākutu, and their family/whānau may describe their behaviour as disturbing, or pōrangi.

The perceived causes of illness may not be talked about for many reasons – one of which may be whakamā (shame). Thus, cultural matters may easily be ignored or overlooked and behavioural symptoms interpreted in terms of a biomedical model of diagnosis and treatment. Any information on illness must take culture and language into account if it is to be effective for whānau. Dyall notes that Māori have limited access to information about early signs and symptoms of both mate Māori and mental illness, and who to see about these.

If mental health promotion programmes are to begin to change the cultural norms, they should be developed with whānau, hapū and iwi. Dyall says that, from a public health perspective, such programmes will need to look carefully at who is delivering the education. For example, Māori are less likely to consult a GP about emotional or behavioural problems, so more appropriate people may need to be trained to deliver information to assist mental health.

Dyall (1997) also describes four Māori models of wellness, which have emerged through hui and consultation. The first was developed by Durie, and describes good health in relation to the four walls of a strong house, te taha wairua (spiritual well-being); te taha hinengaro (mental well-being); te taha tinana (physical well-being); and te taha whānau (family well-being). Each model builds on from Durie’s foundation.

The most recent, developed by Te Puni Kōkiri in 1994, looks to the future. Māori now consider that they have a right to be healthy, and to be so, they need a sense of identity, self-esteem, control over their own destiny, a voice that is heard, knowledge of te reo Māori and tikanga, and economic and whānau security.

2. Pacific Islands
Pacific Islands people’s beliefs shape the way they respond to mental illness. In general Pacific people believe that disturbed behaviour results from spiritual forces, often as a result

15 See Appendix Five and Six for further information.
of violation of tapu. This belief has elements of blame on the person suffering from illness and/or his/her family. The shame often associated with mental illness in Pacific communities is related to this belief as to the causation of mental illness.

The bio-medical beliefs as to causation of mental illness should be made available to Pacific people. The bio-medical explanation as to the causes of mental illness can be empowering for Pacific people suffering from the illness as well as to their families, because it places mental illness in the same category as other illnesses for which there is not stigma, (such as diabetes). If clinical treatment, based on the bio-medical model, is offered to Pacific people, the basis of that treatment needs to be understood if people are to accept it and comply with it.

On the other hand, the philosophy behind the Pacific cultural beliefs as to causation of mental illness suggests that the basis of good mental health is healthy social relationships, and that the violation of health relationships can result in mental illness. This is a cultural insight that is hugely significant and cannot be sacrificed in the face of bio-medical explanation. Both the bio-medical interventions and the focus of Pacific healing protocols on the maintenance and restoration of health relationships, have a place in the restoration and maintenance of good mental health to individuals, their families and the Pacific community at large.

The understanding and appreciation of both the Pacific cultural explanation and the bio-medical explanation requires much educational work, for Pacific people with mental illness, for their families, for Pacific communities and equally for health workers. A successful destigmatisation educational programme will address these issues.
Appendix 2 - Research Evidence: New Zealand and Overseas Literature

The following is a review of literature on changing public attitudes.

Mental Health Promotion

Mental health promotion seeks to actively facilitate coping skills, self-esteem, social support and well-being in individuals, communities and societies, and to work for change in those factors (including stress and discrimination) which threaten mental health.

Reported in Tilford, Delaney & Vogels, 1997

Disley (1997) states that there is a developing body of international knowledge about health promotion and this knowledge is beginning to be applied to mental health. However, public health approaches in the mental health arena in New Zealand have been extremely limited in any coordinated manner, although the efforts of the voluntary sector should be acknowledged in this context. Disley notes that the result of this is a limited infrastructure to support mental health promotion, a limited knowledge base on what works within the cultural context of New Zealand, and an almost non-existent local research base.

Role of Mass Media Advertising in Health Promotion

It is useful to look to wider literature to see how attitudes have been changed using the mass media.

Wyllie (1997) notes that it is important to be aware of what the mass media can realistically achieve. Mass media campaigns have been utilised in a number of health promotion campaigns. Experience from using mass media in alcohol health promotion, for example, suggests that it is good for increasing knowledge or building awareness. It can sometimes contribute to attitude change, but it is difficult to show that it contributes directly to behaviour change. However, there is a benefit in creating a climate of opinion that is supportive of healthy public policies. Public relations activities are often used to assist this process.

Brown (1996) reviewed the use of mass media campaigns as a form of health education. His review indicates that mass media campaigns cannot:

- convey complex information;
- teach complex motor and social skills;
- shift attitude change in people who are resistant; or
- provide the support necessary for motivation of individuals who wish to change their behaviour in adverse physical and social circumstances.
Brown suggests that one way of depicting this be:

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<th>(a)</th>
<th>(b)</th>
<th>(c)</th>
<th>(d)</th>
</tr>
</thead>
<tbody>
<tr>
<td>mass</td>
<td>increased</td>
<td>shift in</td>
<td>change to</td>
</tr>
<tr>
<td>media</td>
<td>awareness &amp;</td>
<td>attitudes</td>
<td>health</td>
</tr>
<tr>
<td>campaign</td>
<td>knowledge</td>
<td>&amp; beliefs</td>
<td>behaviour</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>&amp; mortality</td>
</tr>
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mass media \Rightarrow\text{awareness \& attitudes} \Rightarrow\text{health} \Rightarrow\text{mortality}

Wider literature suggests that mass media campaigns can achieve (a); will have some impact on (b); and will have limited impact on (c) – although only then in the short term, and if the behaviour change advocated is relatively simple. Thus, the implication is not to impose unrealistic and/or rigid evaluatory indicators on campaigns. Indicators should be population coverage, media coverage, public awareness and public attitudes.

The experience of other health promotion programmes designed to effect changes in public knowledge, attitudes and behaviour has demonstrated that mass media initiatives on their own are unlikely to be successful. However, mass media programmes that use realistic outcome criteria and that are backed up by community-based education and training are more effective (e.g. Reid et al 1995).

A Summary of Studies Attempting to Change Attitudes in Large Populations

Brown’s model was demonstrated by a mental health promotion initiative in the state of California, with a population of 22 million (Taylor et al, 1984). The programme, “Friends Can Be Good Medicine” was derived from evidence linking supportive personal relationships with increased physical and mental health. The three major campaign elements were mass media, educational materials and community activities. Evaluation suggested that the campaign was most effective in areas where campaign elements reinforced one another. The authors state:

*Mass media – with its awesome reach and ability to change perception and behaviour – must be viewed as a powerful component of the health care system, for better or worse. ... The challenge is to develop effective ways of harnessing mass media in the interests of health promotion.* (Taylor et al, 1984)

A 1992 campaign in Norway had two goals: to collect money to support psychiatric research, and to inform and educate the public about mental health problems in order to reduce stigma and increase openness (Fonnebo & Sogaard, 1995).

It was a nationwide mass media campaign, consisting of pre-planned activities in the months before one particular day. A campaign newsletter was sent to every household, information on illnesses was sent to institutions and professionals, there were newspaper adverts, three TV adverts, four 40-minute TV programmes, five 40-minute radio programmes, open days at psychiatric institutions, essay competitions and unplanned media coverage of the campaign.

The results found that 94% of those surveyed had heard of the campaign, 75% had watched the pre-campaign TV programmes, and 70% had read about mental illnesses in the literature. A more ‘open’ attitude towards mental illness was found, with people reporting that they were more willing to discuss the issues (Sogaard & Fonnebo, 1995).
Research on the Use of Radio and Print Media
Austin and Husted (1998) reviewed the use of both radio and print media.

They concluded that radio is a cost-effective way to present health messages. Radio also has the advantage of reaching people in their homes or cars or workplace.

Print media - newspapers, magazines, and newsletters - can be cost-effective if magazine or newspaper space is free, but newsletters can be costly due to fixed postage costs. Newsletters can be useful to unite a sector or community. One advantage of print is that it can be re-read, clipped out, copied and passed on to others.

Radio has been used for several years in the US as a means of prevention and education of the public.

Both the American Psychiatric Association and the American Psychological Association have published ethical guidelines for psychiatrists and psychologists working in the media. The guidelines caution that there should be no attempt to make a diagnosis or to 'treat' on the air, and that clinicians should not cite any information about clients or exploit the caller for media purposes (Hickling, 1992). After an analysis of calls and ‘reach’ it was suggested that such shows are a valuable way to destigmatise mental health problems and to enhance community mental health through education (Reuben, 1986; Hickling, 1992).

Similar use of radio in NZ has been undertaken (in 1997 by Framework Trust on Access radio and Gwendoline Smith on Radio Pacific, and in 1998 Dr Peter McGeorge on National Radio). Ratings of, and response to, both shows appear to have been positive overall.

The Australian National Mental Health Campaign
The Australian National Campaign is the closest example to what we are attempting in New Zealand.

This Campaign is led by the Mental Health Branch of the Commonwealth Department of Health and Family Services. It was undertaken in the context of the National Mental Health Strategy (which was itself promoted and publicised).

Commencing in 1995, a mass media approach (TV, brochures, posters, billboards, cinema advertising and public relations activities) was the main method (with smaller sub-projects attached). The cost of using the mass media alone was eight million dollars (Australian) over six years.

1. TV Advertising
The evaluation found that television advertising was effective in raising awareness and increasing positive attitudes towards people with mental illness (82% of people recalled the adverts and 52% reported the adverts making them think about their attitudes).

The key message used was that mental illness is similar to any physical illness and can be managed/treated, as can most physical illnesses. However, the managers of this Campaign recently noted that in their opinion, unless television advertising was at prime time and
repeated often, it would not be effective. Such exposure is very costly (one million dollars Australian was the cost of placement of adverts on TV).

2. Brochures
Seven brochures were developed and distributed widely to consumer groups, GPs, schools, mental health services and community centres. They covered depression, anxiety, schizophrenia, bipolar disorder, eating disorders, stigma and the National Mental Health Strategy. The brochures were also found to be effective, and there was, and still is, a strong demand for them.

The evaluation suggested that it is important to have a phone number on every brochure to enable people to access further information or assistance. In addition, a fax-back order form allowed a database of requesting people/agencies to be established.

The next reprint will delete two brochures (the National Mental Health Strategy was only seen as being useful at the beginning of the Campaign, and eating disorders was found to be redundant as people get this information from a variety of sources, particularly women’s magazines). The re-titling of two brochures to include more publicly known words (e.g. phobia on the anxiety brochure and manic depression on the bipolar disorder brochure) was suggested by the evaluation research.

3. Other Findings
Much time and money was spent on a consumer-developed logo. However stakeholders could not agree on a final design so the words ‘National Mental Health Strategy’ were used as a logo. This logo was seen to be useful in giving the Campaign a national identity, profile and cohesion.

Billboards and cinema advertising were found to be ineffective in comparison with TV and brochures.

Aboriginal peoples and Torres Strait Islanders (and other non-English speaking peoples) were not targeted in the Campaign, but cultural issues are to be addressed in future activities. Similarly, rural people were not well served by the Campaign.

Attitudes of mental health professionals were largely unchanged, so this group was targeted in a separate project.

4. Attitudes of Health Professionals
As consumers/tangata whaiora and carers in Australia identified this group as the most discriminatory, a literature review and benchmark surveys were commissioned. The Australian review included carers in the samples.

The authors (Frank Small & Associates) state ‘there exists no literature that shows real success in altering, in a directly positive fashion, the ways in which mental health professions treat people with a mental illness.’ They also suggest that training and education that uses ideas from differing paradigms (such as psychology, sociology and management practices) may be the way forward.
In Australia, unfortunately, the consultants who undertook to design a project only succeeded in alienating the very group they were targeted to work with – so it is now back to the drawing board.

A national workshop of key stakeholders was held in March 1998 to look at future actions. One issue that emerged strongly is that this is a sector that needs to be worked with at the start of any initiative. If staff are seen as part of the problem, then staff must be part of the solution.

5. Community Development Project
This Project is not yet completed, but involves the training of consumers/tangata whaiora and carers in advocacy. The development of an Advocacy Kit was commissioned. The costs of selling this Kit are currently being examined – an estimate is that each will cost approximately A$50 each.

6. Police
The police were targeted at national level. Two national meetings were held, the aim being to tackle stigma at the policy level. These were found to be very useful in raising issues between police and mental health services, and re-directing national policies.

7. Future National Activities for Australia
The manager of this Campaign stated that overall, using the mass media, particularly TV, was effective (Webber, personal communication). However, the main weakness of this approach was that, as community groups were not involved or informed, the power of the Campaign was not as great as if they had been included in the process. Thus, future efforts may focus on building a community development approach to back up any further use of TV.

The Mental Health Branch is currently undertaking an overall summary (pulling all the threads together) of the Campaign in order to decide on future directions for activities in Australia.
Appendix 3 - Anti-Discrimination and Destigmatisation

The following is an excerpt from the Health Funding Authority National Mental Health Funding Plan 1998-2002.

The HFA has accountability for the national anti-discrimination and destigmatisation programme. Accountability was previously with the Public Health Section of the Ministry of Health but has been transferred to the HFA at the request of the Minister of Health. Mental Health and Public Health, within the HFA, are working jointly to develop the project. Mental Health has the overall accountability for the programme’s progress, whilst Public Health retains the budget and has clear responsibilities for the regional programmes as well as significant involvement in the development of the national programme.

A programme structure has been agreed that will ensure all key stakeholders are involved in the development of the campaign (at both a national and regional level) and that decisions can be made and action agreed in a timely and informed manner. This will also facilitate synergy between the regional and the national programmes.

The national component of this programme now consists mainly of a contract to provide a public relations campaign to address negative community attitudes to mental illness.

Key outputs for the contract are:

- Planning, liaison and networking of the programme.
- Ensuring stakeholder participation.
- Establishing a small group of national and regional spokespeople.
- Achieving effective and timely media coverage.
- Running media seminars.
- Organising other opportunities and events for further positive media coverage in conjunction with mental health week.
- Producing a campaign newsletter.

A national provider workshop was held in March to motivate providers, establish a common understanding in what needs to be done, equip the providers with the strategies and skills needed for the programme, identify any training needs that are required, and to generate ownership of the programme. This is aimed to ensure that everyone is heading in the same direction.

A video of the television documentary and leaflet have already been produced. A research contract has provided some useful qualitative information on public attitudes. However, it will not form the basis of quantitative information. A smaller but more focussed survey to establish initial service provider and professional attitudes will be commissioned. This will include a means of measuring changes in these attitudes as the campaign develops. By its nature this will need to be closely aligned to the regional programmes.
At a local level, the offices of the HFA are funding local programmes which will be supported by the national destigmatisation programme. The goals of these programmes include:

- Training mental health and other health professionals on the effects of stigma for people who have mental illness.
- Community based initiatives, information, and education which challenge attitudes.
- Education and training for Māori by Māori with consumer involvement on attitudes towards mental health and mental illness.
- Consumer workforce development.

**Targets**

- To promote acceptance and tolerance of mental health consumers.
- To decrease discrimination by encouraging dialogue within communities, and among mental health consumers and the wider community they line in to achieve dignity, maintain rights, and encourage acceptance of mental illness.

**Action Plan**

- By April 1998 a Project Coordinator will be appointed.
- By July 1998 an anti-discrimination/destigmatisation project plan will be completed.
- By September 1998 project milestones will be identified for monitoring.
- By December 1998, HFA contracts will require providers to actively promote mental health and accept people affected by mental illness (National Mental Health Standard 2.0).
- Monitoring of national contract annually to ensure progress.

**Mental Health Promotion - Public Health**

Mental Health promotion is about creating supportive environments for people with a mental illness, as well as promoting positive mental health environments such as schools, workplaces and homes for the whole population.

At a local level, the offices of the HFA are currently in the process of working with the sector to develop programme plans which fit with the wider mental health funding plans as well as supporting the national destigmatisation programme. In particular, the Public Health Operating Group of the HFA currently funds programmes aimed at promoting mental well-being and early access to intervention, especially for young people.

**Targets**

- To increase public knowledge and awareness of mental health issues in order to:
  - Create a more supportive environment for people living with a mental illness.
  - Help remove the barriers of discrimination and stigma that stop people seeking early assistance and support (National Strategy objective 7.1).
• To improve and promote the mental health of young people and to reduce death rates from suicide (National Strategy objective 7.2).

**Action Plan**

• Continue to purchase mental health promotion programmes in schools and in the community in 198/99.
• By December 1998 develop a national educational resource for awareness of depression on youth.
Appendix 4 - Findings of Business Research Centre research

The Business Research Centre was contracted by the Ministry of Health to conduct the following market research:

- **Pre-research**: scoping issues for members of the public with respect to the proposed campaign. This was to inform campaign development using qualitative social science methods.
- **Pre-testing the communication materials** developed during the course of the campaign using qualitative methods.
- **Monitoring changes in community attitudes** over time as a result of activity in the campaign. This tracking uses quantitative research methods.

**Modifying the Community’s Attitudes to People with Mental Illness (pre-research, March 1997)**

_Aim_: To review language, messages and themes about mental health and mental illness and to assess knowledge and understanding of mental illness.

_Method_: Using qualitative methods (focus groups and interviews) this phase targeted the general public (15-44 years) and included 39 subjects in eight focus groups (two of which were solely Pacific Islands peoples). The interviews were undertaken in Wellington, Christchurch and Napier.

_Results_: In summary, there was a common belief that ‘mental illness is not my problem’. People displayed a lack of knowledge about what mental illness is, but wished to get more information on it and ways that they could help someone with mental illness. There was a commonly held belief that mental health services were inadequate, an overestimation of ‘dangerousness’ was found and the media was cited as a major source of information. There was no mention of the material specific to Pacific Islands beliefs.

_Outcome_: The conclusions of this report were influential in changing the focus of the campaign (i.e., postponing the advertising).

**Pre-research with Māori (March 1997)**

_Aim_: To review language, messages and themes about mental health and mental illness and to focus on Māori as a priority audience.

_Method_: Using the same qualitative methods, six focus groups were undertaken in Auckland and Hastings. In addition, six interviews were undertaken with mental health services staff (three) and carers (two).

_Results_: The above themes were echoed, but there were additional beliefs that Mental health services were not being responsive to the needs of Māori. The Campaign needed to be culturally relevant, with a focus on education on mental illness for whānau, and on Māori culture for providers.
Pre-testing of the Campaign Materials (March 1997)  
Focus groups included all key stakeholder groups in order to gauge initial reaction to the concepts and design of the documentary *The Person Next Door*, the brochure, four print adverts intended for use in magazines, four taglines and the brand. The separate report on Māori views suggested that overall, the materials were well received. Respondents liked the tagline ‘mental illness isn’t contagious – your attitude is’.

Public Knowledge of, and Attitudes to, Mental Health and Mental Illness (September 1997)  
Aim: To establish a baseline of knowledge and attitudes held about mental illness, including subgroups of managers, employers, landlords and staff in mental health services, whose actions have a significant impact on people with mental illness. This work was designed to provide a comparison measure for evaluation of local activities.

Method: A random nation-wide telephone survey of 1,733 people was conducted. There was a low response rate overall – only 20% of contacts resulted in an interview.

Results: Results were consistent with pre-research, previous NZ studies and overseas data, that is: knowledge of mental illness is poor, the most common source of knowledge is the media, and most people (76%) wanted to know more about specific illnesses and treatment and how to help. Māori responses did not differ from that of the general population (unlike the pre-research). There was no discussion of Pacific Islands peoples’ views. Evaluation of the subgroups showed that employers were less likely to have an employee with mental illness, people working in mental health were less discriminatory and landlords were not less likely to rent a house to a person with mental illness.

Pre-testing of the Documentary, *The Person Next Door* (September 1997)  
Ninox Films made the 50-minute documentary.

Focus groups were held with the general public, consumers/tangata whaiora, family/whānau and providers in order to advise the Ministry of Health on the documentary’s relevance and credibility. The Eru Pomare Māori Health Research Centre did a separate report on Māori views.

Overall, the documentary and brochure were well received by Māori. Recommendations from these focus groups meant that changes were made in the final version of the documentary.

Overall Outcome  
This research supports findings of previous NZ studies (Patten, 1992; Ng et al 1995). It also provides some baseline data about knowledge and attitudes. Unfortunately, because of the low response rate, this data cannot reliably form the basis for a comparison after any intervention with the general public. BRC suggested a communications strategy that makes mental health an issue of relevance to people, creates a positive environment in which to receive information, and improves people’s basic knowledge.
DESTIGMATISATION PROJECT:

Community Attitudes Towards People with Mental Illness
Stage 1 - Pre-Research with Māori

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March 1997
## CONTENTS

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>EXECUTIVE SUMMARY</td>
<td>58</td>
</tr>
<tr>
<td>INTRODUCTION AND OBJECTIVES</td>
<td>60</td>
</tr>
<tr>
<td>Introduction</td>
<td>60</td>
</tr>
<tr>
<td>Objectives</td>
<td>61</td>
</tr>
<tr>
<td>METHOD</td>
<td>62</td>
</tr>
<tr>
<td>Methodology</td>
<td>62</td>
</tr>
<tr>
<td>Sample</td>
<td>62</td>
</tr>
<tr>
<td>Procedure</td>
<td>62</td>
</tr>
<tr>
<td>Reporting</td>
<td>63</td>
</tr>
<tr>
<td>THE CAMPAIGN</td>
<td>64</td>
</tr>
<tr>
<td>DEFINING HEALTH</td>
<td>66</td>
</tr>
<tr>
<td>Good Health</td>
<td>66</td>
</tr>
<tr>
<td>Ill Health</td>
<td>67</td>
</tr>
<tr>
<td>Mental Health/Illness</td>
<td>68</td>
</tr>
<tr>
<td>TERMINOLOGY/DESCRIPTION</td>
<td>69</td>
</tr>
<tr>
<td>WHAT IS NORMAL?</td>
<td>73</td>
</tr>
<tr>
<td>IDENTIFYING MENTAL ILLNESS</td>
<td>74</td>
</tr>
<tr>
<td>ESTIMATES OF PREVALENCE</td>
<td>75</td>
</tr>
<tr>
<td>CAUSES</td>
<td>76</td>
</tr>
<tr>
<td>TREATMENT</td>
<td>78</td>
</tr>
<tr>
<td>PEOPLE IN THE COMMUNITY</td>
<td>80</td>
</tr>
<tr>
<td>CONTACT</td>
<td>82</td>
</tr>
<tr>
<td>BARRIERS TO SERVICES</td>
<td>83</td>
</tr>
<tr>
<td>WHANAU NEEDS</td>
<td>85</td>
</tr>
<tr>
<td>SUPPORT SERVICES</td>
<td>86</td>
</tr>
<tr>
<td>SOURCES OF INFORMATION</td>
<td>88</td>
</tr>
<tr>
<td>EDUCATION</td>
<td>89</td>
</tr>
<tr>
<td>THE CAMI SCALE</td>
<td>92</td>
</tr>
<tr>
<td>KEY MESSAGES</td>
<td>93</td>
</tr>
<tr>
<td>REFERENCES</td>
<td>95</td>
</tr>
</tbody>
</table>
EXECUTIVE SUMMARY
This paper reports on the method and results of the pre-research with Māori.

- Authors have described that Māori have an holistic approach to health that incorporates dimensions of the physical, mental, spiritual and whānau. These interrelationships were often described by Māori in the pre-research interviews and focus groups. Although not much was known by Māori members of the general public about mental illness, there was an overwhelming desire to support those who are ill and to help them stay within or reintegrate them back into the whānau. In this sense, the whānau is the unit that is talked about most often when community is discussed. The campaign therefore needs to work within and support this whānau structure.

- Māori were generally positive about the campaign, although this was accompanied by a degree of skepticism. This skepticism had two readily identifiable sources:
  - the view that the money spent on the campaign might be better directed to mental health services;
  - the view that the campaign would not be relevant to Māori.

- In order for the campaign to be seen as being relevant for Māori, it needs to appeal to people on both an individual and cultural level so that it is relevant to them as Māori, and relevant to their everyday life.

- In addition to relevance, for the campaign to be successful for Māori it needs to be accompanied by improved service accessibility and appropriateness for Māori. A key feature of both the public as well as the carer and provider interviews was the view that the mental health system is not currently meeting Māori needs. This included an inability to provide healing for Māori.

- Participants noted that accessing mental health services was difficult for Māori, so that families may only seek help when a situation with a family member is particularly severe. In addition, knowledge about mental health services and providers was generally lacking among Māori. This has important implications for early intervention. It is suggested that the campaign focus on early indicators of mental illness and how to access help. There is a thirst for this type of information - a key feature of the focus group interviews was the questions about mental illness directed at the facilitator at the end of the discussion.

- A focus on educating families and whānau about mental illness would restore to them a sense of control over what may otherwise be an unusual and/or unpredictable situation. This could help address the issue of dangerousness that was associated with mental illness.

- A campaign that meets Māori needs should also be accompanied by a mental health provider campaign. It is pointless to increase Māori knowledge about mental illness and early intervention if this knowledge is then discounted when Māori attempt to access mental health services.
Carers and providers talked of tūro and wairangi in preference to terms such as client, consumer, patient, etc. Māori terminology was seen to be more positive and healing. It is recommended that the consideration be given to the use of Māori terminology within the campaign and within mainstream mental health services because of the negative connotations associated with labels such as client and patient.
1) Introduction and Objectives

1.1) Introduction

A Multi-Media Attitude Campaign

The Public Policy Group of the Ministry of Health has purchased a multi-media campaign designed to help modify the community’s attitudes to people with mental illness. It is intended that this campaign will be launched about mid 1997 and will continue through to October 2000. As such, it will be part of a wider range of activities initiated in this area by the Ministry.

The campaign has been purchased from Colenso Communications Limited and Huia Communications Limited.

Given the objective of the campaign, it is primarily targeted at members of the general public aged 15-44 years of age. Māori and Pacific Island peoples’ are priority audiences.

A Research Evaluation Programme

In association with this campaign, the Ministry has also purchased research evaluation services from the Business Research Centre. The Centre is providing these services with assistance from Te Rōpū Rangahau Hauora a Eru Pōmare, and the Aotearoa Network of Psychiatric Survivors.

Two specific types of evaluation services have been purchased:

1) Those that will ‘pre-test’ the communication materials that are developed by Colenso Communications Limited.

   - ‘Pre-testing’ will occur before the campaign is launched and use qualitative social science research methods. Given that the campaign is expected to evolve over time, ‘pre-testing’ will also occur at other stages during the term of the campaign.

2) Those that will monitor the campaign against agreed ‘advertising indicators’ and track changes in the community’s attitudes as a result of all the activity undertaken between 1997 and 2000.

   - This monitoring will occur at specific intervals during the term of the campaign and use quantitative social science research methods. A benchmark survey will be undertaken before the campaign commences.

Exploratory Phase of Research (‘Pre-research’)

There is a considerable amount of overseas literature on measuring community attitudes to people with mental illness, but very little New Zealand based research.

The methodologies and conclusions arising from this overseas research may be applicable to the New Zealand situation, but prior to the research programme
Commencing, the Ministry of Health has asked for an exploratory phase of investigation, or ‘pre-research’ to be completed.

This report specifically presents and comments on the results of this ‘pre-research’ with Māori members of the priority groups.

1.2) Objectives

The objective of the pre-research was to explore Māori knowledge of mental illness as well as Māori experiences of, and attitudes towards those with mental illness. These areas were explored in key informant interviews and focus groups with Māori members of the public and with Māori carers and providers.
2) Method

2.1) Methodology
A qualitative approach was adopted for the pre-research to allow participants the freedom to spend more time discussing issues of particular relevance to them. This was set within the context of an interview guide that covered the areas of concern to the investigators and the attitude campaign (see Appendix A in BRC report, March 1997). Thus while all interviews and focus group discussions touched upon the same areas, the depth of discussion in each of the areas may have differed across interviews and groups.

2.2) Sample
Individual interviews with six Māori members of the general public were conducted in Auckland and Wellington. Two participants were recruited in each of the three age groups (15-24 years, 25-34 years, 35-44 years). In addition, six focus groups with Māori members of the general public were conducted: three in Hastings and three in Auckland. Two focus groups (one in Hastings and one in Auckland) were conducted in each of the three age groups (15-24 years, 25-34 years, 35-44 years). All of the focus groups were carried out during early 1997.

Five individual interviews were conducted with providers (n=3) and carers (n=2). These occurred in Hawkes Bay (n=2) and Auckland (n=3). In addition, one focus group interview was conducted with a group of providers in Hawkes Bay. Providers were defined as persons who currently provide a formally recognised service within the mental health system. Carers were defined as persons who provide primarily community support services without formal recognition by the current mental health system.

2.3) Procedure
All interviews and focus groups began with the facilitator(s) introducing themselves, the campaign, and the notion of pre-research. Participants were assured that there were no right or wrong answers and that their responses would be confidential. They were also informed about what would happen to their responses and who would be listening to the discussion tapes and reading the final report. Informed consent was obtained from each participant.

Permission was also sought from the participants for the interview or focus group to be audiotaped. All agreed to this.

Participants in the focus groups were then given the opportunity to introduce themselves. In the individual interviews, participants were asked about themselves and their work.

Individual interviews lasted between 30-45 minutes, while focus group discussions lasted for one and a half to two hours. Carer and provider interviews lasted approximately one hour.
2.4) Reporting

Key themes from the discussions were identified and are presented in this report. Quotes from participants are used to highlight themes. All interviews and focus group discussions are presented under appropriate headings, when these issues were touched upon. ‘Individual interviews’ refers to the interviews that took place with Māori members of the general public; ‘focus groups’ refers to group discussions with Māori members of the general public; ‘carers and providers’ refers to either individual or group discussions with Māori carers and providers in the mental health system.
3) The Campaign

Participants were given an outline of the proposed campaign, the aims and the role of the pre-research stage of the project.

**Individual Interviews**

Feedback from the individual interviews suggested that the campaign might be useful but that in order for it to be received well by Māori, it had to be relevant to Māori.

“There are a number of campaigns with some good messages that just miss the boat with Māori... and that’s because we can tell they aren’t thinking about us”

“You know a few years ago, you hardly saw a brown face on TV... and now there’s heaps more... I like it... but that’s only in certain things like the news... not in adverts... people need to realise that Māori respond to Māori”

Some participants were more apathetic about the campaign.

“Well, it doesn’t affect me ... so why should I be interested... “

“It’s not something I think about on a regular basis or anything... I don’t see it as relevant to me... even if I could see this as relevant for me, what could I do about it?”

Most participants believed that it would be difficult to get people to change their attitudes towards mental illness or to encourage people to begin thinking about it.

**Carers and Providers**

Overall, the carers and providers were sceptical about the usefulness of the campaign; they were generally positive towards the concept of a campaign but most felt that resources might be better directed to other areas.

“Resources are often not available to provide Māori support services...”

“Need for Māori providers of Māori programmes and services...”

“...our whanau need education... about the illness... about where to get help... about when to get help... “

“Like I said before, to start up all these new groups, like this one here for example, how much money goes into setting up that thing? Y ou know I know what needs to happen. Why buy a new car for somebody to go and see what’s happening and they’ve got no resources to do anything?”

Participants agreed that the campaign would be most useful if support systems were also offered to meet community needs.
“And I really hope that if they’re going to do this advertising campaign, that they’re willing to put the money into the community to make sure that there are things offered. Like a drop in centre, like other things that the community needs...”

I agree that something does need to be done to take away the stigma, but people need to know that if they are going to put people in the community... then there need to be the resources to go with it... I mean... you can’t say to people that mental illness is ‘okay’ and then not back it up... I know that if you start to raise the profile of tūroro, then you need to be able to back it up... once people understand that they can get help, they’ll start wanting it...

Carers and providers were clear that in order for the campaign to be of real use, the ‘system’ had to be prepared to make changes that would support peoples’ expectations.

“What I really hope is that this campaign, this research has some impact on the system. People’s attitudes to mental illness needs to change... but more than that, the system’s attitude to people has to change... What I mean is this, if you are going to do this [the campaign]... then people are going to expect certain things to be there... if the system isn’t prepared to change then don’t try to change people’s attitudes...”

“What I want to know is this if I go to get some help... and that’s not there... what is that going to do...”
4) Defining Health

The initial discussion of general views on health and illness helped to warm participants to the interview as well as set the context for the discussion of mental health. In addition, it provided important insight into how participants talked about health, including the language available to them. Three definitional aspects are covered in this section: defining good health, ill health, and mental health/illness. Included in the mental health/illness section are participants reflections on what is normal and how they would identify someone who had a mental illness.

4.1) Good Health

Focus Groups
Participants spontaneously linked being healthy to the mind, body and to the spirit. Overall, there was a general consensus that health extended beyond taking care of physical needs. Many participants believed that mental well-being was as important as physical well-being. A number of participants also distinguished between mental well-being and spiritual well-being.

“Health is about being well, both spiritually and in your body, holistically, and making sure my family is okay”

While terms like wairua and tikanga were used to describe spiritual health, mental health was strongly associated with the mind, thoughts, thinking and the brain.

Common factors identified as being necessary for health included diet (food), cleanliness, shelter, employment, financial security, and communication with and support from family, friends and community.

“...keeping in contact with the people you relate to, friends who you relate to”

All groups identified experiencing autonomy and being able to plan and control one’s life as essential to good health. Participants agreed that having a sense of purpose or usefulness were important aspects of this.

A number of participants said that having knowledge about food and their diet was an important part of maintaining good health. Knowledge about medication was also raised. For one participant, having knowledge about the side effects of particular medications enabled her to make informed decisions and choices.

The notion of identity as a key contributor to health was most strongly articulated by the Hastings 35-44 year age group. Identity was strongly linked to ‘being Māori’ and to the notion of belonging to and having knowledge about community, with the term community referring to family and friends, as well as geographical location.

“Knowing where you are, where you’re from, where you are going, a sense of belonging...”
4.2) Ill Health

Focus Groups

Overall, participants saw poor diet and the use of alcohol, drugs and cigarettes as contributing to ill (physical) health. Symptoms, such as coughing, were also used to describe illness.

For the Auckland groups, unemployment was strongly identified as a key contributor to ill health. Participants linked unemployment to stress and the high costs of living ‘in the city’. Generally, participants appeared to believe that living in Auckland required ‘more money’ than living in rural areas.

Unemployment was also seen as a barrier to people accessing health providers. Many participants identified a number of occasions they had not gone to the doctor’s because of the high cost.

“Y ou’ve got to make a choice between making sure there’s food on the table or going to the doctors. By the time you’ve got the kids organised, made the appointment and got the prescription that’s sixty bucks... I can’t afford to be sick...”

Participants acknowledged that there were some illnesses that people had difficulty talking about while there were others that people appeared to find relatively easy. Colds, flu, aches, asthma and broken bones were clearly identified as illnesses that people found easy to talk about. This ease appeared to reflect participants’ familiarity with particular sicknesses.

Illnesses such as cancer, AIDS, STDs and mental illnesses were identified as health problems that people had difficulty talking about. Auckland groups were more likely than their Hastings counterparts to spontaneously mention these illnesses.

When exploring the notion of what made certain sicknesses difficult to talk about, participants identified:

- social stigma;
- lack of information; and,
- not being able to do anything about it.

Some participants believed that particular groups of people would be less comfortable talking about particular illnesses. The most commonly identified group were those older than the participants, even for the oldest focus groups. The Auckland based 15-24 year group perceived older people as having greatest difficulty talking about matters related to sex (including STDs and AIDS). Correspondingly, participants from the Auckland groups identified that they would have difficulty talking to older age groups about particular illnesses (including those related to sex). These participants indicated feeling less apprehensive about talking to members of their own peer group.
4.3) Mental Health/Illness

Focus Groups
When asked to define the term ‘mental health’, some participants were hesitant and appeared unsure what was being asked for. Common definitions that emerged were:

“Something that sticks in their minds”

“The behaviour of a person... I mean for the likes of me, it’d be the way they act, that’s part of it... how they talk, and what they say... what comes out”

“Emotionally, like if you’re upset and that... different situations and how you react... affects your mind”

There was less confusion over the definitions of mental illness among participants who had a family member who suffered from a mental illness. These participants were also more likely to say that they typically interacted with people with mental illness. Almost all of the other participants had knowledge of someone, outside of their family circle, who had a mental illness.

Individual Interviews
Participants strongly associated strange behaviours and bizarre thoughts with mental illness. Included in the description of strange behaviours was the story of a well known young man on a busy inner city street who habitually shook the hands of passers-by. Generally, participants identified that while there were some who people with mental illness were ‘obviously’ unwell, in the main, it would be difficult ‘to tell’. Some participants clearly articulated a belief that there were a number of people who ‘looked normal’ but who ‘probably had some problems’.
5) Terminology/Description

Focus Groups
The use of the term mental health, as understood and applied by groups, was strongly tied to notions of mental illness or psychiatric disability. The term ‘mental health’ was frequently perceived as being negative. This may be a reflection of the interchangeable use made by participants of the terms mental health and mental illness. A large number of participants often appeared to get confused by the negative colloquial use of the term mental and the interviewer’s use of the term mental health.

Overall, participants were familiar with, and used unprompted, the terms schizophrenia and depression. However, few were able to identify specific criteria for these conditions. Most groups typically identified depression as feelings of sadness and/or grief. Depression was also linked to low self esteem and/or lack of participation in activity.

Schizophrenia was commonly associated with the notion of ‘multiple personalities’. However, Auckland participants were more likely to identify schizophrenia as ‘bizarre thoughts’. Their heightened awareness may have been due to media reporting of the Raurimu massacre which had included the terms psychiatric illness and schizophrenia.

Auckland participants also identified eating disorders (anorexia and bulimia) as mental illnesses, with some participants being intolerant of people with eating disorders. This may reflect a perception that eating disorders are under the voluntary control of an individual.

Māori terms such as wairangi, pōrangi and tūroto were also generated by a number of participants. Exploring differences in perceptions of these terms, a number of participants identified a preference for the Māori terminology. As one participant stated:

“...it sounds less harsh...”

Participants were also asked to generate words or phrases related to mental illness that were in common usage:

<table>
<thead>
<tr>
<th>Mental</th>
<th>Fucked up</th>
<th>Lost it</th>
</tr>
</thead>
<tbody>
<tr>
<td>loopy loo</td>
<td>lost their marbles</td>
<td>round the bend/twist</td>
</tr>
<tr>
<td>off/over the edge</td>
<td>psycho</td>
<td>schizo</td>
</tr>
<tr>
<td>nuts</td>
<td>doongy</td>
<td>cracked</td>
</tr>
<tr>
<td>freaks</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Colloquial terms like psycho and schizo appeared to convey a sense of extreme mental disturbance and were most frequently associated with violent and unpredictable behaviour.
When discussing or describing a person with a mental illness, providers most frequently used the term tūroro.

“We call them tūroro because we don’t like the word ‘client’... because the... well, tūroro in Māori, it means a person that is unwell...”

While some providers used the term tūroro as an alternative to terms like ‘client’ or ‘patient’, other’s defined its use in ways similar to this:

“... tūroro... it doesn’t just mean client or someone unwell... but it also has a meaning of awhi or support... aroha... to help...”

As an overall impression, tūroro conveyed a positive sense.

Another word that was frequently used by providers was wairangi:

“Wairangi, in the old term, means, it does mean a person who is out of kilter, and who is mad; but they associate it with the dark forces... with spiritual things...”

Some informants seemed reluctant to use wairangi and preferred to use tūroro as an alternative. For these informants, some reluctance can be traced to perceptions of ‘dangerousness’ (spiritual) being associated with wairangi. Related to this was a notion that there is a difference between mental disorder and disorder related to the spirit.

“Perception of wider public is one of craziness, dangerousness - a total misunderstanding. Māori people can’t distinguish between a mental disorder and wairangi”

Other providers indicated being comfortable with its usage and offered a positive definition of it:

“... wairangi... we’ve always got them ‘round the marae... it’s actually quite a positive term... we just make it derogatory... they’re blessed... its got different connotations... if you look at it’s root word, it comes from wairua... so it means to be sprinkled with heavenly waters”

These providers seemed comfortable using tūroro and wairangi interchangeably.

“... what it is, is this... if we think about the work that we do and the way we are used to seeing ‘clients’... then we think about them being mad... you know, really negative... and so, if we just think of tūroro or wairangi as clients... then we see them in a derogatory way... Now, if we remember about the origins of the words and the tuturu Māori way... then it becomes something else... something better...”
When asked for other specifically Māori terms that might be used to describe tūroro or clients, carers and providers provided the terms pōrangi and whānau.

“When we were kids, you were pōrangi, but you don’t hear that... it was better than calling somebody an idiot, wacko or something. It just sounds better... It’s the same meaning, but it sounds better...”

“...pōrangi’s a good word... or whānau... you know, that’s what they are, eh... they’re whānau and sometimes we forget that... pōrangi, well that’s someone who’s crazy... not in a bad way... just crazy...”

Overall, carers and providers attached positive meanings to the terms pōrangi and whānau.

Other terms used to describe persons with a mental illness included a number of psychiatric terms (e.g, psychotic, manic, mental disorder), as well as colloquial phrases. Both groups of carers and providers were familiar with the use of these terms, particularly those involved in the provision of services. Overall, participants were reluctant to use the terms:

“...it’s not a nice thing... patient... it makes you think of hospitals and sickness... people in pyjama’s... I just don’t like it... maybe it’s too impersonal, you know...”

“...clients are people that want a service or want to be in a situation... it makes me think of something for sale... anyway, client’s just another word for patient...”

Exploring more colloquial terms for describing people with mental health issues, carers and providers were generally agreed that the public perception was generally negative.

“Old Joe Bloggs on the street calls them loopy’s or loonies or idiots or wacko’s, you know, real derogatory things... but I don’t know what they call them otherwise...”

“Perception by the wider public is one of craziness or dangerousness...”

“... the public just don’t understand... they’re scared...”

“... the stigma is stopping Māori from helping tūroro...”
Participants were also asked to generate words or phrases related to mental illness that were in common usage:

<table>
<thead>
<tr>
<th>Māori</th>
<th>English</th>
</tr>
</thead>
<tbody>
<tr>
<td>tūoro</td>
<td>client</td>
</tr>
<tr>
<td>wairangi</td>
<td>patient</td>
</tr>
<tr>
<td>pōrangi</td>
<td>psychiatric</td>
</tr>
<tr>
<td>whānau</td>
<td>psychotic</td>
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<td></td>
<td>schizophrenic</td>
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<td></td>
<td>manic</td>
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<td>mental disorder</td>
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<td>psychs</td>
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<td>loopy</td>
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<td>kinked</td>
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<td></td>
<td>crazy</td>
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<tr>
<td></td>
<td>nuts</td>
</tr>
<tr>
<td></td>
<td>fucked in the head</td>
</tr>
<tr>
<td></td>
<td>mentally ill</td>
</tr>
<tr>
<td></td>
<td>loony</td>
</tr>
<tr>
<td></td>
<td>wacko</td>
</tr>
<tr>
<td></td>
<td>idiots</td>
</tr>
</tbody>
</table>
6) What is Normal?

Focus Groups
Following on from the discussion of definitions of mental health and mental illness, participants became interested in the definition of ‘What is normal?’ This issue was most strongly articulated by the Hastings 35-44 year age group. Members of this group gave examples from their community that outsiders identified as being strange or different. For example:

“...dragging a car down the street upside down...”

“...going down the street in her pyjamas... with her dressing gown and everything...”

“...doing my washing at night...”

Another example related to the issue of ‘normal’, which was given by a member of the Hastings 15-24 year age group. She identified a cousin who had been diagnosed with a mental illness. However, because he had ‘always’ behaved in a particular way, family members were ‘used to it’ and did not see his behaviours as unusual.

The issue of ‘what was normal?’ was also raised in the individual interviews. These participants identified that perceptions of normal varied between groups and that this, in turn, reflected what was considered to be ‘strange’ or ‘not normal’.

“I might think that one thing is normal... but somebody else won’t... does this mean I’m not normal... or that they aren’t?...”

“Pākehā people think it’s normal to park their bums on the table... but I don’t. Does that mean that they are mentally ill? It’s about who defines what is and what’s not acceptable...”

Some participants indicated that the definitions of normal were constructed by Pākehā, and that this had significant impact on Māori.

Culturally we’re different... we think about things differently... we live in a different lifestyle... so how is it that Pākehā define what is normal? I think a lot of Māori get into trouble because the system doesn’t know how to deal with us... and we don’t know how to deal with the system... Māori are being judged by criteria that don’t fit with our sense of the world... so of course we end up ‘sick’ or in jail...”

Behaviours might therefore be seen as ‘normal’ by members of a particular family or community, and yet be seen as strange by people from outside of that group. This is tied to issues of acceptance of and familiarity with people’s behaviours so that judgements of what is normal and not normal (and possibly dangerous) may be best made by those inside a community. Participants stressed the need for mental health education to complement this process.
7) Identifying Mental Illness

**Focus Groups**

Overall, participants agreed that it would be difficult to identify someone with a mental illness unless they were known to you. Changes or disturbances to a person’s normal patterns of behaviour were seen as indicative of mental disturbance. Such indicators included social isolation, inactivity, thought distortion, inappropriate affect and breakdowns in communication.

“Can’t understand what they’re saying…”

“...stop communicating... don’t come out of their houses”

“...not wanting to join groups or that…”

“They start behaving differently…”

“People are creatures of habit, and when they start to get out of those habits then you can tell that something’s wrong”

The use of alcohol and other substances was associated with mental illness. A number of participants felt that some people “go schizo” using alcohol or drugs. Participants from both 15-24 year age groups were strongest in their identification of these substances as key contributors to mental illness.

“Tell whether they’re dope users... veins popping out... skinny”

Participants commonly associated unpredictable and unexplainable behaviours, including violence and dangerousness, with identifying mental illness. Dangerousness was linked to self harm, whereas violence was linked to harm of others.

The Auckland 24-35 year age group had the greatest awareness of the effects of the medication used to treat people with mental illness. This group described slow speech, poor or slowed physical coordination, shuffling/halting gait as common side effects of medication. Further inquiry revealed that a number of the participants had family members, or knew of others, with a mental illness. There was a general agreement amongst members of this group that it would be easy to confuse the effects of the medication with the illness.

Auckland participants also had greater awareness of where community-based facilities were located.
8) Estimates of Prevalence

Focus Groups
Participants acknowledged their difficulty estimating the proportion of the general population who suffered from a mental illness, with many participants stating that the prevalence depended on how mental illness was defined.

Most estimates of prevalence were below 20%, although a few participants believed that it could be as high as 50%. When asked what proportion of mentally ill people were violent or dangerous, most estimates were in the region of 50% or greater.
9) Causes

Focus Groups
Participants were asked to identify possible explanations for mental illness. Overall, key explanations included drugs/alcohol, abuse, stress and loss of social support as factors.

Some members of the Auckland groups, particularly those in the 25-34 year age group, identified the effects of colonisation as a key contributor to the poor health status of Māori. Participants citing this as a factor frequently identified ‘loss of land’, ‘te reo’ and the ‘breakdown of traditional Māori values’ as examples of the way colonisation had impacted on Māori.

Participants did not identify biological factors as a cause of mental illness. When this issue was raised as a possible factor, participants would generally wonder about the effects of cigarette smoking and alcohol use during pregnancy.

There was a perception by some participants that people with certain mental illnesses (specifically anorexia/bulimia) are to blame for their condition. As noted earlier, there is a belief that some illnesses are under the voluntary control of the individuals affected.

One participant (15-24 year age group) related a story about a group of girls at her school who had formed a suicide pact and engaged in self harm behaviours (including cutting themselves). She also described them chanting songs/words aloud in the school grounds. A n explanation that had been offered up by a teacher at the school was that the girls were ‘just trying to get attention’.

Another participant (15-24 year age group) had been told by a religious studies teacher that mental illnesses were caused ‘by the devil’.

Individual Interviews
A number of participants identified a relationship between ‘mental illness’ and the effects of colonisation, indicating loss of land, power and cultural alienation as factors contributing to mental health difficulties experienced by Māori.

Participants typically explained mental illness as a reaction to stressful events or a build up of tension. Events identified as stressful included the break up of a family, loss of job, death of someone close, ill health and financial worries. These events were strongly linked to the issues of alienation, the disintegration of Māori values and powerlessness. Powerlessness was defined as the inability to effect change.

Only one participant spontaneously mentioned genetic predisposition as a possible explanation for mental illness. However, this was qualified with the rationale that ‘it’ might only occur under particular circumstances or in relation to particular environmental cues.

One participant identified childhood sexual abuse as a possible reason for people becoming mentally ill.
In general, participants appeared interested in understanding possible causes of mental illness, and to that extent, asked a number of questions relating to causality. The focus group interviews invariably ended with the participants asking numerous questions of the facilitator.
10) Treatment

**Focus Groups**
Overall, participants seemed to have little information about treatment options.

A number of participants had heard of ‘Prosac’, but most were generally unsure what it was used for. Others identified knowing that some types of medication were used to treat mental illnesses. Some participants had a good knowledge about the effects of the medication, however, participants overall were unaware that there could be side effects.

Counselling and therapy were identified as treatment options. Many participants had a vague sense of what this involved and generally identified it as:

“... somewhere you go to talk about your problems...”

Some participants believed that rehabilitation would be useful in helping people ‘get better’. These participants believed that community-based care was an important part of the rehabilitation process:

“They probably need to be treated just like normal people... not to be stared at like freaks”

“It can’t be good for them to be locked away... I mean, how are they s’posed to get better if they don’t get a chance to be normal?”

With prompting, most participants recalled having heard of ‘electric shock treatment’. However, they were generally unaware of what this treatment option involved.

Participants were generally confused about what was meant by the term ‘treatment’. Some believed that treatment resulted in a return to full health, others indicated that treatment referred to the control of symptoms. A number of participants indicated that some people might recover, but many would not.

Many participants believed that people with mental illnesses could easily relapse and fall ill again. This belief was tied to notions of unpredictability and not being able to trust those who are mentally ill.

**Individual Interviews**
Overall, participants had a low awareness of possible treatment options available for people living with a mental illness. Prompting revealed that people had heard of therapy, electric shock treatment and the use of medication (i.e, Prosac) as ways of dealing with mental illness. A number of participants were unaware that counselling and other related services were used in treatment plans.

Participants were asked to identify what things they thought might be useful to help people with mental illness. A number of participants identified that involvement with family and reconnection to social groups could be useful.
“...get them back to their whānau... not just Mum and Dad, but back home too. Sometimes people don’t know who they are or where they come from... and so they get sick... If we can just get them back into the whānau... then things must be better...”

Some participants believed that restoring control was an important step.

“...if I was mentally ill... I’d like a house... that way I’d have something that belonged to me... that I could feel safe in... that way I could have a base to plan from...”

“People need to feel in control of where they are headed... not just those with a mental illness... but everybody... I think that helping those people especially to get some control is important... they probably haven't experienced control before...”

Overall, participants agreed that support services also needed to be offered to whānau involved in the provision of care.

“Whānau need help too... it’s good that something’s being done to get people [with a mental illness] accepted into the community, but what about the families... they need help to get accepted as well, and they need to know that they can get help when they need it...”
11) People in the Community

Focus Groups
Participants were described a scenario in which a residential unit for people with a mental illness was located next door to their home. Participants were asked to describe their thoughts, feelings and potential anxieties about this scenario.

Generally, participants identified feeling curious about the possibility of interacting with their new neighbours.

“It’d be good... it’d give me a chance to find out more”

“At least they’d be quiet...”

“I guess it would be okay... the question is whether or not they’d be able to cope living with us”

“People are scared of what they don’t know... which is stupid really... and when that happens - they start making up stories... a [residential] house would be a real help to breaking down stereotypes... if I was them... I’d be more scared of us”

Many participants felt it would be a good opportunity for finding out more about living and caring with people with a mental illness.

“See, we’ve got this cousin and he... well, no one’s really sure if we’re doing the right things for him, you know... but this way, we might be able to learn from them, or find out how to help”

In general, participants felt that if they were given more information about people with mental illness and how to help them, or provide care, they would feel more prepared.

A common theme that related to learning opportunities concerned children:

it’s embarrassing... sometimes you have to tell your kids not to stare... but they don’t understand... I mean, if they got used to them [people with mental illness] then maybe they wouldn’t stare... who knows, maybe they’re [people with mental illness] staring at us”

Exploring what might make it difficult for people to accept mentally ill people into their community, participants gave a number of common themes, such as:

• not knowing how to act;
• fear; and,
• ignorance... not knowing.

One participant thought that she might benefit from their presence:

“Y eah... at least there’d be someone to watch my house”
Overall, participants had few concerns for themselves about safety. However, most participants said that they would worry about their own or neighbouring children with a residential unit close by. Fears were linked to concerns about unpredictability of behaviour and children being unable to look after themselves. Participants explained their anxiety in very similar terms, for example:

“...well, you just have to be careful with your kids... we’re careful with any new people that move into the neighbourhood”

However, most participants felt that with adequate supervision and care for the residents, they would feel safe.
12) Contact

**Individual Interviews**

Most participants who were individually interviewed, identified having knowledge of or contact with a person living with a mental illness (including, friends, family, colleagues).

Some participants spontaneously related stories of interactions on the street with persons who appeared to have a mental illness. In a number of instances, participants were clearly able to identify suburbs known to have high populations of psychiatric outpatients.

Overall, interactions and contact with persons living with a mental illness appeared to carry few negative overtones. Participants typically identified feeling awkward and not knowing what to say.

A few participants identified feeling embarrassed and awkward when talking to someone with a mental illness.

“*I’m never sure what to say... I was talking to this woman at the bus stop and she was telling me all this stuff... that she owned all these buildings around town... and that people were trying to poison her... I don’t know how to respond to that... anyway, she could have been telling the truth... I don’t know...”*

“*It’s hard you know, even when they’re your own... cos a part of you always knows they were sick... and it’s there but no one’s talking about it...”*

“*We should be able to talk about it... but we don’t know how... I don’t know what questions to ask or anything...”*

One participant described themselves as being extra vigilant, particularly when with a person (friend, family, colleague) known to have a mental illness.

“I find myself watching them, like I’m always checking to see that they’re okay... and I wonder if they notice... or if it’s just me... that kind of thing puts a strain on your relationship...”
13) Barriers to Services

**Focus Groups**
Participants were asked about barriers to help, seeking and accessing services. Common themes identified relating to the individual included fear, shame, and a sense of wanting to manage by themselves.

Some of the participants in the Hastings groups (24-35 year age group and the 35-44 year age group) believed that the idea of ‘managing by themselves’ came from Māori cultural values. A number of those participants related stories of ‘keeping it in the family’ and whakamaa (used in this context as shyness) as barriers to asking for help. A few participants in the Auckland groups also used whakamaa to indicate shame. It can mean both of these and more.

A number of participants identified not knowing when they should ask for help as a barrier. This notion was tied back to the issue of defining ‘normal’. Some participants felt that if they could know what was ‘okay’ and what behaviours needed help, then asking for help or knowing when to, might be easier.

Participants who had family members enter the mental health system identified fear, shame and lack of knowledge as main barriers that had prevented them from accessing services.

Despite a number of the Auckland-based participants having a greater awareness of where psychiatric units and residential houses were located, they were unable to specify how they might access services. Overall, most participants reported not knowing how to access services.

When exploring possible ways of getting help, participants identified doctors (such as the family GP), hospitals, police, a minister (of religion) as likely starting points. However, a number of participants felt things would have to get ‘pretty bad’ before they would go for help.

Gender differences in asking for help were clearly identifiable. Women participants, overall, were clear that they would and did use family or close friends as support networks.

Male participants generally identified feeling unable to ask for help. Exploring barriers with them revealed that they generally felt uncomfortable talking with other men about their problems or feelings. Tied to difficulty was a fear that they would be seen as less male or that they would not be taken seriously by their friends. A few male participants revealed that they felt unsure about how far they could trust their ‘mates’. One male participant felt he had to be ‘nagged’ before he would believe someone was genuinely interested in his problems.

**Individual Interviews**
Overall, participants identified not knowing ‘when’ or ‘where’ to go for help as key barriers.
Participants also identified that the current services seemed unable to respond, at an early stage, to people’s needs.

“It’s more what you have to do to get help that’s the problem... It seems like in order for you to get help or for the system to respond to you, you have to be in some kind of crisis... and then the kind of attention you get when you are in crisis is probably different than the help that you really need...”

“It’s the ambulance at the bottom of the hill mentality... what we really need is the fence at the top of the hill...”

When asked who they might contact if they needed to access mental health services, most participants were unable to identify ‘who’ or ‘where’ they might seek help. This included participants who had been aware of community mental health facilities in their local district.
14) Whānau Needs

Carers and Providers

Participants were clear about the impact of mental illness on the whānau:

“If one of our whānau get sick, the first thing you lose is part of your mana, your dignity... “it’s happened in our whanau, it was meant to happen in somebody else’s”... And so, that’s the first thing they deal with. The second thing is they’re not helped education wise...”

“Most of those people suffering from a mental disorder, they’ve outstayed their welcome with the family and you can’t blame the family... because they are just so stressed out that in the end they just close, although they love that person. In the end they close the door on them because of their own safety, their own mental well-being”

“Families are often driven apart... people can’t handle it on their own...”

“...feelings of guilt and shame [of] having one in the family... don’t want to speak out about it, want to keep it hidden. Hopefully advertising will make a difference here. Whakamāa needs to be overcome”

Overall, carers and providers were in agreement that mental illness had severe impacts on the family and these clearly needed to be addressed. Participants clearly identified education about mental illness, teaching people monitoring skills and the provision of community-based support services as keys to reducing the impact of mental illness on the family. Participants further identified a general belief that work in these areas would contribute to removing some of the stigma of mental illness. Information about how to access services was also seen as an important area of to be addressed.
15) Support Services

Overall, carers and providers identified a need for a greater number of support services to be made available to people with a mental illness and their families. Participants were strong in voicing the opinion that the current mental health system was failing in its delivery of services.

“The system has had it. You go through the system to get help... but they keep saying ‘no’. You can’t get in there”

“In order for somebody to be accepted as part of a community they’ve got to come out of that unit looking like someone from the unit... they don’t have to come out of the unit looking like someone with Down’s Syndrome... Send them out with a whole set of new clothes and surely that must help them mentally to be nice and feel nice…”

“I don’t know if it’s ever going to end either - the system. Nothing seems to have changed from the time people have been released or this stigma thing of being in an institution...”

“My father was in the war and he was shell-shocked and that got real bad when he came out. He was in the one down in Christchurch... To me nothing has changed since then. There’s been all sort’s of money spent, but it’s still the same as it was but the only difference is you can have a state house...”

Participants identified a number of areas that needed better resources and support. These included ‘drop in’ facilities, support networks, more Māori staff and the development of culturally appropriate services:

“...tūroro respond well to the marae environment. They look upon the Psych Unit as having bad mauri... it has bad associations for them.”

“Involvement in tangi and hui on marae so that our people can get used to them [tūroro] and they can get used to our people... What we’ve managed to do is get them to pōwhiri school children onto the marae... but it’s a long slow process…”

“... use of rongoa and massage...”

Participants identified the need for greater interaction between ‘mainstream settings’ and Māori.

“... need to have partnership with the clinical team so that we can work from a Māori perspective within psychiatric units...”

“It takes a Māori to know a Māori...”
“We’ve got to deal with our own... it’s not working, the clinical stuff, it’s clinical, it’s essential in many cases... but there has to be partnership. We can’t do it on our own and I’m bloody sure they can’t do it on their own”
16) Sources of Information

Focus Groups
Participants identified a number of sources of information about mental illness. Common sources included knowledge of friends or family with a mental illness, news reports and television programmes. Auckland-based participants also identified a number of movies that had dealt with the issue of mental illness.

Media sources (particularly television and films) were not typically regarded as portraying people with a mental illness in a favourable way. Most participants’ recollections of items they had seen on programmes such as the news, were that they focussed only on the negative. Indeed, one participant felt that the news was a significant contributor to people feeling depressed.

Participants also regarded the media as heavily sensationalising items.

Auckland participants spontaneously recalled a number of films in which people with mental illness had been depicted as:

- violent;
- unpredictable;
- strange;
- stupid;
- angry;
- evil;
- people to be left alone or ignored;
- sad;
- useless; and,
- harmful to others.

In general, participants were unable to identify other places (apart from the media) where they might access information about mental illness. Some people mentioned ‘the doctors’, ‘hospitals’, ‘ministers of religion’, or the ‘Citizens Advice Bureau’. A few of the Auckland-based participants spontaneously mentioned the Mental Health Foundation, but when probed further, were unsure of what their role or function was. University student members of the Auckland groups thought that they might be able to get information from the Department of Psychology at the University of Auckland.

A number of participants in the individual interviews clearly identified the differences in the images associated with particular groups of persons living with a mental illness. Participants identified that non-Māori persons with a mental illness were perceived more favourably than Māori. Māori were typically associated with living in poor conditions, looking unwashed/dirty and being poorly dressed. Participants believed that Māori persons living with mental illness were more likely to be described as violent or dangerous. Non-Māori persons were more likely to be portrayed as well cared for and coping.
17) Education

Carers and Providers
Carers and providers strongly endorsed the idea of providing education about mental illness. Many identified a belief that increasing public awareness about mental illness would help to remove some of the stigma associated with it. Specifically, carers and providers articulated a need to distinguish between mental health and mental illness. One participant felt that explaining the difference using a lay person’s language and concepts would be useful.

“...about our normal lives and how about if we go up and we’re happy and how we come down and we’re sad. If you go further up than that, you have mania; if you go further than sad, you fall into deep depression... and it goes into paranoia... and if you go and down, well, that’s mania and depression...”

Participants strongly identified the need to educate people about monitoring mental illness.

“Whānau need to understand, be educated about the illness...”

“...in their mind, they can’t see the illness. They think that because that person, because there’s no sickness they can see, they can recognise, they can’t see the illness in the person. They think that the person is just playing up. They don’t realise it’s a real illness, a real disorder, so they’re yelling and shouting at their family member because they don’t understand their illness”

Participants made strong links between monitoring illness and early intervention.

“It’s about getting to whānau that have just got someone that has been ill over the last few weeks... If you can recognise it early you can lessen the damage on that person. It’s like any illness, you get to it early and you can do something about it...”

“...people mostly access the service when they’re really in trouble... the whānau’s had enough. They don’t want to know anymore... usually by the time they see us, no one else cares... And really in this work we rely on family to help pick up the pieces... really we’re at the wrong end. We should be getting to people before things break down... people need to be aware of the difference between ‘okay but pissing you off’ and not okay...”

“Whānau need to understand, be educated about the illness... importance of early recognition of mental illness... often by the time they have come to the attention of support services the whānau is burnt out; had a guts full...”

Participants linked educating families about mental illness as a way of restoring control.
“...talking to them and explaining the illness is part of the process of giving the whānau back some control and a way to deal with and care for their tūroro - to get them back to some sort of normality... ”

Participants who had contact with adolescents identified the lack of awareness about mental health difficulties as an important issue.

“Adeulence also is a big problem as schools are not recognising that some young people have a mental disorder and labelling it a behavioural problem, bullying... being expelled because they are a danger to other children... those kids who are falling out of intermediate and even younger. In this area we have five and seven year olds getting expelled from school, it’s a normal thing... ”

“We got some real sick kids out there and it’s not recognised that they are sick and they’re falling out of the school system... ”

“...adolescents aren’t participating in the school system... going to be real problems when they are older... but nobody recognises it and nobody wants to know in terms of service delivery”

Participants raised the issue of accessing services as an important area that people needed information about.

“I just see the lack of help, that’s all I see out there. We had one girl sit on a fence out there and she sat there all day until somebody could get her into a section. To put her into a unit to get help... So where do you get help for that kid?... ”

“Mental health is just so different. I mean, it just seems to be that there’s nowhere to go for help unless they are caught doing brown eyes on the main road... even that was hard to get help for that woman... ”

One participant, a minister of religion, had this to say:

“...it wouldn’t be unusual for me to get calls in the middle of the night from people wanting help for their whānau... and that’s okay, I mean... it’s part of ministry work helping people... but I wonder, what if I wasn’t there... where would those people go for help? The only reason I know how to get help is because I had to go and find out for myself... sometimes I’m not even sure what to do then... people need to know where to go for help... every other clergy I talk to says the same thing... ”

For some participants, there was a clear distinction between spiritual disease and mental disorders. These participants articulated the need to differentiate between the two.
While acknowledging the important role clergy had to play, one participant had this to say:

“Tūroro having Māori sickness is very real to Māori. Then they call in ministers and that... but sometimes our people get confused over it and we do have a problem in that, well, they find they can’t deal with it”
The Community Attitudes Toward the Mentally Ill (CAMI) scale was designed to measure community attitudes about, and behavioural intentions towards those with a mental illness (Taylor & Dear, 1981). In their use of the CAMI scale, Ng, Martin and Romans (1995) defined people with mental illness as: “...those who have been in a mental hospital and now live in a community. They may need treatment (e.g., medication) for their mental disorder and are capable of living independently of a hospital”.

The standard CAMI scale can be divided into four attitudinal factors:

- Authoritarianism: people with mental illness require coercive management;
- Social Restrictiveness: people with mental illness are viewed as a threat to society;
- Benevolence: people with mental illness are viewed sympathetically; and,
- Community Mental Health Ideology: views about people with mental illness focus on community care provisions.

The destigmatisation project is aimed at shifting community attitudes away from an authoritarianism and social restrictiveness focus toward a benevolence and community mental health ideology perspective.

With this in mind, the appropriateness of the CAMI scale for monitoring changes in attitudes among Māori was assessed in light of the pre-research findings.

Overall, the pre-research demonstrated that Māori attitudes toward people with mental illnesses are currently reflecting the benevolence and community mental health ideology perspectives. Māori talked of restoring individuals to their whānau, with many whānau being the most intimate expression of community. For this restoration to be successful, whānau were seen to need information and appropriate support services.

The use of the CAMI scale as a basis for developing a questionnaire for the benchmark, will provide a quantitative test of this conclusion. However, if the conclusion is supported, the impact of the attitudinal campaign on Māori will be overlooked if the evaluation is largely centred on the CAMI scale. In other words, if Māori are already at a near optimal level, then there is little improvement that can be measured by this instrument. Additional evaluation based on monitoring increasing knowledge about mental illness is therefore suggested to complement this index.

The definition of mental illness that is used when people are asked about their attitudes and behavioural intentions (Ng, Martin & Romans, 1995) may also prove to be problematic for Māori. The pre-research indicated that Māori concerns about mental illness encompasses the identification of those who are having difficulties accessing services for these whānau members. A definition of mental illness that takes into account these pre-diagnosis needs is therefore recommended. A broader evaluation focus might also monitor the gap between Māori mental health needs and service provision.
19) Key Messages

Participants had mixed reactions to the Ministry’s key messages.

Put the person before the illness. The person isn’t the illness; the person is living with a mental illness

This key message was identified by participants as most likely to get a positive response because it made you think about the person. However, some thought that the message was too long and could be shortened. A few participants identified that the section ‘the person is living with a mental illness’ raised some negative connotations. A common criticism was that this message was too boring and one participant said that they got tired waiting.

♦ It’s okay to talk about it

This message was received well, although some participants thought it sounded ‘New Age’. A number of participants thought that this might encourage people to find out more about mental illness. Others felt it could be improved if it was more action oriented - talking was good, but there should be action to follow.

In contrast, it was thought that the following two messages would receive a negative response:

♦ Do not discriminate, especially with accommodation and employment

This message met with the strongest negative response. Participants found this message unclear and did not encourage people to be proactive or open minded. One participant pointed out that discrimination was illegal and that still doesn’t stop people from doing it. Others felt people would react negatively to being told what to do.

♦ If you have or have had a mental illness, you are in good company

Participants felt that this message might cause people to become afraid of others in their community by promoting the belief that the mentally ill were “everywhere”. They saw this as being potentially even more stigmatising. Some participants felt that this message undermined the seriousness of mental illness.

♦ Many people with a mental illness get well; others need your ongoing support

This message received a mixed response. A number of participants thought this message might be useful as an educational message but were unsure about how useful it would be in getting people to accept people with a mental illness. Others indicated that this message was unappealing, predominantly because it was perceived as ‘touchy, feely’ and ‘new age crap’.
Your attitude can make a difference

Participants had mixed views about this message. Some felt that this message was positive and encouraged people to behave differently, and others felt it might lead others to react negatively, i.e., entrench their views. As one participant put it:

“Why should I change?... I’m okay”

Difference is okay

A number of participants thought that this message would be positive if difference really was okay. However, as a number of participants pointed out, difference in this society is not met with approval. As one participant pointed out:

“...you ask any Māori... any gay... whether it’s okay”
REFERENCES


Appendix 6

COMMUNITY ATTITUDES TOWARDS PEOPLE WITH MENTAL ILLNESS:

An Interpretation of Māori Results of the Benchmark

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Te-Whiringa-ā-nuku, 1998
CONTENTS

ACKNOWLEDGEMENTS.................................................................................................100

1) EXECUTIVE SUMMARY.......................................................................................101

2) INTRODUCTION ..............................................................................................103

3) BACKGROUND ...............................................................................................104
   3.1) Pre-Research........................................................................................104
   3.2) Executive Summary of Pre-Research with Māori ......................................104
   3.3) Hypotheses and Objectives ....................................................................105

4) METHOD .........................................................................................................107
   4.1) The Approach........................................................................................107
   4.2) Questionnaire Development ................................................................107
   4.3) Ethical and Safety Issues .......................................................................107
   4.4) Sample and Respondent Selection .......................................................108
   4.5) Fieldwork..............................................................................................108

5) RESULTS......................................................................................................109
   5.1) Key Findings........................................................................................109
   5.2) Additional Findings for Māori..............................................................111

6) DISCUSSION AND INTERPRETATION ............................................................115
   6.1) Knowledge and Information ................................................................115
   6.2) Contact with Mental Illness .................................................................116
   6.3) Prevalence............................................................................................116
   6.4) Causes of Mental Illness ......................................................................117
   6.5) Help seeking and therapy ....................................................................117
   6.6) Conclusions..........................................................................................118

7) REFERENCES................................................................................................120
ACKNOWLEDGEMENTS

Te Rōpū Rangahau Hauora a Eru Pōmare would like to thank all those who took part in this research project as respondents, telephone interviewers, researchers and supporters.

Given Māori experience with mental illness, it is encouraging that so many people took this opportunity to express their voice on this issue of community attitudes towards people with mental illness.

Ehara tāku toa i te toa takitahi
Engari, he toa takitini e.
1) EXECUTIVE SUMMARY

- This paper discusses the findings for Māori from the benchmark survey examining community attitudes towards people with mental illness.

- The research was conducted by a telephone survey and recruited 473 Māori respondents and 1,260 non-Māori respondents. The survey achieved a 20% response rate.

- The Business Research Centre (BRC) benchmark report was produced in November 1997 and noted some differences between Māori and non-Māori.

- For the current report, we have reviewed these results in light of the qualitative pre-research and to examine the influence of socioeconomic factors on Māori findings. The differences between Māori and non-Māori were tested to see if they were eliminated by controlling for adjusted income and community services card eligibility. This report comments on those differences that remain statistically significant after this process.

- Māori were more likely to have close friends or relatives who have a mental illness.

- Despite this close contact, Māori respondents were more likely to be poorly informed about mental illness, more likely to express misinformation, or to give “don’t know” as the answer to questions asking about knowledge of mental illness.

- There is supporting evidence that Māori are likely to experience problems accessing mental health services so that at the time of admission they are seriously ill (Pōmare, et al, 1995:122). Hence, Māori are more likely to experience contact with a close friend or relative who is seriously mentally ill.

- Within this environment of close contact with seriously ill people, Māori respondents were more likely to believe that people with mental illness are unpredictable, dangerous and easy to identify.

- This environment may also be associated with the findings of this study that Māori respondents were more likely to report that mental illnesses were prevalent.

- Māori respondents were less informed about the causes of mental illness, and this may be related to Māori respondents being more likely to say that one of the main causes of mental illness is a “lack of willpower.”

- Māori were more likely to report the association between mental illness and drug and alcohol problems.
Māori knowing less about mental illnesses and their causes was compounded by less knowledge of the full range of management therapies for mental illness, including medical care and medication, but also support groups, etc.

Despite the environmental issues noted above, there was no significant difference between Māori and non-Māori with respect to the level of confidence with mental health services, confidence in general practitioners and comfort with one’s level of informedness. However, Māori respondents were less likely to have sought help for mental illness, and in particular, were less likely to have consulted their general practitioners, seeking help instead from family members.

Furthermore, Māori respondents were more likely to report that they would continue this pattern of seeking help from family before general practitioners in the future.

Many of these results are signs of stigma towards people with mental illness. However, they may also represent the reality of some New Zealanders (among whom Māori are disproportionately represented) who live in an environment of close contact with people who are seriously mentally ill without the full support of adequate information and appropriate services. In this environment, the features noted in this report may represent informal coping mechanisms.

In this scenario, significant efforts must be made to reduce and eliminate these environmental factors to reduce apparent stigma.

Like the qualitative pre-research, this study reinforces the desire by Māori for more information about all aspects of mental illness. This desire for information is atypical of stigma, and supports the above hypothesis of informal coping mechanisms for vulnerable people in unpredictable situations. It is concerning that despite increasing contact with mental health services, Māori remain so poorly informed.

Information alone will not address all the issues noted in this report. Service providers need to reflect on the role they need to play to ensure tūroro Māori and whānau are able to make informed choices and are able to interrelate with a full range of responsive services.

Two key information pathways were “the media” and “whānau.” Both of these pathways need positive information interactions.
2) INTRODUCTION

In late 1996, the Public Health Policy Group of the Ministry of Health purchased a multi-media campaign designed to help modify the community’s attitudes about, and behaviour towards people with mental illness. This campaign was in response to stigma experienced by people with mental illness and noted in the 1996 Mason report (Ministry of Health, 1996).

Colenso Communications Ltd and Huia Communications Ltd were contracted to design and produce the campaign.

The primary audience for the campaign was members of the general public aged 15-44 years. Within this group, Māori were a priority focus. Past and present consumers of mental health services were also identified as being an important audience, in that if the campaign produced any negative backlash, consumers would be particularly vulnerable. Consumers and their advocates were therefore involved in both the design of the campaign and the evaluation research.

The campaign was planned to run from late 1997 through to late in the Year 2000. Electronic and print media were planned as the early strategy of the campaign followed up with support from regional activities organised through the then Regional Health Authorities. Subsequently, the campaign has been modified with the television, video and print material acting as a national lead-in to significant regional events which now become the main campaign activities.

The Ministry of Health also purchased evaluation research services for the campaign from the Business Research Centre (BRC), with support from Te Rōpū Rangahau Hauora a Eru Pōmare (TRRHAEP).

These research services included:

- qualitative pre-research interviews and focus groups;
- pre-testing of campaign materials;
- a quantitative benchmarking of the attitudes, understanding and knowledge about mental health and mental illness among the campaign audience;
- monitoring of campaign activities; and,
- an ‘end of campaign’ quantitative measure of attitudes, understanding and knowledge.

In November 1997, the BRC reported on the benchmark study (quantitative study of attitudes, understanding and knowledge undertaken prior to the campaign launch). That study noted some differences between Māori and non-Māori. This report reviews those differences, attempts to interpret their meaning, and makes recommendations to those involved with the ongoing planning of the campaign.
3) BACKGROUND

3.1) Pre-Research
The hypotheses and objectives which underpinned the benchmark were identified during the project pre-research. This research was qualitative in nature and based on individual interviews with members of the public, carers and mental health service providers, as well as focus group interviews with members of the general public. This pre-research allowed the researchers to explore aspects of Māori (in our case) knowledge of mental illness, as well as Māori experiences of and attitudes towards those with mental illness.

A full description of the pre-research and its results with Māori are presented in the report entitled, “Destigmatisation Project: Community Attitudes Towards People with Mental Illness - Stage 1 Pre-research with Māori” (Cram, Reid, Panapa & Keefe, 1997).

To inform our interpretation of the benchmark quantitative study, the executive summary of the pre-research with Māori is repeated here.

3.2) Executive Summary of Pre-Research with Māori
♦ Authors have described that Māori have an holistic approach to health that incorporates dimensions of the physical, mental, spiritual and whānau. These interrelationships were often described by Māori in the pre-research interviews and focus groups. Although not much was known by Māori members of the general public about mental illness, there was an overwhelming desire to support those who are ill and to help them stay within or reintegrate them back into the whānau. In this sense, the whānau is the unit that is talked about most often when community is discussed. The campaign therefore needs to work within and support this whānau structure.

♦ Māori were generally positive about the campaign, although this was accompanied by a degree of skepticism. This skepticism had two readily identifiable sources:
  1. the view that the money spent on the campaign might be better directed to mental health services;
  2. the view that the campaign would not be relevant to Māori.

♦ In order for the campaign to be seen as being relevant for Māori, it needs to appeal to people on both an individual and cultural level so that it is relevant to them as Māori, and relevant to their everyday life.

♦ In addition to relevance, for the campaign to be successful for Māori it needs to be accompanied by improved service accessibility and appropriateness for Māori. A key feature of both the public as well as the carer and provider interviews was the view that the mental health system is not currently meeting Māori needs. This included an inability to provide healing for Māori.

♦ Participants noted that accessing mental health services was difficult for Māori, so that families may only seek help when a situation with a family member is particularly severe. In addition, knowledge about mental health services and providers was generally lacking among Māori. This has important implications for early intervention. It is suggested that the campaign focus on early indicators
of mental illness and how to access help. There is a thirst for this type of information - a key feature of the focus group interviews was the questions about mental illness directed at the facilitator at the end of the discussion.

- A focus on educating families and whānau about mental illness would restore to them a sense of control over what may otherwise be an unusual and/or unpredictable situation. This could help address the issue of dangerousness that was associated with mental illness.

- A campaign that meets Māori needs should also be accompanied by a mental health provider campaign. It is pointless to increase Māori knowledge about mental illness and early intervention if this knowledge is then discounted when Māori attempt to access mental health services.

- Carers and providers talked of tūroto and wairangi in preference to terms such as client, consumer, patient, etc. Māori terminology was seen to be more positive and healing. It is recommended that consideration be given to the use of Māori terminology within the campaign and within mainstream mental health services because of the negative connotations associated with labels such as client and patient.

In summary, the qualitative pre-research noted that Māori expressed a desire to support whānau who were ill, but there was a need for information and service responsiveness in the mental health area, and any intervention needed to be relevant to Māori.

3.3) Hypotheses and Objectives of the Quantitative Benchmark
Underpinning this quantitative study were several hypotheses and numerous objectives developed from the pre-research. These are described in full in the BRC report entitled, “Modifying the Community’s Attitudes to People with Mental Illness: Baseline Measure” (Dowden & Kalafatelis, 1997).

A summary of the hypotheses and objectives are as follows.

Hypotheses
- Many people feel that mental illness and the issues surrounding mental illness are not relevant to them.

- The public’s knowledge of mental illness is limited. The public has only a moderate understanding of the causes, treatment, care and support that people with mental illness need/receive, in order for them to become well again.

- The public find it difficult to accurately define mental illness. They include many conditions and behaviours that are not mental illnesses.

- There is a social stigma attached to mental illness and people who have a mental illness. Some people show outright discrimination of people with mental illnesses.
- People who have had contact with individuals with a mental illness/mental health services, generally have more positive attitudes towards people with mental illness.

**Objectives**

To identify:

- The extent of the *knowledge* and of the *misperceptions* (knowledge gaps) that are held by the focus audience about people with mental illness.

- The *attitudes* that the focus audience has towards mental health in general and towards people living with mental illness.

- Which *sub-groups* of the focus audience are most poorly informed and/or hold the most extreme negative attitudes.

- The knowledge and attitudes of ‘special’ focus audiences; managers, employers, landlords, and people working in the mental health sector, whose actions can have the most significant impact on the lives of people who have mental illnesses.

These objectives were further expanded in the following areas of study:

1) The meaning of “good health” and “mental illness”.
2) Awareness of mental illnesses, their causes and treatments.
3) Knowledge of the prevalence and duration of mental illnesses.
4) Perception of the capabilities of, social acceptance of, and general attitudes towards mental illness.
5) Mental health services.
6) Perception of knowledge about mental illness, receptiveness to learn more and awareness of discrimination laws.
7) Experience of our own or others’ mental illness, sources of help used in the past and to be used in the future.
4) METHOD

This section briefly reviews issues relating to the method and the process used in the benchmark research, especially pertaining to Māori. Full details are noted in the BRC report of the benchmark.

4.1) The Approach

The benchmark was completed by telephone. A total sample of 1,733 respondents was interviewed.

The total sample was stratified by ethnicity, with 36% (n=473) of all respondents identifying themselves as being of Māori ethnicity. Māori were over-sampled in order to achieve this quota.

The over-sampling of Māori was undertaken using random selection (as was the sampling of the mainstream sample). Oversampling was done to provide a Māori sample of sufficient size to review the study hypotheses within the Māori population.

In analysis, a ‘weighting’ procedure was used so that estimates reflect the true population proportions.

4.2) Questionnaire Development

A fully structured telephone questionnaire was developed by the researchers, in consultation with the Ministry of Health. It was significantly informed by the qualitative pre-research. Consultation with representatives of the Aotearoa Network of Psychiatric Survivors (ANOPS) also occurred during the development of the final draft of the questionnaire.

The questionnaire was piloted first in face-to-face interviews and then later by telephone with Māori and non-Māori. A copy of the questionnaire is appended in the BRC’s benchmark report.

4.3) Ethical and Safety Issues

This project had ethical approval from all regional ethical committees. Appropriate informed consent procedures were followed in all cases before interviewing commenced.

Māori respondents were given the opportunity to be interviewed by Māori interviewers and the interpretation of Māori data has been made by Māori or by Māori researchers in conjunction with non-Māori researchers.

During the concept pre-testing stage, we were reminded that work in this area can trigger memories of emotional issues for some people. Measures were taken during the interview to allow people to discontinue if they felt uncomfortable, to remind people of the confidentiality of their responses and to direct participants to their general practitioner or community health centre if they felt they wanted to talk to someone about mental illness.
4.4) Sample and Respondent Selection

New Zealanders between the ages of 15 and 44 years of age were eligible to participate in the benchmark. Māori comprised 36% of the total sample (n=473), whilst the remaining respondents (n=1,260) were non-Māori. This gave a total sample size of 1,733 respondents. Further details about the sampling can be found in BRC’s benchmark report.

Weighting the Data

While Māori made up 36% of those interviewed, Māori represent 15% of the weighted sample results because Māori are 15% of the New Zealand population aged between 15 and 44 years.

Response Rate

Twenty percent of the people contacted participated by being interviewed by this survey. A full comment on this issue is detailed in the BRC’s benchmark report.

Sampling Error

The BRC’s benchmark report commented on the difference between the Māori and non-Māori where the difference was statistically significant. The size of the sample determines whether the differences between the two proportions is significant. The table below shows the size of significant differences, at 95% confidence, for a variety of different sample sizes.

For example, a significant difference between two proportions based on samples of 473 (Māori) and 1,260 (non-Māori), is a difference of 6% or greater. This means that there is a significant difference between, for example, results of 47% and 53%.

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4.5) Fieldwork

Experienced field workers were fully briefed prior to the commencement of the project on issues including safety. The interviews were conducted by telephone at the BRC in Wellington between June and September 1997. On average, an interview took 25 minutes to complete.

The respondent population had to fill quotas relating to ethnicity and Regional Health Authority (RHA) region. Gender and age were also monitored to enable comment on their respective distributions and that of the general population.
5) RESULTS

Tables of the data from which these analyses are drawn are noted in the BRC benchmark report (Dowden and Kalafateli, 1997) which should be read together with this report.

5.1) Key Findings of the Total Population Sample

The benchmark sought peoples' view on mental illness in general and on four illnesses in particular:

- Schizophrenia
- Depression
- Bipolar illness
- Anxiety disorder

The key findings of the benchmark are as follows:

1) Mental health was not spontaneously identified as a factor contributing to overall good health (mentioned spontaneously by 14% of the total sample).

2) The proposed audience for the campaign had limited knowledge of mental illness and this knowledge base contained significant inaccuracies.

3) ‘Schizophrenia’ was the most well known mental illness. A number of conditions were also incorrectly identified as mental illnesses, including ‘Alzheimer’s’, ‘senile dementia’, ‘Down’s syndrome’ and ‘epilepsy’.

4) While many respondents could name mental illnesses, many were unable to describe these conditions.

5) Respondents felt the four mental illnesses focused on by the campaign were common.

6) Many respondents (81%) had personal experiences of mental illness through a friend, relative or acquaintance.

7) One third of respondents had sought help for mental illness for themselves or for someone else. A quarter of these had experienced difficulty in attaining help.

8) The campaign audience had a moderate understanding of the causes, treatment, care and support required by people with mental illness.

9) Respondents affirmed the rights of people with mental illness but tended to adopt a middle view in attitudinal statements, and significant minorities were concerned about issues of unpredictability and dangerousness.

10) People with mental illness were generally perceived by the majority of respondents as being as capable as others. However, a significant minority disagreed with these statements.
11) There is evidence of stigma. As found in previous New Zealand research (Ng, Martin & Romans, 1995), the benchmark found that respondents’ willingness to interact with people with mental illness clearly decreased as the level of intimacy of the contact increased.

12) Mental health services in New Zealand were perceived to be inadequate.

13) The media was the most common source of information about mental illnesses.

14) Over three quarters of respondents wanted to know more about mental illness. However, 22% did not want to know more.

15) Respondents who worked in the mental health area had a higher awareness and more positive attitudes towards those with mental illness.

16) Twenty percent of respondents could be classified as having low social acceptance of people with mental illness. They are more likely to be male, less likely to know anyone who has a mental illness, less likely to claim to be informed about the subject and less likely to want more information.

17) The benchmark reported that with respect to differences in levels of social acceptance there do not appear to be differences by age (although the age range was narrow), ethnicity (although small differences are noted in the section following), personal or household income. International literature (Sellick & Goodear, 1985) points to differences by age, ethnicity and socio-economic status.

It needs to be noted that with respect to the socioeconomic profile of respondents, in regard to personal income, there is a disproportionately high number of respondents in the $30,000 or more bracket, compared to the population. It is likely to be caused, at least in part, by the reduced availability of telephones in low-income households. The differences between the sample and the population are 12% and 13% for the Māori and non-Māori samples respectively. This research assumes that the similar size of these differences (12% and 13%) means that comparisons between Māori and non-Māori remain reliable.
5.2) Additional Findings for Māori

Within the benchmark results, there were some small (but still statistically significant) differences in the awareness levels, opinions and experiences of Māori when compared with non-Māori.

**CONFOUNDING**

It is possible that many of the differences between Māori and non-Māori reflect differences in socioeconomic status rather than differences in ethnicity. This was tested by seeing if the differences between Māori and non-Māori were eliminated by controlling for income (adjusted by household size) and community services card eligibility.

These analyses cannot definitively rule out the possibility that the differences are primarily socioeconomic rather than due to ethnicity. Key weaknesses of this method include:

- Socioeconomic status was not measured particularly precisely in this questionnaire. For example, educational status was not measured and economic analysis was abbreviated to prevent a long questionnaire getting even longer;
- Multi-collinearity - because ethnicity and income are correlated, their contributions are not easily analysed separately.

The following differences reported in the BRC benchmark report remained statistically significant when differences in socioeconomic status were controlled for using the measurements available (community services card and adjusted income).

Māori appear to have a *lower awareness and knowledge* of mental health and mental illness.

- Māori were **less** likely to spontaneously mention mental health as a contributor to overall good health.

- Māori were **less** likely to know the names of mental illnesses and were more likely to say they “don’t know.”

- 80% of the non-Māori sample could name a condition that was a mental illness, compared with 68% of Māori.

- Māori were **less** likely to mention depression as a mental illness in the unprompted section of the interview. In fact, all four mental illnesses, which are the focus of the campaign, were **less** likely to be named by Māori.

- After prompting, Māori were **less** likely to name anxiety disorders, anorexia, manic depression/bipolar illness and depression, but were **more** likely to mention drug addiction, alcoholism and to give “don’t know” as the answer to questions about knowledge of mental illness.

- When a subsample were asked to describe two or more symptoms of one of the four mental illnesses which are the focus of the campaign, Māori were **less** likely to describe symptoms of the mental illness.
Māori perceived mental illness as more prevalent, compared to non-Māori.

- Māori generally indicated that mental illnesses were more prevalent, especially schizophrenia and bipolar illness.

- Māori were also more likely to give no answer to this question.

- While just over 80% of the total sample said they knew someone with a mental illness or someone who had had a mental illness, Māori were more likely to describe the relationship as close friend/close relative than non-Māori, and Māori were less likely to describe the relationship as an acquaintance.

Māori had slightly different views on the causes and appropriate therapies for mental illnesses.

- Māori were more likely to mention drug or alcohol abuse/addiction as a causal factor for schizophrenia and depression.

- Māori were less likely to mention chemical imbalance in the brain for schizophrenia and bipolar illness.

- In this forum, only 2% of respondents indicated that mental illness was caused by issues surrounding colonisation.

- Generally, respondents indicated that they felt the four mental illnesses (schizophrenia, depression, bipolar illness and anxiety disorders) were similar with respect to duration and severity. Nearly two-thirds of the total sample felt that people “stay well most of the time but occasionally become unwell”. Māori were very similar but were more likely to say they “don’t know” for anxiety disorders.

While respondents generally recognised that support from friends and family, professional care (including medical attention, medication, counselling etc) and normalising activities (including job, sleep routine, stress management, diet and exercise and living with others) were the foundations for managing mental illness, there were some differences in responses, especially the role of professional care.

- Māori were less likely to say medical care and medication were important for bipolar illness, depression and schizophrenia.

Māori perceptions of the capability of people with mental illness and social acceptance of these people.

The November 1997 BRC Benchmark report reported from the benchmark study that “Māori perceived people with mental illness as being less capable and had a slightly lower social acceptance.” These two findings are important, as they are hallmarks of stigma. However, the actual findings are for specific disorders, eg anxiety, schizophrenia, bipolar, depression. Because respondents were only asked about one of the four disorders sample size limits mean that a statistically significant effect was unlikely to be found after adjusting for confounding. No overall trend was noted.
**Māori were less affirming of the rights of people with mental illness**

In an effort to reduce discrimination, the benchmark sought to understand the attitudes of the population towards people with mental illnesses. This will also serve to establish a baseline against which the effectiveness of initiatives directed towards attitudinal change and the reduction of discrimination can be measured.

The scale used in the benchmark was similar, but not identical to those used previously in New Zealand and overseas.

- While respondents were found to be positive in general, Māori respondents in particular were less affirming of the rights of people with mental illness than non-Māori respondents.
  - **people with a mental illness are always unpredictable in their behaviour** (48% of Māori sample strongly agree or agree, compared to 26% of non-Māori);
  - **there is something about people with a mental illness that makes it easy to tell them from other people** (23% of Māori sample strongly agree or agree, compared to 12% of non-Māori);
  - **one of the main causes of mental illness is a lack of will power** (35% of Māori sample strongly agree or agree, compared to 19% of non-Māori);
  - **people with a mental illness are not as dangerous as many people think** (21% of Māori sample strongly disagree or disagree compared to 14% of non-Māori).

[NB: While these are statistically significant we should note that at this level of analysis there could be significant imprecision given the survey response rate etc.]

**Māori were less likely to use the media as a source of information and were more likely to want to learn more.**

In order to clarify sources of information about mental illness, respondents were asked to describe their main source and supplementary sources of knowledge. The media was found to be the most common source of information. This included television, radio and print news, media articles and documentaries and entertainment media such as films, videos and novels.

This supports a previous small New Zealand survey which found that news and entertainment media (books, films and magazines) were the main sources of opinion about mental illness (Ng, Martins & Romans, 1995).

- While Māori were less likely to identify the media as a source of knowledge about mental health compared to non-Māori, it was still the most commonly cited primary source and most commonly cited among all sources. Close experience with one’s own illness or that of a relative/friend was a close second to media, as both the primary source and of all sources.

- Most respondents felt quite confident about the accuracy of their source of information. Sixty nine percent of non-Māori respondents felt their main source
of information was somewhat (54%) or very (15%) accurate, compared with 61% of Māori (48% somewhat and 13% very accurate).

- Over three quarters of respondents indicated that they were interested in knowing more about mental illness. Māori were more likely to say that they were ‘very much interested’ in knowing more.

- About 3% of respondents worked in the mental health sector, 7% provide volunteer or community worker support to the sector, 4% were caregivers in the home. There were no significant differences between Māori and non-Māori.

Māori were less likely to access mental health services.

Respondents were asked whether they had sought help for mental illness, either for themselves or someone else, from where they had sought it, whether they had experienced any difficulties getting help and what would have made it easier for them to obtain help.

- One third of respondents had sought help for mental illness for either themselves or another person. Controlling for income removed the difference between Māori and non-Māori.

- Common sources were general practitioners and mental health professionals. Māori were less likely to have consulted a general practitioner in the past.

- Of those who sought help, about a quarter experienced some difficulty.

- When asked from whom they would seek help in future, Māori were significantly more likely to turn to their whānau in future and continue to be less likely to seek assistance from general practitioners.
6) DISCUSSION AND INTERPRETATION

The purpose of this paper is to interpret the differences between Māori and non-Māori from the quantitative benchmark survey examining community attitudes towards people with mental illness.

The research was conducted in 1997 by telephone interviews with 473 Māori respondents and 1,260 non-Māori respondents. Twenty percent of eligible people contacted agreed to participate in the study. While this response rate is low, the key issue is how representative the respondents are to the New Zealand population.

Of note, the sample had proportional representation by gender and age (within the narrow age-range of 15-44 years). However, with respect to personal income, there was a higher representation of respondents in the $30,000+ per annum range, compared with the New Zealand population of this age group. This is likely to be related to the availability of telephones in low-income households.

While Māori were 36% of those interviewed, at the completion of interviewing, a “weighting” procedure was used to regain the true population proportions before reporting population rates. In this case, the Māori sample was weighted down from 36% to 15%, the population proportion for Māori aged 15-44 years.

The differences between Māori and non-Māori were reviewed and attempts were made to control for confounding by socio-economic status using available measures.

6.1) Knowledge and information

A key finding of both the qualitative and quantitative studies has been the lower awareness and knowledge of Māori about mental illness. In particular, Māori were more likely to be poorly informed, more likely to be misinformed and more likely to be uninformed. This feature was noted at a general level and also for knowledge of all four of the key illnesses in this campaign, but particularly for depression and anxiety disorders.

Māori have had increasing contact with mental health services over the past 15 years (Pōmare & de Boer, 1988; Pōmare et al, 1995), yet do not seem to have benefited with respect to information from these services. This could mean that whānau and tūrero Māori have not been offered or given information which is appropriate for Māori needs, and/or that Māori did not understand or absorb the information, and/or that Māori did not engage with the information, the information provider or the communication process used in information provision.

It is critical for the campaign to recognise this interface between service provider and tūrero/whānau often occurs at a time where good information is essential for informed choice and informed consent. Problems with information transfer must be resolved before this avenue is considered for information transfer tasks in this campaign.
6.2) Contact with mental illness

In this study, about 80% of the respondents had personal experiences of mental illness through a friend, relative or acquaintance. Māori respondents differed from the non-Māori sample only in the reported degree of closeness. This intimacy was also noted in the pre-research.

Given diverse Māori realities, including extensive urbanisation, it is interesting to think about reasons for this difference. For example, whether it relates to a difference in perception - that is, Māori label as “close” a larger proportion of surrounding family and friends than other New Zealanders. It may also relate to Māori feeling “closer” to whānau or members of the communities in which we live, work and socialise.

In essence, while we can read this “closeness” at face-value, it is important to flag that there may also be some issues of validity in interpreting how this question was answered by Māori. It is interesting that during the exercises to control for confounding, adjusted income and community services card eligibility were not significantly associated with this finding of closeness, so it seemed more related to ethnicity than socio-economic status.

This research, the quantitative benchmark, showed some evidence of lower access to mental health services by Māori, but the association lost its statistical significance when adjusted income was controlled for. However, members of the focus groups and interviews in the qualitative pre-research were vociferous in their claims that services were difficult to access and often unresponsive. There is compelling evidence in the literature (Pōmare, et al, 1995) that patterns of Māori psychiatric admissions suggest Māori are over-represented among late admissions with serious illness.

The close contact of Māori respondents in this study therefore, is likely to be close contact with the seriously mentally ill. It is this environment that may lead Māori respondents to believe that people with mental illness are unpredictable, dangerous and easy to identify.

6.3) Prevalence

The finding that Māori respondents were more likely to report that mental illness was prevalent is interesting in many ways. Māori respondents may have been reflecting this from their circle of close friends and whānau, or they may have been reflecting what is happening in their geographic communities.

With deinstitutionalisation, many people with chronic mental illnesses have, through benefit income, become part of the “poor” in our communities. Māori are also over-represented among the poor. It is likely therefore, that these two groups will converge geographically in areas with high ratios of low income households. Through this mechanism, it is highly likely that in some areas, prevalence may be higher than among the national population.

In exercises to control for confounding by socioeconomic factors, lower income was clearly associated with this finding of greater perceived prevalence of mental illness.
but the difference between Māori and non-Māori remained statistically significant after controlling for available socioeconomic variables.

6.4) Causes of Mental Illness
Māori responses around the causes of mental illnesses are also worthy of comment in two ways. Firstly, the association between mental illness and drugs and alcohol, especially for depression and schizophrenia. This association may reflect the close proximity of psychiatric services to drug and alcohol services. That is not to say that Māori do not have significant drug and alcohol problems. Alcohol dependence and abuse continues to be one of the leading causes of first admission to psychiatric hospitals for Māori (and non-Māori) men and women. Drug dependence and abuse as a cause of first admission is also growing (Pomare, et al, 1995).

During the early consultation for this campaign, the issue of the inclusion of drug and alcohol-related mental illness was discussed and rejected as being beyond the scope of this campaign. At that time, TRRHAEP noted the issue as likely to be raised by Māori. This was considered by the Ministry of Health, but the status quo was upheld.

None-the-less, there is now evidence that Māori align drugs and alcohol with mental illness in a causal fashion. The onus is on the campaign to be prepared for and committed to respond to this issue with Māori.

The finding that Māori were more likely to strongly agree that one of the main causes of mental illness is “lack of willpower” is interesting. It reflects the very old-fashioned view that one needs to “snap out of it” and “pull up your socks”. It reflects very much on the poor information base of Māori respondents.

The relationship between drug and alcohol dependence, abuse and depression was more associated with ethnicity than socioeconomic status. This contrasts with schizophrenia where controlling for community services card eligibility and adjusted income were significantly associated with Māori responses. Higher income respondents and those without community services cards were more likely to suggest drug abuse caused schizophrenia. However, controlling for these two effects did not eliminate the differences between Māori and non-Māori.

Limited knowledge of the causes of mental illness was compounded by less knowledge of the full range of therapies for mental illness, Māori were thus less likely to report “going to the doctor” was an appropriate response to mental illness. This finding was not significantly associated with community services card eligibility and adjusted income and remained statistically significant after controlling for available measures of socioeconomic status. This finding may go hand-in-hand with other findings, such as “lack of willpower” as a cause of mental illness.

6.5) Help seeking and therapy
While Māori were less likely to nominate counselling, group therapy and support groups as appropriate therapy, these findings were not statistically significant after confounding was controlled for. However, they may give some indication about the
range of services either being offered to Māori or being found by Māori to be appropriate.

Māori respondents were more likely to describe a different pattern of advice or help-seeking behaviour, with Māori being more likely to favour advice and assistance from whānau than from primary health care providers.

While Māori reported using the media as a source of information less than non-Māori, it was still the primary information source. Whānau were the second significant information source.

Although the benchmark described Māori as being less likely to seek help for mental illness, this was more closely associated with income than with ethnicity. Māori respondents also noted that in the future they would be more likely to seek advice, information and assistance from whānau than from primary health care services. This latter finding was influenced by measures of socioeconomic status, but remained even after this was controlled for.

6.6) Conclusions
The benchmark concluded that there was evidence of stigma. Some of the features noted about Māori reflect levels of stigma towards people with mental illness.

This report has noted that for some Māori, these “hallmarks of stigma” reflect informal coping mechanisms by those in close contact with the seriously mentally ill. These coping mechanisms are compounded with a lack of sound information and adequate access to responsive services. Increasing social distance from those with mental illness may be an appropriate response if one feels vulnerable and without the information or resources to cope with unpredictable situations.

A further factor that provides qualification to the level of stigma among Māori is the very high level of Māori wishing to have more information. This finding is atypical of stigma and reinforces the suggestion of increasing social distance as an informal coping mechanism. If this hypothesis is true, then the environmental and service issues must be addressed before we can expect these signs to be reduced.

The issue of increasing social distance as an informal coping mechanism is not to say that stigma towards those with mental illness does not exist with Māori. The qualitative study highlighted that Māori know many derogatory names for people with mental illness. Other studies describe that stigma is a feature of the lower socioeconomic groups (Sellick, K., Goodear, J. 1985). However, the information from both the benchmark and the qualitative studies recognise that it is a complex issue. Furthermore, Māori are not a population of single experience and expression, but rather, have been described by our “diverse Māori realities (Durie, M H. 1995).

A key feature of this report is the information needs of Māori. While acknowledging that information alone will not be enough to address stigma, information underlies fundamental tenets of the Code of Rights for consumers of health and disability services. To the forefront is the recognition that information underpins effective
communication, the ability to be fully informed and the right to exercise informed choice and informed consent.

Finally, it is important to note that service providers, both Māori and mainstream, need to reflect on the role that they need to play to ensure tūoro Māori and whānau are able to make informed choices, and are able to interrelate with a full range of responsive services.
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