

# FROM DISCRIMINATION TO SOCIAL INCLUSION

**A review of the  
literature on anti  
stigma initiatives  
in mental health**

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# Foreword by Her Excellency Ms Quentin Bryce AC



The way we encounter mental illness is a measure of our health as a society. Whether it disturbs and immobilises us, or engages our humanity and cooperation, depends upon our collective willingness to open ourselves to its sufferers, and include their experience in what it means to be human.

This is a challenge we are increasingly called on to meet, and one which requires the best of our resources, intellect, policy, and practice. Not only to understand the dimensions of mental health and its detriment, but to develop a socially, economically and culturally attuned response.

Vital to constructing that response, I am very pleased to welcome this comprehensive and informed literature review, bringing world best practice and emerging research to bear on mental illness and social inclusion in our context.

As the review makes clear, our journey forward is as much about learning as about 'unlearning'; disavowing the conscious or unconscious stigmas we indulge, and the

attitudes that negate or obstruct our progress. We need to begin afresh, with a model that accounts for the rights, opportunities, dignity, and contribution of every person; that makes room for everyone in our public conscience and our private consciousness.

Behind this review are the leadership and determined energy of the Queensland Alliance, and of the sibling organisations in each state, who together make up a strong network, encouraging dialogue, teamwork,

advocacy, research, information and knowledge sharing, policy and strategy development, negotiation with government, liaison with community.

To this strategic and timely intervention in a national discussion about mental illness, they bring the experience and resilience of daily confrontation with complex, demanding, and heartbreaking issues.

Their commitment, perseverance, courage, and compassion will lead us forward as we build a stronger, richer, more inclusive and cohesive Australia.

**“We need to begin afresh, with a model that accounts for the rights, opportunities, dignity, and contribution of every person”**

A handwritten signature in black ink that reads "Quentin Bryce". The signature is written in a cursive, flowing style.

Governor-General of Australia

# Introduction by Jeff Cheverton

## CEO Queensland Alliance



Mental health issues are very common. The Australian Bureau of Statistics<sup>i</sup> identifies that half of us will experience a mental disorder at some point in our lives, and one in five Australians have experienced mental illness in the last 12 months.

We are in daily contact with people affected by mental health problems. They run our banks, police our communities, and teach our children – they are our friends, neighbours, and family. The stigma attached to mental ill-health, however, prevents most people from disclosing. Fear of discrimination prevents people speaking of their experiences and seeking support from work colleagues, friends or family. The later people leave seeking help, the more significant is their ultimate call on health and social services.

The Medical Journal of Australia has identified that discrimination and stigma are the biggest barriers to recovery for people with mental illness.<sup>ii</sup> SANE Australia's stigma watch report identifies that discrimination against people with mental illness remains high in Australia,<sup>iii</sup> and that fear of discrimination is a key reason people do not seek help early.<sup>iv</sup>

In Australia some valuable anti-stigma programs – like Mindframe or Stigmawatch – and successful awareness and prevention programs – like beyondblue, Mental Health First Aid and Mental Illness Education Australia – already exist. However a more integrated and comprehensive approach such as those already occurring in most other OECD English-speaking countries is urgently required.

There is an emerging body of research and international literature indicating that comprehensive, well structured social inclusion initiatives change public attitudes towards mental illness, and influences our behaviour.

The reduction in stigma increases people's access to health and social services, provides an economic return on the initial investment, and promotes acceptance, social inclusion and enhanced quality of life for people with mental illness.

This document summarises the international evidence on how best to tackle the stigma of mental illness. This summary has been reviewed by leaders in the field internationally. The purpose of this document is to present what the international experience and evidence says about how we can implement an anti-stigma initiative for social inclusion in Australia.

The work has been resourced by peak bodies in mental health around Australia. This demonstrates the widespread interest and support in anti-stigma initiatives across the mental health sector. The first action in Australia's *Fourth National Mental Health Plan 2009–2014* is "a sustained and comprehensive national stigma reduction strategy." The recent Senate Inquiry into Mental Health (2006) and the National Health and Hospitals Reform Commission Final Report (2009), have recommended that Australia invest in a national anti-stigma initiative like the New Zealand or Scottish programs.

CEO, Queensland Alliance

# About the Consultant



**Prepared by  
Neasa Martin for the  
Queensland Alliance**

**October 2009**

This review provides a balanced, informed, and evidence-based review of stigma, discrimination, and social inclusion

programming. It builds on my 27 years of clinical, program management and consulting experience in the area of mental health and addictions.

I have worked with a diverse array of governmental, not-for-profit, hospital-based, and commercial organisations providing research, policy, project management, evaluation support, and user-friendly resource development. Recent clients have included: the Mental Health Commission of Canada working as an advisor on stigma, discrimination, and recovery; the Schizophrenia Society of Canada undertaking a study of Quality of Life; the Canadian Senate Standing Committee of Social Affairs contributing to the *Out of the Shadows at Last* report; the Public Health Agency of Canada; the Canadian Alliance

for Mental Illness and Mental Health; the Mood Disorders Society of Canada, the Centre for Chronic Disease Prevention and Control, amongst others.

I have led a peer-based support service for almost a decade and see myself as a 'boundary walker' working between professional, consumer, family and government stakeholder groups to help improve service design and delivery. I hold an honours degree in Rehabilitation Medicine – Occupational Therapy. In addition I bring an experiential expertise to my work as mental health problems have been a constant companion in my life as a family member, sibling and at a personal level. Sharing an experience of mental health problems is not without risk but it also sows the seeds of hope.

I believe we owe a debt of gratitude to all the consumers who have pushed forward to create a better reality for others. Their voice must play a central role in all aspects of our work.

Consultant, Neasa Martin

# Acknowledgement

The Queensland Alliance would like to acknowledge the following organisations for their funding and support of this publication:



Psychiatric Disability Services  
of Victoria (VICSERV)



# Executive Summary

## Discrimination is real and pervasive

People identified as having mental health problems are one of the most marginalised groups in society. Equal citizenship and active community participation remain highly desired but elusive goals. Stigma is a major barrier and people feel its sting in terms of lost relationships, opportunities denied or their own unwillingness to pursue life's goals for fear of rejection or failure. Stigma refers to the negative internal attitudes and beliefs people hold, discrimination is the external behaviour and institutional arrangements that deny people their rights or limit their social inclusion. For many, the rejection they experience is more disabling than the psychiatric condition itself. Discrimination is experienced when support is withdrawn by family and friends, by being shunned, shamed, through name-calling, being denied employment or having one's rights abused. It is a problem borne of ignorance and bred by fear.

Mental health issues are very common, almost half of us will experience them in our lifetimes, and one in four will have had at least one mental health problem in the last 12 months. People's willingness to share their experience is exceedingly rare. Positive personal contact is a critical means of changing negative beliefs. Ironically, we are in daily contact with people affected by mental health problems. They run our banks, police our communities, and teach our children – they are our friends, neighbours, and family. What we don't have is disclosure. The result of this secrecy is that the myths of violence and incompetence go unchallenged, slights go unchecked, people won't seek out the support they need and many will be rejected or withdraw from their communities. People will continue to accept a reduced share of resources, suffer the loss of their rights, and live a diminished life often without protest. Creating a dialogue between those who have experienced mental health problems and the broader community plants the seeds of change.

**The cost of mental ill-health is estimated at 3% – 4% of the country's GDP**

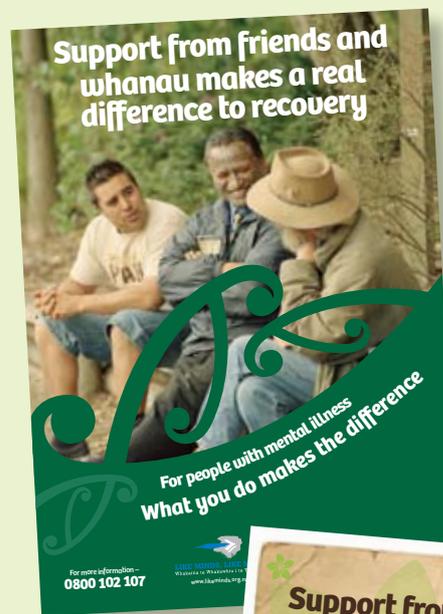
A successful social inclusion program challenges every citizen to re-think their assumptions and take steps to create an inclusive social quilt where rights are respected, differences are valued, and we all belong. However, contact alone is not enough. There are also powerful systemic, social, attitudinal and institutional barriers that need to be simultaneously untangled. A broader lens is required beyond seeing this as a health-based issue. Multi-sectorial planning across government and stakeholder groups is also needed to transform policies and practices, improve services and to enhance legislative protections to stop discrimination, affirm equal rights and support full citizenship. The economic costs of social exclusion are extremely high. Australians spend A\$4.4 billion annually through lost productivity, health and social services, disability pensions, lost taxes and missed opportunity. The cost of mental ill-health is estimated at 3% – 4% of the country's GDP.

Those countries which have undertaken a national anti-stigma and discrimination reduction program, are finding that over time there are measurable changes in public attitudes, behaviours, media reportage, and acceptance of people with mental illness. Economic analysis is also demonstrating that social inclusion programs are cost effective: Researchers estimate the cost of delivering a national social inclusion program at £0.55 per person with a return on investment of £4.26 per person through reduced health and services costs, decreased employment losses, increased taxes and the cost of important social benefits. Mental health promotion programs are found to deliver equally impressive returns on investment.

To be successful a national social inclusion program requires a shared vision and agreed set of values that can guide stakeholders in delivering collective action-plan. Adopting a social inclusion model is compatible with best practice principles in program delivery and aligns with

current government policy in Australia. Social inclusion integrates a rights-based approach to dealing with discrimination, recognises the importance of essential determinants of health, acknowledges the importance of employment and economic inclusion, access to treatment supports and services, and advances ways of nurturing mentally healthy individuals, communities and society. It promotes the importance of locally based approaches for building supportive communities and way to strengthen individual capacity to participate meaningfully as full citizens.

The Queensland Alliance has identified discrimination, social exclusion, and the loss of human rights of people living with mental health problems as an urgent priority and an unmet need. The Australian Government shares this concern and is a signatory to the United Nations Disability Inclusion Convention<sup>v</sup> and the Optional Protocol on the Rights of People with Disabilities.<sup>vi</sup> The Government has recently established a Social Inclusion Ministry<sup>vii</sup> to implement a broad-based and far-reaching social inclusion plan.<sup>viii</sup> Stigma is identified as a barrier to success and this strategy calls for a national plan to eliminate discrimination. The Rudd Government is also creating a National Preventive Health Agency focused on enhancing health promotion and the prevention of chronic diseases. The South Australian Government has also developed a strategic plan that includes reducing stigma and discrimination as priority concern.<sup>ix</sup>



Images from New Zealand's *Like Minds, Like Mine* campaign.



# Recommendations

**Drawing on the research, international anti-stigma programs and advice from research and program experts, the following principles for best practice were identified.<sup>1</sup>**

▲ **Direct personal contact with people who experience mental illness is the best approach.**

Direct contact is the best approach to changing attitudes and behaviours, particularly when there is: a relationship of equal status; a context of cooperation, an opportunity for discussion; and credible presenters who disabuse myths of dangerousness, incompetence, and incapacity.

▲ **Information alone does not change attitudes.**

The goal of education is to increase understanding of the challenges real people face (including discrimination), how difficulties are overcome, what helps, how others can be supportive and include messages of equality, hope and recovery. Use of creative arts and multi-media increases impact.

▲ **Mental health problems are best framed as part of our shared humanity.**

Mental health problems are an understandable response to a unique set of circumstances and not purely as biomedical, genetically based, illnesses, or a diseased state of brain.

▲ **Create a simple and enduring national vision.**

A vision that promotes human rights, social inclusion, full citizenship, and a shared responsibility for change will be most effective, using multi-media, and social marketing tools to create clear program outcomes and benchmarks.

▲ **Support grass-roots, local programming.**

A national campaign that still increases contact, education, and builds consumer leadership from the grass-roots up is important. Change happens at the local level. Encourage bold, creative programming and evaluate carefully.

▲ **Plan strategically at the national level.**

Develop a national strategic plan that works in partnership with government and stakeholders to develop and deliver a multi-level national plan targeting transformative systemic change at a service system, legislative, policy and practice level.

▲ **Support people living with mental health issues in active leadership.**

Consumer leadership should be encouraged to define issues, design programs, undertake research, and evaluate program success. Protest, disclosure and group identification are cornerstones of empowerment. Support consumer leadership and empowerment through the national program.

▲ **Target programs at influential groups.**

Influential groups could include emergency response, policing and corrections, social service providers, employers, educators, friends, family, religious leaders.

▲ **Assist media to play a significant role.**

Require media to have a special focus on increasing depictions of people as competent, capable and productive citizens and utilise 'first person' narratives. Challenge inaccurate or discriminatory portrayals of people with mental health issues.

▲ **Utilise evidence.**

Programs must use evidence-informed approaches. Informed programming should also be evaluated to allow for course correction. Build knowledge through research and findings shared through program networks.

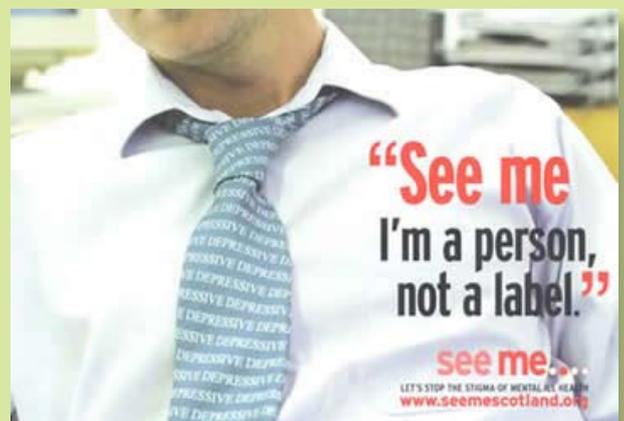


Image from Scotland's See Me campaign.

# Report Background Context

Along with Ireland, Australia remains the only English-speaking OECD countries without a national anti-stigma – social inclusion campaign. New Zealand, Scotland, England, USA and Canada have all received multi-year funding to mount evidence-informed, national anti-discrimination campaigns. Research shows that efforts to shift public attitudes on mental illness have been frustratingly difficult. However, these programs are being carefully evaluated and provide important guidance for action. There is a limited but an emerging body of research indicating that a comprehensive, well structured social inclusion campaign is an economical policy approach that can achieve measurable results in decreasing public health and social service costs, reducing negative public attitudes, improving acceptance, social inclusion, and enhancing quality of life for people living with mental health problems. Where national anti-stigma and social inclusion programs exist there is strong agreement on the importance of this approach and public approval ratings are high. Consumer surveys reveal that people continue to experience broad discrimination but where national programming exists there is a shift towards feeling more included, that media reporting is improving, and people are experiencing less discrimination within their daily lives.

The consultant was asked to:

- ▲ Conduct a high-level review of peer-reviewed journals in the social sciences, psychosocial and bio-medical fields to identify research evidence to inform social inclusion, stigma and discrimination reduction strategies.
- ▲ Review associated literature on quality of life, consumer-led recovery, peer support and empowerment, social marketing and community activism to identify best practice principles.
- ▲ Review existing national anti-stigma and discrimination campaigns from New Zealand, USA, Canada, England and Scotland to identify 'best and promising practices' and lessons learned.
- ▲ Provide a high level analysis of key strategies, program principles and identified promising and emerging principles and make recommendations for action.

The goal of this report is to build a shared understanding of the emerging research evidence and identified best and promising practices in reducing stigma and discrimination at a national level. Leading international academic researchers and program experts reviewed the executive summary to confirm the veracity of the key principles and offered additional advice.<sup>2</sup>

<sup>2</sup>See Appendix A for a list of program and research experts who informed this review.

# CHAPTER 1

## INTRODUCTION AND DEFINITIONS

### Understanding stigma and discrimination

Fear and rejection of people with mental illness has existed throughout history and has not altered significantly irrespective of our changing theories to explain their causes. Stigma interferes with help seeking through label avoidance, adherence to treatment and impedes recovery. It results in social isolation and the withdrawal of support from others.<sup>x</sup> Pat Corrigan has identified three forms of stigma: 1) Public Stigma: which is the harmful effects to people with mental illness when the general population endorses the prejudice and discrimination of mental illness. 2) Self-Stigma: which is the harm that occurs when people internalise negative stereotypes impacting self-esteem ("I am not worthy!") and self-efficacy ("I am not able") leading to self-blame, hopelessness and helplessness. 3) Label Avoidance: refers to those who seek to avoid stigma by not seeking mental health services from which labels are often obtained ("I am not going to see a psychiatrist; people are going to think I am nuts!").<sup>xi</sup> Caregivers and professionals also experience 'courtesy stigma' where they are devalued by association with people who have mental health problems.<sup>xii</sup>

Stigma has been the subject of intense research and the literature is replete with studies defining, describing, and measuring the negative impact of stigma on people's social, vocational, and economic functioning. The psychological, sociological, structural, and interpersonal forces, which create, support and maintain stigma has been dissected and moderating theories explored.<sup>xiii</sup> Much of this research is theoretical and has limited utilitarian application for program development.<sup>xiv</sup> However, understanding stigma as a phenomenon is helpful in explaining the process of 'labeling' and how people react to being 'marked'. Stigma has come to represent a mark of shame or degradation. Thornicroft describes stigma as *'any attribute, trait or disorder that marks an individual as being unacceptably different from the 'normal' people with whom he or she routinely interacts, and that elicits some form of community sanction.'*<sup>xv</sup> Mary O'Hagan refers to stigma

as the internal feelings and attitudes, discrimination as the external behaviour and institutional arrangements that deny people their rights or limit social inclusion. Stigma and discrimination are seen as major barriers to citizenship and social inclusion.

Corrigan describes stigma arising from three inter-related problems: 1) A lack of knowledge of mental health problems leading to ignorance. 2) Ignorance leads to the formation of negative attitudes or prejudice and when knowledge is replaced by myths. 3) Discrimination is the behavioural result of prejudicial attitudes, which results in people excluding or avoiding contact with those who are identified as mentally ill. Corrigan reports that this negative cycle can be interrupted by: providing education on the experience of having a mental health issue and the personal experience of discrimination – not education to improve knowledge of mental illness; by increasing positive contact with competent, capable people who to challenge stereotypes attitudes; and by promoting human rights and protesting against acts of discrimination.<sup>xvi</sup>

Link and Phelan describe within the Attribution Model, a four-step process for understanding how stigma is formed. 1) Labeling: in which some key personal characteristics are signaled to others or recognised by others as conveying an important difference; 2) Stereotyping: where there is a linkage of these differences to undesirable characteristics; 3) Separating: making a distinction between the 'normal' group and the labeled group; and 4) Status loss: leading to discrimination, devaluing, rejecting, and excluding the labeled group. Within this model, discrimination is seen as *'dependent on social, economic and political power.'*<sup>xvii</sup> Discrimination based on public stigma is experienced in the loss of opportunity (not being hired, denied mortgage or housing), coercion by powerful others (family, doctors), and segregation (living in ghettos, segregated service systems).<sup>xviii</sup> The reduction of discrimination therefore requires changing firmly entrenched attitudes and beliefs held by powerful groups that lead to labeling,

stereotyping, devaluing, and discriminating against people with mental health problems or by limiting the power of those groups. Focusing on discrimination shifts the responsibility for change from those who are stigmatised and onto those who stigmatise. For example, employers need to review and revise unjust employment practices and make reasonable accommodations to support people with mental health issues within the work environment.

According to Jeff Cheverton, Executive Director of the Queensland Alliance, “Stigma is at its core the mark of difference of those things we associate in our society as signifying madness. People who are trolling the garbage dumps, panhandling on the street or act impulsively have come to be defined as ‘mad’. The business man walking down the street in a suit is not identified as mad although he may very well meet the defined criteria for a mental illness. The result is that we hold a skewed understanding of what madness looks like. Discrimination is the different way we treat people who we define as mad. A social inclusion strategy is about ways we can unlearn those discriminatory responses we have acquired.”

### Discrimination and human rights

The emerging trend in programming is to focus on discrimination framed as a systemic, social, and political phenomenon. This brings mental illness into closer alignment with the approach of the broader disability community. Reducing discrimination is seen as a critical element of enhancing recovery. It makes clear that the ultimate endpoint of action is equal treatment and greater access to services and resources. The focus on ‘stigma’ as a critical element of intervention is felt by many to set the prejudice towards people with mental illness apart from other forms discrimination like racism, homophobia, or sexism.<sup>xxix</sup> From a policy planning perspective, applying a discrimination lens makes program goals and objectives more measurable and strengthens the ability of researchers to clearly evaluate the outcomes of interventions in ways that are

meaningful to consumers. For example, it is not important to assess whether an employer *would hire* someone with a mental health problem but whether he or she *actually does*.<sup>xxx</sup> This approach provides policy makers with broader recommendations for action including: addressing human rights; civil liberties; health and social service transformation; policy; and legislative changes.

Australia enacted the Disability Discrimination Act 1992<sup>xxxi</sup> which includes people with psychiatric disability and protects their rights in areas such as housing, education and provision of goods and services. It is the first western nation to sign the Optional Protocol of the United Nations (UN) Convention of Rights of Persons with Disabilities in July 2008.<sup>xxii</sup> This protocol provides people with a disability an avenue for appeal to the United Nations if they feel their rights are not being respected. These are complaints-based processes placing the onus on the individual to pursue redress from either the Australian Human Rights Commission or the UN. Given the very real stigma and discrimination associated with mental health issues, people will be reluctant to pursue these options. Limited resources have been committed to educate the public and key target groups (employers, landlords etc.) to the meaning and intent of the charter or their compliance requirements within the legislation. A national social inclusion strategy will need to include promoting an understanding of these mechanisms for action.

### Impact of stigma and discrimination is real

People identified as having a mental health problem remain one of the most marginalised groups in society. They experience social exclusion in a multiplicity of domains including: high rates of unemployment;<sup>xxiii</sup> lower educational achievement; persistent poverty; the loss of friendships; kinship; denial of housing; and rejection by their neighbours.<sup>xxiv</sup> Self-stigma

results in people not pursuing opportunities, advocating for entitlements or accessing mainstream activities. Social isolation, loss of family supports and unemployment all contribute to a worsening in mental health and increase an already high risk for suicide.<sup>xxv xxvi</sup> There is a lack choice and limited access to community, rehabilitation, and treatment supports. People with mental health issues are more likely to have their human rights violated through the use of seclusion, restraints, involuntary admissions, and forced treatments,<sup>xxvii</sup> along with experiencing losses of personal and parental rights.<sup>xxviii</sup>

The negative attitudes and pessimism of health care providers and the lack of client-centred supports within healthcare systems are also felt to interfere with recovery.<sup>xxix</sup> Negative encounters with police, high rates of incarceration and a focus on greater 'risk containment' is resulting in increased government spending focused on incarceration and less investment in supporting community participation and civic opportunities.<sup>xxxiv xxxv xxxvi xxxvii</sup> People with mental health problems are frequently the object of ridicule and derision and are depicted within the media as being violent, impulsive, and incompetent.<sup>xxxiv xxxv xxxvi xxxvii</sup> The myth of violence persists despite evidence to the contrary. Stigma and the denial of rights are identified as significant barriers to recovery.<sup>xxxix xl</sup> The experience of discrimination can intensify existing symptoms and lead to relapses in mental health problems.<sup>xi</sup> The effects of stigma impact people long after the symptoms of mental health problems have been resolved.<sup>xiii</sup> According to the Institute of Psychiatry, Kings College and the London School of Economics, stigma plays a contributing role in the low funding priority affording by

governments to mental health problems relative to other health issues such as cancer or heart disease. This funding neglect is despite higher levels of morbidity and mortality, which are worsened as a consequence of services not being available in a timely manner or at an adequate level.

Stigma also has a deleterious effect on families economically, emotionally, and socially. Families (usually mothers) reduce their participation in the workplace to provide support and to advocate for services. It is estimated that families provide an average of 100 hours per week of voluntary support.<sup>xliii xliiv</sup> They experience high levels of "shame, blame and contamination" from health care providers, and lose important attachments with family and friends.<sup>xlv</sup> Over time, their own physical and emotional health takes a toll as they neglect self-care.



**“ People with mental health problems are frequently the object of ridicule and derision and are depicted within the media as being violent, impulsive, and incompetent.”**

## Economic costs of stigma and discrimination

The World Health Organisation estimates that one in four people will experience a mental health disorder during their lifetime.<sup>xlvi</sup> The Australian Bureau of Statistics (2006) estimates it as being higher with 45.5% of the population experiencing a mental illness and/or substance misuse in their lifetime. The leading cause of 'healthy life' lost due to disability is mental illness (24% of all years lost or around 330,000 years).<sup>xlvii</sup> A conservative estimate of the economic cost of poor mental health is 3% – 4% of GDP in developed nations.<sup>xlviii</sup> The World Health Organisation recognises psychiatric disability as the fastest growing cost sector for occupational disability. There are significant economic losses due to absenteeism; reduced productivity or 'presenteeism', increased morbidity, and higher rates of mortality. According to Harvey Whiteford<sup>3</sup> economic losses in Australia from decreased productivity accounts for about A\$2.6 billion of health care costs. An additional estimated A\$1.8 billion, is spent on disability support pensions. The economic costs of work-related mental health problems have been well documented in other jurisdictions.<sup>xlix | l | liii | liiii</sup> Economic modeling done by Freidle and Parsonage in England highlights the enormous cost of treating mental health problems, and the woeful underfunding of mental health promotion and mental illness prevention within the National Health Services and by local health authority (less than 2%). Relative to other health conditions the cost of mental illness is very high in terms of disability adjusted life years (20%) exceeding cardio-vascular disease (17.2%) and cancer (15.5%). Yet, relative to their importance as a health problem funding is disproportionately low.<sup>liv</sup> The high price of mental ill-health is borne by individuals and their families (lost income for both), by employers (lost productivity, rising health, disability and benefit costs) and by society (welfare payments, lost taxes, lost opportunity) making this an important policy issue for government and industry to address.

<sup>3</sup>The Kratzmann Professor of Psychiatry and Population Health, Queensland Centre for Mental Health Research, the University of Queensland.

# CHAPTER 2

## DIFFERING CONCEPTUAL APPROACHES

Worldwide efforts to reduce stigma and discrimination have gained surprisingly little traction and in some jurisdictions, in fact, discrimination is worsening.<sup>lv</sup> The exception is those jurisdictions with a national strategic social inclusion plan in place. The lack of global momentum can in part be explained by programming, which is ad hoc, poorly funded, short-term, intuitively based and not evidence informed, that lack policy and legislative advocacy and which are not being well evaluated.<sup>lvi</sup> The absence/or misalignment in theoretical models underpinning stigma reduction initiatives may also play a contributing role in a lack of overall progress. Debate continues on how to understand and describe mental health problems and there are differing philosophical beliefs on how stigma and discrimination can be reduced. There conflicting opinions on which approaches will produce positive outcomes with mental health literacy, stigma reduction, mental health promotion, and social inclusion being used as interchangeable concepts, which they are not. Many stakeholders incorrectly believe that any educational activity focused on increasing awareness of mental illness will reduce stigma, discrimination and enhance social inclusion.

### Bio-Medical Model

The bio-medical model sees mental illnesses as diagnostic entities with discrete signs and symptoms, that are biologically driven and genetically influenced disorders. Symptoms of illness interfere with a person's thoughts, feelings, activities of daily living and social behaviour. Severe mental illness is characterised as chemical imbalances or biological malfunctions of the brain. Psychological, situational, and social factors are seen to play a mediating role in illness. Diagnosis is a critical step for establishing a treatment plan, drawing upon evidence-informed guidelines, which help manage, but may not 'cure' the disorder. The primary focus of intervention is

on treating symptoms and managing adverse events. Disability is seen as the consequence of the limitations imposed by the illness. Promotion of personal rights conflicts with a number of current psychiatric practices. This model has been widely used in public educational activities, which seek to bring public knowledge into alignment with medical opinion. The expected goal is to reduce the stigma that acts as a barrier to help seeking behaviours. Early intervention and treatment services support recovery, removing the health barriers that limit participation in work, social roles, and community engagement. Addressing self-stigma and providing support and education to families is increasingly recognised as a critical component of recovery-focused care.

### Mental Health Literacy

Studies show Australians are not well informed about mental illness and believe mental health is a significant issue for which 90% feel they lacked a clear understanding.<sup>lvii</sup> Australians are also more likely to ascribe less stigmatising social or psychological factors than biological causes to explain mental illness.<sup>lviii</sup> Mental health literacy (MHL) is a relatively new public education

concept. It refers to the "knowledge and beliefs about mental disorders which aid their recognition, management or prevention".<sup>lix</sup> Australia leads in promoting MHL through national programs such as beyondblue and



Mental Health First Aid. The overarching goal is to increase the public's ability to recognise the signs of mental illness, knowledge about treatment supports and services, increase willingness to proactively seek out professional services and build the capacity of carers to provide support.

Within MHL problems are primarily framed within the constructs of the bio-medical model. Research does show that this approach can help increase the public's ability to recognise the signs of mental illness and increase their willingness to seek out professional services.<sup>lxvi</sup> MHL also includes the ability to recognise specific disorders, how to seek out information and understanding the risk factors, causes, and of the availability of self-treatments and professional help. Pirkis et al looked at what were the most effective ways of improving mental health literacy at a population level. They identified limitations in the existing research particularly related to how audiences acquire knowledge or motivation to attend to public health messages. They did find that mass media MHL campaigns can achieve positive outcomes and are particularly effective when people with mental health problems deliver the program and involve one or more forms of media. Targeting was also seen as beneficial with good results found with family and carers in terms of knowledge and positive attitude changes.<sup>lxvii</sup> In a recently released Australian study looking at the relationship between resilience factors and caregiver outcomes, mental health literacy was found to have a weaker link to caregiver adjustment, with social connectedness showing more beneficial results.<sup>lxviii</sup> Teaching young people how to understand and cope with common mental health problems (stress, depression, suicide and self-harm eating disorders and experiences of being bullied) not the symptoms of mental illness was found to increase empathy, pro-social behaviour and promote more positive attitudes.<sup>lxix</sup> In a 2007 report by the Canadian Alliance on Mental Illness and Mental Health, *Mental Health Literacy in Canada* the authors raised concerns on the limitations of the MHL approach proposed by Jorm. They felt it did not factor in how enhancing mental health literacy can support individual empowerment or how to address social and situational determinants of health, which may account for or worsen mental health problems. More importantly, they felt that this MHL approach does not address the identified risks associates with framing mental health problems within a

bio-medical model in increasing pessimism, stigma, and desire for social distance.<sup>lxx</sup>

### Disability Inclusion Model

Within a disability inclusion model, disability is seen as a result of the socially imposed barriers and prejudices imposed from outside and faced by the individual that limit their citizenship and full participation in society. It is not the consequence of individual limitation (illness). The disability inclusion model focuses attention on addressing the power imbalances that lie behind discrimination and targets transforming beliefs amongst those who discriminate. It includes adopting a human rights perspective, and addressing the structural barriers and systemic issues that deny people access to the same level of services and resources as those with other health concerns. This approach requires coordinated planning and strategies targeted at building knowledge, changing individual attitudes and behaviours, and in assisting governments and organisations in the development of policies and practices that will prevent discrimination. Critics have argued that this model minimises the potentially debilitating symptoms of illness. Adoption of a social disability model in addressing discrimination is favoured by consumers and is reflected in most national social inclusion campaigns.

### Mental Health Promotion

Mental health promotion is a population-based, multi-disciplinary, approach for achieving positive mental health and is part of a broader health promotion agenda. It looks beyond individual disease prevention and towards the steps that individuals and communities can take to keep people and communities mentally healthy. Good mental health is created within the everyday context of people's lives including: their homes, schools, workplaces, and communities. The focus is

on accessing the basic determinants of health, ways to strengthen individual competencies and build the resources of communities. The presence of mental illness does not mean the absence of good mental health. Nor does the absence of mental illness connote good mental health. According to the World Health Organisation, mental health or well-being is a state in which people can realise their abilities, cope with stress, work productively and contribute to society.<sup>lxviii</sup> The research identifies three key social and economic determinants of mental health and provides themes for action: 1) Increasing social connectedness. 2) Decreasing or eliminating violence and discrimination. 3) Increasing economic participation.<sup>lxix</sup> Confidence, self-esteem, hopefulness, and community integration are acknowledged to improve clinical and quality of life outcomes for people living with mental health problems and the promotion of good mental health is documented as a cost-effective and beneficial approach. Promotion of good mental health is as important, to people living with mental health problems, as the treatment of their illness.<sup>lxx lxxi</sup>

## Social Inclusion Model

The social inclusion model is an emerging framework that integrates the social disability, determinants of health and mental health promotion models. Levitas defines social exclusion as a, *“Complex and multi-dimensional process. It involves the lack of, or denial of, resources, rights, goods and services, and the inability to participate in the normal relationships and activities, available to the majority of people in society, whether in economic, social, cultural, or political arenas. It affects both the quality of life of individuals and the equity and cohesion of society as a whole.”*<sup>lxxii</sup> Social inclusion is described as a journey towards greater participation and citizenship. It is achieved by systematically tackling social exclusion and requires the development of policies and targeted approaches which deal with the economic causes of social exclusion (supporting work, education, training), reducing health inequities, promoting early

intervention, addressing poverty, housing and extended civil rights. It acknowledges that trauma, abuse, neglect, and social inequity play a contributing role in the social determinants of mental ill-health. It also includes promoting a client-centred approach to the design and delivery of health and social services. The social inclusion model focuses on creating inclusive societies where every citizen feels they are valued and have the opportunities to fully participate in all aspects of their community. It does not take an illness-based focus but there is recognition that people with mental health problems are more vulnerable to other types of disadvantages because of weakened workforce attachment, reduced education and limited access to services.<sup>lxxiii lxxiv lxxv</sup> It focuses on ways of providing people with the resources, opportunities, and the capability they need to live, work, play and participate fully in meaningful roles. The role of government and communities is to help reduce the barriers to social inclusion that limit the opportunities of at risk groups. Social inclusion focuses on fostering connections with people through community resources and strengthens the voice people have in influencing decisions, which affect them.<sup>4</sup> Addressing issues related to employment, income and social and community connectedness are strongly correlated to building good mental health.<sup>lxxvi lxxvii</sup>

The social inclusion model is not without its critics. In a recently released parliamentary study by the Social Policy Section limitations were identified within the social inclusion model in the lack of definition and a clear theoretical core. Social inclusion is felt to keep people in a passive role and that their inclusion rests with those who have the power and is not as a right of citizenship. The analysts feel that the model can be improved by locating it *“within a contemporary and reflexive social citizenship framework”* which places greater emphasis on promoting an active participatory approach, promoting rights, duties, full citizenship, and equality. This would bring social inclusion into closer alignment with the social disabilities model.<sup>lxxviii</sup>



### Consultant's observations:

In developing a social inclusion strategy it is critical that consensus is reached amongst all stakeholders on the theoretical approach to be taken. A successful campaign requires a clear vision, set of values, program goals, and organising principles around which all stakeholders can unite. Mental health promotion, mental illness prevention, treatment, rehabilitation, and enhancing social inclusion are complimentary, overlapping but separate elements of a public health approach. Each is important and one is no substitute for another. It is unknown whether anti-stigma programs, which attempt to incorporate mental health promotion, mental health literacy, and social inclusion, achieve the impact of programs delivered as separate elements of a national strategy.

Understanding of how to address stigma and discrimination is evolving and the emerging trend is the adoption of a population based, social disability/social inclusion model. This approach is more likely to produce effective and sustained improvements in quality of life and support community engagement. Despite its acknowledged limitations, the social inclusion model delivers an elegant framework for integrating rights-based approaches, moving away from seeing stigma as a health-based issue, recognising essential determinants of health and ways of promoting a mentally healthy society. It advocates for locally based approaches to

building supportive communities and way to strengthen individual capacity to participate meaningfully as full citizens. The importance of joint responsibilities of all levels of government, non-governmental organisations, business and individual stakeholders in changing policies and practices and develop programs to remove barriers and build bridges to mainstream participation is clearly defined. This includes strengthening legislation and enforcement mechanisms to protect human rights. Engaging people with lived experience is a stated priority.

### Social Inclusion Model aligns with Government policy

The Australian Government has recently established a Social Inclusion Ministry, which is taking a broad approach to enhancing social inclusion and has appointed a director to implement its priorities. Addressing stigma and discrimination, increasing access to resources (particularly work) and building communities that are more inclusive are identified as core elements of its disability strategic plan. The South Australian Government has also targeted social inclusion and discrimination reduction as a priority including this priority in *Stepping Up: A Social Inclusion Action Plan for Mental Health Reform, 2007–2012*.<sup>lxix</sup> There appears to be a high degree of agreement that addressing discrimination and social exclusion is an issue of concern. Should an anti-stigma/social inclusion campaign be funded aligning this program element with the larger policy direction of the Australia Government; it will create coherence, allow for integration of activities and maximise the return on investment.

The social inclusion model delivers an elegant framework for integrating rights-based approaches

# CHAPTER 3

## WHAT THE RESEARCH EVIDENCE SAYS

The consultant undertook a review of the health, social sciences, and psychology field to identify research evidence supporting social inclusion program strategies. The 'grey literature' on stigma and discrimination reduction, recovery and quality of life were also reviewed to identify the most effective approaches for building a more inclusive and less discriminatory relationship with people affected by mental ill-health. The following reflects a high-level overview of the emerging evidence.

### Research is limited – but growing

Although stigma and discrimination has been a subject of intense research for decades the predominant focus in the peer-reviewed literature has been on defining, describing, explaining and measuring its impact. Much of this research has limited applicability in designing anti-discrimination programs.<sup>lxxx</sup> There are also challenges associated in undertaking a review of the literature because of the large volume of research, inconsistencies in definitions, varying conceptual models, and differing research approaches used.<sup>lxxxi</sup> A review of the literature paints a bleak and despairing picture of the impact stigma and discrimination has on peoples' lives and creates an overwhelmingly discouraging sense of the intractability of the problem. There has been surprisingly limited research on program approaches or evaluating the impact of stigma reduction activities. Many of the interventions evaluated utilise a vignette-based approach to assessing attitudes and capture what people believe they would do rather than assessing attitude and behavioural changes in real life situations. The existing peer-reviewed research base does not appear robust or definitive enough to provide, with a high degree of certainty, clear direction in delivering a social inclusion program beyond key strategic principles and approaches.

### Consumers are left out of research

People living with mental health problems have not played a direct or prominent role in defining research priorities or participating beyond being the objects of study.<sup>lxxxii lxxxiii</sup> The absence of the consumer voice has

contributed to a predominant focus on seeing stigma and discrimination as an illness-based phenomena. However, the experiential expertise of consumers is increasingly being recognised and incorporated into research design and program development.<sup>lxxxiv lxxxv</sup> Consumer surveys of their experiences of stigma and discrimination and ways to mitigate their sting is providing important insights and creating more action-oriented, outcomes focused research and programming.<sup>lxxxvi</sup> What is clear is that the priorities, insights, and concerns of people with a lived experience have consistently been at the forefront of emerging knowledge. Whether it is on promoting the capacity for people to recover, the limitations of mental health services and systems, the harm caused by psychiatric labelling, what constitutes quality of life, the importance of hope, the value of peer support and self-help, and the challenges and benefits of disclosure.<sup>lxxxvii</sup>

### Research informed program elements

The peer-reviewed research evidence on social inclusion and discrimination reduction remains something of a moving target. More focused research is underway on what approaches are effective in program delivery. However, this is too urgent and costly an issue to wait for certainty regarding evidence-based approaches. The following summary reflects a high level review of the emerging evidence to support a social inclusion program.

### Contact

Direct contact is consistently identified as the most effective means of producing long-lasting and sustained improvement in public attitudes. Positive emotional contact increases empathy, understanding and pro-social behaviour. Ironically, given the high prevalence of mental health problems within the population (45.5% over a lifetime) we are in constant contact with people who have mental health problems. What is missing is disclosure. Contact is found to be most effective when.<sup>lxxxviii</sup>

- ▲ There is a relationship of equal status;
- ▲ It occurs in a context of active cooperation and the pursuit of shared goals;

- ▲ There is opportunity for interaction and discussion;
- ▲ There is a coexisting relationship such as co-worker, friend, neighbour etc.;
- ▲ Both the message and messenger are culturally appropriate and relevant;
- ▲ Contact disabuses people of common myths (dangerousness and impulsivity);
- ▲ The presenter is 'credible' and challenges stereotypes (incompetence and incapacity).<sup>lxxxix</sup>

Contact appears to resonate most when it is with 'regular people'. Famous people and celebrities do increase public interest and draw media attention. Both *Like Minds, Like Mine* and *Time to Change* have found that the use of celebrities are helping to drive change through their national campaigns. However, too much social distance can decrease credibility and positive change may not generalise. Media-based contact (video, television) has also been found to produce positive changes when 'real life' narratives are used. It is unclear whether it is as effective as face-to-face contact. Advertising, which does not include a person with whom the viewer can identify, does achieve the desired impact.<sup>xc</sup>

### Education to build understanding

Public education is the most frequently used approach to reducing stigma. There is a vast amount of user-friendly information available, which describes in detail the diagnostic classification and treatment approaches for common mental illnesses. Educational conferences, workshop, forums, awareness campaigns, print, web, self-surveys, and multi-media resources explaining the signs and symptoms of illness and emphasising the importance of treatment are broadly available. However, the research indicates this is not the information that achieves positive lasting attitudinal and behavioural change. Education has the greatest resonance when the information provided builds understanding of the human experience of living with and overcoming mental health problems.

Emerging themes from the research of what information is best:

- ▲ Information alone does not change attitudes. Positive shifts in attitude are not necessarily correlated to positive behavioural change.<sup>xcii xciii</sup>
- ▲ People with a lived experience of mental health problems can best deliver education. Contact plus education improves knowledge uptake.<sup>xciv</sup>
- ▲ Education that is multi-faceted and includes confronting common myths (dangerousness, incompetence, impulsivity) improves public attitudes.<sup>xcv xcvi</sup>
- ▲ Stories that touch the heart and mind of the listener increase positive emotional connection. Stories have a long-lasting effective when they describe the challenges encountered; discrimination faced; ways difficulties were overcome; what helps and when hope and optimism of recovery are key messages.<sup>xcvii xcvi</sup>
- ▲ Education that promotes respect, rights, and a shared responsibility of reducing discrimination.
- ▲ Education is best when it is targeted, segmented, delivered locally and the messages are audience-specific (i.e. police, medical students).<sup>xcix</sup> There is no 'general public'.
- ▲ The use of creative art, theatre, comedy, photo-story, poetry, first person-narratives etc. creates a strong emotional response that encourages reflection and helps shift public attitudes. (See appendix for program examples).

## Framing matters – ‘illness like any other’ is not the approach

A prevailing orthodoxy on how to reduce stigma and discrimination has been to increase the public's understanding of mental illness and bring it into closer alignment with medical opinion.

The intuitive belief is that a well-informed public would be more accepting

and understanding towards people with mental illnesses. The use of direct marketing to customers by the pharmaceutical industry has also resulted in the ubiquitous presence of ‘public education’ campaigns that promotes a bio-medical framing of mental illnesses as a disease for which treatment – medications – are effective.<sup>c</sup> Many consumer and family organisations share an enthusiasm for promoting a medical understanding of the causes of mental ill-health based on a belief that this will help to lessen the perception of moral responsibility or character failings that are frequently associated with mental illness. The assumption is that if mental illnesses are attributed to factors outside of the individual's control, then they are not responsible for their own behaviour and the reactions of others will be less negative.<sup>ci</sup>

Research evidence does not support the efficacy of this approach. In fact, this framing is thought to play a contributing role to deepening fears and increasing a greater desire for social distance.<sup>ci</sup> When the disease model is applied to the brain, the belief is that people are incapable of exerting judgment, control, or reason.<sup>ciii</sup> The result is not greater acceptance but



increased fear and a desire for social distance. The public is more pessimistic about recovery, holds an exaggerated perception of difference (them and us), and is more likely to dehumanise people with mental illness. Focusing on causation is not the key to reducing discrimination. As Bruce Link states: “We cannot address these problems through the message we have already delivered... that mental illnesses are illogical and genetic causes that can be treated... those are important messages in themselves but they do not solve the problems of stereotyping and discrimination.”<sup>civ</sup>

### The research suggests:

- ▲ There is less stigma when mental health problems are framed as ‘an understandable response to a unique set of circumstance’ and a part of our ‘shared humanity’. This approach reduces the sense of difference and ‘otherness’.<sup>cvi</sup>
- ▲ Bio-medical framing of mental health problems as ‘diseased’ states, genetically linked, chemically mediated disorders, which are a product of a ‘broken brain’ increases stigma, discrimination and strengthens the link between mental illness, violence, impulsivity, and incompetence and has not increased tolerance as expected.<sup>cvii cviii</sup>
- ▲ Psychiatric labelling (diagnosis), hospitalisation, use of psychotropic medications and being treated by a psychiatrist all increase public fear, desire for social distance and tolerance of ‘risk containment’ through coercive treatment. These treatment elements need to be de-emphasised in public education.
- ▲ Emphasising the bio-medical underpinnings of mental illness and the use of psychiatric diagnosis needs to be presented with caution in both in public education and within the clinical setting.<sup>cix cx</sup>

### Attitudes of professionals may contribute to stigma

Health and mental health care providers have traditionally played a leading role in developing and delivering

educational and anti-stigma programming. They hold authority with the public and policy planners and are recognised 'experts' within the media. Consequently, professionals play an influential role in shaping public attitudes and policy decision-making. Research reveals that both health and mental health professionals hold discriminatory attitudes towards people with mental health problems and are more likely to frame mental illness in a pessimistic and paternalistic manner. Professional-led anti-stigma programming has promoted a bio-medical model and focused on a negative orientation of the impact of illness on people's lives emphasising burden, suffering, morbidity and mortality.<sup>cxix cxii</sup> The following approaches reflect a misalignment with messages that support social inclusion:

- ▲ Health care providers being less optimistic about recovery, taking a more protective stance and discouraging independent decision-making and risk taking.
- ▲ Symptom reduction avoiding adverse incidence of illness taking priority over enhancing quality of life and an over-attention to medication and treatment adherence. Deficits and disability are stressed over strengths and capabilities and limited resources are allocated to rehabilitation and recovery-focused service.<sup>cxiii</sup>
- ▲ Social needs including the importance of employment, parenting, friendship and community engagement are not the focus of medical care and as a result are not being consistently addressed.
- ▲ A psychiatric diagnosis assumes a "master status". Health needs are ascribed to mental illness, are minimised, or ignored. People receive fewer health resources including diagnostic testing and medical procedures.<sup>cxiv</sup> People diagnosed with a mental illness are receiving poorer physical health care, live with more chronic illnesses, and have a shortened life span.<sup>cxv cxvi</sup>

- ▲ The impact of stigma and discrimination is not addressed in the clinical setting beyond promoting education on mental illness.<sup>cxvii</sup>
- ▲ To play a leading role in reducing stigma, psychiatrists need to incorporate recovery into their practice, focus on ways to enhance social inclusion, empowering patients in pursuing self-directed goals and support the human rights of their patients.<sup>cxviii</sup>

It is the opinion of the consultant that the misalignment in public messaging can undermine efforts of an anti-stigma, social inclusion campaign to reduce discrimination, promote rights, and enhance full community participation. Proactive steps to align approaches across disciplines and stakeholder groups will be critical.

### **Empowerment, recovery and reframing madness**

The active leadership of people with mental health problems is helping re-define approaches to reducing stigma and discrimination. Protest has been identified as a critical component of reducing discrimination. This includes challenging the attitudes of powerful groups, advocating for systemic change by confronting policies, practices and laws that are exclusionary or misaligned with recovery. Participation in Mad Pride demonstrations, belonging to peer-support groups, undertaking self-created anti-stigma activities and protesting media misrepresentation have helped people to claim a renewed sense of their own value, builds group identification, lessens social isolation, fosters a sense of purpose and meaning, promotes recovery and enhances quality of life. For decades, consumers have been excluded from decision-making in treatment planning and program development. Despite being marginalised they have organised to find ways to support each other and build

peer-driven, self help supports and services including economic development initiatives.<sup>cxix</sup> Historically people with mental illness were not expected to recover. Through this more pessimistic lens, professional treatment has centred on diagnosis, symptom management, disease containment, and the treatment of psychopathology to prevent relapse and stave off deterioration in function. The concept of recovery emerged from within the consumer community as a challenge to treatment strategies, which are too narrowly focused on symptom alleviation instead of addressing people's multiple residential, social, vocational, and educational needs.<sup>cxx</sup> The effectiveness of the Recovery Model is being documented and as an approach is being adopted by government and policy planners as a way of increasing accountability and measuring outcomes of mental health care budgets. The expertise of consumers is increasingly recognised and included in service delivery, policy and program planning and evaluation. The inclusion of peer-support workers and consumer consultants within health and social service settings is having a positive effect on limiting discriminatory behaviours and in promoting practices that are more inclusive. Providing financial resources to support empowerment activities and building consumer participation is increasingly seen a critical element of social inclusion programming.<sup>cxxi</sup>

Leadership within the consumer community is helping to reframe the language and conceptual models used to understand mental distress and engaging public discourse through groups such as the National Empowerment Centre,<sup>cxvii</sup> the Hearing Voices Network, and New Zealand's 'Out of their Minds.'<sup>cxviii</sup> Internationally consumers have begun to network to

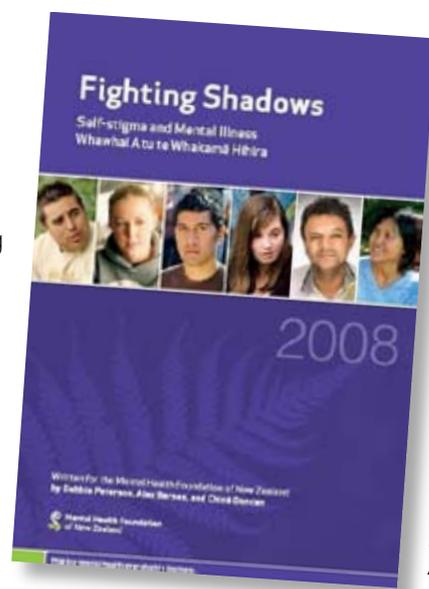
share their insights, resources and provide critical moral support in challenging existing approaches that do not align with recovery goals or may result in increasing discrimination. According to Graham Thornicroft uniting across all sectors will help to develop a stronger and more unified voice in influencing policy planners.

### Disclosure and self-stigma

The importance of addressing self-stigma is being identified in the research as critical because of the harm it causes to self-identity and self-imposed limitations on pursuing life goals and rightful entitlements. In addition, building a leadership base to support anti-stigma education and advocacy efforts requires a willingness to disclose ones' experience. Fear of discrimination and self-stigma are significant barriers to self-identification. Research is helping to untangling the many threads of what are protective factors and what promotes self-stigma. Hiding one's history of illness, social isolation and educating others about mental illness consume a lot of energy and has not been found to reduce self-stigma.<sup>cxv</sup> Participation in peer-support activities does help people practice disclosure in a safe, non-judgmental environment. Disclosure is found to have positive health and social benefits and helps people to reframe the negative experience of illness more positively.<sup>cxvii cxviii</sup> The

*Fighting Shadows* report identified 'circuit-breakers' to counter discrimination and negative thought patterns including: increasing visibility of people with mental illness, building peer support networks, affirming human rights, challenging negative attitudes, and encouraging mental health services to focus on recovery.<sup>cxvii</sup> Empowerment is critical to leadership; helps promote self-disclosure and serves as powerful inoculants against self-stigma.<sup>cxviii cxvix cxxx</sup>

Empowerment also includes the presence and application of anti-discrimination legislation that protects people's human rights within treatment settings, employment, housing etc. Lis Sayce states: "Initiatives to reduce discrimination need to make use



*of the iron fist of law with the velvet glove of persuasion.*<sup>cxxxii</sup>

Although legal redress is a blunt instrument, legislation does serve as a powerful deterrent. Graham Thornicroft recommends drawing on the national Human Rights Acts, Disability Rights Legislation, the Universal Declaration of Human Rights and existing covenants and charters to provide both a legal framework and the moral authority for reducing discrimination. Government legislation can impose a public sector duty to promote equality of opportunity. On this front, the Australian Government has been an international leader in drafting a solid legislative framework to protect the rights of people with disabilities. However, the lack of resources to support people in understanding or accessing these mechanisms blunts their usefulness. Coordinated planning to improve the protection of human rights can also be achieved by bringing together organisations with a shared interest and responsibility for reducing discrimination, an approach recently undertaken in New Zealand. This plan is documented in *Reducing Discrimination Against People with Mental Illness: Te Kekenga: Whakamana i te Tangata Whaiora Multi-Agency Plan 2005–2007* (Mental Health Commission of New Zealand 2005).<sup>cxxxiii</sup>

## Employment is critical to inclusion

Work is critical and social inclusion is not possible without economic inclusion. While some people feel employment is beyond their reach, poverty creates a deep divide in participating within the community and enjoying a good quality of life. Addressing inadequate disabilities pensions, which keep people mired in poverty, is important. However, exclusion from the workforce is a particularly damaging form of discrimination. Emphasis needs to be placed on accessing paid employment with support available to help people get, keep, and progress in their career (not just entry level jobs). Access to education, training, employment and use of programs such as Individual Placement and Support model have been found to be an effective means of getting people back to work.<sup>cxxxiii cxxxiv</sup> Employment is positively associated

with improved self-esteem, hope, recovery, expanding social networks and improved quality of life. Improving the understanding of health and mental health care professionals of both the possibility of recovery and mechanisms for supporting effective return to work is critical along with more robust funding for rehabilitation services. Employers also need support and advice to encourage their engaging or retaining people with mental health problems in the workplace. People living with mental health problems also need to know that employment is possible, what supports are available to them, what are their rights to accommodation and steps that they can take to redress discrimination if it occurs including strengthen the legal framework. Australia has existing services targeted at people with disabilities to be placed in 'real jobs'. Disability Employment Networks provide specialised assistance to jobseekers that require ongoing support to find and maintain employment. This approach is seen to provide a good policy framework that has yet to translate into meaningful outcomes. Australia has also recently released a National Mental Health and Disability Employment Strategy to strengthen its support in assisting people with disabilities, including mental illness, gain access to employment a cornerstone of social inclusion.<sup>cxxxv</sup>

## Media plays a prominent role

Media plays an important mediating role in the public's understanding of health and social issues. Research reveals that the media contributes to promoting stereotypic portrayals of people with mental health problems that increase public perception of violence, incompetence, and incapacity. The extensive reach on media makes it an important target for intervention both to enhance positive reporting and challenge stereotypic, false, or misleading portrayals of people with mental illness.

Research reveals that:

- ▲ The media depiction of people with mental health problems is overwhelmingly 'devoid of admirable attributes'.
- ▲ One in four parental guidance rated films include a character identified as mentally ill and are primarily depicted as villains, psycho-killers, or as incompetent, poor unfortunate people in need of care.<sup>cxxxvi</sup>
- ▲ Media reports focus excessively on violent acts and suggest violence committed by people with mental illness should be viewed differently. Reporting re-enforces negative stereotypes of dangerous, and a perception of 'otherness'.<sup>cxxxvii cxxxviii</sup>
- ▲ Depicting people with mental health problems as being vulnerable and at risk increases tolerance for the use of coercion and control.<sup>cxxxix</sup>
- ▲ There are few 'first person' accounts in media stories with well intentioned others (family or health care professionals) speaking for people with mental health problems. The lack of the first person voice suggests that people are incapable of speaking for themselves or that their voice must be considered as suspect.<sup>cxl</sup>
- ▲ Children are being exposed to high numbers of cartoons and movies that depict mentally ill characters as villainous, dangerous and impulsive. Children learn early to fear people with mental illness.<sup>cxli cxlii</sup>

## Targeting is important

Consumer surveys show that there are specific groups that are more likely to discriminate, hold greater power to block social inclusion goals, or who are in important positions to facilitate greater acceptance and social inclusion. To successfully reduce discrimination, steps need to be taken to change strongly held attitudes and beliefs that lead to the stereotyping of people with mental health problems by those groups who have the greatest power and influence. Research supports the notion that the more targeted the education and specific

the message the greater its impact. Understanding the target audience through researching their perspectives prior to undertaking a campaign is critical in developing key messages. Including the targeted groups in defining the issues, developing and delivering the program also increases message impact and uptake. It also ensures that the approach taken reflects the culture and values of the target group.

There are a number of 'high target' groups, which have been identified:

- ▲ Health and mental health care providers (medical students),
- ▲ Family, friends and caregivers,
- ▲ Politicians, policy planner and funders,
- ▲ Emergency response staff,
- ▲ Schools (teachers, students, guidance departments),
- ▲ Police, courts, probation and correctional officers,
- ▲ Social services staff (welfare, child services, pensions),
- ▲ Media.

There are specific segments of the population who are at greater risk of developing mental health problems or are less likely to seek out the support that they need. Creating targeted approaches to understanding and removing the barriers to inclusion within these communities will be important. Their active engagement in problem identification, program development, and the delivery of culturally sensitive programming is critical.

- ▲ Aboriginal communities,
- ▲ Children and youth,
- ▲ The elderly,
- ▲ Immigrant and refugees.

## Economic Benefits of Social Inclusion

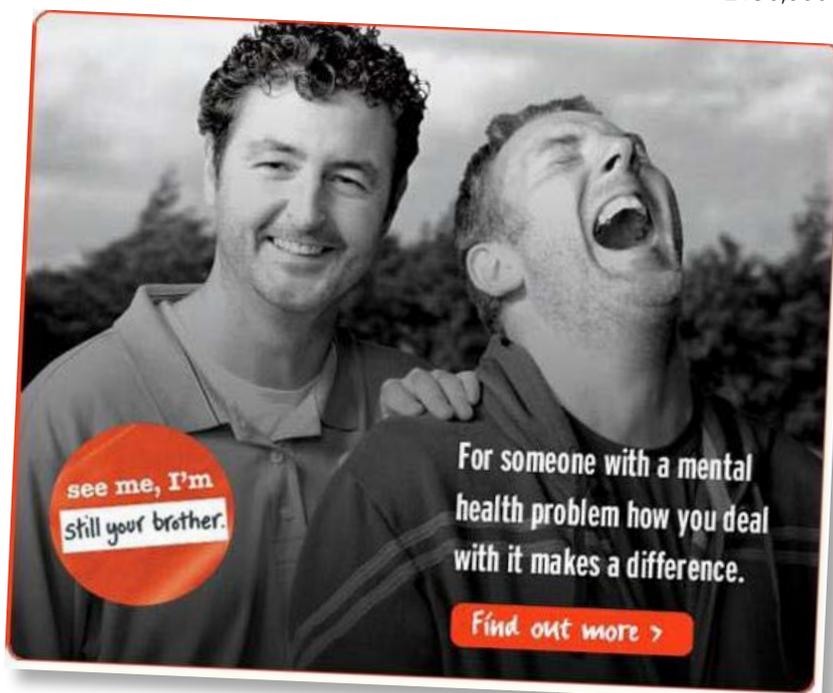
There is a paucity of economic research and analysis of the cost/benefit of different clinical and support options

for mental health problems. This makes it difficult to determine where cash-strapped governments should commit resources to achieve the best outcome. Program evaluations are often done measuring indices not closely aligned with the quality of life goals that consumers and their families' value. Being able to assess economically whether a program's outcomes are worth the resources invested can help governments make a more rational approach to decision making.<sup>cxliii</sup> To this end a cost-effective analysis was recently undertaken of Scotland's *See Me* anti-stigma campaign by the London School of Economics and Institute of Psychiatry, King's College London. The researchers constructed a decision model to estimate the economic impact of the campaign in terms of increased use of services by people with depression and their increased work time. They found that the estimated cost of delivering the *See Me* program

Social inclusion programs are felt to offer considerable social benefits to people living with mental health problems in reducing barriers to their participating fully in community life. They are also cost effective in reducing the period of time before people seek treatment, increasing achievements at work and school, and reducing investment in costly treatment and social services.

Freidle and Parsonage (2007) advance an equally compelling case for the cost effectiveness of population-based mental health promotion. Benefits are gained through promoting positive mental health, prevention and improving the clinical outcomes and quality of life for people with mental health problems. For example, they estimated that preventing conduct disorders in children who are most disturbed would save around £150,000 per case over a lifetime. They estimate that

the total value of prevention would be £172.5 million and in promoting positive mental health amounting to £776.25 million. Although the evidence is admittedly incomplete, the potential benefits of mental health promotion far outweigh the cost of implementation.



was £0.55 per person. By calculating the economic benefits – employment, minus service costs – the extra economic benefit derived by delivering this campaign was an estimated £4.26 per person. The researchers concluded that the modest investment in program cost was far outweighed by the potential economic benefit.<sup>cxliiv</sup>

# CHAPTER 4

## INTERNATIONAL PROGRAM REVIEW

Five English-speaking countries were identified as having national, multi-faceted, long-term, financially sustainable anti-discrimination/social inclusion programs in place. A review of their websites, research reports, strategic plans, surveys and evaluations was undertaken to identify approaches and 'best and promising' principles. A detailed summary of each program, including hyperlinks to specific program elements and reports is available in Appendix B. The programs reviewed include:<sup>5</sup>



New Zealand – *Like Minds, Like Mine*



Scotland – *See Me*



United Kingdom – *Time to Change*



United States – SAMSHA



Canada – Mental Health Commission of Canada (in development)

### Best and Promising Practices in Program Delivery

Of all the programs reviewed in the consultant opinion, New Zealand's *Like Minds, Like Mine* (LMLM) represents a 'gold standard' in program design and delivery. LMLM is the longest running social inclusion program. Its programming is both innovative and evidence-based. They have a well-developed strategic plan that seeks transformative change at the population, organisational and individual level. It has clear, measurable behavioural targets aligned with outcome goals that aim for meaningful change for people living with mental health problems. Where knowledge is missing, they undertake research that builds understanding and share their results broadly. LMLM works in partnership with all stakeholders to develop shared plans for policy, practice, and legislative change.

Of all the national programs, it has made the clearest distinction between social inclusion and mental health literacy and takes a strong human rights focus. LMLM provides a clear roadmap for program development and is the group others look to for guidance. It delivers an award winning national media campaign that sets aspiration goals for the nation. This program has evolved over the years to reflect a more granulated understanding of what works in shifting both attitudes and behaviours. For example the earliest campaign featured world famous figures that experienced mental illnesses, then well known popular New Zealanders. The following campaign highlighted the stories of a diverse group of 'regular' New Zealanders. It's most successful campaign featured 'Aubrey' a schoolteacher living with bipolar illness. His story unfolds from a variety of perspectives including his friends, wife, family, and employer. It emphasises human rights, normalises mental illness and models ways to support people successfully. Recent campaigns feature people from different cultural groups reflecting their specific values and cultural needs. A focus on supporting people in the workplace also reflects the high priority work has in social inclusion. Most recently, LMLM programming is increasingly reflecting the importance of consumer leadership, disclosure, empowerment, and creating more space for the consumer community to develop its voice and perspective. Critics of this program express concern that it focuses too much attention on 'mental illness' rather than on mental distress as a normal consequence of psychological and social causal factors.<sup>cxiv</sup>

*Time to Change* UK has adopted a similar approach but has also incorporated a health promotion component to its anti-stigma activities that encourages physical exercise, stress reduction, and healthy life styles.

The language used to describe mental health problems is a source of considerable debate. Those programs with greater leadership involvement of mental health professional groups and family association appear to psychiatric nomenclature and place greater emphasis on building mental health literacy and encouraging help-

seeking behaviour. Social marketing experts involved in program development have also argued in favour of using the language of mental illness based on their market research with the public. This preference by the public may reflect the success of past educational initiatives focused on promoting a disease model and efforts to enhance mental health literacy. Given the potential risk of increasing social distance and discrimination when issues are framed within a medical model caution is recommended and further research on this issue required.

Based on a broad review of national programs the consultant identified 'best practice principles' in program delivery. Some of the identified principles reflect emerging knowledge and are more 'evidence-informed' than 'evidence-based' approaches. Further research is required to confirm their effectiveness. A chart summarising the application of these identified principles across national programs is included at the end of Appendix B.

The following identified principles were also reviewed by a diverse group of academic researchers, program delivery experts, and leaders within the consumer community. There is broad agreement that these principles do reflect the existing research and emerging program trends. Best advice and promising practices include:

### **Promote a simple and enduring national vision**

Focus on human rights; promote respect, inclusion, and the message that change is a shared responsibility. Develop a highly visible national campaign to elevate the importance of social inclusion, nurture a positive climate for discussion, and create 'buzz'.<sup>cxlvi</sup> Use social marketing tools and adopt a multi-media approach including emerging social media. Profile diverse 'real people' to challenge stereotypes. Use celebrity figures to increase attention and focus. A national campaign represents but the 'tip of the iceberg' and must support local programming, develop resources and lend authority and credibility to local leaders.<sup>6</sup>

### **Plan strategically at the national level**

Work across multiple sectors and build diverse partnerships. Develop multi-sector strategic plans in partnership with government, NGO's, service provider groups, stakeholders, consumers, and allies.<sup>cxlvii</sup> Apply a disability/social inclusion model and focus on systemic transformation through policy and practice changes. Strengthen legislative and enforcement mechanisms to support human rights. Align outcome goals to meaningful improvements that reduce discrimination and improve quality of life.<sup>cxlviii</sup>

### **Support local program delivery**

Sustained change happens at the local grass-roots level. Program development needs to focus on local advocacy, increasing contact and education. Creative, bold and innovative program approaches should be encouraged that reflect the local opportunities and needs. Use creative arts, comedy, and theatre to enhance the emotional impact. Support consumer leadership, partnership, planning with local groups and supports mainstream participation.

### **Protest and empowerment**

Empowerment is core to building leadership. The expertise of people living with mental health problems needs to be explicitly acknowledged and their input included in defining issues, designing programs, undertaking research, and evaluating program success.<sup>cxlix</sup>

Increasing the visibility of people with mental illness, building support networks, affirming human rights, challenging discrimination, and encouraging health care services to focus on recovery goals are powerful inoculates against self-stigma.

Peer-led supports increase group identification, supports disclosure, and requires support. Participating in public education, protesting

<sup>6</sup>Paul Farmer, E.D. Time to Change reports that their nation-wide coordinated campaign appears to be the most successful program element.

discrimination and mutual aid helps people to recover, helps positively re-frame the experience of ill-health, enhanced a sense of purpose and meaning, reduces social isolation and strengthens a sense rightful entitlement.

### Targeting is important

The reduction of discrimination requires changing firmly entrenched beliefs of influential groups that lead them to label, stereotype and discriminate. Programs are most effective when they are targeted, segmented, and culturally relevant and include the target group in program development. High impact groups include: health, emergency response, policing and corrections, social service providers, employers, educators, and those who provide emotional and social support including friends, family, religious leaders.

### Media requires a special focus

Media plays a significant role in shaping public opinion – both good and bad. Increasing the portrayal of people as competent, capable, and productive citizens improves public attitudes. Increasing ‘first person’ narratives, creating resource materials, forming speakers’ bureaus, and providing media training to consumers helps improve media contact. Protest negative, inaccurate or stigmatising portrayals of people across all media is critical – particularly in children’s media.

### Research and evaluation is a priority

Programs must use evidence-informed approaches. Use multiple survey tools to inform programming and evaluate impact (public survey, program evaluations, focus groups, polling). Knowledge is nascent and needs to grow. Partner with researcher to provide external program evaluation. Build on what others are doing across the world. Build knowledge through research and share findings with others. Use action-oriented, outcomes focused qualitative designs; include consumers, respect cultural differences, and ‘other ways of knowing’. Use a

continuous quality improvement approach – evaluate, learn, refine and then evaluate again.

### Apply tool of social marketing

Social marketing is an effective means of encouraging behavioural change through the systematic application of marketing concepts. The strength of social marketing is that it replaces an ad hoc, intuitively based, short-term planning approach with a systematic, phased and process driven planning approach. Programs are built on market research and feedback from people with lived experience and designed to deliver clear actionable and measurable behavioural goals. Benchmarks are established at the outset to support ongoing evaluation and course corrections.<sup>cl</sup> Critics of social marketing feel that too much emphasis is placed on messaging where as effective social change requires systemic thinking and multi-faceted solutions including structural, legislative, policy, and practice changes.<sup>cli</sup>

### Program Success Measures

Drawing from program evaluations, public attitude and consumer surveys national programs are having measurable success in shifting attitudes and behaviours. Specific outcome details, references, and links to evaluations are included in Appendix B.

Some Key Results:

- ▲ Increased awareness of mental health problems and more positive public attitudes.
- ▲ Enhanced supportive behaviours including improvement in desire, willingness, and knowledge of how to support someone with a mental illness.
- ▲ More positive behaviour and respect towards someone with a mental illness.
- ▲ Greater willingness to talk about mental health problems.
- ▲ Greater acceptance by friends.

- ▲ Increased comfort talking to someone with a mental illness.
- ▲ Improvements in belief that recovery is possible.
- ▲ Greater willingness to employ someone with a mental illness.
- ▲ Decreased beliefs that people with mental illness are likely to be violent.
- ▲ Improved non-discriminatory media coverage, expansion in first person narratives.
- ▲ People with mental health problems report positive shifts in public attitudes, decreased stigma, and positive changes in acceptance and support.
- ▲ Increased access to health care services reported.
- ▲ Increased involvement of people with mental illness in planning, program delivery, and education leading to enhanced sense of empowerment.
- ▲ High level of advertisement recall and public approval of campaigns.

### Conclusion:

Reducing discrimination has been an intractable problem because it is a complex Gordian knot of inter-connected issues for which there is no single or simple solution. It requires the promotion of a universal belief in the importance of an inclusive society – for everyone! Reducing discrimination is not a communication exercise and requires more than a well-crafted social marketing campaign (although that is also important). There are powerful systemic, social, attitudinal and institutional barriers that need to be simultaneously untangled. A successful program requires broad-based leadership and political champions to success. The active involvement of decision-makers from across government, partnerships with non-governmental agencies, health, and social services, community stakeholders and consumer leaders is critical. Together stakeholders need to create multi-sectorial strategic plans that target improvements in policies and practices to stop

discrimination and support full and social engagement. Meaningful change also requires legislative improvements and enhanced mechanisms for enforcement to protect and affirm equal rights and entitlements. Although there are many amazingly interesting and evidence-aligned programs being delivered around the world to reduce stigma,<sup>7</sup> in the absence of a nationally coordinated, sustained, and multifaceted approach these programs are not likely to achieve the desired change at a population level.

A social inclusion campaign needs to create a unifying vision that speaks to the aspirations of the nation, the value of diversity, and the shared responsibility of reducing discrimination. A national high-quality multi-media campaign can help to bring visibility and profile to the importance of this issue and signals the

**A social inclusion campaign needs to create a unifying vision that speaks to the aspirations of the nation, the value of diversity, and the shared responsibility of reducing stigma**

commitment of government and stakeholders to act. It increases visibility, lends authority and credibility to local program leaders, and if done well creates ‘buzz’ an essential ingredient in social change. Positively shifting public attitudes and behaviours creates a receptive climate in which broader policy change can occur and will

help support politicians and stakeholders to act. Success requires the commitment of adequate and sustained funding. A well-developed national multi-media campaign supports education and advocacy activities on the ground. This program element is the most visible component of programming but it is just the “tip of the iceberg”. Sustained changes come from diverse programming at the grass-roots level.

<sup>7</sup>Refer to Appendix B examples of programming from around the world.

At its core a successful social inclusion campaign requires engaging every citizen to re-think their assumptions about mental health problems and take steps to create a social quilt where everyone is valued, respected and belongs. This is accomplished at the local level where consumers engage their neighbours, co-workers, faith leaders, and health care provider etc. to improve their understanding about stigma and discrimination and create a conversation about change. Telling people what is the “correct” way to think or feel will not work and can create a boomerang effect. Change requires emphatically increasing contact between people living with mental health problems and the broader community. Given that almost half of us will experience a mental health problem in our lifetime, the problem is not contact but a willingness to disclose ones experience. Addressing the barriers to disclosure will be central to building a leadership team of consumers. This will require putting in place the supports that nurture advocacy, enhancing group identification and fostering empowerment within the consumer community.

There is a high level of agreement amongst stakeholders that steps need to be taken at the national level to strengthen social inclusion and protect the rights people with mental health problems. Using traditional educational approaches will not achieve new and different results. Social inclusion strategies are a paradigm shift in thinking which brings people with a lived experience into a partnership process of change. The evidence is strong that a well-coordinated program produces meaningful results – over time. Australia is ideally positioned to support the development of a campaign as an important thread of its national mental health strategy. Australians as a whole recognise that mental ill-health is a concern and are ready to engage in a discussion that will help them re-think their understanding of mental health problems. Creating a shared vision, coordinating national planning and undertaking robust local activity focused on education,

contact, and protest will serve to transform ignorance, prejudice, and discrimination.

Enjoying supportive friendships, being a productive, working citizen, playing a meaningful role in ones’ family and community, enjoying good-health, emotional well-being, to be able to reach ones full potential, and sharing public resources equally are goals each Australian strives for – including people with mental health problems – if they are given the chance.

### Recommendations:

- ▲ Disseminate research review to key stakeholders and undertake discussions to build a shared understanding of best practices and identify any gaps, issues, or concerns.
- ▲ Identify anti-stigma, discrimination reduction, and social inclusion programming underway across Australia to identify opportunities for coordinated action.
- ▲ Coordinate advocacy efforts across stakeholder groups to support the establishment of a national social inclusion program. Seek funding from the Government of Australia to deliver a national social inclusion campaign built upon evidence based and promising practices.
- ▲ Collaborate with the Ministry of Social Inclusion and the National Preventive Health Agency to integrate activates, coordinate efforts and maximise policy impact. Ensure an anti-discrimination lens is applied to the work of these Agencies.

# APPENDIX A

## EXPERTS CONSULTED

The Executive Summary of this report was sent out for review by leading academic and program delivery experts in social inclusion research to explore the concepts and test the veracity of the recommendations. Special thanks to the following people for their contributions:

**Lis Sayce**, Chief Executive  
Royal Association for Disability and Rehabilitation

**Darryl Bishop**, Program Leader,  
*Like Minds, Like Mine*, Ministry of Health, New Zealand

**John Read**, PhD, Associate Professor, Dept. of Science,  
University of Auckland, Clinical Psychologist

**Martin Knapp**, Professor of Social Policy and Director –  
Personal Social Services Research Unit, London School of  
Economics and Political Science in the United Kingdom

**Pat Corrigan**, Professor of Psychology, Illinois Institute  
of Technology, and Principal Investigator of the Chicago  
Consortium for Stigma Research (CCSR)

**Graham Thornicroft**, Professor – Community Psychiatry,  
Head of the Health Services Research Department,  
Institute of Psychiatry, King's College London

**Dr. Michael Smith**, Management Group Member –  
Consultant Psychiatrist and Clinical Director, *See Me*,  
Scotland, NHS Greater Glasgow and Clyde

**Paul Farmer**, Program Executive Director, *Time to Change*,  
United Kingdom

**Dr. Bruce G. Link**, Professor of Epidemiology and Socio-  
medical Sciences (in Psychiatry), Mailman School of Public  
Health, Columbia University

**Dr. Otto Wahl**, Director of the Graduate Institute of  
Professional Psychology, Professor of Psychology at the  
University of Hartford

**Mary O'Hagan**, Consultant, Writer, Speaker, New Zealand

**Dan Fischer**, M.D., Ph.D. Executive Director, National  
Empowerment Centre, USA

# APPENDIX B

## NATIONAL SOCIAL INCLUSION PROGRAMS

The following is a high level summary of national social inclusion programs and includes hyperlinks to program elements, reports, surveys and program evaluation documents.

### 1. Like Minds, Like Mine – NZ



*Like Minds, Like Mine* is a multi-year project delivered by the New Zealand Ministry of Health. Developed in 1997, following an inquiry into the country's mental health system, *Like Minds* includes five national organisations, each focusing on a specific subject area, and 26 regional organisations with responsibility for education, media, community action and community events in their own areas. *Like Minds, Like Mine* is guided by a comprehensive National Plan 2007–2011.

Program goals are to: reduce the stigma of mental illness and the discrimination that people with experience of mental illness face every day in the community; change discriminatory attitudes and behaviours through direct contact; promoting rights and challenging organisations, communities and individuals not to discriminate. *Like Minds* uses the following approaches:

- ▲ Maintains national focus providing coordination, strategic planning and coordination.
- ▲ Uses a social model of disability and human rights perspective.
- ▲ Delivers evidence-based programs.
- ▲ Undertakes research and program evaluation.
- ▲ Uses a targeted approach.
- ▲ Develops print materials, provides education and training.
- ▲ Media is a target focus (resources and media watch).
- ▲ People with lived experience guide program development and delivery.
- ▲ Delivers programs locally utilising 26 Regional Service Providers

- ▲ Develops national partnerships and collaborates with public health agencies, mental health service providers, consumer control organisations, non-governmental organisations and Maori and Pacific partners.
- ▲ Strategies and approaches target societal, organisational and individual levels to:
  - Promote increased opportunities for people with experience of mental illness to provide direction and deliver program goals.
  - Assist organisations to adopt policies and practices that prevent discrimination.
  - Strengthen approaches to address the needs of Maori, Pacific peoples and specific populations with experience of mental illness.
  - Develop approaches to deal with internalised stigma.
  - Deliver training and resources for consumers.
  - Undertake research and policy development.
  - Deliver public media campaigns using social marketing tools to change discriminatory attitudes and behaviours. Four phases of television and radio advertisements focused on the negative social judgment of people with mental illness.

Evaluation outcomes: an annual independent survey was conducted to assess program impact. The report is available at: [www.likeminds.org.nz/file/downloads/pdf/R4535-12.pdf](http://www.likeminds.org.nz/file/downloads/pdf/R4535-12.pdf)

#### Key findings – impacts

- ▲ The results show changes consistent with the messages of the current campaign, in terms of a significant 10% improvement in level of agreement that: 'I know how I could be supportive of people with mental illness if I wanted to be'.
- ▲ There was also a significant 5% increase in the proportion agreeing with the other attitude statement relating to the campaign message: 'I want to be as supportive as possible to people with mental illness'.

- ▲ There was also a 4% improvement in the percentage giving the desired response for: 'Once a person gets a mental illness they are always unwell'.
- ▲ There was increased acceptance of someone with experience of mental illness as a babysitter and likewise for someone with experience of schizophrenia.
- ▲ A third of people reported having changed their behaviour in relation to people with mental illness over the last five years.
- ▲ There were high proportions who reported specific positive behaviours in the last 12 months, including 65% who had 'behaved in a way that ensured someone with mental illness was treated with respect'.
- ▲ There was a decrease in prompted recall of the advertising, from the previous high of 88% down to 79%, but this was still a high level.
- ▲ Two-thirds (67%) recalled the advertising message of 'acceptance/equality/non-discrimination', which was a significant increase from the level at the end of the previous campaign.
- ▲ Advertising recall was higher for Maori (87%) than the Total Sample (79%).
- ▲ While on several attitude items, Pacific peoples were below the total sample with levels of desired responses; for the item relating to wanting to be supportive they were higher.

### Changes since benchmark

Attitudes relating to the campaign messages have improved over the nine surveys. Largest levels of change were:

- ▲ 23% improvement – acceptance by friends.
- ▲ 16% improvement – comfort in talking to someone with a mental illness.
- ▲ 14% improvement – in people who have a mental illness are more likely than other people to be dangerous.

- ▲ Youth (15 to 19 year olds) have increased levels of acceptance of people with mental illness and schizophrenia.
- ▲ In terms of gender, as much positive impact on males as females.

### Identified program success<sup>8,9</sup>

Changes in public attitudes related to media campaign including:

- ▲ Increased awareness and positive attitudes, enhanced supportive behaviours.
- ▲ 69% of employers, managers or supervisors reported they would likely or very likely employ a qualified candidate with a mental illness.
- ▲ Improved non-discriminatory media coverage, expansion first person narratives.<sup>10</sup>
- ▲ People with experience of mental illness report positive changes.
- ▲ Coordinated regional messaging.
- ▲ Targeted media and programming for Pacific and Maori people.
- ▲ Increased access to health care services.
- ▲ Concrete policy and behaviour changes resulting from *Like Minds* work.
- ▲ Expanded community partnerships.
- ▲ Increased user participation in planning, program delivery and education leading to enhanced sense of individual and community empowerment.
- ▲ Joint planning for disability responsiveness across the public sector.
- ▲ Multiple awards of excellence for media work.

## 2. Time to Change – UK



A national campaign to enhance social inclusion, health promotion and discrimination reduction. The campaign goal is to end discrimination faced by people who experience mental health problems. Their vision is to make lives better for everyone by ending mental health discrimination, and their mission is to inspire people to work together to end the discrimination surrounding mental health.

- ▲ Funded by the Big Lottery Fund, £16m and Comic Relief, £4m.
- ▲ Takes a national focus – delivers local programs.
- ▲ Led by a consortium of mental health groups (Mind, Rethink).
- ▲ Works collaboratively with all sectors and communities.
- ▲ Independently evaluated by the Institute of Psychiatry.
- ▲ Uses an evidence-based approach – helping to building knowledge through research.
- ▲ Program evaluation measuring impact on people's experience of discrimination.
- ▲ People with experience of mental health problems take a leadership role.
- ▲ Uses social marketing principles and tools, including print, social networking tools, and broadcast media.

### Programs include:

A national high-profile campaign that has used a multi-media approach to increase awareness of discrimination and prevalence of mental illness, and encourage support.

Targeted campaigns – 35 projects underway:

- ▲ *Get Moving* – mental health/healthy living promotion run by MIND
- ▲ *Open Up* – consumer empowerment program
- ▲ *Time to Challenge* – legal test cases challenge of discrimination

- ▲ *Education Not Discrimination* – targeted education teachers, doctors etc.
- ▲ Knowledge exchange – website, print and training
- ▲ A network of grass-roots activists combating discrimination<sup>9</sup>
- ▲ Local community projects
- ▲ Research and evaluation.

*Time to Change* will evaluate its impact on public and audience-specific knowledge about stigma and mental illness through surveys throughout the duration of the program, changes in attitude through repeating annually a National Public Attitudes to Mental Illness survey which has been conducted since 1993. Behavioural changes will be tracked by an annual Viewpoint survey of people with mental health problems and their experiences of discrimination and sense of confidence and empowerment. Results of program evaluations and research will be broadly shared.

### Behavioural targets set

- ▲ To create a 5% positive shift in public attitudes towards mental health problems.
- ▲ To achieve a 5% reduction in discrimination by 2012.
- ▲ To increase the ability of 100,000 people with mental health problems to address discrimination.
- ▲ To engage over 250,000 people in physical activity.
- ▲ To produce a powerful evidence base of what works.

### 3. See Me – Scotland

*See Me* is Scotland's national campaign to end the stigma and discrimination of mental ill-health which is essential to improving quality of life and social inclusion. It was created in 2001 as part of the Scottish Executive's National Programme for Improving Mental Health and Well-being. It is based on the theory that eliminating stigma and discrimination.

Website [www.seemescotland.org](http://www.seemescotland.org) or [www.justlikeme.org.uk](http://www.justlikeme.org.uk)

*See Me* is an alliance of five voluntary mental health sector partners:

- ▲ Highland Users Group – national network of service users
- ▲ National Schizophrenia Fellowship Scotland – national carers group
- ▲ Penumbra – association of leading mental health groups
- ▲ Royal College of Psychiatrists (Scottish Division)
- ▲ SAMH – Scotland's leading mental health charity.

The *National Strategic Plan 2008–2011* is available at: <http://www.seemescotland.org.uk/images/pdfs/20412%20Summary%20Plan.pdf>

The vision is for a Scotland in which all people with mental health problems are fully equal and included. Aims are: to change public understanding, attitudes and behaviours so that the stigma and discrimination associated with mental ill-health is eliminated; to enhance the ability of people to challenge stigma and discrimination; to ensure that all organisations value and include people with mental health problems and those who support them; and to improve media reporting of mental ill-health.

#### **See Me:**

- ▲ Provides national leadership with regional and local programming.



- ▲ Takes leadership on legislative and policy changes.
- ▲ Employs people with direct experience to play a leadership role.
- ▲ Uses a strong first person voice: "I'm a person, not a label".
- ▲ Works in partnership with other stakeholders.
- ▲ Supports volunteer engagement and local initiatives. Provides support not program delivery. Builds capacity for individual and group effort.
- ▲ Delivers a national multi-media campaign to target the public and media.
- ▲ Uses social marketing strategies.
- ▲ Provides information about mental health problems.

**Strategies/approaches:** An integrated campaign including: outdoor billboards, leaflets and posters, feature articles in newspapers and television, online resources, cartoons, media volunteers, Stigma Stop Watch, newspaper awards, photo shows, and a comedy tour.

A summary is available at: <http://www.seemescotland.org.uk/seemesofar/campaignstrands>

The *See Me* approach was informed by: the National Scottish Survey of Public Attitudes to Mental Health, Mental Wellbeing and Mental Health Problems in 2002 (provides benchmarking for measuring program impact); *Well? What Do You Think?* (<http://www.penumbra.org.uk/>); and a national survey of the lived-experience of people with mental ill-health. *Hear Me* was summarised in *A Fairer Future*, launched in June 2007.

#### **Evaluation Outcomes:**

*See Me* is using multiple evaluation methods including focus groups, biannual public attitude surveys (*Well? What Do You Think?*), polling on people's experience of discrimination (*Hear Me*), and regional feedback.

### Fairer future highlights:

- ▲ A positive shift in public attitudes has been noted – 50% of people with mental health problems feel they are treated better.
- ▲ There is a greater awareness of the *See Me* campaign.
- ▲ 63% feel the campaign is important for tackling stigma in the workplace.
- ▲ 55% felt a positive change in media reporting.
- ▲ 74% felt *See Me* had a positive effect on the media.
- ▲ Two thirds felt more comfortable talking about their mental health problems.
- ▲ The perception of dangerousness is reduced by half.
- ▲ 95% who have NOT experienced mental health problems feel the campaign is important.

### Hear Me 2006 results

- ▲ 70% of those who had both supported someone and had their own mental health problems felt that the stigma problem in Scotland since 2002 had moved forward for the better.
- ▲ 85% felt able to be more open and talk about their mental health problem or to encourage others to do so.
- ▲ 63% felt that *See Me* had made a difference to how people with mental health problems feel about themselves.
- ▲ 63% of those employed and 58% of those looking for work regarded *See Me* as 'very' important in challenging stigma.

## 4. SAMHSA – USA

The Substance Abuse and Mental Health Services Administration (SAMHSA) is a Government-funded public health agency within the U.S. Department of Health and Human Services. The agency is responsible for improving the accountability, capacity and effectiveness of the nation's substance abuse prevention, addictions, treatment, and mental health services delivery system. It counters stigma



and discrimination by: sharing ideas about what works, promoting evidence-based best practices and connecting people and programs.

The Resource Centre to Promote Acceptance, Dignity and Social Inclusion Associated with Mental Health (ADS Centre) offers:

- ▲ Information about what works to promote acceptance and social inclusion of people with mental illnesses.
- ▲ Training and technical assistance to help create initiatives to promote social inclusion.
- ▲ Information about how to connect with more than 50 existing international, national and local campaigns and programs.
- ▲ Information about available publications, events, research, and issues of relevance regarding prejudice and discrimination associated with mental illnesses.
- ▲ A comprehensive online library of more than 2,000 items that addresses prejudice and discrimination.
- ▲ Resources and information promoting social inclusion related to special populations such as: children, older adults, and racial and gender minorities as well as information for employers, realtors/landlords, medical providers, educators, faith groups, policy makers, and the media.

ADS identifies 12 separate national awareness and education campaigns and dozens of state-wide initiatives.

SAMHSA sponsors the Voice Awards, honouring people in the entertainment industry.

SAMHSA also launched a national campaign *What a Difference a Friend Makes* to encourage, educate, and inspire people between 18 and 25 to support their friends who are experiencing mental health problems.

- ▲ To decrease the negative attitudes that surround mental illness.

- ▲ To encourage young adults to support their friends who are living with mental health problems.
- ▲ Focused on answering the question “What would you do?”, the campaign provides tools for young adults to learn about mental illness, help in the recovery process and read real-life stories of recovery.
- ▲ The campaign includes: public service announcements (radio and television), interactive video, brochures, a fact sheet, and a resource kit: “Developing a Stigma Reduction Initiative”.

## 5. Opening Minds – CANADA



The Opening Minds program is delivered by the Mental Health Commission of Canada (MHCC). The MHCC is a non-profit organisation created in 2007 to focus national attention on mental health issues and to work to improve the health and social outcomes of people living with mental illness. The MHCC is an arm’s length agency funded by the Government of Canada with a ten-year mandate.

The MHCC is in the early stages of developing its anti-stigma programming. A broad literature review, consultation with experts and survey of stakeholders was undertaken and the findings reported in *A Time for Action: Tackling Stigma and Discrimination*.<sup>ciii</sup> *An Operating Plan – 2007/2008* is also available on-line. Public attitude and consumer surveys have not yet been conducted. The goals of the anti-stigma and discrimination strategy are:

- 1) Change views of Canadians so people with mental illness are treated as full citizens by all.
- 2) Encourage organisations to adopt policies and practices to eliminate discrimination against people living with mental illness.
- 3) Ensure people living with mental illness have equal opportunities to participate in society and in everyday life in their communities.

The MHCC recently launched its Opening Minds Campaign (1 October 2009). It includes an anti-stigma and mental health literacy approach. In its first year, the Commission has targeted two specific groups:

- 1) Youth (aged 12 to 18) – to promote early intervention.
- 2) Health care professionals – with a focus on medical front lines e.g., doctors, nurses and emergency room receptions.

The MHCC is also undertaking evaluations of the effectiveness of 36 existing anti-stigma programs to identify successful programs, which could be developed nationally. The Commission intends to work closely with the broad mental health care community, consumers, stakeholders, and professionals to create its strategic plan. It has established a consumer reference group and a youth advisory committee to inform planning.

## Application of Program Principles

National social inclusion programs were reviewed to identify common practices. The following reflects the consultant's opinion, based on a review of program websites of the adoption of identified best practice principles.

Legend:

✓	Element in place
→	In development
×	Not identified
?	Unsure

Leading attributes: Social inclusion programs	New Zealand	England	Scotland	Canada*	USA
Applies disability inclusion mode	✓	✓	✓	×	✓
Benchmark survey – consumer/public	✓	✓	✓	×	✓
Consumer leadership	✓	✓	✓	→	✓
Programs are evaluated	✓	✓	✓	→	✓
Multi-sector planning targeting policy and practices changes	✓	✓	✓	→	✓
National strategic planning	✓	✓	✓	→	✓
Program delivered in partnership	✓	✓	✓	→	✓
Programs are evidence-informed and research is supported	✓	✓	✓	→	✓
Clear behavioural outcomes	✓	✓	✓	→	?
Targets service reform	✓	✓	✓	✓	✓

<b>National media campaign</b>	<b>New Zealand</b>	<b>England</b>	<b>Scotland</b>	<b>Canada</b>	<b>USA</b>
Using multi-media – social marketing	✓	✓	✓	→	✓
Using 'real' people, positive image	✓	✓	✓	✗	✓
Promotes human rights	✓	✓	✓	→	✓
Inclusion a shared responsibility	✓	✓	✓	→	✓

<b>Local program delivery</b>	<b>New Zealand</b>	<b>England</b>	<b>Scotland</b>	<b>Canada*</b>	<b>USA</b>
Building a shared vision	✓	✓	✓	→	✓
Consumer leadership	✓	✓	✓	→	✓
Delivers training and support	✓	✓	✓	?	✓
Education to reduce stereotypes	✓	✓	✓	→	✓
Programs are evaluated	✓	✓	✓	?	✓
Targets high impact groups	✓	✓	✓	✓	✓
Promotes positive contact	✓	✓	✓	→	✓
Supports protesting discrimination	✓	✓	✓	?	✓
Local planning and partnerships	✓	✓	✓	→	✓
Empowerment supported	✓	✓	✓	✗	✓
Targets media +/-	✓	✓	✓	→	✓

\*Canada's anti-stigma program is in its early stages of development and a number of elements are in progress or not yet developed.

# APPENDIX C

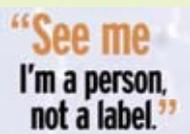
## INTERNATIONAL INITIATIVES

### Like Minds, Like Mine, New Zealand ([www.likeminds.org.nz](http://www.likeminds.org.nz))



Of all the programs reviewed, New Zealand's *Like Minds, Like Mine* (LMLM) is a world leader in program design and delivery. LMLM is the longest running social inclusion program with more than 12 years of population surveys which evidence ongoing reductions in discriminatory attitudes towards people with mental illness. The Ministry of Health invests \$5M annually: half towards localised grass-roots education projects and half to mass media social marketing.

### See Me, Scotland ([www.seemescotland.org.uk](http://www.seemescotland.org.uk))



See Me has been running for seven years and adopts a similar approach to New Zealand by investing in both localised grass-roots education campaigns and broad social marketing campaigns. The first evaluation found the program had halved the percentage of Scots who believe people with mental health problems are dangerous, from 34% to 17%. Research by the London School of Economics found that an investment of £0.55 per adult Scot in the campaign can produce a cost saving of £4.26 per person: an 800% return on investment.

### Time To Change ([www.time-to-change.org.uk](http://www.time-to-change.org.uk))



The UK campaign is the largest investment in anti-stigma initiatives, with an £18m investment over four years. The campaign was launched nationally in January 2009 with targets to change both attitudes and behaviours. It combines local, community projects alongside a national high-profile media campaign and includes a physical health promotion component. Early evaluations have shown a conservative, positive shift in both attitudes and behaviours.

## ▶▶ A way forward

The economic costs of social exclusion are extremely high. Australians spend A\$4.4 billion annually through lost productivity, health and social services, disability pensions, lost taxes and missed opportunity. The cost of mental ill-health is estimated at 3% – 4% of Australia's GDP. Those countries which have undertaken a national anti-stigma and discrimination reduction program, are finding that over time there are measurable changes in public attitudes, behaviours, media reportage, and acceptance of people with mental illness. We know that discrimination is a significant issue. We know how to change, based on the success of international programs. We also know that investment in a social inclusion campaign will provide an overall benefit to the economy.

# APPENDIX D

## REPORT REFERENCES

Many of these resources are available on the Queensland Alliance website:  
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