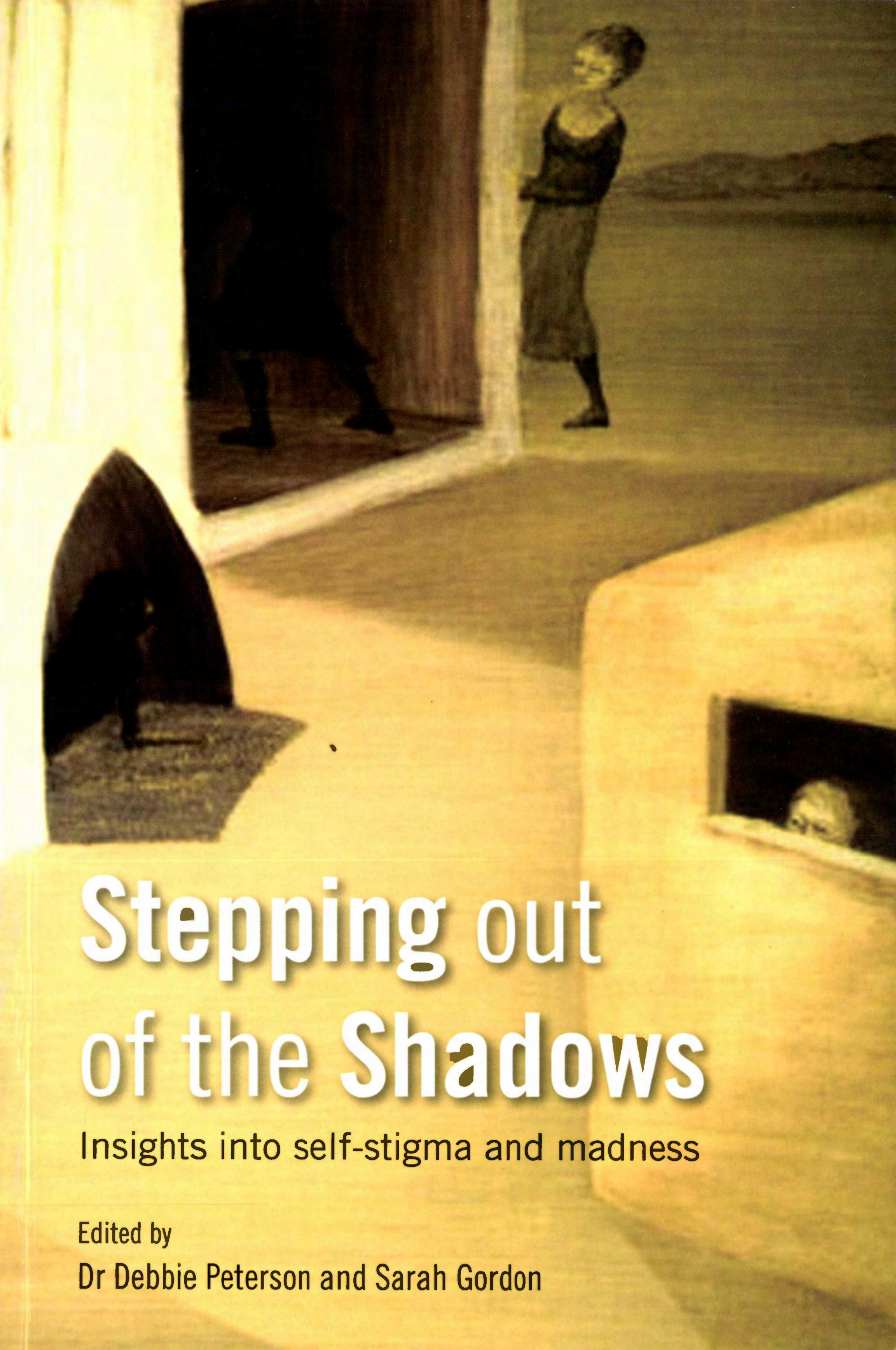

Stepping out of the Shadows

Insights into self-stigma and madness

Edited by
Dr Debbie Peterson and Sarah Gordon

Stepping out of the Shadows

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Foreword

Judi Clements

For the family of Linda Simson, especially her two boys, Simon and Liam,
so you know that many of us continue to be inspired and supported
by Linda's great work.

Contents

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Finally, thank you to Fiona North who assisted with editing and Kerri-June Clayton who managed everything and everyone.

Note

The Like Minds Wellington Postcard competition was organised to celebrate Youth Week in May 2008. Students were invited to design a postcard on the theme 'How to help a friend through a tough time'. The competition was a huge success with students submitting many creative and skilled entries. A selection of these postcards have been used to mark, by way of illustration, the beginning of each chapter of this book. Please note that each of the designers has agreed to the use of their postcard as part of the present publication.

Foreword

'Stigma', according to the *New Collins Shorter English Dictionary*, is 'a distinguishing mark of social disgrace'.

Why then would anyone apply such a mark to themselves; in what circumstances might it occur; and with what results?

This collection of essays and personal accounts considers these questions and provides clues and answers.

There has not been much written about the phenomenon of self-stigma, or the term I rather prefer, internalised stigma, so this book is a welcome addition and contribution to understanding. There is an inevitable, if perverse, logic in the sequence or coincidence of events that give rise to internalised stigma. A good number of years have passed, in the so-called developed world, since the old long-stay hospitals closed. Removing people from their loved ones and communities, separating them from life, often for long periods, under at best not pleasant and many times dreadful conditions, with the attitudes and treatment that accompanied this, was bound to have negative consequences for humanity as a whole and in particular those least powerful or able to challenge or change their circumstances.

We live now in the aftermath of deinstitutionalisation and although there is every reason to acknowledge some progress, vestiges remain like scar tissue, or the appendix, and continue to cause problems and further distress.

In the courageously honest accounts in this collection we hear experiences from the past, but also from very recent times. Experiences that demean the human spirit, particularly when cumulative, have corrosive effects – self-stigma is one of these. The need to recognise the existence and effects of self-stigma is valuable in itself, but of even greater value is to hear of the resistance of the indomitable human spirit, of inside information on how to resist and then of strategies for a whole range of interventions in the vicious circle.

We all have beliefs and belief systems – even those who are trained in science – or perhaps especially those!

I cherish a belief that there will come a time when all experiences are respected and validated; madness is seen as acceptable, sometimes inevitable, sometimes very painful, sometimes extremely valuable – but never a cause or excuse for any form of ill treatment, disrespect or hopelessness.

I hope we get to that point in my lifetime and that any mark of difference is not just tolerated but given genuine respect, and the seeds of optimism are always planted, nourished and nurtured – and then, in the words of Ralph Waldo Emerson:

'The only person you are destined to become is the person you decide to be.'

Judi Clements
Chief Executive
Mental Health Foundation of New Zealand

Introduction

Self-stigma has been described by one of the authors of this book as 'a haunting spectre' and by another as a 'shadow' on the lives of those who experience it.

Research shows that this shadow can have a significant effect on the lives of people with experience of mental illness. However, research has also identified that self-stigma is part of a cycle, and that everyone has an opportunity to intervene in ways that can break that cycle. The chapters of this book explore the concept of self-stigma from the perspective of authors who have experience of mental illness, or have researched self-stigma, or both.

In the beginning there was *Fighting Shadows* . . .

After the 1995 Mason Inquiry[1] reported a need for a public campaign to address discrimination associated with mental illness, the Ministry of Health's *Like Minds, Like Mine* programme was initiated. One of the more recent pieces of research for this programme, undertaken by the Mental Health Foundation, focused on self-stigma and mental illness. The report

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[1] Mason K. *Inquiry under Section 47 of the Health and Disability Services Act 1993 in respect of certain mental health services: report of the ministerial inquiry to the Minister of Health Hon Jenny Shipley.* Wellington: Ministry of Health; 1996.

on that research was published as *Fighting Shadows: Self-stigma and mental illness: Whawhai atu te whakamā hihira.*[2]

The research was ground breaking for New Zealand. It was the first time people with experience of mental illness had been asked to talk about their experiences of self-stigma. The very existence of self-stigma was controversial and new to some. Many people with experience of mental illness (even those not involved in the research) told Alex Barnes and I that they had never really thought about self-stigma before, but could now recognise the effect it had on their lives. And because they recognised it, they could start to do something about it.

The other aspect of *Fighting Shadows*, which was ground breaking, was that it led to development of the Discrimination Intervention model. This model, based on a new definition of self-stigma and discrimination, was derived from an analysis of replies by the research participants to a question about what self-stigma meant to them. The Discrimination Intervention model means that for the first time we can clearly see how self-stigma and discrimination are linked and how self-stigma can be combated. A summary of the *Fighting Shadows* research, and the Discrimination Intervention model, can be found in Chapter 1.

How this book came about

At the first meeting of the reference group for the Mental Health Foundation's self-stigma research (*Fighting Shadows*), Sarah Gordon suggested that we should write a book on the subject, as little was available to inform either service providers or those experiencing self-stigma. Everyone thought this was a great idea, never thinking, I'm sure, that it would actually happen. When the research was about to be published we realised there was definitely a need for a resource that could reach a wider audience than the research would. Thanks to Sarah and her team at CASE Consulting, we found sponsorship, and this book became a serious proposition.

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[2] Peterson D, Barnes A and Duncan C. *Fighting Shadows: Self-stigma and mental illness: Whawhai atu te whakamā hihira.* Wellington: Mental Health Foundation of New Zealand; 2008.

The authors and their chapters

The experiences recounted in this book illustrate the varied paths that many of the authors have travelled in terms of overcoming their own self-stigma. The very act of writing and publishing their stories is another step along this path. The authors were selected because they each have something useful to say on this topic, and because of the unique perspectives they bring to the task. They were given a simple brief: focus on the *Fighting Shadows* research, especially the Discrimination Intervention model, and write something on the topic of self-stigma.

Most of the authors in this book have experience of mental illness themselves and have been involved in the New Zealand consumer movement for some time. Many of us were also associated with the *Fighting Shadows* work. Alex Barnes and I were authors of the research; Sarah Gordon, Lynne Pere, Mary O'Hagan, Dean Manley and Vito Nonumalo were members of the reference group to the project.

The authors

DEBBIE PETERSON

Debbie has a PhD in Social Science Research from Victoria University of Wellington and is currently a researcher with the New Zealand Mental Health Commission. She was formerly a Senior Policy Analyst/Researcher for the Mental Health Foundation of New Zealand, undertaking research for the *Like Minds, Like Mine* programme to counter stigma and discrimination associated with mental illness. Her research has enabled her to develop a unique model of stigma and discrimination (the Discrimination Intervention model) that encapsulates how these two concepts are connected and, more importantly, illustrates how they can be combated.

SARAH GORDON

Sarah identifies as a person with experience of mental illness. This experience shaped her university study with a focus on the areas of medical law and bioethics. Combining this theoretical education and personal experience, Sarah entered the workforce as a consumer advisor to mental health services in 1998. She is the co-founder and current sole director of CASE

Consulting. Established in 2000, CASE is a consumer directed and working company providing services for the development of an improved mental health sector and societal perceptions of mental health from a consumer-focused perspective.

ALEX BARNES

Alex Barnes is a Master of Arts graduate. Presently he is a research officer in the Practice Research and Professional Development Hub, Social Work and Social Policy Programme, Massey University. He is currently working towards a PhD. From 2007–2009 he worked as a Senior Policy Analyst for the Mental Health Foundation of New Zealand, undertaking research and providing policy advocacy as part of the *Like Minds, Like Mine* programme to counter stigma and discrimination associated with mental illness. He is a co-author of *Fighting Shadows: Self-stigma and mental illness: Whawhai atu te whakamā hihira* (2008).

DENNIS DUERR

Dennis Duerr is 33 years old. He is a resident of Wellington from way back and leads a full and varied life. During the course of his life he has worn many hats – friend, tertiary student, creative writer, visionary, poet, wreck, year-long swimmer of the seas, and support person. His principle hobbies and interests are walking, swimming, talking and laughing. Dennis has wrestled with the black dog of mental ill health at times in his life and now uses that experience in his job every day. That job is co-ordinator of the Buddies Peer Support Service which is administered and managed through CASE Consulting. The Buddies service involves volunteers, who have personal experience of mental illness, providing peer support through one-on-one relationships, community events and hospital visits.

ANNE HELM

Anne Helm was the consumer consultant panel member of the Confidential Forum for Former Psychiatric In-patients from 2005–2007. Anne's previous roles have involved work with national projects, the Mental Health Commission and the Ministry of Health. She has been an advisor to the Otago DHB (District Health Board), published internationally on recovery and is currently an independent consultant. Anne has extensive historic and present-day knowledge of the mental health system and works to reshape the paradigm of understanding illness and service delivery. She has a Bachelor of Education and a music degree.

RUTH JACKSON

Ruth has an adventurous background including a BSc. in Physiology from Otago University, two years teaching English in Japan and two tiki tours through acute mental health services. She started working in the mental health field in 2001 as a Consumer Liaison and Development worker for Wellink Trust. Ruth joined CASE Consulting in 2004 and is now a regular contributor to the *Like Minds, Like Mine* (LMLM) newsletter and co-ordinates the LMLM Wellington regional contract.

DEAN MANLEY

Dean had a background in corporate sales and marketing before shifting his attention, as a 'mature' student, to tertiary studies in English Literature, Art History, and Film, Television and Media Studies. He has worked in Supported Employment, a Peer Support pilot scheme, and a consumer-led anti-discrimination research and training organisation before joining the Mental Health Foundation of New Zealand in the role of National Like Minds Project Manager.

VITO NONUMALO

Originally trained as a journalist and having spent almost a decade in broadcasting, Vito has been a relatively staunch advocate for Pacific mental health on the basis of his own personal experience of using the services. Over the past decade he has worked in a number of positions across the mental health sector, but retains a focus of doing so to help other people, in particular, other Pacific people. While Vito has worked in a number of management positions throughout the mental health sector, he still retains a passion for a not-often-seen creative slant. As a hobby he mixes and produces music, plays keyboard, drums and guitar while on a much quieter level, enjoys writing.

SARAH O'CONNOR

Sarah has a BA in sociology and an Introductory Certificate in Community Work. As a person who has experience of mental illness and many years experience as a consumer of mental health services, she is especially interested in mental health research and the sociology of mental health and illness. Sarah currently works as a research assistant with CASE Consulting Ltd.

MARY O'HAGAN

Mary was a key initiator of the mental health service user movement in New Zealand in the late 1980s, and was the first chairperson of the World Network of Users and Survivors of Psychiatry between 1991 and 1995. She was a Mental Health Commissioner in New Zealand between 2000 and 2007. Mary is now an international consultant in mental health. She has written and spoken extensively on user and survivor perspectives in many countries and has been an international leader in the development of the recovery approach.

LYNNE PERE

Dr Lynne Pere (Kai Tahu, Ngāti Kahungunu, Rangitāne, Kāti Māmoe, Ngāti Porou) is a Māori Health Postdoctoral Research Fellow at the Health Services Research Centre, Victoria University of Wellington. Dr Pere has extensive experience in Māori health research, and has a particular passion for Māori mental health. Her doctorate research examined the relationship between cultural identity and well-being, in order to answer the research question: "Does a secure cultural identity lead to improved well-being for Tāngata Whai Ora?"[3] Following on from this, her postdoctoral research investigates the influence of culture on the meaning that indigenous peoples from Aotearoa/New Zealand, Australia and Canada, who have experience of mental illness, impart to their illness.

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[3] The term 'tāngata whai ora' is a general term used in Aotearoa/New Zealand to refer to Māori with experience of mental illness – that is, those who have at some point in their lives personally experienced a mental health disorder or other mental health problem. Tāngata whai ora advice is the term used to mean special, unique and absolute, and is associated with the whakatauaki 'Kia maumahara ki tou mana āhua ake' which means 'Cherish your absolute uniqueness'. Advice from Te Taura Whiri i te Reo Māori is that 'whai ora' literally means 'in search of wellness'; 'tāngata' means 'people' (Pere 2006).

NIKKI SMITH

A myriad 'unskilled' and character-forming positions provided the motivational basis for Nikki's foray into academia. She has a BA in anthropology and a penchant for learning new things. She has been involved with unionism, with a focus on improving working conditions for young fast-food workers. For a number of years she worked as a consumer advisor within the AOD (Alcohol and Other Drug) sector, and is currently employed as a peer support worker and advocate for AOD 'consumers'. Nikki is a feline-o-phile, a lover of music, and remains comfortably rough around the edges.

IVAN YEO

Ivan is a Malaysian Chinese who came to New Zealand in 2001. He was born into a small family with three older sisters. His childhood was not a pleasant time. Growing up with a father with gambling issues led him to experience anxiety and depression through childhood. During his first three years in New Zealand, Ivan was struggling with depression as well as an addiction to alcohol. Through the help and support of AUT (Auckland University of Technology) counsellors Ivan was able to resolve many internal struggles. This included opening up to his family about his sexual orientation. Now he is working in the mental health field and advocating for those who have been through or are going through the same experience.

The term 'self-stigma'

There is some debate around the use of the term 'self-stigma'. It can be argued that self-stigma suggests that there is some fault on the part of the person with experience of mental illness for allowing themselves to feel stigmatised, and therefore the term 'internalised stigma' is preferable. Internalised stigma implies that societal stigma and discrimination have been turned inward. The main problem with using the term 'internalised stigma' is that people often don't relate to it (as we found out through *Fighting Shadows*). For this reason self-stigma has been used throughout the present work.

Who should read this book?

We believe this is a must read for people with experience of mental illness, and those who support us – families, mental health workers and members of the wider community – in fact, anyone with an interest in mental health issues. This book is not an academic text book, although parts of it are more academic than others.

There are many similarities between self-stigma associated with mental illness and other forms of stigma and discrimination, such as racism or sexism. While not specifically addressed in this volume, people interested in oppression of any nature may find something of value here, especially in regard to the Discrimination Intervention model.

The key things we would like people to take from reading this book are an understanding:

- of the experience of self-stigma
- of the role self-stigma can play in the lives of people with experience of mental illness
- of how the effects of self-stigma differ from person to person
- of how interventions can reduce self-stigma and other forms of discrimination
- that many people with experience of mental illness do not experience self-stigma and may never have experienced it
- that, for many people, madness is a valuable part of their life experience.

Debbie Peterson

Melissa Smith, age 14

What is self-stigma?

Debbie Peterson and Alex Barnes

Something is wrong with me, that won't change, which means I'm less worthy than other people and less entitled than other people.

Self-stigma is a phenomenon that most people with experience of mental illness would recognise, seeing it either in themselves or other people. It occurs when a person limits themselves because of a preconception that they are, in some way, not as able, or entitled, as other people. It differs from discrimination, which is treating *others* differently because of their experience of mental illness. It is generally believed that self-stigma arises from internalising the negative messages and behaviour associated with discrimination. In other words, the concept of self-stigma seems fundamentally and inextricably linked to the concept of discrimination.

So how do people actually experience self-stigma? It is something more than just low self-esteem. Some people can have a fine sense of self-esteem, but still feel – unjustifiably so – that they are unable to do something because of their experience of mental illness. It is also more than a fear of discrimination. People may justifiably fear that they will be discriminated against while not actually experiencing self-stigma. It is more than how a person sees themselves; it may limit what they do and how they interact with others. It is also not an essential part of the experience of mental illness. Many people who have experience of mental illness do not experience self-stigma, or maybe at one time experienced it and no longer do.

New Zealand research (Peterson, Barnes and Duncan 2008) provides us with a definition of self-stigma, which has also led to the development of a new model of stigma and discrimination: the Discrimination Intervention model. One of the most significant features of this new model is that it encompasses and addresses the concepts of both self-stigma and discrimination and the complex inter-relationship between the two.

Definition of self-stigma

The research was focused on exploring the concept of self-stigma from the perspective of people with experience of mental illness. More specifically, the definition was developed based on the responses of research participants to the question: 'What does self-stigma mean to you'? Results reflect five components commonly referred to by respondents, and together they form the following definition:

> Something is wrong with me, that won't change, which means I'm less worthy than other people and less entitled than other people. Therefore I. . .

Each component is described below.

SOMETHING IS WRONG WITH ME

The 'something wrong' may not be mental illness. Many of the participants mentioned that self-stigma for them began before they were diagnosed as having a mental illness. For others, however, the thing that was 'wrong' was specifically mental illness. This part of the definition makes it clear that self-stigma is intimate and personal.

WHICH WON'T CHANGE

Many of the participants in the focus groups talked about how they perceived mental illness as being something that was with one for life, which could not be recovered from. There was a sense of inevitability: that they would always be like this for the rest of their lives. There was also a sense that having a mental illness meant that they were changed forever.

WHICH MEANS I'M LESS WORTHY THAN OTHER PEOPLE

This message comes both from within oneself and from other people. The belief that a person is less than other people is often a self-replicating cycle. The person is treated as less worthy than others, they then believe this about themselves and act as if they are, and then others perceive them to be, and so the cycle continues.

Who is telling people with mental illness that they are less than other people? This is where the stereotypes surrounding mental illness come in. If society believes that people with experience of mental illness are in a negative way different to other members of society, then this message can be picked up by the person with experience of mental illness. Internalising these stereotypes contributes to self-stigma.

LESS ENTITLED THAN OTHER PEOPLE

People may believe that, because they have experience of mental illness, they have fewer rights, responsibilities and privileges than other people. Again this is a self-replicating cycle: if people are treated as if they have no rights and responsibilities, then they themselves can believe this and act accordingly.

THEREFORE I . . .

The last part of our definition is an action. Intrinsic to the definition of self-stigma is that the person is affected by it in some way and changes their behaviour because of it. For example, a person may not apply for a job as a result of believing that they are unable to work because of their experience of mental illness. The action is a consequence of the self-stigmatising feelings and attitudes.

Definition of discrimination

This definition can easily be adapted to encompass and address the concept of discrimination. This is done simply by changing the subject focus from the first person to the third person, thereby shifting the perspective from the self to the beliefs and actions of others:

> Something is wrong with you, that won't change, which means you're less worthy than other people and less entitled than other people. Therefore we will treat you differently.

Developing an intervention model

Each component of these definitions of self-stigma and discrimination can be distilled to a basic element. For example, 'something is wrong with me' is about difference; 'that won't change' is about inevitability or unchangeability. Table 1 illustrates this.

Table 1: Components/elements of self-stigma and discrimination

Component of self-stigma and discrimination	Element
Something is wrong with me/you	Difference
That won't change	Inevitability or unchangeability
Which means I'm/you're less worthy than other people	Comparison
And less entitled than other people	Devaluation
Therefore, I/we . . .	Discrimination

Each of the elements that the components correspond to can be linked to form a cycle; this forms the basis of the Discrimination Intervention model.

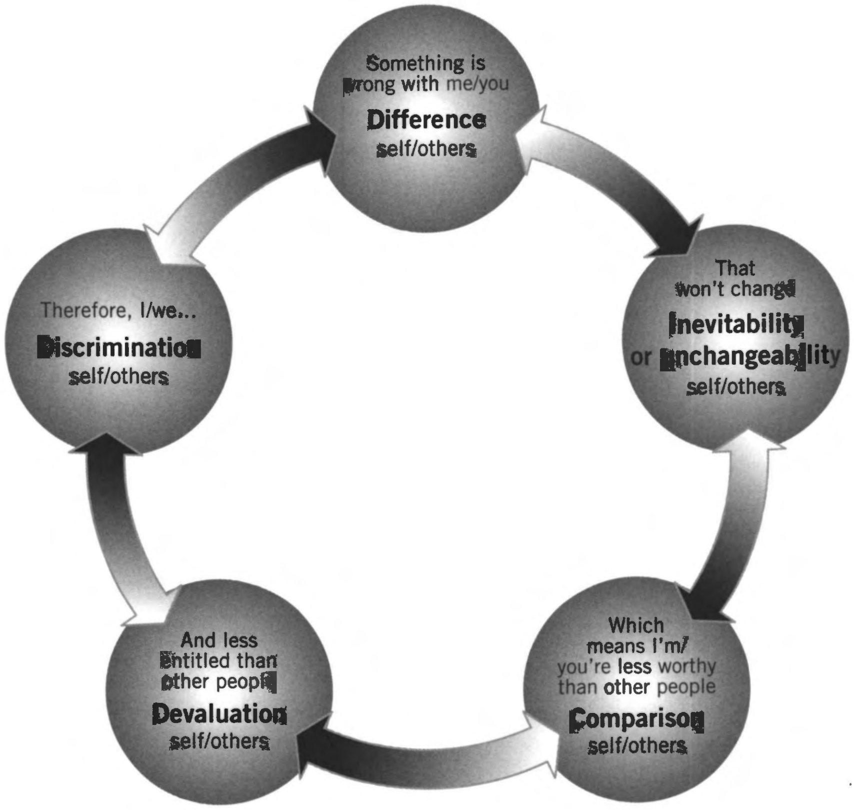

Figure 1: The Discrimination Intervention model

Although the model is circular, the path can be in either direction, and can start at any point. The definitions for self-stigma and discrimination are very similar, but our research identified that, although not always the case, discrimination can lead to self-stigma, so the components are clearly not in a linear relationship.

The model shows how self-stigma and discrimination are intrinsically linked, with each element able to be applied to oneself or to other people. Changing factors at any point can exacerbate or relieve other factors in the cycle.

Identifying actions to interrupt the cycle of self-stigma

The third part of the model is the actions, or circuit breakers, that can happen at each stage to interrupt the cycle. Each point in the cycle has its own circuit breakers. The examples given are not comprehensive or exclusive, only illustrative. It is these circuit breakers that give the model its title – the Discrimination Intervention model – as it reflects not only the cycle of discrimination and stigma, but also how to intervene at each point in the cycle to reduce or stop stigma and discrimination.

Table 2: Circuit breakers (actions) that can interrupt the cycle of self-stigma

Element	Circuit breaker	Explanation
Difference	Celebrating and accepting difference	If society celebrates and accepts difference, rather than rejecting it, people with experience of mental illness will feel more 'normal'
	Disclosure	Disclosure helps normalise mental illness
Inevitability or unchangeability	Recovery-oriented practices	If mental health services instilled hope and people with experience of mental illness knew they could recover, then self-stigma would be reduced
Comparison	Positive role models Peer support Leadership	If people are able to compare themselves with successful people with experience of mental illness, then self-stigma will be reduced. People can also learn how to combat self-stigma from each other. Having visible consumer leaders is vital
Devaluation	Empowerment Affirmation of human rights Recognising the contribution of people with experience of mental illness	If people with experience of mental illness are encouraged to empower themselves, their self-efficacy and self-esteem will increase, thus combating self-stigma. Recognising their human rights, and valuing the contribution to society of people with experience of mental illness will also combat self-stigma
Discrimination	Challenging attitudes and behaviour	If people are encouraged to challenge discrimination when they are discriminated against, anti-stigma and discrimination programmes are implemented, and people with experience of mental illness challenge their own attitudes and behaviour, self-stigma will be reduced Emphasis must continue to be on eliminating societal and public discrimination associated with mental illness

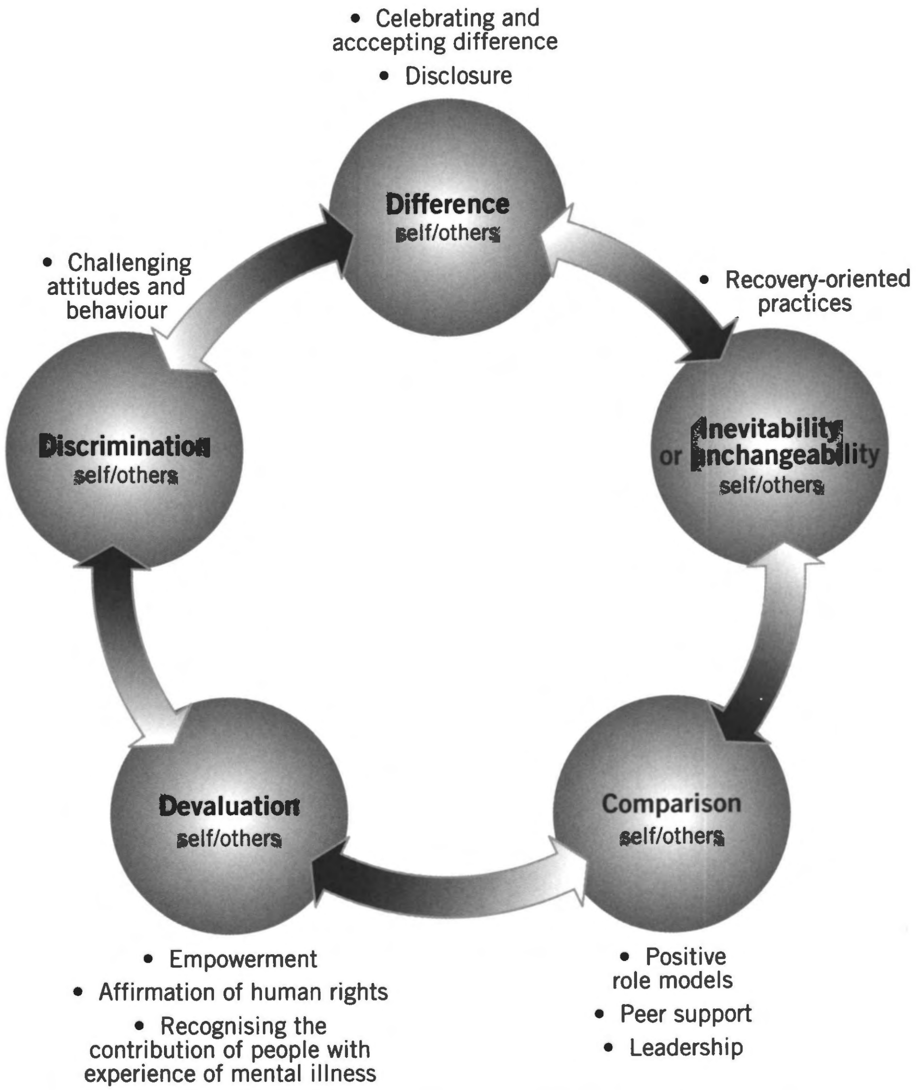

Figure 2: The Discrimination Intervention model with circuit breakers

The research we undertook on self-stigma, which led to the development of the Discrimination Intervention model, provides valuable insight into the concept of self-stigma and the effect it has on the lives of people with experience of mental illness.

The research

Focus groups were used to gather information about self-stigma from different members of the community. A prerequisite for all people who participated in the focus groups was that they had experience of mental illness at some point in their lives.

The focus group method was selected because it offered participants a peer environment, where people could explore their perceptions of self-stigma and engage in dialogue on the subject.

Eleven focus groups were held throughout New Zealand. They comprised:

- five groups of Pākehā (non-Māori) (called the general focus groups)
- two groups of Māori/tāngata whai ora
- one group of refugees
- one group of Chinese
- one group of young people
- one group of Pasifika.

A total of seventy-six people took part in the groups. This inclusive and participatory research approach meant we were able to explore a variety of cultural understandings and perspectives in relation to the concept of self-stigma.

The facilitators asked the following seven questions at each focus group:

- What does internalised stigma mean to you?
- What are some examples of internalised stigma?
- How has internalised stigma affected your life?
- When did you first experience internalised stigma?
- Where do you think internalised stigma comes from?
- What makes internalised stigma worse?
- When you feel internalised stigma, what helps you deal with it and what advice would you give to others experiencing it?

We used the term 'internalised stigma' in our questions, but most people responded using the term 'self-stigma'. As a result we decided to adopt and use the term 'self-stigma' to refer to the concept. The questions were open-ended to explore participants' personal experiences of self-stigma and how people may have managed to overcome it.

Results from each of the focus groups were analysed using the software package Nvivo. Themes were identified for each question and then differences and similarities between groups were sorted and analysed.

DEFINING SELF-STIGMA

When asked how they would define self-stigma, more than twenty characteristics were described by the participants. These ranged from feeling that they were not normal, not good enough, and that this would never change, to feeling that they were a burden to others, a failure, and ashamed of themselves. The answers to this question contributed directly to the development of the Discrimination Intervention model.

The effect of self-stigma on people's lives

> It's cost me jobs, career advancements, relationships and relationship growth. It's cost me time, money and energy. It's taken many years to overcome the bulk of my own self-stigma. I am still affected by it, but I'm working on changing that.

The effect of self-stigma on people's lives was diverse and far-reaching. Some people described the impact in a holistic way, commenting on the negative physical, mental, social and spiritual effects. As a result of its wide-ranging consequences, many people felt they had to 'work harder than others' to prove their worth. One person articulated that they had to be twice as good because 'everything is perceived as twice as bad'.

Participants described their feelings of 'difference' from other people: a range of beliefs and experiences that resulted in a perception that they were not 'normal' members of society.

Some people spoke about the changes that occurred to their bodies and moods because of medication they were on. For them, this was an obvious marker of their difference:

> When you see the side effect of the medication how could you not internalise the fact that you are different from other people such as feeling sleepy, drowsiness, weight gain or loss, issues like this.

Social exclusion was typified by people's fear of discrimination in their daily lives. At times, this fear had the effect of holding people back from possibilities and their life potential. People spoke about change being scary because 'you convince yourself you can't handle it, so life just passes you by'. This fear also related to people's expectations of themselves.

Not believing in their ability and worrying about whether they can 'keep it together' was often how people described their self-doubt. Because of the self-stigma people experienced, they expressed that they were not capable of a variety of things, including studying, maintaining relationships or finding employment. It was common for this to affect participants' behaviour – a type of self-discrimination – with participants explaining that their chances of gaining employment were minimal because of their experience of mental illness:

> Someone told me that you've got to prove that you're the best person when you go for a job. And if you don't believe that, then it's not worth even trying.

Once again, people questioned whether they were indeed 'normal' because of their anxiety about whether they would succeed.

When people reflected about their future role as a parent, some spoke about how this role was questioned and undermined because of self-stigma:

> I won't even think about having kids now; I don't think I'd make a good parent. Before my illness I was really keen to be a father, but not now. I couldn't handle them.

People also acknowledged that barriers to participation were based on the label of mental illness and its 'oppressive power'. For many people, being 'seen as an illness, not a person' underpinned their fear and experience of social exclusion. Generally, however, people returned to the theme of discrimination and its relationship to social exclusion.

Responding to self-stigma by withdrawing socially was common amongst focus group participants. Often people isolated themselves out of fear of being judged by others or because they had an overwhelming sense of hopelessness. This was exhausting for them and added to their sense of social loss:

> After being told what you have, you begin to feel shame, fear, confusion. . . You have a sense of loss. You don't know how this is going to impact on your life, afraid other people might find out. You start to isolate yourself from others and eventually from society.

Withdrawal and isolation also affected friendships negatively. People explained that their friendships often changed because they were afraid of their friends' reactions to their experience of mental illness. These feelings of fear were frequently based on deep insecurities and beliefs about self-inadequacy, which resulted in withdrawal from friendship networks or an unwillingness to make new friends or relationships. Some people believed that, because they had experience of mental illness, they were 'a hindrance and a burden'.

Participant descriptions reflect that self-stigma generally affects people's lives in a negative manner, however, some people recounted positive experiences. These included becoming involved in peer services or groups and mental health advocacy, which were identified to result in a strengthening of understanding and relationships.

When people first experienced self-stigma

> The first time I walked into the psych unit I thought, 'What's happening to me? I'm going where the loonies go. I must be mad too'.

Most participants recalled that their initial experience of self-stigma occurred when they began accessing mental health services and/or were given a diagnosis for the first time. This was important for people, because it signalled a new way of perceiving themselves and being perceived by others. Some had a poor understanding of what their diagnosis meant, while others expressed that the diagnosis provided them with an understanding of their condition, in which case it was 'good to have a label'. However, often the relief of a diagnosis or label soon turned to disbelief as the effect of people's varied reactions to such, set in.

Some people expressed that they had felt 'different' or not 'normal' from a young age. Others spoke about 'standing out' because of how they related to 'normal people', or because they did not believe they functioned as 'normal people'. One person explained that what distinguished them from 'normal people' was that they did not have 'jobs, families, relationships', whereas people free from the experience of mental illness did. The constant comparisons between themselves and others fuelled participants' beliefs about their difference:

> Everywhere you go people make comparisons - you're not like your brother, or you should be doing this by now or having a job at your age - it makes it hard to compete.

Another participant explained that it was only when they saw an old friend in hospital that their self-stigma was triggered. The experience of seeing a friend in the acute ward contributed to them thinking 'I am a nut case'. In this instance, the feelings of difference that set them aside from general society arose through acknowledging similarities – both had accessed mental health services.

The need for social acceptance was vital for people's sense of self-worth and community belonging. Consequently, experiencing discrimination or a fear of discrimination in the community were often the first triggers for people's self-stigma.

People spoke about how, after their first episode, friends were no longer interested in maintaining friendships. One person shared that at age 15 their employer used bullying and verbal intimidation towards them, which triggered their self-stigma. For migrants and refugees, arriving in New Zealand heightened their sense of self-stigma, with many having felt that a mental health condition would be a shameful and negative thing in New Zealand:

> I feel ashamed that I cannot fully participate in New Zealand society and show that I am useful and a good person.

Family were identified as having an important influence on people's first experience of self-stigma. It was identified that negative family experiences were often a result of a lack of understanding and openness about family histories of mental illness. For some, reactions (as a result of a sense of shame) involved families attempting to control who knew and who did not know about their family's experiences of mental illness. Although negative family-related experiences influenced self-stigma for some people, refugee participants explained that it was their natural support systems breaking down when separated from their families, which lead to self-stigma. Others spoke about how their diagnosis made them feel like they had let their families down. This perceived failure to meet family expectations heightened thoughts of suicide.

The relationship between family and partner violence and other abuse was also identified as influencing people's first experience of self-stigma.

Does self-stigma exist?

Members of the Gisborne-Tai Rāwhiti group challenged whether the notion of self-stigma related to experience of mental illness actually existed, arguing that it was only an issue if people 'bought into' the label and its effects.

One person spoke about using a health continuum to understand people's well-being, noting that 'regardless of people's mental state there are always positive aspects. People become what you call them, 'tāngata whai ora' for example'. It is a problem if people only focus on the negative attributes of one's mental health experience:

> If you have an opinion of yourself that you're unlovable, people won't love you. By the same token, if you give people permission to put you down, they will.

Consequently, rather than exploring and defining the concept of 'self-stigma', these participants explained that they would rather focus their energy on building pride in the consumer/tāngata whai ora movement. For them this meant validating one's positive characteristics, moving beyond 'recovery' to being 'out and proud' and strengths focused. Some participants considered 'self-stigma' to be a Pākehā concept which was not consistent with Māori ways of understanding hauora and wairua (people's health and spirituality).

Where self-stigma comes from

> It's taking on board what those around us show and say, about what society also does and says. Not just about ourselves, but also just as importantly about others.

When participants were asked where they thought self-stigma came from they explained that experience of discrimination was the main source. People also identified ignorance, fear and a lack of information and understanding as contributing to self-stigma.

People reported that their experiences in the following three areas were key in terms of sources of self-stigma: (i) through treatment they received from mental health services; (ii) through family experiences; and (iii) through employment.

Some people believed that information included in the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-IV) (American Psychiatric Association 1994) contributed to self-stigma. The point of diagnosis and how other people received it also significantly affected how participants understood their condition and its implications on their lives. People explained that the time of diagnosis was crucial because it was then that they felt most vulnerable to associated mental health stigma and at risk of internalising negative messages.

People reflected that their source of self-stigma and subsequent self-discrimination often depended on how well informed their clinician or general practitioner was about their diagnosis. For example, people spoke about the power of being told they were 'unwell' by their psychiatrist. For some, this experience made them 'go inside' themselves, which resulted in a loss of hope for the future. Others spoke about how their clinician had little understanding and willingness to promote recovery plans. This added further to people's experience of 'oppression and alienation by the system'.

One person shared that when she was accessing treatment in a psychiatric unit, nurses would ask 'a real stupid question' like 'how mental are we today?' These forms of derogatory questions impeded people's recovery, affected their sense of self-worth and contributed to self-stigma.

Another contributor to self-stigma related to how migrants were treated in their original country, which included being locked up, institutionalised, heavily medicated, and told that they were not going to be cured.

Families were also identified as being key in terms of where self-stigma comes from. How family and friends related to people with experience of mental illness created the foundation on which beliefs about the self (negative or positive) were based. It was expressed that, while families wanted to 'make it better', participants often felt they were failures when recovery was slow or did not meet their family's expectations. The understandings that families held in relation to mental illness were also important factors in influencing people's understanding of their own condition.

Family put-downs and hierarchies all played a role in people's understanding of where self-stigma comes from. For example, sibling rivalry, family comparisons and judgements were all cited as contributing sources of self-stigma.

Employment-related sources of self-stigma included employers' 'lack of confidence' in the abilities of a person with experience of mental illness. Some people spoke about how it was difficult to look for work because they did not feel comfortable disclosing their experience of mental illness.

For many, stereotypes about mental ill health were seen as a source of self-stigma. They contributed to general misunderstanding and reinforcement of myths about mental illness, many of which people had learnt from a young age. As one person said, 'If there was no external stigma, self-stigma would not be there. It plants the seeds'.

Many participants blamed the media as being contributors to self-stigma. People believed that the myths and stereotypes associated with mental illness were often the result of negative media coverage of mental health issues. Participants generally agreed that the media had little understanding of the complexity of mental illness and health. The reporting of such frequently being sensationalised, biased and incorrect.

The perception of being 'other' and the act of comparison deepened the self-stigma that people experienced. Participants explained that this happened primarily through negative self-talk such as self-put-downs, doubting one's capability, perspective and intuition, self-blame and not trusting other people's positive comments. Often these things led to insecurity, low self-esteem, disappointment, anger and frustration.

Taking medication was also identified as contributing to self-stigma for two reasons. The first was the side effects of drugs, which dulled peoples' senses and made it difficult to stay motivated. People spoke about how taking medication made them unaware of their living environments, 'medication blankets what's really going on'. The second reason related to constantly being reminded about mental illness as a result of taking medication. One person called this 'the stigma of use, especially when others know you're taking it'.

Dealing with self-stigma

> [I] remind myself that there are people who do care about me or others in a similar situation. I remind myself that others can learn from me about coping skills. I will go and ask for help from services that care.

When asked what helps people to manage and overcome self-stigma, the majority of people reported that noticing and transforming negative internal dialogue into affirming positive self-talk was very helpful.

Some people talked about using affirmations to change patterns of negative thought and self-discrimination. For many, affirmations helped them reframe things in a positive light. People offered various examples of affirmations they had used in their lives that had helped them manage self-stigma effectively. Affirmations were based on people believing they were loved for who they were (that is, being one's own best friend), reading about recovery and people's recovery stories, and being with others who were positive and offered inspiration. Changing the pattern from negative self-thought into a realistic appraisal was key in the use of affirmations.

People also spoke about recognising that stigma results from a judgement, not fact, this helped them keep perspective on the negative self-talk and shift to a more positive state of mind. A conscious acknowledgement and reflection of one's strengths and talents helped combat people's negative thinking. In relation to this it was important for people to be mindful of, and celebrate, the small achievements in their daily lives.

Making the most of personal strengths helped to combine positive (affirming) thoughts with concrete actions or hobbies. Such actions were often deliberate in order to combat self-stigma and, in some cases, small to begin with, but ultimately created a sense of worth and fulfilment. Several participants explained that for them to challenge their negative dialogue of self-stigma it was necessary to accept themselves and their experience of illness. This form of self-acceptance opened up doors for seeking support when needed and helped people integrate their experience into different parts of their lives. Some spoke about valuing their experience as a 'survivor' of mental ill health; for them this offered a unique understanding of themselves and the world.

The role of peer support groups and working with people who have had similar experiences was vital in challenging self-stigma. Such groups helped people disclose their experience to others in ways that did not make them feel vulnerable. The very act of discussing their experience with others, 'seeing my words spoken' as one person put it, helped people stay positive. Participants spoke at length about peer support groups being important in paving the pathway to recovery. Such groups helped people to see themselves as 'normal'. They provided a means of participation, interaction and learning. It was often in groups of peers that people began to develop strategies and tools of self-care and preservation, which they used for themselves and shared with other members of the group.

The support from people who share a culture, an identity or other experiences is also important:

> For me it is to know that I can still do things that I enjoy and am good at, helping others and sharing my experience has enabled me to believe [in] myself.

Often the act of helping others gave people an opportunity to reclaim their sense of self-worth. This, in turn, increased self-confidence and people's sense of control and power over their lives.

Creating and maintaining tools for well-being were seen as essential to people's recovery. They helped people 'learn what to do when . . . unwell', while also giving people a way to enhance their moods. Several participants mentioned the Wellness Recovery Action Plan (WRAP)[1] as a specifically helpful and practical tool for people dealing with self-stigma and recovery generally. Another participant suggested developing a unique 'self-stigma action plan', which would help people regain control over their well-being.

People's culture and identity were important to them and their recovery. Māori/tāngata whai ora explained that re-affirming themselves culturally,

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[1] Copeland M. (1997) *Wellness Recovery Action Plan.* Brattleboro, VT: Peach Press.

by learning waiata [songs] and te reo me ōna tikanga [Māori language and culture] for example, had a hugely positive effect on their sense of well-being and belonging.

Some people acknowledged that at times family and whānau experiences of mental illness took a toll on the wider family and drained people's resources. Therefore, it was important to build strong families and whānau, as they are crucial to supporting people's resilience and sense of belonging and identity.

Conclusion

This new model of stigma and discrimination helps us to appreciate the multi-dimensional nature of these concepts. The Discrimination Intervention model not only illustrates this, showing the complex relationship between self-stigma and discrimination, but also allows us to see how they can be combated. For example, the role that recovery-oriented mental health services can contribute to reducing the self-stigma that many people with experience of mental illness feel, can be seen at a glance.

The research that informed this model highlights the significant impact that self-stigma can have. The main effect of self-stigma on people's lives is the limiting of potential. People limit themselves because of their attitudes towards their experiences of mental illness. They believe that they are not good enough, they are not normal, they are hopeless and without potential, they will never recover and that they should stop dreaming of their future goals and aspirations.

What's more, discrimination from others, including families, the mental health system, employers and the media, often triggers or exacerbates self-stigma.

However, self-stigma can be combated. The experiences of the research participants illustrate how the circuit breakers can and do interrupt the cycle of stigma and discrimination. They highlight the importance of peer support, challenging attitudes and behaviour, developing recovery-oriented strategies, and a strong identity.

So why do we care about self-stigma anyway? Because of the impact it has on the lives of people with experience of mental illness; because of the impact it has on society as a whole. In New Zealand it is estimated that

47 per cent of the population will experience some form of mental illness in their lifetime (Oakley Browne, Wells and Scott 2006). Imagine if 47 per cent of the population felt limited in their potential and gave up on their hopes and dreams. Can we afford that?

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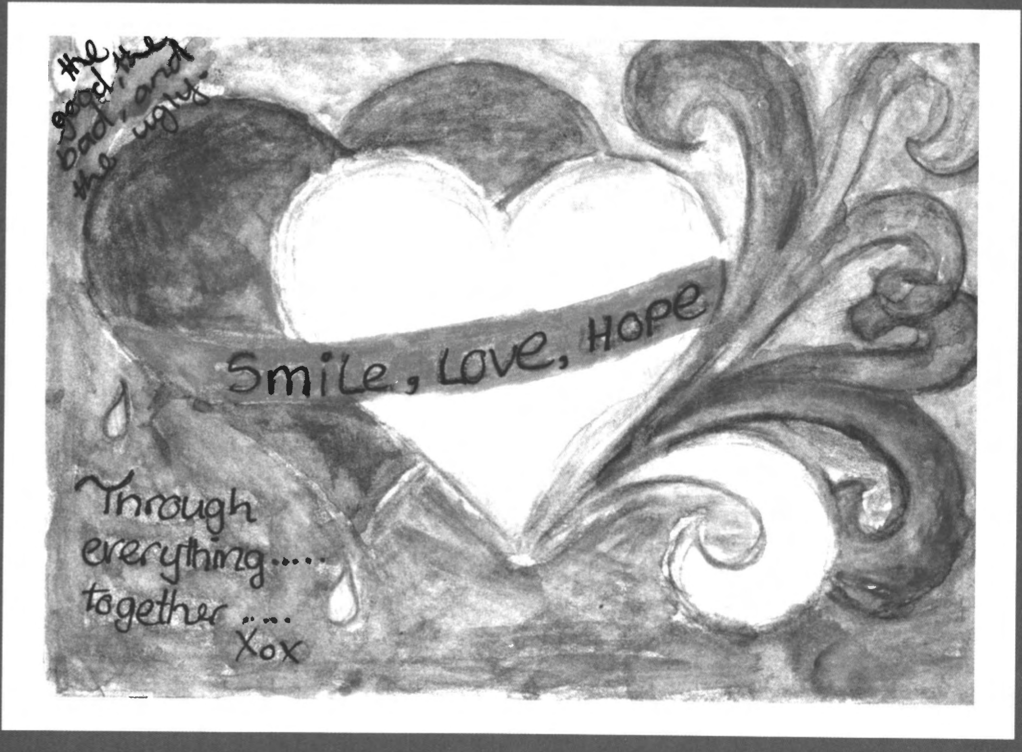

Georgia McCauley age 13

Being one of them

Mary O'Hagan

My friend Siobhan and I are walking home from school with our times-tables and spelling books in our bags. I see something twinkle on the footpath in front of me; it's a 20-cent piece.

Siobhan fastens her big eyes on mine. She leaps on the spot, her hair shoots up and down. 'Hooray, let's get some lollies', she squeals.

We run all the way to the Bakery, the 20-cent piece pressed into my palm, past the public school and the Memorial Hall, which is being painted for a visit by the Queen. There's a strange man standing at the door of the Bakery, wearing a dirty suit, muttering to himself.

'He's one of them, from the funny farm,' whispers Siobhan.

We start giggling; it overtakes us and we can't stop. The man turns and stares at us like we're from another planet. 'Let's get out of here', I say to Siobhan, and we speed past him on the outer edge of the footpath to buy our lollies up the road at the Deli.

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Thirteen years later Siobhan was working as a nurse in a psychiatric ward, and I became 'one of them' when I crossed the threshold of a psychiatric hospital for the first time.

Becoming one of them was instructive for me. Faced with my sudden drop in status, I had three choices: I could decide there had been a terrible mistake and I wasn't really one of them; or I could come to the cruel realisation that I was one of them – they were rejects so I must be too; or I could accept that I had become one of them, deciding that they were okay after all, and so was I.

I was lucky enough to latch onto the third choice almost straight away, but a few people bathe in the borrowed light of the first choice, while many struggle to withstand the lashings of the second.

Why didn't I experience internalised stigma after I crossed that threshold? I have long tried to understand this, with the knowledge that humans like to paper over the void of understanding with flimsy retrospective scraps of narrative, which we often parade as the truth.

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I crossed the threshold because I was locked in a black box. I'd hidden the blackness all my life hoping there was a purpose to everything. I'd painted the walls with false windows and a view of a grand universe. I'd drawn fake pictures of a life worth living. I'd made a pretend door that led into a promising future.

Now all the decorations were gone. The bare boards had closed in on me with the terrible truth that life is a sham. It started when I couldn't see the point in going to my university lectures. Then I couldn't bring myself to see my friends. Now I didn't see the point in being alive.

I'd been in bed for days with my door shut and the curtains drawn. My whole being was screaming at the terrible truth I'd discovered. I struggled to put a thought or a sentence together. I couldn't talk. I could barely move. My chest burned and I rasped with shallow breathing. Sleep came in broken snatches.

I woke. It must have been daytime because light was seeping through the gaps in the curtains. I stared at the clock and slowly realised the day and the time. With enormous effort I lifted myself out of bed and crept down the road to my next appointment with Dr Pilling, the psychiatrist. I crouched in front of him like a snapped stem. After a long silence he said, 'You need to go into hospital'.

Someone drove me to the hospital while I curled up on the back seat.

A big nurse in a white uniform opened the car door and slowly unfolded me. 'Come on, Mary, straighten yourself up'. The nurse took my arm and walked me into a modern long, low building called Ward 7, near a big medical hospital block, through the waiting room where sad people sat staring at the walls.

'New admission, Betty,' she called to the receptionist.

'Oh not another one, Dawn,' Betty grumbled and handed her some forms.

'Fraid so, Betty.'

Dawn had big bones and short black hair. She had a strong, wide face and her jaw went up and down from chewing gum. She reminded me of a discus thrower I knew. She walked me down a long polished corridor into a pale pink room with a steel bed and a chipped wooden bedside cabinet. She handed me a white surgical nightie that didn't do up at the back. Then she picked up her clipboard and asked me some questions, but I had no reason to answer them.

'How about getting into bed,' she said.

She packed all my clothes, wallet and other possessions into a brown paper bag.

'My things,' I mumbled.

'I'm just going to lock them in the property room for safe keeping.'

'But . . .'

Dawn had already left the room.

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I was a privileged citizen until the afternoon I was first admitted to Ward 7. I didn't know I was entering a world that would strip me on both sides of my skin. First came the induction ritual where I was stripped of my clothing and possessions. This was just a taster of things to come; over the following weeks and years a deeper stripping took place as I lost possession of my credibility and dreams.

It would be wrong to attribute all the stripping of mad people's credibility and dreams to mental health professionals. Discrimination in all its other guises, and madness itself, can be just as corrosive. Nothing was more profound for me than the stripping I experienced in the black box. Sometimes our families, friends and others strip us of our status. Worst of all, we can make our own contribution by believing other people are right about us, or by still believing what we thought about mad people before we became mad ourselves.

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Three months later I was in Ward 7 again. A couple of weeks after admittance Dawn came up to me twirling her big key. 'Dr Pilling wants to see you.'

Dr Pilling was standing at his desk sorting through a large untidy stack of files.

'How are you today, Mary?' he muttered at the files.

'I'm really good,' I said. And I acted it too. I didn't feel really good at all but I couldn't bear being in the hospital anymore.

'Oh good, I'd like to discharge you today.' He sat down, opened my file and his face turned serious. 'I think it's timely for me to tell you about the impact your illness is likely to have on you. You have a chronic condition that will recur for the rest of your life.'

'Do I really?'

'The medication can help but you need to reduce stress and lower your horizons. A big career or full-time work probably aren't options I'm afraid. And you need to think very carefully about having children, in case they inherit your illness.'

I'd already seen people in the ward whose lives were like the one Dr Pilling was prescribing for me. They were single, they didn't work and they kept going back to hospital. But Dr Pilling was wrong – they did have careers. They were chronic psychiatric patients: schooled in poverty, low status and loneliness, skilled at passive dependence and living without dreams. It was the career no one wanted.

'Does anyone recover?' I asked.

'Not usually, but you'll find you do have well periods' he said. 'I'll see you next week.'

He looked up and smiled, then started writing his notes as I closed the door behind me. My eyes filled with tears.

Dawn got my stuff from the property cupboard, gave me a prescription and a card with my next appointment with Dr Pilling on it. I walked alone down the long, polished corridor, past Betty the receptionist, past all the sad people in the waiting room and on into the outside world.

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Mental illness, as we know it, was invented by psychiatry a couple of hundred years ago. They took some inspiration from the Greeks who thought madness originated in the humours of the body. To this they applied the scientific tools honed in the Enlightenment. And believing they could uncover the truth about madness through experiments and rational inquiry, they established themselves as the pinnacle of expertise in reasoning about madness.

Two hundred years later, medical science has the technology to peer deep into the brain. They have discovered that the brain has more neurotransmitter pathways than all the roads and tracks in the world put together. They've signposted all the major junctions and analysed the traffic that passes through them. They can see a billion traffic lights blinking in different junctions of the brain every time someone thinks or moves. And they can spot some of the traffic lights that signal madness. But are they really uncovering the truth, or just skating across its surface?

I read somewhere that trying to understand madness through biological psychiatry is like trying to understand Mona Lisa's smile by analysing the chemicals in the paint.

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Many mad people carry the ominous weight of internalised stigma, which gets its nutrition from ancient prejudices, medical reductionism and depersonalising institutional rituals. But others don't carry this weight. If we knew what spared them, we may be able to lessen the load for people who do. So, how did I escape internalised stigma?

I will start with my 'self'. A sense of self is not an emotion or a thought or a sensation. The self is the solid core of one's being. It is an immutable warm, dark nucleus that sits at the centre of our being while all our fickle, changing feelings, thoughts and sensations orbit around it. My madness did not come from my self; it was like an invader that chased my self over the horizon, like the encroaching darkness chases the setting sun.

Most told me my biology was at fault. I didn't see my biology as my self, but as the container my self sat in. Biology absolved me from responsibility. But a few professionals told me my problems were psychological. This didn't relieve my self of responsibility, because I saw my psychology as mingled with it, inside the container. The biological view made me a victim of my pathology, whereas the psychological view made me a more or less unwitting perpetrator in my own demise. Thinking about my madness in this dualistic way, I preferred to be its victim rather than its perpetrator.

I soon discovered that it didn't matter whether biology or psychology won the battle for possession of my troubled mind. They were two sides of the same coin. Professionals who used either frame of reference were equally preoccupied with pathologising my madness and their futile attempts to get rid of it.

My self always came back as strong as ever after my madness subsided; it reoccupied the core of me with its warm, dark aura. Madness did not just extinguish me, it also renewed me. I discovered this one day, near the end of my years of madness, when I watched my flatmate weed and dig the vegetable garden. It had been lying fallow for a year. She came up to me afterwards and said, 'The soil's good; it's had a break'. Then I realised my madness was like the soil, lying fallow. Sometimes it stripped me bare, but it was also the beginning of renewal. Every time I came out of my madness I felt fresh and ready to start again.

Everyone's self comes elaborately wrapped in a personality. Like a plant that needs water, a personality needs interaction with the world to grow. The colour of our personalities helps to determine the colour of the stories we tell ourselves about those interactions. Perhaps some personality features protect us from internalised stigma, like self-esteem, resilience, arrogance, naīvety, rebelliousness or non-conformity. I could label myself with any of these features, but they are probably best revealed through the colour of my stories.

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Perhaps my biggest protection against internalised sigma was the love and luck of my family. My parents, my aunts and uncles and my grandparents were my adult role models. None of them were conquered people. They all had a secure place in the world. No-one in living memory had robbed them of their culture, language or other treasures. None of them had ever gone without a meal. They all lived in their own houses and could afford to buy presents, shoot ducks, play tennis and go on holidays. None of them were bitter, ashamed or angry at their lot in life. Those whose personalities were edged with eccentricity, humour or questioning minds, carried themselves with confidence.

My family knew they had a right to be in the world and that they mattered. They had the skills, connections and language to get around that world with ease. All this fed my self-esteem. If they mattered, I mattered. If their views counted, my views counted. If they could make a contribution to society, so could I.

My parents, for all their inconsistencies, always looked pleased to see me and were interested in what I had to say. They made sure I had enough food, clothing and sleep. They usually comforted me when I cried. They held me close and read me stories. They let me play without interfering. They encouraged me to question others' truths and to develop my talents without pressuring me. I never doubted their love for me.

There was also a long memory in my family, like a backdrop in a darkened theatre, of where they came from, before they made good in the new country – centuries of poverty, famines, 'galloping consumption', and colonisation by the English and the Catholic Church. Most of my forebears and their communities were treated by others as though they were barely human.

Privilege was recent in the story of my family; they knew it was a consequence of favourable circumstances rather than innate superiority.

But my family gave me more than love and luck. My parents showed me a world of diversity and new ideas. They were well-read people who liked to think for themselves. I was born in a conservative rural town at the bottom of the world. My mother stayed at home most of the time with me and my siblings, while my father drove to work in his pale green Volkswagen, with a brown leather case full of bandages, little bottles and syringes.

The world opened up for my parents when we lived in Britain in the mid-1960s. It was the time of Twiggy, the Beatles and of reform in the Catholic Church. The world opened for me there too, much wider than it ever could have in our conservative rural town. I saw crumbling old castles, the biggest toy shop in the world, the Eiffel Tower in France, camels in Egypt, people of all colours and real daleks in a Dr Who pantomime.

When we returned to the small town, my parents were changed people. They were poised between being outsiders and insiders. Their friends spanned the spectrum from farmers with huge red hands and old fashioned hats, to middle-aged drop-outs with long hair and roman sandals. They knew the art of shunning convention but also of tolerating it. Others, like the parish priest, were not always so tolerant of them.

One day I told Sister Ignatius in class that I didn't believe in miracles or the resurrection. She looked at me with concern, as though I had a serious disease and told me to stay after class. Father Dempsey walked in after all the other kids had left. Father Dempsey wasn't that old. He had red hair and a wide Irish face, and he looked like everyone's friend, until he opened his mouth.

He stood over me. 'Sister has been telling me you've been saying some ungodly things in class. Where did you get these ideas from young lady?'

'I don't know. From my mother I suppose.'

'Well, it's your mother who's cracked then.' Father Dempsey looked like he'd just said 'checkmate'.

I was stunned and lowered my head with embarrassment, though deep down I knew Father Dempsey was wrong about my mother. A few days later Father Dempsey went to see my mother.

'We're bringing up our children to question things,' she explained to him.

Father Dempsey went away praying even harder for our salvation.

My parents went on into the 1970s reading Alvin Toffler, Marshall McLuhan and Germaine Greer. Change is coming, they announced, the world will never be the same again. We had long and lively discussions at the dinner table about poetry and politics, environmentalism and nuclear war, counter-culture and the Catholic Church. At 13, I read 'The Little Red Schoolbook' and held a placard that said 'New Zealand troops out of Vietnam now'.

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As a child, I was surrounded by stories of people facing adversity, conquering evil and saving the innocent. I read Ladybird books about Boadicea and Joan of Arc, brave kings and fearless missionaries. I watched 'The Lone Ranger' and 'Flash Gordon' on television and longed to be a hero like them. When I closed my eyes at night I made up stories about saving my classmates from my burning school, running through the flames, dragging them out into the sun, choking, while the nuns cheered me on.

When I went to Ward 7 for the first time I saw all the broken heroes who ended up like me, in places like this, seeking their redemption. There was no shortage of myths and legends about people in our kind of predicament – St George and the dragon, 40 days in the wilderness, the despair of Job, survival in the trenches. I thought the psychiatrists and nurses would feel compassion and respect for my desperate struggle; that they would understand I was fighting the collapse of my self and my whole existence. I expected they would guide me through my despair back into a universe that was rich with meaning. It didn't take long for me to realise that the staff didn't see us reflected in heroic stories. All they saw in me was a sick, deluded, screwed-up 20-year-old who needed their control and containment.

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The trouble was, I couldn't find anyone in my lucky family who had suffered like me, except perhaps my grandfather in the trenches. After he dropped dead at the Returned Servicemen's Association, I read the First World War poets, novels, histories, my grandfather's postcards home and his intelligence reports. Though I'd never been inside a trench, I came to see my madness as trench warfare of the mind.

The networks of trenches, knee-high with mud and barbed wire, were like the nerve pathways in my mind as they clogged up in the tangle of my despair. The men in the trenches and I were both trapped in the shelter of our dug-outs: me retching at my own decaying spirit, they at their comrades' decaying bodies. We knew our respective wars may kill us; they certainly would not be quick or easily won. But we were often past caring.

Many people see a big difference between someone like me and the soldiers. They are heroes who get medals, a national day of remembrance and their names engraved in granite if they die. In the same era as the world wars, the people who died in mental hospitals were buried in unmarked graves and forgotten. There are no gilded tombs of the unknown mental patient, though they died serving their country's need for the enemy in their midst to be removed and locked up outside town, just as the soldiers died serving their country's need to defeat the enemy on the other side of the world.

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My grandfather didn't talk to us much about his war, but he found solace, fun and comradeship every Friday night at the Returned Servicemen's Association. I found it with people who were mad, like me.

My mother's oldest friend, Mavora, who'd also been a patient in Ward 7, came around for dinner the day after Dr Pilling said I could leave. She held court from her chair with conversation that undulated with humour and grand statements. We were half-way through the beef casserole when I told them.

'Dr Pilling told me I've got a chronic illness.'

My mother looked lost for words.

Mavora said, 'Oh, my psychiatrist used to say that to me too. I remember going to see him; that funny wispy bald head with the part down on top of his ear, trotting along in front of me with his bandy little legs, while I followed him to his office. He'd look at me through those filthy specs and told me I was manic depressive. Never mind the drink. He never once thought to ask about the drink, when all I needed to do was dry out. All those years, all those pills, all those visits to that peculiar little man, who really didn't have a clue.'

My mother hooted with delight, 'They are hopeless aren't they.'

'Of course they are,' laughed Mavora. She turned to me. 'You'll get better, I know you will.' In all my years of madness, Mavora was the only person who told me I would recover.

❧

I was in hospital again. Jill, Lizzie, Marcus and I were sitting in a huddle in the Ladies' Lounge. Jill lit a cigarette, sucked hard and blew a stream of smoke out her nostrils.

'We're all in here because we're too sensitive,' she said. 'We're the sane ones. It's the people who put us here that should have their heads read.'

Lizzie looked at Jill like she'd just announced a new discovery that grass is green. 'God, how long did it take to work that one out? I know why I'm here. Just ask the KGB.'

'Yeah,' I said, 'they've put a few people away.'

Marcus jumped off his seat and threw his hands in the air. 'I'm here because I'm mad,' he yelled, and led us laughing out onto the balcony. We lined up at the rail facing the road, which was about ten metres away. A woman and a little boy were walking past. 'Listen to this,' he whispered as he cupped his hands around his mouth. 'It's great to be mad; you should try it sometime,' he bellowed. The woman picked up the boy and ran. We laughed so hard we couldn't stand up. Marcus kept slapping us on the back telling us how fabulous we all were.

❧

When I first went mad I felt as if I was wandering around the crumbling edges of human experience like a lost explorer. But over the years I met many fine people who were mad like me. I learnt that our madness had taken us to a foreign land where only mad people could go to. Some of us stayed in this mad land for a long time while others of us got out and kept returning to it. Mental health professionals stood at the border trying to pull people out, even the ones that wanted to stay. They knew the mad land as a bad place where people got lost, sometimes forever. But many of them had never been there.

My peers helped to show me that I was not the lone, lost explorer I thought I was. The mad land, for all its perils, had some of the most enchanting scenery in the world. Like a land that has mountains and ravines, rivers and caves, blinding sun and swirling storms, the mad land could be a place of beauty as well as danger. My peers helped me to understand that there was a whole tribe of us who had been there and seen many of the same things. Things other people did not understand.

My friends never quite understood in the way other mad people did. But none of them rejected me. Sometimes I could see they'd had enough of me barging into their flats at 5.00 in the morning or sitting in a huddle for days with nothing to say. But they kept coming back. Was it because they understood the rootless alienation of youth, existential despair, protest against authority, dropping out and mind-altering drugs? Was it because an episode of madness or visit to the loony bin was not far off their compass range? Was it because I was never lost in the mad land for long stretches without making a quick visit back into our shared world? Perhaps they were just good, patient people.

◆

Several years later I was sitting in my room, in my flat, staring into the garden; it was raining and misty, the grass had grown higher than my window sill. I felt like lying on the floor and howling.

I'd lost count of how many times I'd gone to hospital.

I turned on the TV to watch a documentary about dolphins. The presenter walked into a dolphin marina in Florida. It was cloudless and the water sparkled. A sick dolphin drifted on its own around the bottom of a big pool. Some men in white shirts and ties wearing sunglasses examined it from the poolside, and sprinkled some powder into the water. They kept peering at the dolphin and stepped back every time the water threatened to wet their feet. The presenter said that, despite the attention of the best experts in the field, the dolphin died a few days later.

I turned off the television feeling more desperate than ever and curled up in my chair. My friend Kim walked in. She took her coat off and shook her dripping hair. Then she gave me a long tender hug and sat down.

'You look really down today,' she said.

'This crap has been going on for eight years and it's not going away,' I told her. 'I went through my diaries for the last 12 months; most days I can't function. I can't live like this.'

'Has your death-wish returned?'

'It's there all the time. I don't see what I've got to live for.'

'You know, you're a real survivor, but I think you've got battle fatigue.' Kim's kind eyes told me I could have a little compassion for myself. 'Maybe you need to stop fighting.'

After Kim left I lay down and let myself relax, and all the fighting drained out of me. Yeah, I was a survivor, but I was also a deeply tired one. Fatigue flooded every corner of my being and I sobbed for hours at how impossible my life had become.

A few days later I went to an appointment with Dr Jolly. He gazed at me and chewed the end of his biro while he waited for me to talk. Part of me wanted to spill all my pain at his feet. Another part of me watched from the wall and savoured the irony of two people talking past each other.

'What's going to become of me?' I asked.

'Why is that worrying you today?'

'It worries me all the time.'

'We're here to help, you know.'

'The word for me is "chronic" isn't it?'

'Oh I don't use that kind of language with my patients.'

'None of the pills work.'

'You could be in a worse state without them.'

'What's worse than never being able to achieve anything and spending half your life in hospital?'

'We want to help. You're depressed about your life. We can help you come to terms with it.'

'Yeah, but talking never helps either.'

After I left, Dr Jolly wrote in his notes: 'Mary has finally accepted, emotionally, not just intellectually, the long-term nature of her illness and disability.'

Neither of us knew that my final admission to hospital was only three months away.

⁂

I'd come to realise that being under the reductionist and pessimistic spell of biological psychiatry was, in most respects, a monumental barrier to my recovery. It meant that the professionals believed my experience of madness had no value or meaning. Mood swings were bad and had to be got rid of. It didn't seem to matter to them that some of the most intense and powerful experiences of my life happened while I was mad.

⁂

With no-one to guide me, I learned to approach the enigma of my madness through words and metaphors. With enormous effort I wrote my journal in tiny handwriting, crouched in the ladies' toilet in the hospital. I learned to make meaning, not in spite of my madness, but because of it. It was not the kind of meaning that answered ambitious intellectual questions such as 'why?' Like haunting music or poetry, it was saturated with soul, an intuitive expression of being, without the labour of logic.

For my madness took me places I had never been. It showed me the universe without its clothes. It stripped my mind of all its chattels. It rubbed my nose in the divine. It turned the lights off all over the undulating continent of my brain. It showed me a world that was too beautiful to look at. Many people pass through this territory at some time in their lives. Most manage to skirt their way around the edge of it and look on with dread at a distance. But those who are forced right into its belly come out with rich pictures of a being that has been lost and found again.

Most people's responses to madness and mad people are based on a bedrock of belief that usually lies under the surface of everyday consciousness. It's the belief that madness has no value. From it comes a tangled array of responses like fear, pity, discrimination, exclusion and the coercion of mad people. Joe Public may be full of crass language like 'psycho', 'barking' and 'axe murderer', but the traditional mental health system can be just as invalidating once you dig beneath the smooth surface of diagnoses, therapeutic language and other clever jargon.

We all know that madness can cause terror, confusion and despair, but so can grief or dying in pain for a just cause; so can the path towards spiritual enlightenment or being falsely accused. The difference between these states and madness is that society legitimises them and allows for the possibility of growth or recovery.

◆

I was starting to make some sense of madness, and in preference to seeing the failure in myself, I decided the biggest failure was in the mental health system. I knew there had to be a better way of responding to madness, but I couldn't find it. So I kept searching library shelves for the answer, not quite knowing what I was looking for. Then one day, a few months before my last admission, I was scanning the psychology section when I noticed a book called *On Our Own: Patient-Controlled Alternatives to the Mental Health System*, by an American called Judi Chamberlin. I opened the book and scanned the introduction:

> For too long mental patients have been faceless, voiceless people. We have been thought of, at worst, as subhuman monsters, or, at best, as pathetic cripples. . . It is only with the emergence and growth of the mental patients' liberation movement that we ex-patients have begun to shake off this distorted image and to see ourselves for what we are – a diverse group of people, with strengths and weaknesses, abilities and needs, and ideas of our own. . . Our ideas about psychiatry, about the nature of mental illness, and about new and better ways to deal with people undergoing emotional distress, differ drastically from

those of mental health professionals...
(p. xi)

With these words, I knew I'd struck gold. I'd already read several autobiographies of mad people who wrote vivid descriptions of their madness and how they were treated. I'd also read anti-psychiatry books written by professionals and academics who argued that madness wasn't a medical condition. But this was the first time I'd read anything by a mad person that challenged the ideological foundations of psychiatry through an analysis based on her own experience. It was my introduction to the mad movement.

Chamberlin started by writing about her own experiences in the mental health system. Much of it resonated with my own: her initial hope that professionals would help her, and her growing awareness that they were controllers rather than healers. The crumbling of her personhood as the hospital took away her possessions, her liberty, her self-belief and the hope that she would ever recover.

Chamberlin recovered some years after her hospital admissions in a ex-patient-run alternative where she was respected, listened to, free to come and go and able to express her feelings. In the book she described ex-patient-run alternatives in the USA and Canada where participation was entirely voluntary, where everyone could both give and receive help, and where there were no hierarchies. Suddenly, after years of wondering if there's a better way, I had found it.

This book validated the experience of madness more than anything else I'd ever read. It slammed the medical model and argued passionately against the power of the mental health system to force treatment on people and control their lives. The mental health system needed to be replaced by responses that respect the experience of madness, and where people could choose what works for them.

I never took Chamberlin's book back to the library. Over 20 years later it still sits on my bookshelf, tattered and browned at the edges; one of those rare books that showed me a new world rather than a familiar world revisited. Between the lines it showed me I could do something good with my madness, that there was a place in the world for mad people to critique the mental health system, to organise, and to come up with better responses to madness than hospitals, toxic drugs and coercion.

Though I didn't quite know it at the time 'On Our Own' became the launch pad for my life's work.

❧

And so it turned out that being one of them gave to me as much as it took away. While many of my contemporaries were gaining qualifications, I was undergoing deeper lessons in existence and survival. Being one of them taught me that a stable existential orientation and a sense of control are necessary illusions, not virtues or strengths. It gave me, an otherwise privileged person, direct experience of the injustice of human inequality and of belonging to a group that is shunned. Being one of them showed me that professional experts usually miss the essence of human struggles by a mile, and that the true heroes are not the official healers but the wounded.

But what if I'd felt shame about being one of them? Internalised stigma, like an eclipse of the sun, would have shrouded these lessons in darkness.

❧

I'm sitting with my old friend Siobhan in her living room.

'Do you remember the day we found the 20-cent piece and ran away from the mad guy standing outside the Bakery?'

Siobhan is curled up on a sofa, chewing a lolly and drinking coffee. Her auburn hair blazes in the morning sun and she looks straight at me.

'Oh yes, wasn't that awful of us.'

'Yeah. We didn't know much then did we? I thought loonies were almost like another species. Then, when I became one myself I realised we are all just as human as anyone else, but we're punished by social stigma and even by mental health services. No wonder so many of us end up punishing ourselves.'

'It's terrible. I see the damage services can do every day. I don't know how long I can stay working at that psych unit. Some of my colleagues are so blinkered and so controlling . . .'

'Yeah, I know. The tragedy is they think they are really helping people.'

'Well, the road to hell is paved with good intentions.'

'It's got to change,' I said.

And I mean it. I'm visiting Siobhan on my way north to start up an advocacy and peer support organisation that we will name Psychiatric Survivors.

❧

In memory of Siobhan who died before her time, and Mavora who died while I was completing this chapter.

Thomas Agar age 13

On reflection: Body dysmorphic disorder and self-stigma

Sarah O'Connor

Flawed

As I stood among the library shelves holding the book I had been looking for in my hands, I found myself turning it over so the cover was not facing outwards. The book in question was about understanding and treating body dysmorphic disorder. I had turned it over because I didn't want other people to see me with it. Then I actually thought about what I had done.

Even after nearly 20 years of knowledge, personal experience, treatment and support for body dysmorphic disorder, a part of me still wanted to hide this aspect of myself from the rest of the world. For me, the self-stigma associated with having this mental illness continues to run deep.

When I first experienced body dysmorphic disorder as a teenager, something else debilitating came along with it. Back then I didn't know what it was, or how to describe it, but looking back on it now, I realise it was self-stigma. I was so embarrassed and ashamed of how I was thinking, feeling and behaving that it became harder and harder to speak to anyone about what was really happening. I began to engage less in life and sank more into believing a whole lot of damaging ideas about myself.

Thankfully, I have not been acutely affected by body dysmorphic disorder for some time, so it no longer dominates my life as it once did. Furthermore, while I still experience self-stigma to a certain extent, this too has improved significantly and I attribute it to a range of support, particularly peer support. As a result, I believe peer support is vital for anyone wanting to break the cycle of self-stigma.

Firstly, let me explain what body dysmorphic disorder is. In order to provide this explanation I have drawn heavily on the published work of Katharine Phillips, one of the few specialists in the area. Body dysmorphic disorder – or BDD as it is now commonly known – is not only difficult to pronounce, but sounds like a terrible affliction, which could possibly be contagious!

At the heart of BDD is the belief that an aspect of your appearance is flawed. The flaw might be slight or entirely imaginary, but the preoccupation and anxiety it induces affects the sufferer to such an extent that it interferes with their life to some degree. Common preoccupations are with features such as the nose, eyes, teeth, skin, ears and hair, but BDD can be about any aspect of one's appearance.

As Katharine Phillips explains, the obsession is not about looking perfect, just ordinary:

> While some people with BDD want to be unusually attractive or look 'perfect' overall, in my experience most don't – they simply want to look normal. What they're obsessed with is getting rid of the perceived defect and looking normal. People with BDD describe their perceived appearance problem in various ways. They say that the defect, or their appearance more generally, is ugly, unattractive or abnormal. Some people use words like 'deformed', 'monstrous' or 'hideous'.[1]

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[1] Phillips KA. *The Broken Mirror: understanding and treating body dysmorphic disorder.* New York, NY: Oxford University Press; 1996. p. 59.

Documentation about body dysmorphic disorder dates back to the 1880s. It was originally termed dysmorphophobia by a psychiatrist who treated many people with this condition. 'Dysmorphophobia' originates from the Greek word 'dysmorfia' meaning ugliness, in particular of the face.

For a person to be diagnosed with BDD, the following criteria must be experienced:

- Preoccupation with an imagined defect or a minor flaw in your appearance.
- The preoccupation causes significant distress or impairment in social, occupation, or other important areas of functioning.[2]

Fixing and/or hiding the flaw can become an all-consuming obsession. Some examples of the behaviours to achieve this end include camouflaging the 'flaw' with makeup, clothing or hair, picking skin, removing hair, combing or cutting hair excessively. In some cases, people may consult surgeons or dermatologists to correct their perceived problem. Many people with BDD spend a great deal of money either on various treatments or appointments with specialists. Often people who undergo surgery end up having repeat surgeries because they still believe that their appearance is defective and that the surgery was unsuccessful.

It is a double-edged sword: when you behave in ways that you think will fix your appearance, it can give you a false sense of control and at times reduce anxiety. However, these behaviours often end up enslaving a person with BDD. Their time and energy gets taken up by trying to fix the 'flaw'.

One thing that is consistent with many people who have BDD is their complex relationship with the mirror. The reflection provides hard evidence for a person with BDD: proof that they are seriously flawed and grotesque to look at. However, the paradox of the mirror is that sometimes the reflection might not appear as terrible as the person believes, leading the checker to think that the flaw has somehow improved. This can result in a renewed sense of hope and alleviate a little anxiety. People with BDD often talk about 'safe' mirrors: mirrors that are in familiar environments (such as the bedroom and bathroom). A person's response to their reflection can be influenced by

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[2] American Psychiatric Association. *Diagnostic and statistical manual of mental disorders (text revision)*. Washington DC: American Psychiatric Association; 2000.

lighting, size and shape and where the mirror is placed.

This complex relationship with the mirror often leads people with BDD to be compelled to regularly check their flaw. The compulsion to check can lead to hours spent in front of the mirror. In contrast, many people avoid mirrors because the distress and anxiety that comes as a result of the checking is too great.

One of Katharine Phillips' clients describes the battle she has between avoidance and compulsion to check in the mirror and the anxiety that goes along with it:

> At least 10 times a day I have the urge to look in the mirror, but I don't. I try to avoid mirrors, because I worry that if I look and I don't like what I see, I'll panic and be debilitated. But there are times when I just can't resist, and I go running - I just hope that what I see won't be exaggerated. About 50% of the time, I don't feel so bad. I even feel somewhat relieved. I don't look that bad, and the problem doesn't seem to be getting worse. I can go about my business. But about half the time, I look worse. Or I think something like 'You look okay today, but you won't next year.' Thoughts like these overwhelm me with anxiety, and I have a panic attack. I have trouble breathing, I get sweaty, and sometimes I feel dizzy. Sometimes I feel so bad I go to bed for the day. Sometimes I don't go to work.[3]

A feeling of being an outcast and different from others is a common experience for someone with BDD. People with BDD often compare their appearance with others, focusing on the part of another's appearance that is the source of their own preoccupation. It is not unusual for people with BDD to believe

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[3] Ibid., p. 90.

that other people take special notice of them, think very negatively about them or are privately laughing at them. This can make a person feel that they are an object of disgust or ridicule, which in turn leads to feelings of discomfort and distress around others in social situations or in the general public. A vicious cycle, this then intensifies the feelings of difference from others and can result in isolating oneself from other people.

It is common for a person with BDD to seek reassurance about their appearance from another person. As might be expected, a common response to such inquiry will often be something along the lines of: 'You like fine; there's nothing wrong with the way you look.' This 'reassurance' can create a lot of frustration on both sides.

One of the reasons for seeking reassurance is because it is a type of 'checking out' about their concern – seeking confirmation that they really do look as bad as they think they look – a validation of their belief. Occasionally receiving reassurance can alleviate some of the anxiety; however, much of the time a person with BDD will not believe the person doing the reassuring, thinking they are lying or being polite to spare their feelings.

The person doing the reassuring can also feel a lot of frustration. Sometimes a response to a person with BDD may be incredulity – they absolutely can't understand why they are even being asked for reassurance – because in their eyes there is nothing to be concerned about. It is very difficult for them to understand the level of distress and preoccupation a person with BDD experiences. A person being asked for reassurance can find it hard to understand why a person with BDD can't just forget about their concern and get on with life.

While a person suffering with BDD is so preoccupied, anxious and consumed by their thoughts about the 'monster in the mirror', it can seem as if they cannot turn to other people in their lives for real understanding, because the people they are turning to for reassurance simply do not see this 'monster' at all. These factors can lead a person with BDD to feel even more isolated in the belief that their concern is considered trivial or not really understood by other people.

Katharine Phillips highlights the significant negative effects that the experience of BDD can have on peoples' lives. In a study of more than 500 people with BDD, nearly all of the study participants (99 per cent) identified that BDD had interfered with their social life with friends, family or intimate relationships. The majority (95 per cent) had periods of avoiding nearly all social interactions and 80 per cent completely avoided work, school or other roles. As a consequence of their BDD, 14 per cent of the study participants had temporarily left school and 11 per cent had permanently left school.

In addition, the majority (94 per cent) experienced depression because of BDD and 38 per cent had been hospitalised in psychiatric care. A significant proportion of participants (80 per cent) had thought about suicide and 14 per cent reported that they had attempted suicide as a direct consequence of having BDD.[4]

Feeling shame, a loss of face, guilt and embarrassment relate to the 'comparison' element of the Discrimination Intervention model (as presented in Chapter 1). People who experience BDD often feel a great deal of shame about their preoccupation. Katharine Phillips describes this:

> Feelings of deep shame make sense because BDD preoccupations involve strongly negative feelings about oneself – thoughts of being unappealing and defective. Another source of suffering is feeling selfish and vain for being so preoccupied with such 'trivial' concerns . . . some people with BDD feel it's wrong – even immoral – to be so focused on how they look. This is what I call the 'double whammy' of BDD: not only do BDD sufferers have painful thoughts they can't stop thinking, they also berate themselves for having those thoughts. Many feel guilty and consider themselves morally weak and defective because they're so preoccupied with something they feel is so trivial. They feel ashamed of being ashamed.[5]

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[4] Ibid., p. 119.

[5] Ibid., pp. 73–4.

On the sidelines

My own experience of BDD began nearly 20 years ago, at the age of 16. It was another five years of experiencing an excruciating and shameful preoccupation with my skin before I received another diagnosis alongside major depression. For the first time in my life a psychiatrist named my distressing obsession. It was called body dysmorphic disorder. Several things happened for me when I received the diagnosis: I was able to make sense of my experience at an intellectual level and I believed that, if it had a name and was a recognised condition, it meant that I was not the only person who experienced this.

Before that diagnosis, I thought I was completely alone in my particular distress as I had never before come across anyone who had experienced the same thing. I didn't know what I was dealing with and that made it even more frightening. One thing that really contributed to my self-stigma was that I knew it was an unusual diagnosis.

I was hospitalised for two years because of my BDD and the psychiatrist I saw would often tell me that I was delusional about my appearance. There was no way I could believe him because I knew what I saw in the mirror. I had a belief and it was like an unshakable religious conviction. I was also ashamed of myself for being overly concerned about something that was so vain and trivial. Yes! At an intellectual level I knew how trivial it was, so it was incredibly frustrating to be so overwhelmed by it.

My obsessive thoughts about my skin were condemnatory, unremorseful and almost lethal. From the minute I woke up I bombarded myself with cruel taunts about my hideous, revolting skin and how ugly and freakish I looked. I became sick with anxiety and locked into a cycle of mirror checking. I would compulsively check my skin in the mirror up to 30 times a day. A 'check' involved a close examination of my skin, standing a few centimetres away from the mirror. The 'checking' would make me feel worse 9.5 times out of 10, but once in a while, I would think that maybe my skin had improved. If this happened, I would feel a rush of relief, almost elation and hope.

In hospital, my life as I had known it stopped. I watched from the sidelines as my friends graduated from university, went travelling and started their careers. I, on the other hand, lost more and more time, knowing that I had been left behind and wondering if it would ever be possible for me to recover and catch up. Along with everything else, I was also ashamed about my lack of progress in life.

'Having a sense of inevitability, that things won't change and recovery is not possible' relates to the 'inevitability or unchangeability' element of the Discrimination Intervention model. During my time in hospital I felt this acutely. For a long time I didn't believe I would ever be able to overcome my BDD. I felt I had no control over it and began to lose sight of the person I had been before. I wondered if she had gone forever.

With a combination of cognitive behavioural therapy and anti-depressants, I gradually began to improve and was eventually discharged from hospital. Despite this, I continued to feel uneasy, afraid that BDD would rear up and take over my life again (which it did in subsequent years). One thing I always remained very aware of is how few people seemed to share this experience. During the two-year period I was in hospital, I only met one other person with BDD, so I still felt very isolated in my experience.

Peer support: breaking the self-stigma cycle

A key thing that has helped me with my experience of BDD and self-stigma is belonging to an online peer support group.[6] About two years ago I discovered a yahoo group for people with body dysmorphic disorder and joined straight away. All of a sudden I had found a group of people from all over the world who shared a similar experience with me.

The yahoo group, founded in 2000, offers many things for its 1031 members, including links to various forums and websites about BDD, information and perspectives about BDD programmes, support groups, tools and resources for recovery, recommended reading, and the sharing of experiences, support and advice.

I believe the thing of most value in relation to the group is peer support. Through the group, people openly discuss what it's like for them to have BDD. The forum is available for members to discuss anything without judgement from others. People almost always get a response to any posting. There is lots of relating to each other. Many people find they have similar obsessions about their appearance and most of us engage in similar types of behaviours.

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[6] BodyDysmorphic@yahoogroups.com

For the purpose of this chapter, I decided to explore if and how other members of the group feel the BDD online peer support forum contributes to their recovery and their ability to deal with self-stigma. In order to do this I posted a communication on the website, inviting members to share their perspectives on the subject with me. All the group members quoted here provided consent for their material to be reproduced in this chapter.

> I believe the yahoo group is a forum where I'm not different from other people. Like everyone else in the group, I share the common experience of BDD and because I can openly discuss it, without judgement, I feel supported and my fear of being so different from others diminishes.

> I felt relief when I joined the group, and know that now I will always have an avenue to communicate with people who understand exactly what I'm talking about.

> The feeling of relief I felt to find this site is overwhelming. Not to feel so alone and 'freakish' has done amazing things for me in the short time since I was accepted. There's something about starting to take control of this disorder that's empowering for me.

> It helps to talk with others with BDD. I don't know of anyone else who has this other than those in the group. It is something that is hidden and not often talked about. I think that it really helps to talk about this and what you go through.

I find I'm not alone… I find that how I see myself is not necessarily how others perceive me.

Thank you so very much for sharing. You've helped me feel less alone, and isn't that the point? To heck with the shame, guilt and secrets, they just feed the BDD monster!

There are times when I have both reached out to others and shared my personal experience, strategies for coping and belief in recovery, and times when they have done the same for me.

Everyone in the group is valued, accepted and connected by the commonality of their experience.

Her response helped me that day; it reminded me that my experience is shared by many people and that openly talking about it robs it of its power.

I think the reciprocity of the support empowers everyone in the group.

I think one of the most important things to do is to start treating yourself with respect, the same respect you would give others. Tell yourself, regardless of how I feel, look, etc., I should be treated in a fair and dignified way. Look at yourself as someone who deserves to be defended. Start looking at your life as a series of court battles in which you have

> to defend yourself and stand up to bad treatment, whether it be obvious or under the radar. Tell yourself [that] no one has the right to say anything bad to you, not even yourself.

There are several reasons why peer support groups can help overcome self-stigma. They provide opportunities for people to openly disclose and discuss their experience, help people to understand and learn from each other, enable people to feel a sense of belonging and connection, support hope and recovery, and evince positive role models. The perspectives shared by members of the BDD online support group reflect experiences of exactly these things and highlight the very real and powerful impact that peer support can have in terms of the circuit breakers necessary to interrupt the cycle of self-stigma.

Kaitlin Clayton-McBride age 8

A tough road to travel: Self-stigma amongst tāngata whāi ora

Dr Lynne Pere[1]

What is self-stigma and how does it relate to discrimination?

Research into the experience of self-stigma amongst people with experience of mental illness in Aotearoa/New Zealand, undertaken by the Mental Health Foundation of New Zealand (Peterson, Barnes and Duncan 2008), resulted in a new definition of self-stigma being identified:

> Something is wrong with me, that won't change, which means I'm less worthy than other people and less entitled than other people. Therefore, I . . .

The Discrimination Intervention model (as presented in Chapter 1), developed out of the self-stigma research, shows how self-stigma and discrimination are intrinsically linked.

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Through the research, a number of examples in illustration of this relationship were relayed:

> [I] believ[ed] what other people told me... all the time... because I wasn't really getting any positive stuff really [and therefore believed all the negative].
>
> I stigmatised myself to actually believe that what they were saying about me was true.
>
> Internally it kills us when we start believing what other people are saying, when we start taking on board what they say.

Fear of discrimination

An argument exists that fear of discrimination is not self-stigma based on the perception that a fear of discrimination is real and appropriate. Discrimination does exist; therefore, having a fear of it is legitimate. Self-stigma on the other hand, concerns the application of myths perpetuated by society. It is premised on prejudicial attitudes that form erroneous beliefs of the self, which can perhaps even lead to an expectation of discrimination.

The difference between a fear of discrimination and self-stigma may be best explained as the difference between a fear of, and acceptance of, discrimination.

Based on the perspectives of tāngata whai ora,[2] this chapter explores the concepts and experiences associated with self-stigma, fear of discrimination and the complex inter-relationship between the two.

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[2] The term 'tāngata whai ora' is a general term used in Aotearoa/New Zealand to refer to Māori with experience of mental illness – that is, those who have at some point in their lives personally experienced a mental health disorder or other mental health problem. Tāngata whai ora advice is the term used to mean special, unique and absolute, and is associated with the whakatauaki 'Kia maumahara ki tou mana āhua ake' which means 'Cherish your absolute uniqueness'. Advice from Te Taura Whiri i te Reo Māori is that 'whai ora' literally means 'in search of wellness'; 'tāngata' means 'people' (Pere 2006).

In 2003, a survey of people with experience of mental illness in Aotearoa/New Zealand was undertaken by the Mental Health Foundation (MHF) of New Zealand to obtain accounts of experiences of discrimination across a broad spectrum of activities (Peterson *et al.* 2004). One of the questions asked of people was whether they had ever been prevented from doing something because they were afraid of being discriminated against. Forty-five per cent of tāngata whai ora who responded to the survey reported that this was their experience. The examples relayed, to elucidate on initial responses to this question, highlight that respondents were referring to both fear of discrimination, self-stigma and the impact of each on the other.

EMPLOYMENT

The most common example for not undertaking some action for fear of discrimination due to their experience of mental illness, as relayed by tāngata whai ora through this survey, was in relation to employment. Ample research has found isolation, alienation and social withdrawal to be common amongst self-stigmatising people with experience of mental illness (Duncan and Peterson 2006). This social isolation includes avoiding employment (Caltraux 2003).

A number of tāngata whai ora respondents to the 2003 MHF discrimination survey implied they did not feel able to apply for jobs because they were fearful of what prospective employers would think of them as people with experience of mental illness. Others reported lying about their experience of mental illness for fear of rejection:

> [I] wanted to apply for numerous jobs but [I] lacked confidence and [experienced] paranoia due to the fact [that] I believed normal people believed I was different.

> I do not tell prospective employers I have a mental illness as I think it will jeopardise my chances of finding work. Because I have been out of work for so long I say I have done a lot of travelling in that time which

> is only partly true. I was too unwell to hold down a job.
>
> I lied on job applications and kept to myself for fear of rejection. It's a tough road to travel.

Strictly speaking, these experiences exemplify a fear of discrimination. The tāngata whai ora concerned are afraid that if prospective employers are aware of their experiences of mental illness, they may discriminate against them. A belief in the legitimacy of those prospective employers' likely unfounded concerns is another matter. It is an issue of self-stigma when people themselves believe that they are not capable of certain types of employment because of their experience of mental illness:

> I have avoided getting jobs where I could work with children because I know that childcare agencies have to be careful about who looks after the children, and I suppose that it is not desirable to be a mental patient.

The experiences of tāngata whai ora participants in the 2008 MHF self-stigma research mirrored those of the tāngata whai ora respondents to the 2003 MHF discrimination survey. One such participant referred to applying for a job and thinking, 'Should I disclose or not disclose in the part where it asks if I have a condition that might affect my job?':

> Then the self-stigma comes into play because it makes you start thinking, 'Maybe I'm not good enough for this job [because I have a 'condition which might affect my employment'].

Caltraux (2003) points out that often self-stigmatising people with experience of mental illness are not aware that their actions are self-stigmatising.

Employers, employment support services and government agencies, therefore, have a responsibility to encourage the development of a workplace culture amenable to employees with experience of mental illness being able to empower themselves.

EDUCATION

Education was another area that was commonly referred to by tāngata whai ora respondents to the 2003 MHF discrimination survey when reporting situations where their fear of discrimination, due to their experience of mental illness, prevented them from doing something. Similar to the employment experiences relayed, some implied that what actually prevented them from applying for educational courses was a self-perception that they would not be able to meet the demands of courses and study due to their experience of mental illness:

> [I] thought 'no, I can't do it'. [I have] not [got] enough confidence to do it.
>
> [Fear of discrimination due to my experience of mental illness, has prevented me from] taking a course or training [when] they say they are looking for [a] focused, goal-orientated person.
>
> [Fear of discrimination due to my experience of mental illness, has] perhaps [resulted in me] not completing my degree. [I] also [have a] feeling [of] not [being] competent enough to do so. Being out in the academic world again and proving myself at present, seems an unattainable goal.

Some tāngata whai ora also reported that this fear of failure was reinforced by others:

> [I] didn't go for School Certificate 'cause friends told me I wouldn't make it.

EMOTIONS

In their study of coping with stigma, Miller and Kaiser (2001) conceptualise stigma and discrimination as stressors. Voluntary means of coping with these stressors are categorised as 'engagement' or 'disengagement' modes, with the disengagement style of coping demonstrated through physical and/or social avoidance of situations in which stigma may occur. Miller and Kaiser (2001) further divide these modes into primary and secondary categories, with the primary engagement style of coping being identified as including emotion regulation, whereby individuals control their behaviour so as not to confirm stereotypes (Duncan and Peterson 2006).

Many tāngata whai ora respondents to the 2003 MHF discrimination survey reported not feeling able or allowed to express emotion like other members of society, lest it be misconstrued as being due to their experience of mental illness. Although subtle, this discrimination is significant because for a number of tāngata whai ora it is something they keep in check every single day of their lives:

> [Fear of discrimination due to my experience of mental illness, has prevented me from expressing my emotions] many times. Due to peer pressure or dependent on what situation I am in, I find that I hold back a lot. Sometimes I feel frustrated by others, [but] mostly [I feel frustrated] by hiding my true feelings.

> I have repeatedly in my life gone to great lengths to look as if I am [all] right, when I am not. [I] have repeatedly behaved 'well' when I have felt like shit, because of fear of discrimination.

The acceptance and reinforcement of this behaviour, of ensuring it is controlled so as not to confirm stereotypes, is self-stigmatising. As a result, some tāngata whai ora do not allow themselves to dream fanciful dreams, lest their imagination be interpreted as part of their mental illness, and they accept this.

The significance of stifling what Durie (1987) refers to as the psychic aspect of a person that is related to the expression of thoughts, feelings and behaviour – te taha hinengaro – in this way, is accentuated for Māori because of the importance placed on emotional communication. Pere (1982) describes te taha hinengaro as the source of mental and emotional experiences, encompassing processes like thinking, knowing, perceiving, remembering, recognising, abstracting, generalising, sensing, responding and reacting. As such, 'the hinengaro is very powerful and . . . influences the way a person acts and feels' (Pere 1991, p. 32):

> Hine (female) is the conscious whole of the mind, including ngaro (hidden) the closed consciousness. Hinengaro refers to the mental, intuitive and 'feeling' seat of the emotions. (Pere 1991, p. 32)

Durie (1998) suggests that emotional communication – the expression of feelings – tends to have more significance for Māori for whom words are often considered unnecessary. The open expression of grief through wailing or tears at someone's death as opposed to written words in a sympathy card is an example of this preference (Pere 2006):

> Māori may be more impressed by the unspoken signals conveyed through subtle gesture, eye movement, or bland expression, and in some situations regard words as superfluous, even demeaning. (Durie 1998, p. 71)

Just as this cultural difference can leave Māori school children having to contend with a sense of frustrated expression when they are reprimanded for expressing emotions such as anger instead of talking about how they feel (Durie 1998), so can tāngata whai ora experience the same frustration through the suppression of their feelings, due to self-stigma.

DISCLOSURE

Stuart (2005) refers to the internalised feelings of guilt, inferiority, shame and the desire for secrecy associated with self-stigma. These can result in 'serious disruptions in family relationships' and the reduction of 'normal social interactions' (Stuart 2005, p. 22), which is clearly evident in the responses of tāngata whai ora participants in the 2003 MHF research:

> [Fear of discrimination due to my experience of mental illness, has prevented me from] going to the movies. [I am] paranoid because people might know [I have] a mental illness.
>
> [My fear of discrimination due to my experience of mental illness, has prevented me from] joining a sports club. . . [or] any club. . . because [I am afraid] of [others'] finding out I had been in a mental hospital.
>
> [I] locked myself in my house without coming out, only to open the door for my friend so he could get me my food and pay all my bills for me [from] 1999-2000, because of fear of people and what they might say or do to me because of me having a mental illness.

Research shows that disclosure of the experience of mental illness may result in very high levels of discrimination (Watson and Corrigan 2001). Not surprisingly then, secrecy – forms of non-disclosure or selective disclosure – is the means most commonly used by people with experience of mental illness to cope with stigma (Chung and Wong 2004):

> I have been in positions where I have felt it unsafe for me to disclose that I have a mental illness. In [one] particular case with the Police, [I thought] that [if I disclosed my experience of mental illness] my credibility would be in question or I would not be taken seriously.

Research suggests that disclosure helps empower members of stigmatised groups (Health and Development Network 2004) through the gaining of self-satisfaction and permission to claim reasonable accommodations (White 2004). It is argued that disclosure also allows people with experience of mental illness to develop fuller social networks, which in turn reduces their social isolation caused by stigma (White 2004).

People with experience of mental illness who internalise stigma, however, report a reluctance to disclose (Dinos *et al.* 2004; Bromley and Cunningham 2004). In the 2004 study of stigma by Dinos *et al.*, all participants who reported subjective feelings of stigma also reported a fear of disclosure. About half of these participants reported being particularly afraid of reactions to their disclosure of the experience of mental illness.

Some people are so concerned about others finding out that they have experience of mental illness that they do not want to be seen associating with anyone who has the same experience. One such young female tāngata whai ora respondent to the 2008 MHF discrimination survey described her fear of this:

> [Fear of discrimination due to my experience of mental illness, has] probably [prevented me from] identifying with others in the community with mental illness. [I] wanted to keep it under wraps. . .

SOCIAL INTERACTION

Discrimination and self-stigma limits the lives of tāngata whai ora in so many ways. Tāngata whai ora participants in the 2007 MHF self-stigma research referred to the caution they exercised in social interaction due to their experience of mental illness:

> You're not as publicly out there as you normally would be.
>
> I'm careful not to say anything. I mainly say nothing.
>
> When we have visitors I retire into my bedroom sometimes [because I fear discrimination due to my experience of mental illness. . . I am] afraid to cook [in case the] cooking is not up to the visitors' standard. [This is an] ongoing [fear].
>
> [Fear of discrimination due to my experience of mental illness, results in me] standing in the background and not saying anything when someone is being put in front of a crowd and made to look small.

Some tāngata whai ora revealed a perceived inability to communicate and competently verbalise their thoughts, which resulted in them not being heard by, and/or pursuing treatment with, mental health services.

> I was afraid to speak up [about] my feelings [about the] medication that [I] was prescribed [from] 1974–2000, especially [in regard to] the side-effects, [because of fear of discrimination due to my experience of mental illness]. I just clammed up.

One tāngata whai ora participant in the 2008 MHF self-stigma research referred to self-stigma causing her to self-doubt her intuition when it came to dealing with mental health professionals. She gave the example of not being comfortable with her psychiatrist, and feeling as if she did not 'relate to him'. Yet, despite others voicing similar concerns about the same psychiatrist, she kept attributing her negative thoughts of him to her experience of mental illness, explaining: 'I thought I might be paranoid'. To her credit, she subsequently identified her reaction as self-stigma and altered it:

> I'm beginning to trust my instinct[s] again now. Now I only tell a psychiatrist what I want them to know.

A tāngata whai ora respondent to the 2003 MHF discrimination survey implied that her inability to make herself understood had resulted in her not being willing to make any attempt to do so again. She suggested she would rather just be left alone:

> I tell you, they misunderstand or get the wrong message. [So] I prefer to be left alone if that is what people think.

Self-stigma can be triggered and/or exacerbated when people experience so much discrimination that they come to accept it and believe it as founded. This is not always the case. Some people may experience a lot of discrimination, yet they do not internalise it. However, they might still have what could arguably be described as a 'healthy' fear of discrimination. This fear of discrimination deters some tāngata whai ora from entering into intimate relationships. For others it becomes self-stigmatising, such as the tāngata whai ora respondent to the 2003 MHF discrimination survey who believed that only those with experience of mental illness would want to be with her.

For tāngata whai ora, as members of an indigenous group, being socially disadvantaged because of stigma and discrimination has added consequences. Cultural expectations dictate certain roles and responsibilities which for many, cannot be fulfilled due to a fear of discrimination:

> I have shied away from hui and tangi because I was afraid of [being discriminated against, due to my experience of mental illness].

Throughout the reported experiences of discrimination there were examples relayed that were not only due to the experience of mental illness, but also racially based. For many tāngata whai ora, particularly Māori women, discrimination is multi-level. Tāngata whai ora participants in the 2008 MHF self-stigma research reiterated this finding; one woman explained that she felt stigma first because of her experience of mental illness, and then because of being Māori.

WHĀNAU INTERACTION

Tāngata whai ora participants in the 2008 MHF self-stigma research suggested that the experience of self-stigma was also commonly linked to the discriminatory practices of whānau:[3]

> I can block out what other people think of me, but the depth of what my whānau think of me hits in the heart.

Whānau is the prime support system for Māori. It provides care and nurturing, physically as well as culturally and emotionally (Pere 2006).

For tāngata whai ora whose experiences of whānau fall well short of the ideal, the resultant stigma and discrimination can be soul-destroying, as was evident in the experience relayed by one tāngata whai ora participant in the 2008 MHF self-stigma research. A mother of seven, this woman talked of the effects of being excluded from the whānau, with her own mother referring to people with experience of mental illness as hukihuki:

> I believed that [I was hukihuki] because my family was there, and I was over there... [That] stayed with me for a long time...

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[3] The term 'whānau' is used to refer to family or families, but encompasses a wide understanding of what and who constitutes a family. For Māori, whānau are commonly regarded as including both immediate and extended family members.

> I still don't talk to my family because I still believe that I don't have much to say. I'm hukihuki.

Intertwined within te taha whānau is the concept of whanaungatanga. Habermann (1997) suggests that this concept, similar to kinship, is manifest through collectively beneficial behavioural interaction among whānau members and households. Cherrington (1994) refers to this interaction as obligations and expectations. Just as the whānau has an intrinsic obligation towards supporting its members, so does the same expectation amongst the members towards the whānau exist. Responsibility and reciprocity may be regarded as the moral fibre to a well-functioning whānau, or a well whānau:

> Knowing one's links and obligations binds members into a cohesive unit and provides members with physical, spiritual and emotion[al] sustenance. (Cherrington 1994, p. 24)

When whanaungatanga fails due to discrimination, whānau members who are also tāngata whai ora are often stripped both of the support they should be afforded as members of the whānau and of their right to participate through fulfilling roles of responsibility and reciprocity. One tāngata whai ora participant in the 2008 MHF self-stigma research illustrated this point through an example they had witnessed within their whānau at a whānau hui:

> [My aunty] knew the stuff we needed to know about land, but when she spoke she was told 'yeah, we hear you' and then they moved on.

Another referred to the ostracism he felt from his wider whānau because of his experience of mental illness. Members of his hapū perceived his 'affliction' of mental illness as a 'curse', and were accordingly wary of him. Their discrimination of him was manifested in an exclusion from more senior roles:

> When I went to whānau hui at the marae I was always the one sent to clean the wharepaku – and no-one will help me.

This disregard of whānau members with experience of mental illness by other whānau members is common. However, when tāngata whai ora come to regard this discriminatory behaviour as acceptable because of their experience of mental illness, that is self-stigmatisation.

Combating self-stigma

Despite being aware of negative attitudes and prejudices towards them due to their experiences of mental illness, many consumers of mental health services do not 'buy into' the discrimination (Shih 2004). Both the 2003 MHF discrimination survey and the 2008 MHF self-stigma research reinforced this finding, with a number of tāngata whai ora reporting that they did not fear discrimination or experience self-stigma. This appears to be primarily due to the adoption of an attitude that did not allow them to be intimidated by discrimination levered against them due to their experience of mental illness:

> Many times this has happened [I have been prevented from doing something because of a fear of discrimination due to my experience of mental illness] but I try not to let it affect me. I cope [all] right with it.

> [I] have never been afraid of nothing or no-one, [and I] have no intention of starting now or in the near future.

> I am very open about my situation [as a person with experience of mental illness] and I am confident to respond to those that have an attitude that permeates stigma.

One tāngata whai ora participant in the 2008 MHF self-stigma research defined self-stigma as 'absolute doubt'. In relaying his own experience of it, he described this 'inner doubt all in his head' and his absolute belief that 'you've built yourself a house of cards and it will all come tumbling down'. Recognition of it as self-stigma was implied as instrumental to combating it:

> We screw ourselves with that sort of crap. . . That's what stunts your growth. That's what kills you – the inner self-doubt. . .

Research specifically with Māori has shown this identification and rejection of self-stigma to be a common approach to overcoming it (Peterson, Barnes and Duncan 2008). One possible reason for the rebuff of self-stigma by some tāngata whai ora is that it is not considered as being culturally significant:

> Stigma is a Pākehā concept. . . One goes on your waka wairua[4]. . .

Shih (2004, p. 182) suggests that 'in trying to understand how to ward off the negative consequences of stigma', it is important to 'also focus attention on the individuals who are successful in overcoming stigmas and identify factors that allow them to achieve this successful outcome'. When asked what helped them to deal with self-stigma and what advice they would give to others experiencing it, tāngata whai ora participants in the 2008 MHF self-stigma research offered a number of engagement-style coping strategies:

> [My advice to others dealing with self-stigma is] instead of looking at the negatives, look at the positives.

> [My advice to help others deal with self-stigma is to] talk to them about how they could self-maintain themselves, for example

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[4] 'Waka wairua' was the term/concept that this tāngata whai ora participant in the 2008 MHF self-stigma research used to describe her experience of mental illness.

> through art, helping out other people, a hobby, starting on a career path. . .
>
> [My advice to help others deal with self-stigma is] to be positive. I've gotta do something real physical with myself. So I try to encourage the guys at the Māori mental health team to do physical stuff. And work helps. Having a part-time job [helps]. Without these you start thinking negative rather than positive.
>
> What [has helped me deal with self-stigma is] doing a writing class. . .
>
> What I found healing [in dealing with self-stigma] was listening to waiata, and listening to my language. . . gave me a bit of grounding. . . Gaining that identity, I felt much stronger.

The support of others, both through formal peer support and informal social contact, was identified as particularly useful in combating self-stigma. For Māori, the need to belong is an important component of cultural identity; a secure cultural identity being hugely relevant to mental health recovery (Pere 2006). Some participants identified that support from other tāngata whai ora was of value to them in this regard:

> I hung around with people who were more positive than me [to help me deal with self-stigma].
>
> Feeling a sense of belonging within Māori mental health consumers like this group [helps me deal with self-stigma]. . . [It]

> gives me compassion for my peers, listening to their stories, and them listening to me.

Shih (2004, p. 177) refers to another component of self-stigma – a possible positive side-effect – by which 'stigmatised individuals develop skills to compensate for the stigma':

> These skills help them to achieve their goals and overcome the disadvantages associated with the stigma. (Shih 2004, p. 177)

Tāngata whai ora participants in the 2008 MHF self-stigma research again exemplified this in their responses:

> I believe everybody is good at something that is unique to you. . . and when you feel good at that thing that you do, when it shows, it will benefit.

The recovery process for tāngata whai ora is not a linear one. It can be extremely erratic and uneven (Pere 2006). For those tāngata whai ora who experience self-stigma, this road can be even rockier. The realisation that they 'do have self-worth' goes a long way towards both combating self-stigma and enhancing recovery:

> It's about mana - enhancing that person.

> I think one of the important things is to say you're a survivor. If you can face the trauma, it gives you a well-being to feel what you've got is unique to you. . .

The last comment on how to deal with this potentially injurious phenomenon, capable of disfiguring those already scarred, is left to the advice of one who knows:

Put your heads up high. We've all got
stronger hearts than what you realise.

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Louisa Ayres age 13

Finding a way to a resilient sense of self

Ruth Jackson

Loss of sense of self: the creeping toll of self-stigma

I was diagnosed with bipolar disorder when I was 21. At that time it felt as if my life was over before it had even begun.

Leading up to my hospitalisation I had the sensation that I was drowning in this psychological crisis. Like someone drowning, I had reached out to many people around me – family, friends and even some people I hadn't seen or spoken to for years – desperate for someone who could help me and save me from the current that was sucking me under.

Afterwards I was left with a huge and crushing sense of embarrassment at the out-of-control and demanding behaviour I'd displayed. I was also hit with all the stigmatising ideas I had previously carried around regarding mental illness. Now those stigmatising beliefs were turned inward on myself.

I expected to be kicked out of my flat. I expected my boyfriend at that time to break up with me. These things didn't happen, but I was in constant fear of the rejection I was sure I deserved.

Being locked up in a mental institution was the ultimate invalidation. As the eldest of four children, I had previously enjoyed a reputation as the responsible, trustworthy one in my family. Now I was sure that no one would ever take me seriously again. I would be the mad one and nothing I said would be given credence.

Leading up to my episode I had also spent a lot of money. I now had a considerable overdraft and had maxed out my credit card. What's more, I had no job, so was reliant on a benefit that was barely covering my living costs. Experiences I had, such as being forced to ask for a food parcel from the food bank and finding myself unable to afford the cost of my prescriptions at the pharmacy, entrenched my sense of failure and dejection and fed into the cycle of self-stigma.

I had reached my lowest point and my sense of self was shattered. How is it then that I was able to overcome those obstacles? How was I able to regain my sense of self?

Resilience

Mental illness is not a life sentence. Neither is the self-stigma that can accompany mental illness. I believe people are able to recover from mental illness and self-stigma through resilience.

So what is resilience? The Oxford dictionary defines resilience as 'being able to withstand or recover quickly from difficult conditions'.

Resilience is often talked about in relation to young people and a lot of research has been conducted in this area. Michael Ungar, Professor at the School of Social Work at Dalhousie University in Halifax, Nova Scotia, Canada and leader of an international team of resilience researchers that spans more than a dozen countries on six continents, maintains:

> First, resilience is the capacity of individuals to navigate their way to resources that sustain their well-being;
>
> Second, resilience is the capacity of individuals' physical and social ecologies to provide these resources; and

> Third, resilience is the capacity of individuals and their families and communities to negotiate culturally meaningful ways for resources to be shared.[1]

I think this definition is important because it emphasises the need for the right conditions to be present to support a person, as well as their intrinsic qualities and resources.

When I became unwell I had some intrinsic resilience factors, such as determination and previous experience at overcoming obstacles. I had some positive environmental factors, such as a highly responsive early intervention team, a supportive family and a positive living environment.

I was able to navigate my way to resources I needed, such as health care and unemployment benefit, then later employment and wider social interactions. The relationship between my intrinsic resilience factors and the availability of resources around me enabled me to overcome the crippling sense of self-stigma that I felt after my diagnosis.

Mania: everything made bigger

Mania is a huge magnifier. Rather than depression, when someone might withdraw into their own private torment, my every thought and feeling was written large – broadcast to everyone who might care to listen to me. I phoned friends and acquaintances at odd hours of the night to talk about my various neuroses. I dominated conversations, and confided my innermost thoughts and feelings to near strangers.

Consequently, I think the self-stigma that hits following a period of mania has its own special flavour. It's like suddenly discovering oneself inside out and shamefully trying to turn back in. Every pronouncement, every silly thing that I'd done and said resounded in my brain inducing severe attacks of cringing. A sense of self can become small and dark under these circumstances, just wanting a hole to hide in.

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[1] Ungar M and Liebenberg L, editors. *Resilience in Action: working with youth across cultures and contexts.* Toronto, ON: University of Toronto Press Incorporated; 2008. p. 22.

What makes up my sense of self?

I think we get our sense of self from a variety of areas in our lives, all of which serve to contribute to the whole. We each have different and often changing priorities in relation to these areas and sometimes, if one area isn't performing too well, we can compensate with another.

Visually, I imagine my sense of self like this:

As you can see, work is pretty big in my diagram. I place a lot of value on work.

Why is a sense of self so important?

My sense of self is the very foundation upon which I interact in the world. It is my self-identity. Self-esteem is a component of this, but not the whole.

Through mentally altered states I can find myself behaving in ways that contradict and undermine every aspect of my sense of self, my sense of who I am. People, including myself, often emerge from an episode of mental illness to find themselves feeling alienated from friends and family, unsure of their connection to the community, without meaningful work and lacking a social life. In this place, internalised stigmatising attitudes about mental illness can easily take root and this can strike at the very core of a sense of self.

I believe the way to combat self-stigma starts through rebuilding a sense of self that includes, but is not limited by, an experience of mental illness. When a sense of self is strengthened by healthy relationships with family, connection to community, meaningful work and vibrant social interaction, the barbs of self-stigma lose their sting.

Rebuilding my sense of self

The Discrimination Intervention model (as presented in Chapter 1) explains the process of stigma and discrimination, including 'circuit breakers' that can interrupt the cycle, in a manner that definitely resonates with my own experience.

The first element identified through the model is 'difference' (i.e. something is wrong with me). I think this was the hardest aspect for me. All of a sudden I had joined the ranks of the 'crazy'. I'd been so bad that I had to be locked up. Emerging from this experience I was assailed by inescapable thoughts of how 'other' and invalidated I was. I also felt terrible embarrassment. I had behaved outrageously and said all kinds of weird things to lots of different people. It felt as if everybody *knew*.

There are many different ways to overcome embarrassment. I think apologising to some people was helpful for me. Taking responsibility to put things right where I could also helped. At other times it was just a process of forgiving myself, and remembering that when I said or did those things I was not in my right mind.

The circuit breakers identified for addressing the element of difference are to celebrate difference and disclose. Well, disclosure was taken care of because one aspect of my experience was that I'd told just about anybody and everybody about what was happening. I was really lucky at the time to be living with some wonderful open-minded flatmates. They accepted me as I was, visited me in hospital and insisted that I return to the flat when it was time to come home. My immediate and extended family also came and visited me in hospital, as did my friends. In their own way they all affirmed that difference was ok. 'Everyone hits the wall in their own way', said my aunt. 'It's nothing to be ashamed of.'

I realised that I couldn't change the past, but, by taking practical steps, I could start influencing the present.

My most immediate source of distress after getting out of hospital was the terrible state of my finances. I had an overdraft of several thousand dollars and the benefit I was receiving just didn't seem to stretch to cover my expenses. My financial situation was a direct and practical consequence of my illness, but it fed my experience of self-stigma with feelings of panic, failure and shame.

I went for budgeting advice, but my advisor couldn't understand why my benefit was so low. Eventually I went to a benefit rights advocate who worked out that my benefit was being calculated incorrectly and I was due hundreds of dollars in back-pay. The advocate went to Work and Income with me and arranged for my benefit to be increased and the back-pay to be paid out. While he talked to Work and Income staff, I sat there with tears streaming down my face. I was relieved, but exhausted, from all the struggle that had got me to that point.

On my new benefit I could afford to pay the bank just enough to cover the interest on my overdraft. I could now also contribute equally to the flat's finances. I managed to get a disability allowance that covered the cost of a bus pass so I could get around town easily. These things gave me a new sense of stability and independence and I think they were the first step to recovering my sense of self.

Believing in recovery

A funny thing happens when I get unwell. I lose sight of all belief in recovery. When I am well I have no doubt about recovery. I believe it is absolutely true and self-evident that people can and do live well in the presence or absence of their mental illness.

However, when I'm depressed, following a manic episode, I just can't see my way out of it. I feel sluggish and stupid and I'm scared that I will always feel this way.

Another element of the Discrimination Intervention model is 'inevitability or unchangeability': the idea that things won't change. Negative thoughts about myself can have incredible power and sometimes my ability to combat them is weak. It is during this time that I really need family, friends and health professionals to hold the belief that I will recover and live the life that I want to. I require this to be affirmed in words and actions on a daily basis. I think self-stigma is part of the reason why I am not able to hold my own belief in recovery at these times. I see every aspect of my illness as a personal, unchangeable failure and I don't have the strength to break out of those feelings and beliefs myself, so I need people around me to carry the hope of recovery for me.

It is here that I think the input of clinicians is really vital. My first engagement with mental health services following my hospital stay was with the Early Intervention Team and through them I had access to a psychiatrist, nurse and psychologist. All these people impressed on me the knowledge that I would recover, that the way I was feeling would not be forever.

Working myself well

My next challenge was finding work. I really felt the stigma of being unemployed. I remember sitting on the bus as it drove through the central business district of Wellington, seeing all these people walking briskly, and thinking: 'All these people are contributing something and I am not'. Of course, I don't believe that now. Everyone is a valuable member of their community, whether they have paid employment or not. But back then I felt so cut off from the world and a lot of that was to do with not working. My status as an unemployed person stoked the feelings of hopelessness and uselessness that self-stigma burns on.

The Discrimination Intervention model describes this element of the stigma and discrimination process as 'comparison with others'. As for me, it often leads to feelings of 'less than'. Suggested circuit breakers to combat these 'less than' feelings include positive role models, peer support and leadership. It took me a long time to find these.

At first, my return to work seemed like pure chance and circumstance. One day I was buying a snack from a café and the man behind the counter said: 'Do you want a part-time job?' They were looking for a kitchen hand to do the morning shift. I couldn't believe my luck. It was pretty menial work, washing dishes and cleaning kitchen equipment and the starts were at 6 a.m., but I was delighted to be doing something.

I soon felt ready to take on more. I started talking with my case manager about finding work and he referred me to an occupational therapist. Together we drew up a plan for what kind of work I wanted and how I could go about finding it. The first step was to fix up my CV and drop it in to a health food shop.

Within a week I received a call from the owner of the shop to come in for an interview. There was an opening for a part-time sandwich maker and shop assistant. I got the job, just like that. It was only part-time, but it was enough for me to make a dent in my overdraft balance. More importantly, I had a sense of purpose. Having an interest in natural health care, this job gave me a chance to learn more. It helped me to regain my sense of identity, which had been buried for the months since I'd been in hospital.

For these first two jobs I was too nervous to disclose my experience of mental illness to my employers. This made it quite hard at my job at the health food shop because I was a slow worker, partly due to my natural pace and partly as a result of the tranquillisers and mood stabilisers I was on at the time. Sometimes my boss would snap at me to 'hurry up!' This could induce panic attacks, which would paralyse me even more. The secrecy of my illness and the feeling that I could not disclose it to anyone deepened my feelings of being 'less than' and not up to scratch. Sometimes I would call in sick as I'd wake up and feel that my nerves couldn't take being around my boss.

Finally, I saw a job in the paper with Wellink Trust, a residential and support service for people with mental health issues in the Wellington region. The position involved working as part of a consumer team and liaising with people using the service. I got the job. For the first time I was working alongside people with lived experiences of mental health issues. My boss was a consumer and understood what I'd been through. Now I had positive role models, peer support and could see consumer leadership in action. This was the start of my career in mental health and I've never looked back.

Sorting out the social side

With work taken care of, it was now time to focus on my social life. I was really lucky to be living with some fabulously supportive flatmates. They included me in their social gatherings and were incredibly patient as I worked on getting well. However, I felt the need to branch out and find my own group of friends. At the time I had my first episode, I had only just arrived in Wellington after two years away at university. Many of my friends had moved elsewhere or lost touch.

I feel the real turning point in terms of regaining my social confidence was when I joined the Green Party. It was a few months before the election and I went along to a meeting of young volunteers who were organising an event to promote the party. It was there that I met Anne-Marie and her husband Scott.

Anne-Marie and I were rostered to run a stall together in town. We started talking and something just clicked. We even worked out that our mothers knew each other.

As well as weekly meetings to organise the Green Party event, Anne-Marie invited me to parties with her extended group of friends. I really started to feel in the swing of things. The day of the event came. It was a beautiful sunny October day. We had a canopy with a stall, musical performances, free organic food and people dressed as native birds handing out pamphlets. It was a huge success and a big boost to my confidence.

My involvement in the Green Party eventually tailed off, but I kept in touch with Anne-Marie and Scott. To this day they remain treasured friends of mine.

Family focus

Rebuilding my family relationships was the next step in rebuilding my sense of self. As I've mentioned, I was deeply afraid of losing my respected place in the family.

My mother lived two hours north from me and I was really tentative about going to visit her. Before my episode, we had enjoyed a very close relationship. During my unwellness, however, a rift had developed. Mum wanted to be the one to take care of me and help me get better. This had scared me because I didn't feel listened to and I was terrified of losing control. Also, I had been obsessed with some traumatic events in my mum's life and their subsequent effect on me. Mum disagreed with my interpretation of these events and was acutely embarrassed that I kept bringing them up.

My first visit to my mum wasn't until about three months after my episode. Together we played it very safe, keeping to neutral topics. Both of us had been on a journey since my diagnosis and hospitalisation. Mum had read every book on bipolar that she could get her hands on. I had been working hard at re-establishing a 'normal' life.

As time went by, with a few more visits and phone calls, we began to repair our relationship. There were still some things we couldn't talk about, but we decided to focus on common ground. I realised that my family didn't write me off as I had expected them to.

If anything, my family seemed to respect me more for what I had been through. The Discrimination Intervention model refers to 'devaluation': the feeling of being less entitled than others. I was afraid that because of my mental illness I would be less entitled to the respect of my family. The opposite was true. My family recognise the contribution that mental illness has made to my life.

Fake it until you make it

Part of recovering my sense of self has involved pretending that I can do things, despite massive self-doubt.

I found this especially relevant at work. Just going through the motions, despite the self-doubts screaming in my head, seemed to help me get there eventually. Taking on challenges one step at a time and acting as if I could do them, resulted in me surprising myself when I did actually achieve my goals.

Self-stigma tears away at confidence in every aspect of a person's life. By faking confidence and self-belief, it is possible to rebuild hope and faith in oneself.

I had many stigmatising attitudes towards myself, a key element identified as part of the Discrimination Intervention model. One of my deepest fears was that I just couldn't cut it at work anymore; that because of my mental illness I was now unemployable. Working in mental health, in an area that challenges these attitudes and behaviours, allowed me to gradually regain my confidence and 'fake it till I made it'.

Routine

Another thing that helped me combat self-stigma was following a routine. By knowing what I needed to do next it was easier to go through the paces, even when assailed by self-doubt and self-loathing at every turn. Putting one foot in front of the other and doing what needed to be done eventually quietened those negative thoughts.

At first I required quite a lot of help to stick to a routine. I arranged for my support worker to visit me at 8.30 a.m each morning. This meant that I needed to be up, showered and dressed before then. By the time my support worker left I was ready to go to work.

For some time I didn't feel as if I was achieving much at work, but, by being there at regular times and going through the motions, my abilities and responsibilities gradually increased.

Swings and roundabouts: coping with the bad days

Recovery and self-stigma are not static experiences. Some days I still tend to remember and obsess over embarrassing things that I did while I was unwell; other days I feel completely free of that time. What I find helps me if I am having a hard day is to name the experience as self-stigma, to see it as something destructive and outside of myself and then to focus on the good things that I have in my life. I find that keeping a gratitude journal – writing down five good things in my life each day – has helped me to see myself in a more positive light.

Self-stigma the second time around

It took me about a year after my first episode to start feeling like myself again. I then returned to full-time study. After that I went to Japan and taught English for two years. There I met my partner and we returned to New Zealand and got married. With each new adventure my confidence in myself and my recovery grew. Self-stigma moved further into the background and became less and less of a hindrance to my everyday life.

My partner and I decided to try to start a family. As the medication I was on was known to cause birth defects, my doctor recommended that I stop taking it. Within three months of ceasing my medication I was admitted to hospital with a full-blown manic episode. I couldn't believe that this nightmare was repeating itself.

Several weeks after I left hospital, as my mania subsided and gave way to depression, I was hit full force with intense feelings of self-stigma. Again, I had done all manner of stupid and embarrassing things and memories of each foolish word or action haunted me.

It would make sense that, having been through all of this before, I would have some insight and find it easier. Unfortunately this was not the case. If anything, I felt worse because I had fallen back in this hole even though I should have known better.

Again, I was lucky. My family rallied around and supported my partner, who had never seen me like this before. My mother assured my partner that

I would recover and that we would get back the life we had had.

My partner herself was incredibly patient and giving, committed to taking this journey with me.

My friends visited me in hospital and later at home to give my partner some time out.

My employer was extremely supportive, giving me more than the sick leave due to me and then allowing me to return to work very gradually, slowly building up my hours and responsibilities until, after six months, I was fully back on board.

My experience reflects how my physical and social ecologies provided the resources I needed, and although it was often difficult, I was able to navigate those resources in a way that allowed me to regain my sense of self. There were enough 'circuit breakers' in my life to ensure that, while self-stigma had its hold on me for a while, it didn't choke me completely.

I think self-stigma has an interesting relationship with recovery. My self-stigmatising thoughts definitely eased as the depression improved. However, I think it is possible to be completely 'recovered', in terms of living life as normal, and to still experience self-stigma. All it takes is driving past the hospital or seeing one of the people on the bus who nursed me when I was in an acute state, and I can be assailed with negative memories that feed self-stigmatising thoughts. When I am in a good space it is just that much easier to combat them when they do arise.

Finding a way from the pit of self-stigma to a resilient sense of self was not an easy journey, but nevertheless it was one I succeeded in with hard work and a lot of support. My partner and I are now expecting our first child in July 2009.

Caitlin Dougherty-Kelly age 14

Self-stigma and addiction

Nikki Smith

I understand self-stigma as a kind of toxic osmosis where a person's self-identification process is negatively impacted by prejudicial social attitudes. These attitudes are internally nurtured and if left unchecked they become increasingly destructive. While I have not explicitly stated how self-stigma impedes recovery, I am taking it as a given that people have a general understanding of the fact that when a person feels crap about themselves, they will not achieve their full potential . . .

Personal bit

Upon being invited to contribute to a book on self-stigma, my initial and overwhelming sense was that I have never bought into any of the discriminatory stereotypical imaginings about 'addicts', hence there would be little of value that I could contribute. Actually, there's a certain truth to the thought; the clichéd conceptions of a criminal deviant or antisocial waste of space has happily been a million miles from my self-identification process.

Nevertheless, perhaps one of the true luxuries of writing is that it affords the opportunity for introspection. As I remained typically non-committal about whether or not I would write an AOD (Alcohol and Other Drug) perspective for this book, I began to reflect on my own experience:

In terms of the loss of potential that I equate with self-stigma, there were, in truth, periods where I was hitting the ball right out of the park. I came to understand myself, at least in part, as one of the terminally unemployed – one with a simultaneous and sideline penchant for opiates (well, to be fair, the odd joint never went astray either!). For a bright girl, I watched a spectacular amount of comprehensively crap television. It was the kind of stuff where taking the edge off was an absolute prerequisite. And so it came to pass that I did . . .

But over and above that, what springs to mind is the pall of fatigue that descended on me throughout the late 1990s. I would get up in the morning, head down to the pharmacy for my daily tonic, cruise home again, and maintain an hour's active functionality before an overwhelmingly leaden body was rendered bedridden. That was my status quo – and I never questioned it.

For the four or so years that all this was going on, it never occurred to me to do anything about it – no GP (General Practitioner) consult, no herbalist or naturopathic intervention, no yoga guru input, zero discussion with my peers to see if any of them had experienced something similar – not even a single feeble attempt to induce the placebo effect with unspecified over-the-counter medication, for God's sake!

As it turned out, the issue I was having related to the fact that I had glandular fever. From the lofty perspective of now, I look back and wonder why the hell I literally lay down and succumbed. How could it be that during all those frequent interactions with my GP (a precondition of methadone treatment) the word 'tired' managed not once to flow unfettered from my mouth!?

Putting aside the obvious questions it raises about the relationship I had with my doctor, I understand that whole episode as being driven by self-stigma. I'm not suggesting that I thought I was worthless, or that low self-opinion precluded me from seeking help. Sadly I hadn't even realised there was an issue. The combination of terminal unemployment and years' worth of hammering my body made constant low energy levels seem a perfectly logical outcome. I was not consciously aware of ever coming to that as a decision – it just was. Obviously this story bespeaks the sub-basement expectations I had of myself at the time, but I think it also underscores the insidious and sometimes elusive nature of the self-stigmatising process.

Risk management

As a result of that introspection, the hamster on the big wheel upstairs concentrated his efforts and geared up a notch . . . I began noting what my peers were saying about self-stigma. Upon prompting, one of my consumer colleagues recounted what seemed a gem of an opportunity for our AOD peers: a collaboration of AOD services had just taken the plunge and agreed to fund a consumer group that would provide both general feedback and review policy. Hallelujah!

The first meeting attracted a number of keen punters, but the noteworthy thing in terms of this dialogue is that the focus of conversation quickly turned to risk: what are we going to do when people come to the group 'off their face' and how are we going to stay safe when people get aggressive? The underlying subtext of this is the notion that AOD consumers are a bunch of volatile critters requiring careful management.

As a realist from way back, I am aware that risk is a factor in organising any significant gathering of people. Nevertheless, that it should be the first thing on the agenda is somewhat discouraging. That it highlights an acceptance of self as inherently unstable or hostile is even more so.

Ultimately, this focus on risk management reflects the broader social understanding of 'addict'. A myriad images of addicts as dodgy, deviant and degenerate (and therefore as 'others' to be held at arm's length) remain for the most part unchallenged. I intend to come back to this thought later.

What is readily apparent to me in this story is the adoption of an overtly clinical understanding of self: individuals become clients. Clients need case management. Successful case management is to a greater or lesser extent dependent upon risk assessment. Implicit in this process is the disparity of power: those who manage and those who get managed, the safe and the potentially hazardous. That this dialogue is perpetuated into a conversation about oneself and one's peers highlights the twilight zone that is self-stigma.

So the million dollar question is: how does this happen?

If we take it as given that recovery does not happen in a vacuum, then it would be fair to say that a common thread of recovery for most of my AOD peers is treatment, be that abstinence-based rehabilitation or a structured maintenance regime. At its rose-coloured and essential best, treatment is a forum for personal revelation: any insight a person can gain about what will transport life into the realm of recovery is a definite bonus, so, too, is an appreciation of what triggers a speed-fuelled plummet that apparently only a handful of valium can cure . . .

It therefore follows that any link to that knowledge is quite possibly going to be contextualised as a helpful thing. Ergo treatment – all things clinical – including the associated language of management and risk might well be understood as a minimal or acceptable trade-off. You can counsel me about the importance of self-surveillance in sounding the alarm of relapse . . . provided you continue to house/teach/or prescribe for me, then I'll accept that there's a certain validity to your words.

Alternatively, it might be seen as an unadulterated revelation; the welcome reprieve of calling a spade a spade, and publicly articulating the private and previously unmentionable bits of self. If clinicians articulate risk-taking and volatility as inherent to the 'disease' of addiction, and if you, off your scone, have been known to swing off a small piece of string over a two-hundred foot gorge, then what's there to argue about? There is a certain grass-roots legitimacy to the suggestion that to overlook volatility is the potential for jeopardising well-being.

In effect, I am suggesting that treatment can be a precursor to a person's experience of self-stigma. The very act of diagnosis (DSM IV axis 1)[1] can catalyse a person's self-identification towards sickness and difference. That realisation is likely to crystallise and entrench itself in an environment where security cameras surveille, where receptionists hunker behind reinforced glass, and where panic buttons indiscreetly adorn interview rooms (welcome to your AOD treatment experience)! The subtext clearly articulates that 'other' people are fearful of your presence: you are someone to be held at arm's length.

Anonymous maintenance

Nevertheless, for some people, the process of attaining the confidence to

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[1] American Psychiatric Association. *Diagnostic and statistical manual of mental disorders (text revision)*. Washington DC: American Psychiatric Association; 2000.

achieve a personal recovery necessarily includes the overlay of a clinical knowledge framework. Step into any Alcoholics Anonymous (AA) or Narcotics Anonymous (NA) meeting around the world and you will, without a doubt, hear 'hi my name is... and I'm an alcoholic/addict'. For AA/NA regulars, constant repetition of that phraseology affirms personal responsibility and self-honesty, and ultimately promotes well-being.

For others, the process of identifying and labelling self as 'addict' is almost by definition incompatible with their ability to view themselves as a whole and functional person. Doing it repeatedly (90 meetings in 90 days) makes it ever more irreconcilable, disempowering and self-stigmatising. The internal understanding goes from 'I am a person with a monkey on my back' to 'I am a monkey who used to be a person'.

This discussion/debate is one familiar to anyone who has spent more than five minutes in the AOD consumer movement. It speaks to the different philosophical underpinnings prevalent within the broader AOD sector: notably harm minimisation and the abstinence model.

People whose pathway to recovery has relied on harm minimisation strategies often experience a poor fit within AA/NA (which is abstinence-based). They speak about feeling unwelcome and stigmatised. While inclusion at AA/NA is based on a *willingness* to stop drinking/drugging, it is also suggested that those who 'use' prior to attending a meeting should not share, and must merely listen. This can be entirely problematic for someone whose 'normality' is maintained through regular administration of a substance, for example, methadone maintenance treatment.

At this point it ought to be apparent that I have honed down the discussion to its barest essentials. That is because I want to highlight that there are different nuances in the perception of AOD recovery. AA/NA members and the abstinence model clearly articulate the need to give up alcohol/drugs in order to be 'normal' or 'recovered'. People on methadone and the harm minimisation model emphasise behavioural aspects of recovery and place less emphasis on the substance itself. One perspective suggests that methadone is just another drug; the other, that it is legitimate medication.

It is not my intention to take sides or get drawn into the debate itself. My perspective is particularly non-partisan on this one. I'm comfortable with the fact that methadone has the potential to be both or either thing. Where it lies, depends on the person: their headspace, their home life, and perhaps a whole heap of stuff that they don't have the words to articulate . . . and in point of fact, something similar applies to alcohol.

What does seem worthy of consideration is the suggestion that people from various AOD backgrounds internalise stigma differently. Again I will oversimplify and hone things down to an alcohol versus illegal drugs type of discussion, which is not to discount the myriad of folk with a foot in both camps, but rather to acknowledge difference.

Current social understandings of alcohol portray the fact that it's legal, sociable and complements achievement and celebration; it warrants a damned fine shaggy dog story; like the time you were at the Wunderbar and that particularly voluptuous Tui's brewer bought you a beer and told you that she's always had a thing for small bespectacled men much like yourself . . . so in the popular imagination, alcohol is acceptable and affirming and maybe even a little bit sexy.

Nevertheless, negative stereotypes about alcohol and people who indulge in alcohol are part of our social consciousness. There is a commonly held acceptance that young people plus alcohol necessarily equate to a disaster in the making. There is also burgeoning acknowledgement about the existence of problematic alcohol use (the recent Alcohol Advisory Council of New Zealand advertisement campaign for example[2]). But in a culture where alcohol is so widely accepted, alcoholism almost implies some type of inherent character flaw. You can't handle it. You must be a loser . . .

But when compared to the widely accepted understandings of drug use and drug users, it becomes immediately apparent that there are absolutely no moderating images surrounding that camp at all: drug addicts are criminals and gang members. As such, they do not warrant any consideration over and above whether or not you've just rented your house out to them, and if you have, how you can get them out of there before they explode the P lab they've got in the back bedroom!

It is precisely the illegality of drugs that lynchpins our stigmatising

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[2] A series of print and television advertisements designed to help change New Zealand's risky drinking culture was launched in March 2005. The advertisements are the most visible component of the Alcohol Advisory Council's (ALAC) programme of work that aims to help New Zealanders reduce the amount of alcohol they drink on any one occasion. The advertisements aim to get New Zealanders to see the connection between getting drunk and the harms that result.

attitudes. If you can't purchase marijuana or heroin legitimately then drug addiction necessarily encompasses criminal activity. Hence there is a collective wariness of and repulsion for the drug addicted. They are literally out of control – they're on God-only-knows-what drug. They are perceived as prison bait who will steal whatever isn't bolted down. They are contaminated – be it that they have Hepatitis C or HIV. They will distort your teenaged daughter's thinking until she too launches herself speed racer-like through the doorway of drug addiction.

Given this extra layer of negative and publicly unchallenged imagery, it seems entirely plausible that people who are drug addicted might be particularly sensitised to stigma, and that being the case, that there are ramifications in terms of self-stigma. If being a drug addict (as opposed to an alcoholic) is so comprehensively and universally unacceptable, then it's perhaps not surprising that it could translate into these people having difficulty in embracing a philosophy (AA/NA) that requires self-identification with a shameful and dirty word (addict).

Disease versus bad behaviour

At this point there is another really significant part of the self-stigma equation that I want to address. The generally accepted understanding of mental illness is that it is caused by an imbalance in a person's brain chemistry. It is, therefore, a biological feature of the human condition: people are mentally unwell through no fault of their own. For that reason, we can at least see our way clear to feeling compassion. Having said that, I fully acknowledge that this does not preclude stigmatising attitudes and/or different cultural interpretations of mental illness; this book would be redundant were that the case.

There is also a fairly widespread appreciation of a parallel process occurring in the brain chemistry of the drug/alcohol addicted (the disease model of addiction). Nevertheless, there is a persistent and widely held belief, which intimates that, because you go to the pub and down a few, then graduate to getting plastered, consequently developing a regular pattern that progresses to losing control and becoming dependent, you have chosen ultimately to screw things up. Addiction is not illness, it is choice. All you need to do is stop. Stop drinking and stop whinging.

Addiction, then, is at least partially understood as poor behaviour stemming from bad choice, behaviour that needs to and can be controlled. In some sense then, people with addiction issues are viewed as unworthy. Support and treatment, particularly in today's economic/health climate is reserved for the truly sick, not for interlopers who palm themselves off as having a problem. The underlying subtext is that addicts should go away, sort themselves out and let the health system focus on people with legitimate illness. If you believe that addiction occurs through choice, then ongoing drug taking and relapse must appear as a deep-seated resistance to change, not to mention some kind of resource-draining narcissism. Clearly this is a particularly unhelpful viewpoint for a health professional to hold, and where it is held, one that translates as being openly discriminatory in its application.

So it follows that a common theme, which my AOD peers talk and feel huge frustration about, is what I would describe as the attitudinal negligence of some health care providers. Many of my peers feel that they receive substandard care because they come from a socially stigmatised group. I am regularly regaled with stories where the narrative begins with, 'If I was anyone else this wouldn't have happened . . . and if I was anyone else I wouldn't have put up with it either for that matter'. Here is an example:

Imagine having injured yourself to the extent that the administration of strong/addictive medication is warranted, but at the same time being an identified 'addict' wherein the motivation for wanting strong/addictive medication is immediately suspect. 'I see you're specifically requesting morphine, Mr Pleb. Why is that exactly? Now I see on your file that you're a client of the Community Alcohol and Drug Service. I think the best thing is for us to give them a quick call so that they can advise us how to proceed . . .' And, hey presto, the Emergency Department doctor who daily addresses the complex needs of people who have hurt themselves suddenly requires the input of an addiction specialist to manage a basic pain issue.

What happens to our person in pain then? They likely understand that their unusually high tolerance to medication complicates the situation somewhat, hence the doctor's desire for consultation; they are also aware of being treated differently, of things taking longer than usual and of an implicit questioning of their integrity: the underlying and breathtaking suggestion that they purposefully fell down a flight of stairs, dislocated their ankle, all as part of some clever ploy to score some 'free' drugs. In the immediate term they feel singled out, shameful and angry. That fairly quickly cements as a healthy distrust for the medical system.

If our person in pain is unfortunate enough to have sustained a permanent injury, much like anyone else with enduring pain, the longer-term sees them defining themselves (at least in part) in terms of that pain; the toxic add-on to this identification process is that there is a simultaneous and vehement rejection of any personal addictive tendency. So, in the pragmatic quest to have their ongoing physical needs addressed (I'm more likely to get help if I'm 'normal'), there is a mental disconnect and a denial of an inherent part of self. 'I am a person in pain who needs/deserves drugs, so sod off with your talk about addiction . . .'

The harshest and most intensely negative commentary about self/other addicts, and the most palpable anger I have witnessed in working with my peers, has come from people with concurrent pain and addiction. 'Addicts' are contextualised as the lowest form of life, as selfish losers who bugger it up for everyone else. The difficulty in maintaining a regular supply of medication is perceived as resulting from the medical profession's collective vigilance for 'drug-seeking' behaviour, and a belief that it has been mistakenly applied to them (as opposed to the fact that they are personally struggling with addiction issues and that it has been recognised).

The condemnation of others (addicts and medics alike) and concurrent denial of self is a real feat of mental gymnastics. How a person reconciles that degree of anger and rejection is not clear; that it speaks of serious self-stigma is absolutely crystal. Implicit is the notion that addiction issues somehow invalidate a person's experience of physical pain, and therefore their right to respectful and responsive treatment. It is to bear witness to a person who has internalised a morality whose very nature rejects their own existence. It is volatility in the making.

While anger can be a useful tool in rebuffing stigmatising stereotypes – stigma as impetus for change – raw and righteous indignation suggests full-on disempowerment. When everything that you perceive as wrong in your life is understood as being the fault of 'the system', then it speaks to feeling crap about yourself and powerless in the world. Apparently the internalisation of someone else's toxic shame grinds the bearer down to an impotent nub.

So what to do about it?

Starting small and working to the big finale

Trite though it sounds, before anyone can resist self-stigma they need to have an understanding of what it is and how it happens. Absolutely every person that I have supported has had a solid understanding of social stigma and discrimination; but the idea that it necessarily translates as having insight enough to realise how toxic stereotypes might have tarnished their conception of self, is a rather glaring assumption. Obviously, then, there is a place for education within all of this and I believe that peer services are best placed to deliver it. I'll come back to this thought shortly.

On an individual level, people can challenge and reframe their internal thinking. As part of that process many people find positive affirmations helpful and many treatment programmes encourage the usefulness of positive self-talk as a tool. Attempting to rise above negative self-imagery requires some initial first step, and consciously changing the internal dialogue with managed sound bites might be a workable proposition. If it works, then more power to you, affirm away. On the other hand, some people find the experience of repeating mantras such as 'I am a good person who is worthy of love' an overly simplistic and somewhat humiliating one. That being the case, it might be worth considering other options. We need not buy into the culture of one size fits all.

Challenging thinking really needs to be an external process as well. Paralleling the process of self-stigma.

I believe that addiction, too, is, in large part, socially constructed. That is not to deny a biological component, just to acknowledge a broader range of influence. So economic status, familial background, access (or not) to education and a whole raft of other factors influence and define our place in the world and therefore the choices we make. In terms of combating stigma and of establishing a recovered perspective, some appreciation of the bigger picture is eminently valuable. Particularly so, I think, where you're talking about individuals who struggle with the implications of the disease model of addiction.

In my own case, it was the desire to come to grips with the inherent inequalities of capitalism and its requisite focus on individual as opposed to collective responsibility that gave me a power base from which to reject and challenge stigma. I became interested in the process whereby individuals are medicated; how behaviour deemed to be unacceptable is pathologised, and how the fallout from that frequently sees the individual reduced to excessive self-surveillance in the hopes of fitting in. 'The rest of the world is okay, Jack; it's me with the problem.' This type of thinking is an embodied microcosm of self-stigma and living in it strips away a person's resilience in the face of social stigma. It needs to be recognised and challenged.

That is not to deny the importance of individuals taking personal responsibility for their actions; in terms of affecting a personal recovery, honesty and responsibility are key. What I am saying is that it is important to strike a balance between the two, and in my experience we often weigh in on the side of individual responsibility and completely overlook the larger framework. I think that a politicising process wherein mainstream attitudes are contextualised and challenged can be cathartic.

I'm not suggesting that, in order to attain the lofty heights of recovery, people must stand in protest lines waving dodgily-drawn placards, or read the communist manifesto; just that the world does not work on a strictly level playing field and an awareness of that fact can render powerful insight. In effect, it allows people the understanding that while some of their personal choices may have been misguided, they didn't happen in a vacuum.

There is definitely something to be said for moving beyond thinking about self (if there's any truth to the myriad of AOD medical reports I have read, then an apparently egocentric worldview would seem a common theme of people's experience of addiction). So, connecting with family, with cultural heritage, with whatever group of like-minded individuals makes sense is fundamental, it is possible that drinking/drugging buddies might be an exception here!

In connecting with people with a shared experience and a vested interest in one's well-being, there is a simultaneous focus on something larger and shared, and there is also a natural buffer through which stigmatising attitudes will have trouble passing. When people identify you as someone other than the 'hero' who can still stand after 10 consecutive spots; when they see good in you and feel good about you (jeez, they might even go so far as to respect you), then ultimately you start to feel the same way about yourself. If self-stigma is identifying and embracing self as 'less than', then let other people support you to move the bar.

Suggestions for treatment providers

Individuals working within the AOD sector (and elsewhere for that matter) can contribute to positive change and reduce stigma as well. Obviously, an awareness and a preparedness to make a stand against what I previously described as attitudinal negligence is useful. Stigmatising attitudes about 'addicts' are socially entrenched, so, as much as we'd like to think that AOD workers are above it, that is absolutely an unrealistic expectation. Where those attitudes are permitted to coalesce into a culture of overt power disparity, then, Houston, we have a problem. A pervasive 'us and them' atmosphere is incongruent within a therapeutic, or at least 'first do no harm', environment, and given the radar sensitivity to discrimination of many of my peers, it is detriment-on-a-stick.

I suggest that all services put energy into meaningful anti-discrimination policies and procedures. In the first instance, it encourages awareness, and in the second it gives a base from which to challenge stigmatising practice. There are plenty of AOD workers with a passion for their 'clients', and a desire to nurture their well-being in a best practice kind of environment. And those who don't feel that way could doubtless use a damned fine challenge!

In terms of working with people with addiction issues (yes, that would be 'clients') it's really crucial not to make assumptions about people's experience. As previously mentioned, people's perception of stigma and the way they process it runs the gamut: for some it's an ominous and omnipresent mantle, so you're talking about people who are likely to be depressed, low in the esteem department and perhaps struggling in general terms. Others wear it as a badge of honour; that would be my more challenging and defiant peers. Yet others maintain that the whole concept is just so much flatulence in a vigorous breeze. And everything else in between pretty much goes without saying.

Before you're ever really going to find out where on that spectrum a person sits, and certainly before making any credible challenge to their thinking, you need to develop an honest working relationship with them as much as possible. Some of the shoddiest and most damaging clinician/client interactions I've been privy to have involved the clinician throwing suggestions bull-at-a-gate-like until their client is completely overwhelmed and withdrawn. Ultimately the client staggers out of the room feeling patronised and resistant; the 'beneficial relationship' train has long since departed and accelerated away like a methamphetamine-fuelled bullet.

Peer support

People with AOD issues often cite a desire to have people with first-hand experience of addiction work alongside them. They feel that a peer will acknowledge them on a deeper, more insightful level, and that they will feel less on the back foot. And while each person's experience of addiction is unique, there are commonalities that promote a base of understanding and acceptance. Peer relationships are inherently less hampered by the power disparity of client/clinician relationships.

For this reason I believe that peer services offer a really robust mechanism for promoting people's understanding of the concept and process of self-stigma, the opportunity to personally identify with that process if they want to (self-stigma is merely another verbose academic construct for some of our guys) and the forum to gain resolve, become resilient, and generally get on with it.

At a recent and smouldering consumer group, a discussion started about how the group wanted to participate in some process of meaningful change, in order to improve the experience of addiction and AOD treatment (yeah, okay, that's not exactly how they said it, but it's a fair representation nevertheless). In about five short minutes these guys had concluded that they needed to identify a single quality improvement initiative (work in progress), do some kind of cost analysis, attract funding and then drive the thing into reality. 'We need to take charge of it and do it for ourselves rather than wait around for an invitation to the AOD sector's big ideas table.' In terms of this dialogue about combating self-stigma and promoting a recovered perspective, these guys might just be legends in the making.

Where one is talking about a socially stigmatised group of people who, for experiential reasons, do not particularly trust 'the system', then it is precisely this type of opportunity to connect with peers, to challenge each other and to do something proactive that can be liberating. I'm not saying that 60 minutes of peer support and discussion necessarily instils sterling citizenship. But realistically speaking, if people are to be challenged to move forward in their thinking, then the challenge has to make it under the radar in the first instance. That's just fundamental. Nothing too flash is required, just someone credible to deliver the information.

A final couple of thoughts on the issue: if what constitutes stigma depends on the experience of a person and their understanding of the world, then so, too, people need the opportunity to define what constitutes a personal recovery. The learning curve of self-acceptance and the desire to participate in life can mean incredibly different things for different people. I work alongside people who deserve recognition for consistently getting out of bed of a morning, surviving a trip through the supermarket intact and steering clear of excessive drug use most days. All things being relative, that is progress; that is recovery. Naming it thus does not preclude the possibility that, further down the track, more intense participation and a stronger self-assurance might be the new reality.

If we want people to get through and rise above their experience of addiction, then we need to collectively permit that possibility. Waiting around until the substance is removed before acknowledging an individual's abilities and choices – their personal understanding of recovery – is counterproductive. Exclusion creates resentment and feels suspiciously like stigma. I absolutely recognise that we are powerless to stop society as a whole from stigmatising 'addicts'; but from our shared peer base we can consciously and cooperatively choose not to do it to each other. In so doing, we will hopefully learn to respect ourselves.

Tristan Kang age 13

Tight in my mind

Ivan Yeo[1]

I still find it hard to think about myself as someone who experiences mental illness. After all, it is a Western model, which is somewhat unfamiliar to my upbringing. That I hold down a job, live a great life and have someone who loves me, does not fit into what I recognise as being someone who is described as 'crazy' in my culture. Each morning, however, when I am taking my 40 mg of Loxamine I am reminded of how medication has changed my life. I could never have been able to handle daily stress or feel so much better without years of counselling and medication. Part of me is still unable to accept it. The belief that I had, resulting from my culture perceiving mental illness to

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[1] I dedicate this chapter to my dearest friend, Mahinarangi Tocker, a beautiful friend who had the most beautiful heart and who has shown me how to love selflessly. You are missed.

be a personal weakness, still somehow holds tight in my mind.

This chapter examines how negative messages can be internalised and become self-stigma. For me it was somewhat like looking at myself through a distorted mirror. I had no idea that the mirror had been distorted and believed that this is how I really looked.

Childhood

My name is Ivan Yeo, a Malaysian-Chinese, born in Singapore. I came to New Zealand in 2001 when I was 29 years old. For the first 28 years I lived in a collective society. My mother tongue is Mandarin, and I was brought up in a family with a strong belief in Confucianism. Both my parents had been strongly influenced by the Buddhist and Taoist religions.

I grew up in a family of six, the only son, with three beautiful older sisters. My father was a compulsive gambler and someone who associated with gangs. This was disapproved of by my family. I was often told, by my mother and relatives, not to grow up like my father. My mother was a very loving and caring person who tried her best to be the family provider. I often felt ashamed of being my father's son. On the other hand, I was constantly hoping to gain approval from him. My father's behaviour was contradictory to what it means to be a good Buddhist. This led to us hiding the problem and being unwilling to seek help from others. As you can imagine, living in this environment could only have a negative impact on a child.

My illness was also a matter to be ashamed of. I still remember the cleansing ritual that took place in my house. This was held in response to some bizarre behaviour that I had displayed. I experienced psychosis when I was very young; although now I can't remember any of it. My parents thought I was being possessed by evil spirits. I also had episodes of panic attacks from time to time, which I can remember. I didn't know what they were and neither did my parents. I learned about it much later when I studied psychology. Taosim, Buddhism and Confucianism regard mental well-being as having a good interpersonal relationship with family. A person who experiences mental illness is perceived as incapable of fulfilling their role and obligations in society, and is regarded as a personal failure.

School

I experienced bullying at school as a child in Singapore. I was teased by mates because I was very 'pale' and 'soft'. They called me 'Pondan' and 'Aqua', which are derogatory Malay terms for transsexuals. Sometime they would call me 'a little white face', a Chinese expression referring to a 'sissy boy'. When I told my father about this, he didn't care and told me to stand up for myself. Sometimes he would say to me, 'why can't you look more like a man, and behave like a man?' I felt hurt and ashamed of myself for not being man enough, and began to think that I deserved to be teased.

From a collective point of view, our sense of well-being is determined by external validation. A successful interpersonal relationship means one needs to be seen as being 'appropriate' and 'as normal as possible' at all times; both concepts are defined by the majority.

Sexual abuse

I was sexually abused by a relative when I was about nine. I did not know at the time that the behaviour he taught me was sexual. However, I did ask myself why someone could be so 'close' to me, yet not talk to me when others were around. I was craving for his attention. I told myself that he must be ashamed of being associated with me in public. After all, no one really wanted to be my friend because I didn't behave like a man.

Being gay

I read an article about homosexuality when I was about 12. What the article described enabled me to realise I was 'gay'. I rationalised that this must be the reason why I wasn't man enough. I was deeply ashamed of myself and felt that I would never gain the approval and love from my father because of this. I began to build a wall of protection between myself and other people. I did not believe that I mattered to anyone else. I felt that I was less of a person than other people. I began to shrink inside and became reserved, timid and scared.

In the collective society, each person is given a role with obligations. A man should be the provider of the family; a son should be able to carry on the family name through reproduction. A person who fails to fulfil this expected role is regarded as a 'useless' family member.

Self-stigma

Self-stigma is a very powerful poison. For me it was all wrapped up in believing that I deserved these negative experiences because I was not good enough.

My mother took us to see fortune tellers from time to time. When I look back, I believe she was seeking reassurance of her future. They would say to her 'don't put too much hope in Ivan, because he will not be very successful in life'. This experience confirmed that I wasn't master of my own destiny. They also told my mum that her future revolved around constant struggle and hardship.

Both Buddhism and Taoism deem that our current life is determined by our previous life. When someone is suffering it is believed to be a result of either the wrong doing of our ancestors or wrong doing in our previous life. This includes distress in relation to the experience of mental illness.

Teen

I did not understand why my friends had a normal family and I had a broken one. In order to support my sisters to further their education, my mother decided to leave Malaysia and work in Australia as a housemaid.

I missed my mother and my sisters, who were studying in Singapore. My third sister left school against my parents' wishes. I was home alone most of the time and felt extremely lonely. I believe this was when my depression began. However, I did not have the knowledge to realise what I was experiencing, or the vocabulary to explain it. Chinese traditional medicine has no description close to the terms 'mental health' or 'mental illness'.

I remember my mother sent an audio tape to us from Australia. We were really excited to hear what she had to tell us. However, her voice on the tape sounded like someone who had lost all hope. It was truly heart-breaking hearing her loneliness through the recording. We decided to contact my father and ask him to come home and listen to the tape.

He came home and asked us 'What is the urgency?' We told him about the tape and expressed concerns about our mother. He asked us about the money my mother had sent back. He did not show any concern or care about my mother's situation. I began to cry and felt extremely angry. He told me to stop crying and be a man. I was going to tell him what an irresponsible father he had been. My sisters, who were sitting next to me, told me not to say anything. Despite this, I felt a sense of injustice and that someone needed to speak up. Unfortunately, the collective culture does not allow a person to speak against their father. In Confucius' teaching there is an emphasis on Filial Piety, which means an unconditional obedience to your parents. A child should never question their parents; instead, they should show respect with full loyalty. This led to an internal conflict, which I did not know how to resolve. I wanted so much to protect my mother and sisters, yet I couldn't. Our father walked away from us after asking my sister to transfer the money into his account. His friends, a group of men and women, were waiting outside for him. I saw him leave without checking how his son and daughters were doing. It was as if we did not matter to him. This was just one of the many incidents in my life that led to me feeling hopeless and powerless. It is as if you are in a sinking ship, yet there is nothing you can do to save yourself.

First love

I had my first boyfriend when I was about 16. He was my classmate. We were very secretive and careful about our relationship. We knew this was wrong in our culture and yet couldn't resist our feelings for each other. Being gay or having a gay relationship is unacceptable in Malaysia and it is also against the law.

We soon learned that it was impossible to sustain this relationship with each of us still living with our families and studying at the time. In my culture, we are not encouraged to move away from home. Both of us were devastated; he coped with the separation by racing motorbikes. I denied my feelings and refused to keep in touch with him. I also began to think that my feelings, my needs, and what I wanted did not matter.

Adulthood

I decided to study towards a Diploma in Fine Arts after leaving school. My father couldn't understand why I wanted to do this, telling me that fine art could never bring a stable income. He said that I was stubborn and would regret it someday. Nevertheless, I carried on with my studies and finished my diploma. I landed a job teaching children art at a private school. I worked hard to prove my father wrong and eventually started a small business teaching art. Somehow I felt I couldn't carry on hiding my secret life as a gay man any longer. After about five years of teaching and slowly building up my name in the sector, I broke down and did not know how to carry on with my life. I reached a point of thinking about ending it. I knew I felt miserable; however, I associated all these feelings with the fact that I couldn't tell people about my being gay. I did not realise that I was experiencing depression.

When my mum took me to see a Chinese traditional doctor, he described my symptoms as 'weak heart', explaining that it was not a heart disease, but that it would impact on my whole life. This all made sense to me when I later did a psychology paper. In our society there is no language for the Western conceptualisation of mental illness – it is an unfamiliar model to us. According to Chinese medicine, the heart is the centre of the universe for our well-being.

I told my family I would like to go overseas and further my education. My father thought I was out of my mind. He said that I never did well in my studies, so what made me think I could get a degree from overseas? I thought my father was right; after all, I never did well at school. However, there was a burning feeling that I really wanted to do this and I was to follow it through. A couple of years ago I read a book called *On Becoming a Person*[2] written by Carl Rogers. It suggests that we all have the potential to achieve greatness despite growing up in challenging environments. Since reading his book, this thought has been the cornerstone of believing in myself and others. Despite the adversity from my childhood, and the self-stigma that had led me to think I was not good enough, somehow there remained a little voice telling me that I could achieve great things.

In spite of the belief of my family, my father decided to support me financially to come to New Zealand. (It is a common practice for Chinese parents to support their children financially to further their education.) I took this as an opportunity to compensate for the loss of my childhood innocence and the abandonment I felt.

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[2] Rogers C. *On Becoming a Person: a therapist's view of psychotherapy*. London: Constable; 1961.

In New Zealand

When I first came to New Zealand the only goal I had was to gain a tertiary qualification. I majored in Social Science. The initial year was really hard because of the language barrier. Now, looking back, the knowledge I gained from my degree has significantly changed my life.

The first paper I took was Sociology. It involved examining societies, cultures, genders, sexual orientations and so on. This learning gave me great insight into how we can be bound by a worldview based on our cultural context. I was so pleased to find out that homosexuality was legalised in New Zealand in 1986. This led me to re-negotiate my life and begin to look at myself differently.

Another life-changing experience occurred while I was doing a psychology paper. I discovered that what I had endured for many years were symptoms of depression. Knowing this, I decided to seek help and get support from professional people. I was first diagnosed by my family doctor and a year later was referred to a mental health community centre after a suicide attempt. However, the fear of stigma and discrimination prevented me from actually engaging with the mental health service.

I refused to take medication because I believed it would be a sign of personal weakness. I rationalised my experience of mental illness as being a result of what happened through my childhood. Taking medication, however, was an entirely different category. To do that would affirm that I was a weak person who did not have the skills to deal with my own problem.

As much as I loved my study and was passionate about it, I was experiencing a lot of personal pain. Coming to New Zealand forced me to look at myself in a way I never had before. Gaining new knowledge and cultural perspectives really shook my core beliefs. I was very sad and unhappy, and most of my friends didn't understand what depression was and why I was feeling this way. They were from a different part of the world, most having only been in New Zealand for less than 2 years. Mental illness and depression were unknown concepts to them too, with terms such as 'crazy' and 'psycho' being what they were most familiar with at the time. I remember one of my friends asked me why I would say I was 'crazy' when I was simply just being a weak person and overly sensitive. This reaffirmed what I was afraid of: my mental illness being perceived as a personal weakness.

Coming out

During my first year in New Zealand, I decided to 'come out' as gay to my family. Unfortunately, in response to that I experienced the most condescending words from some of the people I love the most. It was yet another thing that reaffirmed my feelings of not being good enough.

I was living a self-destructive life. In the morning I would attend university and then go to work. At night I would drink until I fell asleep. I was constantly in tears and the only thought I had was to end my life. I felt as if I would never be accepted by my parents again. I was extremely lonely and isolated during my first year in New Zealand, having lost all my support networks, friends and family.

One person in my life who has never given up on me is my mother. She has always loved and supported me. My mother called me one day to ask what had happened in my life to make me decide to tell my family now. I told her that I was still the son she knew; the only difference being that the truth had finally come out. I told her that the reason I was being honest was because I wanted them to be part of my life. I was sick and tired of hiding my true identity. She told me that she knew I was a great son and that she accepted me regardless of who I am.

Having a social support network is key to well-being for many Chinese. It is because our society is based on a collective, rather than individual, sense of identity. We see helping friends, taking care of each other, and having interdependent relationships as normal. The best description for us is: 'your business is my business'. This applies to any relationship in addition to family.

I started to explore the gay scene in New Zealand and had a few relationships before I met my lovely partner, Gerry. The relationships from the past were a huge learning curve. I unconsciously sought relationships that would reinforce the belief that I was not good enough. I knew I had to change and that involved learning how to love and accept myself rather than expecting this to come from someone else.

Peer support worker

After three years, I regarded New Zealand as my home. I had truly grown and learned about who I was as a person. I was finally living the life that I desired. It was the first time in my life that I felt I could be myself without fear of being judged.

I was someone who had first-hand experience of both mental illness and being an Asian migrant to New Zealand. I really wanted to use what I had learned to support other people who were in similar situations. Unfortunately, I wasn't granted a work permit from the Immigration Service. Because of this, my student visa expired before I had time to renew the appropriate visa that would allow me to stay in New Zealand legally.

I stayed illegally in New Zealand for nearly seven months and did not know if I was going or remaining. However, I decided to fight for the right to stay. I had help from many people, especially my current partner. During this time I learned that people do appreciate me.

After seven months of waiting, my residency came as great news. I was granted a year's working permit. I got a job as a peer support worker, which meant I was now able to support people who had had similar experiences to myself. I used my language skills (Cantonese, Mandarin and English) to communicate with people who accessed and utilised the service. I was very honest and candid about my experience of mental illness. I was also upfront about my sexual orientation.

Recent years

Lately my sisters have been able to accept me for who I am. They realised that they really missed me and loved me. This was a dream come true.

Out of the blue my father called me to have a long conversation. He told me that he was really proud of me and what I have been able to achieve. This came as a huge surprise. By that time I had got over needing his acceptance and approval; I was simply doing what my heart told me to do. I have also come to forgive him. I have learned that forgiveness is not about saying whether a person is wrong or right. Forgiveness is a way to move on. The feeling of resentment towards my dad was only holding me back from wellness.

Now

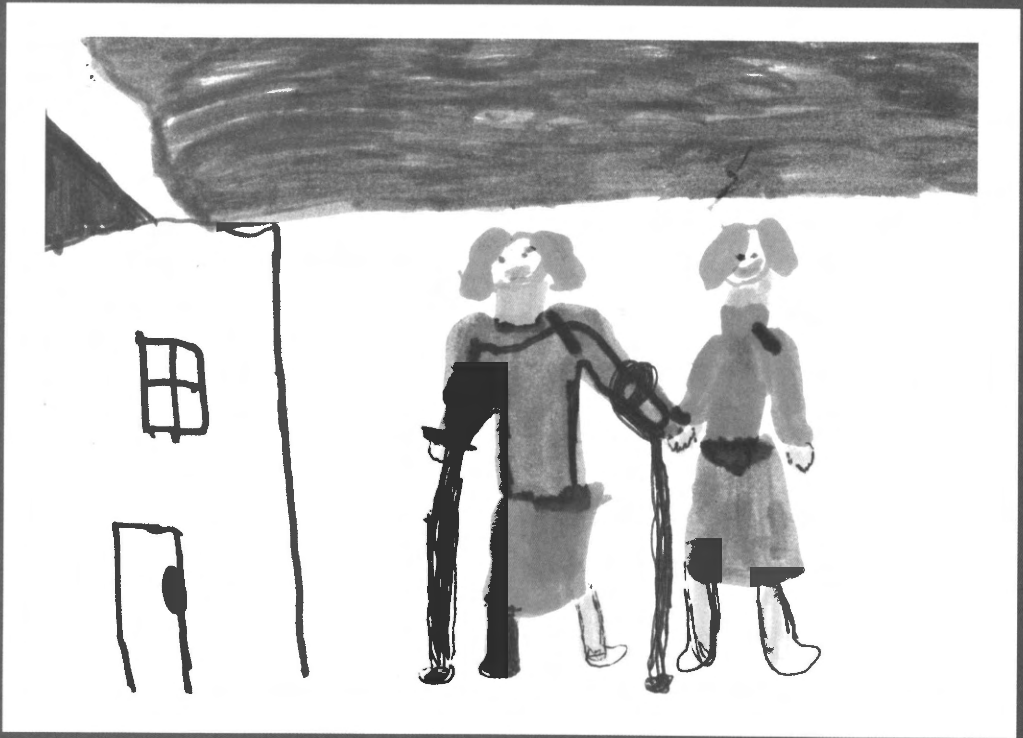
I continue to work in an area that I am personally passionate about. I am working with great people and a team who share the same enthusiasm as me.

My personal experience is made even more meaningful because I use it as the basis of my work.

I had my Civil Union in February 2008, with my mother's and sisters' blessing. I have visited my parents, sisters, brothers-in-law, niece and nephews and they all really like my partner, Gerry.

I am truly grateful to have come to New Zealand where society accepts, respects and embraces difference, something that is supported through the existence and implementation of a human rights framework.

I know there is a long way to go before I can honestly say that I have overcome my depression. However, when I look at where I was compared to where I am now, I can't help but simply appreciate my journey.



Rebecca Farr age 7

Live like there is no stigma

Sarah Gordon

READER BEWARE: This chapter consists solely of personal reflections and musings on self-stigma in relation to my own journey with mental illness. I can't even claim that any of my recounted experience is accurate in either fact or perception. I prefer to blame my significant memory loss on the side-effects of electro convulsive therapy (ECT) rather than any of the myriad of other potential causes. At least with ECT I am able to take full responsibility. At those times of deepest despair I have begged to be electrocuted. My reasoning (perhaps rational only to those who have ever been in this kind of desperate place) was that if it didn't help at least I wouldn't remember. However, like most issues associated with mental illness, it isn't quite that simple. Nowadays I get incredibly frustrated with my lack of memory or perhaps, more correctly, my awareness of my lack of memory. This prompted me to actually think about it, about why an appreciation of the past is of any concern to our present and future. I have come to the realisation that memory doesn't only serve to provide a record of what has gone before, but it actually informs who we are in the here and now. I have subsequently read that:

> Memory is fundamental. It is on the memory of the past that the present is built and it will be on the memory of the present that the future will be built.[1]

Lacking memory sometimes feels like aspects of me are somehow in limbo: existing without foundation.

Anyway, with that effusively described caveat in place let's see what and how I do remember.

I first became aware of my experience of mental illness by way of admission to a psychiatric hospital 17 years ago. Obviously there were lots of clinical risks identified, documented and addressed at that time. But what were the main risks I felt back then? Firstly, that anyone knew where I was and what was happening to me. You see, I had been one of the most stigmatising and discriminatory people around. In the past, I had actually known a couple of people with experience of mental illness and I had been horrible both to and about them. Suddenly it was all about me.

The second main risk I felt was that the boy I was going round with at the time might dump me. I mean, really, who would want to carry on a relationship with someone that was mentally ill?

So, what was the outcome in relation to these risks? Word soon spread about where I was and one of the main responses was, 'that is such a shame, she had so much potential'. But on the bright side, my boyfriend didn't dump me – he actually visited me twice a week for the entire six months I was at that hospital. Bizarre – had you asked me – and lucky; if the roles had been reversed I'm sure you wouldn't have seen me for dust. Often nowadays people do ask him about why he did this. His response is, 'there was a really good pool table at the hospital and it was free'.

Having been discharged and sent home, with strict instructions that ongoing support was necessary and that a return to university would not be wise (which I thought was quite reasonable, given who I now was), life was looking a bit bleak. You see, I am the ultimate geek at heart. All I had wanted to do for several years was go to university and this dream was at severe risk.

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[1] Kathrada A. *A Simple Freedom: the strong mind of Robben Island Prisoner No. 468/64.* Sydney, NSW: Hachette in association with PQ Blackwell; 2008.

However, as I soon discovered, my parents were not going to be compliant. Their beliefs about who I was, and perhaps more importantly, their expectations of what I was capable of, never diminished. And that was even with my newly acquired 'status'. Rather than encouraging me to forget university, they organised (and paid for) wrap-around mental health support to enable me to realise my dream.

Uni was great for me at this time, as I was learning about, and experimenting with, my mental illness. What better place to do this than at a 'higher school of learning' where you spend the majority of time on holiday, and the times when you are not on holiday, nobody actually knows whether you turn up to lectures or not. And sometimes I couldn't turn up – there were even a few times when I had to return home for most of a semester, but somehow I always managed to pass my papers. Looking back now, my university grades reflect a series of mental health outcome measures – times when I was well: mainly As; times when I was unwell: mainly Cs. The best thing for me about the uni situation was that I could keep my secret. Nobody knew that I had experience of mental illness unless I chose to tell them. I had complete control and I was vigilant about assessing potential response prior to any disclosure. Only when I was absolutely assured of no possible detrimental repercussions did I share my precious secret.

I maintained this tightly controlled management of 'those in the know' until I got my first job. Mid-way through doing my thesis towards my Masters degree, disillusioned with the application of my learning to the real world, I decided to seek a part-time job. Two adverts caught my eye: one as a researcher with the high court and one as a consumer advisor with local public mental health services. I was interviewed for, and offered, both. I decided to accept the consumer advisor position as the hours suited me better and the 'systemic advocacy' nature of the role really appealed to my latent idealistic aspirations to change the mental health service world. Now, I don't think I'm stupid (I suppose no one does), but at this time I didn't appreciate that EVERYONE would know that I had a mental illness by virtue solely of my position title: consumer advisor, the number one specification of the role being that you had personal experience of mental illness. No longer could I vigilantly gate-keep who knew about the contents of my closet. What's more, for those people whom I was meeting through work, the first and only thing they knew about me when introduced was that I had mental illness. I was devastated . . . for about a week. Upon calling my mum and dad looking for some sympathy, given the disastrous situation I now found myself in, I was bluntly told, 'things will never change if people like you don't start doing it differently'. That resulted in a very significant turning point in my life. From someone who staunchly protected my mental illness as a secret (to be disclosed only in the absolutely 'safest' of situations), I developed into someone whose personal experience of mental illness is very much a feature of my public persona.

A person who loves challenges by nature, this new role was the perfect focus for my energies in that regard. I spent hours 'behind the scenes' to ensure that all my work was not only as good as anyone elses, but better: better informed, better prepared, better organised, better argued, better presented, better all round. I relished, and was further energised by, seeing peoples' regard for me change. At the time I believed that what I was experiencing was the sense of empowerment that can accompany disclosure. In fact, I now realise that what I was actually doing was not really any different to what I had been doing prior to taking on the role of consumer advisor. Previously, I made sure people believed I was competent BEFORE I let them know about my mental illness, now I just as vigorously (perhaps even more so) worked to prove my competence after the fact.

The other thing that was new to me at this time was the real sense of camaraderie that can come with the sharing of common experiences and a collective crusade with peers. My peers are other people with experience of mental illness. I have been incredibly lucky to have met and developed lasting relationships with innumerable people who have taught and inspired me through both their individual personal journeys and occupational pursuits. At times, some people would try to impinge on this sense of unity and connection through peer discrimination based on perceived hierarchy of mental illness experience. One of my greatest downfalls in this regard was not having done any 'institutional' time. Luckily for me, in terms of treatment, these institutions had all closed before the onset of my mental illness. While I wasn't particularly concerned about these pecking-order wrangles within our own ranks, it did bemuse me somewhat. Why would people, many of whom had fought hard for the development of more humane services, then use different mental health services experience for the purposes of informing 'status'. In addition, what did it matter? It isn't as if claiming that you have experience of mental illness (no matter how severe) brings with it a whole lot of benefits and rewards.

In 1997 I got married to the guy that liked pool. By this time I had come to understand and experiment within my mental illness enough to know what I needed to do to live well most of the time.

In 1999 I fell pregnant. Having been advised that this would be a particularly vulnerable time for me, I decided to resign from work and concentrate all my efforts on being a healthy mum, with a healthy baby. I had the time, focus, energy and support to ensure this was a reality. Consequently, it didn't feel at all difficult to stay well in spite of the change in lifestyle that comes with having a baby. I was well aware that one of the main things I, like most people, could struggle with was sleep deprivation. Easily solved: I just slept whenever the baby slept. We were also extremely lucky to have such a contented baby. Basically he (and I) spent the first year of his life eating and sleeping. But it seems that some people can never be content – I was so bored. That is when I met Gary Platz and together we set up a mental health consultancy business known as CASE Consulting. CASE stands for Consumers as Advisers, Supervisors and Educators. Through CASE we wanted to provide consultancy services, all informed primarily from a consumer perspective, of a high professional and ethical standard. What I could never have imagined was how CASE was to develop and become what could now be described as an organisation (several staff of which have also written chapters for the present book).

It was a couple of years after CASE had been set up that my husband first proposed the possibility of me working full-time and him resigning and studying for his PhD. At first I was shocked – I had never imagined working full-time (you know, because of 'that') and then I was scared – I would be responsible for the livelihood of my family. After considerable discussion we decided to do it, but put contingencies in place – my husband never resigned from his job; he was just on leave without pay for three and a half years. About half way into his PhD I fell pregnant again. It was also at this time that I decided to do a PhD 'on the side' (of everything else). Looking back now, I had become 'cocky'. I neglected to make sure I continued to consider, and live, in a way that maximised the likelihood of me keeping well. I ignored my earlier learning.

After the baby arrived I was going to take six months leave from work. In reality you can't do this when you are the managing director of a small organisation. Despite being on leave, I had planned to do some work while our new baby was sleeping 'all the time'. The old adage 'don't think your second baby is going to be like your first' bit me on the ass with this one. Our second child slept, at the most, one hour during the day and didn't sleep through the night until he was a year old. So when he was six months old, I stopped breastfeeding him. I stopped breastfeeding him so that I could drink. I needed to drink to keep myself awake in order to work through the night. After a while I started to increase and modify my meds because they just didn't seem to be working. Then I began going out to drink after work until I would stagger home to an incredibly anxious pool player at 2, 3, 4, 5 a.m. I would spend the next day in bed trying to recover from both a terrible hangover and the intense guilt about what I was doing. Then I would work frantically until 2, 3, 4, 5 a.m. for the next few nights to try and catch up on the time I had 'wasted'. I was putting everything at risk:

- my family
- my marriage
- my health, and
- my work.

And so I spent the next two years like a swinging pendulum, from inpatient unit back to what had now become the chaos of my life, back to inpatient unit. Each time I reached a reasonable level of 'recovery', I plunged head-first back into the frantic work, study, home regime. I was getting really pissed off with my mental illness – it was hampering what I needed and wanted to do. I never contemplated the possibility of giving something up (or even cutting down) to make my life more manageable. No way; I thought of that as failure and my reasoning for any failure – my mental illness. It was both the cause and the result of all my problems. With each swing of the pendulum my mental illness presentation got more severe. Finally, I reached the place where my desire and actions for self-destruction overwhelmed any last remaining grasp at survival.

That end-point resulted in my most recent recovery journey, which involved being an inpatient of a therapeutic community for seven months – what felt like an awfully long time. In fact, I constantly argued this time frame with my psychiatrist. You see, after I had been there for just two months, the immediate presenting symptoms of my mental illness were under control. So, I thought, that meant I was good to go. However, my psychiatrist did not agree. She was adamant that I was still not in a place to be able to live well, that I would be at huge risk if I was to be discharged, and that she would be acting negligently to support me in leaving at that time.

So, what was her reasoning? Apparently I was not in relationship with people. Being in relationship with people is absolutely fundamental to living well. And while there are many benefits that result from being in relationship, it is bloody hard work. So, that is what I spent the next five months working on – re-learning and actively practicing how to be in relationship with people. I believe that that five months of working at being in relationship with people has meant that now, once again, I have the ability to live well. Upon being discharged I was very nervous. What if I got 'sick' again? That was one year ago and I haven't even had one appointment with a psychiatrist in that time.

Recently I did a presentation at a conference about my experiences of the past couple of years (just as I have shared it with you through this chapter). I then proceeded to tell the audience that I had disengaged from being in relationship with people because of my mental illness. I now realise that my explanation was wrong. Having had more time to reflect, I now know that it was my over-committed life that meant I wasn't able to be in relationship. Quite simply, I didn't have time! And, of course (as my psychiatrist quite wisely advised me) being in relationship is absolutely fundamental to living well (whether you have experience of mental illness or not). I had it the wrong way round. It was, in fact, not being in relationship that resulted in me being unwell. It seems incredibly ironic to me now. While I was working so very hard to prove that I could do 'everything' in spite of my mental illness, my mental illness forced me realise that I couldn't actually do anything unless I was real.

Someone close to me recently asked what I was planning for the future. I told them that I was still considering my options. They advised me that

I had better make sure it was nothing too full-on given my 'disposition'. I interpreted 'disposition' as meaning 'mental illness'. At the time I had not thought this through well enough to respond as I now know would have been appropriate. Don't ever focus on my 'disposition' when considering what I either can or can't do, it is not (never has been and never will be) my definitive feature. It will now be easy for me to communicate this to others. What will be harder is actually believing, and living based on those beliefs, myself. You see, since the beginning of my journey with mental illness, self-stigma has been the main constant impacting factor. In fact, I am aware of only a handful of occasions when I have been personally affected by the discrimination of others. Whether this is, in fact, the case or not, I do not know. I am very lucky to be in a situation where I am not generally dependant on how others perceive or treat me. So for me self-stigma has been more significant than anything else. In the past I have argued that this has had positive as well as negative consequences in that it has driven me to pursue a raft of opportunities that have contributed to me achieving my potential. I realise now that that claim is only a half-truth. It is positive, that I have achieved things; it is sad that my constant underlying motivation has been a belief that I needed to prove myself: prove that I can still achieve even though I have experience of mental illness. And perhaps what is even sadder is that the person I was actually trying to convince is me. But I am lucky (and grateful) that I have another chance and, once again, an opportunity to do things differently.

My priority and focus now is on being in relationship with people. Along with all the other wonderful benefits, opportunities and challenges that come with this, it also serves to assist me with being aware and contemplative of how my own self-stigma might be impacting on my decision making and actions. The reason is that those closest to me never stigmatise and/or discriminate against me because of my mental illness so they can really help me – first, to identify and second, to challenge anything that they believe might be the result of self-stigma. The key to this is me being truly reflective, honest and actually communicating my thinking so that there is the opportunity for response from others.

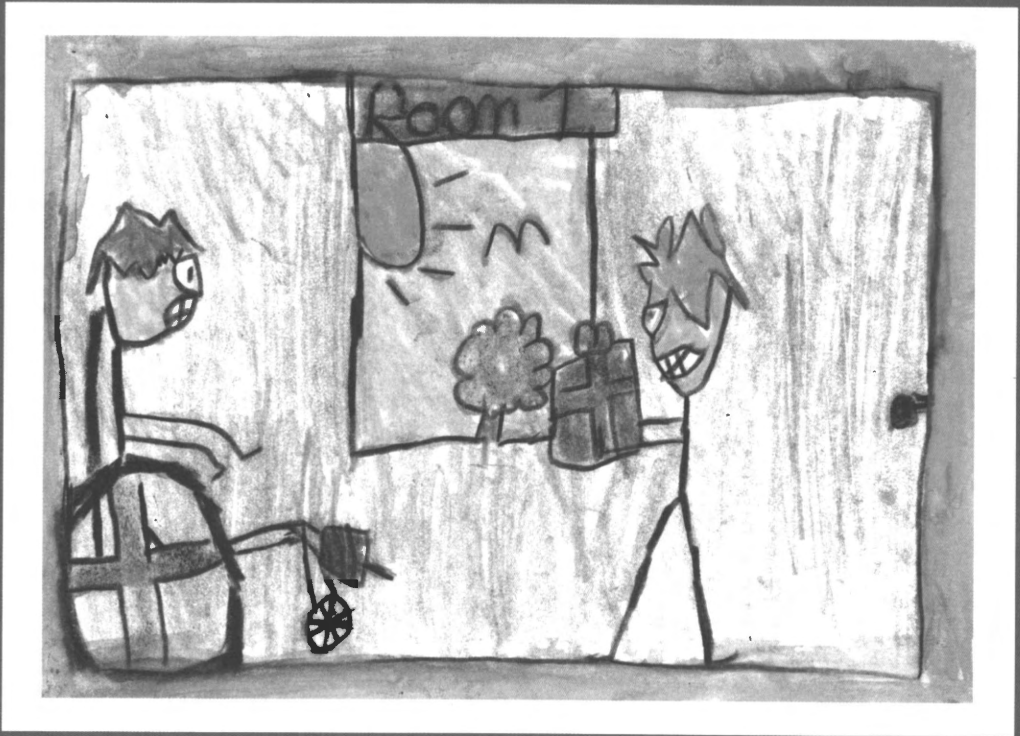
I am well aware that the area of greatest challenge as I go forward will be my role as a mother. The reason for this is that nowadays my feelings of failing are most often and acutely associated with self-perceptions of being a lousy mum: I don't play with them enough; I am always telling them off; I lose my patience with them; I don't spend enough time with them; I don't make them nutritious enough meals; I don't supervise them satisfactorily; I yell at them; I don't feel upset about leaving them and going off to work in the morning; I don't do enough for them; I don't make them do enough for themselves. It would be very easy and very stupid to blame this on my experience of mental illness. If I was to do that I would, once again, be wrong.

As far as I can tell, this perpetual sense of failure is a natural state of mind associated with being a parent. What would be worse than any of my perceived parental failures could ever be, is not being in any kind of relationship with my children because I am so preoccupied with trying to prove myself as a result of my own self-stigma. More recently, I have realised that I need to be working together with my children to counter my own self-stigma and their potential self-stigma. In the past, I had idealistically assumed that in their day and age they wouldn't be growing up with those negative beliefs and myths surrounding mental illness that could later be internalised (or externalised, for that matter). Yet again, I was wrong.

Not long after my eldest son started school he came home with a new verbal taunt for his brother: 'Uuuuuh mental', 'cuckoo; cuckoo'. I couldn't believe my ears, but there was worse to come when my youngest son started to copy his older brother, so I had both a discriminatory five-year-old and a discriminatory two-year-old. Going into a bit of a panic, I thought that maybe I should race into work, grab my materials and put them both through a one-day anti-stigma and discrimination workshop. However, after some thought, I considered the best approach was to sit down and talk with the boys. The first thing I asked was what 'Uuuuuh mental' meant. The response: 'cuckoo; cuckoo'. So the quite obvious next question was what does 'cuckoo; cuckoo' mean? Well, apparently this means 'uuuuuh mental'. So, I explained that both those terms referred to mental illness and that by using them in that way, they were actually being mean about people with experience of mental illness. And of course, as they were both well aware, Mummy has a mental illness. Following best practise anti-stigma and discrimination techniques I asked the boys to tell me everything they knew about Mummy in addition to the fact she has mental illness. 'Well' said my eldest, 'she has boobies and fluff where her diddle is meant to be'. Here I had been waiting for, 'She is a good cook; she is a good driver; she is a good gardener'. I was probably being a bit ambitious in relation to all those things, but shit, just boobies and fluff! Not at all what I was expecting, but I persevered and we did manage to get some more productive material. We will continue to jointly explore their developing beliefs about mental illness. I am really hoping that by doing this now, if either of my children do go on to develop mental illness, self-stigma will not be an issue for them.

So, that is my memory... and my ramblings about it. I believe it would not be nearly so interesting (or warrant a chapter in a book) in reality or perception if it wasn't for my experience of mental illness. I have no idea how that claim might be interpreted in relation to self-stigma – and I actually don't care! Wow! That is a first for me. Maybe now I am really empowered.

So, what would I like readers to take from this yarn? Do I have some profound learning that might assist a 17-year-old just embarking on their journey with mental illness? Yes! Live like there is no stigma. But how? I believe the circuit breakers in the Discrimination Intervention model (as presented in Chapter 1) provide us with great direction in relation to the 'how'. Personally, I think mental health services have a big part to play in actioning these things as part of supporting people with experience of mental illness. I am well aware of the argument that campaigns to counter stigma and discrimination need to be exclusively and resolutely about addressing societal stigma (which will also serve to combat self-stigma). However, while stigma and discrimination continue to have such an impact on recovery, I feel that not addressing this issue as part of routine mental health service provision is remiss and possibly even negligent. The experiences of people presented through the chapters of this book consistently highlight the significant impact that the circuit breakers (of the Discrimination Intervention model) can have on individuals' journeys of recovery and ultimately their lives. It is through these interventions that people can have the best chance to truly live like there is no stigma.



Rega Johnston age 13

The asylum discourse and self-stigma

Dean Manley

This chapter explores how self-stigma arises from what I term the *asylum discourse.* Simplified, the asylum discourse is the complex weave of communications that confirm stereotypes of madness and justify associated discrimination.

The past use of asylums to house people with mental illness has an ongoing effect on people diagnosed with mental illness today. Asylums emerged from old leper colonies when leprosy had vanished after the Crusades. Mad people were contained in them. The asylum discourse penetrates society beyond the institution, and has now become an imaginary asylum which is promulgated through myth, representation, social systems, and practices. Culture assures us (via stigma and discrimination) that mad people are Other, of lesser humanity, not part of orderly and lawful society.

Difference: Some origins (derivations) of self-stigma

My PhD research examined how the asylum discourse generates and supports assumptions about madness. I consider that self-stigma is a private haunting, a spectre unsettling a person's sense of identity and belonging, coded into a diagnosis of (so called severe) mental illness. People are told, by virtue of the diagnostic label, that they are flawed and defective, less human than others, and not entitled to community resources and benefits. Diagnosis devalues people by contrasting them with ideal healthy people. These ideas permit and manufacture consent for discrimination against 'them' by confirming difference, aberrance, dangerousness and unpredictability.

French philosopher Michel Foucault (1926–1984) identified the 'zero point' in Western society, where madness was separated out from the 'norm' via the asylum (Foucault 1967). The asylum became the holding pen for community's Others, the mad person's 'natural abode', origin of today's mental health services.

The asylum era continues to impact on beliefs today through the asylum discourse – depictions in the media, communicated through policy and cemented in diagnoses. Stereotypes and scapegoating representations of madness confirm for society, and the individual, the Otherness of those diagnosed with mental illness. Examples include *Shortland Street*, a current New Zealand television hospital drama, which recently portrayed the 'nut job' mental patient 'off his meds' causing mayhem in a triage seclusion room, holding the virtuous and saintly nurse hostage. After stabbing the heroic, handsome nurse who tries to reason with him, the 'nut job' cuts the hostage and generally causes distress. Even if the diagnosed viewer doesn't identify with the designated 'nut job', they are aware that the general public associates them with this representation.

Self-stigma derives from communications about who belongs and who doesn't – who is Other. Mass media spread ideas and retellings of stigmatising representations, whipping up a 'sociology of censure' (a general expression of extreme disapproval or condemnation) (Pickering 2001). Censure colonises the individual when the majority agree with stigmatising representations. When this censure overwhelms a person's identity through the weight of insistence and repetition, it can trigger and exacerbate self-stigma.

Stigma and identity

Stigma operates in the imaginary space where cultural identity is formed, where an individual negotiates their belonging to, and identity in, the world. Here people form their social roles through adopting labels – boy/girl; son/

daughter; brother/sister etc. – based on role models in myth, story, and news. Representations of character traits circulate in popular culture media; an individual differentiates their identity in relation to other roles represented in the media. This is also the space where a culture identifies its Others. Stigma works within this space, influencing values, ethics, and roles of the group, and the actions of its members.

To qualify for mental health services a person must usually be diagnosed, requiring formal judgment of an 'expert' clinician to be eligible. Diagnosis determines the treatment the 'expert' prescribes, and the diagnosed person must conform to this treatment, which is based on the specialist's knowledge and expertise. It is this classification that places a person in the category of Other within the imaginary space of cultural and individual identity formation. The patient is differentiated in the social structure in terms of sickness and abnormality, as receiver and subordinate in the doctor/patient relationship. The respective labels determine who has the power and who is the beneficiary of power. The doctor and 'expert' mental health services create policies and practices to deal with patients, depending on the label they receive and the severity of disorder in the hierarchy of abnormality.

Self-stigma is often affected by people's experience of discrimination. Treating someone differently *makes* them different – Other. Feeling Other has consequences, causing someone to accept bullying because of their perceived deficit, to believe that this is deserved, and that bewilderment and self-doubt arising from bullying is the result of deficiency. Self-stigma occurs when someone feels worthless, accepting maltreatment or lack of respect as inevitable, and believing that discrimination is deserved.

Stigma exists in the politics of power: economics, science, law, medicine, education, social development, insurance, government policies and reports – or Ministry of Health statistics – sometimes masquerading as truth, often as objective observation. In collaborating and complementing each other, all contribute to the weave and fabric that acts as a barrier to people connecting with, and feeling they belong within, a community. Policies and practices, according to Foucault, contribute to madness being one of the emergencies of the age, a potential threat requiring action (Foucault 1967). When stigma is formulated in terms of these authoritative constructs, it can seem 'normal' and right. The New Zealand government, for example, communicates

Otherness by rating disabled people as 70 per cent productive for the purposes of determining the subsidy an employer will receive from the government for employing a disabled person. Through this policy, diagnosis is translated into a financial sum based on deficiency. That someone without a 'disability' could be less productive is ignored; the disabled person is officially 'less than' due to this policy. Social welfare benefit systems are another example. An invalid's benefit relies on an expert's official clearance to be endowed. Official terms and policies can hold assumptions of Otherness and deficiency, and these can carry forth into actions of discrimination.

Diagnosis

The asylum discourse is condensed and coded into stereotypes, categories of abnormality, and hierarchies of level of disability. The DSM-IV is used to categorise people through an ordering system based on syndromes of symptoms. This grouping excludes as much as it includes people from categories, differentiating diagnoses and ranking them in order of seriousness.

Some people believe that a diagnosis gives them something tangible to address; for many, 'being told their diagnosis for the first time was also the first time they felt self-stigma ... internalising beliefs and myths surrounding mental illness ... realising that all of these now applied to them.' (Peterson, Barnes and Duncan 2008, p. 57). Being diagnosed with mental illness means conforming to the entry requirement for specialist mental health services: categories of Otherness, symptoms and signs of deviance which stand in the cultural place where the asylum once stood.

Stigma works in Other people with or without their consent, assisting the colonising process by imposing its dominance on an-Other through multiple channels of communication to 'sell' its messages. This compounds problems for people colonised by stigma in the long-term as a result of the 'special' status brought by diagnosis, as it encourages self-stigmatisation and discrimination in the group as well as the individual:

> contributing to self-stigma was a perceived hierarchy of experience of mental illness amongst consumers working in the mental health area. ... some experiences of mental

> illness were deemed to be 'worse' than other experiences. Some people believe the worse the experience of mental illness the more value [or more negative value in terms of the asylum discourse] the person was perceived to be able to add to a peer support group. Those whose experience was perceived as less valuable [in asylum terms] experienced an increase in self-stigma (Peterson, Barnes and Duncan 2008, p. 57).

Accepting and integrating a diagnosis of mental illness means identifying with negative, stigmatising representations of madness presented in media, myths, stories, and popular culture communications. Receiving a diagnosis forces people to either accept the communications the asylum set up in culture, or reject them. To identify with the representation of difference and threat requires Othering yourself. To reject it is to risk labels of delusion or denial, symptoms of madness. This double-bind (no-choice choice) can cause people to devalue their own worth to society, to others and to themselves. Self-stigma reflects this tension of identifying or rejecting stereotypes, the latter of which actually involves the rejection of centuries of societal investment in Othering.

Media is where most people get their information about madness. Through myths and misunderstandings about madness and the experience of mental illness, people with a diagnosis are represented as incompetent, irrelevant, deviant, dangerous and/or violent. For instance, a political party issues a policy statement during an election campaign stating that mental illness is a driver of criminality: 'Mental illness is a significant driver of criminal activity, and drug related offences fall into this category' (ACT Law and Order Policy, Election 2008). Those in power draw a direct link between madness, drugs and criminality, so this comparison with law-abiding, contributing, orderly citizens becomes fact. People included in this official policy are powerless to object; their protest is dismissed by the voting public. Mental illness, criminality and drug addiction are weighed as equal threats; the comparison (with law-abiding citizens) is unfavourable – it is the official policy of the elected party (in this case), so it must be true.

The general public internalises the stigma of madness as fear and loathing, often breeding reluctance to identify with the group differentiated as Other, and (not surprisingly) stopping people from seeking help and assistance in time of need. Stigma can cause people to deny early signs of distress and trauma. When distress and trauma become overwhelming, and formal medical systems unavoidable, stigma ensures that a person is captured in the asylum discourse. When it is too late, Othering becomes inevitable and unchangeable.

The spectacle of madness: Visibility is a trap

> Yet there is nothing in common between
> this organised exhibition of madness in
> the eighteenth century and the freedom
> which came to light in the Renaissance. . . .
> Madness had become a thing to look at
> (Foucault 1967, p. 70).[1]

Foucault (1967) exposed how asylums displayed mad people as a spectacle, a practice which served to confirm that mad people needed containing and confining in locked cells for their and the public's safety. In those days they were displayed, in person and through stories, to allow 'normal' people to assure themselves of their own 'normality' in contrast to these brutalised and ill-treated people.[2] These spectacles helped validate inhumane treatment by confirming suspicions of the de-humanised people as regressive and 'primitive', base and disgusting, and in need of caging. Representation today in various media serves a similar purpose.

Where the asylum spectacle framed madness in the cell and observation

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[1] Foucault elaborates on this further: 'In the Renaissance, madness was present everywhere and mingled with every experience by its images or its dangers. During the classical period, madness was shown, but on the other side of the bars; if present, it was at a distance, under the eyes of reason that no longer felt any relation to it and that would not compromise itself by too close a resemblance...' (Foucault 1967, p. 70).

[2] 'At the retreat, the madman was observed, and knew he was observed... madness had no immediate grasp of its own character. With Pinel, on the contrary, observation operated only within the space defined by madness, without surface or exterior limits. Madness would see itself, would be seen by itself—pure spectacle and absolute subject.' (Foucault 1967, p. 262).

window, stigmatising representations transcribed into culture's broadcast mechanisms serve the same purpose today; the medium has changed, but not the message.

Narratives are artificial, man-made ordering systems of logic. Stories enable the repeated witnessing and exposure of threat, human lapse, and chronic illness to be successfully contained and explained in set rules and configurations (agreed upon by culture). Madness is the simplest, most understandable answer to inexplicable human behaviour and criminal acts of violence.

Representations of madness not only keep these inexplicable elements of human nature visible, but attempt to simplify them. *Psycho* (Hitchcock 1960), for instance, has a psychiatrist explaining diagnostic categorisation to the characters and indirectly to the spectator at the end, 'wrapping up' the frightening (and thrilling) tale of sexual perversion and deviant transgression in narrative and popular psychology terms. He stands as the culture's representative for the forces of order, closing in on the unchecked threat, deciphering and unravelling the evil madness on the audience's behalf.

Psycho became a popular cultural phenomenon and sensationalised the pejorative term for madness that entered the lexicon; 'psycho'[3] has become verbal shorthand for the dangerous, irrational, murderous person of dubious (probably incestuous) sexual identity. Images such as those in *Psycho* bear witness to the right to imprison failures and malcontents so that they can be 'tamed', legally and clinically, due to their potential for dangerous deviance.

Representations like this enter the cultural identity-forming mythology bank. Narratives stand for knowledge about madness and the designation of people labelled as such. They provide certainty and closure to a vague amorphous entity that is worrying the human condition.

Discrimination

The asylum's 'great confinement' introduced the social policies and practices that supported a community's right to remove the human rights of people

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[3] '**psy·cho**: (sī'kō) n. *pl.* **psy·chos** A psychopath. adj. Crazy; insane' (http://dictionary.reference.com).

sent there. Myths of horror and degeneracy helped this process.

The asylum transformed people from being mad because of what they *did* into being mad because of what they *were* – their core identity and designation. This becomes what Foucault calls a *controlled* derivation; it categorises someone within a 'brand' of mental illness, defining 'what' they are, their particular brand of aberrance, and how they should be treated. In mental illness, diagnosis has much more effect on the perception of threat to either the moral or physical health of the community than in physical illnesses.

People with mental illness are often acutely aware of the stigma attached to their diagnostic label, sometimes to such an extent that they may expect and anticipate rejection and fulfil the stereotype (Caird and Stephens 2000). Madness can become a career, with individuals striving to live up to its designation, the one repeated in media and confirmed in stereotypes and popular language. Self-stigma can mean complying with discriminations implied and authorised by the diagnosis.

Unemployment is high amongst people diagnosed with mental illness. So, consequently, are benefits paid at the taxpayers' expense. Benefits come with strict rules for those that meet the definition of 'Invalid' which is a greater, long-term version of a sickness beneficiary. 'Invalid' derives from the Latin for 'weak', and has been used in military contexts for someone no longer of use to the cause.

Mad people's lives are shortened because of the treatment and lifestyle partly imposed by a diagnosis, partly by Othering, partly by self-stigma. Their status makes 'them' a burden on the health dollar due to chronic illness, their treatment and care a liability to a responsible society. Reduced positive health outcomes are a passive discrimination against those diagnosed with mental health problems, and accepting them amounts to self-stigma.

Mad people have a lower life expectancy due to the rigours of medication, their predisposition to smoking, sedentary unhealthy lifestyles and bad eating habits. Because of this, insurance and other social responsibilities are denied them. Their value as citizens is less because they earn less (as a result of unemployment or less earning time due to a shorter life) and therefore consume less. Stigma also suggests that this lesser lifespan is a mercy, both for mad people and the community. They bring shame on family and friends, causing disruption and mayhem in all relationships, including romantic ones.

Probably for the best, their genetic faults are a good reason for sterilisation or at least non-breeding.

These discriminations are overt violations of the human rights of diagnosed people, but they are also ones that often seem natural, even to diagnosed people themselves, that being a result of self-stigma.

Resistance: Circuit breakers

My research into media depictions looked at many examples of representation confirming asylum stigmas of difference and madness. However, I also identified an example of reframing madness and talking back to stereotypes. Others speaking for themselves have a role in modelling recovery and dismantling asylum myths and stigmas. A dramatisation of Janet Frame's autobiography which was signed off by her, Jane Campion's film *An Angel at My Table*, has the mad person controlling their representation. Frame challenges designation and destiny of difference and Othering through the mediums of literature and visual storytelling, some of the same methods stigma has used since the asylums began to Other madness. *Angel* tells the story from Frame's own viewpoint, the antipodean identity at odds with her environment and society. It is the culture that alienates her. Her distress and trauma arise from a patriarchal Western society that doesn't recognise alternative perceptions and language as creative but rather sees them as symptoms of a diseased mind. In this example, the Othered person speaks for herself, breaking the silence and making a spectacle of the asylum discourse, challenging its dominance and authority. Her story is (arguably) a refusal of discrimination, a circuit breaker defying self-stigma.

Frame's story shows how official diagnosis can cause social devaluation and isolation, remove a person's human rights and discard their freedoms. Frame is contained in an asylum, subjected to electro convulsive 'therapy' (ECT) and diagnosed as needing a leucotomy (lobotomy). Her intelligence and personality were saved by chance when a clinician, who also knew of literary discourses, recognised her writings as valuable and not symptomatic. *An Angel at My Table* is a graphic illustration of the nature of identity constructed through framing (pun intended) and how the story of a person diagnosed as mad can be a spectacle, depending on Foucault's query: Who speaks, and from what position?

Messages of difference and belonging are dependent on who speaks, in what medium, and how the voice is framed. Notions of difference 'sold' to the general population, of which people diagnosed with mental illness are a part, depend on who has access to the channels of communication.

When people with a diagnosis of mental illness are in control of their messages and the channels through which they are distributed, stigma will begin to be addressed. This includes societal stigma and self-stigma.

Frame is an example of someone whose identity and personality overcomes the colonising strategies of asylum stigma and rejects its dominance. She is the exception, not a gifted-genius exception, but a person whose character, with some luck, defies the asylum discourse.

If people diagnosed with mental health problems say stigma exists, and they speak from the position of those who know how it is to be labelled and represented as different, then it does exist, at least for them. These people do not speak for others, but they speak from experience and encounters, as recipients of asylum stigma from a myriad of channels in the community.

The Discrimination Intervention model (as presented in Chapter 1) suggests that the antidote to self-stigma is the circuit breakers which serve to interrupt the cycle. Disclosure is an example of such a circuit breaker and one that would support the reframing of madness, with mad people controlling their own representation. But disclosure comes at a cost. While societal stigma exists, disclosure risks social suicide, character assassination, and status loss – in other words, discrimination. Examples include job loss or career limits (the glass ceiling that women are well aware of), blacklisting, or being denied employment, housing, insurance, resources and inclusion in the wider society. Individuals may reject the asylum myths and stereotypes, and the scapegoating nature of blame and disapproval of diagnosis, but while society supports and repeats them, disclosure is a personal sacrifice of identity which is too much to ask on its own.

As citizens in a post-asylum culture, the people represented in these Othering discourses are subject to and subjects of them. The asylum discourse persists with perpetrators, bystanders and victims. Making a difference will involve everyone working together to challenge and eradicate the asylum stigma.

The other circuit breakers, of the Discrimination Intervention model, provide us all with guidance as to how this can be achieved. These include an acceptance of diversity, recognition of madness as a valid human experience, appreciation and celebration of difference, recognition of the contribution of people with experience of mental illness, zero tolerance of discrimination, and affirmation of human rights.

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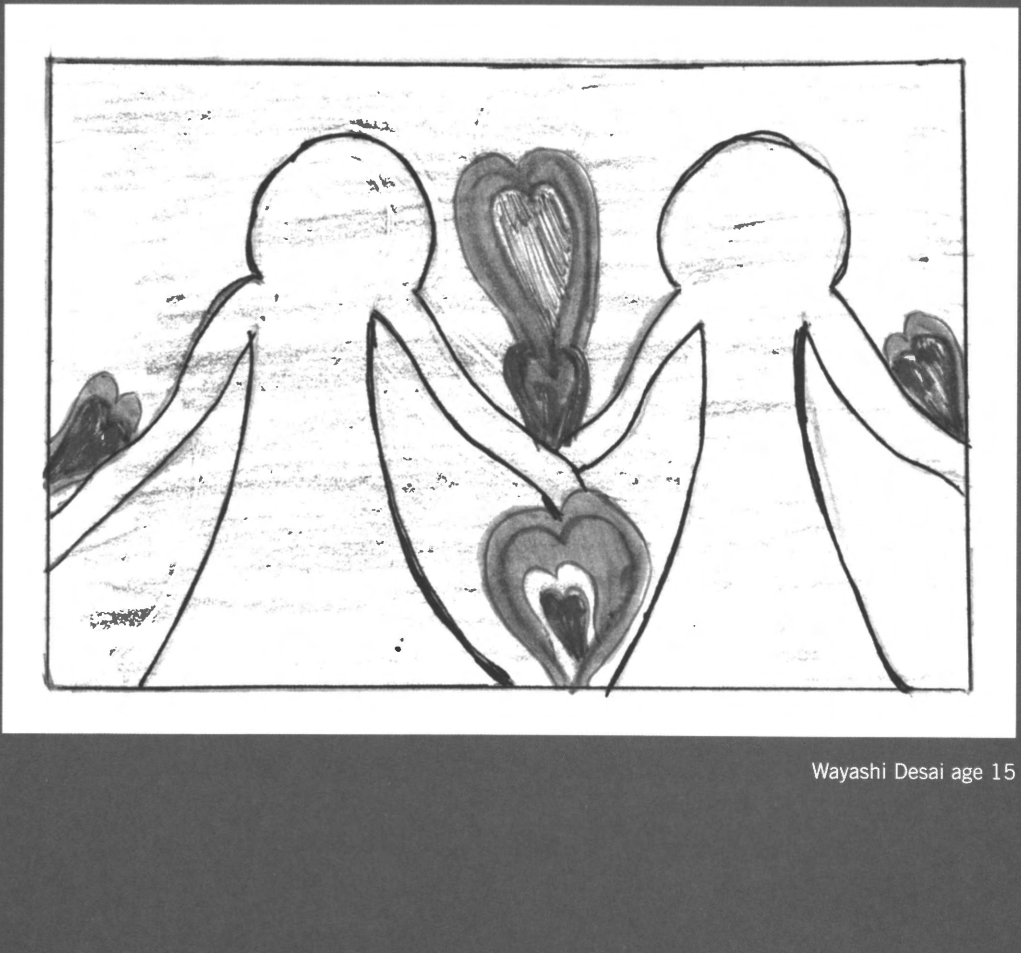

Wayashi Desai age 15

Life is about boxes

Vito Nonumalo

It's not easy living up to a stereotype; it's even harder to run away from one. Many people spend a lifetime trying to climb into boxes. I have spent most of my life trying to climb out of them.

Far be it for me to break normal convention and go against the expectations of a society that is driven by degrees of collective thinking and collective beliefs – driven by underlying societal schema.

It's difficult enough to traverse the stereotypes which associate themselves with being a Pacific Island person, without those of having been a mental health patient, also being ruggedly thrown into the mix.

Memories of a mental health ward

My first memories of a mental health ward are not what most people would believe to be typical of someone who has had the auspicious opportunity of being treated to what was once New Zealand's psychiatric dogma of treatment.

Even though I hadn't grown up in Porirua, I knew that it was synonymous with 'mental people'. I had family members who lived there who were ashamed of being associated with Porirua, or rather, with the 'mental people'. You had to qualify your sanity before you could be accepted by the rest of us 'normal' folk, and even then, you weren't spared the jibes and taunts of a few mindless mental jokes – not if you lived in . . . Porirua!

I would have been no more than ten years old. I don't know if I had any idea of the fact that I was visiting a 'mental ward' or whether I had any preconceived ideas as to what a psychiatric ward was. Unfortunately, and it's something of a sad indictment on the way the system worked then, I don't even remember who it was we were visiting except to say that it was a family member. I don't know if that person ever became well, or got out. I don't know if they passed away quietly and alone, without any of our family ever being there.

My younger brother and I followed my father anxiously, that much I do remember.

The image that sticks firmly in my mind from this visit is of a tall and lanky man, who appeared to be in his fifties. Knowing what I know now, I would say he was probably only in his thirties at the time. What made this memorable is that he was stark naked. Not an inch of clothing protected my then innocent eyes from his 'full monty'.

If not for the fact that he was naked, he didn't appear to be raving mad or a blithering lunatic. He didn't even seem to be that odd, in the simplest definition of the word. But he was naked, reading a book to himself in the corner of a room. Despite the fact that he didn't appear threatening in any way, I was scared of him. I remember cowering behind my father. My father was my staunch protector who would fend off any attempt by the naked man to try and steal me away.

Funny how young minds work; it does make one wonder what excuse we have as adults, though.

I never visited the psychiatric ward with my father again, at least not simply as a visitor.

Discriminating features

My parents emigrated to New Zealand from Samoa in the late 1960s. Like many others, they had been lured by the prospect of somehow making a fortune in the caverns of factories. Standing alongside many others, just like them, also hoping to make a fortune on the assembly line.

Having met in New Zealand, both my parents had come here with intentions of being able to help support their respective families back in Samoa. As young kids we were immediately exposed to having to adapt to 'fit in' with everyone else.

My father, in the hopes of making life easier for his children, shortened our last name, having deemed it far too long for Palagi to be able to pronounce. Not that this helped me too much – having what I thought was a very Samoan name that meant most Palagi struggled to get past my first name without completely cocking it up, let alone the battle with my last name.

The period of the 'dawn raids' came, named so for the early morning raids undertaken by police and immigration officials on homes and workplaces.

When the economy started to slow, factories closed and jobs vanished. The Government decided it could now not afford all these people it lured to New Zealand. No longer were Pacific Islanders wanted or desired in New Zealand; after all, they were a strain on social services as the economy worsened – or so the politicians spouted.

Thus began the process, if it can be called a process, of trying to send them all back – or at least the ones with expired visas, the overstayers.

My dad told me of the random checks that would occur to ensure that they were legally entitled to be in New Zealand. The net of suspicion was cast over anyone who was even remotely brown, this despite the fact that many overstayers were in fact English or Australian.

Discrimination wasn't a word that we grew up with, and yet, thinking back, it was all around us, and on a daily basis at that, mostly due to the colour of our skin.

It probably wasn't helped by the occasional image of rebellion often conveyed by myself and many of my fellow Polynesian brothers. Don't get me wrong though, I wasn't a complete and utter mongrel either.

It was common to be followed by security personnel around stores and supermarkets, or to have the police beam their side light on you as you walked innocently along the road at night. Every so often, they would even go to the effort of stopping you and having you empty your pockets.

I recall having people cross the road, not because they didn't want to share the footpath with me, but because brown men were seen to be intimidating. Not least because, by the age of 14, many of us were able to grow full beards and had physical appearances that would look fitting in an All Blacks rugby jersey.

To have watched and read the news back then, you would have learned to believe that domestic violence was rampant amongst Pacific families; that we all ate Kentucky Fried Chicken and that our fathers gambled away their money at the TAB. If they happened to be employed, they gambled away even more. What little was left of any money earned was tithed at church on Sunday. Most, if not all of us, wore jandals and we were, for the most part, on visas that had long since expired.

Outwardly it was a joke, but I know that for many of us, it was hurtful on some level.

You'd think that would be enough turmoil for a kid to have to go through, but apart from the usual battles of being labelled by skin colour, I also had to endure the taunts of having been scarred as a result of a car accident. Being labelled by skin colour I could handle. Being made to fit into certain categories because I was brown was something that I accepted as far too big a challenge to tackle.

The fact that racism was often hidden and invisible somehow made it easier to put up with.

Having facial scars brought everything so much closer to home. Perhaps the taunts were exaggerated in my mind; nevertheless the fact that I couldn't physically see a racist person versus the fact that I could see people staring at my face made me take on another unwanted label.

Growing up, discrimination did indeed have a place in my life. Not only did I learn to wear some of that, like so many other Pacific Islanders, I also learned to regurgitate discrimination and both internalise and externalise it.

Most people understand the value, or curse, of fitting in. Particularly in those formative years of teenagedness, be that a word or not. For males it's those years when physical maturation outstrips mental. I sometimes feel like it was the other way around for me.

Nowhere was it more obvious that I didn't quite fit than in New Plymouth, where I was one of only a handful of Pacific Islanders living in the coastal city, only one of whom I actually got to know.

In New Plymouth it wasn't unusual to walk down the street and have 'nigger' shouted from a passing car. The first few times, I had to look around to see who they were referring to. When I realised they were talking to me, it was more amusement than shock or insult that I felt. Having come from a city where people dare not call a brown person anything offensive, it was a novel way to be excluded and made to feel different.

Broken

My father was the first one in my family to realise that there was more troubling me than the usual teenage male angst. While I did my best to express myself either through music or art, it did not halt my internalised mental suffering altogether.

Inside I had grown to dislike myself. The weight of labels was far too heavy a burden for me to bear, and somewhere along the way something must have broken.

Sleeping became unnecessary on many an occasion. Not from a lack of wanting to, but because to lie down and close my eyes surrendered nothing more than tears to the whim of my pillow and my state of mind to the torturous thoughts of being me.

Instead, I would shelter myself from the world in the darkness of my blankets. Darkness became my friend, as well as my tormentor. The same darkness that brought me to my knees when I closed my eyes was a blank canvas of unlimited possibilities when my eyes were open. While everyone else slept, my mind found a modicum of peace in that same darkness, short-lived as it was.

Night was my haven.

The night meant that I wouldn't have to wear the weight of the labels that I hated so much. At night, alone, there was nobody to judge me. Nobody could see my scars. Nobody could make fun of me, or bring my spirit down. My only problem was that 'nobody' was me.

I almost felt like I lived two separate lives at times. The one people saw during the day and the real me which revealed itself when the sun went down. It was the real me that suffered most; it was the real me that felt tortured. The fake me merely put up with it all. Laughing off the occasional taunt, pretending not to care too much when insults were so easily given.

The tortured me struggled with the very thought of having to go through another day. The tortured me toyed with the idea of death as a much welcome intervention.

Becoming a radio announcer gave me further opportunity to pretend not to be so tortured. I learned how to sound as if I was smiling when speaking, even when I wasn't actually doing so.

Radio was perfect for me. It was a form of darkness in the middle of the day. Through the technology of FM radio I could be surrounded by people and never have to actually face any of them at any point in time. I could hold their attention, subject them to my thoughts and make them listen to whatever music grabbed my fancy. I can laugh about it now, but I am sorry to all the poor souls who had to endure the endless drone of Mariah Carey and Boyz II Men singing *One Sweet Day* simply because I was in a bummer of a mood. It was simply the most depressing song I could think of at the time, and it befitted my mood.

The many buttons, switches, sliders, vinyl records, reels and CDs, not to mention the multitude of phone lines and callers that had to be managed, meant that I was always able to keep myself well and truly distracted. Had it not been for that continuous distraction, Mariah and Boyz II Men would have surely earned a dedicated spot on one of my shows.

It was the first time I had ever experienced that ability to control my environment outside of the darkness of my blankets.

In my favour was the fact that, for the most part, I worked nights on radio. This meant that nobody else was around in the office. I was often alone in the studio, apart from the many listeners. Or what I at least hoped were many listeners.

Nothing was ever quite right with me though. I can say that now looking back. In the midst of it all, all number of successes were overshadowed in the recesses of my mind by the things that didn't go so well, or went wrong altogether.

Radio, while good for me on some levels, perpetuated or even hid many other things, even from myself.

I would pull down the microphone so that it rested just above my lips, my hand extended to press the switch that turned on both the microphone and the red light above the door, warning anyone who was around not to enter the studio. Not that there was ever anyone there to do so.

My mind would fill with a thousand things to say, my eyes would glance sideways to glimpse the time. My right hand would be holding key information on a piece of paper for me to say and my left hand would be perched just above some button that activated the next song or advertisement. Then I would open my mouth.

At times I spoke as fast as I thought. I was known for being an incredibly fast speaker. I had the voice intonation perfected, so much so that many wondered if I was even a Pacific Islander. I didn't necessarily have to be so on radio.

Radio announcers were supposed to be full to the brim with energy, bouncing off the walls pressing buttons and playing music seamlessly with sultry-toned voice breaks interspersed. I always did feel like a fake.

Locked inside myself

It's all a bit of a blur now. The bathroom mirror that I couldn't bring myself to look into for fear of seeing myself. Even if I had been able to look into the mirror, I'm not sure I would have recognised myself. My eyes and face displaying the torment I felt inside, swollen and reddened from attempts to stem the flow of tears with a swipe of my white business shirt sleeve.

Blood stained my shirt. It stained the floor. It twirled around the drain of the sink before vanishing forever in a rush of water. My problems didn't vanish so easily.

Sitting opposite two members of the Crisis Assessment Treatment Team (CATT) in a side room attached to the Emergency Department. The ambulance had been responsible for bringing me to this place. I don't remember wanting to go with them, but chances are I wouldn't have had a lot of choice anyway. There were a lot of choices I was about to lose in the next 24 hours, and eventually the next year. This was made clear by CATT from the outset. I even asked them if I had a choice when offered a chance to have a 'break away'. I didn't, of course.

A break away. The way they said it made me think of a holiday resort on a remote Pacific Island in 30-degree temperatures with a pool to cool off in, and some of the local women serving me cocktails. It was more like an oversized goldfish bowl where the goldfish did all the watching from the inside out.

I was about to enter a mental health ward.

This was my new world for the next seven days. At least I was told it was the next seven days. I was nervous and anxious, even fearful of what to expect and what was awaiting me as I entered the ward.

'I'm not the same as these other nutters!' I thought to myself.

My name was already on the whiteboard in the goldfish bowl when I was escorted to the ward. The whiteboard appeared almost suffocated with the scribbles and scrawls of people's lives in blue marker.

First names, last names, identification numbers, room numbers and the names of their responsible goldfish.

There was a name that I recognised on the whiteboard, apart from my own that is. He was one of the guys I had grown up with. I had gone to school with his older brothers. Played casual games of rugby with them at the local park, even gotten into a heap of trouble with one of them in particular.

There he stood with a broad smile. You wouldn't think that anyone could possibly be so happy to see someone, but for some odd reason, he seemed happy to see me. In a lot of ways, I was really happy to see him too.

To me he was the guy I had grown up with. The kid from down the road. He wasn't just another patient in a psychiatric ward. He was like me. He was normal.

If only I had seen myself. Dressed in a business shirt and dress pants, with blood staining the front of my shirt, I probably appeared about as far from normal as I could've been right at that moment.

The day had been a rugged one for me. I was still reeling from the complimentary charcoal martini offered to me upon entry to the Emergency Department. Not to mention the free acupuncture session undertaken with a needle and thread.

He greeted me with a 'Hey bro'; it was the best 'Hey bro' I had ever heard.

The ward was oddly laid out. The structure of the ward resembled a doughnut. Bedrooms extended down one end and meeting and interview rooms down the other, with the goldfish bowl taking pride of place at the 12 o'clock slot. I didn't realise it then, but there was a short corridor behind a locked door which led to another suite of rooms – I would eventually get a much closer look when seven days turned into a couple of weeks and then a couple of months.

I asked myself how I could possibly be in this ward with all these other 'crazy' people. I'd seen enough television, read enough newspapers to know what kind of people ended up in these places. I didn't want to end up sitting in the corner of the room, reading the latest Stephen King book, completely nude!

I wasn't going to get my answer, at least not immediately anyway.

We sat around an outdoor bench which was situated in the middle of the doughnut ward. It was covered in fake green turf, possibly to replicate a peaceful and serene field of grass as much as possible. They only missed by a few thousand metres in trying to do so.

This was where the smokers gathered. Not just the smokers, though. With very little else to do in this place, all the 'mental patients' congregated in this field of fake turf.

They were not the sort of people I expected to find in the ward. There was the car salesman, the 21-year-old student from Otago University, the 17-year-old skateboarding-looking male kid who had befriended a similar -aged skateboarding-looking girl. The druggie who was also from my neighbourhood and the Indian woman who kept to herself, not to mention another 'chick' who reminded me of the chicks I had grown up around. All far too normal to fit the stereotypes that I had grown up to believe, it really did make understanding my environment a little bit harder.

What amazed me even more about this eclectic group of people was how they recalled the names of all the different medications and their associated side-effects. If I hadn't known better, I could've sworn that I was sharing a ward with a group of pharmacists.

I was in awe at their ability to do so; but more than anything I was in awe of how normal these people seemed to be. Not only would I grow to enjoy the company of these people, but I would grow to understand that for once in my life, I actually felt that I fitted in.

Despite the extreme differences in our backgrounds, our experiences and our upbringing, we had one thing in common. A shared understanding of how fragile our lives could be.

The goldfish weren't all so bad. In fact, it seems a bit offensive to refer to some of them as goldfish because a few did actually manage to get out of the bowl and interact with the people around them. Amphibians perhaps? No, even that sounds a tad offensive.

The nicer nurses, for lack of a better term, didn't treat me like a patient. If anything, the nicer ones were as normal as the patients. Given that we were made up of people with impressive jobs and backgrounds, interesting hobbies and lives that didn't involve working shifts, that's quite a statement to make.

My parents feared having too many people know that their son was in a mental ward. The son of one of the local Samoan communities nonetheless. What would people think then? For a while, not even extended family members were told about my break away; my parents thought it best that they didn't know. I'm not sure who they considered it best for, but I didn't entirely disagree with the secret being kept either.

Despite feeling that I fitted in with my new flatmates, I wasn't exactly proud of my current residence. Most of all, I was least impressed with the landlord.

At first I appreciated the dingy doughnut ward for what it was supposed to be, a break away. That all changed when I was subjected to my first dose of a sedative, Pro Re Nata (PRN).

Something had happened on the ward to upset me. I felt myself slipping back for the first time in a week, grabbing hold of all of those negative mental images, thoughts and labels as I did so – aspects of my life that I had clung to so steadfastly for all those years.

My responsible goldfish offered me a small concoction to help get me through this period. Having surrounded myself with negativity for a good part of my life, I had a natural and healthy disdain for anything that seemed like an offer of goodwill. (That's why I wasn't so trusting of the holiday breakaway offer made by CATT in the first place.) As was my response to them, I asked if I had a choice in the matter. Once again, I was given an indication that I didn't have an option.

The pills vanished down my throat.

I awoke the next day, 'awoke' being a loose description of what I actually managed to do: open my eyes, get out of bed and somehow dress myself. My body felt slow and lethargic. My movements would have appeared considered and they were, but I was considering more how to get one foot in front of the other without falling over.

My father had come to visit me this day, but when I tried to speak to him, I merely spluttered and spat. Unable to prevent the saliva from leaving my mouth as my tongue fumbled around what was supposed to be the English language.

After years of working in radio, earning a living from speaking, I was finding it hard to mutter even a few words and when I did, I spat on my father in the process of doing so. This frustrated me no end; I grew more and more upset and angry until I lashed out at the only thing I could, the walls.

My father grew more confused till the situation was explained to him by the responsible goldfish.

My father later learned the reason why I was offered the concoction. In my upset state, I was deemed a risk by some of the goldfish, because of my physical appearance and most likely aided by the fact that I am brown. Great, another label to have to put up with, one based on physical appearances. I wasn't even that big a guy.

Seeing the boxes

That moment was life-changing for me.

Before going into hospital I was a seemingly well-known and popular DJ. I appeared to have a privileged lifestyle. I had plenty of friends and socialised with the 'in-crowd', despite never quite feeling that I was a part of them.

Having been so wrongly judged by someone who was supposed to have been there to help me, you would think I would have dived further and deeper into me, finding it even harder to break free. Somehow I found motivation and inspiration in it. The greatest of which came from having shared stories and experiences with other people who were much like me.

I still didn't like myself that much, but I somehow realised that I couldn't be so bad if I was like so many other people.

Coming out, it was almost as if I had contracted an infectious disease, going by the reaction of the in-crowd I was once a part of, most choosing not to associate with me. Under normal circumstances, I would have taken this personally, internalised it and thrown it up as another reason for self-hatred.

I was stronger for my experiences in some respects, but I was ashamed to tell people that I had been in a psychiatric ward. It was a very long time before I even wore short sleeves again. The act of receiving change in a store meant that my now scarred wrists were on display for everyone. It wasn't that I was ashamed of having cut my wrists, or having felt tormented to a point where I thought that was the only option. I was ashamed more because of what it often meant to other people, that I was either a weak individual or that I was completely and utterly nuts. The nuts part I could almost live with.

I have learned to have pride in many of the things that make me who I am.

I have always been proud of being Samoan. I just don't think I ever truly realised it as much as I did when I met other Pacific Islanders who also had their own experiences of mental illness. The identity I shared with them was so much more than just the colour of my skin or the similarities in language. It was the identity of knowing who we are, something I had struggled to understand throughout my life.

I was given an opportunity, not long after being discharged from hospital, to speak to other Pacific people who had experience of mental illness. Based on our shared perspectives, I wrote a resource to help people working in mental health to better understand Pacific people. The experience was a blessing.

The people I met and had the chance to speak to all displayed a level of courage that I was yet to master. Some of them had experiences more harrowing than mine. They showed me the underlying values of being Pacific. Despite all their experiences, they remained humble and brave in the retelling of their stories.

I had spent so much time trying to climb out of many boxes that had contained me that I failed to realise that ultimately they were the very boxes that could provide me with the walls to protect me.

All the boxes still carry negative connotations with them.

Some time after leaving hospital, I was working as a support worker in a youth residential house. One of the nicer nurses I had come across during my time in hospital was visiting a young lady staying in the house. I hadn't seen this nurse in some time. See, I had graduated from the initial ward and was eventually moved to a longer-term unit where I spent a number of months before being discharged. Greeting each other with a hello, she asked if I was also living there.

With a smile I recall, I corrected her.

Despite this, I have even discovered that the box of having a mental illness is also a protective one. I have learned to appreciate my strengths, acknowledge and accept my weaknesses and challenge my very own fears.

Milan Patei age 13

On a loss of faith

Dennis Duerr

While writing this chapter I have been plagued by self-doubts. Doubts as to whether disclosure of the experiences I write of is wise. Thinking on it, I wonder . . . were these experiences to be presented in a different context, perhaps as part of a new-age book, a fantasy novel, or a frank and honest discussion on psychic phenomena? Would they be taken more seriously than they will be in a book about self-stigma associated with mental illness? Disclosing like this is unusual for me. Because of societal stigma, I very rarely choose to be outspoken in regards to 'psychotic' experiences, including voices, ideas and concepts that the 'sane' world would class solely and simply as being delusional. But that is the point – societal stigma has had such a significant impact on my self-perceptions that I now need to present an alternative view, a view which has enabled me to once again fully appreciate and make use of all my abilities in every sense.

Self-stigma is often talked about in relation to the vocational, social, and familial domains. My experience involved a blanket self-denial of my 'sixth sense'[1] as a result of the internalisation of views, upon being diagnosed with

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[1] What I mean by a 'sixth sense' is my sensitivity, telepathy, intuition and psychic experience.

psychosis, that all such things were simply delusions. These views came from friends and family, from people who are held up as being wise in the ways of mental illness, such as psychiatrists, and from society's conventional wisdom – that the mad are mad . . . and that is it.

Before my psychotic episode, I believed very strongly in telepathy and trusted my intuition. I come from incredibly sensitive parents, and was raised together with my two brothers and two sisters, all of whom are also sensitive. I was bought up to think of sixth-sensory experience as being just another sense with which to register life.

I remember being told at an early age about something that had happened just after my mother and father first met. My mother found a card which she thought was completely perfect for my father. She believed the card reflected exactly how she felt about him. She spent that day looking forward to giving the card to my father. When she finally saw him, she handed him the card, and he handed her a card. They each opened the cards and found that they had bought one another the same card. This story was never presented to me as being an event of coincidence. When it was told, and it was told a few times by both my mother and my father, it was reasoned to be a meeting of the minds through love.

My belief is that traumatic events often trigger heightened sensitivity, intuition, telepathy and psychic experience. The experience of mental illness is a traumatic experience and it happened to me, someone already possessed of heightened awareness in these areas. So then, I find it interesting that when I was recovering from mental illness I lost faith in the validity of my sixth sense. Even now, somewhere on the axis of recovery, I have a partial loss of faith.

When talking to observers who were there at the time of my acute mental distress, I presented as being withdrawn, sad and disconnected. Observers believed that I was lacking emotion and empathy towards others. In fact, most of the time I was feeling more emotional, more tuned in to the emotions of those around me and, therefore, deeply empathic. On top of this, when I was experiencing psychosis, I was hearing voices and receiving communication that I believed to be valid and real. So, my experience of being unwell was that I was in fact more connected, more sensitive – to the point of believing myself to be telepathic.

Paradoxically, it was also at this time that I was told that this enormous life-changing experience was madness. That it was schizophrenia and it meant nothing other than a chemical imbalance.

After my first psychotic episode, having been told by psychiatrists, loved friends, family and support people that there was no truth in my psychosis, I went through a two-year phase of believing all things 'other' to be false. Anything 'other' that went on in my head was treated as delusion and shut up with medication.

My second psychosis blew all this out of the water – to my mind there was inconvertible proof that what was happening was no mere illness.

I am a writer. Sometimes I wonder where the writing comes from. The most interesting insight I have ever had to this question came in the middle of my second psychosis. The year before I had written three pages of dialogue. The dialogue involved two people having a very intense argument, during which one of the characters emotionally manipulates the other into thinking an important part of themselves has died. When I say it was writing, it was actually more like dictation. I didn't need to think, I just wrote what the two said. A year after writing this, I was psychotic. I was in a room with two women, and they were having the exact same intense argument as that which I had relayed through my writing. It was as if life had made a play of my dialogue.

An amusing anecdote that I sometimes tell the 'right' people – those who have gained my trust – is that of being locked up at Kenepuru Hospital and thinking that a fellow patient was talking to me in my head. He was telling me I reminded him of the central character from the New Zealand film by Peter Jackson, *The Frighteners*. He compared himself to the character's nemesis, an FBI agent who hated ghosts and all things supernatural. Now, I had never seen the movie before and can honestly say I don't recall reading a review or synopsis, or talking to anyone of the finer details of the film – yet when I finally saw the movie, all of what my 'delusions' told me actually happened in the film.

Even with such an experience, writing this, fairly secure in my own version of the world, Brother Doubt comes in and says: 'Perhaps you glanced upon a synopsis, perhaps you overheard a conversation.' The problem is that, looking back with reason, so much of the psychosis was actually delusion. It was an overload of information, which I am still processing as to what was true and untrue. And the filtration process leaves dregs of self-doubt.

It is my 17th year, the time of my first psychosis. I was staying at a boarding house. I had a cup that I was very fond of. The fondness came from a complex mix of beliefs – mostly deluded ones. I believed it was a magical cup. One of the guys there noticed my attachment to the cup. While I was not looking, he took the cup. I wondered where my magical cup was – 'Where is my cup? – Where is my cup?'

The guy who had taken the cup smiled at me and said: 'See if you can find where I have hidden it.' The boarding house was having repairs done at the time. I climbed up the ladder, through a window and into a bedroom that was being renovated. I walked to the chest of drawers, opened the first draw, and in it was my magical cup. I was happy.

I cannot think of any other explanation for this other than a psychic experience.

There are other experiences that I am still puzzled about. One of the beliefs of my psychosis was that all my clothes had different properties. There was my evil cut-off checked shirt, called evil because I had borrowed it off a friend whom I thought was evil. I also had a pair of shoes that were my 'nerd shoes'. They had been given to me by my father and reminded me of the shoes of a nerd at school. I thought that they were the actual pair of shoes that the nerd had worn, and I had to wear the shoes as a penance for giving that same nerd a hard time.

I had a farmer's shirt that had been given to me by a farmer. I had a jersey that was my 'schizophrenic' jersey, given to me by someone with the diagnosis of schizophrenia. I had a pair of jeans with magical powers.

I began to worry about all the properties the clothes and decided that I no longer wanted such strange clothes. It was nighttime. There was a skip bin outside. I walked outside and put the clothes into the skip bin. When I returned inside, the clothes were back in the house. I put them into the skip bin again. When I walked back they were there, in the house again. I walked out and put them in the bin once more. Finally, they stayed there.

Thinking back on that experience, I wonder still. I talked about it with a counsellor, and his belief was that I had forgotten bringing the clothes back from the skip to the house each time. Hmmm, maybe... the experience puzzles me to this day.

My personal belief is that not all psychic experiences in acute unwellness, especially psychosis, are true. I think that, in instances of psychosis, a large number of experiences are in fact delusional. Certainly that is the case in relation to my own experience. Many instances of what I thought to be true in psychosis were actually delusion.

The main problem in dealing with my psychosis, even years later, is confusion. There are so many concepts and ideas, voices, hallucinations, so many untruths, that to find the truth is difficult. The fact that the Western notion of psychosis tells me I have to let go of all these experiences, that to me are just as real as the sense of touch, makes it even more difficult. During my psychosis I had delusions of all five senses – sight, smell, touch, hearing, taste... and I had delusions of the sixth sense too. So, since psychosis, I have had doubts as to the validity of all six senses.

Unfortunately Western culture has no respect for psychosis as a spiritual experience. In Native American culture, someone who begins to exhibit what Western culture interprets as psychotic experience, is seen as being possessed by the souls of a dead shaman. In addition, there is ancient tradition, dating back thousands of years, about how to respond. In that culture it is believed that the spirits of the shaman are trying to show that the person is meant to be a shaman. They are then initiated as such through a complex and ritualistic ceremony. I am not proclaiming this to be the correct way to respond to such events. My point is that that culture has a tried and true way of containing the psychosis and turning it into a unique and privileged experience. The person who receives the gift of psychosis in Native American culture is not usually happy about it. It is seen as a very painful experience, involving suffering and hardship. But they do have the support, partially due to the respect accorded as a result of being considered spiritually treasured and precious, of the ancient shamanic tradition.

The Western world has a kind of code of silence when dealing with the sixth sense, a stoic denial of something that, to my mind, is so obviously there. Couple this with the stigma that the Western world heaps on mad people's experiences, and then triple that with the fact that someone dealing with psychosis actually has to admit at some point that, yes, parts of what they experience as reality is erroneous and this all serves to make people who are already confused even more confused.

As I was recovering, I gained an understanding of which psychic experiences were valid, which voices were simply manifestations of their inner self, and which voices had come from an exterior source. I also gained a personal appreciation of my delusions and what they mean. In this process came a reassessment of my reality. I looked at the thoughts and emotions I had and questioned them.

I saw and see this process as valuable. However, it involves being brutally honest to myself about what is true and what is false. It brings doubts into truths previously held. Through this upheaval I, as a sane person, choose to believe in a reality that others don't. This choice distances me from the world at large, supporting a belief that I am 'other'. Consequently, I feel stigmatised by society as well as self-stigma that comes from rejection and otherness.

I have experienced two states of being in the aftermath of psychosis: the time when I denied all validity of, and suppressed, any sixth-sense perceptions, and the time, as is the case now, when I accept and appreciate my experience as one that, simultaneously, has elements founded in both delusion and a reality that is of value and importance to me.

These days the middle ground involves me undertaking a critical self-examination whenever I encounter my sixth sense. Essentially I have to do a double-think and assessment – is it real or is it my illness? Should I listen to it or should I ignore it?

When I am making this assessment, I ask: 'Is this a thread of thought that has tried to trick me before?' If it is, I can dismiss the thought outright, no matter how convincing it tries to be.

An example of this comes from last year when I was trying to decide whether or not a new medication would work for me. During this time, I started becoming very anxious around crowds. I was worried that I had been slandered by someone and that the slander had been taken up by the whole of Wellington. When contemplating whether this perception was true or not, I examined the fear. The basis of it was that I was in telepathic contact with the slanderer. Some days I would almost be convinced that the slander was really happening. However, there was a part of me that knew the truth: that this perception was, in fact, a fearful delusion. I knew this because, upon examination, I recalled having had similar false chains of thought previously. In my first psychosis, I had the belief that I was in telepathic contact with someone who was telling me they were making T-shirts with photos and insulting messages about me on them. So I had a precedent set – I had already attempted to fool myself with a similar thread of thought. This made it a lot easier to dismiss the fear that I was being slandered. Because the core of this fear came from a supposed telepathic connection, dismissing it involved denying my sixth sense.

There have been times when I have considered my sixth sense and, despite this consideration, it has turned out to have been wrong. This happens to everyone, mental illness or no mental illness. On the flip side, when I have not acted on my sixth sense, through fear that it was erroneous, I have ignored what was real.

It always makes me very sad when I have to dismiss what I thought was genuine sixth-sensory activity. I have a romantic attachment to my sixth sense ... it's so mysterious.

Family and friends have found it very difficult to let go of their perception of me that they gained when I was in an acute state – as being victim, other, deluded, in need of correction. I have found that there have been people in my life who, despite a deep belief in their own and others' sixth sense, have denied mine. This is because they view a lot of what I believe to be psychic experience as delusion. I guess they think that a blanket denial of all things psychic will be easier for me. Knowing this to be the case, that they are allowed to believe in their own and others' experiences of these but I am not, definitely makes me feel different. It makes it hard to compete when this important part of me is denied.

The way that I have learnt to compete is to use my sixth sense as an asset. Currently I work as co-ordinator of a peer support service. On a daily basis I interact with people who have similar experiences to mine. The extreme confusion that I felt, and occasionally still feel, means I have the ability to truly empathise with my peers. I can also use the understanding I have come to have for my experience to support others – by listening and believing that their experience is just as valid as anyone else's ... and often a lot more interesting! As a professional, I am not running around telling people that they are having sixth-sensory experiences – but I sure as hell am not going to deny them the truth of their experience.

Yes, I do sometimes feel 'other', but when I consider what I am 'other' to, I am often glad. Deluded … well more like allowing myself the freedom of thought to contemplate things that others turn a blind eye to. In need of correction … I don't think anyone has the right to correct my way of thinking, a way of thinking that has been hard come by and is constantly being honed.

And to those who would deny my sixth sense because of that word which has been thrust onto me: schizophrenia … and to the part of myself that would self-stigmatise to the point where I doubt something that, to me, is as real as looking at the sky, I would quote Ursula K. Le Guin:

> This is. And thou art. There is no safety. There is no end. The world must be darkness to see the stars. The dance is always danced above the hollow place, above the terrible abyss.[2]

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[2] Le Guin, U. K. (1972). *The Furthest Shore.* New York: Atheneum Books.

Jo Doherty age 24

A call to value madness as one of many human experiences

Anne Helm

A reflection from a bygone age where sanity was synonymous with survival, and value was found amidst a life of incarceration. Self-worth was fashioned in relationship to other patients, and against staff's often humiliating response and disinterest. Family shame and fragmentation was exasperated by the dominance of the fear-filled diagnosis as the primary reason for behaviours. Societal discrimination was so extreme that having been in institutions had to be denied in order to create a life on the outside. For someone contained by law in institutions it was accepted that anything other than a life of diminished possibilities, containment and State care was just not possible.

I write as someone whose life throughout my twenties was marked by incarcerations into New Zealand's major psychiatric institutions. By 'incarcerations' I mean being held without choice or recourse. No writing about self-stigma from my perspective can begin to be explored without reference to this institutional time, a time that is the most profound marker of my life. You might rightly ask, 'Are such reflections on institutions relevant in an age where service provision is moving towards a dominant community response and acute care is envisaged for the shortest period of time within the least restrictive environments?' I argue that what we learn from the past will create history in the present, so it is always relevant.

Respect for the madness experience

Ideation about the self is never as fragile or perplexing than at times of severe distress, in whatever shape it takes. One of my premises for the relevancy of historic reflection is that attitudes toward the *experience of mental distress itself* have not changed. In treating the experience as alien to the person's collection of life experiences, we assist in the fragmentation process from which ideas about relative goodness or OK-ness are based. This is particularly relevant to the topic of self-stigma. Not only are we, the clients of service, treated as people who experience some weird kind of otherness, but we also have to come to terms with these experiences, their cost and their manifestations as being deficits and battles to 'live well in spite of'. It is a framework that negates personal effort to gain deeper understandings and tools of self-efficacy to both minimise impact and celebrate sensitivities that lie at the root of the 'illness'. As a result, these experiences become conveyed in a language of deficit and negativity rather than rich, valid human experience. How these events are then talked of impacts on the overall appreciation of oneself and that appreciation (or non-appreciation, as the case may be) is at the heart of self-stigma.

In my case, these experiences came out of my fundamental self. They were/are not some alien visitation. As a girl and younger woman, I always had a feeling of an otherness outside of, or greater than, myself. A 'spirit consciousness' if you like. This, when manifest in God-talk at times of distress, became confused by health professionals as some mystical delusion. Yet, ironically, this self-knowledge, of a stronger essence, was the very thing that enabled me to retain some dignity in a world where very little else existed.

Underneath many experiences, which I will refer to as altered perceptions, is a scramble to make sense out of a crashing world. This world may be the result of accumulative stress, or a severe trauma. Fractionating that experience by labelling it, mitigating its effect by medication, without offering talking therapies, or better still peer understanding, dislocates the healing process and denies the opportunity for learning. Given the context in which these experiences emerge, it is not preposterous to suppose that human distress and madness, in many cases, is not an illness but a valid expression of the self seeking wellness and understanding amidst complexity, albeit sometimes in random and chaotic fashion. In truth, demonstrations of the mad self are never too far removed from the personality or natural interest of the individual. This is not denying the intricacies that can surround the manifestation of madness or illness.

Institutional life and the developing self

Removing people from their natural community is one of the most extreme ways of maintaining 'otherness' and the mystique of illness. It also limits the self-efficacy born of understanding the crisis and the potential for change it presents. Furthermore, it widens distance in relatedness and minimises opportunities for connection and empathy.

Institutions were places of remoteness where stories could develop mythic proportions. And while I witnessed the effects of outrageous atrocities as a result of unwieldy, unbridled power, in the depths of this darkness I was also privy to basic human responses of compassion and goodness. The light-filled shafts of these experiences could only confirm the possibility of beneficence in the most awful of human conditions.

This place was regarded as 'the end of the line' and my family, wearied by incarcerations and holding no hope, had their own grief and lives to attend to. At 27 years of age, this was it. This was my life. In the microcosm of community one must find purpose and meaning. As a young woman forming ideas about who and what I was, the institution was my community.

Scouring one's fogged rationality for explanations of treatment regimes and the acute disconnect between the two worlds of patients (those who always stayed) and staff (those who had a life outside of the long driveways in communities where love, lust, money and family where allowed to flourish) was a constant task. So, too, was the desire to understand the relative nature of madness as it was displayed in these places.

A vivid memory I have is of a particular trained staff member who would take off his shoe and talk into it in response to the telephone ringing and then laugh crazily at us as we sat in the day ward. I contrast this with a woman patient, who came in and talked as fast as her knitting needles clicked, saying she was in for a rest from her 12 children, but that her husband's jersey needed finishing first. Which is more rational? Craziness did not reside in residents alone.

We develop our self-concepts in conversations and in relationship to others. Removed from the common place of societal interactions, hugely overmedicated for mass control, taking into account overworked staff and the vastness of the scale of inmate 'care', meant that relatedness with staff could only happen in rare moments. Their primary task was housing, feeding and medicating, with no thought of therapy or possible change in condition. Illness/diagnosis was a fixed, continually marking, minimal expectation of a diminished life. There was blandness to institutional living with its powdered scrambled egg and one-cup-fits-all very sugary milky tea to serve the mass. The presence of the loud television in the day room, blaring the concerns of the outer world, was what I came to call the universal nurse. Nurse aides introduced everyday experiences such as a game of 500, a game of pool, or a vigorous game of badminton with the adolescents. Being the only young female player dodging, and occasionally hitting, flying shuttlecocks fuelled by the pent-up frustration of male adolescent confinement was something I both feared and loved. At least in those moments there was life!

The worst attempts at normality were a nightmare experience of beautification with blue eyeshadow and hair curlers. What we would ever be beautified for, apart from an on-the-spot pantomime we looked part of, seemed an irrelevant question. This obviously fell under the 'look good equals feel good' mission. Remember, these were places where outsiders in the form of visitors were rarely seen. Neither, too, were doctors, as the bulk of the work was done by a psychiatric-nurse-to-nurse-aide hierarchy that retained the treatment status quo. In the seventies, this treatment could include such things as deep-sleep therapy, control by seclusion use, electro convulsive therapy (ECT) and generally paralysing amounts of medication, especially the wonder drug of the time: chlorpromazine. This drug rendered all takers with a photosensitivity which meant that only minutes in the sun resulted in fierce skin-burning. And so, adding to the feeling of lumbering body paralysis, patients had the indignity of having white cream smeared across exposed skin before being led on routes around the vast unpopulated grounds under the supervision of nurses whose containment keys swung from their hips.

The other exercise regime consisted of herding inmates into the corridor where, in a tight-packed bunch, we would do weird limb-stretching exercises from our bottoms to the count and demonstration of a young fit female nurse aide. Limbs in various states of atrophy would wave with accompanying moans. If ever there was a time I felt that I was in some human raft of the condemned, it was then.

The only way to establish OK-ness in this world was through conversations and interactions with my fellow inmates, those in my waka. It was through this that I was able to create a sense of goodness within myself.

I am aware that in writing this that I am one of the privileged ones. Many people I slept alongside, in overcrowded dormitories, did not ever make it outside of the long driveways to the wider community. One of my steepest learning curves happened when I was placed in a geriatric women's villa in Lake Alice. Seeking respite in the night, loud snufflers and snorers tested mental endurance and patience. The only way to endure this was by finding a way of relating. I did this by listening to fragments of the stories of the women's lives. A tall, one-time-elegant woman would call out the same beautiful names daily as the sun was setting. I wondered how many staff knew she was calling her favourite cows by name to the milking. One day I had swept up a tiny woman in a dance across the day ward while singing 'You Are My Sunshine'. This woman, who had not talked in years, sang in a reedy voice in my ear the very words of the song! These people at one time had rich lives and were still wonders in themselves. I assisted at meal times to spoon feed some of the less able and fondness towards my fellow inmates grew, and, as it did, sleeping beside them became easier.

Medications meant that eyesight was continually blurred, so I could not read music or books any more. I did, however, create a scheme of getting 'ground parole'. By carrying a few sheets of music I could go to other villas that had old out-of-tune pianos, where I would play songs and sing to inmates. I did Vera Lynn-impersonations for old men in pyjamas and they grinned as if an angel had visited them. The irony of 'Don't Fence Me In' was never lost on me. When I returned to my own villa, to be locked in behind that big wooden front door, I knew that I had achieved something. I had found the ability to give to others within my community, and I reaped the momentary rewards of their smiles and enjoyment. And with that, self-worth grew. I maintain that the origins of peer support are to be found in the lives of people in institutions and I pay respect in particular to the beautiful old women who taught me that. We each gained from each other.

The young adolescent boys' energy and deviance in the face of often brutish response was something I also valued greatly. Their lives had often been a series of travesties beyond description and yet, they had pluck, energy and a life force that was indomitable. My favourite young man was in his mid-teens, experiencing an identity dilemma of what we would now call transgender identification. He was ostracised by his own peer group and blatantly ridiculed and brutishly manhandled by male staff. Yet he remained tenacious and true to his quest for understanding and identity. His courage to be who he believed he was, against incredible odds and huge disdain, both societal and institutional, was heroic.

Some women were caught up in male-engineered plots of removal from their own communities in order for ex-husbands to legitimise new relationships. Grief and hysteria at the natural injustice of such stories only served to verify their diagnosis. The classic catch-22 situation. I came across many everyday people, often with stories of incredible personal injustice, who had found themselves shut off and denied interactions with their own children and family.

I was, in fact, one of them myself. And so, in all the faces and interactions, I related to a part of me: the cows called home were those of my grandfather's farm; the stories of family misunderstandings and abandonment were fragments of my own story; the 'I will be who I will be' heroism of the youth gave me strength beyond imagining; and the rekindled song in the heart of the little stick-like geriatric woman were signs of life in the depths of a perceived blank mind. These were my people, and in relatedness I loved them. They gave me courage and personal worth.

An element of self-stigma is based on difference and comparison and yet, within this community I found commonalities and value. People choosing to disclose their circumstances allowed me to see what parallels of experience we had. This was an incredibly valuable thing to learn for later. Being able to sense, and connect through, commonality was a key part of rebuilding my self in the wider community, once I got that opportunity.

My initial experience of Lake Alice had caused me to question my very right to existence at all. My struggle for a rational explanation as to 'why' became bound up in a belief of having committed a horrific crime. No other explanation could make sense. Convinced of a mind-blank, where I must have taken the life of a precious child, I rocked, constantly pleading to an inner god that it had not been so. The break from that torture came when I was taken by staff to a bathroom and, while in a bath, a slim dark-haired endorsed nurse washed my hair with the gentle fingertips of an angel. Goodness still existed somewhere and it was being shown towards me. I was not, therefore, the monster that had been born by this unreasonable response to my madness. My own thoughts of having killed a child, as an explanation for the treatment given out to me, were not that far from rational sense. I carry a lifelong grief caused by the removal of my first child by a system that believed I could never be an adequate mother.

Through this time I found, and then hung onto an essential belief that there was a core essence deep within me that was untouchable and impervious to human altering. This core belief became the bedrock of my self-esteem and key to my survival. A tiny spark of essence, always there and unalterable, it cannot be touched. It is pure spirit.

With regard to family, our challenge today is as it was years ago. Like many others from the era of institutionalisation, I have an enduring struggle to be accorded familial respect and honour as a member of my family of origin. Acknowledgement of severe stressors, profound loss and trauma as being significant contributors to my 'break down' was never given by my family. The diagnosis, so common in those days, of schizophrenia was too painful for them to mention. Shame and silence were not just things experienced by the person institutionalised. It also became the burden of their families. Mental illness was not something that was talked about. There was no language around these events other than the schizophrenia diagnosis which equalled travesty and hopelessness. Diagnosis also provided an explanation for my behaviour. It was, after all, a medical problem.

Communication between the services and families was minimal. In an effort to understand the reason I had been part of the deep-sleep experiments at Cherry Farm in the 70s, I recently obtained my notes from that period.

They make for sombre reading of a system that responded to behaviours without ever asking the reason for such actions. My placement in a programme of deep sleep, that ultimately left the greatest challenge in recreating my self, happened because I had gone AWOL from an open ward. I had got myself to Dunedin where I was seeking another opinion and a magistrate. The exasperation into mania happened as a result of being raped in the city and, as usual, my survival instinct put me in a place of beauty rather than a place of terror.

I was apprehended and brought back. Deemed unsuitable for an open ward, I was placed in the six-week deep-sleep programme where the main concern was the constant taking of blood pressure because the huge amounts of medication coursing through my body could potentially paralyse and stop fundamental functioning. At the end of this 'treatment', my legs atrophied from complete bed rest, I could not support my bloated weight. I was released to family so overly medicated that I was barely able to lift my head from a pillow. Yet little, if any, of this was discussed with my family. There is a letter in my file from my father expressing concern at my lack of motivation, as I preferred to 'sleep like a cat' around the house.

Two events around that time are anchored in my mind as examples of the tremendous disservice we can give friends and family of the person in so-called treatment. One is of an old school friend who came to visit but left early. On contacting her mother, I was told that she was too upset to be able to continue a friendship with me. And she didn't. The other is of my brother who had the most contact with me during those years. After driving some miles to see me, near the end of the deep-sleep treatment, he sat with tears running down his face, then got up and left without saying a word. Those years we do not talk about, not ever.

The language we use to frame the madness experience and the way we pathologise the experience into an illness mode with medication responses so dominant, make loved ones weary, disconnected and at a loss as to how best to support us. If services assisted the individual and their significant others in their lives to understand the contextual underlay of altered perceptual experiences, there would be more opportunity for compassion and connection in contrast to suspicion, mistrust and separation.

Legacy of institutionalisation

Deep-rooted beliefs of basic unworthiness meant that the self-improvement pop psychology of personal affirmations simply did not work. For every affirmation chanted, the negative creep of self-doubt replied from the murky pool of the subconscious.

Creating oneself in a post-institutional world seemed to be more a hit-and-miss game of random chance. A legacy from institutional life was the feeling that I had little power to change personal outcomes. Most of my young adult life had been decided for me and believing I had the ability to change my own destiny remained difficult. Finding a sense of place in the wider community seemed to be determined, not by how one played, but by other players. Being more than 'the crazy one' was a work of re-creation. Having been labelled 'crazy' and removed from society is incredibly powerful, and dealing with the effects of this on my perceptions of personal difference and deficits has been a lifelong challenge.

Back then I expected little of myself. My focus was merely on survival. Poverty, homelessness and being an embarrassment to kin, as my very presence reminded them of where I had been, peppered those early years of freedom. Finding one's integrity as a human being was difficult. So much of a sense of place originates within the family. Yet mine were at a loss to understand and accept what had happened and it became too hard to find a place within that unit again. I was motivated by one thing: to survive – to keep picking myself up and making sure I remained outside those hidden, kept communities.

Denial of experience also deeply buried the etched traumatic memory of some institutional experiences and invalidated healthy reactions of natural grief and anger. Earlier losses – the death of my mother, the loss of a singing career, and the removal of my first-born daughter to others' care – lay unattended. No one had deemed these events important enough to support me to talk about them. If my life events did not matter, why would I matter? To think too deeply about these things became self-indulgence, something a Presbyterian upbringing discouraged. There was a job to do. One had to forge a life on the outside. Coping under all, and any, conditions (a trait that became its own mantra, even to this day) in post-institutional life became paramount. I remained dulled, but still easily ignited by challenge (particularly from any authority) and with a sensitivity to criticism that could be said at times (without knowing my past history) to be irrational. Self-protection rallies in the face of judgement, even today, my skin still tender years on from that decade of feeling lesser than others.

Later, in the eighties, focusing on the role of parenting became imperative. I pay tribute here to the Playcentre movement in New Zealand that assisted me in my mothering of two very young children, provided me with loving acceptance and creative joy, and gave me a platform to develop my 'social reformer' skills. By this stage I also had an important friend who stood by me. They knew where I had been and loved me all the more because of it. This friendship and the validation of my own unique contributing strengths remain a cornerstone of my overall recovery.

My desire to prove my sanity became equated with taking on Herculean tasks, coping single-handedly with guy-ropes in my teeth to navigate the storms. I set high expectations of myself when I finally returned to tertiary study some years later to prove that 'mad' did not equal 'dumb'. I accepted nothing less than A-passes in everything. This was while I solo-parented two teenagers, taught singing and worked on an extra degree in music performance. I know now that much of that drive was to prove that my brain cells had not been destroyed by ECT and medication. It was also in order to create a new life as an educated woman. I particularly needed to prove to my family of origin that I was still functional.

My incarcerations have left me with a high sense of social justice and I did not get through training college without being an openly outspoken adult student, challenging students and lecturers wherever I perceived there were attitudes of any kind of discrimination. While being awarded a scholarship for being a top academic student, I was not endorsed as a new teacher who would have slipped easily into the education system. As a result, I did not find teaching work and, instead, took up the role of establishing an advocacy service in Dunedin for people who use mental health services. Finally, I no longer had to conceal the secrets of my past.

Context of madness denied

As a woman nearer 60 now, I can plot back and understand the trigger factors of my madness and have an appreciation of my altered perceptions as being a gift for survival. My manic states are something I am grateful for. They kept me alive where, contextually, suicide would have been more logical. This gratitude has resulted in me personally rejecting the negativity associated with diagnosis and celebrating the gift that illness can bring. The Discrimination Intervention model (as presented in Chapter 1) identifies the reframing of experience in its own positive worth as a 'circuit breaker' that can interrupt the cycle of stigmatising behaviours.

With regard to the contextualised events that precipitated my shift in altered perceptions, as I write, the State-sensitive claims mechanism continues to deny me therapy. It opens the door to feelings of being less entitled than others and the possibility of self-devaluation. I find it hard to keep pursuing what is rightfully mine in terms of healing treatment. It was never given and, even now, seems unobtainable. In my 'less sure' self-states I wonder if I am making too big an issue of this. Yet 'my surer, more confident' self knows that I am entitled.

Conclusion

Recently I was part of an attempt at addressing the institutional hurts of the past through an initiative set up by the New Zealand government called the Confidential Forum. Our main appointed task was to listen to the personal accounts of people whose lives had been affected by the institutions prior to 1992. This work involved two years of travelling and bearing witness to just under 500 individual stories of people who had been patients, family or staff. While I cannot comment on those stories, I can, in this compilation, tell part of my own story and, by doing so, represent a viewpoint of the effects of institutionalisation. It is an era we can never return to in any shape or form.

The culture that defines how we respond to acuity is important. Culture is more a response from the gut than the head and so actions are rarely rationally questioned until afterwards. Nurses today are encouraged in reflective practice, but changing the cultural understanding of causality of illness, and therefore treatment, is difficult.

We are all called to make sense out of our experiences of humanness. Our commonality of stresses and, in some cases, trauma, or grief and loss, joys and celebrations should open the door to an understanding of the huge variety of possible responses to life. However, those of us who have experienced the acute distress of the psychiatric system know that mitigating symptoms, management of behaviours, and in some cases containment of the individual, often become a paramount modality. Without exploring the nature of the experience at all, assumptions are made, and with risk aversion paramount, we are sandwiched into a set of responses that can only denigrate the experience itself and, with that, part of ourselves also.

I am reminded of how rare it is to find a clinician who understands how disempowering this framework is for one who has lived all their adult life diagnosed by one label or another. In more recent times, a teaching psychiatrist introduced me to his student sitting in on the consultation with 'Anne suffers from . . .'. I put my hand up and said 'Hold it right there!' If I allow others to appraise my life as one of suffering, what concepts of myself am I left with? What value do I give the experiences of wonder and amazement and the profound interconnectivity of people I have seen and witnessed like ripples on a vast ocean? My experiences are not negligible. They are a valued part of my overall life experience. To give value to the experience rather than to frame it in a form of deficit is the greatest challenge.

Celebrating my own life's journey and victories only came when I could disclose my background and work actively for change within mental health. Post-institutional denial of experience served to fragment my life and make invalid, even to myself, experiences that were deemed not worthy of the light of day. This silent shame probably, most insidiously, fuelled my self-stigma. Reframing my experience as a tool for survival and richness was also a counterfoil to the negative deficit-focused medical model of diagnosis. I have had to make a proactive choice to accept the injustices in my life's story in order to live without embitterment. This has not been easy. But the power of choice is mine and I try to live in awareness of what Buddha has said:

> We are what we think. All that we are arises with our thoughts. With our thoughts, we make our world.

Jacob Farr age 9

Me and my shadow

Debbie Peterson

The self-stigma I feel comes from a sense of being different, present since I was a child. Lying in bed one day as a ten-year-old, watching the sunrise, I heard a voice talking to me as the sun came up. I wasn't scared or anything, it was saying positive things, but even at that age, I knew that if I told people that the sun spoke to me, nothing good would come of it. This was my first experience of self-stigma, though some would call it being prudent.

It wasn't the first time I knew I was different. I had always felt different. Not many kids are so powerful that when they wished their father to be dead, that's exactly what happened. I did. At age four. While I now know it was a coincidence, I grew up scared of my power. I thought I was evil. The abuse that subsequently happened in my family confirmed this.

As I grew up, feeling different grew into feeling apart from everyone else, then into feeling unreal, then into feeling crazy. Eventually, as a 15-year-old, I was referred to the mental health services.

I've had a label of bipolar disorder since I was 21. I started experiencing mood swings when I was 13 and saw my first psychiatrist on my 16th birthday. As an adult I have tried every medication under the sun, have been admitted to hospital 13 times, spent 7½ months of my life there. Hospital and I have had a long association. I have always been admitted voluntarily. I have usually fought like anything not to be admitted, reluctantly agreed, and then tried to run away. Eventually I settle in and find it very hard to leave.

I have been determined not to let mental illness ruin my life. I completed school, went to university and found a good job. I gained a masters degree, and then a PhD in social science research, and have worked on interesting research projects, mainly in the mental health area. People often ask me how I manage to do what I do while having a mental illness.

I don't hide my label of bipolar disorder. It's an acceptable mental illness. A real mental illness. One which you can take medication for. Completely misunderstood by the public, and sometimes romanticised. More serious than depression, not as serious as schizophrenia. The mental illness of writers and artists. If you have to have a mental illness, then bipolar disorder is the one to have. Or so I've been told by well-meaning websites and email groups. This hasn't stopped me from experiencing self-stigma, however.

The feeling of difference and its links to self-stigma can start pretty young. Some of the people in the focus groups for the self-stigma research (see Chapter 1) stated that their self-stigma predated any diagnosis of mental illness. I agree with this. My feeling of difference eventually became linked to my experience of mental illness, when I finally had the words to describe what was going on. For me, this feeling, which I later came to realise was a form of self-stigma, is something that has dogged me most of my life.

Yet I don't feel any shame about my experience of mental illness. I have never deliberately concealed it, except where I can't be bothered engaging in one of those inane conversations with people convinced that all people with mental illness should be locked up and forced to take their medication to avoid killing innocent people. Every job I've had I've been open about my experiences.

However, I've never exactly shouted it from the rooftops either. My excuse has always been that, as a researcher, I wanted my research findings and the experiences of the participants to have all the attention. I didn't want the quality of the work or the message that was being portrayed to be overshadowed by the fact that the researcher also had experience of mental illness. I also did not want my work to be dismissed as not being proper research because it was carried out by someone with mental illness. Upon reflection, that sounds a lot like self-stigma as well.

On the face of it, my self-stigma doesn't appear to be such a big issue – feeling a bit different or putting my research first could even be seen as a good thing. On the face of it. Except that something keeps niggling at me. Something keeps interfering with how I get on in the world. It holds me back.

When I think about it now, I realise that part of the reason for not actively publicising my experience of mental illness is that I feel uncomfortable about doing so. In 2007, when I was working at the Mental Health Foundation, my latest piece of research was publicly released (*I Haven't Told Them, They Haven't Asked*[1]). It was about the employment experiences of a group of people who had experience of mental illness. As part of the media interest, I was asked if I would be interviewed for a radio programme. I agreed.

As part of that interview I mentioned my own experience of mental illness. Last year (2008), I was approached by the producer of that programme. She had won a Like Minds media grant and wanted to interview me about my experience of mental illness as part of her project. The transcript was to be made available for other media people to access when they were doing stories about mental illness. I agreed to do the interview.

At that stage I had not had a severe episode related to my bipolar disorder for six years. It seemed that I was on top of it. Whenever I felt symptoms coming on, I would deal with them and nothing major would happen. I was happy to talk to the interviewer. After all, I had dealt with my mental illness and had come out the other side. Except that this wasn't true. This is what most of the rest of the world thought, and was a myth that I'd never dispelled.

I did the interview and then sat on the transcript for months. Something didn't feel right about it. It wasn't till I ended up in hospital again a few months later, shocked by the speed at which I went from being okay to experiencing my 14th admission, that I realised why I didn't feel comfortable with it. I felt like a fraud somehow – I was supposed to be okay now, my previous psychiatrist had even told me that I would never need to go into hospital again – yet here I was.

Over the years, my feelings of difference had developed into feelings of blame, shame and the belief that I was evil, surfacing at my weakest moments. These feelings seemed to be rooted in my childhood and had become linked

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[1] Peterson, D. (2007). *I Haven't Told Them, They Haven't Asked: The Employment Experiences of People with Experience of Mental Illness.* Auckland: Mental Health Foundation of New Zealand.

to my experience of mental illness. It was these feelings that arose after that media grant interview, and prevented me from agreeing to its use. It is also these feelings, which I identify as part of my self-stigma, that have prevented me from talking about the aspects of my mental illness that are not associated with my bipolar diagnosis.

What I don't tell people about is an aspect of my mental illness that affects me just as much as my mood swings. It's what brought me to the attention of mental health services in the beginning, all those years ago when I was at school.

One of the effects of the experiences I lived through when growing up, among other things, is that I learned to dissociate. Very effectively. To the point, where, by the time I got to high school, I was able to sit in class for an hour staring into space, completely unaware of my surroundings and not being able to recall what had taken place. I kept passing my classes though, and it made the time go quicker, so this wasn't of great concern, except to one teacher who noted it on my school report.

By the time I was 15, however, it was a concern. Whereas previously the dissociation was just an inconvenience, by 5th form I had lost control of it. It could be triggered by anything, especially if anyone asked me about my family circumstances. I was losing more and more time, felt less and less real, and thought I was seriously going crazy. It culminated in me leaving home in the middle of the night and arriving at school the next morning, five kilometres away, without any idea of how I got there. Twice.

I remember my mother yelling at me after the second time. She kept asking me why I did it, and I kept answering that I didn't know. She said that she'd rather I was pregnant, at least then she would know what to do. So the school referred me to the mental health service, where I saw a social worker, then a psychiatrist. I was diagnosed with depression and put on antidepressants. It seemed as if everyone at school knew I was seeing a psychiatrist. Some of the teachers treated me differently when they found out. I never got told off for not tying my hair up again. I found I could come and go from classes as I pleased and no one would question me.

The only time I felt any self-stigma around people knowing of my condition while I was at school was when I found out that, not only did my French teacher know my grandmother, she told her about the difficulties

I was having. I was mortified. I didn't want my grandmother to know that I was less than perfect. I couldn't handle my grandmother's deep concern for me – the thought of her thinking I was crazy was too much – and I resented my French teacher so much I refused to go back to her class.

I saw the psychiatrist for two years, but the dissociation, the thing that was making me feel crazy, was never discussed. I thought I must really be seriously crazy if even a psychiatrist wouldn't talk about it. Self-stigma again.

This dissociation, feeling unreal, and my intense fear of being judged, which developed alongside it, increased to the point where it interfered with my study, my work and my life. Coupled with the mood swings I was experiencing, I was a mess. I tried to get help, I saw several counsellors, but with the mood swings and the dissociation they didn't know what to do. Eventually I was referred to the mental health services again. I began a cycle of hospital admission, getting a little bit better, being discharged, getting worse and then being admitted again. I tried several different medications, and I was in therapy, but not much seemed to help.

During one hospital admission when I was 26, something happened that changed my perception of myself and mental health services permanently. I had been very depressed, I had gone to see my psychiatrist for help and her reaction was, 'Well what do you expect me to do about it?' Eventually, after coming pretty close to doing something drastic and final, it was agreed that I needed to be admitted. Except that there was a bed shortage, so I ended up in a ward I'd never been in before.

Towards the end of my stay, I was sexually abused by a male nurse. I reported it and eventually the police were called.

I was taken to the police station, gave my statement and then returned to the ward. Naively, I thought I'd be okay there. Instead I was put in the same seclusion room the incident had happened in, told I wasn't to talk to anyone, and was 'looked after' by some very angry nurses. It was apparent that they didn't believe me and that they thought that what had happened was my fault. I was terrified. The next morning I was transferred to the hospital closer to my home.

The case eventually ended up in the High Court over a year later. The nurse was convicted of sexual violation. The judge sentenced him to community service. I was devastated. The crown prosecutor decided there should be an appeal because the sentence was too lenient. The Court of Appeal agreed, sentencing the nurse (or ex-nurse as he was then) to a prison term. Part of me felt guilty about him going to prison because I kept wondering if it was maybe my fault. Part of me was glad though, as it meant that he would be in the position of needing to rely on professionals to do their job and keep him safe.

To this day I don't talk about the court case much. I still feel the self-stigma associated with it, though at least I can, for the most part, recognise it as being that. The case has followed me around during my contacts with the mental health services, however. I heard from someone that people in the mental health services were reluctant to see me because I had been labelled as 'dangerous' – dangerous to them that was. I was considered a troublemaker. After the court case, my perception of hospital was that it was a very unsafe place. During one admission, I came across a nurse who had been on duty the nights of the abuse. I freaked out, tried to leave and found myself in the psychiatric intensive care unit under the Mental Health Act. I don't know what was more scary, remembering the abuse, or being dragged down the full length of the ward by five nurses and then locked up. When I think about it, it was the thought of the staff finding out about what had happened and thinking it was my fault (which part of me still believed) that freaked me out.

My treatment by sections of the mental health services due to the dissociation and the other behaviour associated with it, such as self-harming, has often reinforced my self-stigma. The only time that I took an overdose and ended up in the Emergency Department, I was treated like dirt. Physically I was roughly handled, and I could hear the nurses talking about me in disparaging terms. I already felt bad about myself for doing it – the treatment I received just confirmed it.

On occasion, when I was admitted to hospital, some of the staff would treat me as if I, somehow, did not deserve to be there, that I was wasting their time. I was treated like a naughty child. At one stage I was even thrown out. This just confirmed my feeling of worthlessness – I couldn't even be crazy properly.

I had tried many different medications in order to bring my mood swings under control. One of my psychiatrists told me to give up trying and just accept that nothing was going to change. I refused to believe her. My next psychiatrist was determined to find something to help. At one stage I was admitted to hospital in a very bad way. I was on heaps of medication and none of it was working. I was at the point of giving up – the staff seemed to have reached that place as well. Then my psychiatrist suggested I try clozapine. Just the suggestion of this heralded an amazing change of attitude from the hospital staff. They could see hope, as clozapine was seen as a wonder drug. They were even positively excited. And they conveyed this optimism to me. But it left me wondering, after feeling the effect of their positivity, just what impact was their normal negativity having on me and other people around them?

What has this to do with self-stigma? Feeling that there is no hope and feeling less than other people are components of the Discrimination Intervention model (as presented in Chapter 1). In many of my interactions with mental health services these feelings have been fed by the attitudes of some of the staff. My more positive experiences of mental health services, however, have had the opposite effect.

My last admission to hospital – number 14 – saw me being treated like a human being, for the most part. Looking back on it now, I realise that, at first, I felt as if I had failed by being admitted again, but can now see positive aspects to it. For once it was recognised that the issues that had developed for me from when I was a child and my mood swings both needed to be addressed instead of being seen as separate. I realised I can't ignore one at the expense of the other, and I need to deal with them both in order to overcome that nagging feeling of difference that still holds me back – my feelings of self-stigma.

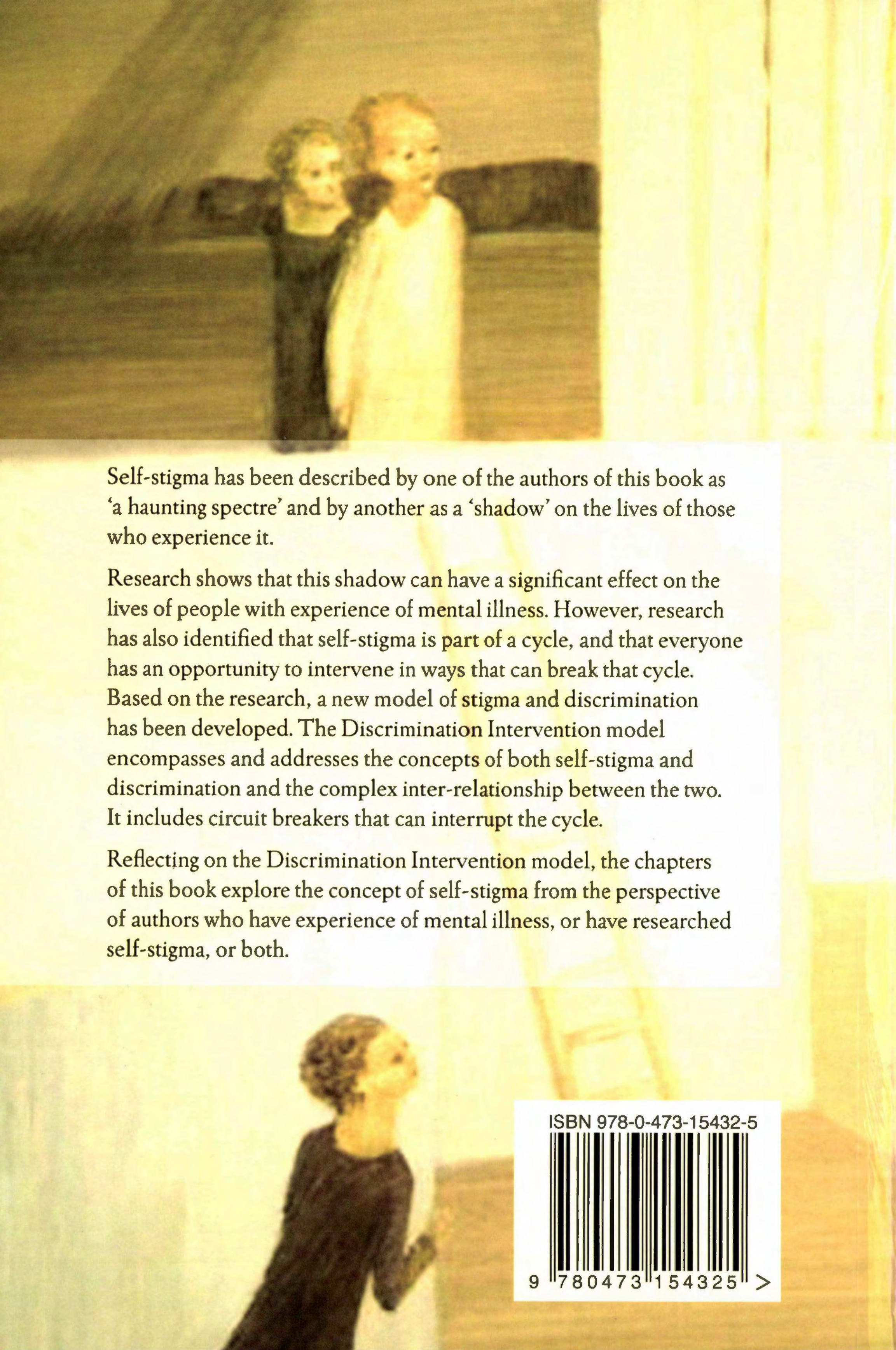
These feelings are inextricably linked to the totality of my experience. On the surface it may not seem that they are there, or if they are, that they have a major effect on my life. I'm successful at what I do and am open about my experiences. Many of them anyway. Yet these feelings of self-stigma run deep under the surface, often coming up when I'm most unwell and vulnerable. They are reflected in the voices I hear, in how I see myself, and in how other people treat me when I get like that. They can leave me with an inability to ask for what I need and unable to decide what it is that I do need.

When I end up in that place of unwellness, I need to remember those circuit breakers identified in the model. I need others to remember them too.

Most of all, I need hope, because when I am in that place, hope is the first thing I lose.

When I look back on my experiences, my self-stigma has had some positive effects. It has acted as a shield to protect me from harm. The fear of discrimination, limiting self-disclosure at times, has meant that I haven't been exposed to unhelpful attitudes and behaviour. The thoughts of shame, blame and evilness mean that I work extra hard to avoid justifying even more of these thoughts.

So I don't necessarily want my self-stigma to disappear entirely. I don't feel at the stage where I can fully embrace my mental illness. It still causes me pain and distress at times. Yet I can acknowledge that my mental illness does serve a useful purpose. After all, I wouldn't be who I am today, or doing the job I do, without it.



Self-stigma has been described by one of the authors of this book as 'a haunting spectre' and by another as a 'shadow' on the lives of those who experience it.

Research shows that this shadow can have a significant effect on the lives of people with experience of mental illness. However, research has also identified that self-stigma is part of a cycle, and that everyone has an opportunity to intervene in ways that can break that cycle. Based on the research, a new model of stigma and discrimination has been developed. The Discrimination Intervention model encompasses and addresses the concepts of both self-stigma and discrimination and the complex inter-relationship between the two. It includes circuit breakers that can interrupt the cycle.

Reflecting on the Discrimination Intervention model, the chapters of this book explore the concept of self-stigma from the perspective of authors who have experience of mental illness, or have researched self-stigma, or both.

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