



THE UNIVERSITY OF
WAIKATO
Te Whare Wānanga o Waikato

Research Commons

<http://researchcommons.waikato.ac.nz/>

Research Commons at the University of Waikato

Copyright Statement:

The digital copy of this thesis is protected by the Copyright Act 1994 (New Zealand).

The thesis may be consulted by you, provided you comply with the provisions of the Act and the following conditions of use:

- Any use you make of these documents or images must be for research or private study purposes only, and you may not make them available to any other person.
- Authors control the copyright of their thesis. You will recognise the author's right to be identified as the author of the thesis, and due acknowledgement will be made to the author where appropriate.
- You will obtain the author's permission before publishing any material from the thesis.

Living with uncertainty:
A grounded theory of psychiatric stigma
when seeking or maintaining employment

A thesis
submitted in partial fulfilment
of the requirements for the Degree
of
Doctor of Philosophy
at the
University of Waikato
by

HAMISH CAMERON MACKENZIE

University of Waikato

2002

SYNOPSIS

The aim of this study was to investigate stigma for people who have experienced psychiatric disorder. Psychiatric stigma can exclude people both from economic roles and from participation in daily community life. Social and psychological reaction models of stigma adequately explain parts of this process but do not provide an integrated account that addresses the unique illness experience of psychiatric disorder. Nor do they provide an experiential account of psychiatric stigma that reflects its unique difference in a valued life situation - employment.

The 31 Participants had all used psychiatric services and comprised 20 men and 11 women ranging in age from 20-59 years. There were 11 Maori, 18 Pakeha and 2 Pacific Islanders. At the time of this study they were all seeking or maintaining employment. Participants completed multiple open-ended interviews over a two year period. The interviews were transcribed and analysed using Glaser's method of grounded theory. Constant comparison within and between stigmatising events found most of the variance in Participants' accounts was captured in the core category of *uncertainty* (See Table 1).

Table 1:

Uncertainty as a Core Category - Substantive Properties

Condition	used a psychiatric service and participating in everyday life
Context	personally significant, highly evaluative, salient outcomes
Contingent on	the possibilities for self being mediated by psychiatric illness
Causes	everyday life is marked with, and marked out by, psychiatric illness
Consequences	reduced doing, being, knowing and subjective meaning: -ve = biased attribution and thinking styles; stereotype threat/confirmation, increased monitoring, hypervigilance, passing, guarding, reduced experience of novel situations, loss of hope and a restricted life. +ve = realistic appraisal of perceptual, thinking, emotional and memory processes; narrows the range of situations which are uncomfortable; strengthens relationship to other consumers.

Uncertainty ruptured possibilities for health, identity, relationships and positive life trajectories. Consequently, Participants faced the task of managing a stigmatised identity by striving to resolve uncertainty. Yet the process of *resolving uncertainty* and negotiating a stigmatised identity had the ironic effect of *creating*

uncertainty. This was theorised as a mutually interacting and self-generating process of *creating-resolving uncertainty* (see Table 2).

Table 2:

Uncertainty as a Core Category – Theoretical Properties

Process	Resolving-Creating Uncertainty
Sub-Core	Monitoring – by Self and Others
Sub-Core	Stages of Uncertainty – Constructing Identity, Haunting, Vigilance, Disclosure

Utilising a psychiatric service entailed changing from a person to a patient and this was accompanied by a change in social role and personal expectations. Staff monitored their patients for illness. This implicitly trained patients to self-monitor for signs of illness and embedded a medical language to achieve it. Any behaviour or expression was perceived as indicative of their mental health status. When patients tried to become everyday people again, self-monitoring and monitoring by other people suffused any actions with concerns about their mental health.

The impact of this and living an illness-mediated life required the continuous *constructing* of *identity*. The need to monitor for illness signs ensured that Participants’ lives became marked by and marked out by their disorder, so everyday performance became a performance of mental health. This entailed a vulnerability and caution in every day life where the *haunting* prospect of their disorder occurring again intruded into both self-concept and self processes. Life became uncertain and this required a *vigil* to prospect for ‘mad’ signs and sort everyday perceptions for unreality, inappropriateness and illness related events. This was crucial within the workplace where Participants may or may not have disclosed their psychiatric history to their colleagues. *Disclosure* was fraught with the uncertainty of whether to display or not to display; to tell or not tell; to let on or not let on; to lie or not lie; and, in each case, to whom, how, what, when and where.

This study developed an innovative theory of psychiatric stigma that integrates the effects of illness experience on self-concept, the experiential demands of participating in employment and the interpersonal and intra-psychic processes Participants employed to resolve psychiatric stigma. Resolving and creating

uncertainty explained the task of negotiating a uniquely stigmatised identity and increased understanding of the stigmatisation that could accompany other illnesses or disorders.

The theory can now be used to examine psychiatric stigma in distinct population groupings and to predict its effects in more diverse settings. Future research should aim to develop measures of its dimensions, so that it can be used to distinguish between the stigma experienced by people with psychiatric illness across time and place, among different groups. The effects of variables such as community attitude change and professional intervention could then be investigated. Thus the theory could be used to improve the quality of life for people who experience psychiatric disorder.

Acknowledgements

A PhD is a singular effort and I wish to recognise the considerable support I have had from others during this process.

Thank you to the Participants for the rare and valued privilege of hearing their personal stories.

Starting a PhD was easy, completing one has required considerable understanding from my family. Thank you Sandra, Mum, Robyn and Andrew for your support.

Without the generous assistance of Kevin MacKen (Manager, Centre 401) I would not have achieved the community participation required for this project. Kevin's guiding support, personal networks, insights and experience within the mental health consumer movement, hastened my understanding of the research topic in a unique way. Many thanks mate.

With out the guidance and thought provoking discussions of my primary supervisor, Mike Hills, the ideas in this thesis would have remained untempered. Mike's national, international and first-hand experience of both epilepsy and research into the psychology of disability, was a tremendous resource for me. Supporting supervisors were Judy MacDonald (Medical Anthropologist, UW) and Hilary Lapsley (Senior Analyst, MHC). Thank you for your encouragement and insightful reviews.

I owe a tremendous debt to a wise woman, Helen Warren. The discussions we had enabled us both to develop our knowledge of grounded theory. More importantly your personal support both inspired and sustained my efforts, and never more so than near the end. Thank you, always.

Thank you Frank, Richard and Peter, and my dear office colleagues Nikki and Veronika, for your counsel and personal support.

For their review of individual thesis sections, thank you:

Andrew Dobbs (Clin. Co-ord., Lakeland Mental Health Service), Cathy Colebone (Historian, UW), Barbara Hart (Consumer Advisor, Lakeland Health), Paul Evans-McLeod (Consumer Reviewer, Waik.), Jacob Reid

(Analyst, Mental Health Workforce Dev., HRC) and Jane Ritchie (Prof. Psych., UW)

I am very grateful to the following people for the productive discussions we have had and the extremely generous assistance and service access they were able to give. In order of appearance:

Steve Stoppard (Mgr, Framework Trust); Linda Nikora (Com. Psych., UW); Averil Herbert (Clin. Psych., UW); Rex Wright-St Clair, (MD, Medical Historian); Henry Bennett (MD, *Deceased*); Mason Durie (Dpsych/MD, Prof., MU); Maureen Beswick (Consumer Supported Employment Consultant); Ian Mackenzie (Mgr, Framework Trust); Lois Carter (Mgr, Transitions Supported Employment); Rob Warriner (Res. & Dev., Edge Employment); Ngaire Moore (Mgr, Aroha ki te Tangata), John MacKintosh (Mgr, Workbridge); Kay Palmer, (CEO, NPE); Ray Wirihana (CEO, Hauora Waikato); Fran Hartnett (Dir. of Disability Studies, ACE); Janet Peters (Psychologist, HRCNZ Strategist); Antoinette McCallin (Grounded theorist, MU) Rob Gill (Dir., Natural Supports), Keay Bishop (CEO, Workforce Auckland), Jackie Harvey (Mgr, Edge Employment); Dean Manley (Consultant, Edge Employment); Kirstyn Mitchell (Co-ord., Workfocus Employment Services), Mary O'Hagan (Mental Health Commissioner, MHC), Ruth Gerzon (CEO, Serious Fun & Mind Charitable Trust).

I thank in particular these organisations, their staff and members for their assistance:

Centre 401, Aroha ki te Tangata, New Progress Enterprises, Hauora Waikato, Edge Employment, and Framework Trust.

Funding:

This PhD was completed during the tenure of a Post-Graduate Scholarship from the Health Research Council of New Zealand. Ref: 99/232A/PHR/AW/PGS/WU. I gratefully acknowledge financial assistance from Centre 401 Trust and University of Waikato to attend conferences.

PROLOGUE

My interest in stigma developed from an undergraduate project on epilepsy at the University of Sydney. This led to a regional survey of attitudes to and knowledge about epilepsy in the Waikato. In 1997, following the release of a report that showed the significant problem of stigma for people who use psychiatric services, I became interested in psychiatric stigma and the first-hand experience of stigma in daily life. At the same time, proposals for programmes were being put forward to destigmatise mental illness. I was curious as to how destigmatisation was going to proceed when there were no New Zealand empirical studies to conceptualise psychiatric stigma, let alone consider its process in a focussed situation like employment. This study begins to address the dearth of material on this topic and develops a local and better-informed understanding of psychiatric stigma in the key action scene of employment.

TABLE OF CONTENTS

Synopsis	i
Acknowledgements.....	v
Prologue	vii
Table of contents	ix
List of Tables	xiii
List of Figures	xv
List of Appendices	xvii
List of Abbreviations	xix
Introduction to the Thesis	xxi
Chapter 1 - Psychiatric Stigma & Employment: A Review	1
Introduction.....	1
Section I – Origins of Psychiatric Stigma in New Zealand	4
Introduction.....	4
The British Experience.....	6
The New Zealand Experience	12
Summary and Conclusion	28
Section II - Theorising the Concept of Psychiatric Stigma.....	31
Introduction.....	31
Social Stigma	31
Labelling	32
Psychiatric Stigma.....	36
Stigma and Illness Experiences.....	45
Summary and Key Points.....	60
Chapter 2: Location and Evaluation of Grounded Theory	63
Paradigm Considerations	63
Utility of Grounded Theory	65
What is Grounded Theory?.....	67
Grounded Theory Paradigm.....	70
Symbolic Interactionism	71
Logic of Justification	76
Evaluation of Methodology	80
Paradigmatic Considerations.....	80
My Grounded Theory Position	83
Suitability of Grounded Theory	84
Chapter 3 - Method Section	87
Participants.....	87
Selection.....	87
Recruitment.....	87
Characteristics	88
The Interview	89
Materials.....	89
Data Management	93
Transcription	93
Data Entry	93
Data Storage.....	94
Data Administration.....	94
Software	94

Analysis Method and Coding Strategy	95
Initial Coding Strategy	96
Coding Psychiatric Illness Trajectory – Person to Patient	97
Coding Psychiatric Illness Trajectory – Struggles of Identity	98
Coding Psychiatric Illness Trajectory – Resolving Identity	100
Primary Codes: Resolving Identity, Haunting, Monitoring and Disclosure	102
Emergence of Core Category – Uncertainty	103
Chapter 4 - Constructing Identity	107
Section A – Process of Constructing Identity	108
Naming the ‘Problem’/Marking the Person	108
Taking on the Mark of ‘Madness’	110
Making Sense	114
Turning Points	124
Section B - Passing	127
Outed	131
Summary	132
Chapter 5 - The Haunting	133
Primary Attributions about Psychiatric Disorder	138
Caution	139
Vulnerable	140
Problems of ‘My Own Making’	142
Sliding Between Crisis and Recovery	147
Influence of Self and Other Expectations	148
Adaptation Occurs	150
Summary	152
Chapter 6 - The Vigil	155
On Guard	156
On Guard Process - Alerting, Differentiating, Deciding, Generating	158
Alerting	159
Differentiating	162
Deciding	169
Generating	171
Making sense	172
Reviewing	172
Making Sense is Mental Health	174
Summary	176
Chapter 7 - Disclosure	177
Introduction	177
Personal and Social Uncertainty	178
Awkward Moments	179
Social Unravelling	180
Social Shedding	181
Disclosure to Monitoring Others	183
Psychiatric and Support Service Staff	183
Consumers	189
Disclosure in the workplace	191
Inadvertent disclosure	193
‘Tell-You-Straight’ Approach	195
‘If Needed’ Disclosure	200
No Disclosure	204
Uncertain Effects	204

Summary	211
Chapter 8	213
Uncertainty in the Workplace.....	213
Job sorting.....	213
Marked	215
Scrutiny	217
On Guard.....	218
Testing.....	219
Testing by Presence	220
Testing by Inquiry.....	221
Testing by Instruction	224
Testing by Activity.....	225
Close Scrutiny	228
Practical Interest.....	237
Monitoring Partisan.....	239
Not Marked	241
Summary	242
Chapter 9 - DISCUSSION.....	245
Introduction.....	245
Theoretical Framework	247
Core Category	247
Basic Social Process.....	249
Sub-Core Categories - Monitoring.....	249
Sub-Core Categories – Stages of Uncertainty.....	250
Comparisons with Existing Literature	251
Stigma and Social Distance.....	251
Stigma and Stereotyping	252
Stigma and Social Categorisation	252
Stigma Congruence	253
Stigma and Labelling	254
Stigma as Threat.....	255
Stigma and Social Role	256
Stigma and Media Influence	257
Stigmatisation.....	257
Stigma and Illness	258
Illness and Uncertainty.....	258
Theorising Psychiatric Stigma as Uncertainty	259
Grounded Theory	265
Qualifications	266
Future Research and Significance.....	267
Appendices.....	269
Appendix A - Notes from a Pre-Research Meeting with a Community Organisation	271
Appendix B - Information Sheet.....	273
Appendix C - Consent Form	277
Appendix D - Preliminary Questions.....	279
Appendix E - Example of Mapping a Sub-Core Category	281
Appendix F – Memo’s on terms referred to in ‘ <i>Problems of my own making</i> ’	283
Bibliography	289

LIST OF TABLES

Table		Page
1	Uncertainty as a core category – substantive properties	i
2	Uncertainty as a Core Category – Theoretical Properties	ii
3.1	Participant ethnicity and age by gender	88
3.2	Participants retained at interview and follow-up	91
4	Substantive properties of the core category	104

LIST OF FIGURES

Figures		Page
1	Basic Social Process	105
		107
		133
		155
		177
		212
2	Theoretical framework: Incorporation of Basic Social Process (BSP), Core and Sub-core Categories	248

LIST OF APPENDICES

Appendix		Page
A	Notes from a Pre-Recruitment Meeting with a Community Organisation	271
B	Information Sheet	273
C	Consent Form	277
D	Preliminary Questions	279
E	Example of Mapping a Sub-Core Category - Haunting	281
F	Definitions of Terms Referred to in 'Problems of My Own Making'	283
G	Consumer Thesis Review	287

LIST OF ABBREVIATIONS

Abbreviation	Full Text
ACE	Auckland College of Education
BSP	Basic Social Process
BSPP	Basic Social Psychological Process
CBMT	Communication Boundary Management Theory
CHE	Crown Health Enterprises
GT	Grounded Theory
HFA	Health Funding Authority
HRCNZ	Health Research Council of New Zealand
MHAC	Mental Health Advocacy Coalition
MHC	Mental Health Commission
MHS	Mental Health Service
MOH	Ministry of Health
MU	Massey University
NPE	New Progress Enterprises
NZ	New Zealand
PI	Psychiatric Illness
PSP	Psychological Social Psychology
RHA	Regional Health Authority
SI	Symbolic Interactionism
SSP	Sociological Social Psychology
UW	University of Waikato

INTRODUCTION TO THE THESIS

Inquiries into the treatment of people with psychiatric illness have examined the historical legacies, negative public perception and discriminatory attitudes towards psychiatric illness and persons receiving or discharged from psychiatric treatment (Mason, Ryan & Bennett, 1988). Such inquiries have suggested that psychiatric stigma is the most significant issue and barrier to improving the lives of people with serious psychiatric illness (Mason, Johnston & Crowe, 1996). This introduction sketches why this might be so and outlines opportunities for researching psychiatric stigma.

Unlike other Western nations, New Zealand has had 'trends' towards deinstitutionalisation (Haines & Abbot, 1985) but not an explicit policy to deliver it. Rather the adoption of a community care treatment model and reduced funding of the old public psychiatric institutions has led to their closure (Brunton, 1997). Psychiatric services now discharge and maintain people with non-acute psychiatric illness in community residences. When these service activities go wrong and unpleasant or violent events occur the ensuing public debate raises the public profile of people with psychiatric disorder (NZ Herald, 02/09/99). Media accounts often fuse psychiatric disorder with violence, which does little to allay community fears about inclusiveness and safety (NZ Herald, 20/08/97). Like most people, those who experience psychiatric disorder live in their communities and in addition to any complications with their illness, they face the same demands and aspirations in everyday life.

Such people are no longer 'out of sight out of mind', and neither is their stigmatisation and discrimination. Rather, as people with psychiatric illness reclaim the right to be people first and not patients, to recover and live as they are able, with hopes and dreams for their future, so increases the demand to provide access to the important facets of social life they were previously denied. As people with serious psychiatric illness now live in the community, so too, do communities now live side-by-side with 'them'. The unavoidability of this fact has intensified and expanded recent public concerns about people who use

psychiatric services. Embedded within these public concerns are old fears about 'madness' and new uncertainties relating to treatment. While treatment can reduce the symptoms of psychiatric illness, carrying the mark or stigma of psychiatric illness is still an onerous task for many people (Spiro, Siassi, & Crocetti, 1972).

State sponsored efforts in response to consumer (psychiatric patient) demands have established a firm agenda for removing the stigma attached to psychiatric illness. The Mental Health Commission (MHC) established in 1996 as a result of the 'Mason Inquiry', has as its second priority to ensure "discrimination and prejudice against those with psychiatric illness is reduced" (MHC, p.7, 1997a). The Ministry of Health (MOH) has embarked on a national and regional programme to destigmatise psychiatric illness. Similarly the MHC's Blueprint for Mental Health Services (MHC, 1998a) has six destinations for service development intended to address the stigma and discrimination experienced by consumers. In trying to arrive at these destinations there is an explicit obligation placed on the New Zealand public, mental health sector, public organisations (e.g. Judiciary, Police, general health service providers) and private organisations (e.g. Insurers, landlords, community welfare agencies) to recognise how they discriminate against people and to reduce the effects of stigma. Overall there is both a state and mental health sector recognition that 'something needs to be done'. Yet it is not clear how this can effectively take place when there has been an absence of research on:

- conceptualising stigma in relation to psychiatric illness within a New Zealand context, and
- its role and effects for people who experience psychiatric illness.

There is also some controversy over whether to focus on the 'stigma' of psychiatric illness or 'discrimination' against those with a psychiatric illness (MHC, 1997a). The rationale for changing the focus to discrimination is that it directly targets the people who do the discriminating and not those who incur its effects. Supporting this proposition is the contention that little has changed within New Zealand society through investigating stigma via attitudinal research (e.g. Green, McCormick, Walkey & Taylor, 1987). Discrimination is conceptually

easier to understand and legal remedy for discrimination in other domains (e.g. racial, sexual) has an historical precedent.

My thesis argues that discrimination is only one outcome, amongst others, that derives its form and action from the more central construct of stigma. Focussing on the outcome (discrimination) and not the process (stigmatisation) will lead to an incomplete explanation. To develop a more complete account of stigma from the existing literature, my review will explore the social and cultural construction of stigma within historical processes, complex social relationships and participation in everyday life.

Stigma may be a primary event with a myriad of adverse and complementary sequelae. For instance, psychiatric services can have positive effects on dimensions of quality of life such as financial position, accommodation, family relations and health and safety, while stigma has similarly strong negative effects on the same dimensions. The importance of these dual and opposite processes of psychiatric stigma and service benefits is increased by psychiatric health intervention. Psychotherapeutic and pharmacological interventions produce positive treatment benefits, yet these are often short-term. Over time treatment benefits evaporate. Thus it is possible that unidentified processes operate simultaneously to offset and ultimately erode treatment benefits. Stigmatisation is an obvious possibility, as official labelling and treatment of psychiatric illness simultaneously leads to positive treatment effects and negative stigma effects (Link, Struening, Rahav, Phelan, & Nuttbrock, 1997).

Generally the primary domains where stigma influences negative outcomes for consumers are: housing, employment, use of psychiatric/related services and community inclusiveness. The major health service trend related to psychiatric illness is that there will be a reduced focus on 'intervening and removing people' and more on the 'living' with psychiatric illness in their community of choice. Thus State and mental health sector policies support the integration of people with psychiatric illness into mainstream social life as both the course and environment to recovery (MHC, 1998a). Yet it is with regard to employment that the poorest outcomes are obtained (MHC, 1999a). Consumers frequently rate participation in

employment as one of their most important life goals, yet it is the one many consumers fail to obtain. Many consumers are not included in an activity which is known to be critically important in recovery from psychiatric illness (MHC, 1999a).

One study of a government disability employment service showed only 7% of people who experience serious psychiatric illness went on to participate in open employment (Harris, 1995). Psychiatric health consumers are also the disability group least likely to be placed in employment (Bennie, 1996, 1997; MHC 1999a). Yet unlike many other disabilities, psychiatric illness is frequently cyclic or periodic. That is, the person moves through periods of wellness and illness. The person, in terms of their wellness, often has times when they are as employable as anybody else, yet frequently they are not employed. Getting and holding down a job is more than just paid labour. It is a critical factor in both predicting and preventing ill health. The employment status of mental health consumers should be targeted as an improved health outcome. If more consumers were participating in open employment the personal and public health gain would be considerable, especially as employment can result in an improvement in health that cannot be obtained through psychotherapeutic or pharmacological interventions. Psychological research which can adequately account for internal processes to explain external outcomes cognisant of consumer experiences around employment, would greatly assist this task.

The literature review will show how internal processes, such as attitudes, are often used to examine the psychiatric stigma. However, few studies have demonstrated how things such as attitudes relate to stigma and even fewer still have theorised the personal experience of stigma. Whatever the exact nature and direction of the presumably complex relationship between stigma and other factors, efforts in recent times have afforded stigma research the long overdue recognition it deserves. Potent forces serve to maintain stigma. To cite Allport (1954) in his seminal text *The Nature of Prejudice*, which initiated much research in this area: “Stereotypes and stigma aid people in simplifying their mental categories, justify hostility and serve as projection screens for personal conflicts” (p.195). This study

brings together existing explanations within the literature to re-theorise stigma so that it matches everyday experience for people with psychiatric disorder.

In the first chapter of this thesis an historical background to psychiatric stigma is outlined by tracking the development of the psychiatric institutions, the psychiatric profession and the characteristics of patient populations that emerged from these beginnings. The relationship of madness, badness and unemployment is linked to the changing perceptions of people with psychiatric illness. This chapter also examines what is a social stigma and the distinctive shape it has within psychiatric stigma. The chapter concludes with an outline for researching psychiatric stigma. Chapter Two presents and locates the method and methodology I employed. Chapter Three shows the research methods for Participant recruitment, interviewing and data analysis. These led to the development of concepts that captured the efforts of Participants in resolving psychiatric stigma. In chapters Four to Eight key features of Participant experience show how the grounded theory was developed and then sustained through theoretical sampling. Chapter Nine provides a general discussion to link previous research with a new theory that develops an innovative approach to understanding psychiatric stigma.

CHAPTER 1 - PSYCHIATRIC STIGMA & EMPLOYMENT: A REVIEW

Introduction

Social stigmas have been around a long time. The term stigma originated in classical Greece and was used to refer to “bodily signs designed to expose something unusual and bad about the moral status of the signifier” (Goffman, 1963, p.11). These signs were burnt or cut into the body and were publicly visible. They indicated the bearer was a slave, traitor or criminal - a “blemished person, ritually polluted” and to be publicly avoided (Goffman, 1963, p.11). Their identity was tarnished and held to be a degraded status that was constantly confirmed by the way people interacted with them. The bearer, in avoiding interactions that rejected or degraded them, was faced with implicit and explicit restrictions on who they could interact with and where they could live. A further two layers of metaphor have been added to the term (Goffman, 1963). The Roman Catholic Church has recognised stigmata as a Divine malady of Saints since the thirteenth century (Catholic Encyclopedia, 2001). The stigmata were signs that mirrored the wounds and suffering of Christ. These signs involved visible eruptions on the skin, a supernatural ecstasy and religious visions. Medical recognition of the physical signs that corresponded to the religious signs has added the second layer of meaning (Goffman, 1963). Use of the term today still embraces its original meaning as a sign of disgrace but without its bodily evidence. In applying stigma to visible or invisible conditions of illness, it tends to define the bearer and not the sign carried by the bearer, so that the bearer becomes known by the condition itself (Goldin, 1990). The forms of disgrace that arouse concern today have changed and so has the severity of social sanctions, but the manner in which stigma occurs still endures.

Stigma as a social phenomenon has involved a person, an audience and a powerful set of negative beliefs, interactions and sanctions that connected the two. Yet the social undesirability of a stigma is more than the negative perceptions of others, which can exist in regard to many human conditions. It is when the individual takes on a “new degraded identity that produces mortification, and when such

identity comes to negatively affect the quality of social interactions directed at him and/or comes to affect his location in social and physical space that one can confidently speak of social stigma” (Fabrega, 1990, p.290). The mark becomes an arbiter of experience for both a person and their audience, which in turn feeds social and personal processes. Its outcome affects social trajectories for stigmatised people and deleterious consequences can ensue.

In most societies there are myths about madness or psychiatric illness (Fabrega, 1991). Myth is not concerned with fact but with meaning (for a discussion, Armstrong 2000). Myth only becomes reality when involved in rituals and ceremonies, evoking within people a sense of significance and apprehension of the deeper layers to existence. Ritual practices, especially symbolic practices, feed myth, and myth feeds symbolic practices or rituals. What happens in a palpable way is that the rituals and practices around ‘madness’ have the capacity to develop myths about ‘madness’ and vice-versa. They are not concerned with facts but meanings about personal existence and humanity. These meanings lodge within the New Zealand cultural frame of mental illness as social representations and are constituted by past practices that have deeply hurt and distressed people [for a discussion of social representations see (Moscovici, 1984) and of attitudes (Moliner & Tafani, 1997) and on their evaluative nature see Moliner (1995)]. Associated with this hurt and distress has been the stigma of psychiatric illness.

Generally, studies and discussion about psychiatric stigma draw on three main disciplines – psychology, sociology and medicine. Each discipline treats the topic in similar but different ways. Within sociology most accounts usually involve some aspect of ‘labelling’ or ‘deviance’ theory. Explanations are often about social processes and rarely touch on intra-psychic processes. Within medicine both psychological and sociological accounts are apparent, but they are offset by physiological concerns. Within psychology, accounts often draw on intra-psychic processes or interpersonal transactions, leaving aside the social processes that distribute status, health, resources and opportunities. Literature on stigma in all three disciplines, until recently, has focused more on social perceptions by an audience rather than the experience of people who have had to negotiate a social and personal trajectory bearing the mark of psychiatric stigma. What is needed in

a more robust account of psychiatric stigma is analysis of how and why stigmatisation is played out for persons with the stigma. In particular we need to understand how and why people resolve issues arising from living with the presence of stigma. Research needs both to capture first-person stories that so vividly portray experience and to derive a theoretical explanation for the experience of stigmatised people.

In Section One of this chapter, I consider the historical background to psychiatric stigma in New Zealand. Then in Section Two I examine how the concept of psychiatric stigma has been developed and applied in international literature. Finally I bring this material together and outline an approach that addresses some unexplored areas in researching this topic.

Section I – Origins of Psychiatric Stigma in New Zealand

Introduction

Much of the international literature on stigma draws from an outsider's perspective. Although labelling theory, in particular, has informed some very productive research on stigma, this sociological approach side-steps intra-psychic explanations of how people manage stigma in everyday life. Within psychology, discussion of intra-psychic processes is drawn from theories about social identity, social comparison, attributions, the 'just world' hypothesis, stereotyping mechanisms, self-perception, self-esteem, prejudice, attitudes, beliefs, behavioural repertoires and trait or state cognitive processing (for a review see Crocker, Major & Steele, 1998).

When lay first person accounts of psychiatric stigma are considered they often draw on a different set of ideas. They focus on practicalities: somewhere to work, somewhere to play, somewhere to live, somewhere to belong (Marrone & Golowka, 1999), and the personal difficulties or capacity in achieving these things in the face of stigma and discrimination whilst maintaining their wellbeing. People who have used mental health services frequently comment about difficulties in coping with everyday life after mental health treatment. People living in the community rarely experience psychiatric illness symptoms 365 days of the year. A lot of living takes place between and beyond illness re-occurrence. It is during these periods of living that changes in personal trajectory from person to patient and patient to person are experienced. This seems to foster distinct needs and processes that disrupt, hinder, complicate and distress people in their pursuit of everyday activities. In the context of these experiences are often found the most vivid accounts and negative effects of psychiatric stigma. There is a gap between the experience of psychiatric stigma and theoretical writing that is drawn from experimental studies.

Psychiatric disorder is present in most societies and has historical roots (Fabrega, 1992). When a psychiatric disorder develops into an illness it becomes a social phenomenon mediated by the culture in which it manifests, is interpreted and

handled (and whether a disorder is seen as an a illness in the first place is culturally determined) (Wang, 1992). Psychiatric illness can be viewed as a construction within a social culture that has a distinct system of symbols and practices (D'Andrade, 1984). A consequence has been to group populations in the madhouse (madness), prison (badness) and workhouse (unemployment) together and treat them in similar ways (Scull, 1981a). These associations do not suddenly appear within our cultural systems of meaning and expectation about psychiatric illness. They resonate from a distinct pedigree within New Zealand's colonial past and its relationship to imperial Britain.

New Zealand's early beginning as a British colony reflected the Victorian age from which its social institutions and practices emerged. The Victorian era saw a transformation of its mental illness institutions - madhouse into asylum into the mental hospital; of its practitioners - mad-doctor into alienist into psychiatrist; treatments - restraint into moral therapy into psychological medicine; and of the 'mad' man or woman into lunatic into mental patient (Scull, 1981a). New words indicated changes in the perception of 'madness'. This shift in the language of 'madness' was more than a change in description of an accepted static reality. It coincided with changes in society's responses to madness, which fundamentally altered the institutions and practices engaged by the mentally ill (Garton, 1988). The effects of the changes increased both medicalisation of the field of mental illness and created a new group of practitioners to manage it – the psychiatric profession. Most importantly these changes demonstrated how social context and institutional practices were closely linked to produce characteristic patient populations and responses from the social milieu they inhabited.

I will outline an historical background to psychiatric stigma in New Zealand by tracking the development of the psychiatric institutions, the psychiatric profession and the characteristics of patient populations that emerged from these beginnings. Links between these early psychiatric services and their populations and the current situation in New Zealand illustrate key aspects of psychiatric stigma. They help explain what has shaped and embedded the properties and dimensions of psychiatric stigma that inhabit social life today.

The British Experience

Sorting mad, bad and poor

The rise of a secular authority – the State of England – during the seventeenth century sharpened the earlier classification of people who used to be labelled ‘able’, ‘disabled’ or ‘destitute’. In the seventeenth and eighteenth centuries the rising pauper population became an acute social problem (Garton, 1988). Changes in agriculture and in population growth and distribution led to many people being vulnerable to poverty. This big and unstable group of people threatened social order, provoking a crisis response from local and national authorities. Legal reform increased the latitude with which criminal law, charitable and Poor Law provisions could be applied to control the crisis. Lunatics, who traditionally had been ignored or existed on the margins of community life, were increasingly separated, along with other groups, by their economic status (Jones, 1972). This separation then gave weight to fiscal, legal and political sanctions against those who failed to labour. Failing to labour incurred the threat of the workhouse as a deterrent to malingering (Digby, 1989). As the workhouse failed to deter, it then became the panacea of institutional ‘care’ for paupers; and at the same time it sought to ‘cure’ residents of their predicament at a ‘profit’ for its owners (Crowther, 1982).

Asylums housed criminal and pauper lunatics who were separated from other residents. Pauper lunatics were also distinct from paupers in workhouses and for many lunatics the workhouse remained their home (Longmate, 1974). By the early nineteenth century, massive institutionalisation of poverty placed 75% of all persons judged to be of unsound mind under the poor laws authorities (Bartlett, 1999; Crowther, 1982). The difficulty of sorting the ‘mad’ from the feeble-minded, bad, poor or malingerer inspired legislation by the late eighteenth century that ruled inmates were either lunatics by certification, or sane and could be treated as paupers (Longmate, 1974). The removal of the insane and the poor along with those who “threatened the powerful classes in mainstream society was socially tolerable, politically expedient and financially affordable” (Brunton, 1997, p.9). Lunatic asylums, like workhouses, increased social distance from people who were social problems. It was social distance as well as physical distance between such groups that mattered and the outcome entailed both. It was

an extension of existing practices that dealt with social problems by applying the practices of colonisation on its own indigenous population. This entailed “social and legal differentiation, intentional segregation, state regulation and administration” (Brunton, 1997, p.9).

With large sections of the population unemployed, the presence of pauper lunatics in workhouses was disruptive and difficult to manage in an overcrowded environment (Brunton, 1987). Workhouses were required to run at a profit for their owners and that proved difficult with pauper lunatics present (Longmate, 1974). The need to separate out those who could work from those who could not led to removal of the insane and mentally disordered to the madhouse (for those that could pay), the asylum (for those that could not) or prison. In the early nineteenth century, the magistrate initially handled admittance and this later shifted to a medical superintendent.

Mad Doctors, Profit and the Poor

Medical intervention dramatically altered the character and course of what was considered to be mental illness. Medical intervention was aided by the Cartesian separation of mind from the body making room for the rise of somatic medicine (for a review see Scull, 1981a). This change caused a shift from the classification of mental disorder as moral disorder, where the ‘mad’ were just as likely to be under the care of the priest, to physical disorder of the brain, under the care of doctors and responsive to somatic medicine. Entrepreneurial efforts by mad-doctors to secure a client population led to the rise of the private asylum and a trade in lunacy began (Parry-Jones, 1971).

The development of public asylums for pauper lunatics in the nineteenth century led to a huge influx of patients (Butler, 1985). The increased expectations by the populace of cure created a paradox. Horrified by the presence of lunatics roaming their community the public supported involuntary confinement (McCandless, 1981). Yet they were equally concerned about sane people being wrongly committed, or cured and not released, and they forcibly criticised those responsible. The fear of wrongful committal to, or exit from an asylum, was aided by inflammatory accounts in news-sheets. The advent of accessible media spread information about such events and the fear they invoked. Public rage against

wrongful committal nearly always centred on the people who operated the system and not the system itself. The lunacy panics of the 1850s and 1870s led to appointment of select committees to investigate (a similar practice is also found today when media whip up a lunacy panic) (McCandless, 1981).

Doctors argued for boundaries between the insane and sane, which required the expertise of medical men to delineate. By licensing doctors, the law ousted charlatans and granted doctors the authority through a legal framework. This formed an enduring association between medicine and law, which gave doctors power equal to magistrates in their ability to confine and commit people to régimes of treatment (Butler, 1985). While the British public relied on doctors, they never gave up their suspicions about the competence of doctors. Scull (1981a) suggests that these suspicions were aroused firstly by frequent differences of opinion between doctors over a person's mental state; secondly, the enlargement of categories for insanity and symptoms indicative of it; and the third, the doctor's sense of normalcy became the measurement of mental disorder. This "inspired fear and, periodically, rage" (McCandless, 1981, p.341). The violence with which alienists were attacked as "hypocrites, frauds, sadists, knaves and moneygrubbers" (McCandless, 1981, p.342) was anchored in the belief that committal as a lunatic was one of the worst things that could possibly happen.

A lunatic, in law language, is *civilitus mortuus*... If committed unduly, he receives in his single person nearly all the civil injuries that can be inflicted; for not only is his liberty thereby taken away and his property removed from his control but he suffers an imputation which operates with all the force of a libel A party detained on a charge on insanity may be acquitted and restored to liberty; but we all know that this is a question of such a nature that it cannot even be raised without attaching suspicion ever after to the individual to whom it relates (*Spectator* 1839, quoted in McCandless, 1981, p.342).

The beginnings of stigmatisation of the insane has been attributed to fears associated with the committal process, although other fears around contamination or pollution, spiritual possession and the imputation of poverty were also involved (Brunton, 1997).

The dilemma of certification and committal occupied Victorian officials much as it still does today in New Zealand. Especially difficult was the declaring of a person sane only to find out later that they had disgraced their family and

themselves. The act of being declared insane and being committed entailed a moral loss by the patient. Conversely, failure to diagnose and commit appropriately entailed moral vilification of doctors by the public and newspapers. Public perceptions about the inability of professionals to make accurate assessments regarding patient dangerousness were nurtured by unfavourable findings of commissions of inquiry. Nor was public confidence in the efficacy of treatment bolstered when inconsistent diagnoses and outcomes were still present after years of management. It gave fresh impetus to the perceived incurability of psychiatric illness. However, there were changing meanings about the asylum as an institution. There was a growing confidence in and acceptance of the alienist or medical superintendent of the asylum, because people continued to use asylums to control and deal with family members (Finnane, 1985).

Edward Davies was the subject of a well-known English Commission of Inquiry held in 1829 (McCandless, 1981). His mother had him committed when he started to rebel against her and she acquired legal guardianship to protect his property. At the tribunal, which was attended by noted physicians, it was argued that Davies was suffering delusions regarding the conduct of his mother. The physicians were unable to consistently evaluate their primary grounds for considering insanity and committal. Once Davies was thought to be 'mad' all his behaviours appeared to confirm this. Any patient view that was contrary to that of the physicians or conveyed suspicion about their motivations was taken as further confirmation of their diagnosis and action. Upon hearing the physician's evidence the jury stopped the proceedings and returned a verdict in Davies' favour. The inconsistent behaviour by medical men caused much public concern.

The medical testimony in this case was carefully scrutinised in the *Quarterly Review*, a magazine of the day, in a similar manner to the contemporary investigative journalism of *60 Minutes* or *20/20*. Explanations were sought about how eminent physicians of good character and education could present such absurdity to an official hearing. Physicians were found to view any mood or manner as an expression of morbidity when it was not proportionate to its cause; and they would "pronounce the patient to be of unsound mind, and then infer, as a necessary consequence, that he ought to be confined" (*Observations on Madness*

and Melancholy, quoted in McCandless, 1981, p.350). Diagnosis and committal were linked to the process of judgement that physicians used. Crucial elements in this process to infer insanity included the patient's distance from accepted social norms for a person of that status and occupation; and judgement of the patient's state of mind with reference to an understanding of their own minds (McCandless, 1981). If the physician's basis of diagnosis rested on value-laden judgements, then both within the public mind and their own, insanity was often linked to immorality and deviation from social norms. But families also contributed to ideas about what constituted 'odd' behaviour when they used the asylum to manage those who could not be controlled at home (Theriot, 1993).

'Madness', Morality and Social Deviancy

The social norms of Victorian England in the nineteenth century developed from the expansion of middle class values to those of other class and status groups, and were substantially more 'puritan' than those of the previous century (Skultans, 1979). The Victorian moral code pressured people to conform, if not in substance, then at least in manner (Elias, 1994). Especially important was being respectable in speech, dress and conduct. Being respectable, and the expectation of being respectable, equated to rational behaviour. Conversely, not being respectable indicated irrational behaviour. Overstepping the bounds of respectability for one's social position into extravagance, gluttony, drunkenness or sexual licence risked the allegation of madness. Assigning deviance from social norms to insanity implicitly placed physicians as guardians of these social norms and the processes used to enforce them (McCandless, 1981). In effect they were using their scientific authority to give foundation to the community's moral values.

The moralisation of poverty and viewing its related social problem of lunacy as a moral problem, too, changed the view that these things were incapable of reform. They were no longer to be accommodated as inevitable and natural, they had to be changed. The naturalistic view, that an insane person reverted to an animalistic state that needed to be controlled, underwent a sustained challenge. In moral reform the "social discipline of the asylum replaced the chains for animals" (Garton, 1988, p.14). Moral therapy required no medical expertise and as a movement presented a threat to the medicalization of insanity. This did not mean that doctors denied the importance of 'moral therapy' when faced with some very

good results; rather they argued it was more effective when combined with somatic medicine.

However, the close association of immorality with insanity fused 'madness' with badness. It medicalized social deviance (Smith, 1981). The transgression of Victorian moral codes through antisocial behaviour (especially sexual licence) was viewed as immoral (Skultans, 1975). The implication of confusing 'madness' with immorality and behaviour that failed to meet social norms was that it encouraged practices in the asylum that were little different from the reformatory. Confinement prevented a loss of respectability as much for the patient as for the family. What was prevented by restraint and seclusion within the asylum was as much social as it was medical. Committal proceedings were initiated because of the views presented by magistrates, police, alienists, family and friends, that other forms of care and control were not available or could not be encouraged by the patient themselves (McCandless, 1981).

Nonetheless, someone had to make a decision between the sane and the insane, as the system of involuntary confinement demanded this. Alienists were appointed to this task of removing the insane from public life (Rosen, 1968). Yet there were concerns about doctors and the discharge of their tasks. The lack of information from doctors regarding 'madness' and their patients; the doubtful and subjective basis used in arriving at a diagnosis of madness; the confusion of immorality and anti-social behaviour with madness; and the association between doctors and asylum proprietors for patient recruitment, all created a sense of insecure personal liberty (McCandless, 1981). Such a danger to individual freedom, on the one hand was necessary – the public were convinced of the need for involuntary committal - but on the other hand caused discomfort with the ramifications of the asylum, and the fear and loathing it inspired (McCandless, 1981). The rise of a new group of mental disease experts who had expectations of curing rather than restraining the insane led to the development of the psychiatric profession.

The New Zealand Experience

Madness within British Coloniser and Settler Practices

The first psychiatric centre in New Zealand was a pauper lunatic asylum attached to the Wellington jail in 1844. Prior to that, mental illness was seen as a law and order problem, where lunatics were herded together in prison along with other social undesirables who disturbed the peace, such as convicts, debtors, prostitutes, vagabonds and the like (Williams, 1987). Otherwise they were free to roam the countryside, much as they were in other colonial countries (Grob, 1973). The reality of colonial life was such that lunatics either looked after themselves or perished. In colonial New Zealand, 'drinking' was a response to, and a way of escape from, the harshness of colonial life and led to rates of insanity in 1879 that were 35% higher than in England (Tucker, 1887). Support for the insane was entirely a charge on General Government while relief of the sane poor was a charge on local bodies. This "allowed the elastic term of 'insanity' to be applied with the utmost latitude, and to place many persons in Lunatic Asylums who might be well enough or better provided for elsewhere" (Tucker, 1887, p.671). Those of wealth or means could be maintained by understanding families and paid help. For the jailers, handling lunatics proved difficult, and official inspectors often wanted them removed (Adams, 2000/2001). Growing public recognition that placing lunatics in a penal population was inappropriate led to demand for a refuge quite unconnected to a jail or hospital (Williams, 1987).

The first New Zealand legislation on the mentally ill was the Lunatics Ordinance of 1846. Shaped by the asylum movement, this legislation paved the way for a state provision for the insane funded by the public purse, with guidelines for certification and admittance to a jail, house of correction, public hospital or asylum. The term 'lunatic' had considerable latitude in its application, for it embraced all those unable to manage their own concerns (Brooks, 1987). Until 1911 two medical certificates were required to commit a person to a licensed house, hospital or asylum (Fennell, 1981/2001). Usually it was because it was impossible to manage them at home (Reed, 1993/2001). There were no voluntary admissions and committal only occurred when a person was deemed a 'dangerous lunatic' (Brooks, 1987, p.172). As a consequence police were used to restrain and deliver patients to a place of treatment, furthering associations of lunacy with

social deviancy. However other considerations were also present. The link between poverty and sickness was quickly felt as a catalyst that “nudged individuals and their families from meagre survival to abject poverty” (Tennant, 1987, p.44). The first hospitals were constructed with this in mind and were intended for indigent patients, both non-Maori and Maori (Tennant, 1987).

Colonial control and state ideology had an important function of maintaining order based on racial and class myths of intellectual and moral superiority (Lattas, 1987; Hage, 1998). In the Australian colony of Victoria the initial separation of patients by sex shifted to classifications of bodily difference based on gender, race and class (Coleborne, 1997). Class differences led private asylums to find the right sort of patient - people in ‘good positions’. These folks did not want to mix with the insane poor. This was something distasteful to families and friends, and “detrimental to recovery of the former class” (Sommerville, 1996/2001, p.87). In 1911 a statute defined lunatics as “unfortunate folk”. Its five categories of insanity – mentally infirm, unsound mind, epileptic, idiots, imbeciles – were expanded to include ‘social defectives’ in 1928 (Holloway, 1991/2001). As Holloway’s account suggests, it was possible for men who failed to provide for families and women who could not keep house to be incarcerated. The latitude with which these terms could be applied was amended. However committal still retained a factor of social causes in its considerations that the early colonists had tried to guard against.

The first influx of settlers into previously Maori dominated communities brought all the problems that Britain had tried to eliminate by emigration and what the anti-colonists had warned about: violence, crime, vagrancy, deprivation, destitution, debauchery and prostitution (Ernst, 1991). The presence of misery amongst the colonists and settlers would have challenged the dream of a ‘better life’ and a more humane society for many. Perhaps this may explain why special premises were built for pauper lunatics only three years after the first official case of Pakeha insanity in 1841 and why lunacy was treated as a law and order problem. Pakeha lunacy could have been seen to tarnish the superiority and civilising mission of an aspiring white ruling class with Victorian values (Ernst,

1991). Removing such people was based on the need for social and physical distance to preserve social order.

Concerns about the race of patients, specifically Chinese in the Dunedin asylum in 1872, focussed on the 'injurious' effect of daily contact on European lunatics by Chinese lunatics (Bloomfield, 1979/2001). Early accounts suggest that instances of insanity within Maori communities prior to 1900 were a comparatively rare event as such people were expelled to die (Gluckman, 1976). These explanations seem somewhat simplistic. Prior to legal suppression of Maori healers (*tohunga*) in 1902, it was likely Maori would have had easy access to their tribal healers; and no doubt continued to do so after their suppression as this remained part of Maori law (*tikanga*) (Durie, 1988). Obligations within Maori extended family (*whanau*) would have provided the care they needed. Exactly what was insanity for Maori had a culturally specific aetiology. Pathological and functional illness had the same aetiology as specifically Maori illnesses that were known as *mate* Maori (*makutu*) (Gluckman, 1971). This was to distinguish them from Pakeha illness – *mate* Pakeha. Maori illness occurred from knowingly or unknowingly breaking positive prohibitions (*tapu*). In breaching *tapu* this also breached 'being' (*mana* Maori) within the order of things (Marsden, 2001).

Treatment was carried out by a *tohunga*¹. If Maori experienced *mate* Pakeha illness they would attend non-Maori psychiatric treatment, especially if it worked. By the 1920s, disillusionment with both modern scientific medicine and traditional *tohunga* healing helped boost faith-healing movements, such as the *Ratana* faith (Rice, 1988).

Custody to Cure

Coinciding with the provincial period, a network of asylums was established throughout New Zealand, with the first one opening at Karori² in 1854. The public demanded that treatment within Karori should be free from mechanical restraint and should seek to restore the lunatics' mental order through a system of moral

¹ Words relating to Maori notions of 'illness' barely touch on the complex meanings, interpretations and obligations within Maori custom/law for such terms as *mana*, *tapu*, *mate* Maori, *makutu* and *tohunga*. For a review of such terms by a non-Maori psychiatrist see Gluckman (1976, pp.221-265) and by a Maori psychiatrist see Durie (1998).

² For a more detailed explanation see Wendy Hunter Williams' (1987) account of Karori lunatic asylum and its development into Porirua hospital – '*Out of mind out of sight*'.

management (Williams, 1987). Moral management was inspired by the work of Tuke in England and Pinel in France (Scull, 1981b). More than anything else it was a recognition that “kindness, reason and tactful manipulation was more effective in dealing with inmates than were fear, brutal coercion, restraint, and medical therapy” (Scull, 1981b, p.106). Moral therapy usually consisted of work, church and recreation in an environment that was structured, peaceful and designed to promote harmony, without physical restraint. The ability to participate in daily community life and for that community to be self-sufficient was also part of the cure. These values and norms heavily mirrored the Protestant and colonial work ethic. Since moral management was not medical treatment, staff were lay keepers and superintendents. At the heart of this treatment system was a hope and belief that lunacy could be cured, and that such asylums were effective in doing so. This promise, that moral management at Karori would cure lunacy, was not fulfilled, although despite misgivings by contemporaries, it promoted recovery in many cases (Williams, 1987).

Up until the early 1900s public asylums experienced a large growth in population, exceeding the capacity that they were originally built to hold. With the demise of the provincial asylum system in 1876 central government inherited poor conditions, inappropriate staffing and overcrowding in their public asylums. The development of an administrative structure reflected the desire not to import from Victorian Britain the problems of the industrial revolution, class restrictions and poor laws (Brunton, 1983). During the formative years of the colony, myths of egalitarianism, concern for the underdog and governmental obligations in the absence of alternative institutions affected the provision of medical services. This thrust the state into the role of providing social services and by implication it became “keeper of a community’s conscience for social distress” (Brunton, 1983, p.3). The hospital system, as a charitable service run by medical superintendents, was seen to be abused. As the real responsibility for running the hospital system was increasingly being passed to the State, statutory bodies, such as hospital/charitable aid boards, took over their management and funding. Left to their own devices these bodies made by-laws to exclude patients who were therapeutic liabilities, such as patients with incurable diseases or the mentally ill. Central government was left to deal with these residual problems, such as

psychiatric hospitals. Increasing numbers of discrete municipalities and the ad hoc establishment of new structures in response to administrative problems characterised the New Zealand response to problems and administrative reform (Brunton, 1983).

Cure to custody

With asylums now taking incurables they were transformed from places of acute care to places with a predominantly custodial function. Therapeutic régimes became cheap hotel keeping; work therapy had mercenary ideals; and smaller staff numbers to handle more, especially chronic patients, with less room led to mechanical restraint and seclusion (Brunton, 1972). The early halcyon days (to the late 1870s), when discharge/cure rates were better than in Britain, were over. This coincided with an economic depression (lasting to the 1890s) and a vocal emancipatory movement that sought to 'save the sane'. These influences cast a pall over therapeutic services and saw incurables rise to 93% of the patient population towards the end of the century, eventually dropping to 60% by 1945 (Brunton, 1972). The high ratio of 'incurables' fuelled the perception in New Zealand that people never leave asylums and this stigmatised any asylum care. This was in stark contrast to the expectations of asylum care prior to the 1880s.

The advent of the cheap daily newspaper circulated stories from British journals and imported British portrayals and attitudes towards lunatics and asylums, which found a willing audience (Ernst, 1991). Public attitudes, which before were concerned, compassionate and benevolent, changed to indifference, suspicion and self-protection (Brunton, 1985). The public expected to find situations in New Zealand that matched those of Britain, and they were not disappointed. The shift in management practice within public asylums that Brunton called "from cure to custody" began in the late 1870s (Brunton, 1997, p.21). Stereotypical views of asylums were rarely disconfirmed as asylums predominately sought to isolate and insulate themselves from adverse public opinion.

Closure of the first asylums in the early 1900s, where overcrowding was both a cause and effect of their management, led to the second generation of asylums, e.g. Tokanui. These asylums were built even further away from the communities that they were intended to serve, or else higher walls achieved a similar effect of

insulation from the public gaze. The barriers were to keep the patients in as well as to keep the public out and both sides wanted these barriers (Brunton, 1972), though not all asylums followed such restrictive practices (see Brunton's 1997 history of the Seaview asylum). The ideas of insulation and incurability strengthened the institutional response to psychiatric illness and led to closed systems. Within closed systems, self-management and lack of public inspection made it easier for patient welfare to be met by substandard conditions. Inadequate resourcing led institutions to expect it and public works to deliver it, so that overcrowding and pursuant problems reoccurred. Patients were shifted around asylums or to prisons to handle the overflow. They were also filtered through the admission services and front wards that received the bulk of scarce resources. Failing to respond, patients progressed to the back wards (or 'bins) and became 'incurables' where there was little hope, interest and largely custodial management. In the public mind, this furthered associations about mental illness with incarceration (e.g. bad/uncontrollable), incurability (e.g. permanent/loss of hope) and social loathing (e.g. patients are 'out of sight, out of mind'/not worthy).

Despite the seemingly bleak picture above, New Zealand appointed medical superintendents to manage their asylums. Some, like Truby King, were men of vision, tremendous personality and resilience who did their best in attempting to do a very difficult job. Then, as now, they spent much of their time fighting situations arising from a decreasing supply of funding and an increasing demand spiral coupled with adverse public perceptions. Their education was derived from an era that embraced restraint and institutionalisation. Institutionalisation was congruent with a somatic approach that placed insanity as a bodily disease squarely in the province of physicians. Despite their efforts, brutality was frequent, as Royal Commissions of Inquiry found. Their institutional approach limited any options of inpatient care until the 1920s (Brunton, 1972).

Custody and 'Care'

The return of service personnel from WW1 transformed the perception and treatment of lunatics. Here were men and women who went away sane but came back with 'shell shock' and 'nervous breakdowns'. 'Nervous illness' did not have the stigma of madness, especially if it were attributable to war service (Blake-Palmer, 1962). The association of traumatic experience with milder versions of

insanity blurred the line between sanity and insanity and kindled public demand for housing and services that were separate from mental hospitals, but only for ex-service personnel (Grant, 1998/2001). The differentiation and separation of psychiatric patients into special wards or 'villas', the introduction of trained nurses to replace attendants and the development of outpatient hospital clinics in 1925, began the de-centring of psychiatric institutions. But it was not until the introduction of psychotropic drugs and their use in psychiatric institutions, that these institutions' provision of acute care was slowly shared with general hospital services in the late 1950's. This development dramatically altered attendance at and access to psychiatric services, as well as public perception of people who used them. Ideally the new voluntary admission system meant that people could enter psychiatric care, recover and return to their everyday life, without judicial proceedings.

Custody and 'Care' of Inpatients and Outpatients

The 'mental hygiene' movement (Klein, 1960) and a more aggressive psychiatric approach in New Zealand stemmed from worldwide trends of 1945-55 (Grant, 1998/2001). There was more emphasis on patient freedoms, recreational activities, better quality of care and optimistic treatment³. Mental health was not just a medical subject within hospitals but embraced all the institutions that influenced human conduct (Gray, 1959). The effect was to colonise the conduct of everyday life, both personal and private, with the influence of mental illness. The implication for treatment was that for people to regain everyday life they needed to participate in it. Underlying this approach was the need to "wean people from their erroneous beliefs as to mental patients" (Gray, 1959, p.129). Doing so could reduce the unnecessarily pessimistic beliefs about mental disorders that they were unresponsive to treatment. Blake-Palmer (1962) was one of the first to draw attention to social prejudice around mental health in New Zealand Pakeha culture. Most of all, with changed attitudes it could reduce the disgrace, shame and horror associated with mental illness (Beaglehole, 1950) and increase the perception that a psychiatric hospital functioned in the same way as a general hospital

³ See Grant 2001 for discussion about the rhetoric and reality of this period. Despite this optimism the language of staff-patient relationship revealed a strong sense of separateness and superiority. In practice, nurses regulated patient toilet and bathing habits. Therapeutic techniques (e.g. locks, walls, cells, restraint, drugs and 'other' things) were still being used to manage uncooperative patients.

(Stallworthy, 1958). However, continuing separate administration for mental hygiene within the Department of Health contributed to fears about all forms of mental disorder (Grant, 1998/2001). Psychiatric hospitals were not integrated with general hospitals until 1972 and patients still lacked a voice that could reach the outside (Sainsbury, 1947).

Families and Patients

Despite the optimism about mental illness in post war accounts, earlier prejudices and social distance between the public and patients still existed. In *The Facts of Mental Health and Illness* Stallworthy (1958) indicated that families preferred to discuss mental illness as a 'nervous breakdown' even in the more extreme instances of insanity. Grant's (1998/2001) summary of four New Zealand surveys in the 1960s and fictional and non-fictional accounts by authors with asylum experience (e.g. Janet Frame), indicates that many families had deliberate strategies of concealment. This could be from those outside the immediate family and between family members. Two thirds of male and 90% of female admissions were initiated from within their own homes, and this was likely to have continued beyond the analysis period of 1928-1937 examined by Holloway (1991/2001). The separation of 'madness' and reason was performed within families and "confirmed a view of the mentally ill as frightening enough to be excluded even from their own families" (Grant, 1998/2001, p.249).

As families lived in separate worlds when their members were removed, so too did patients after they had adjusted to the elaborate social systems and social status of ward life (Grant, 1998/2001). Grant's analysis of Janet Frame's account of life within 'Ward 4' (*Faces in the Water*) provides some insight. Social status within the ward was important and was awarded on degree of functionality, trustworthiness and proximity to discharge. Employment among those that ran the hospital was a visible and tangible indication of social status. The transition back to the world again was like landing in a foreign place where patients looked for signs and acknowledgement that they were a "genuine citizen of the world of reason" (Grant, 1998/2001, p. 254). The change in an identity bounded by reason and 'madness' through psychiatric treatment inveigled families into the marginalization of their members and their unchallenged ideas of separate worlds.

The growth in outpatient services was accompanied by changes in mental health legislation, transfer of hospital control to hospital boards and a proliferation of specialist psychiatric, psychological and social work services (for reviews see Abbot, 1983; Haines & Abbott, 1985). The reduced reliance on psychiatric hospitals for psychiatric care was underpinned by treatment methods that shortened or prevented patient stays. Policy restrictions both on psychiatric hospital expansion, inclusion of psychiatric wards within public hospitals and anti-institutional attitudes amongst the public and health professionals also contributed to closure of psychiatric hospitals. Institutional closure occurred more as a result of historical trends and adoption of a 'community care' model than as an explicit de-institutionalisation process (Haines & Abbott, 1985). While community care has been seen as the antithesis of institutional care, both are a limited goal when barriers of exclusion to economic and social life remain. As Sayce (2000) succinctly comments about any form of 'care': - "It fails to require that one role of mental health services should be to facilitate social inclusion" (p.81).

Recent Times: Services of Custody, Treatment, and 'Care' in the Community

During the 1980s and 1990s, high profile psychiatric cases attracted vigorous attention from commissions of inquiry. Judge Mason, responsible for the most recent ministerial inquiry in 1996, noted there had been 67 reviews or inquiries into mental health services over the last decade (Mason, Johnston & Crowe 1996). The problems – staffing, patient overcrowding, ethnocentrism, treatment failures, negative public perceptions, funding, high profile cases of violence, human tragedies – were given persistent review without significantly altering these outcomes. A cohesive approach with legal force to implement change was lacking. Mason's recommendation led to the setting up of the Mental Health Commission (MHC) as a monitoring body with plenty of 'bark' but little legal 'bite'. The Commission's strong policy and consultation role in service development and delivery has reduced the parochialism of mental health service providers and ad hoc service provision. MHC commentary on solutions to specific well-documented needs has increased the information flow within and between services and government (MHC reports 1997a-b; 1998a-c; 1999a-e; 2000a-e; 2001a-b). It has assisted a national effort to provide cohesive mental health

services and to prevent people from ‘falling through the gaps’ in service provision.

Despite these endeavours, structural profiles based on ethnicity suggest that people still ‘fall through the gaps’ in very unequal proportions. Admission rates for Maori were below those of non-Maori until 1970 but by 1982 had become three times higher (Durie, 1998). Maori now account for 67% of mental health inpatient admissions whilst comprising only 12% of the New Zealand population (Durie, 1998). For many Maori, the disproportionate loss of wellbeing has been attributed to their distress and ill-health arising from colonisation (from the 1880s) and urbanisation (from the 1950s) (Mason, Ryan, & Bennett, 1988). The social control functions of institutions inaugurated in nineteenth-century Britain have driven a structural response to Maori behaviour deviating from non-Maori norms. Colonies within prison (e.g. detention within prison communities of Maori), work (e.g. community work programmes), housing (e.g. substandard housing groups) and mental health (e.g. acute, sub-acute and accommodation services) have been paternalistic responses to deep seated alienation and deprivation that has only recently been addressed by the Crown. Multiple stigma can ensue where psychiatric history (e.g. ‘mad’) is one stigma amongst others, such as low education (e.g. ‘stupid’), unemployment (e.g. ‘bludger’), criminal history (e.g. ‘bad’) and low economic status (e.g. ‘broke’). Recent efforts have sought a psychiatric service based on Maori conceptions of wellbeing (Durie, 1998).

With the closure of the last old institutions, the fourth wave of psychiatric hospital construction began in the 1990s. These are now called units (e.g. Connolly Unit) or centres (e.g. Henry Bennett Centre) and are centrally located within communities. Staff from the old institutions were made to re-apply for these new positions with the intention of eliminating staff who had an institutional focus⁴. These services are for acute care only, so people have to be very unwell (dangerous to self or others) to be eligible for a bed. Often children or adolescents are domiciled in adult accommodation. When people are unable to fulfil the

⁴ A MOH publication in 1996 on mental health workforce development was still talking about the effects of change from institutional to community care on staff (i.e. residual institutional mindsets and practices within staff and their training).

criteria for inpatient admission⁵, they attend community mental health support services⁶ and have to contend with a shortage of medium and long-term stay accommodation. Acute units face staff shortages of permanent and large dimensions (MOH, 1996). In response services have had to recruit international staff some of whom experience linguistic and cultural difficulties with patients. The shortage of staff, high turnover of existing staff and uncertain resourcing of services can create a workplace culture of uncertainty for those who provide a service, and uncertainty for those who use it (McClelland & Warren, 1996).

The Mental Health Commission has shown how the poor regard for psychiatric services has undermined the desirability for employment in mental health and is now targeting workforce development as a central issue in improving psychiatric services (MHC, 1999c). Yet the difficulties of training, recruiting, retaining and developing staff to work in psychiatric services may have more to do with the undesirable nature and place of psychiatric service work than just the conditions of employment. Improving the conditions of employment in psychiatric services may only enhance the trend to recruit international staff as it does not address the social stigma that inhibits local people pursuing such careers or taxpayers funding these services. Furthermore, an intense public scrutiny that is waiting to pounce on any service errors can suggest services are places of 'siege and conflict' rather than growth and opportunity. This does not improve the desirability of psychiatric service employment and can contribute to the social loathing associated with such an environment (MOH, 1996).

Psychiatric services today face similar difficulties in providing their services as those of yesteryear. Despite best intentions, overcrowding, permanent staff vacancies, fiscal shortages and debt servicing are likely to constrain service delivery and privilege clinical services at the expense of community prevention

⁵ Primarily, a person has to be at risk of causing harm to their self or other people, and this will lead to a Mental Health Status Assessment completed by a registered health professional in accordance with the Mental Health Act.

⁶ Support services require a person to complete a Ministry of Health Brief Support Needs assessment and meet the funding requirements of their local District Health Board (e.g. aged 18-65, live within the District Health Board service area, have high support needs, have limited or exhausted resources, a mental health condition that has been identified as a psychiatric disability which is likely to continue for a minimum of 6 months or more and results in a reduction of independent functioning to the extent that ongoing support is required).

and support. The New Zealand approach to service problems as administrative difficulties re-emerged in the late 20th century as a response to service problems that were similar to those of the 19th century. Its health services underwent the most radical of restructuring during the 1990s as New Zealand embraced economic rationalism. Hospitals became Crown Health Enterprises (CHE) within a Regional Health Authority (RHA) instead of hospital boards. RHAs were then amalgamated into a health funding authority (HFA) and administered by Hospital and Health Services. CHEs became Crown Health Agencies (CHA). RHAs were then subsumed back into the Ministry of Health for a short period only to re-emerge as area district health boards in 2001. CHEs have been disbanded and are now called 'hospitals', managed by hospital boards at a local level. These large structural changes caused massive staff and client uncertainty, doing little to change the poor regard in which psychiatric services and clients were held. If these services could be changed so dramatically and frequently without improving fiscal difficulties and service effectiveness, then this only served to underscore the intractability of service problems and their clients.

A more visible consumer movement has given rise to current efforts to de-stigmatise mental illness. With consumers delivering de-stigmatisation programmes to mental health services, staff have had to face the consequences of their past and current practices. Mental health service funding is now linked to consumer participation and service delivery (MHC, 2000a). Stakeholder perceptions of service strengths and weaknesses are solicited (McClellan & Warren, 1996; MHC, 1998b). Publication of first-person patient experiences of New Zealand mental health services (e.g. Bishop & Beynon, 2000; Leibrich, 1999; Miller, 1984,1987; MHC 1997a, 2000b-d), conference presentations (e.g. O'Hagan, 1999; Pearson, 2001) and research directions (e.g. Health Research Council of New Zealand, 2000) suggest a new role for mental health consumers - a role that embraces work within the very psychiatric services which they may have used, or are currently using. The separation between staff and patient or 'us' and 'them' accompanied by a voice that strives to be valued rather than ignored, has been particularly challenging for both parties.

Consumer direction within mental health policy has led to the formulation of recovery competencies (MHC, 2000e, 2001a). Basing health outcomes on patient-defined recovery and employing staff based on their recovery competencies for patients is likely to re-orientate service culture and practices in new directions. Consumer-run services that are effective for their clients across a wide range of roles (e.g. advocacy, employment, training, education) while remaining fiscally prudent, are not the exception any more (Macken, 2000). The presence of people who actively employ their past experience of psychiatric service use and are open about this in discharging their jobs within services and before public groups, has challenged stereotypical views about psychiatric patients (MHC, 2000a).

Perceptions of 'Madness' and 'Mad' People

While only a small percentage (3%) of people will experience a severe and ongoing mental disorder, at least one period of impaired functioning due to mental disorder will be experienced by two thirds of all New Zealanders (Disley, 1997). The development of treatment within the community has led to a more visible presence of psychiatric service consumers on the streets. Despite the familiarity with mental disorder suggested by these prevalence rates and increased visibility, New Zealanders still retain a mixture of beliefs and attitudes towards psychiatric illness and users of psychiatric services that is negative and very slow to change (Green, McCormick, et. al, 1987). Co-existing with this prejudice has been a degree of concern and sympathy for the plight of the mentally ill (Ng, Romans, & Martin, 1995; Patten, 1992).

Events over the last few years concerning psychiatric patients' activities in the community⁷ and in treatment⁸ continually refocused public attention on the

⁷ Difficulties with social acceptance of new accommodations are underpinned by fears that are only assuaged by rejection – "It's not just the [violent] incidents that we are frightened of, it's the way it will effect our normal, everyday lives. I don't just want them out of our area. I don't want them living near my mother or near a school" (NZ Herald 20/08/97, p.A11).

Police cells can end up as 'reluctant holding pens'. As in the colony's early days, substance abuse is strongly associated with acute admissions today. Crisis teams on call out to police response may not assess people if they are intoxicated, which means police stay involved and take the person into custody for their own protection (NZ Herald 20/10/97, p.A14).

In an article about systems failures - 'Community care: a step too far' - half the article is devoted to a litany of rape and multiple murder (death by mutilation, beheading, strangulation, stabbing, bludgeoning) by patients of their friends, families and strangers. It concludes – "The experiment has failed... How many families must get hurt before New Zealand learns" (NZ Herald 2/9/99, p.A11).

negative aspects of psychiatric illness. Increased media access and distribution of information quickly disseminates negative events. Repeatedly hearing about the same event through multiple media can amplify the perception that such events are frequent. Relaying real-time events that show psychiatric patients engaging with police or performing violent acts that injure or kill innocent people, has increased the immediacy and impact of these events. Blaming psychiatric services for failures and repeated reviews of mental health policy and treatment options after such incidents, further magnifies the public uncertainty about dangerousness and treatment success. This uncertainty influences people to think the ‘worst’ and confirms that psychiatric illness symptoms are realistically characterised as socially dangerous, frightening, shameful and incurable (Disley, 1989).

Descriptions of people with a psychiatric illness are that they are violent, unpredictable, irrational, unstable, to blame for their problems, cannot be trusted and lack intelligence (Canadian Mental Health Assoc., 1994). Psychiatrically ill persons are less likely to be your friends, workmates or neighbours (Bhugra, 1989). Attitudinal studies in New Zealand share similarities with international studies in that users of psychiatric services are perceived as violent and dangerous; are unpredictable in their behaviours; and produce a feeling of unease or awkwardness (Blizzard, 1968; Business Research Centre, 1997; Green, McCormick, et al., 1987; Green, Walkey, Taylor, & McCormick, 1987; Ng, Martin, & Romans, 1995; Patten, 1992). Such attitudes are part of society’s discursive resources about ‘community care’ of psychiatric illness and patients (Tuffin & Danks, 1999) and spill over into negative depictions in prime-time drama (Wilson, Nairn, Coverdale, & Panapa, 1999). Media presentations about psychiatric illness and patients in New Zealand are organised around themes⁹ of: ‘dangerous-aggressive/incompetent’, vulnerability asocial, social outcast,

⁸ Concerns about the opening of a 114 bed facility in a provincial city were around patient ‘dangerousness’ and ‘escape’ not therapeutic efficacy (NZ Herald 1/10/97, p.A7).

Inconsistent decision-making between psychiatric service staff led to patient discharge and murder (NZ Herald 16/12/97, p.A15).

Discharging of a patient only to find they then commit murder, makes headline news - ‘Psycho’ flatmate took man’s life: Killer had left hospital against medical advice’ (NZ Herald 1/9/99, p.A1). It takes only a short time before media accounts of multiple murders by psychiatric patients are turned into a collective memory, such as the “Raurimu massacre” covered in Allen & Nairn (1997).

⁹ A theme is a collection of words, images and story lines best summed up as a consistent discursive resource (Allen & Nairn, 1997).

untrustworthy, failure/unproductive, simple/childlike, caring/empathetic (Allen & Nairn, 1997). These themes summon up a creature suited to custodial restraint and straight out of the asylum of the previous century. They do not involve a concept of recovery.

Similar themes have been found in international studies. Implicitly connected to socio-cultural constructions of mental illness is the idea of chronicity (Lefley, 1990). In American studies, chronicity is the single best predictor of violent behaviour across all psychiatric illnesses (Torrey, 1994). Studies have shown that psychiatric patients engage in violent or threatening behaviour both prior to admission (Rossi et al., 1986) and upon discharge (Monahan, 1992). The low competence and dangerousness of mentally ill people, justifies their need for legal coercion (Pescosolodo, Monahan, Link, Stueve & Kikuzawa, 1999). To the extent that violent behaviour is connected to a sub-group of mentally ill people (usually those with paranoid schizophrenia and substance abuse, see Mulvey, 1994), then public responses in attitudinal research (which frequently note violent and unpredictable behaviour as the prime concern with mental illness) are based on reality, and not stigma. However the most people seeking help from psychiatric services have symptoms of depression and anxiety and present no threat to anyone but themselves (Mullen, 1991). The association of psychiatric disorder with criminal offending is more likely to be due to poverty. Social dislocation and its consequences of being vagrant, homeless and drifting places people in situations where they become objects of fear and leads to their arrest on charges of public nuisance. It is the minor fraud and petty theft occasioned by poverty that contributes to the disproportionate offending of the mentally disordered (Mullen, 1991).

However, the public perceives most, not just some, people with mental illness as being violent¹⁰ (Link, Phelan, Bresnahan, Stueve & Pescosolido, 1999). This is also the view proffered by media representations of mental illness behaviour (Signorelli, 1989; Wahl & Lefkowitz, 1989) and similar to those found in New Zealand. Gerbner (1993) has noted nearly three-quarters of mentally ill characters

¹⁰ In relation to the 'Raurimu massacre' a spokesman for a New Zealand national consumer network (ANOPS) mentioned that of the 67,000 using mental health services only three made the headlines, and asked what happened to the other 66,997? (NZ Herald 1/10/97, p.A18).

on film are violent and four-fifths are victims of violence; they are not just dangerous but are also imbued with a presence of evil that justifies their mistrust and eventual victimisation. Mentally ill people in popular television programming are frequently portrayed as perpetrators or victims of violence and as something like zoo specimens (Hyler, 1988; Hyler, Gabbard & Schneider, 1991). These media portrayals are often the source of lay perceptions about mental illness behaviours, both internationally (Wahl & Lefkowitz, 1989) and locally (Business Research Centre, 1997).

Psychiatric Stigma in New Zealand

In an overview of psychiatric stigma in New Zealand, Disley (1989) suggested that stigma impacts on the mental health of consumers through: derogatory public comments, scapegoating (e.g. false associations with violent crime), shame (e.g. not wanting to reveal their mental health status for fear of sanctions), dehumanisation (e.g. ordinary physical, emotional and social needs are not seen as important) and denial of access to goods and services (e.g. alienation from mainstream community life) (MHC, 1997a). Most New Zealanders do not know psychiatric illness symptoms, treatment and prognosis (Patten, 1992), are misinformed (Ng, Martin & Romans, 1995), and hold entrenched views (Green, McCormick, et al., 1987) that people with psychiatric illness are violent and dangerous, with unpredictable behaviours which produce a feeling of unease or awkwardness (Patten, 1992).

Views in the media of psychiatric illness and of consumers mirror public attitude studies (Allen & Nairn, 1997), and it is little wonder that most people acquire these negative perceptions through the media (Business Research Centre, 1997). These negative perceptions affect consumer participation in open employment. More than 93% of Workbridge clients with psychiatric illness never reach open employment in New Zealand (Harris, 1995). Although there is a growing professional consensus that this should change, beliefs to the contrary are pervasive and affect not only potential employers but also clients themselves (Ellis, 1991). Consequently I contend that stigmatisation is a major factor that affects the success of vocational efforts of consumers (of psychiatric services) in New Zealand in 2002.

While there are some general New Zealand studies and commentaries on psychiatric illness and employment seeking (Ellis, 1991; Harris, 1995; Hurst-Turner, 1990; Warriner, 1996; Walmisley, 1997), I could not locate any specific empirical study on psychiatric stigma and employment. This was noteworthy as there are currently national and regional projects to destigmatise psychiatric illness, and public bodies set up for this task. Given the risk factors and lowered health status associated with psychiatric illness (Disley, 1997), high unemployment (Harris, 1995) and low standard of living (Nuthall, 1997), a better understanding of the relationship between psychiatric stigma and employment in a New Zealand context may improve consumers' health status through increased psychological wellbeing.

Summary and Conclusion

This brief historical view provides a background to the current social environment of psychiatric service users. British medical officers who ran New Zealand asylums came from a culture that had fused madness, badness and unemployment. Medicine separated these in order to socially manage moral and therapeutic concerns in both Britain and New Zealand. Mental health policy in New Zealand has varied from a law and order approach to cure/therapy by work; to custody and work; to custody, work and therapy; and currently to custody, therapy and community care. In nineteenth century accounts of asylums, work was a key premise within the moral management approach that sought to cure people of mental illness. Mid-twentieth century accounts located work as crucial for social status within institutional life as a patient. The close association of social role with work not only separated patients and staff within the asylum but failure to work was a prime cause for admission within families. With closure of the old institutions and opening of new psychiatric centres the only role for a patient was to be a patient. Very recently, attempts have been made to re-introduce work into psychiatric services for current and ex-patients, turning service users into both users and providers.

Public opinion in New Zealand has been moved by the plight of mentally ill people. Attitudes toward psychiatric illness include hope, sympathy, ignorance, distance, contamination, danger and threat. The rural alienation of asylums caught

and held patients, away from a world that did not understand them. 'Out of sight and out of mind' was as much for the public's protection as it was for the institution. Sometimes forced into an institutional world that appeared unjust, the patient's feeling of rejection was complete if they re-emerged into the outside world and found that people thought they had been appropriately treated. Such treatment despite, or because of best intentions, could be brutal and abusive to 'unco-operative' patients. 'Madness' and reason and the people who experienced both, inhabited separate worlds. Changes to psychiatric service practices have seen dramatic shifts away from institutional approaches. Physical restraint has shifted to chemical and social restraints within 'community care' resulting in an increased presence of psychiatric service consumers on the streets and in communities.

Their increased visibility has not always led to increased acceptance. In particular fear and ignorance (e.g. poor or incorrect knowledge) leading to pessimistic outcomes (e.g. incurability) and social distance has endured since the mid 1880's. Current knowledge and beliefs about mental illness are influenced by negative media accounts as much in the twenty-first century as in the nineteenth century. Needs of the mentally ill have been aggravated by state responses as much as they have been helped. State responses show a consistent pattern of administrative change that has left untouched the distress and health of service users (and their families) in everyday life. Until recently the voice of service consumers criticising their treatment was seen as indicative of further pathology in a manner similar to nineteenth century accounts. The public then, as now, has struggled with the uncertainty of treatment success by psychiatric services. Inconsistent decisions about committal and discharge, when this has led to violent (sensationally publicised) crime, are perceived as a disreputable discharge of professional duties and abilities. The expectations of dangerousness, incurability and low confidence in treatment of psychiatric patients are matched by what appear to be frequent occasions when this happens. Living within a social environment that transmits these values and beliefs about psychiatric illness, service consumers are likely to have similar expectations to those of the general public.

This review has mainly concentrated on negative aspects around psychiatric illness because these have influenced New Zealand public opinion the most, until very recent times. This opinion is based on the fact that there have been few attempts to disconfirm negative views or seek alternative opinions. To explain in a more thorough way the resilience of negative stereotypes and beliefs that form attitudes towards psychiatric illness, Section II examines the phenomenon of social stigma generally and psychiatric stigma specifically.

Section II - Theorising the Concept of Psychiatric Stigma

Introduction

Psychiatric stigma is part of a wider concept that has been examined within psychological and social reaction models. In this section, a discussion of social stigma and labelling theory prefaces, and is integral to, an exploration of psychiatric stigma that follows.

Social Stigma

Social stigmas have been around much longer than the theories that have been used to account for them. There has been much variability in defining the concept of stigma (Stafford & Scott, 1986). Often researchers provide no explicit definition or theory to induce a proposition about stigma, which is then tested or examined. Most seem to refer to an approximate dictionary definition ("a mark of disgrace") or make inferences to stigma from attributions, attitudes or stereotyping (Link & Phelan, 1999a). When an explicit definition is given, authors often quote Goffman's definition of stigma as an "attribute that is deeply discrediting" which reduces the bearer "from a whole and usual person to a tainted, discounted one" (Goffman, 1963, p. 3). A particularly influential definition by Jones, Farina, Hastorf, Markus, Miller, and Scott (1984) has extended Goffman's observations that stigma is a relationship between an attribute and a stereotype. Stigma is defined as a "mark" (attribute) that links a person to undesirable characteristics (stereotypes) with negative consequences. Crocker et al. (1998) have indicated the importance of social context - "stigmatized individuals possess (or are believed to possess) some attribute, or characteristic, that conveys a social identity that is devalued in a particular social context." (p. 505). Link & Phelan (1999a) then added the component of discrimination to the Jones et al. (1984) definition. In sum there appears to be a social and personal reaction model for stigma.

The phenomena of social stigma are part of everyday life; hence its complexity and ubiquity presents a challenge for social psychological analysis. The stigmatising process and its maintenance produce devastating consequences for a person's identity, thoughts, behaviour and emotions (Jones et al., 1984). This process has a number of parts to it, which are examined next – briefly from an

audience's view and in more depth from the target's perspective. Social stigma has generally been well covered in recent reviews (see Crocker et al., 1998; Farina, 1998; Heatherton, Kleck, Hebl, & Hull, 2000; Link & Phelan, 1999a, 2001). This review will not cover all the literature on stigma, especially the large volume of work on stereotyping and attitudes. Instead I will explore research that is most useful in developing a better conceptualisation of psychiatric stigma.

Is stigma a useful concept from the perspectives of persons who are stigmatised? Fine and Asch (1988), Scambler (1984) and Sayce (1998) assert that social science research studies give precedence to the language and ideas of able-bodied people rather than the words and perceptions of the people under study. This can lead to misunderstanding the experience of stigmatised people and reifying unwarranted assumptions or predictions. Within psychology a large body of stigma research focuses on the attributes of stigmatised people rather than the processes they employ in managing their social situation. It is by examining these self processes that the relationships between social reactions (eg structural features, such as discrimination) and personal experiences (e.g. shame) may achieve a fuller explanation of stigmatisation in experience.

Labelling

The labelling theory of mental illness has been foundational to many studies of psychiatric stigma (e.g. Goffman, 1963; Scheff, 1984). Briefly stated, a label is a definition. When applied to people it both identifies and defines the type of person they are. Violation of social norms (taken for granted social rules) results in a 'deviant' label as opposed to a 'normal' one where there is no rule violation. Psychiatric illness breaks social norms about behaviour when, for instance, a person perceives that external forces are planting thoughts in his or her head. Scheff (1966) has argued that many of the experiences associated with psychiatric illness (hearing voices or having imaginary friends or saying things that make no sense) are quite common. These experiences in themselves may not be considered noteworthy by others and can be viewed as transitory or eccentric. What determines the label of psychiatric illness is when deviations from norms of social behaviour occur, for a person of that status. Once labelling has occurred, social expectations and pressures occur that can lead to a stable pattern of behaviour

consistent with, and conforming to cultural stereotypes of psychiatric illness. This also occurs for clinicians when diagnostic categories of 'madness' and their prototypes approximate to the roles and role stereotypes of groups that tend to receive the diagnoses most often (Landrine, 1987). There is an intimate relationship between social and psychiatric taxonomies of madness. What determines negative social outcomes from this process is stigma. Stigma is a form of punishment that occurs when people try to break out of the role of a psychiatric patient.

Modifications to labelling theory now include the breaking of assumed 'feeling rules' in social situations, such as anxiety or depression, (Thoits, 1985). An individual's behaviour does not have to be outwardly condemned, nor do they need to experience negative reactions of others, in order for that person to see himself or herself as deviant. In short, "individuals can self-label because they are able to observe and classify their behaviours, thoughts, and feelings from the perspective of the wider community" (Thoits, 1985, p.243). Scheff and Retzinger (1991) have revised Scheff's earlier theory to include 'unacknowledged shame' and weakening of social bonds that occurs when stigma is experienced.

Scheff's inclusion of emotion in labelling theory has addressed a major deficit in its previous formulations (1998). Overt shame is characterised by painful feelings that may not be recognised by the person experiencing them. It can be hidden in non-verbal shame (e.g. pauses in speech, looking away) or verbal shame (e.g. speech designed to hide the shame experience) (Scheff, 1990). In bypassed shame people respond to negative evaluations as if they never have happened. Without the direct reactions of others (e.g. because of a partisan milieu) or not knowing the problem exists, people are not able to anticipate and respond when shame occurs. In not questioning their own behaviour, unacknowledged shame is likely to go unnoticed, especially as labelling often occurs through innuendo rather than via explicit or direct means (Scheff & Retzinger, 1991). Hence it can be suggestive rather than coercive (Hayes, 2000), either through verbal means (e.g. questions, tone of voice, suggestions, recommendations) or non-verbal (e.g. body language, facial expressions) or a combination of both. Shame appears to occur following a period of denial after the labelling event and has no 'shelf-life'. The ability of

people to recall their past experiences suggests that different types of shame at different points in time can be evoked by a single labelling episode (Hayes, 2000).

However these theories of labelling and stigma have come under considerable challenge, both in the past and more recently. Some researchers have suggested that barriers created by psychiatric stigma, are either absent (Torrey, 1994) or transitory (Gove, 1980). Psychiatric patients enjoy acceptance in most relationships (Crocetti, Spiro, Lemkau & Siassi, 1972) and social difficulties are inappropriately attributed to labelling and stigma (Lehman, Joy, Kreisman & Simmens, 1976) when in fact they are due to deviant behaviour (Clausen, 1981). Not everyone experiences a sharp decline in self-esteem and coping upon diagnosis as labelling theory would predict (e.g. Karmel, 1969; Teichman, Bazzoui, & Foa, 1974). Patients who experience relief from their troubling symptoms may positively evaluate their experience (Gregoire, 1990). In a review of 35 studies in this area, Weinstein (1983) found patients were far less positive in talking about labelling as an abstract concept than when they discussed their own personal experiences of being given a diagnosis. Understandably, people may want to avoid labelling themselves in a negative way (Quadagno & Antonio, 1975).

So far I have presented two opposing approaches: one where labelling people as psychiatric patients is beneficial as it ushers them into appropriate treatment; the other where labelling and stigma can adversely transform both patients and their audiences. Despite some doubts, there have been extensive and long-term research programmes about stigma, such as those of Farina and with Colleagues (1966, 1968, 1971, 1973 (2), 1974, 1975, 1976, 1977, 1978(2), 1981, 1984, 1986, 1991, 1996, 1998) and Link and with Colleagues (1983, 1986(2), 1987(2), 1989, 1990, 1991, 1992, 1997, 1999(4), 2001(2)). Farina and Colleagues have used a psychological approach, and Link and Colleagues employed a sociological approach to investigate social rejection caused by psychiatric stigma. Both these research programmes show labelling leads to social rejection that cannot be explained by deviant behaviour (for a review of this debate see Farina, 1998; Link & Phelan, 1999b).

The stigma of psychiatric illness remains a “deep and persistent one and will not disappear simply by changing the terms we use” (Mechanic, McAlpine, Rosenfield, & Davis, 1994, p. 163). Labelling and stigma affects responses even when socially incongruent behaviour is not present. For instance, the labelling of psychiatric illness activates beliefs about dangerousness that then increase social distance (Link & Phelan, 1999b). Whether participants are confederates or people who do have a psychiatric illness, their responses are all mediated by labelling. Labelling by itself causes behaviour that leads to rejection (Link & Phelan, 1999a). This has been called the “self-fulfilling prophecy” effect of stigma (Jussim, 1986; Jussim, Palumbo, Chatman, Madon & Smith, 2000). Stigma involves stereotypes (Biernat & Dovidio, 2000), prejudice (Miller & Major, 2000), ‘lay’ theories that justify it (Crandall, 2000), and threats in social interactions (Blascovich, Mendes, Hunter & Lickel, 2000) that create ‘awkward moments’ for both parties (Hebl, Tickle & Heatherton, 2000). There are ‘hidden costs’ to stigma when those with concealable stigmas (like psychiatric stigma), in an effort to hide their identities, “must face an internal struggle that leads to anguish and perhaps even psychopathology” (Smart & Wegner, 2000, p.220).

There is a close association between the experience of stigma and personal experiences of shame (Scheff, 1998) and low self-esteem (Crocker & Quinn, 2000). Defining a person as deviant and then linking deviance to marginality seems to capture how a person departs from social norms and incurs social sanctions (Link & Phelan, 2001). However, people are stigmatised for an undesirable characteristic whereas a person can deviate from social norms and feel marginalized yet have positive characteristics (e.g. financial wealth) (Dovidio, Crocker & Major, 2000). Even when deviance is associated with negative characteristics, unless the distinguishing mark leads to attributions that discredit the bearer, stigmatisation does not occur (Jones, et al., 1984). Perceptions of deviance do relate to stigma but it is more than that. Stigma is also a relational and contextual product. One person’s label is another person’s badge of honour. What is deviant or discrediting in one view can be viewed as a charming eccentricity and thus benign, by another (Jones et al., 1984). Similarly, as Crocker et al. (1998) argue, “stigmatised individuals possess (or are believed to possess) some attribute

or characteristic, that conveys a social identity that is devalued in some particular context” (p.5).

Stigma has figured largely in studies on prejudice because it is the target that is usually prejudged (for reviews see Heatherton et al., 2000; Swim & Stangor 1998; Zanna & Olson, 1994) Prejudice has been defined as a negative attitude that is inaccurate and over-generalised (Brown, 1995). As Jones et al. (1984) suggest, prejudice is “a faulty generalisation from a group characterisation (stereotype) to an individual member of that group irrespective of either (1) the accuracy of the group stereotype, or (2) the applicability of the group characterisation to the individual in question” (p.288). Stigma involves these aspects of prejudice that are informed by cultural messages about the value of different groups but it encompasses more than this. In particular there is something unusual about psychiatric illness that suggests its social stigma is distinctively different from other stigmas.

Psychiatric Stigma

Psychiatric disorders are just as much a social evaluation as an illness (Davis & George, 1993). A consequence of such social evaluations in Western countries is that people who receive them often come to think of themselves negatively; they develop expectations of how ‘normals’ will view and behave towards them (Lieban, 1992). Labels occur when the process of psychiatric treatment ‘rationalizes’ psychiatric phenomena in the language of a ‘professional’ or ‘specialist’ context (Goldin, 1990). As a consequence, any associated mental illness ‘symptoms’ or ‘signs’ are socially ameliorated in the very process of help-seeking, diagnosis and treatment (Petersen, 1994). This creates an interesting paradox. When psychiatric illness phenomena are medically labelled they can also be socially discredited, condemned and/or rejected. The tendency for Western notions of psychiatric illness to possess opposing valuations (socially ameliorative and socially discrediting) makes psychiatric stigma a topic that should be examined in the light of culture and local conventions of illness.

Stereotypes and Prejudice

Current reviews about stereotyping and prejudice abound (for a summary see Fiske, 1998; specific to stigma see Biernat & Dovidio, 2000; and from the target’s

perspective see Swim & Stangor, 1998). Humans sort people in their world into categories, such as in-groups and out-groups (Allport, 1954). Allport's core insight into stereotyping was:

Impressions that are similar ... especially if a label is attached ... tend to cohere into categories (generalisations, concepts). All categories engender meaning upon the world ... they give order to our life-space...The principle of least effort inclines us to hold early-formed generalisations as long as they can possibly be made to serve our purposes... [about] a category concerning a group of people, not based on defining attributes primarily, but including various "noisy" (nonessential, possibly false) attributes, leading to disparagement of the group as a whole (1954, p.175-176).

Extending Allport's work, social identity theory built on the need for people to establish a social identity by categorising others into 'them' and 'us' (Tajfel & Turner, 1986). It was obtained by an in-group membership that depended on an identity based on devaluing a contrasting out-group. Perception of group membership triggers in-group favouritism and out-group discrimination. It leads to minimising in-group differences and accentuating out-group differences. Prejudice occurs when one group desires a more positive social identity. Categorisation processes are dependent on within-group salience and perceived boundaries between them. Self-categorisation theory extended social identity theory by specifying the principles used to categorise people and self (Oakes, Haslam & Turner, 1994). To the extent that within-group differences are small relative to the perceived differences between out-groups, then people will be characterised by their group membership.

The process for this is stereotyping, prejudice and discrimination. When people categorise others as 'mad' they use the same processes of categorisation to achieve a 'normative fit'. This is based on social meanings about the differences between sane people and stereotypes around madness. Stereotypes access various categorisations in some conditions and not others. (For a more detailed discussion of social identity theory and social categorisation theory see Brewer & Brown, 1998; and regarding the importance of these theories for stigma see Crocker et al., 1998). What determines the distinctiveness of categorisation and the distinctions people make is when something is culturally stigmatised in contrast to being culturally valued (Frable, 1993). People pay more attention to negative information than to positive information (Skowronski & Carlston, 1989).

Stereotypes about groups may not be true but that does not stop them being employed (Fiske, 1998). People can make the stereotype salient by making it true for the individual, and vice-versa. Known as a “self-fulfilling prophecy, the perceiver [e.g. sane person] who holds the stereotype [e.g. ‘mad’ people are dangerous] behaves accordingly [e.g. uncertain, anxious, fearful] and thereby elicits confirmatory behaviour [e.g. uncertainty, erratic confidence] from the target” (Fiske, 1998, p. 382; for a review see Jussim, 1986). In making the stereotype true it gives some predictability to the target’s behaviour, which is therefore perceived as more controllable.

The target does not have to internalise a negative stereotype for behavioural confirmation to do damage (Fiske, 1998). The mere salience of a stereotype creates a threat (stigma), which can lead to its confirmation by a target (for a discussion of social threat and stigma see Blascovich et al., 2000; Stangor & Crandall, 2000). It appears that the existence of stigma and sensitivity to it actually produces stigmatisation (Farina, 1998). Related to self-fulfilling prophecy effects is ‘stigma consciousness’- the extent to which a person expects to be stereotyped irrespective of their behaviour (Pinel, 1999). People high in stigma consciousness were more likely to perceive discrimination, provide sound evidence for such perceptions, and avoid stereotype relevant situations and opportunities to disconfirm their group stereotypes. This creates stress when people anticipate prejudice and stigma on a daily basis. Daily life then requires people to “maintain *vigilance* in the face of potential threats and the immediate emotional consequences of the encounters” (Swim & Stangor, 1998, p. 3).

In response to the need for monitoring and vigilance in the face of threats to wellbeing people employ strategies that are economical and pragmatic - discounting and devaluing (Major & Schmader, 1998). They psychologically disengage from domains where self-esteem from external feedback or outcomes is dependent on success or failure within those domains. Being impervious to feedback or outcomes enhances self and collective esteem in the face of threats to personal and social identity. This perspective assumes people use social feedback and outcomes to shape inferences about abilities and outcomes that are domain

specific. Devaluing or discounting within domain feedback either removes or shifts the centrality of the domain for self-concept and self-worth.

Seeking similar others with a concealable stigma is one way to lift self-esteem and mood (Frable, Hoey & Platt, 1998). Consumers of psychiatric services may withdraw from everyday life domains (e.g. employment, the pub, sports club) and seek domains inhabited by other service users who are less different and therefore less threatening. The stereotypical aspects of service user life are matched by what takes place within services, and experiences from these domains become integral to self-concept. Thus people can derive a self-concept based on a stigmatised identity from the domain in which they feel most comfortable – the one inhabited by other stigmatised individuals.

Attitudes and Attributions

Since the 1950s, international researchers using attitudinal and behavioural measures have asserted there was something distinctly adverse in public attitudes towards mental illness (e.g. for reviews see Allport, 1954; Bhugra, 1989; Cumming & Cumming, 1957; Johannsen, 1969; Kreisman & Joy, 1974; Lamy, 1966; Nunnally, 1961; Olmsted & Durham, 1976; Rabkin, 1972, 1974; Sarbin & Mancuso, 1970; Weinstein, 1983;). Attitudinal measures, usually based on social distance, have indicated a distinct hierarchy of acceptance for users of psychiatric services. People who use or have used psychiatric services received the lowest rankings compared to any other disability group, both in international studies (Abrams & Kodera, 1979; Albrecht, Walker & Levy, 1982; Cloerkes & Neubert, 1984; Corrigan, River, Lundin, Uphoff, 2000; Harasymiw, Horne, & Lewis, 1978; Socall & Holtgraves, 1992; Thomas, 2000; Tringo, 1970; Trute, Tefft & Segall, 1989) and in Australia (Westbrook, Legge & Pennay, 1993). The low esteem of psychiatric patients is also held by patients themselves (Linn, 1968; Weinstein, 1979), and of the services they receive (Huxley & Warner, 1992).

Attitudes towards patients within professional groupings that deliver psychiatric services vary considerably (Roskin, Carsen, Rabiner & Marell, 1988) and affect the quality of patient relationships (Tattan & TARRIER, 2000). Adverse attitudes of staff can alter attributions about patient problems and impoverish relationships with patients to reduce health outcomes (Barrowclough et al., 2001). Exactly how

staff interact with patients affects patient attributions about psychiatric illness. Patients who attribute illness in medical or bio-physical terms show a better quality of life than those using terms like 'mental illness' (Mechanic, Alpine, Rosenfield & Davis, 1994). Presumably, mental illness explanations supply little in the way of useful information and contribute to a personal sense of social stigma. However, the use of bio-medical terms invoked harsher treatment than using psycho-social explanations (Mehta & Farina, 1997). Viewing a person with a mental disorder as diseased sets them apart as bio-chemically and physically distinct which can engender callousness. The uncertainties created by diseases are that they are invisible and can strike at any time. Psycho-social explanations put causative factors back into discernible and controllable areas of people's lives. Similarly terms such as 'consumer of mental health services' as opposed to 'schizophrenic' are viewed by the public as reflecting a condition more likely to change with less negative reactions (Penn & Nowlin-Drummond, 2001). Attitudes, and the stereotypical beliefs that support them, are expressed in prejudicial ways within language and actions. They transcend therapeutic encounters and initiatives for both parties (For reviews see Eagly & Chaiken (1998); Fiske, (1998).

Stigma applies as much to psychiatric terms as to the behaviour associated with serious symptoms that may frighten and repel people. When psychiatric terms are applied to benign behaviour they tarnish identity and discredit the stigmatised person (Mechanic et al., 1994). People show surprising resilience in holding on to negative stereotypical beliefs about psychiatric service users, even in the absence of bizarre behaviour (Piner & Kahle, 1984). In one study (Skinner, Berry, Griffith & Byers, 1995) the stigma of an ex-mental patient role was generalised across a variety of functioning areas (e.g. psychological, social) and groups of people (e.g. family, workmates), with a negative evaluation specific to ex-mental patients and not other deviant social roles (e.g. ex-convict, ex-drug addict). The most entrenched attitudes were not the expressed attitudes (i.e. verbal report of personal attitudes) or acted-upon attitudes (i.e. behaviours) but the deep-level attitudes (i.e. societal attitudes: things we should or ought to do). The deep-level attitudes of embedded beliefs and values (which exerted a strong impact) were the most negative and slow to change.

Attitudes are important but so are attributions. Weiner, Perry & Magnusson (1984) have used attributional theory (for a review see Hewstone, 1989) to analyse reactions of people to stigma. The delimiting of possibilities for an audience to make alternative attributions (e.g. not stigma bound ones) about a target suggests stigma directly affects attributional processes. At an interpersonal level attributional bias can alter perceptions of cause and responsibility for the illness (and stigma) so that an audience attributes them to the target. Targets usually attribute their circumstance to external causes (e.g. 'I'm not to blame') in order to minimise their personal responsibility. This is a self-protective function for maintaining esteem.

What happens with stigmatisation is that attributions of responsibility by the target shift, so that the person feels responsible for their circumstance (e.g. acceptance which can then lead to shame). In viewing themselves as others do and having occasions when expectations about psychiatric illness are matched with personal experiences, the person acquires a similar attributional bias that over time becomes more negative. The audience's attributional bias about psychiatric illness is that it is internal, stable and global, as is stigma. The interpersonal bias becomes an intra-personal attributional bias. The person attributes psychiatric illness to their self (internal) for being who they are (e.g. it is something about me), it is not going to change (stable) and it affects all aspects of living and their being (global). This can explain three things: (1) the enduring nature of stigma as it is woven into cognitive processing; (2) why psychiatric patients hold more negative views of themselves than do the general public; and (3) why an audience dissociates understandable explanations and elicits a stigmatised response that then turns the blame back on the person. The person is blamed for their illness behaviour and blamed again for being stigmatised. Attributions can cease to be individual activities and become social attributions (Corrigan, 2000).

Stigma can have aspects of physical and social pollution (Mehta & Farina, 1988; Wahl & Harman, 1989). Thus stigma can affect social interactions (e.g. Albrecht, Walker & Levy, 1982), social networks (e.g. Rosenfield, & Wenzel, 1997), housing (e.g. Page, 1977; Page & Day, 1990), employment opportunities (e.g.

Farina et al., 1971), and wellbeing and life satisfaction (Markowitz, 1998). Some evidence suggests that women tend to treat those with psychiatric disorders better and that women with such disorders also receive more favourable attention than do men (Farina, 1981; Farina & Hagelauer, 1975; Farina, Murray & Groh, 1978). The presence of psychiatric stigma and its effects has noticeably different outcomes from other stigmas and conditions.

A Theoretical Approach

In his classic work *Stigma*, Goffman (1963) argued that stigma was best explained by a notion of deviance from prevalent or valued social norms that was overwhelmingly discrediting to an individual and incurred the application of rules and sanctions. Importantly, Goffman demonstrated that stigma was not an inherent property until a person's acts or attributes were perceived as negatively different. Stigma occurred when negative perceptions were linked to a personal attribute. Thus Goffman's work showed it was not just the functional limitations of impairment that constituted the greatest problems of psychiatric illness but rather the societal and social responses to it and their contingency in some situations and not others.

Jones et al's (1984) book *Social Stigma: The Psychology of Marked Relationships* summarised existing explanations and expanded them into a detailed social psychological format. Stigma operates along 6 dimensions – concealability, course, disruptiveness, aesthetic qualities, origin and peril – that affect interactions. Interactions are also shaped by additional variables of the situation, personal characteristics, areas of functioning and the nature of the interactions themselves. It was Jones et al's dimensional approach to stigma generally that spelled out the salience of psychiatric stigma within first person accounts. Something that is *concealable*, like psychiatric illness, is fraught with uncertainty about being found out. Its *course* is uncertain and the disorder could occur at any moment. So an audience, like the person, are never quite sure whom they are going to find interacting with them and in what manner. Notions of incurability can erode a sense of hope and change. Psychiatric illness *disrupts* the social ease people have with one another. Its *aesthetic qualities* result in very negative portrayals of people within media, literature and film. People are never sure of its *origin*, and are more blaming and less understanding when the person is seen as

responsible and capable of having exercised some control. Psychiatric illness has worse associations with *dangerousness* than any other disability. Put these six factors together and it makes sense that first-person accounts often refer to the disastrous social consequences of psychiatric stigma, over and above their experiences of illness. Unlike other stigmatised human conditions that only occur by a virus (e.g. AIDS), an accident (e.g. paraplegia), social deviancy (e.g. prison), sexual orientation (e.g. homosexual) or birth (e.g. Downs syndrome), psychiatric disorder and its stigma are distinctively different from one another.

Stigmatisation also has a process. It is contingent on situations and depends on the valence and salience of the stigma for target and audience. The process involves:

“distinctive internal processes (affective/cognitive expectancies, self concept, plans, goals, perceptions, attributions), external cues (appearances, situational context, behaviour in the context), and the overt behaviour itself. As interactions proceed through time, cues shape internal processes which in turn shape behaviour, which in turn shapes internal processes” (Jones et al., 1984, pp.18-19).

Jones et al. describe the process of stigmatisation as: (1) taking on a ‘mark’ or label; (2) that sets a person apart from others; (3) links them to a set of undesirable characteristics (e.g. dangerousness); and (4) which results in negative consequences (e.g. rejection). Thus stigmatisation includes both cognitive processes (where inferences are made from the mark to undesirable personal characteristics) and affective processes (that introduce unease and behavioural sequelae such as withdrawal). Jones et al’s theory describes very clearly what happens between an audience and their target. While a target may employ similar processes to the ones the general public uses on them; whether psychiatric patients employ this process when they stigmatise themselves is less clear. In particular Jones et al. overcame the lack of intra-psychic explanations that were absent in a predominately sociological theory of stigma that hinged on early labelling theory (e.g. Scheff, 1984).

Expanding on the fourth feature (negative consequences e.g. rejection) in the Jones et al. (1984) account of stigmatisation, Link et al. (1989) suggested there were: (1) culturally induced expectations of rejection; (2) matching experiences of rejection; and (3) efforts at coping. Not only is there triggering of expectations of rejection that erode self-esteem and social and occupational functioning, but the

actual experiences of rejection can lead to coping strategies of secrecy and withdrawal (Link, Mirotznik, & Cullen, 1991). Adopting this response protects the person from rejection that might occur if they sought friends and jobs in a wider social sphere (Crocker et al., 1998). At the same time it also limits opportunities to disconfirm acquired social and personal beliefs.

Stigma and Coping

Examining how people cope with stigma has shown that it impairs the social and psychological functioning of people labelled mentally ill (Link, Cullen, Frank & Wozniak, 1987). When stigmatised people try to dispel the unfavourable impression (which they perceive themselves as having created) their behaviour is affected in such a way as to cause those with whom they are interacting to reject them (Farina, Allen & Saul, 1968). Stigmas are not uniform in their social outcomes across different stigmatizing conditions, and personal characteristics in some studies can mediate their negative effects (Farina, Thaw, Felner & Hust, 1976). Link et al. (1991) found none of the coping strategies of secrecy, withdrawal and education used by their mentally ill participants were effective in diminishing psychological distress and unemployment, due to the negative labelling effects. The use of coping strategies produced more harm than good. The participants failed in their attempts to overcome psychiatric stigma. Their coping strategies reinforced a view for themselves and others that they were flawed and not competent at managing their affairs. The authors concluded that the main source of stigma lies at the socio-cultural level of beliefs about mental illness, not within individual behavioural or attitudinal orientations. While this explains the outcome of the coping strategies employed, it does not adequately explain the internal events that these strategies were required to resolve, nor why these coping orientations were chosen. But it does suggest that what impels people to choose a method to resolve stigma also contributes to its negative outcomes in some unspecified way.

Few studies have attempted to link socio-cultural variables with the status of people with a disability stigma (Lieban, 1992; Scheer & Groce, 1988). Those that have suggest that individualistic cultures have more positive attitudes to disabilities than do those held by a collectivist society, as the effects of stigma are individualised, not shared or held as a collective responsibility invoking a shared

guilt or repression (Westbrook, Legge & Pennay, 1993). The individual outcome as a result of a collective activity, led Link and Phelan (1999, 2001) to refine their social reaction model of stigma. The process involves: (1) distinguishing and labelling difference; (2) associating being different with negative attributes (e.g. stereotyping); (3) separating 'us' from 'them'; and (4) status loss and discrimination leading to unequal outcomes. This social reaction model suggests that stigma is contingent on the access to power that enables allocation and enforcement of difference, stereotype construction, separation and the full range of social exclusion to be employed against stigmatised people. However it is not clear whether the internal process of stigmatisation for the target mirrors the external process of social interactions and sanctions that Link and Colleagues describe so well.

Link's social reaction model of stigma shows how the structural processes in social life operate at a personal level. Similarly Scheff (1998) shows how labels are integral to the manufacture and internal workings of shame that then loosen social bonds. The Crocker et al. (1998), Farina (1998) and Heatherton et al., (2000) reviews show the importance of labels in their psychological effects. Psychological theories are able to demonstrate how labels interact with social representations, beliefs, attributions, in-group/out-group processes, stereotypes and attitudes. These alter the way people think, feel and act. While psychological theories provide in-depth description of parts of the process, they are insufficiently integrated to provide an adequate description of the complete process.

Stigma and Illness Experiences

Felt Stigma and Enacted Stigma

Epilepsy and psychiatric disorder have shared similar public perceptions. Both are marked by presence and absence in symptom display, share similar medications and until recently in New Zealand have shared similar treatments (e.g. incarceration). The prospect of sudden and unpredictable onset of seizures and the disruption they cause can create adverse reactions in those who witness them. The personal shame and discomfort experienced by people who have seizures have encouraged specific strategies to maintain social comfort for themselves. These

strategies can assist but they are just as likely to magnify the problems that are faced. Particularly vivid in theorising about the stigma of epilepsy, has been the notion of 'being in the closet' and managing impressions (Schneider & Conrad, 1980). The very act of doing this primes the social discomfort people experience to the extent that their cognitions, behaviours and emotions are more negative about their seizure activity than are those of the general public (Jacoby, 1994)- as has been found with mental illnesses (Cioffi, 2000; Smart & Wegner, 2000). People come to believe and act in ways that confirm the negative beliefs of others. This enables ways of being and behaving to transfer in time beyond the immediate occasions when an audience is present and the individual feels discomfort.

The public aspects where people defined as different are discriminated against are called 'enacted stigma'. The private aspects, where fear of discovery about this difference and the shame in having it are based on internalised cultural values, are called 'felt stigma' (Jacoby, 1994; Scambler, 1984; Scambler & Hopkins, 1988). Scambler and Hopkins (1988) reported on a study of experiences by people with epilepsy. Their participants were found to limit occasions for 'enacted stigma' because it is so aversive and to act more on 'felt stigma', although experiencing little enacted stigma. In applying these insights from epilepsy to chronic illness in general Charmaz (2000a) indicates:

"enacted stigma dramatises personal difference, it magnifies loss. Discovering how others view one's self can be shocking. Such events live on in the minds of those who felt marked by them. When possible the ill person will henceforth try to conceal or limit potentially discrediting views of self. What to tell, when to tell, how to tell and how much to tell all pose ethical dilemmas to a chronically ill person. Relationships, resources, control, and especially risks figure in the calculus of telling, and fateful telling occurs at points within the life course" (p.285).

Acceptance of the moral accountability embedded in cultural myths about illness is revealed when existential questions arise of "Why me?" and "What have I done to deserve this?" (Charmaz, 2000a, p.285). Felt stigma is characterised by shame, guilt and fear. This is especially so with a concealable disorder like psychiatric illness because in the absence of a visible handicap people are judged by conventional standards (Charmaz, 2000a). Transgressions are judged more harshly. Having a sick mind as opposed to a sick body, leads to private doubts around concealable disability as to what is real and usurping the rights of the handicapped. Maintaining felt stigma by secrecy leads to a heightened sense of

vulnerability. While this “reduces enacted stigma it does so at the cost of disrupting people’s lives” (Charmaz, 2000a, p.285). As Charmaz suggests, efforts at concealment enlarge the importance of the illness so it intrudes into self-concept and meanings around identity. The person is unable to put these new elements of self into context, as normal social comparisons are unavailable. This creates uncertainty with interpersonal and intra-personal processes. The concepts of felt stigma and enacted stigma have yet to be explored within the context of psychiatric disorder.

Stigma and Identity

Stigma forces new, unwanted ways of conceiving self, relationships and situations (Charmaz, 2000a). The same stigma can spread to other family members affecting their identity as well (Phelan, Bromet, & Link, 1998). People may try to forestall for a considerable time the effects of illness on self while still acknowledging its presence within their lives. The continuity that used to exist with identity and relationships is irrevocably changed. The uncertainty about who and how they will be tomorrow requires people to think repeatedly how they are living and who they are becoming (Charmaz, 1995a). Life can be narrow when the ingredients for valued social identity and roles are available to other people and not for ‘them’. The more resources a person has the more latitude they have in taking time-out for illness. While loss of identity can comprise intense suffering, long periods of reflection can lead to a positive reintegration of self, consistent with current experiences. It would be useful to consider how the reintegration of identity in psychiatric disorder takes place in the presence of psychiatric stigma.

People learn what illness is through their experience of it (Charmaz, 1991). Merely being told about it does not suffice. Until a person registers changes in feeling or function states and then defines them, the illness does not seem real even though its effects can be (Charmaz, 2000a). Comparisons with ‘past’ performances dramatically indicate decline and loss. New indicators of capacity have to be acquired, either derived by personal experience or supplied by someone else (Charmaz, 2000a). They become measures that cannot be camouflaged or glossed over. These measures multiply and become personalised standards. People learn to handle symptoms in their own way and use various strategies to achieve the standards they aspire to. There is a search for identity and meaning in

the recovery process (Pettie & Triolo, 1999). Concerted efforts to maintain hopes, responsibilities and aspirations require innovation and are usually aided by local support groups. Members of these groups share personal stories, gain information about treatments and professional expertise, and offer support to each other in the effort to keep going. The innovation required to keep going when ‘treatment’ offers only limited success and an ambivalent stance by service staff, can lead to new ways of managing their illness. New insights, experiences, values and metaphors are employed because they work and can then be used for training service staff (Mackenzie & MacKen, 2000a; MacKenzie & MacKen, 2000b). It would be useful to consider the generic processes that people employ to resolve the daily challenge of shifts in feeling and functional states while negotiating a stigmatised identity.

Rarely are people passive receptors of stigma stereotyping, prejudice or discrimination. Rather they actively attempt to construct a “buffering life space” and retain pragmatic strategies to cope (Osyerman & Swim, 2001, p.1). Life is uncertain (Charmaz 2000a). In response to this, people engage in (1) ‘making sense’ of their experiences or symptoms by defining it in their terms, (2) ‘reconstructing order’ to manage illness and a regimen to get through the day, and (3) ‘maintaining control’ through daily activities and “regaining continuity and coherence of self and one’s world” (Charmaz, 2000a, p.280). Psychiatric illness creates uncertainty by the effects of illness on life trajectory and on robustness of their cognitive and emotional processes. People with other disabilities usually retain and have confidence in their psychological processes. With psychiatric illness and stigma, uncertainty can be as much part of the illness as of the disorder it creates and the situation they are experiencing. In “crucial respects [consumers are] in the position of travellers in a strange country, equipped with only a rudimentary map for guidance, trying to make their way through the uncertainty and ambiguity in which each path contained a snare and frequently led nowhere” (Barham & Hayward, 1995, p.136). Somewhere amongst all the loss, uncertainty, pleasant and unpleasant experiences there is a person in there. When “identity is synonymous with disease [e.g. I am a schizophrenic], then there is no one left inside to take on the enormous work of recovery” (Deegan, 1996). Evidence of daily concerns and challenges needs to be included in any theory of the effects of

illness on life trajectory and provide an experiential element so that it better fits with consumer experience.

Illness and Uncertainty

Mishel and Colleagues have examined the uncertainty produced by stress during hospitalisation (1981, 1984, 1988(2), 1991, 1992 1995). They draw on Lazarus' (1974) insight that the cognitive state of uncertainty produces an inability to predict the impact of situations resulting in them being evaluated as threatening. In high threat situations misperception of events occurs. Significant information is ignored and there is an inability to distinguish the helpful from the harmful (Mishel, 1984). The inability to structure appropriate meanings and appraise illness leads to a definition – “Uncertainty is defined as the inability to determine meaning of illness-related events” (Mishel, 1988, p.225). People define meaning by a personal schema about their illness. A schema is developed from an ‘antecedent stimuli frame’ (i.e. symptom pattern, event familiarity and congruence), ‘cognitive capacity’ (i.e. information processing abilities) and ‘structure providers’ (i.e. sources available to assist with interpreting the stimuli frame) (Mishel, 1988, p.225). Uncertainty develops when a person is unable to form a cognitive schema of their subjective illness experience (Mishel, 1988). It occurs from the ambiguity and unpredictability of diagnosis, symptoms, illness course, treatments, information and feedback about health. The model proposes that there is a perception of illness-related events, which are then incompletely appraised. Threats occur that result in avoidance, *vigilance*, direct action and seeking information, resulting in stress (Mishel, 1981). There are four stages of (1) antecedents that generate uncertainty, (2) appraisal of uncertainty as opportunity or danger, (3) efforts at coping to reduce danger and maintain opportunities, and (4) effective coping leading to adaptation states (Mishel & Braden, 1988). This points to a key role of uncertainty in psychiatric illness and that uncertainty should be incorporated in any account of psychiatric stigma.

Mishel (1991) detected little perception of (threat) danger during patient hospitalisations. Hence appraisal of uncertainty was likely to be blunted during hospitalisation because a patient is occupied with the experience of treatment or illness. Uncertainty can be held in abeyance until the effects of illness on life trajectory are experienced. However unlike other forms of hospital treatment,

psychiatric treatment is perceived to be a dangerous one and is sometimes involuntary. People are forced to appraise their illness because of the threat that it can represent and this can result in uncertainty. Mishel (1991) found an inverse relationship between uncertainty and mastery (beliefs about one's ability to handle the situation). The more uncertainty a person experiences the less they are able to handle their situation. A related finding by Sorrentino and Roney (1990) showed uncertainty-orientated people were more likely both to interpret interpersonal messages in a self-relevant manner and to be more persuaded by them. People were motivated to resolve uncertainty about themselves regardless of their ability to do so and whether their resolution would lead to negative or positive consequences (Trope, 1979). There appear to be strong similarities between the effects of uncertainty on coping with general illness states and how people cope with psychiatric stigma.

Although illness related factors (e.g. cognitive impairments) do contribute to adjustment outcomes, the psychological response to the highly stressful nature of psychiatric disorders may also influence outcome. The notion of illness intrusiveness (i.e. illness-induced disruptions that interfere with continued involvements in valued activities and interests) has been hypothesized to compromise quality of life in chronic and disabling health conditions (Devins, 1994). Illness intrusiveness, as described by Devins et al. (1996), altered quality of life both by: (a) decreasing occasions for positive experiences because of less involvement in valued activities, and (b) limiting perceived control over valued outcomes. The psychosocial impact of illness intrusiveness was even more disturbing in the context of a highly stigmatised self-perception. The close similarity between illness intrusiveness and stigma encouraged Devins, Stam, and Koopmans (1994) to test whether the psychosocial impact of perceived stigma from laryngectomy operated through illness intrusiveness. Both perceived stigma and illness intrusiveness were found to be related to psychosocial wellbeing and emotional distress. For people with psychiatric disorders (e.g. anxiety) illness intrusiveness ratings are even higher than those of chronically ill medical patients (Antony, Roth, Swinson, Huta, & Devins, 1998; Bieling, Rowa, Antony, Summerfeldt & Swinson, 2001). While the relationship between stigma and illness intrusiveness has been examined in relation to other medical conditions,

there is little research available about such a relationship with psychiatric disorder, despite mental illness being the most stigmatising of all medical conditions.

Furthermore when illness is unpredictable there is a greater likelihood that individuals will attribute negative mood states to illness effects irrespective of functional capacity (Wineman, O'Brien, Nealon & Kaskel, 1993). Ambiguous or uncertain illness conditions can eliminate valued activities as well as affecting the identity associated with performing the behaviour in those situations. This encourages a perception of illness that is both highly intrusive and increases uncertainty. Mullins et al. (2001) have examined both the effects of illness uncertainty and of illness intrusiveness on psychological distress of individuals with Multiple Sclerosis (MS). Using Mishel and Braden's (1988) definition of uncertainty and Devin's construct of illness intrusiveness, they found both variables to be uniquely related to psychological distress. Higher uncertainty and intrusiveness caused more distress and increased distress raised uncertainty and intrusiveness. For MS sufferers uncertainty and intrusiveness were independent constructs and both directly affected adjustment. This was in contrast to illness intrusiveness mediating the uncertainty-adjustment relation found in studies on end-stage renal disease (Devins, Beanlands, Mandin, & Paul, 1997) and diabetes (Talbot, Nouwen, Gingras, Belanger & Audet, 1999). Significantly, Mullins et al. found that appraisal of intrusiveness and uncertainty were more salient predictors of adjustment than were the objective indices of illness severity. This indicates the importance of understanding how psychological adjustment in psychiatric disorder is affected by stigma, illness intrusiveness and uncertainty.

Psychiatric Illness and Uncertainty

Considering uncertainty as an appraisal of subjective meaning about their psychiatric disorder explains why consumers' first-person accounts are often focused on meanings about self. The less able people are to develop a subjective account of their experience the more uncertainty intrudes. Increasing uncertainty reduces personal mastery in a situation and their behaviour is perceived as more congruence with stereotypes. The more stereotype congruence, the more believable stereotypes are and hence more stigmatising. People will try to resolve uncertainty induced through the experience of psychiatric disorder, irrespective of

how productive this may be (as found in Link et al., 1991). Including uncertainty in a theory of adjustment to psychiatric illness therefore could offer an explanation of psychiatric stigma which comes closer to the reality of first-person accounts of illness experiences.

The central concern about uncertainty in illness narratives has been absent from social psychological accounts of psychiatric illness and stigma. I located only one article by Farina and Burns (1984) where uncertainty was examined in relationship to psychiatric stigma. In this study the targets were perceived as nervous when their status was known and unfavourable. Uncertainty had negative effects on the perceiver irrespective of whether the target was subjectively uncertain about negative or positive things. Uncertainty can lead to a hesitancy requiring a search for cues in another's behaviour, making the target appear nervous and tense. These two responses are usually evaluated negatively when experienced by an audience (Farina, 1998). Most important was that believing a person to be mentally ill negatively altered the perception of them held by their co-workers without any behaviour to justify such a perception. The linking of psychiatric disorder and uncertainty in this study is even further evidence that uncertainty must be included in any theory of psychiatric stigma.

Illness and Coping

As discussed earlier, in addition to stigma and uncertainty, both stereotyping and prejudice can create a threat, which may induce stress. Even when there is no overt presence of these elements, the possibility leads to increased appraisal and *vigilance* with negative effects for the target. So whether these elements are present, impending or absent, they can still invoke a stress response and tension maintenance. Stigma as a stress response has been examined within literature on coping (e.g. Miller & Kaiser, 2001). Coping and stress literature focus on the super-strategies of cognitive avoidance and *vigilance* (for a review see Krohne, 1993). Cognitive avoidance is often conceptualised as a personal process for reducing emotional arousal (e.g. reducing distress by avoiding situations where it occurs). *Vigilance* is a process that clarifies meaning in a situation by obtaining information (e.g. reduces uncertainty). Thus what disposes people to *vigilance* and avoidance is intolerance of uncertainty and emotional arousal, respectively (Krohne, 1993). However, things are not always this clear cut. Avoidance

strategies are not always associated with lowering of distress (Carver & Sheier 1993). Thus while people do use cognitive avoidance and *vigilance*, these features may be more complex, especially when first person accounts are considered.

Being watchful and vigilant for threat cues and stigma by the individual requires constant thinking about threats. Two consequences can ensue from this. Constantly appraising situations for threat and stigma increases thinking about them, so intrusive thoughts about their illness are more likely. Attempts at secrecy about a stigmatising condition activate a set of cognitive processes that encourage an obsessive pre-occupation with the secret (Lane & Wegner, 1995). The first step of secrecy is to suppress thinking about the topic. In conversation, thought suppression pushes the secret out of mind so attention can be focussed redirecting talk away from the topic area. The next step of the secrecy cycle is an ironic tendency for thought suppression to increase intrusive thoughts about the topic that is secret (Wegner, Erber & Zanakos, 1993). People with concealable stigmas like psychiatric disorder, may not be conscious of their stigma all the time but rather experience stigma thoughts as periodic intrusions when they try not to think about them (Smart & Wegner, 1999). As Smart and Wegner (1999) suggest, prior conceptions of stigma have not encompassed its potential to pre-occupy daily thinking.

Monitoring as a form of coping or self-regulation embraces the aspects of avoidance and *vigilance* in a slightly different way. People monitor to (1) acquire control over their actions, (2) modulate affect, and (3) to reduce uncertainty (Miller, Combs & Kruus, 1993). However in order to monitor for unsatisfactory situations people rehearse the threat and attend to its negative affect in a manner that sustains intrusive ideation. Rehearsing the threat through rumination can involve re-experiencing the aversive event so that extreme *vigilance* and avoidance can ensue. Coping by: (1) disengagement leads to avoidance, denial and wishful thinking, (2) engagement leads to secondary control coping (distraction, cognitive restructuring, acceptance), while (3) primary control coping (problem solving, emotional regulation, expression) leads to voluntary responses to stigma (Compas, Connor, Saltzman, Thomsen & Wadsworth, 1999). Involuntary responses lead to (1) engagement responses of physiological and

emotional arousal, rumination, intrusive thoughts and impulsive actions; and (2) disengagement responses of avoidance (Compas et al., 1999). What this model suggests is that people have diverse, interdependent, involuntary and voluntary responses to stress and coping. There are similarities in coping with stigma-related stressors as people experience daily hassles and major events (Alison, 1998). People try different alternatives, and feedback from one response affects other responses made. However, research on coping with stigma is in its infancy (Miller & Kaiser, 2001).

Disclosure of stigma has been likened to “going into and coming out of the closet” (Dindia, 1998). People can dislike having to talk about features of their lives they find unsatisfactory. On the other hand talk therapies in psychology require disclosure or they do not proceed. Underlying therapeutic concerns is a well-tested assumption that repression harms health while disclosure facilitates it (Pennebaker, 1989). In particular, disclosures that explain rather than describe help assimilate traumatic experiences into memory. Pennebaker’s studies provide strong support that it is *how* we communicate as much as *what* we communicate, that is important. When a stigmatising condition is present disclosure becomes fraught with risk. Unlike other patients, disclosure by psychiatric patients is explicitly about how they communicate as much as what they communicate. It is precisely inferences from disclosure activities that determine their diagnosis, treatment and trajectory through psychiatric services. Disclosure becomes a performance of mental health with all its attendant risks for the patient (Blum, 1970). Given the uniqueness of psychiatric stigma and the pronounced discomfort it engenders, there could be qualitatively different aspects of disclosure of psychiatric illness that are not found with other stigmatising conditions.

Difficulties arise in psychiatric service user accounts about practices within services. Talk about people and their conditions in a psychiatric service are shaped by the medical linguistic practices that are employed by staff (Rosenhan, 1975). Medical language can remove the person and institute the patient (Barham & Hayward, 1995). A patient can be perceived as a collection of symptoms that cohere around a diagnosis that then determines treatment. People can be known collectively by their illness (e.g. “schizophrenics”) and as their illness (e.g. “she is

a PD – personality disorder”) (Rosenhan, 1975). Psychiatric taxonomies map onto social taxonomies of ‘madness’ (Landrine, 1987) which can then become a personal identity. As their illness is the reference point for inclusion into a psychiatric service so too does a person’s illness locate the linguistic practices used. People do not have ‘bad’ days: they are depressed. Disputing a diagnosis is evidence of ‘denial’. Refusing treatment with adverse effects is being ‘treatment resistant’ (Deegan, 1993). The “great danger is that you might undergo that radically devaluing and dehumanising transformation from being a person to being an illness” (Deegan, 1993, p.9). The implication of this for consumers is that recovery from mental illness involves recovery from the effects of being labelled mentally ill. Linguistic practices adopted by patients so they can exit services can entail assumptions about identity and possibilities that impoverish and are antithetical to personal recovery (Sayce, 2000). Therefore we should try to understand the complex relation between the person with psychiatric illness, the psychiatric services that they use, and their experiences of psychiatric stigma.

Goffman (1963) gave the first theorised account of personal challenges in living with a stigmatised identity. His analysis, often cited, and drawn from his studies in the 1950’s, is as cogent today as it was then:

By intention or effect the ex-mental patient conceals information about his real social identity, receiving and accepting treatment based on false suppositions concerning himself. While the mental patient is in the hospital ... he is faced with being treated tactfully as if he were sane when there is known to be some doubt. [When discharged] he must face prejudice against himself by individuals who are prejudiced against persons of the kind he can be revealed to be. And in each case. To display or not to display: to tell or not tell; to let on or not let on; to lie or not lie; and each case, to whom, how, when and where. He finds himself not knowing how far information about himself has gone (Goffman, 1963, pp.57-58).

As a result of this uncertainty the:

Partitioning of the individual’s world into forbidden, civil and back places establishes the going price for revealing or concealing [identity]. [T]he individual’s spatial world will be divided into regions according to the contingencies [for] management of social and personal identity (Goffman, 1963, p.104).

Strategies for identity require a pragmatic use of impression management by *passing* and *covering*:

Because of the great rewards in being considered normal, almost all persons who are in a position to pass will do so on some occasion by intent. When an individual (...)passes it is possible for discrediting to occur....He who passes leaves himself open to learning what others ‘really’ think of persons of his kind....

Many of those who rarely try to pass, routinely try to cover....[P]ersons who are ready to admit possession of a stigma...make a great effort to keep the stigma from looming large. The individual's object is to reduce tension, that is, to make it easier for himself and others to withdraw covert attention from the stigma and to sustain spontaneous involvement in the official content of the interaction (Goffman, 1963, p.95, 105).

However, anything that interferes with communication is always latent to the interaction and is difficult genuinely to ignore:

The person with a secret failing, then, must be alive to the social situation as a scanner of possibilities, and is therefore likely to be alienated from the simpler world in which those around him apparently dwell.... risks are handled by dividing the world into a large group who he tells nothing, and a small group to whom he tells all ... It is to be expected that voluntary maintenance of various types of social distance will be employed strategically by those who pass, the discreditable here using much the same devices as do the discredited, but for slightly different reasons. [Keeping distance] reduces time spent with another [and] the more chance of unanticipated events that discloses secrets... (Goffman, 1963, p.110,117, 122).

When exposure can result in an exclusion, that both parties by tacit co-operation may want to avoid, the distress and "painfulness, then, of sudden stigmatisation can come not from the individual's confusion about his identity, but from knowing too well what he has become" (Goffman, 1963, p.159).

Recent studies of stigma disclosure have extended Goffman's analysis of selective disclosure and concealment (for a review of self-disclosure see Petronio, 2000; for stigma disclosure see Dindia, 1998). Disclosure is not a mutually exclusive phenomenon (disclosure-concealment). The praxis of self-disclosure involves a dialectical relationship and contradiction between disclosure and concealment which Dindia conceives as a "spiral" (1998, p.89). It is an ongoing, open ended, ever-changing process across interactions and people's lives – it is "unfinished business" (Duck, 1990, p.5). There is selective disclosure, staging information (e.g. testing the waters), indirect disclosure, non-disclosure and open disclosure (Dindia, 1998). The importance of things that are private is that they affect conceptions we hold about ourselves and our relationships with others (Fishbein & Laird, 1979). The boundaries people put around private information and the rules they use to manage information flow, intersect and result in "communication boundary management" (Petronio, 2000, p.38). Communication boundary management theory (CBMT) suggests people balance the need for privacy with that of disclosure because it is risky and can make people vulnerable (Petronio, 1991). This is achieved by a metaphoric boundary people erect to control

autonomy and vulnerability. This reduces the possibility of rejection or hurt and increases self-protection. Rules are developed to decide on the mechanics of disclosure (e.g. who, what, when, how, whom) and how to respond to disclosure. Research on stigma disclosure indicates the use of CBMT when people disclose stigma (Dindia, 1998). However, some stigmas are more rejected than others. So disclosure for people with highly stigmatising conditions, like psychiatric disorder, is likely to be more precarious in its consequences of exclusion and rejection.

Employment

Exclusion and rejection matter most when they relate to highly valued activities, such as employment (Link & Phelan, 2001). Being involved in an insignificant task can lead to people being treated pleasantly. Once a person places themselves in a situation with a high degree of adaptive significance or ego involvement then they can face intense opposition and rejection (Piner & Kahle, 1984). Disclosure in the workplace can result in immediate and enduring negative or punitive actions by employers and fellow employees (Farina, Felner & Boudreau, 1973; Susman, 1994). This can alter the course of a job interview (Farina & Felner, 1973), hasten an exit from employment (MHC, 1999a), encourage underemployment (Dooley, Prause & Ham-Rowbottom, 2000) and generate a reluctance to return to the workplace (Vickers, 1997). Other less blatant, but just as intolerable forms of social disapproval exist, such as innuendo, misunderstandings and social distance (Vickers, 2000).

Employers describe a range of experiences when employing people who have people with psychiatric disorders. Some New Zealand employers have had adverse experiences, and assume that such employees are unreliable, easily fatigued, depressed and lack motivation (MHC, 1999a). One international study found that employers of people with psychiatric disorders did not react differently to employers without this experience (Olshansky, Grob & Malamud, 1959). Apparently experience is not necessarily a good teacher. O'Hagan's (2000) study of Workbridge (disability employment service) staff, employers and consumers provides some a careful consideration of what happens from all perspectives when consumers enter employment. Employers' attitudes towards mental illness were usually derived from outside the work setting and were probably in conformity

with the attitudes of their colleagues, friends and neighbours. While a large majority of employers said they were willing to hire, fewer employers actually did so if the person disclosed (O'Hagan, 2000). It would be incongruous to expect employers to hire people whom they consider to be violent, unpredictable and uncontrollable or depressed, unmotivated and easily fatigued, as this interferes with productivity. Stigma and misunderstanding by employers and employees are seen as a primary barrier to consumer participation in employment (Consumer Employment Group, 1997). Discrimination was most likely to be mentioned by consumers and least likely to be mentioned by employers (O'Hagan, 2000). Other barriers O'Hagan mentioned were perceived untrustworthiness, lowered productivity, under-estimation of skill, patronisation, harassment, poor communication skills and ignorance. Hiring is even less likely in a competitive job market when the number of job applicants permits greater employer choice (MHC, 1999a).

The New Zealand *Disability Counts* (Statistics New Zealand, 1998) of labour force employment showed 37% of people had a disability status and while only 3% of these were unemployed, it probably reflected a high proportion of discouraged job seekers or those in inadequate employment. Employment for people with disability is less likely to be highly paid and more likely to occur within elementary work. This is problematic as only 28% of people with a disability without qualifications were employed compared to 53% of adults without a disability and no qualifications (Statistics New Zealand, 1998). Being in employment can mask unmet work needs and thus the prospect of underemployment. Full employment is no longer a government policy in New Zealand and recent labour market changes have impacted unequally on people with disability (Mental Health Advocacy Coalition [MHAC], 1999). Mainstream disability services are generally ineffective in assisting people with a psychiatric disability into employment (MHC, 1999a). They tend to have low vocational expectations, focussing on pre-vocational or segregated work training that traps people into getting 'work ready' for a job that never arrives (MHAC, 1999). While only 13% of all people with disabilities had a psychological or psychiatric disability, this group had the highest unmet need of all disability groups from health services.

The irony for mental health services is that vocational and daytime activities have been identified as the area of highest unmet need by their service users (Kydd, Mahoney & Turbott, 1997). Mental health services assist people to achieve a minimal level of functioning and wellness but do not continue this through to full recovery by facilitating participation in employment (MacKenzie, 2000a; MHC, 1999a). Thus when discharged from hospital, a person has a greater chance of returning to hospital than to work (Anthony & Blanch 1987). In this situation psychiatric illness results in a career of illness and support and not a career of recovery and employment (Mackenzie et al., 2000). Therefore it is not surprising that people with psychiatric disorder tend to conceal their past and current history of psychiatric disorder, in order to maximise their entry into employment (MacKenzie, 2000b; Vickers, 2000).

Vickers has examined life at work with an unseen illness and given special attention to the “unseen, unspoken, unrecognised dilemma of disclosure” (1997, p.240). Decisions about information management are important because in employment unseen disorders, like psychiatric disorders, enable people to ‘pass’ undetected or use ‘covering’ to conceal things which could lead to forced disclosure (Goffman, 1963). Unseen disorders that are low on recognition and high on perceived danger are the most likely to be concealed and stigmatised (Fabrega, 1981). When disclosure does happen, work “colleagues, in their ignorance are more likely to trivialise than stigmatise conditions they know nothing about” and react inappropriately (Vickers, 2000, p.141). However, being found out can be a serious social offence when there is an expectation to disclose, even negative data that is detrimental to the person’s own work status (Goffman, 1963). Perception of the person’s work ability may change and colleagues fearing a ‘social contagion’ can disassociate themselves (Das, 2001). Alternatively a positive response bias could occur, due to a leniency effect (Forgas, 1985), sympathy effect (Susman, 1994) or the use of co-workers as ‘natural supports’ (Nisbet & Hagner, 1988) in the workplace. Either way, the person’s workplace identity is vulnerable and can present uncertainty both for those with whom they interact and for the future reception of their actions (MacKenzie, 2000a).

Vickers' (2000) taxonomy of unseen illness stigma in the Australian work place indicates that it is based on moral judgement, knowledge, fear and social discomfort. Stigma can embrace a moral judgement, because 'ascribed stigma' is attributed to a person's state of being as: "the nature of his or her offence is perhaps best characterised as ontological" (Scambler, 1984, p.208). The ontological aspects of stigma can create an existential anxiety for work colleagues in dealing socially with a person who could become unwell and has an impending loss of function. Colleagues may feel threatened in the presence of the vulnerability in another person (e.g. fear for self). There can be suspicions of malingering where "watchdog individuals" challenge people who look well and thus do not appear deserving of provisions for their disability (Donoghue & Seigel, 1992, p.63). Social discomfort can ensue for work colleagues when awkward (e.g. excessive sweating) or irritating moments (e.g. confusion) occur and social taboos about work-place behaviour are transgressed. When a person in the workplace employs non-normative behaviour, such as needing to rest during work-breaks, they may incorrectly be judged as 'not able' when instead an unknown illness process has caused this. Work colleagues tend to seek information to confirm, rather than disconfirm their negative views (MacKenzie, 2000a). Thus in only considering work colleagues' reactions it appears easy to confuse the uncertainty of outcomes in illness process, social skills, cognitive deficits and social unease with the effects of stigma in the workplace.

Only careful examination of individual experience within the workplace can move beyond the inference to stigma that is often made from social processes by other people. A New Zealand study of multiple individual workplace experiences would move beyond a taxonomy of stigma in this setting and develop a theory that explains, predicts and remains congruent to personal experience.

Summary and Key Points

New Zealand's beginning as a British colony imported psychiatric services that have since undergone considerable change. What have not changed are public perceptions of 'madness' and 'mad' people. They have been enduringly negative. The history of such people as best 'out of sight and out of mind' has been viewed as necessary for the public and desirable by the institutions. Recent changes to

'community care' bring old fears about the efficacy of treatment and dangerousness of patients to communities that do not understand illness behaviour. This has resulted in a devalued social identity that the public and consumers, who are also members of that public, both share.

A devalued social identity has been fundamental to accounts of stigma and the process of stigmatisation. Sociological and social psychological literature is able to portray interpersonal and intra-personal processes at work. People are distinguished as different in a way that sets them apart. This links them to a set of negative characteristics which can result in negative consequences. Theories around labelling, attitudes, stereotyping, prejudice, attributions, social representations, monitoring and disclosure are able to explain some of the parts and processes. However there appears to be a gap. How do these parts and processes map onto the personal accounts of illness? Illness narrative research renders different conceptual terms, processes and priorities. It would be useful to theorise psychiatric stigma from those who directly experience psychiatric illness and stigma. This review has shown the need for research on psychiatric stigma to consider:

1. The complex relation between the person with psychiatric illness, the psychiatric services that they have used and their experiences of psychiatric stigma.
2. The distinctiveness of psychiatric stigma and its effects that have noticeably different outcomes from other stigmas and conditions.
3. The sociological (e.g. Link & Phelan, 2001) and psychological (e.g. Jones et al., 1984) reaction models of stigma that provide an in-depth description of parts of processes involved with stigma, but are not sufficiently integrated to provide an adequate description of the complete process.
4. How people resolve stigma. This also contributes to its negative outcomes in some unspecified way and it is not clear what these internal processes are.
5. The processes that people employ to resolve the daily challenge of shifts in feeling and function states and reintegration of identity while negotiating a stigmatised identity.

6. Evidence of daily concerns and challenges about the effects of mental illness on life trajectory, such as employment, and providing an experiential element so that it better fits with consumer experience.
7. The strong similarities between the effects of uncertainty on coping with general illness states and how people cope with psychiatric stigma.
8. The relationship between stigma and illness intrusiveness in psychiatric disorder, the potential of stigma to pre-occupy daily thinking and the ways people cope with this.
9. The concepts of felt stigma, inscribed stigma and enacted stigma. These require further investigation within the context of psychiatric disorder.
10. The key role of uncertainty in psychiatric illness and the need to incorporate uncertainty into accounts of psychiatric stigma.

There has been a close association between work and madness. Social identity is characteristically involved with how people participate in social life. A central aspect to this participation has been work. Failure to work is seen as a failure in social role, which in itself are grounds for considering psychopathology. Understandably people with a devalued social identity may not want to associate with those who do the devaluing and excluding. But in today's world, social exclusion results in economic and social loss. Not working results in loss of social identity and a range of other health benefits. Those who do not obtain work or have to accept inadequate employment because of the psychiatric stigma are excluded from an activity that is crucial for their recovery. Developing a theory of psychiatric stigma that is grounded in the everyday experience of people regarding employment would improve our understanding of these outcomes. Such a theory should be able to account for the ways in which psychiatric stigma affects this most important feature of social identity, a feature that once a person experiences psychiatric illness, can be out of reach.

CHAPTER 2: LOCATION AND EVALUATION OF GROUNDED THEORY

Paradigm Considerations

A paradigm is essentially a world view that entails four considerations: Ontological – the nature of reality and the extent that it can be known; Epistemological – what can be known and the warrant used to obtain knowledge; Methodological – how ontological and epistemological location influence the inquirer as they proceed in finding out what can be known; and Method – what the inquirer does with research data to discern the problem under study. Various researchers (e.g. Annells, 1996; Guba & Lincoln, 1994) suggest that it is useful to discern the paradigm the inquirer employs as the flexibility within qualitative inquiry places high demands on the researcher's reflexive capabilities. One way to reveal to a reader my theoretical position and hence the paradigm I employ in my interpretations is to state my understanding of grounded theory. This chapter outlines what I perceive to be the paradigm of grounded theory, as applied to the current study.

Grounded Theory (GT) was initially formulated through the combined efforts of Glaser and Strauss (Glaser & Strauss, 1967). From their combined efforts two distinctive approaches appeared (Glaser, 1992; Melia 1996; Stern, 1994), which have loosely been translated as the Strauss and Corbin (1990, 1994, 1998) approach and the Glaser (1978, 1992, 1994, 1996a, 1996b, 1998) approach. The method and methodology I employed were based on Grounded Theory as developed and explained by Glaser. However, I am not a 'Grounded Theorist' but employ GT as a method to build a theory of psychiatric stigma. The distinction is important because I only drew what was needed from the methodology of GT to enable me to use it as a method. Nor as Charmaz (2000b) suggests, do I need fully to embrace the sociological social psychology from which its theoretical precedents were developed. This thesis is located within the field of psychological social psychology.

There is some ambiguity in the term ‘social psychology’. This stems from its use by two disciplines, Psychology and Sociology. The approach to psychological social psychology (PSP) is best summed up in Allport’s (1968) definition as the “attempt to understand and explain how the thought, feeling, and behavior of individuals are influenced by the actual, imagined, or implied presence of others”. Psychological social psychologists today generally do not ignore the cultural and social forces that shape an environment within which the psychological processes of emotion, cognition and behaviour occur. Rather their interest is in the processes themselves instead of in the social milieu. Sociological social psychologists (SSP) (e.g. Rosenberg & Turner, 1981) on the other hand seek to explain and predict patterns of behaviour among larger groups of folk (e.g. groups, communities, social class, societies and nation states). As a result their units of analysis take society and human association as the starting point for analysis, whereas psychological social psychologists make the individual their main unit of analysis. Thus psychologists tend to explain what, how and why individual life functions and sociologists tend to explain what, how and why social life functions. Both the macro and micro view of human behaviour are useful as the larger framework of social institutions, power, coercion and freedom in sociological analysis can make purely psychological analysis seem naive or reductionist.

In my view neither one is better as they have both common and differing goals. The relevance of the above comments for my project is that I drew from both disciplines. Grounded theory as a sociological method was designed to explain and predict generic behaviour by discovering the underlying social processes that shape human behaviour and interactions. Its purpose is to “type behaviour not people” (Glaser, 1992, p.69). There is a tension for me in using a method that discerns *social* SSP processes to infer *individual* PSP explanations and predictions of behaviour. I therefore argue that GT can be used with sensitising concepts from other perspectives, namely psychology. I address this tension by examining the method and paradigm of Glaser’s GT and evaluating its appropriateness for the task at hand.

Utility of Grounded Theory

The method of Grounded theory (GT) has frequently been employed within the field of nursing research (for a review see Benoliel, 1996). As some authors have mentioned (Charmaz, 1995b; Edwards, 1998; Henwood & Pidgeon, 1992, 1995; Pidgeon & Henwood, 1997) the method of GT seems very suited to more current practices of psychology, in particular qualitative psychological research. I became engaged with GT as a psychological method because of the changes that took place in how I approached my field of interest. Initially my PhD proposal involved an experimental approach to examine psychiatric stigma. It was traditional social psychology in the sense of using undergraduate students in a controlled experimental situation. However after a period of further reading, conference attendance and contact with mental health service users, I felt both the method and the participants would not give me the theoretical elaboration I required. In particular, key discussions at Centre 401 (local consumer advocacy service) were very supportive of a qualitative inquiry that examined the meaning of psychiatric stigma for the people who experienced it and presented it in their own words. I then reworked my proposal adopting a 'naturalistic' as opposed to an 'experimental' inquiry. Why?

It seemed to me that embodiment (Csordas, 1994; Groz, 1994) and practices of everyday life (de Certeau, 1988) around psychiatric illness could be important in determining psychological processes about stigma. For instance Young's (1990) study on 'throwing like a girl' showed how gender influenced bodily comportment, motility and use of public spaces, which in turn shaped everyday intentions. I was interested in knowing if psychiatric illness resulted in personal social-spatial correlates when experiencing psychiatric stigma that similarly influenced intrapersonal and interpersonal operations. Thus information on the social and intra-personal aspects of living with psychiatric illness would be better derived from direct everyday experience rather than pseudo experience (e.g. imagined or intentional). Secondly, I wanted something on the durability of experience. People are rarely static. Usually most folks experience change in work, relationships, accommodation and interests over a period of time. I wanted to obtain some idea of a personal life trajectory where I learned about a Participant's past and then was able to stay with them over a two year period.

Thirdly, my primary interest shifted to what was happening for the person with psychiatric illness and how they made sense of their world and experience rather than the perceptions of other people. Thus I wanted to develop a theoretical account that could emerge from the rich experience of everyday personal accounts in a manner that could be understood by the Participants themselves via their own words and conceptual processes. Grounded theory can utilise psychological knowledge to theorise an insider's experience of psychiatric stigma in a manner analogous to approaches previously taken within phenomenology (e.g. Vickers, 2000) and anthropology (e.g. Hannan, 1990).

However, there were some concerns with using this method. Having been primarily self-educated in using the method or in Glaser's words "minus mentoring" I was mindful of some of the criticisms that have been raised. Often when an inquirer employs GT it can be difficult to discern whose grounded theory approach they are using; hence "method slurring" can happen (Baker, Wuest, & Stern, 1992, p.1355). There has been some confusion as to what GT is and whose GT is best, which has led experienced researchers using this method to ask "will the real grounded theorist please step forth" (Charmaz, 2000b).

According to Lofland and Lofland (1984) there is some justification to the accusation that some grounded theorists have been 'slighting' their data. Paucity within the method has led some researchers to find GT insufficient in portraying narratives (Riessman, 1990) and has alienated them from their subject matter in interviews (Richardson, 1993). As Richardson (1994) has mentioned, qualitative research reports can be inconsistent. It is not uncommon for authors to "choose evidence selectively, clean up subjects' statements, unconsciously adopt value-laden metaphors, assume omniscience, and bore readers" (Charmaz, 2000b, p.521). There are also specific criticisms of the method itself. When grounded theorists aim for analysis their fracturing of data may resist a fuller portrayal of subjective experience (Beck, 1990). The co-construction of dialogue through interpretation can leave unchallenged the representations of subjective experience, the interpretative warrant used, and location of the writer's voice (Charmaz, 2000b). What the above criticisms imply, as Charmaz (2000b) bluntly states, is that the GT method "(a) limits entry into the subjects' world, and thus reduces

understanding; (b) curtails representation of both the social world and subjective experience; (c) relies on the viewer's authority as expert observer; and (d) posits a set of objectivist procedures on which the analysis rests" (p.521). Ever the pragmatist, Glaser's (1998) response to these comments is that GT is "but one method among many to choose from, even though it is being used with great results. Its justification and legitimacy is found in the rich proof of its products and in its roots. Choosing grounded theory is all that's necessary. To choose is to do" (p.35).

What is Grounded Theory?

Without wanting to reprise the whole method of Grounded Theory, the following offers a very brief account. Grounded theory (GT) is a discovery-based method, that is, it produces new theory as opposed to testing pre-existing theory. GT induces a theory on the area under study that is built up from Participants' experiences. How does this happen?

Open Coding and Constant Comparison

Grounded theory begins by 'open coding'. Glaser (1978) suggests the analyst must constantly ask a set of questions regarding what is happening in their data: "What is this data a study of? What category does this incident indicate? [and lastly] What is actually happening in the data?" (p.57). This encourages the direction of study to emerge before becoming selective and focussed on the problem under study. In GT "a multi-concept-indicator model" is used, as the focus is on "conceptual specification" not "conceptual definition" (Glaser, 1978, p.62-64). Empirical indicators are conceptually coded, providing a direct association between data and concept that generates a theory of Participants' experience. The constant comparing of incident to incident, incident to concept, and concept to concept achieves conceptual categories that are continually sharpened by indicators to achieve best fit. Further indicators are then used to develop the properties of conceptual categories until the code is validated and saturated. Codes therefore earn their way into the theory from "their data determined distinctions and systematic generation" (Glaser, 1978, p.64). If relevant data are unable to be coded, then the emerging theory does not fully fit the data and the theory requires modification. At the same time open coding encourages the full range of theoretical sensitivity to be used as it permits the

generation of any codes that could fit and work. Thus new conceptions of psychiatric stigma could emerge from Participant interviews.

Theoretical Sensitivity

The idea of *theoretical sensitivity* is so intrinsic and fundamental to performing GT, that Glaser (1978) has devoted a full book to its elaboration. Put simply, it entails being able to render theoretically the grounded categories that the inquirer discovers. Thus any knowledge or conceptual lens that the researcher employs is useful if it renders theoretical categories that are internally consistent and grounded in the data they emerge from. Hence in coding Glaser indicated that two main types of categories should be developed. In addition to in-vivo codes, there are codes of psychological constructs (e.g. stigma, prejudice) formulated by the analyst that are based on their research and scholarly knowledge of the substantive field. These can add more meaning to the in-vivo codes as they stretch beyond local meanings to much broader psychological concerns. Moreover, theoretical sensitivity requires the use of psychological concepts if they enable capture of the data into theoretical categories that are consistent with Participant experience. Theoretical sensitivity, in encouraging inductive theorising about psychiatric stigma, could result in an innovative yet pragmatic account of this phenomenon.

Core Category

Open codes therefore emerge, are validated, corrected, are saturated (so all the data fit) and are located by their relationships to other codes. Essentially this means finding their relevancy to the *core category*. This is a category that in the Participant's view is central and conceptually functional in that it resolves the main problem or concern they are facing. Thus the core category sums up in a "pattern of behaviour the substance of what is going on in the data" (Glaser, 1978, p.94). Glaser suggests that this happens by systematic and constant comparisons: "Categories emerge upon comparison and properties emerge upon more comparison. And that is all there is to it" (Glaser, 1992, p.43). The *principle of emergence* is central to all conceptual development and internal consistency.

Basic Social Process

When a core category is a process, additional criteria apply. A basic social process (BSP) is what Participants use to resolve key parts of their experiences. It has

“two or more clear emergent stages” (Glaser, 1978, p.97) that bring out process and account for change over time. Not everyone will engage a BSP in the same manner as there can be much individual variation. While BSPs emerge from the units of analysis (e.g. individuals, groups, organisation) they are abstract from these units’ structure because they can vary sufficiently to occur in very different other units. This ability to fully vary independent of their place and time and the Participant’s perspective enables BSPs to generalise as abstract processes wherever they are found to emerge. In transcending the boundary of analytic units, BSPs shape peoples’ lives and not just their participation within that analytic unit. According to Glaser, BSPs present as two types – *basic social psychological processes* and *basic social structural processes*. This project is focussed on the social psychological processes that Participants employ to resolve psychiatric stigma on a daily basis. Therefore, any reference to a BSP in this study refers to a basic social psychological process.

Theoretical Sampling

Once the core category and BSP has emerged and the theory remains internally consistent with all available data, then *theoretical sampling* occurs. All the existing codes are re-ordered or re-coded in light of the core category, and then further theoretical sampling occurs outside of the immediate Participant data. Thus alternative data that are still within the substantive field of interest are sampled to see whether the core category is able to capture the variability of new data. Saturation occurs when the data are reviewed and nothing new happens. Thus when indicators are interchanged and no new meaning for a concept occurs, the categories and its properties are said to *exhaust the data* or *pattern out*. This interchangeability of indicators whilst still retaining the conceptual meaning suggests parsimony is occurring. Hence there can be transferability of the theory to other substantive areas by finding whether their indicators produce the same conceptual category and its properties. At the same time *saturation* through interchangeability reduces the need to find all meanings and their indicators. The “constant comparative method ... requires only saturation of the data – not consideration of all available data” (Glaser & Strauss, 1967, p.104). Saturation is only fully achieved by theoretical coding.

Memoing and Evaluation

The central process in generating Grounded Theory is the writing up of theoretical memos. While coding is happening, ideas about codes and their relationships to other codes are written up as memos. The development of ideas in memos creates a memo fund which can then be sorted into a theoretical outline to achieve integration. Evaluation of a GT proceeds across the following criteria: fit, work, relevance and modifiability (Glaser, 1978). All theoretical categories must emerge from the data so that any analysis must *fit* the data. A GT must *work* to the extent that it conceptually renders and orders the data in a manner that best explains the phenomena being studied. Conceptual categories and processes from which analytic explanations emerge are derived from the research setting so that the GT has *relevance* for both Participant and inquirer. A GT can be durable and flexible because it is *modifiable* when new analyses emerge or conditions change.

Grounded Theory Paradigm

Grounded theory was developed by Glaser and Strauss (1967) to advance the discovery-orientated approach of theory development within sociology. Yet the theoretical origins for each author were divergent. Strauss was trained by Everett Hughes and Herbert Blumer in symbolic interactionism and qualitative analysis at the University of Chicago (Glaser, 1996). In contrast Glaser (1998) was influenced by Lazarfields' techniques of quantitative analysis and Mertons' structural-functional analysis and theory development while at Columbia University. In the method of GT both qualitative and quantitative research traditions were merged.

A primary theoretical antecedent for GT is symbolic interactionism (Glaser, 1998). It consists of three basic premises: people act towards things because of the meanings these things have for them; meanings are produced via social interaction; and these meanings are modified through an interpretative process used by people in managing the signs they encounter (Meltzer, Petras, & Reynolds, 1975). Symbolic interactionism is an American perspective whose origins are found in the philosophy of pragmatism. This philosophical tradition spawned scholars such as C.S. Peirce, W. James, J. Dewey and G.H. Mead. Proponents of this view take experience as a transaction between the organism

and environment. The intention of living things is to make practical adjustments to their conditions of existence. In meeting the demands of their environment in practical ways, knowledge or ideas undergo practical tests of utility. An idea is true, if it works. Thus the consequences of ideas determine their currency, and consequences ensue from the needs and interests of people as they probe and test their surroundings. Truth or meaning is therefore real. It emerges from how people act in, perceive and interpret their world.

Firstly, in order to connect pragmatism with symbolic interactionism, a brief outline of G. Mead's (e.g. Mead, 1934, 1938; Strauss, 1964) work will help convey these approaches within social psychology (Meltzer, 1959/1972; Hewitt 1997). While it has been said (e.g. Lindesmith, Strauss & Denzin, 1988; Snow 2001) that Blumer's (1966, 1968a, 1969b) work provides a canonical basis of symbolic interactionism, I choose to focus primarily on Mead's work due to his close association with psychology. Secondly, GT's 'logic of justification' requires a brief elaboration, for the whole method hinges on this aspect and draws from the pragmatist C. Peirce.

Symbolic Interactionism

As a methodology GT assumes some features about society, self and mind which have been attributed, amongst others, to the influence of George Herbert Mead and his student Herbert Blumer (Hewitt, 1997). Mead postulated the social nature and origin of self. Each individual in beginning an *act* engages in actions or gestures that are then used by an audience to determine how they will respond. Mead saw that the most important gestures people made were linguistic. Bodily acts seemed to be preceded and followed by speech acts. Secondly, acts of speech had the capacity to arouse in others a response similar to that being expressed by the person initiating it. In Mead's words they are *significant symbols*. For instance, the symbolic nature of the word 'fire' when shouted in a public place, does more than elicit a flight response. Similarly words such as 'madness', 'lunatics' and 'lunatic asylum' have distinct connotations. The words invoke, both in the person who said it and their audience, a specific attitude – a disposition to act in a certain way and an image of the required actions in that situation (Hewitt, 1997). The function of forming a common attitude through shared linguistic

symbols is that it develops a control over personal conduct. The shared symbol permits people to anticipate what others would do in response to their acts. This then enables people to plan their subsequent acts, thus exerting control over their actions.

In addition to symbols enabling control over behaviour they also permit a *consciousness* of self. The capacity to imagine the responses of others by employing symbols extends a similar capacity to imagining ourselves. In being able to act towards others we become able to act towards ourselves, and vice-versa. Thus the sense of *self* arises as a *process*. It is created and recreated as a two-phase process. In responding to *objects* or *generalised others* in their surroundings a *subject* phase gives rise to the sense of "I". The *object* phase gives rise to a "me" when the person imagines himself/herself as an object in their situation. Thus a person in a psychiatric service acquires a subjectivity from the staff as generalised others. Human conduct is viewed as a continuous alternation between "I" and "me". Individuals act and respond towards their environment and its objects as an "I"; next individual responses pass into memory and become part of the "me". Within memory the response is now available as an image of self or "me" for reflection. The individual then further responds as an "I" to this "me" and so on. It is this alternation between "I" and "me" as states of consciousness that permits individual action and reflection to achieve control over personal conduct. The capacity for self-conscious control over conduct suggests people can engage in both approved and disapproved social conduct as alternative choices are available. Thus people would engage in behaviour characteristic of 'mad people' even when they know such behaviour deviates from social norms and will incur social sanctions.

To be able to anticipate other people's actions also suggests that during an activity a person knows the situation they are in because they are able to define it. A person usually knows what is expected or prohibited, atypical or typical, what it is they are doing and how others are responding. In knowing who others are and how to interact, people have knowledge of their *role* in the situation and the roles of other people present. Thus when in the social milieu of a psychiatric service, people learn the role of being a psychiatric patient. Definitions of situations and

roles assist people to anticipate the course of interactions with others; and to make sense of those actions we do not anticipate. Conduct formation and social interaction are shaped by social roles in a two phase process. In constructing an activity to fit the definition of the situation, their self role and other people's activities, *role making* occurs. When the person views self and their situation from the imaginative vantage point of another person to engage in *role making*, then *role taking* occurs. This explains how people when entering a psychiatric service shift from being a person to being a patient because of the strong social contingencies of reinforcement that keep people in such roles.

Roles organise the frame of reference we use to make a performance that addresses our needs within a specific situation. In order to perform roles we have to be self-conscious within activities and interactions so that they fit the situation for the person and their audience. Roles are informed by perspectives, not only from the person and another, but from the generalised perspective of other people Mead called the *generalised other*. *Reference groups* act as a social group providing the generalised other as a standard to which the person refers when evaluating their own conduct. Social life within social groups is not just a cognitive activity but is accompanied by emotions. Emotions are an essential part of social life, that when named, the name may shape and determine the experience of that emotion. Emotions arise in completing personal and social acts, defining the situation and roles to such an extent that our experience of emotion can be an experience of self. Thus the experience of self and social life is affective and cognitive. A psychiatric patient learns to think and feel as a patient and to act to the standards of conduct required for this role, both from staff (generalised others) and other patients (reference groups). Interactions take place not only in terms of affect and cognition, but in terms of the symbols we employ as we manifest and exchange identities. Symbols are public. They make it possible for common attitudes to transfer from one person to another and be part of the environment to which people respond. Symbols expand the scope of any human environment as they can transfer spatially and temporally. Interactions are interactions of symbols and therefore in Mead's view a symbolic interaction. Blumer (1969b) coined the term *symbolic interactionism (SI)*, when he extended Mead's views.

While accepting Mead's view that self is constructed through social interaction (e.g. communication), Blumer (1969a) suggested that with people it is the meanings things have that shape what actions will occur as they seek and achieve their material and social ends. Communication is symbolic as we communicate through language; and in doing so create significant symbols. Meanings, in being derived from social interaction, occur within an interpretative process that directs and modifies them within each situation: "The actor selects, checks, suspends, regroups, and transforms the meanings in light of the situation in which he is placed and the direction of his action ... meanings are used and revised as instruments for the guidance and the formation of action" (Blumer, 1969a, p.5). People not only transform meaning in a contingent manner but such transformation can endure: "Established patterns of group life exist and persist only through the continued use of the same schemes of interpretation; and [these] are maintained only through their continued confirmation by the defining acts of others" (Blumer, 1966, p.538). The principle of emergence (Snow, 2001) encompasses the way people transform their situation, so that new cognitive-emotional states and social entities arise. The centrality of this principle is found both in Mead's (1938) primary focus on the emergent nature of the act and in how Blumer construes the new and emergent phenomena of social life. The principle of emergence lies at the heart of the GT method and the discerning of both the core category and basic social psychological process people use to resolve their concerns in everyday life.

Comment on Symbolic Interactionism

The Mead-Blumer version of SI suggests that people "confront a world that they must interpret in order to act" (Schwandt, 1998, p.233). Dingwall (2001) suggests that despite the powerful synthesis in Mead's work, relatively few of his ideas are unique. Antecedents drawing on Kant (Rock, 1979), Mead's location within pragmatism (Diggins, 1994) and relationship to psychology (Joas, 1985) have been covered by others. According to Denzin (1989), the attention to behaviour settings, interactions and overt behaviours can render accounts of people as "behaviour specimens" (p.79ff). Thus SI endorses a form of methodological behaviourism, while still respecting the empirical world even if it is a matter of dispute as to whether it can be directly apprehended (Blumer, 1980; Hammersley, 1989).

Symbolic interactionism requires the analyst to enter the Participant's world to: "see the situation as it is seen by the actor, observing what the actor takes into account, observing how he interprets what is taken into account" (Blumer, 1969a, p.56). I agree with Schwandt (1998) that SI encourages the inquirer to develop explanatory theories grounded, interpretative and close to the data. However, the Mead-Blumer SI has presented some difficulties (for reviews see Charon, 1985; Meltzer, 1959/1972; Meltzer, Petras, & Reynolds, 1975). As mentioned it seems to adopt a naïve empiricism. It is based on a realist and loosely positivistic ontology and epistemology and could lose its pretensions to ethnography, engaging more with the insights from post-structural philosophy; in particular, feminism and cultural studies (Schwandt, 1998). By becoming more interpretivist it would connect cultural representations (via media) with first-person experiences and develop a more phenomenological and existential account of self and society, where embodiment, ideology and power are addressed.

Impact of Symbolic Interactionism on Grounded Theory

Within GT, the impact of symbolic interactionism suggests both the self and social life spring from social interaction. It is only by social interaction that self and social life can be understood, and in particular, how activities within social interaction resolve practical concerns in everyday surroundings. Meaning is produced in social interaction, and though contingent to that situation, also transfers by the use of language. It is within language and how meanings occupy its symbolic content through interaction, that self and social life are known. The focus of Mead and Blumer interwoven with the theoretical concerns of pragmatism and symbolic interactionism, has led to the methodological foci of Grounded Theory.

These foci are the study of what, how and why human action achieves resolve of everyday needs and the utility of these actions for self and others within their surroundings. These aspects can be known by observing people in their environs and examining the language they use. The person having the experience is in a better position to know its meaning. At the same time the meanings within language also access the lived features of shared social life, dispositions to act, and rules for social behaviour because the symbolic content of language transacts

information and meaning beyond the confines of individual experience. Grounded theory attempts to understand the experience of others as mediated by a text from which an interpretation emerges of the interplay between internal and external personal experience.

Three things follow from the above account concerning the nature of inquiry for GT. Firstly, anything can count as legitimate data so long as it can be taken to mean something and any internal data are relevant if they lead to action and consequence. Secondly, experience structures self and social life. In examining personal experiences, social life is revealed by the utility of people's activity and this is the object for inquiry. Thirdly, meanings about self and social life emerge through human interaction within their surroundings. Thus the method of GT mirrors a similar process. If the principle of emergence gives rise to social life and self, then a method to examine social life and self consists of a similar principle – *emergence*. Having briefly explained one aspect of GT's methodological heritage, symbolic interactionism, I turn now to its 'logic of justification'.

Logic of Justification

Unlike Glaser (1998), Rennie (1998) suggests that when using Glaser's GT methodology there is "pressing need for a coherent logic of justification" (p.101). Grounded theory is recognised for its discovery approach and emphasises this more than the context of justification (Reichenbach, 1949). It uses data to create theory rather than test it. Its purpose is to develop theory that is accountable to data. To reprise briefly, gathering of data and analysis proceed together, as conceptualisation about what is happening in the data results in categories which reduce its complexity. The method of *constant comparison* is used to determine which incidents in the data fit what concept that categorises the data. It is the researcher's *theoretical sensitivity* that refines conceptual capture of the data. Categories are grouped according to how they explain the phenomena in question, until a *core category* is found that subsumes all previous categories and captures most of the variation in the data. The writing of memos throughout the research process and validation of categories with Participants tracks both the researcher's observations and how they were made. Taking the *core category/BSP* and maintaining its coherence while sampling alternative sources of data (*theoretical*

sampling) addresses its generalizability and utility. Thus there is a move between objectivity and reflexivity for both the researcher and the Participant. Grounded theories about the meaning of experience are both ‘emic’ and ‘etic’.

In GT, support for the tenability of inductions occurs by deducing *hypotheses* or hunches from inductions (e.g. phenomena) about the data, and *validating* them through constant comparison with the original data. Inductions are sustained when they are not disconfirmed by new data and account for most of the within category variation – they are *saturated*. Secondly, inductions are sustained to the extent that they can be validated through *theoretical sampling* of similar other data. The *verification* of these inductions occurs when hypotheses from the GT are developed and then tested in the way of normal science. This is similar to the general impetus within psychology of inducting a hypothesis or hunch and then deductively testing it – the hypothetico-deductive method – that has led to an emphasis on the latter at the expense of the former. Thus Glaser appears to reify concepts from the logical positivists and adopt them through using a similar language. The difficulty with this is that it provides no method for validating claims of the original inductions apart from the deductive step (Rennie, 1998). This is the same difficulty that Glaser runs into in his appeal for checks on internal consistency. Yet these checks for internal consistency are what Glaser suggests constitute the method of GT. Thus according to Rennie (1998), in preserving the subjective, Glaser appeals to the objective for his warrant in making truth claims. However, I think this is to misrepresent Glaser’s position. In the “Rhetorical wrestle” chapter in *Doing Grounded Theory*, Glaser (1998) specifically responds to such misrepresentations and criticisms.

As a method of discovery, categories are inductively derived from the data and then must obtain logical (e.g. deductive) relations between categories for the theoretical structure to cohere. Looking at the logic of justification that Glaser employs, GT is inherently *validational*, as Rennie (1998) suggests; but perhaps this is just a rewording of the “subtle nature of the interaction of induction and deduction as one theoretically samples” (Glaser, 1998, p.39). Inductive arguments are sustained by the validation that occurs through use of the *constant comparative method*. Induction is usually conceived as: an inference made from

the knowledge that some observed instances of *A* (e.g. data - incidents) have a property *B* (e.g. phenomena or property - stigma) so that all *A* have the property *B* (or in the probabilistic case, that many *As* are *B*). Two questions arise from this concern about GT – its generalisability and its form of inductivism. Thus under which observed instances can it be said to validate the inductive generalisation that all *As* are *Bs*? Secondly, it is useful to spell out the method of induction Glaser employs and whether the inductive inference is adductive, eliminative, enumerative or something else (Haig, 1995).

Generalizability

I respond to this concern by looking at issues of *stability*, *salience frequency*, *background knowledge* and *utility*. On the issue of *stability* - the above argument presumes that the situation and the property are stable or probably so. People and behaviour, unlike objects, and properties, are not necessarily presumed to be stable. Generalisations about people often lead to the expectation that our observations are based on stable properties about the person. However, human behaviour can vary so much and misattributions occur undetected, that when properties are observed they may not be stable in themselves, even when we think them to be. Hence inductive generalisations cease to be generalisations. GT appears to get round this issue by determining *basic social processes* and thus properties of general behaviour rather than individual behaviour. GT takes a premise from symbolic interactionism that self and society are made through interactions and that the *process* of interaction is shared by members of *reference groups*. Consequently there will be a social process taking place with groups of people, whether discerned by the analyst or not, that is employed generically by people of the reference group to achieve their aims.

Secondly, the frequency of *As* to *B* which is used in quantitative studies to sustain generalizations (e.g. reference of sample to a population) is not used in GT. What does occur is the use of *salience frequency* instead of *number frequency*. With salience frequency, it is the greatest number of properties in fitting the least number of concepts that obtains the most frequent salience in the data. Thus the most salient *A* (data/incident) gives rise to the most salient *B* (phenomenon/property). And the most salient *Bs* then give rise to the most salient *C* (category) and so on, until the most salient *D* (core category) emerges that then

captures most of the variation in *As*. The criterion for salience in GT is a *basic social process* - this must irreducibly process the problem for the person in a way that makes their life viable within an action scene.

Thirdly, *background knowledge* is required in order to determine and recognise the properties that are being generalised. If *As* are invariant with little fluctuation then few instances of salience may be required. Conversely if *As* are variable and many, then it is necessary to establish a reference class for events, to determine what kind of events they are. In GT reference is made to the use of concept (*code*) hierarchies that order (*sort*) concepts by salience so that some are subordinate and others are super-ordinate. The organisation of concepts into hierarchies is crucial to managing salience, coherence, complexity, frequency and variability. It is background knowledge or in Glaser's words, *theoretical sensitivity* that enables discernment of *Bs, Cs & D (codes)* and the ordering (*sorting*) of them into hierarchies (*coding families*). This is a "pragmatically reasonable inference task" (Holland, Holyoak, Nisbett & Tharbard, 1987, p.235). Concepts (such as *B,C,D*) that bear no relevance will not be generated nor irrelevant data (*As*) selected as they do not form part of the concept hierarchy that was used in making the inductive generalisation (Holland et. al, 1987).

Fourthly, what sustains generalizability is *utility*. Glaser always keeps coming back to this point. Theoretical sampling checks conceptual fit of categories to indicators that were not generated by the researcher. Thus any theory is sustained to the point that it is able to utilise new data and phenomena. Secondly, a GT has to 'work' for the Participants who provided data. It must be able to utilise parts of their experience in a coherent, pragmatic and clear way for them, as well as for the inquirer.

The Inductive Method of Grounded Theory

In response to the second concern: Haig (1995) and Kelle (1997) have described the inductive inference employed by Glaser as neither just inductive nor deductive. Grounded theory's comparative method entails a special kind of reasoning where a set of empirical phenomena entail a premise and whose conclusion is a hypothesis that best accounts for the phenomena. This form of hypothetical reasoning is based on a theory of logical inference described by

Peirce (1965) as abduction, induction and deduction. Abductions are any form of idea, intuition or hunch. They combine in a novel way empirical facts with theoretical knowledge to create new knowledge. Induction involves the testing of abductions by sorting which abductions achieve the best explanatory coherence. There is a symbiosis between abduction and induction. This is achieved by (1) bracketing conceptions and pre-conceptions relating to the phenomena of interest, and then (2) delaying development of conceptualisations until they emerge from the data related phenomena under study. Thus final conceptualisation is contingent on being supported by the data as a whole. Hence abductions arise from the activity of induction and are validated by the same induction. However, Glaser (1998) suggests that he employs Peirce's logic of inference which includes abduction, induction and deduction.

Evaluation of Methodology

Grounded theory engages a symbolic interactionist *ontology* reflecting its pragmatist heritage (Annells, 1996). Although natural and social worlds contain differing realities, they are apprehensible even if only on a probabilistic or imperfect basis. Glaser (1992) insists that GT focuses on "concepts of reality" by looking for "what is, not what might be" (p.14). The inquirer looks for "true meaning" (p.55) that gives rise to a grounded theory of what "really exists in the data" (p.53). The following contrasts the epistemic consequences of this ontological position with other ontological and epistemic perspectives so as to better situate the paradigm of GT for my inquiry. As Annells (1996) suggests, any paradigm of inquiry should be "evaluated for congruence with the inquiry paradigm to which the researcher subscribes, or at least...has a comfortable fit" (p.380).

Paradigmatic Considerations

Grounded theory positions itself as a middle ground theoretical approach, in that it seems to have a bet each way. On one hand its admitted subjective interpretivist roots are found within the traditions of hermeneutics (Blicher, 1980; Heidegger 1962), ethnography (Garfinkle, 1967) the *Verstehen* tradition in sociology (Outhwaite, 1975) and the phenomenology of Schutz (1967). On the other hand, as mentioned above, its positivistic roots support a form of methodological

objectivity, which Annells (1996) has called a “modified objectivist epistemological view” (p.386-7). I will elaborate on the former position and in doing so contrast this with the latter.

In GT there is a celebration of real world first-person subjective experience. It seems to embrace the ethnographical approach, where the inquirer is able to merge into the Participant’s world thereby gaining an insider perspective via the Participant’s own practices, linguistic and cultural representations. In common with phenomenology, the inquirer *brackets* Participant and inquirer experience to separate out events that are characteristic of the problem under consideration. This action is hermeneutical because it requires the interpreting Participant/inquirer to address a self-interpreting referent (Rennie, 2000). While this is rhetorical in nature, in GT it is also functional, because in resolving relativism and realism there is saliency that makes some interpretations better than others.

This is similar to Margolis’s (1986) compelling reconciliation of realism and relativism that discounts Descartes’s mind-body dualism (and which has led to further dualisms of subject-object and appearance-reality) as a mistake to begin with. While embracing a relativism that all knowing is relative to the perceptual framework of the knower, Margolis asserts that this does not necessarily lead to a subjective idealism. Rather, in virtue of our embodiment which creates a symbiotic relation to the world, our relativism is a relativism about the real world. In essence we know about the world because we are part of it. As Rennie (1998) suggests, grounded theory is hermeneutical but improves on that because it can escape the threat of circularity in the hermeneutic circle (Packer & Addison, 1989). Circularity is reduced because the holistic understandings about particularities are derived from the meanings of the particularities themselves, unlike the limitation of particularism within traditional hermeneutics (Rennie, 1998).

Grounded theory achieves an objective (e.g. testable) account of human conduct without the collapse into relativism by the struggle to develop an objective interpretative science from subjective human experience. Nor does the close association between interpretivism and constructivism (Guba & Lincoln, 1989;

Schwandt, 1998) lead GT to fully embrace constructivism. It seems to support “everyday constructivist thinking” (Denzin, 1989, p.237) that the mind is active in constructing knowledge and meaning. This occurs as we make sense of experience which we then modify in the light of further experience. As Strike (1987, in Schwandt, 1998) points out, this claim is “uninteresting because no one, beyond a few aberrant behaviorists, denies it” (p.283). However GT does fly close to some versions of constructivism, such as social constructivism (Gergen, 1985) and radical constructivism (von Glaserfeld, 1991), which I briefly comment on next.

Grounded theory rejects radical constructivism’s first premise that the warrant for truth claims can not be found in the relationship of knowledge to an independently existing world and hence there is no objective world apart from our experience of it. Glaser clearly supports the notion that basic social psychological or structural processes are objective and can be independent of our experience of them; they continue on without us, whether we are there to perceive them or not. Thus GT supports a realist and objectivist account of knowledge contra radical constructivism and rejects a relativism where all knowledge collapses into perspectivism. Grounded theory supports radical constructivism’s second premise that knowledge claims are valid if they permit a person by thinking and acting to achieve the goals they have chosen (von Glaserfeld, 1991). Thus GT supports a form of instrumentalism (Rennie, 2000), where the relationship between reality and knowledge is instrumental (Thayer, 1968).

Similarly to social constructivism (Gergen, 1985), GT does support a view that “Accounts of the world ... take place within shared systems of intelligibility – usually a spoken or written language” (Gergen & Gergen, 1991, p.78). Thus meaning-making is collectively generated through language and other social processes. Unlike social constructivism’s idealism (Denzin, 1989) and linguistic relativism (Fish, 1989) where language is at once the actor, the road and the destination, GT only uses language as the road to its destination of self and society. Its aims are social analysis not discourse analysis (Stern, 1994). Knowledge claims within GT are intelligible and debatable outside of the context and community within which the observed activity has taken place or been

'textualised'. They are also *modifiable*. Thus GT supports a limited relativism, where truth claims are the "best informed and most sophisticated construction on which there is consensus at a given time" (Denzin, 1989, p.243). It necessarily embraces some relativism, as this is the key to *theoretical sensitivity*; however it rejects a full relativism in that it is possible to disentangle the knower from their knowing and truth claims can be parsimonious.

Despite the conceptual language of grounded theory having been appropriated for the constructivist paradigm: "the activity of inquiry can be evaluated for ... 'fit' with the data ...; the extent to which they 'work', that is, provide a credible level of understanding; and the extent to which they have 'relevance' and are 'modifiable'" (Guba & Lincoln, 1989, p.179); it has different methodological imperatives as I have explained. In seeking a middle-ground theoretical approach, both its methodology and logic of justification require the inquirer to take into account the relativity of their own theoretical formulation and the subjective utility of Participant experience, and then to use it to develop a modifiable parsimonious account of human conduct that is not constrained by instrumentalism, relativism or the experimental method (Rennie, 2000).

My Grounded Theory Position

In summary, the form of GT I have employed adheres to the Glaser approach. Where I differ from Glaser however, is that I do not consider it is a waste of time to understand where the idea's in grounded theory come from and how they are employed to make GT work. I agree in part with Rennie's attempt to locate GT within a history of idea's and to clarify the basis used to make truth claims in GT. GT derives its methodology from a "family of traits of symbiotized realism and relativism, a nonfoundational theory of truth, hermeneutics, bracketing and Peirce's logic of inference" (Rennie, in Glaser 1998, p.38). Where I disagree with Rennie, is his attempt to reformulate GT in a manner that pulls it back into a series of working parts (e.g phenomenology, hermeneutics, Peircian logic) instead of a working whole. Therefore I agree with Glaser in praxis of GT and what GT can achieve.

The knowledge an inquirer produces is the result of an interactive and emergent process, as much as between the inquirer and Participant as between the inquirer's conceptual elaborations. The "researcher does not approach reality as a *tabula rasa*. He [she] must have a perspective [to perceive] relevant data and abstract significant categories from his [her] scrutiny of the data" (Glaser & Strauss, 1967, p.3). Therefore the theory-laden quality of observation (Chalmers, 1982), where the inquirer brings their own theoretical lens and conceptual framework, is present and necessary for the inquirer's task. As an inquirer I cannot drop them, for without them phenomena would just be chaotic, fragmented and meaningless. What I argue is that the theory-laden quality of observation does not necessarily lead to relativism, idealism and constructivism. The requirement of pragmatism that a GT must emerge from the utility it employs pulls the theory-laden character of observation away from the incommensurability of relativism. It takes GT to a commensurability based on the shared salience of social processes that are individually performed to resolve the Participants' generic concerns and thus reconciles relativism with realism (Glaser, 1998).

Moreover GT does more than explain; as a theory, GT can predict human conduct. Grounded theory is coherent and persuasive in its own right and does not necessarily require testing to achieve further truth claims for a wider audience. As Glaser (1978) suggests, a robust GT works, fits and is relevant for its audience because it indicates a basic social process that people employ to achieve their activities and modify in the light of new experience. The "rhetorical wrestle makes too much talk about the grounded theory and too much wrestling with its prospects for a field. The "book" is already written. Just use it" (Glaser, 1998, p.41).

Suitability of Grounded Theory

My starting position concerning psychiatric stigma is: People who experience psychiatric illness appear to have a changed life trajectory across many factors. I did not want to assume that this occurred because of stigma, as found in other international studies, if indeed stigma was a highly significant, salient and corrosive feature of Participants' lives. Nevertheless, if people do not talk about stigma - what are they talking about? When does it occur? With whom? Under

what conditions/contingencies? How central is it to their experience? How do people resolve this? And what effects ensue? It may well be that Participants do talk about a thing like stigma. Alternatively, the New Zealand experience may produce something idiosyncratic to its cultural diversity. But I would not find this out if I maintained a pre-conceived notion about stigma and its role and effects. Thus grounded theory was chosen for the reasons mentioned above and because it is a method of discovery that develops robust theory with a high utility and relevance to any Participant's experience.

In particular, the use of qualitative analysis has been critical to developing an internationally accepted model of epileptic stigma (Scambler & Hopkins, 1980). Furthermore GT has been used successfully in theorising how people make sense of illness or impairment internationally (e.g. Charmaz, 1990, 1994, 1995a) and within New Zealand (Cody & Woolley, 1997). Grounded theory "works with any data because all is data for generating theory" (Glaser 1998, p.41). The sensitising concepts I draw from my training in psychology, plus the background conceptualisations from psychology and sociology and the practice of everyday life, suggests grounded theory is suitable for conducting psychological research (Charmaz 2000a; Edwards 1998; Henwood & Pidgeon 1992).

CHAPTER 3 - METHOD SECTION

Participants

Selection

The researcher approached three organisations that have provided support and advocacy services to past and current users of the mental health system, within a provincial city in New Zealand. I was particularly interested in Participants with diverse experiences around employment. For instance, full-time, part-time, casual, unemployed, employer, employee or self-employed. One organisation was a consumer run support and advocacy service. The other two provided generic support services. I used my informal contact with staff and clients of these organisations whom I had met at conferences and public meetings as a precursor to a more formal approach. After making an appointment to speak with a contact person, a copy of the research proposal, ethical review, information sheet, consent form and question sheet were sent to each service before I arrived to begin discussions. Contact people were generally the most senior person in the service (e.g. manager, co-ordinator). In these discussions I acquainted myself with each service's history and culture; explored how to meet the needs of the service during the life of the project; and reviewed and amended the research procedures and materials to best suit the service environment I was in (see Appendix A for typical notes from a pre-recruitment meeting).

Recruitment

Most Participants were members of mental health support or advocacy services. Those who were not had heard of the project by word-of-mouth. Key contacts within each service facilitated an opportunity for the project to be presented to their membership. All Participants were informed about the project by a contact person within their service organisation via a telephone call or mailout or at a service meeting. Participants expressing an interest in this project then received an information pack, and were given the opportunity to have their questions answered either by their service organisation or the researcher. No service organisation refused to participate and all permitted the researcher an opportunity to present the project to their membership.

After introducing myself and presenting the project to service members at a general service meeting, I then arranged to speak with smaller groups of less than six people who were interested. My intention was to facilitate greater ease of communication as some members were inhibited when asked to respond in a large group situation. After a discussion about the project some members would arrange an interview time and others would just leave. No inducements were used to encourage participation, although the promised provision of an interview transcript as a record of their experiences acted as an encouragement for some Participants. Other Participants either phoned me directly to arrange an interview time or they consented to their service supplying their phone number to me and I contacted them. Participants used self-selection to determine their participation in an interview by completing the consent form and returning it to the researcher. Alternatively they gave their initial consent over the phone and completed the consent form prior to commencing the first interview.

Participants were invited to attend with a support person, if desired. Before any interview commenced, I asked all Participants if they had read and understood the information sheet and consent form. I then explained their personal rights within the research protocols and gave them the opportunity to have their questions answered to their satisfaction. After signing the consent form recruitment was completed. Every person who wanted to participate was interviewed and where possible received a follow-up contact or interview either over the phone or in person.

Characteristics

There were 20 men and 11 women, whose ages ranged from their twenties to their sixties (see Table 3.1). No Pacific Island men were spoken with.

Table 3.1
Participant Ethnicity and Age by Gender

Gender	Ethnicity			Age range in years			
	Pakeha*	Maori*	P.I.*	20-29	30-39	40-49	50-59
Male	10	10	-	4	7	6	3
Female	8	1	2	2	3	4	2

*Pakeha – descendants and new arrivals predominantly of British and European origin from the second wave of colonisation begun in the eighteenth century;

*Maori – descendants from first colonisation pre-eighteenth century;

*P.I. – descendants and new arrivals from neighbouring Pacific Islands

All Participants had experienced psychiatric illness and were past or current users of the mental health system. The shortest period of illness was 5 years and the longest was 35 years. All Participants had received at least two DSM-IV diagnoses with one receiving six. Everyone had experienced psychiatric acute/non-acute inpatient care, community treatment, mental health accommodation, employment, unemployment and being a sickness beneficiary.

The Interview

Materials

All interview materials were submitted to and approved by the Psychology Department Ethics Committee and the Waikato Ethics Committee.

Information Sheet

A general information sheet (see Appendix B) was developed to cover the broad aspects of the project, such as aims, objectives, procedures and ethical concerns. In consultation with a local consumer advocacy and support service, a specific information sheet was developed for and appraised by consumers. Their concerns I addressed were the use of larger print, spacious layout, everyday language and brevity.

Consent Form

A standard form (see Appendix C) developed by the University of Waikato's Department of Psychology was used.

Preliminary Questions

Initial questions (see Appendix D) ranged across the following topic areas

1. The beginning of problems/difficulties
2. Illness, wellness and recovery
3. The effects of (1) and (2) on employment and unemployment
4. Experiences and perceptions of people and organisations involved with Participant access to, and retention of, open employment.

Further questions and subject areas were added to focus on experiences around employment and stigma. Any new subject areas and questions were indicative of themes and issues that arose during the Participant's narrative. Open questions

were used to promote a free flow of communication and open up areas of dialogue that were relevant to the project. Later interviews were primarily used to explore certain key themes in depth. Consumers at a local consumer advocacy and support service evaluated the initial question sheet, prior to its use.

Interview Setting

Participants were asked where they would prefer to be interviewed. The most frequent choice was the Participant's own home and we usually sat around the kitchen table. Preferred interview times were weekdays between 10-12am and 2-5pm, although interviews took place outside these times for people who were employed or in training/education. Other venues were the Participant's service organisation's premises. On these occasions a room with chairs, table, window and a closing door were used. For those Participants who did not want to be interviewed at home or at their service's premises, I arranged an interview room on campus with a window, table, chairs and a closing door. Some Participants wanted to be interviewed out of doors and this took place within the beautiful campus gardens. With permission a flat boundary microphone was unobtrusively placed on the table and the audio-cassette recorder was left visible so Participants, if they wanted to, could clearly see when recording was happening by observing the tape turning.

When visiting people's homes I supplied some morning or afternoon tea, and while on campus Participants had access to drinks and coffee. I picked up and drove home those Participants who wanted to be interviewed on campus. For the other venues Participants were either picked up by their services van or they used public transport.

Procedure

I met all Participants for an informal chat before asking whether they were ready to begin the interview. I asked where they would like me to sit, if they were comfortable and began the conversation by outlining the project, explaining the research protocols, answering questions and asking them to sign the consent form. During this chat I set up the recording equipment and explained it was at their discretion if they wanted the tape turned off and restarted at any time. I asked "Shall we begin now?" The interview began with an introduction like, "Where

would you like to begin?”, “Where should we start?”. Further prompts were “When did you first experience a mental health problem?” I then encouraged the Participant to tell the story of their experiences of mental illness and employment. Prompts were used to establish dates and times, to move the story ahead chronologically in a narrative, and to both recall what had happened and their reflections on that.

After approximately an hour (unless requested otherwise) I would suggest we take a short break and reflect on the interview so far. After consulting the question sheet I would ask questions on subject areas or themes that had not been fully covered and request further details on their previous comments. The interview was generally concluded with prompts like “Have you told your story to your satisfaction”? ... “Is there anything further you would like to add”? At other times if the Participant appeared very tired and was becoming less responsive or interview time reached 1.5 hours, I would offer to terminate our discussion by saying, for instance “Shall we finish here and we can meet another time to finish off”? The Participant was thanked and asked for their comments on the interview process and the participation of the researcher. If necessary, procedures for contact persons to provide support or further information were canvassed.

Interview Follow-up

A follow-up contact either by phone or in person was made to ask the Participant how they were subsequent to the interview and whether they had any further comments they would like to make. The interview was transcribed and returned to the Participant for their comments. Despite my intention to retain people for follow-up interviews it did not happen for everyone. After 6 months many Participants had changed support services or accommodation services, had left the district or were no longer contactable. Thus less than 50% received repeat interviews. The interview period was from August 1998 to June 2000. Repeat interviews occurred at the convenience of the Participants (see Table 3.2).

Table 3.2
Participants Retained at Interview and Follow-up

	No. of interviews			
	1	2	3	4
No. of Participants	31	15	11	8

The follow-up discussions brought the researcher up to date with some of the issues Participants were currently facing and how their circumstances might have changed since our previous interview. The follow-up contacts were also used to monitor, evaluate, expand and crosscheck Participant perspectives within and between the emerging categories of analysis.

Maintaining Safety of Participants

It was important that those who participated in this project did not suffer any adverse direct or indirect effects from their participation. I was mindful of areas of risk for Participants during and after the interviews. These were:

- On occasions some Participants when disclosing or discussing parts of their personal experiences felt negative emotions, usually briefly (e.g. recalling their experience of discrimination, failure, lowered self-esteem, hurt, loss).
- Interviewing Participants when they were mentally unwell could negatively affect their health.

To assist with addressing these areas of risk and maintaining the wellness of the Participants, I used the following strategies developed with the assistance of the local consumer support and advocacy services:

- (1) A Consumer Advisory Group (CAG) was organised by the local support and advocacy service. They provided support to Participants and gave an ongoing safety review of the researcher's practices and procedures, during meetings with the researcher. Members of the CAG had the skills to assist Participants in whatever manner they required. The CAG included both non-Maori and Maori Participants. The CAG helped provide a safe environment both during contact and between contacts with the researcher and Participants. Members of the CAG also acted as a resource to support consumers after the research period.
- (2) I asked all source contacts within each service organisation to provide open and honest comments about the research process and feedback, the interview and its effects on Participants, and the impact of the researcher within their settings.

When negative emotions became apparent, Participants were asked if they wanted to take a break, cease the interview completely or to continue when they felt ready. Without exception, all Participants wanted to complete the discussion when their inner turbulence had subsided. I asked all Participants at the end of the interview about their thoughts and feelings on what had taken place. This gave me a chance to debrief the Participant and provided me with useful information about how better to proceed next time.

Follow-up contact enabled the Participant to report any adverse feelings or experiences that may have been associated with the interview. As a precaution I interviewed only when the Participant felt they were confident and able to do so. I ceased interviewing when the Participant was unwell or becoming unwell or recovering from an acute admission/crisis, during the interview period¹¹. When this happened, as a precaution, I would either wait until the person contacted me or phone after a period of 6 months. Sometimes I would come across Participants during my visits to their service organisations. Without exception all Participants who resumed contact wanted to finish their original discussions.

Data Management

Transcription

All audio-tape recordings were transcribed mainly by the researcher into Microsoft Word 97 for review and editing. Written notes from meetings and follow-up contacts were annotated to the Participant's file. The transcripts were then converted to a text file suitable for data entry.

Data Entry

The transcripts were entered as a Participant document file into the qualitative analysis programme NUD*ST (Richards & Richards, 1994). Memoranda, meetings, reports and follow-up interviews were linked to each Participant file.

¹¹ There was one exception to this - a Participant particularly wanted to meet towards the end of his stay in an inpatient unit, which I did.

Data Storage

All electronic project files required password access. Electronic files were stored on hard-drive, diskette and hard-copy. The Participants' names and telephone numbers, interview tapes, completed questionnaires and all material relating to interviews, were stored under lock and key, with the researcher having sole keyed access. All material will be held until three years after publication of the research and then the tapes will be erased and transcripts with any identifying material destroyed.

Data Administration

The qualitative software programme NUD*IST was chosen for preliminary analysis (for a comparison of NUD*IST with other software see Barry, 1998). This software has compatibility with qualitative theorising (e.g. Henwood & Pidgeon, 1992) and a grounded theory approach (e.g. Lonkila, 1995), and has been used before in psychological research (e.g. Cody & Woolley, 1997). Data were coded on a line-by-line basis. The NUD*IST storage and retrieval system enabled specific Participant text to be linked to that code. Memos were developed and stored with codes. Further codes were then grouped according to their conceptual function under further codes, and so on, until a coding diagram took shape. Leaving NUD*IST, higher order codes that captured most of their subordinate data were then recorded on labels and manipulated visually on whiteboards. This enabled me to grasp all codes and more importantly their relationships to each other, at one viewing moment (see Appendix E for an example of within category mapping of properties and processes). This visual representation then fed back into further memoing and theoretical elaboration, until the core category emerged.

Software

Using computers to compile and analyse qualitative research data has gained increasing acceptance over the last twenty years. However there has been much debate about the implications these new tools have for the manner in which qualitative analysis is pursued (Buston, 1997; Coffey, Holbrook & Atkinson, 1996; Kelle 1995; Lee & Fielding, 1996; Richards & Richards, 1991). An important aspect of this debate centres on both the method and methodological

approaches that qualitative researchers employ. The concern is that use of computer assisted qualitative analysis software entails implicit biases that explicitly alter data analysis (Seidel, 1991). The coding, storage and retrieval functions assume that all data is hierarchical and linear (Kelle, 1997). Consequently when entering data, it necessarily has to perform in this manner in order to be retrieved and portrayed. The seduction I found was that the method of storing, coding and retrieving large amounts of narrative text is easily facilitated by NUD*IST. Thus assuming that because the method was compatible then the methodology would be compatible at all levels of analysis. It was not (for a brief review of similar concerns see Opie, 2001). The constant comparative method used in Grounded Theory appears to be easily replicated when using NUD*IST. For instance, open coding of large amounts of Participant narrative into codes, subsequent coding of codes into conceptual categories, with clear links of concepts to their indicators. NU*IST was excellent for doing this. It was when I applied the methodology of Grounded theory in refining my categories to arrive at the core category that an implicit bias in using NU*IST was made visible (for a review of employing Grounded Theory when using NUD*IST see Kelle, 1997, pp.6-13). I found that my data were not behaving in a linear manner and attempts to force them to do so were unproductive. I then moved to using large white boards with categories on small cards and flow lines between. Laying out all my categories, so that in one visual moment I could see everything rather than the multiple viewing moments of screen-by-screen presentation within NUD*IST, enabled me to discern the core category. I could perceive the ebb and flow within categories and between different categories more effectively. Essentially I used NUD*IST as a text storage, coding and retrieval system only, doing my conceptual mapping independent of NUD*IST, and this worked extremely well.

Analysis Method and Coding Strategy

This section explains the methods I used for coding and how I developed the theoretical structure which best fitted them. In presenting the starting point for my analysis, emergent categories and the basic social process used to resolve psychiatric stigma, I describe my coding methods and decisions. This is not a presentation of findings, but an elaboration of how I arrived at the theoretical

structure which was then used in my findings to theorise Participant experience. Hence this material fits within this chapter on method.

Unlike quantitative reports where analysis happens separate to data collection, in Grounded Theory data collection happens with analysis and is dependent on analysis occurring at the same time. Thus instead of there being a clear separation of ‘what I did’ (method) and ‘what I found out’ (findings), the two are interdependent. Presenting one without the other impoverishes any elaboration. Thus I present some of ‘what I found out’, but only to the extent that it enables a reviewer to discern ‘what I did’. The following is assembled from memoranda that guided coding and the development of my theoretical structure. Specific quotes from Participants are in quotation marks and codes are in italics for chapters 4-8.

Initial Coding Strategy

During open coding there emerged many ‘in-vivo’ codes of people’s experience in becoming unwell or in crisis and their recovery. These experiences interwove with the difficulties people faced generally, and specifically when in employment. People rarely talked of the difficulties (i.e. events or processes) they faced without discussing aspects of their mental health. Given this close association I began examining these events and processes through Participants’ experiences and repeated interviews focusing on the emerging codes.

My initial reasoning was that if, as some literature (e.g. Link et al., 1997) suggests, people experience stigma and its most negative effects after they leave a psychiatric or support service and try to pick up the reins of everyday life, then it may be useful to examine both their process of becoming a psychiatric patient and their experiences exiting those services and becoming an independent person again. It seemed possible that in addition to the actual illness experience itself (e.g. stigma as an artefact of psychiatric illness), something could have occurred during a person’s journey through psychiatric services that had rendered them vulnerable to psychiatric stigma whereas before they were not. In particular, I asked what, if anything, people had learnt during their course of mental health

service (MHS) involvement that had transferred in a maladaptive way to their everyday life.

Despite my stated aims of wanting to examine the role and effects of psychiatric stigma for people with a psychiatric disorder in employment, I did not want to assume that psychiatric stigma was something every person experienced, either in a substantive or trivial way. Psychiatric stigma, whatever its form, had to earn its way into my analysis. If it was a significant and corrosive aspect of psychiatric disorder then people would talk about it or something similar to it, and it would be a key part of the personal and social difficulties they faced. More importantly, how people attempted to resolve these difficulties (given the constraint of recalling memories accurately) would give direct access to shared experiences of stigma - especially when compared with prior psychiatric disorder experiences. So as a beginning to my interviews I asked people to tell of their journey from a time before psychiatric disorder had occurred to times of crisis and acute admission.

Coding Psychiatric Illness Trajectory – Person to Patient

People entering a psychiatric service often do so at times of extreme experiential distress. They are there (voluntarily or involuntarily) because who they were and what they have done is no longer acceptable, either to themselves or to others or both. The distress and dysfunction felt, implacably faced people with the prospect that they were not adequately managing their lives, and that this was sufficiently acute that others had to assume their management because they were not capable of it themselves. Neither were the systems of therapy capable of producing a lasting cure, though they often produced lasting treatment. This *uncertainty* about their psychiatric illness/disorder's origin, course, treatments, effects and recovery magnifies its generic input into all features of personal life. The marking or labelling of the person according to their condition further enhanced the subsuming of the person into their illness/disorder by becoming a 'patient'. The reference point for the person to the service was their illness/disorder - they would not be in a psychiatric service without it. Similarly the illness/disorder became a reference point by the person to, and about, himself or herself.

The transition required to become a psychiatric patient involved a change in being who they once were. It is a role unlike other roles of sickness or injury, where the person moves into a sick role for a period of treatment/recovery and then regains access to their previous life and identity. Becoming a psychiatric patient involved moving into a role and identity where transition back to everyday life was marred by *uncertainty* of treatment, functioning, acceptance and recovery. For many there could be no return to who and how they were before, as to do so would be to reproduce the same being that brought them to the attention of a psychiatric service in the first place - with all the consequences that that might involve. Psychiatric illness therefore involved a departure from one's 'before' illness identity in some way. This shift was not just on the surface of identity, but in depth. Who they were, how they knew their world and how their world knew them through interactions with others, had shifted. As such, psychiatric illness/disorder involved a crisis of identity. Who they are and who they will be was by no means certain. The very modalities of sense, memory and cognition no longer produced certainty of inference as to what was happening with them and around them. Implicitly, psychiatric treatment involved a change in being who they were, ably assisted by place, drug and talk therapies. People were initiated into this identity and role through admission procedures.

Coding Psychiatric Illness Trajectory – Struggles of Identity

The first line of approach to my data began by examining change around identity from experiencing psychiatric illness. While on paper people became psychiatric patients overnight, in terms of themselves people were often in a conflicting struggle with coming to terms with who they now are, how they got there and what needs to be done to get out. The persons they had to become to be admitted to, live in and leave a MHS service had involved change to their identity. This identity was now prone to psychiatric stigma.

People talked about:

- their approaching illness in terms of a self - "I" ;
- what happened when identity slipped between a 'well' self and an 'ill' self, and they used an action metaphor to describe this movement into crisis of - "slip", "fall", "slide", "dance", "swing", "jump";

- a loss of self: “lost it”, “lost the plot” “lost touch”
- a “nowhere” and no-when: “out of it”, “being no-one”, “lost”, “gone”
- an extreme *uncertainty* around future activities and possibilities,
- mainly ‘getting by’, ‘coping’ with or ‘existing’ by living “one day at a time”.

They spoke of an ‘I’ that was located by absence, not presence. Hence their sense of absence about self and the capabilities of this self were:

- “not”: “able”, “fit”, “functioning”, “competent”, “capable”, “worthy”, “respected”, “valued”, “adequate”, “well”, “wanted”;
- marked by things they had had “before” illness/disorder onset into crisis;
- expressed as “lost” or “lack” - “self-confidence”, “self-esteem”, “hope”, “future”, “opportunities”, “security”.

People also expressed a sense of crisis or recovery characterised by “nots” and loss:

- they knew when they were becoming unwell by what they did not have or what they had departed from,
- in the same manner recovery involved being “not unwell”, “not in crisis”, “not sick”, “not crazy”, “not mad¹²”, “not stressed”.

Thus people spoke of a self that was usually moving between possibilities of crisis and recovery. People usually knew when they were going off the recovery road by what was lost or not present compared with ‘before’. When people were heading towards recovery this was also shaped in a similar language of ‘nots’ and ‘loss’.

I then tried to find out more about when this was happening and what was achieved by talking in this way about self. The best explanation was: If ‘madness’ has no limit (how ‘mad’ can you be?) and well/recovery has no limit (how well can you be?) then this could explain why people spoke of departing and arriving from a middle ground in between wellness and illness. This arrival and departure usually mirrored the uncertainties of crisis and recovery. From there Participants

¹² ‘Mad’ and ‘madness’ were terms used by Participants to describe psychiatric disorder and the state of experiencing psychiatric disorder. ‘Madness’ is what the public fear about psychiatric disorder. While I am aware that such an approach could be stigmatizing, that is the term Participants used, so I will also use it where appropriate.

talked of an identity that hovered between wellness and illness: a liminal ontology where one's self/being constantly moved around the threshold of either becoming well or entering crisis and requiring emergency intervention. This often located a person as "not well but not mad"; not well enough to be fully accepted/included in everyday social life and not 'mad' enough to be totally removed/secluded.

When people were discussing how they arrived at unfavourable perceptions of themselves, either assisted by others or by their own solo efforts, they reported a form of identity change. Their overall feelings of self-worth and ability to function in social interactions (which usually can provide opportunities to build a sense of self) had very mixed outcomes. Moreover the strategies used to learn, build and manage identity also had very mixed degrees of effectiveness. It seemed that at any time some event could step through their guard and deal terrible blows to feelings of self worth and identity consistency.

Coding Psychiatric Illness Trajectory – Resolving Identity

The above briefly discusses the process of developing a 'liminal identity'¹³, but I was also interested in what was provoked or achieved for the person by these changes. Consequently I began to look closer at discussion linked to incidents around identity change. Examples of identity change were examined concerning:

- conditions and contingencies of occurrence,
- contexts,
- causes,
- consequences.

I found this *in-between identity* seemed to be contingent on an *uncertainty* that was magnified in contexts that were evaluative and had important outcomes. Most people harbour some cultural expectations about 'madness' and 'mad' people that are particularly negative, whether they act on them or not. However people with a psychiatric disorder not only harbour these same negative expectations as everyone else but also experience the personal and social rejection which they produce. This can create an invidious position. By having the same latent

¹³ Liminality is the property of being near-to or on the threshold of becoming fully realised; a point past which sensation is almost to faint to experience. A liminal identity is one that exists on the margins, below threshold, blurred and not quite fully realised or completely experienced.

prejudices regarding 'mad' people and 'madness' and then having actual experiences that confirm these expectations about themselves, their self image was undermined both from within and without. Stigma became acute when *uncertainty* corroborated negative social expectations of 'madness' and 'mad' people, and what they would or could do. The consequences were that *uncertainty* appeared to undermine personal competence and disrupt social ease. This evoked an unpleasant experience that was often accompanied by undesirable outcomes.

Antecedent to realising these expectations was the activation of personal triggers in social situations or during internal processing of events. Such events were marked by an *uncertainty* which disrupted social ease, internal processing of events and perceptual personal competence. Triggering of *uncertainty* took place whether the person was alone or in social situations. These event triggers appeared to:

- take a person to a threshold that, once reached, initiated habitual responses to reduce internal arousal (e.g. anxiety) or social discomfort (e.g. embarrassment). They "evade", "go", "leave", "withdraw", "shrink", "escape", "get out", "out of here", "are gone";
- cause intense feelings of 'not fitting' or 'not belonging' that endured beyond the event;
- be coupled with a lack or loss of perceived personal competence;
- make the experience and memory of events like these to be sufficiently unpleasant or disruptive to cause personal strategies to evolve to avoid or cope with similar incidents;
- result in people developing ways of acting to improve self-esteem and feelings of confidence and social competence should similar incidents happen again (e.g. such as delaying a response until they are able to retort, or building up a list of possible replies to be used in similar situations).
- intensify *uncertainty* when it did occur again;

In all interviews the loss of self-confidence and/or self-esteem was reported. Turning these words around gives them greater meaning. Thus people 'lose confidence in one's self' and 'lose esteem of one's self'.

From this I began looking closely at the use of 'I' statements by Participants and in particular what preceded them and what followed them. I paid particular attention to incidents that were in highly evaluative contexts for Participants and whose outcomes were unavoidably salient. As there was a high frequency of 'I' statements, it seemed reasonable that the main problem people were striving to resolve concerned identity in some way. Hence *resolving identity* seemed initially to be appropriate.

For instance, the drive to be somebody and the need to accept a diagnosis (the mark or label of psychiatric illness) creates a push-pull situation. The push by the MHS to resume an independent life (service exit) and at the same time the pull by the MHS to accept treatment (service entrance) institutes a revolving door of identity, between person and patient. The struggle to be a someone they would want to be (either beyond or inclusive of illness identities), entails more than just reacting to circumstance. There is an active attempt to make sense or sort out the 'I'; an action of *resolving identity*, because it is never completely resolved as psychiatric illness is 'unfinished business'; a 'life sentence'. It therefore continues to 'haunt' people long after their periods or experiences of crisis. From these properties emerged a key category called *haunting*. If a person's sense of being is 'no where', then absence of being can create extreme dissonance, which must be resolved - by *resolving identity*.

Primary Codes: Resolving Identity, Haunting, Monitoring and Disclosure

With the *haunting* and *resolving identity* categories went two others that appeared to co-vary in some way. These were *monitoring* and *disclosure*. Basically people watch (monitor) and talk to others (disclose) about themselves, and others watch and talk about them. Yet the motivation for this is far from casual. Often there is a strong evaluative context for both parties and linked to this is a potential for negative events and perceptions to ensue. From a greater understanding of how/who/what/when/why people were trying to resolve socially challenging events, emerged two categories – *monitoring* and *disclosure*.

Every Participant engaged in some aspect of *monitoring* and *disclosing*. These are activities in which everyone engages, but they take on a distinctive role for people

with a psychiatric disorder. Not only are they essential for the performance of social roles and interactions, but they are linked to perceiving and maintaining mental health. For example, inability to *monitor* the self is inability to know when one's self is becoming unwell. Inappropriate or ineffective *disclosure* can invite social rejection and is seen as indicative of poor mental health, not just a lapse in social competence.

Monitoring and *disclosing/not disclosing* arose frequently and were prime activities whose ineffectiveness was linked to experiences of social discomfort/disturbing arousal. The environment and context changed in social scenes, but the core features of how people responded/reacted were consistent across these scenes. However when I tried to develop the relationship between the properties of these key categories - *monitoring* and *disclosing* - I found it difficult to maintain a central link to *resolving identity*.

Emergence of Core Category – Uncertainty

As mentioned before, the element of *uncertainty* appeared to be a fundamental contingency during experiences of social discomfort/disturbing arousal. Logically if doing something around *uncertainty* leads to *resolving identity* then this something must necessarily be prior.

Resolving identity and *uncertainty* can take place in any social situation. For example, in a work situation, especially a new one, these things are amplified. There is an expectation of continual improvement ('proving yourself alright') to achieve job competency, workplace enculturation and peer acceptance. This requires interactions with others and competency in managing how they are perceived by others. Thus *monitoring* of self and others is integral to this process for anyone, but for people with a psychiatric disorder there is often another overlay of difficulties.

Not only is there *uncertainty* with achieving job competency, but there is often *uncertainty* around how internal and external events are perceived, understood and remembered. The very modalities of sense, memory and cognition no longer produce certain inference as to what is happening with them and around them.

Thus, ‘is that person really talking about me’ or ‘am I just imagining it’? In thinking that person is talking about me, ‘am I experiencing one of the signs/markers I use that suggest I am becoming unwell’ (with all the implications of what that may mean based on past unpleasant experiences)? Hence any *monitoring* is often fraught with the uncertainty/contradiction of:

- appropriate vs inappropriate actions
- real vs imagined perceptions
- well vs unwell experiences

If there exists *uncertainty* with not only how a person is measuring up in a job or other social situations (e.g. risk of failure/competence) and this is then amplified by *uncertainty* in perceiving and thinking (about themselves, others and events), it is likely that *uncertainty* plays a key role (See Table 4 for the core’s substantive properties).

Table 4:
Substantive Properties of the Core Category

Condition:	used a psychiatric service and participating in everyday life
Context:	personally significant, highly evaluative and with salient outcomes
Contingent on:	the possibilities for self being mediated by psychiatric illness
Causes:	everyday life is marked with, and marked out by, psychiatric illness
Consequences:	reduced doing, being, knowing and subjective meaning: negative = biased attribution and thinking styles; stereotype threat/confirmation, increased monitoring, hypervigilance, passing, guarding, reduced experience of novel situations, loss of hope and a restricted life. positive = realistic appraisal of perceptual, thinking, emotional and memory processes; narrows the range of situations which are uncomfortable; strengthens relationship to other consumers.

Thus if *uncertainty* was a precipitator of most adverse personal and social outcomes for people in employment (and not just efforts at resolving identity), and this was constant across different social scenes, then the *resolving of uncertainty* should figure substantially in personal accounts. I began to use *uncertainty* as the central phenomenon that people face. *Resolving of uncertainty* was part of a Basic Social Process (BSP) in which Participants engaged when faced with *uncertainty*. However efforts to resolve uncertainty could create further uncertainty (see Figure 1).

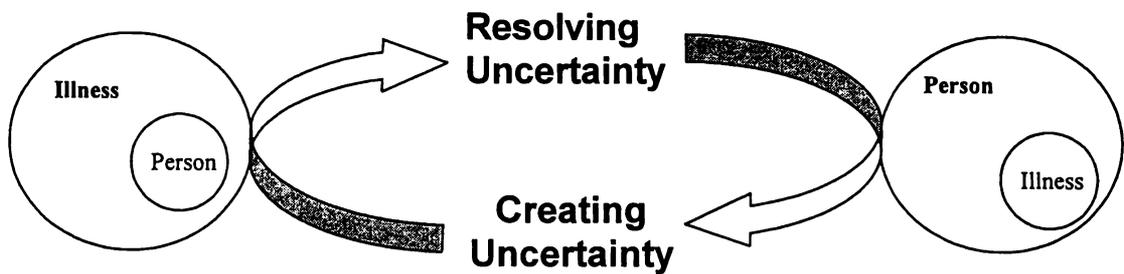


Figure 1. Basic Social Process

Participants were continually *resolving uncertainty* because *uncertainty* was never fully resolved by them or their associates. *Uncertainty* was precarious. It implied a substitution of identity; an identity marked out and marked by psychiatric illness. Psychiatric illness had a tenure and residue that created *uncertainty*. It was a perpetual task that they faced, which over time they increasingly managed better, but never resolved. Intuitively it would seem to make good sense, as creation of *uncertainty* of self is precisely the condition that gives rise to reduced self-confidence/esteem, as there is no longer a certain self to build anything on or around. Thus the second part to the BSP of *creating uncertainty* emerged. Using the *uncertainty* as the core category and *resolving-creating uncertainty* as the BSP, existing categories were re-ordered (see Figure 2., p248)

The emergent stages of uncertainty were *constructing identity, haunting, vigil and disclosure*. These stages arose from developing a *monitoring self* and the presence of *monitoring others*. The process used to manage *uncertainty* for both self and others was *resolving/creating*.

The next chapters present the core category – *uncertainty* – and the social psychological process – *resolving/creating uncertainty* - in greater depth. This is achieved by a close examination of the emergent stages to the process *resolving/creating uncertainty*. Chapter 4 shows how *constructing identity* occurred once psychiatric disorder was diagnosed. In Chapter 5, the *haunting* prospect of psychiatric disorder is used to demonstrate how *uncertainty* intrudes into internal processes and future life events. Chapter 6 examines the *vigil* that Participants used to sort and make sense of everyday experience when *haunted* by the uncertainty of psychiatric disorder. In Chapter 7, when and how Participants

disclosed or concealed their psychiatric disorder showed the origin and effectiveness of the strategies they employed. These stages of *resolving/creating uncertainty* are then applied to the workplace in Chapter 8. They account for Participant experiences in employment and demonstrate the conceptual capture of these experiences by the core category *uncertainty*. The discussion in Chapter 9 brings together the earlier chapters and presents a theory that improves existing knowledge about psychiatric stigma.

CHAPTER 4 - CONSTRUCTING IDENTITY

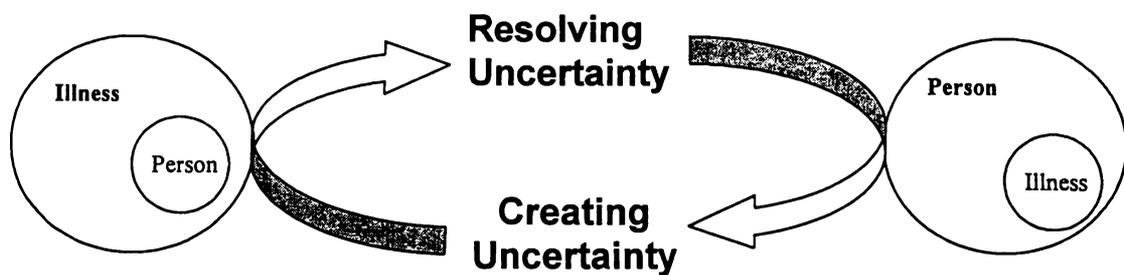


Figure 1. Basic Social Process

Constructing identity occurred when a psychiatric diagnosis became wedded to the disturbing and disruptive phenomena in Participants' lives. Like any wedding, it required some agreement from both parties involved as to its consummation and sometimes this did not happen easily. Participants were informed of their diagnosis but might not accept or believe it. Sometimes it could take years before a suitable diagnosis was able to capture the Participant's illness and everyday experience. Until this happened suspected diagnoses and uncertain treatments hovered around the Participant which reinforced previous suspicions that there was something 'wrong'. But it was the shift from something 'wrong' to something 'mad' that was a dramatic step. Even suspicions of 'madness' could mark a Participant as 'mad' just as easily as when they had received a stable diagnosis. Both suspicions and diagnosis promoted *uncertainty*.

When Participants were admitted into emergency care and experienced the loss of independent action, a disruption to relationships and inability to maintain a healthy self, their dire situation could not be ignored. They were in a serious situation because prior events had affected their mental health and now mental health was going to affect future possibilities. The realisation that there was not a productive future without psychiatric health considerations integrated a psychiatric diagnosis into their episteme of perception. Non-epistemic perception about psychiatric illness was precluded. As perception incorporated psychiatric illness so too were ontological considerations now pervious to psychiatrically ill being. Participant knowing and being-in-the-world was irrevocably reframed by

the prospect of psychiatric illness and *uncertainty*. External views about their psychiatric disorder now had internal correlates that were enmeshed in *uncertainty*. This demanded *constructing identity*.

The following shows how this had taken place for Participants. In Section A the general process of *constructing identity* is examined. In Section B, a consequence of *constructing identity*, labelled *passing*, demonstrates a key strategy that most Participants explicitly used.

Section A – Process of Constructing Identity

Naming the ‘Problem’/Marking the Person

Over the course of their lives Participants had had experiences that were disturbing, distressful and disruptive to themselves and others. Participants perceived events such as trauma (e.g. sexual abuse, grief), social dislocation (e.g. not fitting in, not coping), physiological insults (e.g. abuse of licit or illicit substances, head injury) or extreme stress, as driving occasions of experiential distress. They became aware that something was ‘wrong’:

Laura: I’d always thought something was wrong but I didn’t think that was ... a mental disorder. Once I did a bit of reading and went, oh my God, yeah, this is a mental illness ... that’s most bizarre.

The effects of these disturbing and disruptive experiences were that they significantly reduced individual functioning and dislocated the Participant in some way in everyday life. These experiences and effects while unique at the time started to coalesce and in retrospect were seen to be precursors to later psychiatric disorder. Usually the ‘shape’ of their psychiatric disorder took time to fit to a diagnosis and make sense of personal experience:

King: I first heard the concept of bi-polar mood disorder and a name to something [that] really brought a bit of stability too and because you could just see the nature of ... of manic depression and the shape of it.

However there was considerable *uncertainty* about when and how diagnosis occurred. This could happen upon contact with their GP, at first crisis admission or not until many years (and diagnoses) later. Some did not know what their diagnosis was and therefore the rationale for the treatment they were receiving.

With *uncertainty* over causes and definition (diagnosis) this magnified *uncertainty* over the course of the disorder and what could be done about it:

King: The diagnosis itself probably came a year and half later. I think the impact for everyone, including myself was pretty disastrous because we basically did not know what had happened and the effects of that. Like how long would it last. It was very much a step by step thing and quite a bit of trial and error.

Constructing identity paralleled the crucial step in "naming" or "making sense" of the conglomerate of difficulties Participants had faced. When Participants received crisis intervention or attention, the problem that could have been written off before as just a personal characteristic or product of family or working life, became elevated into something that drew serious attention. Participants did not want the deleterious effects of their situation to continue or to recycle in and out with changes in their psychiatric health. The seriousness of their situation extended through key relationships and responsibilities and compelled them to take action. Joan had felt "an underlying churning going on there the whole time" and:

...knew that there was going to have to be some decision made that we couldn't be doing this to this kid [daughter] while her mother went in and out, in and out, in and out [of 'madness' and hospital].

Realising that the internal battle Joan had been fighting was costing her dearly and its outcome was mental illness, Joan had to bluntly concede the effectiveness of her actions to date:

...and at that stage I think I had started to come to the dawning realisation that yes there is a mental illness working here, one that you are not in control of, that has a life of its own and you're going to have to learn new ways and new strategies to live a healthy happy life.

The way back to a 'healthy happy life' was through recognition that mental illness was afoot and this marked a new beginning in learning the 'ways' and 'strategies' for productive living. It required *constructing identity*. 'Mental illness' caused her exit from a happy life and 'mental illness' was the path back to one. Thus the path and boundary for a 'happy life' was marked out by mental illness; a mental illness that Joan had no 'control' over and which could roam at will in her life. The mark of 'madness' could imply *uncertainty* in any future sense of agency. Therefore taking on this mark could be met with both relief (e.g. named the 'problem') and reluctance (e.g. *uncertainty* with illness course). Either way the mark of 'madness'

occupied a central place in the Participant's knowing and being in the world. I will look more closely at how this happened.

Taking on the Mark of 'Madness'

Just being in a psychiatric service required Participants to accept that a significant change had occurred in their health and social roles. Only 'mad' people got taken to 'mad' places with other 'mad' people. Just being in a psychiatric service unavoidably confronted a person with the outcome of their behaviour and its perception by others.

Genevieve: They took me over in an ambulance - committed me and I got strip searched and put into a little room with a mattress on the floor and a pillow with no pillow slip, no sheets just a couple of blankets and I was like that for a couple of days then they transferred me to a ward. There were just so sick people there and I just oh - it was a nightmare.

Personal efforts in *resolving uncertainty* about events and personal health states increased Participant desire for understanding. When psychiatric service staff said that a Participant 'fulfilled the criteria' for a diagnosis it was not usually considered as an opinion, but a fact. There were powerful pressures exerted on Participants to take on the mark of 'madness', not the least being the Participant's own desire to resolve *uncertainty* about themselves:

Cathy: ...sometimes when you been given a label of psychiatric illness, it's become something that probably you may not move away from ... for me I was given a label of being bi-polar which I suppose it was a relief in a wee way to know ... there was a label they could put on me... I then decided that it was something I had to learn to live with and educate myself about.

As Cathy mentioned the label was 'psychiatric illness' and the label was part of her person. The label also had a stickiness to it so that when a person was diagnosed they 'may not move away from' it. But the label was more than a tag which followed people around. It was a label that marked people, and marked them out in distinct ways:

Genevieve: Because I had been in a psychiatric hospital, I was marked, I was like a marked person. People just run a mile when they hear you have been in a psych (sic) hospital.

In taking on the mark of 'madness' Genevieve perceived she became a target for the prejudice and rejection of others. The social disapprobation she felt not only marked her out as someone different but avoidance by others could quickly slip into perceived rejection by other people. The valence of negative emotion

associated with such a transaction meant that others wanted to avoid future interactions, thus avoiding the negative emotions associated with such encounters. At the same time the negative emotions and sense of rejection could travel inward. It was an easy step to believe there was something shameful about the mark and the perceived rejection confirmed this proposition as realistic and probable. As Participants expected others to set them apart, they began to set themselves apart. In setting themselves apart they moved into a role and expectations which were supported by daily interactions congruent with their diagnosis:

Sal: You spend your time talking about your medication and I cannot do this cause of this and I am getting all these side effects. But you spend more time dwelling on your side effects. There is times that you know what is expected of somebody with a particular illness you've got. You don't feel you can be any different from what is actually expected of you. You take on that as yourself.

Taking on the mark/diagnosis of 'madness' in Sal's view meant 'you know what's expected'. Participants learnt the characteristics of their 'madness' and consequently "what is expected of somebody with a particular illness you've got" (Sal). There was a process afoot that involved becoming and being the person whose self was shaped through expectations around madness, 'mad' people and 'mad' places. The result was an ontological commitment to psychiatric illness where "you take on that [mark] as yourself" (Sal). Taking on the mark of 'madness' precluded other identities "you don't feel you can be any different from what is actually expected of you"(Sal). The *haunting* prospect that personal and social lives were going to be marked with and marked out by 'madness' generated *uncertainty* about accepting a diagnosis. At the same time *resolving uncertainty* by acquiring a diagnosis also created *uncertainty* about future activities, because now there was a mark or label that could have a life of its own as it travelled formally and informally through social networks and public records. The fear and *uncertainty* which accompanied being marked as 'mad' could make it difficult to accept a diagnosis. People did not accept their mark/diagnosis for many reasons: disbelief, rejection, denial, confusion, stigma, poor information, not human anymore and its permanent.

Unfortunately accepting the diagnosis and the treatment needed, meant embracing what it was to be mad, to be seen to be 'mad' and the journey required to convince others that they were well enough to leave. Often this meant accepting they were

now, officially, a 'mad' or 'crazy' person. They could be 'treated' as 'mad' because they inhabited a 'mad place' and therefore incurred regimes for 'mad people' – "if you weren't 'crazy' enough when you went in there like you definitely go 'crazy' with this [treatment]" (Sal). Sal perceived the change in role, expectations and everyday experience within a psychiatric ward was enough to send a person 'crazy'. With 'madness' in their head, 'madness' around them in others and staff treating them as 'mad', there was little doubt as to the change in personal status. A status which embraced all the scorn, prejudice, fear, rejection and shame that people had learnt regarding 'madness' and 'mad' people, now applied to them in some form.

Robert: When I first went into a hospital I was full of stigma against mental hospitals, mental health, the whole area of being crazy. I mean the thoughts going through my head were "I am in a crazy house, I must be crazy.

The marking of 'madness' occurred upon entry to and discharge from a psychiatric service. This marked a point of arrival – where to from here? - and departure; there was no going back to a 'before' mental illness state. In order to get discharged, people usually had to accept that they were 'mad' in some way. Their behaviour had put them there in the first place and it would be their efforts that would get them out. Therein lay the tension. Attributions of responsibility for their 'madness' fell on the individual because only the individual was treated. The mark of 'madness' disentangled aspects of their 'madness' and rendered it visible at an individual level. Aspects of their 'madness' might resolve but people were more than the aspects of their 'madness'. Resolving one did not necessarily resolve the other, although patients learned from staff that this might happen. The loss of status (e.g. not 'normal') and the gaining of another status (e.g. mad/patient) subsumed other status considerations (e.g. person).

Yet not everyone perceived they had lost something or that going to a psychiatric hospital was necessarily an aversive experience. Going to a psychiatric hospital for some Participants was a step up in resources and quality of life. They found friends there - both staff and patients.

Toa: Oh it was it was strange coming out of [hospital] and coming back home. It was not so much people, like when you're in [hospital] you got a lot of friends. I was mostly missing my friends than being at home and my freedom. I wanted to go back to [hospital].

In hospital people knew how get the extra things they needed. There were activities to participate in that did not cost money. They got somewhere to sleep and meals provided. Moreover, if they stayed out of 'trouble' staff usually left them alone. The conditions they faced on coming out of hospital were more difficult, threatening and uncertain than those they faced 'inside' and for this small group of Participants had very little to lose by being marked as 'mad'. There was very little psychiatric stigma as they were vulnerable to other competing stigmas – low education, no resources, unemployed, transient living and being Maori.

During Participant stay in acute care, there was *uncertainty* about what had happened, was happening now and was likely to happen in the future. This could be further exacerbated by disbelief or rejection that the diagnosis they had received was believable, acceptable or appropriate. In declining or disbelieving their diagnosis, people sought other ways of understanding what was taking place by drawing on their own cultural views. Whether their understanding developed from a diverse clinical metaphor or was derived from personal/cultural metaphors, people tried to achieve a sense of 'fit' between the metaphor used and their experiencing.

Evan: I was told that I was a paranoid schizophrenic. I don't know where they got the paranoid from. Schizophrenic I can understand in my own terms in like there were like two parts of me before that instant - there were two parts of me before my son was born and one had disappeared and in a sense it knocked the feet out or the carpet out from under the other part of me which was to be have a career and the loss of one caused the irrelevance of the other. I could see there had kind of been a duality to my mind but whether that amounted to schizophrenia I really wouldn't have known.

Subjective understanding of their illness experience reframed activities, which led to crisis and acute-admission. It shifted the explanation away from psychiatric disorder and its mark of 'madness' as the only explanation and the only way to respond to its threat and *haunting*. Once some degree of outer fit between experience and diagnosis was achieved there could develop a sense of *inner fit*:

Sal: It helps explain things as to why I'm feeling the way I do at times. It helps me understand things a lot better so I do agree with that. Some of it seems very general and you don't know how far to believe it. [When] I have not been coping so well or something like that, I guess it seems more acceptable.

This was when the metaphor used to describe, explain and predict their disorder received an internal recognition; it was believed. Inner acceptance rarely happened quickly for Participants and usually developed after two or more acute admissions. It usually required a distinct effort to make sense of what had happened and what was likely to happen in the future.

Making Sense

Making sense was when Participants tried to understand everyday life and illness experiences. It involved sorting the difficulties people faced in a way that developed their own understanding of what had happened and what was happening via their own words and processes. People who tried *making sense* of their experiences and sought employment appeared to go through a process of *retracing, experiential learning, re-evaluation/resolution* and *rethinking capability*. At the same time this experiential process interwove with developing *resilience*, engaging in *recovery* and having a *companion* that stayed with them. From there *turning points* occurred both in *making sense* of not only their illness but how to recover from it and live their life with agency, an agency that could express itself in employment outcomes or be co-constituted by it.

Psychiatric disorder, from a Participant's view was rarely the generic disorder the DSMIV described. Attempts to collapse a wide variety of experiences into recognisable categories for labelling and reporting could create a disjunction between Participant experience and clinician perception. The requirement to engage with clinical language and its 'objective terms' as metaphors for diverse experiences was difficult to do for some Participants and impossible for others. It could encourage disbelief, as what and how things were talked about seemed removed from their own idiosyncratic view. Those Participants that were able to make sense of their experiences usually found someone to assist them in sorting the difficulties they faced. This was done in a way that developed their own understanding of what was happening and what had happened via their own words and processes.

Making sense of their experiences was not an easy task. Irrespective of ethnicity, education and class, people found this was a particularly challenging thing to do.

The difficulty was twofold. First the bio-medical model of psychiatric disorder promoted symptoms as indices of dysfunction. Thus treating symptoms only, could reduce them to a threshold for discharge. Secondly, this left untouched the causes of symptoms that could re-await people on discharge - causes whose origins were not discrete amidst the *uncertainty* of everyday life and which were often part of it.

Treating the symptoms was very useful when people were in an acute phase and required stabilisation to restore functioning. However this treatment took place in a controlled environment unlike what was to be experienced on discharge. Required post discharge was an indication of how to resume their life again. Participants recalled information about maintaining their medications and *monitoring* of symptoms, but recalled very little about how to achieve a valued life trajectory. Yet *constructing identity* demanded consideration of larger life concerns which either included or eclipsed the presence of psychiatric illness. Overt focus on symptoms seemed to encourage a lack of interest and of cogent advice about achieving a desirable life trajectory. This lack of support about future self possibilities induced an *uncertainty* about the future and the self that could occupy it. Without much of a self to occupy a future there was not much of a future to occupy a self. Hence there could be a profound loss of hope and *uncertainty* over future selves beyond an illness identity. This was one of the iatrogenic effects of bio-medical practice. Thus taking on the mark of 'madness' was also to take on the prospects of a reduced life trajectory; a life that was shrunk solely to considerations of illness during clinical care but on discharge had rapidly to expand to embrace many other things. This included a set of experiences that wove together illness symptoms and the demands of familial, social and working life in a way that Participants had very little preparation to manage.

Clinical care was there during an emergency response but could be difficult to get pre-crisis or during stress spikes to prevent crisis intervention. Moreover when Participants were acutely unwell, someone was there to rescue them. This could set up a pattern of response that pre-crisis events would lead to crisis, 'madness' and removal to safety (acute-care). In this scenario the Participant had no control over outcomes from precipitating events. Getting 'sick' again was a very real

prospect. Participation in everyday life receded as their *caution* and *vulnerable* self-states inhibited non-illness-focused pursuits. The mark of ‘madness’ was then associated with the prospect that ‘madness’ would reoccur in a florid stereotypical fashion. Expectations of their diagnoses became congruent with how they managed their madness. The Participant managed their illness by only managing crisis because in crisis there was someone there to rescue them.

Sal: But it is actually something just being outside the system to which just feels nice and stuff but once you have been in the system for quite a few years you sort of seem just to go around in circles. Its like a vicious cycle and when ever anything gets to you someone always pulls you out in a way sort of rescues you, one of the nurses or seems to be a system where you are rescued a lot from your own stuff at times.

Participants could lurch from one crisis to the next, because they had not learnt how to manage their ‘madness’ in everyday life. But this could change when Participants realised that there had to be a way for them to live their lives, as well as to live with their illness. This was when consumer support, advocacy and training services were very effective in providing skilled insider perspectives on how to live with their illness and make sense of their lives. The following sections – *retracing, experiential learning, re-evaluation/resolution, rethinking-capablity, resilience, recovery and companion* - explain a process of how Participants were *making sense* of their lives while pursuing employment and resolving *uncertainty*.

Retracing

For most people it was not until they were discharged from psychiatric care or in supported accommodation that they then attempted to get into life in an everyday manner. They did this by trying to undertake activities that brought them into contact with non-consumers. The interest base for these activities might be new or promoted as therapeutic. Usually these activities included some aspect of what the person used to do before or was capable of doing before. When these activities moved from ‘meaningful activities’ to employment people often experienced the harsh reality of their new position and the loss of prior capabilities it now entailed. *Retracing* occurred when people tried to do what they did before they became unwell. This usually resulted in finding out that they could not work at the same level or capacity or activity as they used to: “you cannot go back to what you were before” (King). *Retracing* brought to attention more than just the loss of skill. It invoked a loss of being, a loss of the self that used to be immersed in performance

of that skill or activity. Experiencing such a loss of self amplified *uncertainty* about an economic future and how they were going to be able to participate in one.

Reg: the same sort of pattern I had to kind of come to terms with being hospitalised and going through the second occasion quite traumatised by the fact that I never felt as though I was going to allow myself to get into that position again, but I had.

Having tried to be and do as he used to 'before', Reg found himself in the position of being hospitalized, 'again'. It was a traumatic experience finding out that he was not as capable as he used to be and that he had 'allowed' himself to be hospitalized. *Constructing identity* was taking place without his permission. In essence, living his life as he used to meant he could not keep himself out of hospital. Something had to change. From the recurrence of those extremely unpleasant circumstances could develop *experiential learning*.

Experiential Learning

People seemed to experience change when they actually went through the loss of their former work trajectories and experienced an inability to take on something new and to sustain it as worthwhile.

Robert: I believed that I was crazy that my brain was damaged and that I had tried to commit suicide and I just again felt like I was having been through psych (sic) hospitals, especially for the second time. I felt like I was at the bottom of the heap and I needed help to sort myself out.

Usually it was only when they hit 'bottom' that Participants acknowledged they "needed help to sort myself out" (Robert). They had to experience being utterly dissatisfied with where they had ended up, again, and having to deal with the effects that acute-care and post-crisis activities can cause to families, relationships, employment and resources. These experiences developed both the need and the resolve to change the future from the past experiences:

Hauraki: But I had to start all over again. If you make a mistake you have to restart recap it again eh. And it is a horrible thought of doing that [laughter] And in the end you say to yourself, 'you have got to do it anyway' because if you don't know one else will yeah.

Overcoming the 'horrible thought' of having to start again can lead to resolution/re-evaluation of their ability to proceed.

Resolution/Re-evaluation

After *retracing* and the grief that went with this loss of what they were before, a new resolve could occur, that this was not the end of their working life and they began to look to new horizons. This 'looking' frequently entailed an evaluation of some sort and a conscious attempt at *constructing identity*: who they were, what they would like to become, what they would like to work at and where, and what steps were required to begin that journey. It could mean being able to prove that they were capable and had aspirations beyond just putting food on the table. The beginnings to this could be quite humble:

John: ...talking to an old friend of mine and I mentioned to him that I'd been cleaning for a year and he just said "What a waste of your intelligence" and I thought that these people can see these things and I don't really take in much notice of things like that. But he saw that and I thought I tended to agree with him it would be a waste of my intelligence but it serves its purpose. It's been paying the bills it's given me a work ethic it's got me out into the community doing things instead of cloistered around the place like this [psych accommodation] all day.

and start with 'low expectations',

Digger: It was pretty hard actually, I started off picking asparagus, chuck 'em (sic) in a bag, things like that, it doesn't put much stress on you. I think boredom, free from stress for start was a good thing and then I got this job in factory it wasn't much stress in there... It did not require you to think about anything, but it kept you occupied, you are busy for eight hours a day, then you caught the bus and went home. You sort of battle with things in your head. I think it was all predictable. I think that's important for a start. I think getting back in the work force you gotta (sic) start off with pretty low expectations of what you can handle.

Within three years Digger held a national appointment within government and a very public role within a primary industry. There was a sustained rethinking of his capability that was followed by persistent actions to explore his work capacity.

Rethinking-Capability

The combination of *retracing*, *experiential learning* and *resolution/re-evaluation* can lead to *rethinking-capability* within everyday life and employment. *Rethinking-capability* occurred when Participants past experience provided steps into a future of their own desire. They were able to do this because they fused believing they were capable with actions that showed they were capable. This then could deliver outcomes that took them to such goals as employment.

The steps into employment could be fraught with *uncertainty*, as it required stepping into distinct socio-cultural roles. The rituals for inclusion and exclusion into employment were not only about skill suitability but also people suitability. Hence the basis and bias of employee evaluation reflected social values and beliefs about employment and employees. Discrimination was more likely to be encountered when individuals were asked to discriminate between people, such as during job interviews or evaluations. Participants in rethinking their capabilities had to rethink how they were going to move through and resolve the uncertainties they faced, in particular *uncertainty* with their thinking. Resolving *uncertainty* about their thinking did not proceed by reducing symptoms but by situating their experience amongst other employee experiences. It was when Participants were in the social milieu of the workplace that appropriateness was learned and lived on a day-to-day basis. In a workplace other people would look at and talk about them. It did not necessarily mean that the Participant was getting suspicious (e.g. paranoid/unwell) or that everybody was against them (e.g. conspiracy). Participants seemed better placed to rethink their capabilities when they had the everyday contact of a workplace. Pseudo work environments could model it, but the dynamic lacked authenticity and the Participants knew this. There were none of the ‘real world’ gains that took place within open employment. The conditions for *rethinking-capability* were optimized when a Participant was in open employment.

Achilles: ...if you invite some people along who are in a stage of thinking about working and they mix with these people they are empowered enormously ... the ‘felt stigma’ starts to fall away when they see people "succeeding" in everyday life, they get a flat, someone got a flat, shit he was in a boarding house before and now he has got a flat now, he has got a girlfriend too, oh shit, he’s got a car, why [not me].

There was realistic appraisal of the workplace and the *uncertainty* present when working. On one hand it could be an unhealthy place, on the other it could be a path to a productive self:

Claude: Employment means health right. I’ve worked in [employment X] and in the [employment Y]. X dragged me down. It wasn’t a place where I could feel healthy whereas Y is a place that furthers me in my own mind, my own personal growth.

Not all employment had to be paid to reap its rewards. The non-material rewards of work could propel Participants to seek voluntary work when their paid employment was unsuitable:

Mary: Work is everything to me work if I am working then I feel successful as a human being but I have now learned after having my illness for 13 years that work is not necessarily important. Paid employment is not necessarily important. You can still be happy doing voluntary work. You can still be feeling healthy and happy.

The everyday experience of the workplace delivered realizations about seeking work. Not getting job interviews, or getting interviews but not proceeding to employment, was not just the prerogative of people with a psychiatric disorder. Many other people did not get jobs or performed poorly in interviews without experiences of mental illness: "...you find that other people have problems with some of the things too. You might find it a bit more extreme, but they just have different ways of coping with them" (Sal).

Rethinking-capability grounded the Participants' attributions about their causes of employment and unemployment. Participating in everyday life led to enmeshment within values and norms about what was 'normal' employment. For instance, often there was an implicit double standard. There was no general socio-cultural expectation for people in mainstream employment to have one job for life; in fact the way the labour market is operating suggests employment mobility is here to stay. Yet Participants were often expected to stay at one job and if they did not then the reason why could be pathologised (e.g. unwell). Moreover the time it could take for a Participant to get a job represented a sizeable investment in both job preparation, seeking and support. With this investment an outcome of short term employment could be seen as a failure. Although it might not be. It could be seen as a success. People leave a job for a whole host of reasons, yet it was not the leaving which was important but the job seeking and obtaining. The skill of seeking and obtaining employment could encourage a person to persist through various job interviews and experiences of employment to obtain the job(s) they desired.

Claude: ...often it was just a little bit of work that kept me going. And that's what I've been doing ever since. I've been working casually. Now instead of dragging me down its built me up. I've learnt things that I can better cope with in

my life and that's where I'm at the moment. Just going on and learning things, rather than being brought down by things that I cannot cope with.

The *rethinking-capability* of employment could have a consequent effect on other areas of a person's life.

John: I feel good about myself and feel more confident in myself and what I say and what I do whereas in the past I was hesitant to let that out. I just felt too shy, too whakama to express myself and with this job of having to articulate how I feel on a regular basis and being truthful and honest, it just means things right across the board are opening up and I am being truthful and honest about our home-life and our daughter and their son. It has a real positive effect on our home life. And not be afraid of someone who has a different opinion, learn not to take it personally and realise that not all people think the same or have experienced the same thing.

Rethinking capability laid a foundation to build *resilience*.

Resilience

Resilience occurred when Participants developed the ability to bounce back from the difficulties they faced. *Resilience* was a key part in *rethinking-capability* as it developed hope for the future and their capacity to have a productive future. Instead of 'falling over' and staying fallen, they were able to resume an everyday life without the weight of past events pulling them back into illness patterns. Past events were cause for reflection and steps to learn from. Understanding their past developed capacity to reconcile the tension and *uncertainty* of living an everyday life that could cause ill health as easily as health. And when ill health occurred their *resilience* developed a confidence in their recovery.

Claude: the little that you get from day to day in the way that you make your way through life, survival, survival techniques and working even though if somebody that you knew was feeling ill would they go to work? Exactly. Now I regularly did that. I had to go to work just the same.

Their resilience enabled them to keep going even when they were 'feeling ill'. As Claude mentioned, it was in day-to-day living that people learned how to survive while working and feeling ill. But resilience was more than just surviving. It entailed a confidence with life's endeavors that enabled them to travel through their experiences and reach their objectives.

King: ...the effects of becoming unwell and having experience within the mental health system and the associated services, I believe have made us better people. Although it is something that I would not wish on your worst enemy, nevertheless it had been a road that I have walked through, and come out the other end.

Even when crisis could take a person right to the very 'edge' of their sanity and they were so close to completely 'losing it' resilience sustained the struggle to keep going and belief in alternate outcomes to crisis:

Cathy: I have had lots of sessions where I have been trugged to the edge of the cliff and sort of had quite a determination that I am not going over the edge I am going to struggle yeah.... But I think getting back into employment was just such a huge boost to my morale.

But it is not an easy task: "Well you just got to force ya (sic) self to do it and it's quite hard, aye. It's like somebody pulling sandpaper through your head sometimes. But you just got to do it really' (Digger). Developing *resilience* encouraged the belief that people could keep going in a productive way. Keeping going usually entailed some notion of *recovery*.

Recovery

With *resilience* and *rethinking capability* people adapted to the *haunting* by learning *recovery*. It was through *recovery* and its competencies that Participants resolved some of the uncertainties that the *haunting* created. Recovering a life that they would desire to live was more important than just reduction of symptoms. In *recovery* resolving symptoms took place amongst resolving other aspects of everyday life. The focus was on the person as a whole rather than on a individual feature, such as their illness. *Recovery* decentred psychiatric illness as a core feature of the person and reinserted everyday life as the main feature that people wanted to recover. It could entail recovering a life that was imbued with hope, opportunity and fulfillment as well as the everyday difficulties that most folks encountered. *Recovery* was an approach to everyday living that was either discerned over time or acquired through consumer learning programmes. Recovery had diverse meanings for people. However a central feature was the recovery of an everyday life that they would enjoy to live and not just better management or reduction in illness symptoms, although this could and did occur. Participants who used a recovery approach reported having fewer crisis admissions over time, an increasing time interval between crisis admissions, shorter length of stay in crisis and sub-acute care, and faster resumption of everyday life activities. Participants who experienced *turning points* in their lives had acquired recovery competencies, and had learnt to do this in unique ways. All

Participants who were in employment engaged in *recovery* and usually had a *companion* who assisted them on their journey.

Companion

In addition to *resilience* and *recovery* those who reached *turning points* had a companion who stayed with them. This person was more likely to be a friend, support worker or consumer representative. The *companion* provided an objective point of view about the course of events in their lives. They were someone the Participant could talk with in an unbiased fashion. A *companion* was a person who listened to what they had to say and believed in them and what they were capable of, even if the Participant themselves had doubts. In particular this person was able to assist them by focusing on both micro issues (e.g. how to get through the day) and macro issues (e.g. where to go from here). Having that one person who believed in them when events were difficult to manage and *uncertainty* was shrinking possibilities, gave them the comfort to go forward.

Digger: Like I've only been up here a few years I have not really got any close friends up here you know. I did talk to a mate of mine D that I used to work with. Good mate of mine. I talked to him about it over the phone and he said "look there's no way I'd know if its in ya head or not" you know. Which was a help to me to think well you know I've explained it all to him why I think it and he still thinks it could be in my head so you know. But he's the only guy really I talked to about it.

Having one solid relationship in a field of uncertain ones encouraged a confidence that they could competently 'reality check' when *uncertainty* occurred with perception.

Joan: I knew that I was going to be going from hospital to be living at my parent's place cause I had a thing I just couldn't be alone. If I was alone then it all became too much. You need other people there just to be sort of reality anchors, yeah.

Hamish: How does that work?

Joan: Oh what do you think about so and so if you are sort of churning about the fact that you've seen two cats in a tree that morning you know. To be able to say to somebody oh yeah you have seen two cats in a tree and that's quite ok that's quite normal. [laughing] You do need that.

Bizarre things could occur which were not related to illness altered perception. Having the confidence to share their perceptions of the world with other people assisted in resolving Participant *uncertainty*.

Turning Points

Turning points were points of arrival or departure that affected the Participant's life course in a significant manner. They occurred during or shortly after a conjuncture of events. What enabled these events to contribute to personal understandings was their translation into persistent efforts towards practical outcomes.

Hauraki: If you stick your mind to it y'know you think your number one priority is to get out, then that is going to be your way out and be your number one goal. So I thought I'll do something to get out of here. So I have improved and I just automatically went from bad to good. From worse to good and all that. It's just blown me away how ... that stepping stone was just the right stone. Y'know you throw a stone and just want to see how far it reaches, and you got to think to yourself well how am I going to get to that stone y'know. So you got to get a ladder and throw that ladder down and make your way down there. And that is how I worked it out eh. Yeah. I did not care how long it took but it I still got there.

They were moments that made individual life journeys easier in some way.

Digger: ...at first I took it pretty negatively I suppose I'm a schizophrenic so I'll never be normal. But then as I sort of steadily got better over the first few years I got books out of the library on schizophrenia. I thought well if I can understand this thing I can probably beat it [I] read a lot about it I think I took a lot of comfort in the fact they say it's a chemical imbalance in the brain. ... that takes away ... guilty feelings and there's something wrong with me.

Both the inference and outcomes from these events re-orientated the Participant's life course.

Neil: Rock bottom. I didn't want to get out of bed ... I had no ambitions to do anything at all. I just couldn't have cared less I said "up the world" and ... then after that I made up my mind ... I started thinking well perhaps I could do something outside so I started gardening ...I think when I finally did start talking about it then I started to come to terms with it. I started to pick up in fact I've picked up too much I've put on nearly 4 stone [laughing] ... even my doctor he said, "that's amazing it's just a turn around"... I think that the biggest thing was getting back into work. It may only 3 or 4 hours a week, it just got me out of the house. I felt for a long while I didn't have control but now I do its starting to come back and I'm starting to have control. You know and I'm starting to make decisions that's right for me you know.

The *retracing* of former work trajectories and *experiential learning* developed what *turning points* occurred.

Evan: So I came out and said to myself, 'bugger it', I have busted my ass for twenty something years for other people. I will go on the benefit I will take advantage of everything that's going for nothing. I did that and after a few years I sort of thought why don't I pick up and carry on with what I intended to do when I left home before other people started getting in my life. Came back to university ... did a couple of Tops Courses to prepare for it, test myself out. ... and in the process [I was] learning to start to enjoy myself. It was a big change, an extremely good one.

Re-evaluation/resolution and *re-thinking/capability* fashioned how *turning points* took place.

Joan: ...went back in came out went back in three times. I finally accepted yes ok there is something not quite right here and then just decided that I had to learn to live with this and I had to live as well as I could and have been reconstructing ever since.

Resilience, recovery and a *companion* enabled Participants to be a person who could carry out the 'what' and 'how' of *turning points*. A consequence of *turning points* were that they lifted the capacity for *making sense* of past and future experiences, and raised expectations.

Cathy: ...it was back to proving to everybody that I could do it, because when I started to become quite well I keep on thinking well this is no good just sitting at home here, being on a benefit. Which was OK it put food on my table, it served its purpose, but I wanted to be somebody, just like everybody else.

Making sense of experience involved *making sense of uncertainty*. Thus *turning points* could assist in *resolving uncertainty* with *haunting* and improve the effectiveness of *vigil* and *disclosure*.

When *turning points* occurred Participant life trajectory altered. The change was usually at both:

- a conceptual level - such as making sense of difficult experiences (e.g. King), and
- a functional level - where increased personal efficacy could accelerate an employment trajectory (e.g. Digger).

Thus *turning points* could also alter Participant life, treatment and support, because with new understandings and orientation towards their problems old strategies were no longer relevant.

Laura: The nurses ... gave me ideas and said, "right, stop taking drugs and see how you go". So I stopped taking drugs. I stopped drinking and I don't quite know how I did that... I just felt desperate ... for as long as I could remember I'd been really unhappy and I would be really depressed and I just thought, oh fuck, I would try anything, you know. This isn't making me feel any better, so I've nothing to lose if I stop doing it, and I went back to work, although that took me three tries before I got back to work.

Turning points also generated a sense of hope, possibility and pleasure in life. Their resilience lent confidence to trying out new situations like employment.

Sal: You have to find your own limits as to what you can do, and sometimes it is experimenting to find your own limits.

Turning points reducing the movement from pre-crisis to crisis and the occurrence of psychiatric service intervention. They altered the 'get well game' as a game that was played for others, to a game that was played for themselves. In *making sense* of their experiences and learning the 'get well game' for themselves, Participants altered their illness cycles by a different perception of personal events.

King: ... then the penny finally dropped to a degree when I saw [they] were really late warning signs rather than early warning signs. So re-evaluating that [I] came to see that really the early warning signs were some of the thoughts and feelings that were going on ... before that stage. Things like, the feeling of helplessness, becoming tired, feeling inadequate, feeling run down and vulnerable. And then leading on to frustration and anger aggressiveness.

Rather than cycle through support to crisis to psychiatric service intervention and treatment people had different options. When events, perceptions and experiences became uncertain they were not amplified to become disturbing, distressful and disruptive in everyday living for themselves and others. With reduced escalation to crisis there was less likelihood of crisis intervention and better pre-crisis management.

Sal:... you learn to be helpless many times.[However] when I have not been coping lately the staff have been brilliant. They've rang up and encouraged me instead of trying to get me into hospital. ... I've just found that so helpful and they've been excellent in that way. They've found ways to help me with the practical side of things instead of seeing a psych nurse now I see an occupational therapist who actually works through areas where I need help to get things sorted through. And I've just found the difference in that way has been brilliant [compared with] trying to rush me into hospital and tell you [what] you cannot do which actually makes it many times worse because then all the things that you're trying to do you've got to leave ... and you don't get them back.

Participants experienced pre-crisis and crisis management that did not involve hospitalisation. This improved their confidence with vigilance and *resolving* the *uncertainty* created by the *haunting*. Reducing dramatic events involving psychiatric health, reduced iconic memories of when they were 'mad'. It demonstrated their knowledge and skill as a person who was managing everyday life instead of a patient who was managing their illness.

Naming the problem resolved *uncertainty* by making the unknown knowable. However the very process of making things known could be uncertain. What was known could serve to create further uncertainty. What created and resolved *uncertainty* was just as important as how this took place. Inner fit of experiences with outer knowing by other people could lead to making sense of things. The

frame of inner and outer experiences could alter views produced from reflective experience, and *turning points* could occur in consequence. As the view of life trajectory shifted so too did the frames of the reference. *Constructing identity* was ongoing as new views occurred and Participants sought to resolve *uncertainty*. Participants were resourceful in meeting the demands of everyday social interaction. One effective strategy was *passing*.

Section B - Passing

Passing enabled Participants to negotiate social spaces without an illness identity. They passed themselves off as a ‘normal’ person. *Passing* arose as means of resolving a conundrum people faced. They wanted to step out of consumer life, identified by illness, and into an everyday life that they perceived most people enjoyed. At the same time they had only been able to experience an everyday life through an illness identity. An effective way to participate in everyday life without having to battle the effects of being labelled as a “nutter, ‘crazy’ or psycho” was to leave the label behind. Participants departed from the people who knew them and the places where their illness identity located them. Stepping out of their former life with its social world, illness expectations and identity enabled Participants to create a new idealised/adaptive social self; a social self that was pulled forward with positive self-possibilities and not pulled back by negative associations to psychiatric disorder. *Passing* created a public face with which to negotiate social spaces. However it still hid an inner life that had to resolve the *uncertainty* of psychiatric disorder.

People had to start living this new social self in order to become it. They had to acquire experiences or repertoires consistent with a social self they aspired to and hence were plausible. But most of all they needed to have learned how:

Laura: ...I was stubborn and I was determined to get out of the mental health system because I absolutely hated it ... They’ve got a big thing on ‘functional’ [You] do a year without taking any time off work, go into your appointments looking well groomed, speak nicely, show no emotion, don’t get upset, don’t get angry ... I did a bit of research on what the normal person was and I faked it ... basically. What I was getting told was that I had all these different disorders and I was never going to go anywhere in life and wow they were surprised that I could even hold down a job ... if I was to go anywhere well, I’d be lucky if I could just work in a factory for the rest of my life ... it was all portrayed.

As soon as Participants started *passing* they built up a set of experiences common to other people, rules for social conduct and learned small talk. These then enabled them to pass through the questioning about social location and personal ability which habitually occurred. Such as the often asked question of, 'what do you do?':

Cathy: ...when I was at home ... I used to teach a little bit of music... and had a couple of pupils. When people used to say to me, 'what do you do', I used say I teach music part time.

Passing as an everyday person acquired the *pass* to enter various social and economic worlds which previously were inaccessible:

Laura: ...when I went through Tech (sic) and started getting these good marks it was totally different ... I went to where nobody knew me and I made no effort to make any friends and for the first time in my life ... I kept my tattoos covered all the time, changed my hair style and I started wearing completely different types of clothes... But I just kept completely to myself and people perceived me as this really brainy nerd. And I'd never had that before ... people thought I was very very innocent. That's when I started acting very different ... I didn't swear and when people talked about ... guys beating up girls or whatever, I sort of went 'Oh, oh!' you know, as if I had never seen or been in that situation ... I just pretended (...) just acted ... I made up this little character for myself and just stuck with it.

Passing could involve a social *mask* that was worn in public spaces. The mask presented a socially acceptable appearance, preserved the status quo and did nothing to attract attention except success. It hid a past and presented a future of the Participant's own desires unmitigated by stereotype influence. It gave opportunities to present a self in everyday life that could gain social reward. It kept other people close to the desired self and its abilities yet distant enough not to find out about a 'mad' self. In wearing the *mask*, the Participant avoided opportunities and occasions with other people from "before":

Sal: I don't actually talk to a lot people [consumers] now I stay pretty much out of the mental [health] system ... I'm not very involved in it any more than I have to be. I don't go places... I actually just try and get on with things. And I guess sometimes I try to avoid it and try to pretend its not really there.

It took time to cultivate the *mask* they wore and to learn how to manage it with different audiences. When this was effective then it gave a *pass out* from *consumer life* into *everyday life*. After a while *passing* no longer became *passing* but rather an identity to thrive in. At the very least this facilitated choice and provided first hand training in pro-social behaviours. There was a reverse side to this. *Passing* involved intense *monitoring* of self and others and impression

management. It was necessary to be *on guard* against disclosing or revealing clues to a former self. Should such *disclosure* happen it could initiate stereotyping and Participants current social role/status could be either downgraded or lost. More importantly it could eliminate the rewards the strategy provided. Covert strategies were required to elicit feedback regarding self-states. Extreme impression management demanded *vigilance* at all times and avoidance of former locales where Participants were known. Thus keeping the *mask* in place involved a performance anxiety. There was regular replay of events to ensure there was no *disclosure* where they could be 'outed' by an audience. Different audiences demanded different strategies of adaptation and participation. Despite these demands and risks, their efforts could bring considerable personal rewards and increased social achievement.

Passing also entailed *covering* - where cues to their illness identity were avoided by using tactical replies that shifted conversation in safe directions - and *avoidance* of people who used to know them or other consumers. The art of *passing* entailed knowing where they were likely to meet such people and avoid them. The need to know who was around them in social situations, introduced *uncertainty* about what people did or did not know about them. Any interaction had the potential for *disclosure* to occur. Intense stress could occur from holding back reactions:

Laura:... at the same time, I found it quite stressful as well because I had to be on my guard all the time not to let it slip. And it was very hard to be sitting around conversations of those psychos (sic) out at [hospital X] ... and not react. I was just poker-faced, the whole time. I just wouldn't react. Oh I would just say 'Oh, I've got to go and get a coffee' and walk off and I felt like just screaming at the people.

Every social moment they were on parade and having to perform, there could be anxiety about disclosure. Their current life, with all its investments and their resulting acceptance or achievement, might be jeopardised by *disclosure*. This could intensify afterwards when events were reviewed to ascertain whether they had successfully passed.

In masking their emotions, increasing arousal could exceed personal comfort levels, resulting in avoidance, retreat, escape and delaying tactics during social

interactions. Successful *passing* increased the frequency and depth of personal and social rewards, satisfaction and achievements. There were several such rewards. *Acceptance* as 'normal' enabled a profound change in acceptance from others. It could be the first time in ages they had felt acceptance and belonging as a person and not as a label or problem. It was human warmth and interaction based on shared mutual worth and not as a paid caregiver or support person. It was done on their own merits. In getting acceptance as a person there was *life without labels*. Others did not see a 'crazy' person (past or present) and so reacted in an everyday manner.

Laura: It's the first time in my whole life I hadn't been told that I was strange or, you know, and for the first time in about three years I wasn't getting called crazy and nutty and screwed up and everything. It was really good, I really enjoyed it.

While there could be *life without labels*, *vigilance* was still required. Participants could be so caught up in *passing* that they failed to see warning signs and became unwell. *Life without labels* assisted with building social experiences that anchored in the person they could be, based on a non-labelled self. *Passing* enabled people to see, hear and experience what others who did not have a psychiatric illness actually thought and said about those that do. It was a temporary leave of absence from an illness identity. This achieved a way of *looking from the outside in*. Generally when this happened it served to consolidate the desire to keep *passing* and never disclose unless it was absolutely necessary.

Laura: ... that's when you start really noticing the stigma thing... It's really, really obvious when you're around people and people directly call you all these names and things like that. But then when ... you create a new identity for yourself ...people say more when they don't realise you're one of those people... then you really hear about what people think of that type of people.

Sometimes when Participants passed within the workplace they did this with some people and not others. Rather than a blanket approach of *no disclosure*, there was '*as needed*' disclosure to some people. What this could mean for the Participant was increased *uncertainty*. They were not sure who they could pass with and who they could not:

John: ...with the cleaning job there were people that I wouldn't tell that I had a mental illness in the past. I was always worried whether or not they had been told behind my back and yes or what the story was and I was a bit edgy about that at times.

They were never really sure if *disclosure* had occurred because two plausible explanations existed. Others might be discerning something about them because they were disclosing something indicative of their psychiatric status. On the other hand somebody might have been told about their psychiatric status so it had not been revealed by *disclosure* but by prior knowledge. This dilemma created *uncertainty*, as much with what other people knew about the Participant, as with how other people knew it.

Disclosure did not always lead to being *outed* in a public way or having to be *out* in a public way about their psychiatric status. Sometimes when *disclosure* occurred Participants had ready fallback positions that enabled them to retrieve their *passing*. In acknowledging they had had a psychiatric status, it could be relegated to a very plausible event that had happened a long time ago. Events chosen for this were more likely to be familiar to their audience and the consequence in terms of their health were context dependent. That way the health consequences were seen as an injury or accident from which they had recovered, rather than as an underlying or pre-existing condition whose resolution was uncertain. These aspects are discussed in greater detail in Chapter 7 - Disclosure.

Outed

When *disclosure* occurred Participants could be *outed* about their psychiatric status. This usually involved a forced disclosure. When Participants were *outed* about their psychiatric status they no longer were able to *pass* in the same way that they had before with everyone. Some people would continue an interaction style similar to that which the Participant had experienced when they were successfully *passing*, but *passing* might no longer be possible with other people. The insider perspective that Participants obtained into how 'normal' people overtly thought they were and how they covertly acted with psychiatric service users was now about to be turned on to them. Other people might feel very uncomfortable when they had revealed their prejudices about a group only to have found a member of that group in their midst. Moreover when a surprise disclosure occurred other people could experience a social discomfort in having revealed an immodest perspective concerning members of that group. The Participant was not

immune to the level of discomfort they perceived in others and now experienced the same as an unease or *uncertainty* with some people.

Summary

Conceptions and expectations, about being and knowing, were critically changed during *constructing identity*. *Naming the problem* often equated to *marking the person*, so that psychiatric diagnosis shaped the Participant's being-in-the-world. How Participants viewed themselves and their world, became mediated by psychiatric health considerations. A similar change took place in relation to employment, family and friends. This marked a departure from what they could do before and increased *uncertainty* about what they could do in future life activities. Participants struggled in their *making sense* of everyday life as there were no shortcuts to both *experiential learning* and *recovery*. *Turning points* occurred that both developed a subjective understanding of their illness experience and reoriented them towards new possibilities, such as employment. One response to resolving *uncertainty* about a devalued social identity in employment, was the practice of *passing*. The next chapter on *haunting* illustrates the intra-psychic process of *uncertainty*.

CHAPTER 5 - THE HAUNTING

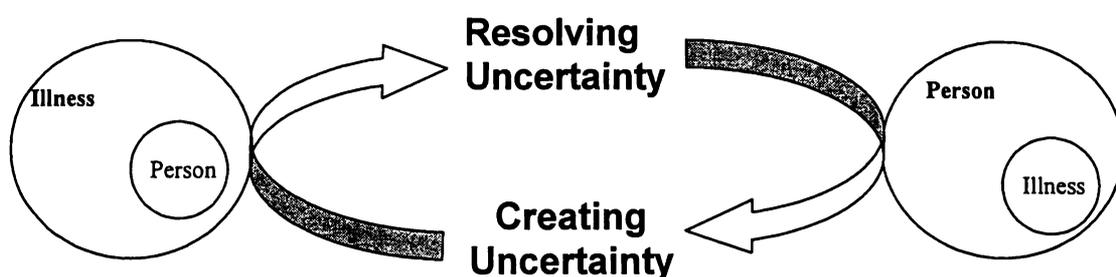


Figure 1. Basic Social Process

Participants described their psychiatric health (and particularly how it amplified or restrained aspects of living) as a presence that interwove with all their endeavours; a presence that was not only present but quickly became predominant. To the extent that this happened, a *haunting* of Participant's past, present and future lives took place with the prospect and consequence of crisis (based on past experiences or expectations) reoccurring. The *haunting* prospect of psychiatric disorder dramatically altered what was 'normal' for Participants. It was the *haunting* presence and prospect of psychiatric disorder, and intrusion of this into everyday life that manufactured and diversified *uncertainty* in a myriad of ways. This chapter describes the processes that give rise to *haunting*. Participants' accounts are used to track specific attributions, expectations and adaptations that occurred from *constructing identity*. The *uncertainty* that arose from *constructing identity* was extended by the *haunting* prospect of psychiatric disorder. Everyday life, interpersonal and intrapsychic processes, can become a site for *uncertainty* as consideration of *haunting* pervades life choices and activities.

For instance Participants were haunted by the:

- 'loss of security' they had in themselves;

Digger: ... found the most devastating thing was the ... loss of security. Like you have always felt that you might get physically sick or you might be short of money or something, but having your sanity taken away is quite devastating. And I have found a huge loss of self confidence ... that flowed over into everything.

- increased social 'distance' within friendships;

John: ...friends ... keep a distance from me they're not too sure of how to approach me cause they think is he sick is he still mental or is he mad, still you know they think I'm mad all the time.

- unknown dimensions to their recovery;

Reg: ... are you more manic, are you more depressive, how intense, is it going to be a short period, is it going to be a long period. The psychiatrist said, 'you know it is too early to say whether you will have another bout where you will need hospitalisation at the moment.

- irrevocable incidents that had occurred;

Veila: ...and I got sick again. I got psychotic again, I was hearing voices, I stood up in church and I thought I was Princess Diana [laughter] and announced in front of everybody. I don't want to be a brood mare, because I thought that Princess Diana was used like a brood mare by Prince Charles. The church had expelled me from the congregation and said they did not want me to be part of the congregation again because of what I did.

- 'big' interruption and dislocation from their life course;

Cathy: It was something that had interrupted my life in a big way, because I was travelling along a road to going to build myself quite a nice career ... I had my children and I was going back to work and going to do something with my life. Then all of a sudden this mental illness knocked on my door, and just blew everything to pieces.

- loss of hope, social and material wellbeing;

Robert: Like when I lost the technician's career job, for six months I had tried to get jobs and I couldn't get jobs and I refused to go on the benefit ... when I had sold everything I had owned I had no money left for paying rent or food and it was when I got to that stage, that I then ate humble pie and went down to social welfare, stood in a line with smoking pregnant mothers and people fresh out of jail, and just a totally... that's where my social education really began. This is from being flown down to Wellington to go to school ... to this ... to the bottom of the heap as far as I was concerned.

- disconcertingly 'fast' emotional changes;

Digger: It happened so fast you can go from one minute to thinking every thing's all right and something comes into ya (sic) head that somebody's said something and so this whole thing boom boom boom, a progression of thoughts and you're almost at the point where ya could hit somebody or something ya (sic) know it can happen really fast ... suddenly going from feeling quite happy and relaxed to feel on the point of being violent very quickly like the next minute.

- rapid 'overwhelming' that could occur;

Lass: It was all it all happened so quickly and I was just overwhelmed. I was just overwhelmed by the speed of events and finding myself in [hospital X] it was quite dreadful.

- inexorable fall or slide in to ‘madness’;

Joan: I was sliding back again it was just like a panic it was a real panic.

- loss of control and the way back to it;

Daly: The thoughts I was having they weren't right they felt uneasy all the time every thing was always like you had to be on the move to be well you know just sitting there wasn't the way to be because you thought about these things and these things came into your mind and you thought jeeze (sic) this isn't right. What can I do and before you know it you're you don't know what you're doing or how to go about it.

- ‘inability to determine’ real or unreal;

Reg: Perhaps the most disturbing feature of my illness becomes the inability to determine what is reality and what isn't and I would get to the stage where I am watching the television news and it is almost I begin to interpret some of the news stories and perhaps some of the people on the screen trying to communicate a message to me which is unknown to others around me and other television programmes for that matter too.

- ‘nightmare’ that could return;

Robert: it was horrendous it was a secure ward, and there were real real lunatics real crazy men in there and the staff there who are now still involved in the health system were absolutely diabolical. They should have had nothing to do with them now. For a start it was all foul language and you were treated like absolute dirt. It was like the most severest of the foulest language you can imagine was used and you were described as utter dirt and you were treated like utter dirt. You were physically ... picked up, shaken and sworn at and thrown into a chair and it was really very hairy, while you were on these drugs it was very heavy. I thought it was a nightmare.

- degradation they had experienced;

Sada: “...horrible being in hospital though its degrading man chucking you in a room all by yourself.

- things they ‘cannot do’;

Sal: “tell you that you cannot do this which actually makes it worse many times because then all the things that you're trying to do you've got to leave. And trying to sort through you've just got to walk away from and you don't get them back”.

- ‘loss of faculties’ and independence;

King: loss of abilities, loss of faculties, a very depleted level of fitness which I had noticed you know and the inabilities included things like being able to fend for myself in terms of the basics like cooking and cleaning and things like that.

- ‘past’ being ‘used’ to undermine their future;

Laura: ... a psychiatric file following you that’s got all these different diagnoses, and I don’t ... know, when or if it is going to crop up later on in my life, when maybe I do have an important career? And that is something that can be used against you.

- need to hide their ‘difference’;

Sal: You hide the fact that you’re different ... labelling that I guess you’re a little bit crazy things like that.

- ‘invisible’ sign that others can ‘see’;

Evan: ...if you’re going round thinking that there’s something invisible about you that people can see or detect which inclines them towards making life difficult for you or making personal attacks or false accusations or assumptions for which you cannot see any basis, life sort of takes on the aspect of being a mystery which you cannot solve but unfortunately you have to, to survive.

Participants’ prior psychiatric status could haunt future events and interactions. Participants might not display symptoms within their behaviour to others, yet any future behaviour could be rendered symptomatic of psychiatric disorder. This was done in a manner that permanently discounted what the Participant said, because the mark of ‘madness’ irrevocably undermined their currency in human worth and recognition. Once ‘crazy’ always ‘crazy’, and therefore anything they said or did could come with the liability and *uncertainty* of being ‘crazy’ too:

Laura: I became a scapegoat in their group of friends ...if I had a debate ... like with one of the guys ... I had a go at him for beating up his girl friend. ‘Well you were just a fucking nutter (sic), I don’t have to listen to anything you have to say because you’ve been in a psychiatric institution’ ... that was their valid argument for everything. Every opinion I had or any time I disagreed with anybody or brought anything up it was very easy for people just to say well, hey man, you know and you’ve been in a psychiatric institute, you’re crazy.

Going ‘crazy’ and ‘losing it’ really *haunted* Participants. It marked the start of going ‘mad’, with all the implications and unpleasantness that this could produce. There was a pronounced *uncertainty* about the future, because psychiatric ‘madness’ could occur again. Hence being ‘mad’ once entailed the prospect of being ‘mad’ again, which introduced a precariousness about psychiatric health that was believable and believed.

and suspicions. What drove the *haunting* were *primary attributions* about psychiatric disorder and the central attention on psychiatric health by Participants and others.

Primary Attributions about Psychiatric Disorder

Attributions have important aspects to them. As common-sense explanations their function is to shape thinking on past, present and future events; to affect self-esteem; and to affect self-presentation and thus the view others have of us. The consequences of attributions then influenced thinking and decisions on social information, how Participants behaved (e.g. interpersonal expectancies and self-fulfilling prophecies) and the emotions Participants felt. What primed the *haunting* for informants were three attributions about their madness:

- (1) *Psychiatric illness is ever present.* Concerns about their psychiatric health loaded on to most activities Participants did and hence they became internal to daily thinking. There was an increased sensitivity as to what was a risk to their psychiatric health.
- (2) *Psychiatric illness is unfinished business.* No one knew how much or how little ‘madness’ awaited them and when it would occur. When the therapeutic goal was care not cure, there was no guarantee that a person would ever be well enough to resume everyday life.
- (3) *Psychiatric illness is a life sentence.* It was permanent and irrevocably bound to Participants. Even when a person was recovered, their ‘illness’ was seen as ‘in remission’. There was no escape, only respite. The records of their crisis/treatment experiences were permanently logged into official data-bases. Access to hospital treatments for general medical conditions revealed their psychiatric files, so that any health consultation implicitly became a psychiatric health consultation. Their previous life ‘before’ was now permanently previous, both personally and publicly. They had received a life sentence, not knowing why they deserved it, where there was only parole and not pardon, in which confession did not re-admit into social life but further isolated them with the rejection and sense of dis-ease they experienced.

Examining a first person description shows how these attribution codes worked when Participants talked about their psychiatric experiences. For instance:

Reg: ...the same sort of pattern I had to kind of come to terms with. Being hospitalised and going through the second occasion quite traumatised by the fact that I never felt as though I was going to allow myself to get into that position again but I had [it] was like returning home after World War 2 and being lost - kind of the old boundary the old familiar surroundings were not quite there and meantime I had experienced a battlefield during that time in hospital.

Yet it was more than just the probability of some vague form of psychiatric illness which haunted Participants. It was a probability grounded in previously aversive personal experiences with little expectation of a sympathetic response:

Laura: ... down once more I came out because you couldn't do anything and you felt like you'd been abandoned. You're in hospital, you've got two nurses running around after you, you got your meals cooked for you, you got everything and you've got all these people you can talk to, and it helps. It's making you feel better. Then they pull the rug out from under yer (sic) ... chuck you out into the world and you've got nobody, and I tell you what ... your friends don't give a shit. Your family don't want to know about it. Nobody wants to know.

Dramatic consequences for relationships and obligations to others could ensue, that were just as disturbing to their self. There was also the time, effort and *uncertainty* of recovery from crisis or emergency intervention; the battle to get out of hospital changed to a battle to keep out of hospital. Each time crisis and acute admission occurred there was *uncertainty* over recovery. The euphemisms of 'getting well' or 'getting better' that normally applied to illness or accident did not apply easily with psychiatric disorder:

Joan: you know I was sort of saying "when am I going to get better when am I going to get better". [laughing] Because there was this want to get back into the work force I mean I just didn't want to be on a sickness benefit I didn't want to be in hospital.

Getting 'well' or 'better' was fraught with *uncertainty* and only occurred in a reduced form for some Participants. It was these prospects that haunted Participants' lives. In this way, the *haunting* required a constant prospecting for 'madness' in everyday life. This was achieved by a *vigil* that drove an *on guard* process for 'madness', producing information to assist the *monitoring self* in resolving *uncertainty*. The *haunting* precipitated an *uncertainty* which the *monitoring self* endeavoured to resolve.

Usage of the category *haunting* embraced two aspects of its definition. That *haunting* was a practice or exercise that was built up from everyday experience; and secondly, that this customary resort was frequented by a visitation of fears

Genevieve: ...I was always conscious of the fact that I had been hiding the fact that I had been a psychiatric patient so it was like some unspoken or unfinished business there.

The attributions in Genevieve's comments shaped psychiatric disorder as:

- *Ever present* - "I was always conscious"
- *Unfinished business* - "like some unspoken or unfinished business there"
- *Life sentence* - "the fact" – the immutability of a psychiatric diagnosis

In hiding her past as a psychiatric patient Genevieve was using *caution* as to whom she would disclose, because to disclose indiscriminately made her *vulnerable* to the misconceptions of others (and had invoked disastrous outcomes previously). Using *caution* and experiencing *vulnerability* were two consequences of *haunting*.

Caution

Caution is prudence in the face of danger, and the need to observe *caution* serves as a warning and a reminder of personal *vulnerability*. It was a strategy for maintaining balance, the taking of 'one-step-at-a-time'. *Caution* was necessary because psychiatric illness could occur at any time and the vulnerability Participants felt maintained an acute awareness that there was a risk to their psychiatric health in everything they did:

Joan: And never a day I know I don't know whether it's stress or not, I know for me never a day goes by that I don't think 'god' I've got a mental illness And I need to go easy you know.

Caution was worthwhile because it could pre-empt crisis and thus without it Participants could 'fall over'. Yet living a cautious life could lead to 'I cannot' or 'I do not', resulting in increased restrictiveness with personal and social life, and future hopes.

Sal: I put more limits on my self than other people put on me I think I find that there's things I don't feel I should be doing because I have a psychiatric illness because I am different.

Caution could maintain adaptation downwards, when Participants expected less of themselves and this was seen as safe, reasonable, practical and necessary. The *caution* could shift from a life with some restrictions to living a restricted life.

Reg: ...you don't want to socialise a lot you have this kind of this mind set that not everybody understands the fact where you have been or what your illness might be so you don't push yourself in social occasions if you ever want to get involved. For me it was like television and books became my best friends because there wasn't so much need for interaction.

Expecting less by living a restricted life reduced the need for *caution*, reduced feelings of *vulnerability* and thus improved their sense of ease or comfort. *Caution* could be a way of obtaining hope about their future. A cautious approach could reduce incidents that promoted symptom onset, thus reducing the expectancy of illness re-occurrence and promoting future possibilities of being crisis free.

Linked to *caution* were notions of social expectations. While Participants could adopt a cautious approach, they were usually trying to be cautious about specific things. It could be difficult to discern what to be cautious about when there was *uncertainty* with perceptions and their interpretation. Using the 'right' caution for the 'right' activity required time to learn and when *caution* was used in the workplace it carried a social risk. Adopting a *caution* with activities that was not shared by others, might mark a Participant as different (e.g. plays into perceptions of weakness) to everyday workmates. When a Participant used *caution*, they were concerned whether it was appropriate to their task or were they confusing reasonable and shared activities with warning signs - such as having a bad day at work or feeling stressed at work? *Resolving uncertainty* around such fundamental and important activities was an ongoing task; a task which in its execution could create further *uncertainty*. Adopting appropriate *caution* could reduce dependence on *monitoring others*. The learning required to discern warning signs and to stay out of crisis enabled *caution* to proceed in a tangible and functional way. The visibility of *caution* and being able to maintain this over a period of time and with care, demonstrated an independence. But still the main reason Participants adopted *caution* was because they were *vulnerable*.

Vulnerable

Vulnerable was what Participants felt when their psychiatric illness was *ever present* and an *unfinished business*. Having faced the harrowing prospect of regaining their psychiatric health, there was increased sensitivity to what

influenced their psychiatric health and the knowledge that this was ‘at stake’ in anything they did:

Joan: mental illness is ... deepening my awareness of decisions that I make for my future. It makes them more thorough because they have to be because you know that there is more at stake. You know that your actual grasp on reality and your living in the so-called ‘real world’ is actually at stake based on decisions that you make about your daily life.

The decisions that Participants took made them *vulnerable* to the everyday world in a way that the everyday world did not often understand:

Sal: ...I tend to put more limits on my self than other people do and if I tell other people I don’t want to do it because of that they cannot understand they think why. And I see many reasons in myself but they cannot see them.

A *vulnerability* could erode hopes and dreams, leaving a sense of loss and the need to reconstruct new opportunities, that were shaped by the pragmatic demands of staying healthy:

Joan: Stigma operates by isolating people, it operates by dis-empowering people. The dis-empowering means doubting themselves. Like I had an image of myself as at this stage of my career at age thirty eight of being either in a senior teachers position a DP or AP or principal of my own small country school. That’s gone. I no longer aspire to that because I don’t have the courage to risk my mental health to the stresses that I know that a job of that nature would entail. So that’s a stigma that is perhaps out that has been outwardly projected onto me or that I am projecting onto myself.

There was prolonged adaptation required to meet the demands of living with the *haunting* prospect of ‘madness’. Participants were *vulnerable* when either ‘sliding’ towards crisis or towards recovery. Thus going to the threshold of ‘madness’ could bring threats (e.g. intensive care), and becoming well could bring threats (e.g. having to go out into a world that was the source of their ‘madness’). The undercurrent of vulnerability (to stressors real or imagined) could act as a safety guide when attempting to do things, and ignoring it raised expectations of extremely unpleasant/disruptive outcomes occurring.

Yet at the same time, Participants were being guided by what they could not do, rather than what they could do. When the most likely folk they talked with were other consumers who were also guided by what ‘cannot be done’ because of illness, then psychiatric disorder could seem like a trap of reduced possibilities.

Sal: There is no one else apart from those within the psychiatric system and you spend all your time talking about illnesses and stuff and what you cannot do instead of what you can do.

Their illness marked out their world by what they could not do, in the name of *caution*. The *caution* needed to manage feeling *vulnerable* fed back into the attributions Participants made about their psychiatric disorder. This in turn increased and diversified the *haunting* Participants experienced. In resolving the *uncertainty* with *haunting*, Participants were adapting to the challenges they faced. Their adaptation, however, could sometimes be just as problematic as the difficulties they faced. Creating *uncertainty* seemed to accompany resolving *uncertainty*. Problems occurred that were inherent to experiencing psychiatric illness.

Problems of 'My Own Making'

When Participants encountered difficulties and problems, it was hard to resolve the *uncertainty* of a problems source because:

- Was the problem with others or me or both?
- How important was it?
- What was really happening here?

In other words, was the locus of control external or internal and were perceptual/cognitive/affective processes reliably informed?

If problems were externally driven then a possible means of changing that problem's source was to remove one's self from it. On the other hand if the problem's source was recognised as internal then it might be possible to change the way the problem was understood and responded to without having to withdraw from the world. It became crucial to differentiate where the source of personal problems lay in order to be able to manage them better:

King: I succeeded more in placing the blame for the situation on myself and blaming myself for my present position ... I was quite internalising everything as being my fault and it was the reason why I got there. And I had not acknowledged at an earlier stage my thoughts and feelings of the situation. Again it was looking at the external things rather than the internal. Well since I have been out of hospital I have started looking at more the internal things that were happening at that time for me, and some of the thoughts and personal messages I was giving myself about my own worthiness and my own ability to get through this predicament.

Discerning sources of attributions enabled people to discern the origin of thoughts and feelings. At the same time the *uncertainty* with information and decisions from perceptual and cognitive processes could amplify confusion, further undermining confidence in their ability to make sense of things:

Leila: ... it's hard to know what is happening because part of the illness is that you have these suspicions all the time that people are doing things to you and it's very hard to differentiate between what is actual and what is imaginary.

Uncertainty with perceptions can lead to a spiral between suspicions about their interpretations which increases stress, which in turn creates further uncertainty, leading to more suspicions. Thus the task of trying to resolve uncertainty can create further uncertainty. This was when the *haunting* could accelerate the slide into crisis: by limiting thinking around alternate possibilities or outcomes from problems, and affirming the slide into crisis as the most likely outcome.

Resolving the *uncertainty* that *haunting* created then, was a fruitful task in which to engage for recovery. One way that Participants proceeded with this was to arrive at a perspective that they fully participate in both the problems they faced and their resolution. From there they could then develop their own individual ways to make sense of experiences. This usually meant that a *vigil* was maintained to examine everyday experience for 'mad' signs, and this was especially so when problems and difficulties arose. It was this shift from being immersed in *uncertainty*, to locating sources of *uncertainty* that enabled Participants to say there were '*problems of my own making*'. With 'before' there was just one social flow, now there is a real/normal/actual social flow and an illness-mediated one:

Hamish: So what do you think hindered you in any way with getting and maintaining employment?

Digger: Oh I think I think my own attitude really ... I was a lot more out going and open with people before I had schizophrenia and I find that at times when I've had problems with it I still have a few occasional paranoid thoughts and not sure whether that happened or not. And I tend to withdraw into myself when that happens. And I've heard people say at work [you can] have a good chat with him and other times ... you just get a grunt out of him and I'm sure that's true ... and I wasn't that moody before I had the schizophrenia.

This multiplied the stimuli that Participants had to attend to, and hence implied an overlaying stress vector (e.g. not just discerning whether something was real or not, but whether their reaction was also real/appropriate/well or not, or some shade in between). When perceptual, cognitive and emotive processes created

uncertainty, Participants tried to resolve the *uncertainty* they experienced in different ways. Some examples of '*problems of my own making*' were: *narrowing, withdrawal, scared, scarring, misinterpretation, motility/comportment, trapped, rescued, secrecy, bolt* (see Appendix F for memos on these terms). How Participants acted with and reacted to '*problems of my own making*' influenced their desires around *place, identity, making sense* and *opportunities*.

Desire for Place

Place refers to both a person's physical and social location. When Participants inhabited a location (e.g. "psych system"), their location could be seen to co-constitute their habits (e.g. typical consumer) and relationships to other people. This can provide a *place* to preserve comfort and safety, yet it seemed also to create further boundaries to inclusion:

Sal: ...you see yourself as different from others when you've lots of the time when you've been in the psych (sic) system then it's really hard to get out of it. You get into a group where there's no one else around you who has not been in the psych (sic) system. And when you are around other people who have not you just don't know how to behave, you don't know how to act, you don't know what's expected of you ... A lot of people just throw around the word you're crazy when you do something silly and you take it more seriously. You seem to spend more time actually looking for ways to prove that you're not. I think lots of it is you seem to have a very closed in community. Once you've been in the psych (sic) system you shut off other people outside it. You get involved in discussions you all know the same people same system and that's what the discussions revolve around. When it's trying to actually converse about regular things it's a lot harder.

Participants lived in a mixture of physical locations but all at some stage had passed through very similar accommodations and positions within public space. Beyond sub-acute care, Participants were usually transferred to supported accommodations (e.g. either housing complex or group home) and then, when ready, into solo/shared flats or to family homes. Supported accommodation (with its levels of support and security from four [highest] - to one [lowest]) provided important steps and visible markers to personal recovery. Yet each type of accommodation was shaped by boundaries of inclusion or exclusion and thus entailed a certain status that Participants learned and became accustomed to. The Participants also shaped their status in a daily manner:

Robert: ...again I was in a ... supported housing for psychiatric survivors type thing and so I had this whole stigma thing, I mean it was horrible. I go to the local dairy and for something to be delivered, 'where are you' oh 'I am at such

and such address' and obviously the people realised what that meant. Because in the local neighbourhood it became well known that this address was full of loonies.

The boundaries for inclusion into accommodation could become the boundaries for expectancies by self and others. When *problems of my own making* occurred, the safety and familiarity of a supported accommodation environment or 'consumer only' association could harbour a social ease, not experienced elsewhere. Inhabiting a physical location developed habits of use and associations with others present that could give rise to social habits. Social habits cohered and were sustained by a sharedness of experiences, people and expectations in a way that developed a social locatedness known to the person and recognised by others. This sharedness was anchored by a common difference that inaugurated its own rules and obligations regarding appearance, manner, language and exchange.

Sal: ...you think that you are so different from everyone else ... special in a ways that a psyche person is special. But you get a higher opinion of yourself you think basically that you can do what you want at times because you don't actually have the same boundaries and stuff that everybody else has, it's not expected of you. You are not expected to work, and if you don't want to work you don't have to. If you want to be in a place where everybody pays your bills for you and stuff you can. Or you want to be in a place where everybody looks after you and does everything for you, you can get that arranged. You don't actually have the same rules for everything as everybody else put on you like the other people outside the system in a way. It is just not expected of you. Like ... on invalid's benefit I did not have to work and it just was not expected that I had to work, yet everybody else does. There may be things that I do that I have to do to help myself because I cannot cope with the same stuff as everybody else. But sometimes it is finding your ways around it rather than saying you cannot do it.

The shared difference extended to sharing similar problems, difficulties and all faced the prospect that their disorder could occur again. Being in a place where this prospect was a norm developed psychiatric illness attributions which gave rise to the *haunting*. Hence the *haunting* prospect of psychiatric disorder was also shared, and how Participants coped with the difficulties that arose from this influenced how and where Participants lived.

Desire for Making Sense

When *problems of my own making* occurred Participants wanted to make sense of their experience and know that they were *making sense* to others. The *haunting* and other problems arising from adaptation to psychiatric disorder could introduce a suspicion about their communicative competence. On one hand the journey back

to everyday life was dependent on the efforts and assessments of psychiatric/support services. This required a demonstration of competence that they were not 'mad' and were coping independently. On the other hand, the task of demonstrating competence was challenging. The feedback tools Participants used to gauge emotion, social appropriateness, personal value and cognitive congruence were at risk or under suspicion during the demonstration of competence. This created an *uncertainty* difficult to resolve.

Desire for Getting By

As Participants experienced *problems of my own making* they wanted to manage their lives as best they could and this was described as *getting by*. It did not suggest thriving. There were different degrees to this. *Getting by* as a fully employed professional required distinctly more resources, opportunities for social mobility and rewards than as someone who had never been employed. Yet despite disparate class and status, Participants still faced similar personal difficulties and social threats and *getting by* became their goal. At times it was a very realistic appraisal of what they were doing and a substantial achievement that they were able to do this, compared with how they had managed previously. How Participants were *getting by* depended on *problems of my own making*, which in turn influenced how Participants were *getting by*. This often entailed living life one-day-at-a-time:

Digger: Then after a while I got positive and with my second wife, that I'm married to now you know; she's actually got manic depression. And she's got a good attitude, like you take it a day at a time. You think, I'm alive: It's a good day.

Living one-day-at-a-time was a practical strategy to rein in the unexpected and the uncertain. The prospect of having to get through a whole week might be overwhelming, but getting through one day was very likely to be achievable and manageable. It may be all that a person was capable of and an adaptive strategy that had a high probability of success. Succeeding in doing so promoted a degree of hope, a display of confidence and an expectation of competence, if only for this day. At the same time it reduced attention and concerns to only what had to be faced today, and enabled Participants to get by. *Getting by* could be a holding strategy, a way of weathering the vagaries of psychiatric illness by just doing

enough to get by. Sometimes *getting by* involved a reduction in expectations of self and the shrinking of opportunities that accompanied this.

Desire for Opportunities

When Participants experienced *problems of my own making* and tried *getting by* in the face of demands by everyday life there could be an actual and perceptual delimiting of *opportunities*. New *opportunities* were often rendered daunting and unacceptable due to the intrusion of the risk and *uncertainty* caused by the *haunting*. This could give rise to considerable tension for Participants and immobilise them. Realising their predicament, they knew they needed to change and sought new *opportunities* to permit this. At the same time these *opportunities* carried the risk of damaging their psychiatric health – a possibility of two steps forward and three steps back. Facing *opportunities* and not being able to fully realise them carried risks to self competency and personal esteem.

Sometimes the pursuit of opportunities was closely watched by other consumers. It was almost as if they carried others' hopes and possibilities. If Participants failed, then that confirmed the reduced expectations they had of themselves. Conversely if they succeeded then that could emphasise the gap between where they were now and how far they had to go to be able to do what they had just seen someone else do. Yet the benefits of employment could be tantalising. People noticed the change in dress and appearance, or a change in resources, such as having a car and living independently, as well as the shift in self-confidence that could spill over into new relationships – such as with a girlfriend or boyfriend. The observable elements of success that could occur as a result of pursuing opportunities could be a powerful motivator to breach the sense of risk, stress and *uncertainty* that haunted such activities. Yet what was viewed as an opportunity, let alone being ready or able to pursue one, could be shaped or constrained by 'sliding between crisis and recovery'.

Sliding Between Crisis and Recovery

In the early stages of their illness trajectory, Participants often had more frequent occasions of crisis that could then slide into 'madness' and acute care. The time involved in moving from acute care to community care was usually longer. People spent more of their time feeling 'unwell' than 'well'. Compared to before, this

created an inversion between time spent feeling well and time spent in or near crisis or hospitalisation followed by sub-acute care. The drama and unpleasantness created by near or in crisis events provided an overt focus for most Participants. It seemed that Participants moved only in or out of crisis, rather than in or out of recovery/wellness. However, with experience, Participants developed (a) a sense of the time phases involved when becoming unwell, and (b) increased confidence in their recovery from crisis and acute episodes.

Yet even when Participants were managing independently in employment and had adopted a recovery focus they were still *haunted* by the prospect of psychiatric illness reoccurring and this intruded into daily life. Employment created a different value base to their activities. There was now something very precious to lose. They had no recourse to an illness identity because in *passing* they appeared as ‘normal’ as anyone else. There was considerable pressure to stay ‘well’ or appear to be ‘well’. They might be ‘unwell’ but not ‘mad’; not well enough to be fully accepted as everyone else, yet not ‘mad’ enough to be fully removed or secluded. The ambiguity and *uncertainty* this could create both personally and during social intercourse was persistent: “...the biggest problem today with mental health is that people cannot accept that you’re not mad. I don’t feel I’m mad, I feel I’m not well but I’m not mad” (Neil). The *haunting* positioning of identity as “I am not well but I am not mad” then loaded onto self expectations and the expectations of others.

Influence of Self and Other Expectations

The *haunting*, driven by attributions about psychiatric illness that resulted in *caution* and *vulnerability*, primed the Participants’ expectations and the expectations of other people. All people live immersed in social worlds built from experience, sectarian interests (e.g. gender, ethnicity, class, age), imagination and historical inheritance. To the extent that people share a general social world irrespective of sectarian interests, they share in general understandings about features of that society. The general understandings acquired about ‘madness’, ‘mad’ people and ‘mad’ places, whether they are believed or not, are harboured by those with and without a psychiatric disorder. In addition to these beliefs, consumers developed firsthand experiences of what it was like to live while

experiencing *problems of my own making* that arose from their psychiatric disorder. Underscoring daily events was the *haunting* presence of psychiatric illness and the acquisition of a liminal identity - neither not well but not mad. The ambiguity and *uncertainty* that arose from experiencing these factors could lower self-esteem and confidence.

Other people also carried shared understandings about psychiatric disorder. It was likely that without alternative experiences to disconfirm these shared understandings, people would act on them and use them as a base for their expectations:

Nev: Oh my brother used to laugh at me. He didn't characterise me as a person. He characterised me as a as a loony ... He just used to say I was useless ... and no good and I'm a loony and all that.

When these expectations were negative (and usually they were) they introduced a sense of unease and *uncertainty* during interaction. People when faced with social and personal *uncertainty* were usually more likely to find this a negative experience. They invariably sought information from that action scene to confirm rather than discount their held beliefs and understandings about psychiatric disorder. Other peoples' negative perceptions could be conveyed in both a verbal and non-verbal manner so the Participant was rarely oblivious to the exchange. Stereotypical behaviour could be played out by both parties, each confirming the expectations they had of the other. Some of these perceptions and expectations held by Participants were that they could expect other people to think them 'crazy', 'bad' and that other people feared violence from 'them':

Sada: They say "Oh I didn't know that. I thought you were you". It's like they didn't - they didn't - see me as any different from anybody else. And I sort of expect them to think I was this really crazy strange person I think people are scared to [associate] - aye - 'cause you know you see stuff on the TV ... This psychiatric person shot all these people and shot himself and stuff like that, aye. Cause psychiatric people are bad, aye.

➤ The mark of 'madness' could transfer to others by association:

Veila: ... [family did not] visit me at [hospital]: They would not come. So I was quite disappointed. I thought that must be the stigma again of psychiatric illness; people don't want to associate with you or be seen with you because they might get labelled the same thing by association.

➤ They were 'not able':

King: I only had ... a relatively short period of being able to function adequately enough to be able to listen to instructions and to take in all the information that I needed, as well as the energy to perform certain tasks. So those periods of time were really quite limited and before real tiredness would creep in, and... All I really wanted to do was go back to bed and rest.

- They were “not worth talking to [and] not fit to even be in the community” (Nev), “unstable” (King), have “guilty feelings ... there’s something wrong with me” (Digger) , and could be treated “like a baby ...like a child” (Mary). This led Participants to think “you’re not a proper human being to some extent ‘cause you been diagnosed and labelled. Even if it’s only labelled in your own head, it’s happening”(Digger).

The person with a psychiatric disorder could find themselves in situations where their firsthand experiences started matching the negative expectations about ‘madness’ and ‘mad’ people.

Robert: When I first went into a hospital ... the whole area of something wrong with the head ... someone's funny in the head and that, and if someone crazy was seen on the street the parental warnings to keep away from people like that ... yeah, oh don't go and visit so and so - he is a bit funny in the head ... so and so is crazy ... it is the whole social gestalt about the whole thing and I found that would be the most difficult area to come to terms with was my own stigma and when I found myself receiving psychiatric treatment, my self esteem, which had been severely damaged by the coma, went out the window. It really did. I felt I was at the bottom of the heap in society.

This conjoining of expectation and experience can substantiate the ‘myths’ about ‘madness’ and ‘mad’ people as the ‘truths’. When the myths become the truths internal stereotypes solidify and self expectations can become congruent to stereotypical beliefs.

Adaptation Occurs

Participants adapted to the *caution, vulnerability, problems of my own making, not well not ‘mad’* and stereotypical self expectations through their different ways of *constructing identity*. From this all Participants experienced alteration to their *knowing, doing* and *being-in-the-world*. They were unsure about the degree of change or permanence, as *haunting* created an *uncertainty* that could be pervasive. When people faced the need to resolve *uncertainty* on a daily basis, they could adapt by restricting the range of what they could do. Knowing the risk to their psychiatric health and the consequences of hospitalisation were present in anything they did, Participants adapted downwards. They became ‘not able’, ‘not

competent' or 'not fit'. They lacked 'self-esteem', 'self-confidence' and self-worth.

Sal: I actually found it quite difficult. I found it hard to know what is expected of me. I felt really unsure about whether I was doing right at the end. I was suddenly thinking have I done this ok or not? Are they going to tell them that I cannot do it properly? And I was feeling really lousy. I just felt oh I must have mucked this up. I have done this wrong, and I was thinking of all the things I've done wrong. Oh I cannot even do this for one day sort of thing. I felt sad.

They 'cannot do' what they did 'before' in quite the same way. The nots, lacks and cannots sometimes developed into 'will nots' and put limits on future possibilities. There could be a shrinking of personal self-hood, to the extent that a person felt they had become a 'no one'.

Nev:: Yeah, I had periods of when I was well but - ah -, I don't know. People just sort of forgot about me and left me there and my parents loved me and cared for me but ... I didn't see anyone in that time"

With little personal agency the 'no how' encouraged a 'no when' which could park a person in 'no where'.

Hamish: Were you just mainly at home?

Nev: Yeah I stayed I stayed on the couch watching TV for a long time.

Hamish: You had a year on the couch?

Nev: Yeah.

Their situation could appear to be very unreal:

Nev: I was capable of working. Felt as though - yeah , felt as though it wasn't a real situation. Just, you know, if I walked out of a job - a good job - and then I just go come to laze around at home... I just became a cabbage. I did nothing all year.

Experiences of this nature and the sense people made of them established, re-established and confirmed the centrality of their psychiatric health and the overt importance it had for self and others.

Lass: Mental illness takes a tremendous toll ...I loved my work, I loved the challenge, I enjoyed getting dressed and going out everyday. Having a job to go to. I enjoyed the intellectual stimulation of working. I loved all these things and ... if the mental illness had not got in the way I would have still been working ...mental illness encroached so much on my life, I really felt that I had no intelligence. You just have to be a bit careful because generally people do feel a wee bit of fear. There is still that lingering fear - it is ignorance really. I was told in the mental health service, to see it as a human thing similar to being sick. I was just mentally sick. I just needed my head fixed. But these are very nice words. They don't really fly. People don't think like that at all. This particular woman - my farmer friend - now said to me, "Well there is no point in you ever, you have stuffed the rest of your life if you been in the 'loony bin'" as she referred to it.

She claims to be a responsible person herself in her 50's. "You'll never get another partner. There is no point in you looking in the contacts or anything like that she said, "You will never get another partner because any man would just y'know back up immediately" and she said that 'in a small place like [provincial city X] it is easily found out so there is no way you will ever get another partner'. The more I thought about it the less inclined I was to do it.

How to break free or leave behind past events proved difficult when those events continually reached forward and haunted future possibilities.

Robert: ...I had been committed and that just did colossal damage to my self-esteem ... I used to walk around and I used to think that [on] my forehead, I had the stamp that says 'psychiatric patient'. And because I did have, particularly then, I had worse difficulties than I do now.

Their past experience of psychiatric illness and the effects of this on others was difficult to forget or ignore. What others had to contend with was the person and the illness. Whereas before they may have got on with the person, it could be a definite battle to manage with the illness. As the illness achieved prominence and created the difficulties they had to attend to, so could others start overtly to focus on the illness changing their interaction with, and obligation to, the Participant. These things then fed into and shaped primary attributions about psychiatric illness; that it was "*ever present*", "*a life sentence*" and an "*unfinished business*". Living day-by-day required an applied resourcefulness. Participants had to contend with the disruptive effects of psychiatric disorder on thinking, perception and memory coupled with distorting side-effects of medication. These required considerable effort, persistence and practical strategies if they were to resolve the *uncertainty* that *haunting* created.

Summary

Signs of psychiatric disorder were accompanied by an *uncertainty* over their course and consequence, so that the prospect of psychiatric disorder signalled *uncertainty*. Participants' lives were marked with, and marked out, by *uncertainty* with their psychiatric health. Using illness signs to mark out an identity that could access everyday life inculcated these signs into intrapsychic, interpersonal and spatial practices. This became the *haunting* prospect of psychiatric illness that now could permeate identity and future life trajectories with an *uncertainty* around knowing, doing and being. Concerns about psychiatric disorder intruded into cognitive, affective and behavioural considerations about themselves and

with other people. *Haunting* created *uncertainty* about psychiatric health but also resolved it by forcing people to consider illness signs within life choices and activities. Within employment, the ironic effects of *haunting* heightened concerns about self-presentation, yet assisted Participants to be mindful of their psychiatric health. Despite the variation in how Participants managed to get by and the results of these attempts, people used a central strategy - *vigil* - to manage their *haunting*. The *vigil*, which the *monitoring self* employs to resolve the *uncertainty* of *haunting*, is discussed in the next chapter.

CHAPTER 6 - THE VIGIL

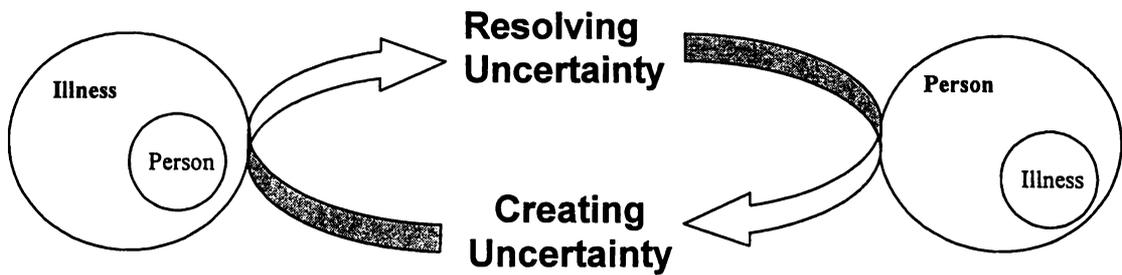


Figure 1. Basic Social Process

The *vigil* is a learned strategy first encountered within inpatient and outpatient services called self-monitoring. There, Participants were trained to observe, sort and sift everyday thoughts and actions for their 'madness'. Hence *vigil* precisely mirrored the activity in which staff engaged with clients, and thus served as a model or template for the client to reproduce. Just knowing there had to be a *vigil* was the first step to self remembering or reflection and thus provided 'insight' into their illness. Developing 'insight' was a key plank in becoming well and showing 'progress'. Hence learning both to maintain a *vigil* and to process *vigil* information appropriately was central to being discharged. The activity of *vigil* then transferred beyond acute care.

Central to the *vigil* was the character of the information it produced. As people learned this technique from psychiatric staff they inherited a bias concerning what target information or signs they needed to look out for. What was of most concern to psychiatric staff was when a client was at risk. Hence, signs that were looked for implicitly indicated when a person was 'at risk' of becoming unwell or heading towards crisis. The targeting of 'at risk' signs enabled Participants to self monitor independently. At the same time, with the overt focus of personal attention on psychiatric health, it primed the *haunting* and in turn was the best response to the 'ever present', 'life sentence' and 'unfinished business' of psychiatric disorder.

On Guard

Participants were *on guard* for signs of impending 'madness'. The *on guard* position (watchful, cautious and vigilant) was both an offensive and a defensive tactic. In offensive mode it sought information to make sense of what was taking place. In defensive mode it reduced inadvertent *disclosure* about illness identity or attributes. The *on guard* process resolved *uncertainty* around knowing, doing and being by comprehending '*mad*' signs. These were discerned via:

- behavioural perceptions (i.e. appearing mad)
- behavioural actions/inactions (i.e. acting mad)
- thinking bizarre thoughts (i.e. thinking mad)
- the saying of bizarre things (i.e. talking mad)
- living 'crazy' (i.e. being mad)

Participant success at guarding ranged from being *outed* (ineffective guarding) about their psychiatric status, to suspicion (poor guarding) and to normal workplace interactions (effective guarding).

The outcome of effective guarding was impression management that then enabled *passing* to proceed. Guarding was necessary because with *haunting* the prospect of psychiatric illness occurring without their detection intruded into events. At the same time its protective function could install hope because less detection of 'mad' signs indicated the person was improving. Greater *disclosure* of illness signs could mean that they had slipped through a Participant's guard, raising their suspicion that they were becoming unwell because they could not detect it when other people could (or that the social environment permitted *disclosure* like this in a productive way). Not having to guard against *disclosure* could be very freeing. People no longer had that inner tension or fear linked to hiding and secrecy. Moreover when *disclosure* of illness signs escalated into crisis then people were prepared and could be supportive. Alternatively, not guarding meant reality could distort in some small way and then proceed rapidly to amplify into the completely 'bizarre'.

The Participant's *on guard* focus created a disposition to interpret, and motivation to seek, the marks or signs of their illness. Hence being vigilant (the *vigil*) carried the same motivation and values from the psychiatric service about psychiatric

illness - primarily looking for signs of the illness instead of looking for signs of recovery. Looking for signs of the illness was an effective early detection and self management strategy, yet it implicitly entailed looking for information to confirm their diagnosis and their mark of psychiatric illness, not disconfirm it. The bias of looking for illness insinuated itself into personal inferences, attributional and attitudinal processes.

For instance, a common bias Participants had was about stress. Stress was something to look for, detect, and if present could lead to symptom onset or escalation. Participants were told that they did not handle stress well and therefore should avoid activities and occasions when stress was likely to occur. But Participants rarely experienced opportunities to learn when stress was appropriate for them. Unfortunately when this prospect (e.g. get stressed therefore get sick) transferred into everyday life and occupied a global position (e.g. all stress is bad), Participants rarely got the opportunity to disconfirm this perspective and its global appropriateness. Getting stressed and feeling stressed can be part of everyday working life. Most jobs entail some degree of stress. However, instead of attributing stress to external contingent factors like a 'busy day', the attribution Participants often used was 'I am getting stressed therefore I am getting unwell' or 'I am getting unwell because I am getting stressed'. The issue was not stress but how to manage it.

Sal: Even with psych (sic) nurses and stuff like that. At times lot of them say you cannot cope with stress, but sometimes you spend so much time avoiding stress you never learn how to handle it. And I find that you have to learn how to handle it in small doses.

The overt focus on stress events that were then turned into psychiatric health events (e.g. becoming unwell), rendered all actions that invoked stress as threats to their psychiatric health. This made threats to psychiatric health highly probable, present in everyday events and unlikely to change. Participants declined social opportunities because psychiatric health concerns so colonised their life-world that 'not doing' became the way to manage psychiatric health: "...you seem to spend so much time avoiding stress that you don't get out and do things" (Sal). This bias might have been useful when they were acutely unwell within the MHS. However transferring this processing schema to other everyday situations could manufacture *uncertainty* in anything that required 'doing'. Such an *uncertainty*

needed resolving, yet the manner of resolving it was intertwined with its manufacture. When the Participant was continually on the lookout for signs/marks of unwellness or impending crisis, this activity could occupy such a central piece of their attentional resources, that out of habit the signs they were trying to find became the boundary signs of the self. Participants were marked with, and marked out by their psychiatric disorder. In particular, they were marked by the *on guard process* used to examine thought processes and events for ‘mad’ signs, and the *uncertainty* that this process generated and how they sought to alleviate it.

On Guard Process - Alerting, Differentiating, Deciding, Generating

Being *on guard* seemed to entail-

- a process of alerting, differentiating and deciding;
- a discernment of doing ‘mad’ things, appearing ‘mad’, thinking ‘mad’, talking ‘mad’ and being ‘mad’;
- a sorting of what actions, perceptions, feelings, thinking and experiences were inappropriate, imagined or illness generated.

Generating a ‘real’-ity in which people had confidence reduced the *uncertainty* about their memory production. Knowing that their perception and memory of events were similar to other people’s increased their capacity for social interaction and congruence, thus assisting in making sense of their world and themselves. Discerning ‘mad’ signs helped resolving *uncertainty* in everyday life, because it became possible to make sense of things in their own individual ways. Once people had re-evaluated the causes/conditions present when they had become unwell in the past they could use these as markers of becoming unwell in the future. Thus the impression that ‘going mad’ came suddenly and from nowhere, was allayed and could be portrayed as the sum total of experiential events, internal processes and ‘chemical imbalance’.

There was an alertness required that was built up from past experience, as to what these signs were. “A mental illness is that you’re constantly ... self reflecting on your own thought processes” (Joan). This self-reflecting was for signs that were individual yet the roles of which were shared in a similar way. Once alertness

indicated that ‘mad’ signs were happening, Participants attempted to differentiate these signs. Experiences were differentiated for at least three main reasons: to sort signs of impending crisis/becoming unwell, to sort the normal (i.e. appropriateness) and to distinguish what was ‘real’ from what had been imagined. Once the imagined, inappropriate and unwell signs had been differentiated they then required deciding upon. This could involve using others as *partisans* to check out their differentiations. It might involve logic traps or similar routines used to review an event that then permitted generating ‘real’ consensual information. The building up of perceptions that were probably ‘real’ (in the sense that their perceptions were shared within their social environment), could lay a base for future thinking and behaviour that was grounded and appropriate to their social milieu. Over time suspicions and uncertainties were reduced as their thinking processes had the alternative of becoming more congruent with those around them:

Digger: Yeah after about the first three or four years I think the medication really kicked in, and also I got out of the sort of the trap of the paranoid thinking you know. Got towards thinking like a normal person.

As everyday life and their illness became more managed Participants still needed strategies to watch for the traps of disordered thinking.

Alerting

The process of *alerting* developed a state of mind that was alert to the onset of symptoms. Onset was indicated by the personal markers or signs Participants had learned from their own experience or had been taught. Participants had to be alert because when they learned about the course of their disorder and that it was likely to occur again, then it was going to be themselves who would have the first opportunity to prevent crisis. Being alert to the impending signs of crisis or illness onset then created an opportunity to reduce escalation.

Cathy: ...then I found out it was something that could come back. I decided ... to learn about this psychiatric illness that I had and how to start the road to recovery ...a lot of it is helping yourself because I think the main person to keep yourself well is yourself. In that process I learnt stress levels, signposts of things that I know when things are ...not going well and then take heed of those signposts.

The *alerting* required attentional resources to be engaged over and above those required for regular interactions. Being alert to the ‘mad’ signs required constant

vigilance. The main cause for *alerting* was the disposition to *haunting* from *constructing identity*. The context in which *alerting* occurred could vary from the current event time frame to later in the day when reviewing and rerunning of events took place (or with assisted event reviewing by psychiatric or support staff). The conditions under which *alerting* was amplified were when something seemed 'bizarre', and during moments of social and personal *uncertainty*, such as during interactions that were evaluative and had salient and highly probable negative outcomes.

What alerted people could vary. For instance, self-states, and particularly changes in self-states that promoted *uncertainty*, were a psychiatric health flag. Thus being alert for particular self-states provoked considerable speculation (e.g. a bad or 'mad' day?). Were things the way they were because that was how they felt about them or was that the way things really were? Increases in clinical indicators (e.g. altered sleep, mood, thinking) tended to be the same indicators that people themselves used to make inference about their self-states. Thus each of the message, medium and method of *vigil* appeared to derive from clinical experience. Changes in self-states acted as causes and consequences to the *vigil*, and shaped how/when/what was disclosed or not disclosed.

Alerting is a key plank in notions of recovery where a person learns to monitor by being alert to their recovery on their own terms. It serves as a way of gauging illness progress in a self-directed manner. The paradox in having to do this is that it affirms a level of disability, while at the same time it becomes a path to independence (taking a place in the social world).

Reg: ...had to face the facts that what I was experiencing was like warning signs. I liken it to warning signs, you know, about having a heart attack. I knew that if I was to continue any longer I would sort of plummet down to some murky depths that I am all too familiar with.

The signs that alerted people were not just warnings of probable negative mental health, but predictions that entailed consequences to all areas of their lives and relationships. Thus *alerting* was not an emotionally neutral activity because the outcomes from *alerting* were strident in their effects. As a pre-emptive strategy it both relieved building anxiety and gave confidence to future actions. As a post hoc activity, the Participant realised their anxiety/stress/*uncertainty* and sought to

reduce it or resolve the contradictions of conflicting interpretations of it. In this case *alerting* took place in a raised affect state, where negative heuristics were more likely to be engaged, negative interpretations were more likely to occur (i.e. better to think the worst) and the *uncertainty* surrounding the event was further compounded with the *uncertainty* of the process (i.e. was this strategy really working/accurate/reliable?).

Alerting was then a way to achieve some predictability, confidence and knowledge of what was 'real'. It had the ironic capacity both to increase and to reduce anxiety, *uncertainty* and confusion. The first consequence of *alerting* was that it enabled the bracketing of perceptions as flags or signs that were associated with warnings about their psychiatric health. It permitted separation of the daily life into the pre-cursors for onset or deterioration in psychiatric health. The effect of this was that 'madness' did not come out of nowhere but proceeded from how people lived their lives. This enabled recognition of the infant stages to their disorder by signs that configured 'madness' as a possibility. Alertness was more effective when warning signs occurred in a robust way over a short time frame. However when there was a slow creep or deterioration over an extended period of time with a gradual adaptation down into illness behaviour, Participants could lose the perspective of a 'before'.

Claude: ... people started talking to me... at work and ... somebody thought in my mind 'I can see your bum', so I pulled up my trousers and they all laughed at me. And I sort of thought to myself "oh Jesus Christ, what's going on here?" ... their minds aren't mine, you know. All sorts of questions, what's going on here? Why'd they do that you know? What was so funny? Why are they all laughing at me and embarrassing me like this? ... It was thrown in my face. It was completely foreign to me that this could happen ... And things went on and I started to think rather than speak. I started to take on board things that people would think rather than things that they would speak. They would speak to me and sometimes I would not listen or I couldn't hear. Which was another problem for me because if somebody speaks to you and says something to you, gives you an instruction and you don't hear but you see what they think then you get it all wrong, and of course this interfered with my work. Completely, because I would go on what people would think rather than what they would speak and of course I'd get it all wrong. I'd do the wrong thing or I'd go to the wrong place or things like that would start happening.

The signs could become the norm for their behaviour. A way out of this situation was to write down their individual warning signs, so that even when their alertness faded, they had a resource to bring it back again. The second

consequence was that once Participants were alert to 'mad' signs, then they could start differentiating between them.

Differentiating

Being alert to 'mad' signs required Participants to differentiate between the 'real' and the 'imagined', the 'abnormal' and the 'normal', and the 'unwell' and the 'well'. This was assisted by learning to differentiate between perception and events. These events usually involved interactions. *Differentiating* enabled confidence in comprehending what other people were saying and doing, in a manner appropriate to the social demands or expectations of the situation. From their ability to differentiate came a strong probability that what they had thought happened was 'real'. Therefore their memory of that event and the basis for future behaviour was appropriate. Occasionally their *differentiating* needed a differentiation check-up via a *monitoring partisan* or via disclosing their mental health status so that other people could realise that they truly were confused and were genuinely checking to confirm whether their thinking was accurate:

Digger: I was still drinking pretty heavily and then I got this idea that my girlfriend was screwing around, ya know, and I sort of had all these sort of things in me head that she had been and what I thought was proof and she said, 'no that's all crap that never happened', and all that sort of thing.

Differentiating enabled recovery to take place. If Participants could not differentiate then the boundaries disappeared between what was inappropriate, what was 'mad' and what was unreal. To walk a social path in the world involved interaction with others and necessitated some knowing of the accepted boundaries concerning 'real', appropriate and well. When this was not present it could create ambiguity and *uncertainty* that disrupted communication and raised anxiety by removing the sense of predictability and confidence Participants had.

What Participants differentiated was genuinely believed and could create further difficulties. This was particularly true in relationships, where misperceptions often underpinned the difficulties they faced.

Digger: I thought, na (sic) she's ... bullshitting me. She really is screwing around, so I split up with her, but she insisted that there was nothing wrong with [me], keeping coming around and seeing me.

While Digger's differentiation of what took place with his girlfriend was resolved, when the Participant's partner had ulterior motives of their own, the *uncertainty* over differentiation could make Participants very vulnerable to manipulation by others.

Evan: I don't think it is vicious to say that she [wife] made the most of it for herself, in that I recall things like paying for rent, paying for food and things like that and she had a teaching income and I don't remember seeing much financial assistance from her, and I think she walked away with a fairly healthy bank account, although she did pay for the bills, but she left me with a lot of financial obligations that we had taken on and I had quite a struggle for a while - they did very well, they moved into a new house not long after we separated - but I really wasn't with it enough to sort of latch onto the fact that some one that you were married to might do things like that.

The *uncertainty* with *differentiating* what was appropriate in their relationship for Evan, was extended to *uncertainty* with anything he used to be responsible for:

Evan: ...that was, sort of, like, that side of it was between her and me a bit different but, yeah, that was her sort of attitude. After that she became very parental towards me, which I actually found quite devastating.

And what used to be differentiated as emotionally congruent with the situation now found its expression as psychiatric illness:

Evan: ...one of the contentions with my domestic situation was that my wife had a fairly defiant attitude, and there were certain things I didn't like happening, and of course if I got angry she sort of expressed that as a manifestation of my illness.

When behaviour that used to be 'normal' was now perceived as 'mad' by other people, then the internal referents (of past experience) people used to differentiate their 'mad' signs became riddled with *uncertainty*. Due to this *uncertainty differentiating* had to be learned and relearned. It involved specific practical strategies that Participants had developed over time. Following on with Digger's scenario:

...I sort of caught myself thinking ... No I never saw her that night. So then I caught myself out. That's the sort of ... [the] way to do it. Like approach it logically and say, 'where was I when that was happening (Digger)?

When these strategies were employed to differentiate 'mad' signs, they needed to be able to differentiate the 'real' from the unreal.

Differentiating the 'Real'

When *uncertainty* undermined what was 'real' and what was not, then *differentiating* could resolve *uncertainty* over what was 'real'. However this was difficult to do and so much depended on it:

Sal: ... I'd been seeing things that were really untrue. I wasn't sure of reality. I didn't know what was 'real' and what wasn't 'real' any more. I found it really difficult to distinguish between unreality and reality.

Sometimes what was 'real' got lost and their *differentiating* might be suspect too? What gave Participants confidence in their accuracy in *differentiating* what was 'real', was when they could logically account for what had happened.

Digger: Well I managed to pick up on it, not at first admittedly, but when my girlfriend said that she wasn't screwing around - it's all in my head. And I sat down, thought about it logically and caught myself out in one of these logical traps that, yeah, I wasn't there at the time, so that memory couldn't have happened. I thought, 'yeah, snap, that's it. I'm having schizophrenia again'. And you went and got treatment for it. So that gives me confidence that if I do start suffering from it again that it will not be very long before I pick up on the symptoms, you know.

When events and perceptions could not logically be accounted for after *reviewing* then perceptions were seen to be illness affected and accounted for as 'not real'. Thus what was 'real' was differentiated by what was 'not real'. And 'not real' was used to differentiate illness mediated perceptions. It could seem that there was no starting point that could be seen as existing concretely because their illness haunted actions and event processing with a precarious *uncertainty*:

Joan: ... is that not part of the illness? That you suspect that that is happening because part of the illness is that you have these suspicions all the time. That people are doing things to you and it's very hard to differentiate between what is actual and what is imaginary.

Participants could describe what they were 'not' or had 'lost' or 'lacked' and thus described a self bounded by these same items. This talk developed a proxy identity - an 'I' by omission. When the Participant engaged in *differentiating* they used the same strategy of omission by *differentiating* what things were not. Hence an event was subtracted from until nothing further could be subtracted. For example:

Digger: Well I described the logical traps. You think one of the symptoms is - these things sort of run away with ya, you know. You get one thought like 'H came in here and he looked at me funny, and then he said this and then he picked

up the bottle and smashed it against the wall and then he screamed at me', and then ya (sic) think 'now hold on, hold on, you know. And you have to go back like and think now / did he pick up the bottle and you think 'no he couldn't have picked up the bottle cause I didn't open a bottle until after he'd left'. You see what I mean?

This would seem to mirror therapeutic techniques of restoration where events are first stripped to reality test; people are stripped of their disordered thinking to restore ordered thinking; stripped of their former self to become a patient; and restored to health by focussing on what they do not have. The task of having to differentiate what was 'real' implicitly involved a dislocation from this 'reality', but not so far away that it became impossible to grasp. Moreover it could only be grasped when there was an 'I' that could do the grasping and hence the *differentiating*. Thus the ability to differentiate involved locating the 'I' and hence resolving *uncertainty* about identity in some practical way.

As the task of differentiation proceeded, so too did the sense of location and identity coalesce. In *differentiating* a 'reality', Participants were *differentiating* a self in relation to what was 'real'. Knowing and sharing a 'reality' that other people subscribed to, greatly improved Participants' ability to negotiate and process different social situations. This could then build confidence and trust in a social self, in self processes (e.g. cognition) and recovery. The down side was that there was never any guarantee. Over time individual strategies could become more robust but the underlying *uncertainty* with having to differentiate still filled this activity with unease. This was especially true when Participants had to differentiate appropriateness.

Differentiating Appropriateness (normal)

Differentiating what was 'normal' was essential if a person was going to fit in and share with others in a similar social milieu. The vexed question arose of how to differentiate a normal psychology when what had been experienced was an abnormal psychology. This involved determining both what 'normal' was and how to get there. Generally this was only gained by experience:

Digger: At times I felt like, well, maybe these guys have been talking about me or saying some things like that, but the thing is you got to rationalise and say, 'well people sometimes do talk about ya (sic) anyway'. And don't worry about it. And if it's in ya (sic) head, well, it's not a big, it's not like thinking there's

aliens plotting to take over the planet. Which is what I was thinking when I was seriously ill.

A task for Participants was to become acculturated to an everyday life outside of psychiatric services. If this did not occur it became difficult to acquire the values, norms, expectations and communicative competence that were needed:

Sal: ... you see yourself as different from others when you're lots of the time... when you've been in the psych (sic) system then it's really hard to get out of it. You get into a group where there's no one else around you who has not been in the psych (sic) system. And when you are around other people who have not, you just don't know how to behave, you don't know how to act, you don't know what's expected of you. And the other thing is a lot of people just throw around the word you're crazy when you do something silly and you take it more seriously. You seem to spend more time actually looking for ways to prove that you're not. I think lots of it is, you seem to have a very closed in community once you've been in the psych (sic) system. You shut off other people outside it. And you're trying to actually interact with people. You get involved in discussions. You all know the same people, same system and that's what the discussions revolve around. When it's trying to actually converse about regular things it's a lot harder.

Sal's dilemma was this: How do you determine what was appropriate for a 'normal'/well life with 'normal'/well people, when -

- All you could draw on were experiences where abnormal behaviour seemed 'normal' and 'normal behaviour' was abnormal? and
- Primary socialisation had been within an environment of other unwell people?

The task Sal faced for living a 'normal life' was how to know:

- What she was expected to know?
- What she needed to know?
- When she did not know these things and the path to them was riddled with *uncertainty*?

For Sal, it was essential to get out of the psychiatric system and the people who inhabited it. This gave her a set of experiences to use to discern her views, values and boundaries:

Sal: It's actually me who seems to expect them to worry about it more than they do. They don't seem to worry about it so much. I expect them to notice a difference and if I ask them about it they just want to treat me like everyone else. Actually weird, in a way, because it seems to come more from me than it does from them. It's quite strange in that way. It's - um - they're pretty good the people, they've never really treated me much different. Probably 'cause I just got in and did things.

Her psychiatric disorder did not present as a distinguishing feature to others during interactions in the workplace. The mark of psychiatric disorder which was so visible to her, as she had learned and used it to 'mark out' her life, was invisible to other work colleagues and did not set her apart, although she expected it to:

Sal: They say, "Oh, I didn't know that. I thought you were you". It's like they didn't, they didn't see me as any different from anybody else. And I sort of expect them to think I was this really crazy strange person [laughing].

Learning to see themselves without the lens of illness enabled Participants to discern an everyday life shared by other people. They discerned everyday life by *differentiating* 'normal' and their appropriateness from their social milieu; which required learning not to see themselves as a psychiatric problem. Sal's supra identity of 'crazy' needed relocating to a place amongst her other identities, such as therapist, work colleague, parent, woman, artist, daughter and Pakeha. She was surprised to find her 'crazy' identity had a low salience, and it disconfirmed her expectations about this identity when other people found her other identities more important. At the same time it could manufacture *uncertainty* because if other people did not see her as 'mad' nor saw her 'madness' as relevant, then was she still 'mad'? Primarily *differentiating* gave Participants a measure and means for appropriateness that was experientially based in the shared conduct with others. Participants wanted to 'fit in'.

Fitting in

Fitting in was a task to achieve social congruence. It was a comfortable experience, which was why a lot of psychiatric service users socialised with each other (e.g. at support or advocacy services, or places to get cheap food/clothes/furniture). *Fitting in* was a crucial demonstration of identity competence and facilitated a sense of belonging somewhere. It was closely linked to *making sense* and Participants fitted in because they did make sense. However, 'fitting in' could be uncertain. Thus Participants adopted a trial and error approach where they tested themselves out in different situations to find if they were as 'mad' as they or others thought they were. Participants often looked for cues of when they were not *fitting in* rather than when they were. Poor social fit indicated reduced competence with their psychiatric health, as opposed to by-products of poor social interaction or misunderstanding that could happen to anyone. The

primacy of their psychiatric health acted as a singular reference to self interpretation and how others would interpret them. When Participants were able to differentiate what was 'real' and what was appropriate, it furthered *differentiating* their illness within everyday life.

Differentiating Illness

When events and perceptions started to seem 'out of the ordinary', extremely unusual or bizarre, Participants tried to make sense about what was taking place.

Digger: You don't really know until it starts to get bizarre, you know. It's only when things get bizarre and you think, 'now, hang on, did that really happen?', that you think that maybe you're not having a good day. I mean everybody has bad days. Everybody gets stressed sometimes, or has a shit day at work.

Seeing the 'bizarre' could mark the descent into crisis again, but were things really like this or were Participants just imagining it? There was a need to run these events through the *on guard* process to manage and cope with *uncertainty*. Thus, seeing 'bizarre' or 'crazy' things could mark a deterioration in their mental health. At other times the 'bizarre' could happen slowly and the progression was difficult to spot from the inside. However Participants also talked about 'waking up in the bizarre', where suddenly after a few days/weeks/months it suddenly dawned on them that things were not right. For others, even though they were alert to their descent into the bizarre, they could not be pulled back by solo efforts and either voluntarily or under section (i.e. committal), were admitted to a psychiatric service.

Differentiating illness' experiences via the signs for onset was a permanent task and necessitated being *on guard* for these '*mad*' signs in their events or perceptions. Digger had what he called 'logical traps' that entailed a pre-ordered strategy of replay, evaluation, checking with other time flows, then remembering the event in a 'real mode' thus making this event authentic and stepping over the difficulty of whether he was recalling a 'real' or false memory. Digger also 'checked in' with other Participants about his perceptions and what he thought might have happened. For example:

Digger: ...these things tend to build up from one incident to another ... and the first one might actually be real. That you put perhaps even the right interpretation, or maybe someone says, 'oh he's an asshole' sort of thing, and you just heard him say that, you know. And they tend to sort of race away and sort of

exponential curve, if you know what I mean. You know, they get more and more bizarre and if you can sort of break them down into what you're actually doing at the time. Yeah, that - that's the most difficult part not knowing whether a memory's real or whether it's just bullshit in ya (sic) head, you know. And I suppose, over the years I've developed this logical trap way of doing it, you know. But it doesn't always work if it's only one thing you remember like somebody rang you up and said, 'oh this is so and so I'm pretty pissed off about ya (sic) wife having sex with my husband', and slam down the phone and you think 'shit', you know. And then you think about it an hour later and think did that happen and ya (sic) think well if it happened she would of said who she was wouldn't she, you know?. You see what I mean, you know? And like, logic is quite a big help.

Once *differentiating* the signs of the 'mad' things had taken place, then *deciding* about them could begin.

Deciding

The third stage of the *on guard process* was *deciding* what to do about perceptions of events. Once perceptions of events had alerted Participants to the possibility or presence of '*mad*' signs, and they had differentiated them from background events, they then were able to decide what to do about them. As mentioned, when Participants differentiated what were inappropriate, imagined or illness experiences, they then used these as guides to differentiate what were appropriate, 'real' or well experiences. *Deciding* what were appropriate, 'real' and well experiences for themselves could lead to *deciding* the same in others. The two went hand-in-hand and mirrored each other. Participants could not decide what to do about '*mad*' signs if first they had not been able to differentiate them.

Deciding was an intentional act and moved from just reaction to action. Accumulating decisions that had a probable basis in an everyday life that most people shared strengthened their belief in the perceptual foundation they were using. Outcomes from *deciding* after the *differentiation* of '*mad*' signs had taken place, structured a basis for *deciding* by others about the Participant. The clarity (*differentiation*) that they could bring to their perception of events established a rationale for *deciding* about them. This became crucial to communicate to others when misunderstandings occurred:

Digger: ...she was my girlfriend. I thought she was screwing around and all this sort of stuff. And her insisting that she wasn't and helping me with these logical traps sort of thing, and her sticking by me when most women would have just pissed off, you know. Like, I think the fact is that what she told me that 'cause she had a mental illness herself she could understand it was all in my head, and it

wasn't really, you know, my fault that I thought all that the horrible stuff about it, you know.

Deciding was also critical to the attributions Participants made about events and their behaviours. *Differentiating* an illness related event permitted *deciding* where their 'locus of control' was regarding such events. Locus of control refers to whether an event was attributed to factors that were internal (self) or external (others/environment), stable (fixed/never) or unstable (changeable/sometimes), global (everywhere) or local (situated). *Deciding* that a stressful event at work was not handled well, as opposed to being an illness pre-cursor, flowed into the attributions Participants made about themselves within the course of the event and afterwards during *reviewing*. For instance, thinking a work event was composed of illness factors attributed the work event and their controllability over what happened as:

- 'internal' 'I am responsible, it is my illness'
- 'global' 'everything turns to custard'
- 'stable' 'it's not going to change, this is what always happens before I get sick'

Which sustained illness attributions that drove the *haunting*:

- psychiatric illness is 'ever present' 'internal'
- psychiatric illness is 'unfinished business' 'global'
- psychiatric illness is a 'life sentence' 'stable'

Deciding that the work event was just a work event and not an illness pre-cursor altered the Participant's sense of controllability with what had happened and the attributions that they made about themselves:

- 'external' 'this is what happens in the workplace to other people and not just me'
- 'local' 'it was a busy day, other days I do very well'
- 'unstable' 'this only happens sometimes, not all the time'

Deciding controllability over the event altered their perception of the event, and hence resolved some of the *uncertainty* over the veracity of their understandings about what took place.

Resolving uncertainty when *deciding* about perceptions also extended to memories. Even when events had been differentiated and decided about there could be doubts about whether they were recalling a false memory: "You cannot trust your memory, you have these memories, but you don't know if they are real

or not, and you are trying to figure [it] out logically”(Digger). Digger sorted through his memory using logic and plausibility to determine the fallibility of his memories. Again Participants used *partisans* to check out their decision making regarding sense information and internal processing and their memory of it. The need to decide with confidence was essential to resolving *uncertainty*, yet that *haunting* aspect never permitted 100% certainty. What deciding normal, ‘real’ and well experiences did do was act as a conduit to ‘*generating*’ these items.

Generating

Deciding ‘real’, appropriate and well perceptions was necessary when there was *uncertainty* about them. A consequence of *deciding* was that it contributed to development of memories which were more reliably informed. They were more reliably informed because the experiential base for them was now shared with others. Access to the experiential base of others was through participation in everyday life and through the understandings of others. Knowing a ‘real’ event that was appropriate and mirrored a reality that was shared personally and socially with others was only part of the equation. Without the facility to accumulate and track experiencing of a ‘real’ event shared by others, then knowing what was ‘real’ became a day-to-day activity entangled with an *uncertainty*. *Generating* refers to the activity of accumulating ‘real’ perceptions that were reliably based on ‘real’ events within memory. These could then transfer out of the time frame they occurred in and generate a ‘real’ perception in other action scenes with other people.

Generating was a critical part of the *on guard process* as it provided the warrant for what was ‘real’. Without this, reality was totally contingent on discerning what was ‘real’ within that moment. To be *on guard* for ‘*mad signs*’ and not be able either to discern what was ‘real’ within that moment, or to generate one from prior experience, undermined the *on guard process*. This introduced a destabilising *uncertainty*; an *uncertainty* over the foundation of being ‘someone’. Once a ‘real’ perception was generated and had a good probability of being appropriate, further verification with others was used to confirm that perception. Events and perceptions could be stored and retrieved and then acted upon with confidence that they fitted a social reality shared by others. It consolidated learning of

appropriate social cues and behavioural expectations. However, the management of what was 'real' was uncertain as one day's *alerting, differentiating and deciding* could vary in quality, as could personal comfort with self-states. The final stage of the *on guard* process was *making sense*.

Making sense

After sorting '*mad*' signs for what were *inappropriate, imagined* and *unwell* experiences, Participants tried to make sense of the signs and background information that were present. They also wanted to be seen as *making sense* to people around them. This happened in at least two ways. First there was 'real time' *making sense* when Participants were current with their discerning of '*mad*' signs and inappropriate, illness generated and imagined events. They were cognisant of these things during the time frame in which they occurred and completed their *making sense* of things then. The second way of *making sense* was to engage in a process that was not completed in the current time frame of events. In this situation Participants often took their perceptions of events out of the action scene into a quiet place later, and then attempted to sort through what had taken place:

Evan. But not for me. I have to keep tabs on how far I am influenced by other people and I have to also come to the point where I make my own decision about who is nuts here, you know. Who is nuts, me or them? And one of the biggest things I have found that helps me to deal with that is having my own place to myself. I can pick and choose what I am influenced by. It is entirely my own fault if I make the wrong choices and I like that.

The heart of the matter was getting to (a) what was the course of events (i.e. a timeline)? and (b) what veracity could be given to their perception of the event?

Reviewing

Reviewing was when events were passed through a mental review to sort out what was the event and what was their perception of the event. This process has three parts:

- a. *Rumination* was the activity where events were rerun over and over again in a Participant's mind. This checked whether something was missed; it verified whether what did happen actually did; and then enabled prediction of what consequences could ensue; and what

their course of action would be. *Rumination* was driven by *uncertainty* so that even though 'mad' signs were discerned, further replaying of events only served to multiply the possible consequences that could occur. *Rumination* was not an emotionally neutral activity. It had a sense of urgency and high probability of very salient consequences, which led Participants to agonise over the course of events.

- b. *Agonising* – was the exertion, writhing, anguish, distress, worry and struggle of their efforts to arrive at a decision. It was the *agonising* about an event that made *ruminating* an exhausting activity when the *uncertainty* of task, let alone the outcome, might not be resolved. There was no promise of a decision, although Participants expected there could be. The *agonising* about an event could drive further *uncertainty* and vacillation over direction for actions and satisfaction with outcomes.
- c. *Magnification* could blow up the significance of an event until it was out of proportion to its context and consequence. The *rumination* and *agonising* struggle about an event suggested that it really was important. This magnified smaller or related concerns into more worrisome ones (i.e. 'getting worked up'). All of a sudden a small indiscretion or misinterpretation was magnified into a larger one, and so not only were the concerns perceived as bigger, but there were also more of them - and increased consequences as well.

Reviewing could lead to sorting through events in a practical and relaxed way, outside of the time frame within which the event occurred. However, *uncertainty* could amplify this process and concern over expected outcomes. Consequently the Participant could end up more distressed than they were at the time the event occurred. It could promote a sense of *caution* and *vulnerability* that could reduce self-esteem when events insignificant to other people were suddenly magnified and threatened important aspects of social relationships:

Digger: you sort of agonizing all night ...Did this happen or didn't this happen [at work]?... No, I was there at the time so I couldn't be at so and so's place at the

time when I think this happened, so that didn't happen. So you spend half the night doing that, so you are dog tired.

Participants could agonise about events and feed and re-feed them through their internal processing in order to make sense of what had happened. Sometimes denouement was only achieved by discussing the events and their perception of them with someone else. However, the *magnification of uncertainty by reviewing* could be so distressful that Participants would cease employment rather than sort through their difficulties with the people in their workplace. Alternatively, they could approach the person who was the source of their concerns to discuss things. After disclosing about what they thought had happened (and also about their psychiatric disorder), Participants often expected the worst. At times other people appreciated their candour and were helpful. On other occasions they did not.

What greatly assisted *making sense* for Participants was personalisation of their illness experiences. When Participants were marked and thus labelled as mentally ill, it usually involved a diagnosis. When a diagnosis occurred, it involved fitting the diagnosis to the person in a non-consensual way. When this happened the person could reject their diagnosis and hence had difficulty following a treatment plan they did not believe in or were confused about. Not believing in their diagnosis and hence what was symptomatic of their disorder, could make it difficult to believe in their '*mad*' signs, let alone try to recognise them independently and respond appropriately. These aspects of 'making sense' are discussed more fully in Chapter 7 - Disclosure. What is important here is that with time, experience and insight Participants start to perceive warning signs. These signs are often very individual but when effective they spring from the understanding the person has of their disorder via their own words and processes.

Making Sense is Mental Health

Making sense was a flag for good mental health. It was not only whether the self was making sense but whether events, actions, and interactions were 'making sense' in terms of place, expectations, appropriateness, and whether this was shared in some way with others. *Making sense* was not dependent on being 'not mad' although Participants often thought it was. Participants achieved '*making sense*' when there was a sense of fit between personal experiencing and the

demands and expectations of their social environment. When there was *uncertainty* around social fit for Participants then ‘*making sense*’ permitted the question: was it me or was it them? *Making sense* enabled Participants to sort through such a question without having to disclose about their psychiatric status.

Illness Signs

The problem with internal and external markers for ‘making sense’ was that they were defined by psychiatric health. Being alert to ‘*mad*’ signs; having to discern inappropriate, illness and imagined events; and using *reviewing* to sort *uncertainty* with events, all enabled sense to be made of everyday experiences. They were the boundary points or doorway for accessing everyday experiences that were shared by other people. But the way to everyday life for most people was in knowing:

- What was abnormal by what is normal,
- What was imagined by what was ‘real’, and
- What was illness by what was wellness.

The difficulty with this was that when Participants were not seen to be participating in everyday life in an everyday way (i.e. normal, real, well) their identity of employee could suddenly get pulled back into a psychiatric identity. It was as if the categories of membership for employment such as white collar, blue collar and pink collar now had an overarching category called ‘mad’ collar, which subsumed prior membership of other categories. This was particularly so when the loss of *making sense* to other people was collared by ‘madness’ and not other possibilities shared by fellow workmates. The net effect of this could be:

- Competency in mental health was competency at *making sense*
- Competency in employment was competency at *making sense*
- Therefore competency in employment was competency in mental health.

Hence poor job competence could equal poor mental health competence, so that a lapse of performance at work (when Participants were not *making sense*) could be seen as a consequence of their psychiatric problems rather than as a lapse in social or other competencies. Thus managing a job could get subsumed into managing mental health, which reprised the centrality of psychiatric illness as a core feature of working life, with all the *haunting* prospects that that entailed.

Summary

The *vigil* was crucial in *resolving uncertainty* in the workplace. However, having to attend to the signs of their psychiatric disorder, when perceptual and cognitive processes themselves were uncertain, increased uncertainty about *vigilance*. Increased attunement to these signs instituted them as personal markers between illness and wellness which then reified them as boundaries between self and others. *Vigilance* enabled Participants to make sense of their self-perceptions and workplace interactions in a manner that was likely to be shared by other work colleagues. It resolved *uncertainty* about psychiatric health and yet it also created further *uncertainty*. The *on guard process*, despite best attempts, could be uncertain, and the need for *vigilance* primed *haunting*, so that workplace and mental health performance were often perceived to be the same. Interactions with other people took on a new meaning when the promise for acceptance could easily swing to rejection. Failure in social interactions was a failure of mental health and not a lapse in social competence that could happen to anybody. The issues and concerns about disclosing psychiatric status are expanded on in the next chapter on *disclosure*.

CHAPTER 7 - DISCLOSURE

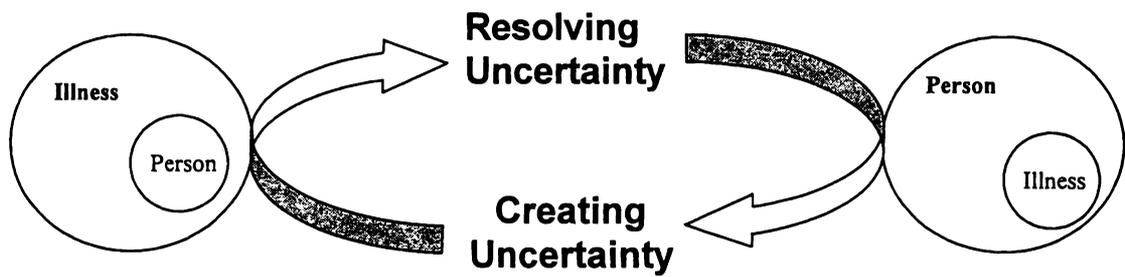


Figure 1. Basic Social Process

Introduction

Disclosure to other people involved revealing something about psychiatric diagnosis, status, health, experience or associations to an audience. Deciding who to disclose to, when this was required, how to go about it and what consequences could ensue, created *uncertainty* for both Participant and audience. From this *uncertainty* Participants accumulated experience in *disclosure*. They then employed strategies to maximise outcomes and resolve *uncertainty*, based on these experiences. *Vigilance* was required to resolve the *uncertainty* that *disclosure* could create. Apart from *inadvertent disclosure* three main strategies for selective *disclosure* were used. These were a 'needed', an 'if needed' and 'tell-you-straight' approach to *disclosure*. These strategies were learned and developed from interactions and the consequences of talking to other people.

Disclosure to others was an important event for most Participants that often had dramatic and unintended consequences, especially when entering or maintaining employment. The effects of *disclosure* haunted Participants' future life activities. The consequences from interactions with others affected personal and social identity, their competence and self-worth. As psychiatric stigma occurred from using a psychiatric service, there were important facets of Participant experience gained from this activity. Whether implicit or explicit, Participants learned both how and how not to talk about psychiatric disorder from psychiatric service

experiences. Transfer of talk practices to an employment setting that had different imperatives infused *disclosure* with a further *uncertainty*. How this happened and what consequences ensued are examined in detail next because *disclosure* was a central concern in the negotiation and practice of everyday life.

Personal and Social Uncertainty

Disclosing to others had a dual capacity for *resolving uncertainty* and creating further *uncertainty* personally and socially. When Participants disclosed there was no guarantee that this would achieve a positive or negative outcome. The *uncertainty* over outcomes *haunted* most activities of *disclosure*. *Uncertainties* were:

Personal - perceptual processes (e.g. hearing, seeing), cognition (e.g. memory, recall, thinking) and emotional fit (e.g. comfort, anxiety, anger, frustration),

Social - adversely affect their sense of social competence or social belonging and future social possibilities, via the comments and actions of others.

The resolving of personal and social *uncertainty* during *monitoring* was amplified when *disclosure* took place in situations involving evaluative contexts with highly salient outcomes. In these situations, any aspect of their person could inform an audience of their mental health status. Participants' efforts at *monitoring* themselves and their situation, and so resolving *uncertainty*, were influenced by what was said or not said about their psychiatric disorder. The extent of this influence was shaped by:

- the character of their talk,
- the context,
- previous talk experiences,
- others' talk,
- what consequences resulted from talking,
- socially and culturally shared messages about 'madness' and 'mad' people,
- and inferences they made from their experiences about self-identity, competency, self worth and social fit.

Disclosure of information about their psychiatric disorder had the potential to create both adverse and complimentary outcomes for people when heard and remembered by an audience. The valence and durability of these outcomes

affected reciprocity with others and spread beyond the immediate time-frame and persons present (i.e. *haunting*). *Disclosure* and experiences around *disclosure* involved a risk. *Uncertainty* over outcomes was the risk that Reg experienced: “whenever you mention the fact you are a psychiatric survivor to anybody you are not sure about whether they are going to understand it or not. It is always going to be a risk”. The *uncertainty* over other people’s understanding could generate an *uncertainty* over likely outcomes.

When risk occurred, Participants were likely to perceive that they were risking negative outcomes rather than positive ones. Thus negative outcomes were more likely to be associated with *uncertainty*. Hence any *uncertainty* in *disclosure* was that it could invoke negative outcomes, both for other people (i.e. fear):

Digger: ...the woman next door came and introduced herself and said, ‘Oh the last person that was in here was a woman that had paranoid schizophrenia. God, imagine what she was like! I was really very scared for her’ I didn’t think it was very appropriate to tell her that I had paranoid schizophrenia myself, you know. I did later on when we got pretty friendly and got to know her. But yeah some people are quite afraid of people with mental illness.

and for themselves (i.e. social degrading). Robert had entered a bank to withdraw money and the teller was polite and helpful until, in his own words:

Robert: ... I let out more than I should have and the reaction of the bank teller taking down my details for an overdraft application ... just the moment I said I was on a benefit for the psychiatric problem it was instantaneous transformation of the body language. The attitude that I was ... it just changed like that. It made things very difficult.

The dynamics in Robert’s situation were familiar to most Participants. The situation was highly evaluative (e.g. an overdraft application) and the outcomes were very important to both parties. When Robert disclosed, an *awkward moment* occurred.

Awkward Moments.

Awkward moments were perceived as a betrayal of confidence, adverse to one’s course and disagreeable to experience. They resulted in embarrassment, perversity, clumsiness, inconvenience and an unease that underscored the *uncertainty* over outcomes. They were not easy to deal with and required cautious action. The *awkward moment* with the bank teller occurred when Robert was not presenting any bizarre behaviour. The only *disclosure* was that he had a

'psychiatric problem'. The manner, attitude and speech of the teller were perceived suddenly to have changed. The emotional valence went from positive to negative, from helpfulness to impatience to finish. It was 'instantaneous' and for Robert in this situation, immutable - "It made things very difficult". He felt embarrassed and ashamed. *Social uncertainty* led to *personal uncertainty*. As his *personal uncertainty* escalated, his sense of social competence reduced. He started to fluster as inner turmoil swamped his ability to recover the situation and he exited quickly. But future behaviour did not have to mirror past behaviour as 'hard learning' could also be a *turning point*: "one of the hard learning points was where I learned to remodify my explanations of where I had been and what I was doing or why I needed help" (Robert).

In similar instances again Robert might employ explanations and behavioural repertoires that could skirt around the *awkward moments* of past situations. Alternatively, as some Participants did, they avoided situations that generated overwhelming personal and social *uncertainty*. This was done to avoid *awkward moments* that were produced from *uncertainty* and experiences that:

...make[s] you feel like a piece of shit. Make you feel angry. It makes you feel like isolating yourself. Makes you feel like not talking to people without emotional illnesses because you feel safe and comfortable with them. Because they understand and they are actually kinder and nicer than some of the people who are so-called normal (Mary).

Other consequences that can occur after *disclosure* are discussed as *social unravelling* and *social shedding*. These two categories demonstrate how everyday life confirmed the negative expectations held about those who have used psychiatric services.

Social Unravelling

Social unravelling occurs when the threads of social life start to unravel. For Veila these threads were employment and relationships:

Veila: I did not like the [workplace] culture. There was a lot of snobbery around [job status] Here I was with a university education and I could not utilise that because, I was..., I had..., I thought of myself as being too unworthy to use that. So I just went for menial jobs, and I remember applying once for a research position and I just got it all wrong [laughter] and I think my world was unravelling.

Social uncertainty arose as Veila increasingly felt she was not *fitting in*. Not *fitting in* could lead to feeling rejected (“snobbery”). Initial external explanations (“the culture”) were not sustained. Unrealised goals when Veila had the skill base (“university education”) to achieve them created a disjuncture with external explanations. They did not suffice. External explanations did not match internal expectations. Resolving *uncertainty* while achieving these internal expectations, led her to reduce them. Her expectations (“menial jobs”) became congruent with her being-in-the-world. Finishing the comments Veila started takes you through her thinking to her conclusion about being-in-the-world: “I was [a consumer]; I had [a mental illness]; I thought of myself as being too unworthy”. No aspect of knowing about the world holds it together when your being-in-the-world is unravelling. It was not that Veila was ‘unable’; it was because she was ‘unworthy’. That was why she ‘could not utilise’ her knowledge. Knowing proceeds from being. Her change in being had altered her knowing. This change in being was recognised by others.

Social Shedding

When *social unravelling* occurred it was often accompanied by *social shedding*, where people shed the Participant from their social orbit.

Piha: I had one cousin who was my bridesmaid who as soon as I got mentally ill she will not even come and visit me, even though I have come back to being my old self ... I see her ... but she is just not comfortable.

Social shedding was rarely explained to the Participant by the person doing it. The person was usually just avoided from the moment of *disclosure*. In some instances, as with Piha, it was not easy to avoid your neighbours so Participants “get comments”. While the explanation for others’ behaviour could create *uncertainty*, there was little ambiguity of the intention behind those actions. Participants were experiencing a rejection that set them apart from their pre-existing social milieu. Their mark of ‘madness’ marked them out and marked them off from other people. Explanations were not able to retrieve the social warrant that some Participants used to enjoy with friends. Daily interaction with ‘nice people’ created a thin veneer over their very negative views and could render such people as ‘superficial’ to the Participant.

Lass: I lived in a very nice little community which had always been warm and accepting, and one of my neighbours said to me, ‘We heard you were in

[hospital] and we were surprised to see you back here'. Oh well why is that? It has been my home for the last ten years. Why is it a surprise? He said "because don't you realise that the shame and disgrace of mental illness reflects poorly on family and friends and neighbours, and we expected that you would have moved on"

Lass found it hard to believe that friends and neighbours could turn on her so quickly. Lass was expected to know that she had accrued a social shame and that her social status no longer matched those around them. She did not fit, she had been rejected, she should have known that she did not fit, and she should be gone; because to stay brought 'shame and disgrace' to her friends and neighbours.

The experience of psychiatric disorder inaugurated a new social self and trajectory by *constructing identity*, which could destabilise previous familial and friendly associations. With previous friendships under threat it was easy to attribute the reasons for this to external things, such as group membership. Thus 'normal' people who had never experienced psychiatric illness, had not used psychiatric services and did not comprehend psychiatric disorder became sources of threat; again this created *uncertainty*. To move back into everyday life required associations with everyday people (some of whom may have been consumers) yet this was the very group that manufactured the social *uncertainty* they faced. The threat also worked in the opposite direction. *Disclosure* could breed a fear that the people to whom they had disclosed could be labelled as 'mad' too.

Veila: I was staying with friends of the family and I asked them to visit me at [hospital] but they would not come. So I was quite disappointed. I thought that must be the stigma again of psychiatric illness. People don't want to associate with you or be seen with you because they may get labelled the same thing by association.

The mark of 'madness' could restrict access to the social spaces they used to occupy. It could permanently revoke the social warrant they had with friends. *Disclosure* could haunt future interaction with an *uncertainty* about encounters irrespective of former close friendships. When the Participant was shed from social relationships they were faced with a conundrum of *uncertainty*. The desire for social contact and to be human in the way that other people did, required social contact. Yet social contact could be a potent source of uncertain outcomes about self-worth and self-competence, hence an *uncertainty*. *Resolving uncertainty* could turn into a pull-push process. Participants were pulled into

social contact by the desire to attain a social self. Conversely the social self they experienced was diminished by the reactions of others and they were pushed back from social contact.

Disclosure was a precarious activity, fraught with *uncertainty* over action and consequence. *Uncertainty* underwrote the risk in *disclosure*. The *haunting* prospect of psychiatric disorder, the *uncertainty* of when it was present with difficulties for self and others, and the bracketing of people as ‘mad’ eroded their being-in-the-world. But being-in-the-world of people required social contact to have a social life. Resolving *uncertainty* around *disclosure* was therefore an important feature in developing interactional competence and participating in a productive social life during everyday activities. The prototype for *disclosure* to others was developed from earlier experiences within acute or support psychiatric services. It was during these experiences of contact with psychiatric services that Participants were trained to disclose. *Disclosure* to service personnel is an essential part of most therapeutic intervention, management and support. At the same time that a person was being asked to disclose about their psychiatric disorder and related experiences, they were also learning the how, when, where and who of *disclosure* talk. The next section demonstrates a key tenet of this thesis that stigma can arise from using psychiatric services. How this happens is examined through features of *disclosure* talk with psychiatric and support staff.

Disclosure to Monitoring Others

Psychiatric and Support Service Staff

Disclosure in psychiatric services can be seen as something that is necessary and contingent for service personnel to discharge their care. *Disclosure* in this instance was a *needed disclosure*. Participants needed to disclose in order for staff to receive feedback on self-states, monitor medication regimes and to use talking therapies. The manner and substance of *disclosure* about client self states could be both directed and undirected. *Directed disclosure* elicited specific client information regarding mental health issues, such as during a consultation with a registrar. Yet *undirected disclosure* (e.g. during everyday interaction with nursing staff) could also elicit similar information. Any interaction with staff or clients

was indicative of mental health and so provided information to staff for mental health assessment, *monitoring* and records. This could act as a Participant template for being and knowing, so that any action or interaction was indicative of mental health status.

Participants learned the importance and necessity of *disclosure* via the outcomes of this activity with staff. They could conclude that the service received and their service exit was contingent upon their *disclosure*. It was likely that unless a person had disclosed about their disorder in some way, they would not be able to leave a psychiatric service. Apart from losing a major source of information which informed staff decision making, not disclosing could be indicative of continuing psychopathology (e.g. lack of insight, treatment resistance, and intransigence). Thus *disclosures* about psychiatric disorder to staff were expected to be authentic and made frequently. Not disclosing was implicitly discouraged and could be indicative of regression rather than advancement.

Looking at this more closely, engaging in *disclosure* built reciprocal information for both Participants and staff. During psychiatric care and support, Participants learned the expectations of these staff by their questions/responses regarding their disorder experiences and the status or power staff hold. Both the way of thinking about their illness and the language used were configured in the interactions with staff. The way out of personal confusion and back out into the world was through interaction with mental health service staff. They held the keys to their exit. Staff modelled 'well' behaviour, emotions and thinking. Talking the same language and using a conceptual approach to their experiences similar to those modelled by staff was more likely to be reinforced as appropriate. However, language and discursive actions were rarely value-free.

Disclosure is an action that locates people by:

- Who does/does not decide the questions?
- Who can/cannot ask the questions?
- Who has/has not to respond?
- Who can/cannot challenge the answers?
- Who does/does not decide the answer is appropriate to the task?
- Who is/is not believed?

➤ Who writes the record of events?

Answers to the above locate a person in a field of relationships, power, control and identity. They were rarely explicit, as in the following example, but infused roles with rules and expectations that were quickly learned and adapted to by both parties or resisted.

When Robert was visiting a psychiatrist with his nurse present, the psychiatrist went through his drug regime and arrived at a decision to raise his medication. He then asked Robert for his consent in an expectation of agreement. Robert replied in an even voice that he did not have a psychiatric illness and that he should not be on any psychiatric medication, as what he was suffering from were the effects of a head injury not a psychiatric disorder. Hence as the diagnosis was inappropriate so was the medication. Robert said, "So please take me off it". The expected agreement by Robert to the psychiatrist's assessment was not forthcoming. His denial led to an escalation of frustration within the psychiatrist who exploded: "I am not the crazy one, you are!" As a 'patient', when you get out of role, you can be reminded to return to it. "This was the case where the doctor had me in a box labelled nutter and his only response to that was medication" (Robert). Notice the psychiatrist did not say Robert was saying anything 'crazy'. Rather Robert *was* 'crazy' in his being, which altered his knowing and precluded his saying non-'crazy' things. From *disclosure* can ensue *uncertainty*. *Disclosure* socially located Participants and could entrap them within roles of disrepute.

Disclosure in role-based interactions could incur judgements and pre-judgements that appeared immutable and thus impervious to alternate explanations. It trapped these judgements within mental health considerations and pulled Participant knowing and embodiment back into the bounds of their diagnosis. Thus experiences of *disclosure* could be closely linked to experiences of disempowerment, where psychiatric status located Participants in a subordinate position during clinical interactions. Hence Robert's reasoned denial, instead of presenting new information to the psychiatrist, was viewed as challenging the psychiatrist's role; usurping his power/knowledge. It further confirmed Robert's

position as ‘crazy’ and in need of treatment¹⁴. Nothing he could have said would have been believed in support of his view. Rather it provided further confirmation of his need for treatment. *Disclosure* could invoke the wielding of power by others that then shrinks the Participant into pre-existing categories and possibilities.

In this situation the Participant might learn that their only needs were psychiatric needs. When other people rendered their needs as psychiatric needs, this inclined the Participant to do likewise. The flow of power was such that other people could author both what was ‘need’ and what was the ‘response’. When the Participant had no authorship of their need and treatment they had to rely on other people to do it for them all the time, instead of just some of the time. *Disclosure* could invite helplessness:

Sal: ...you get used to relying on people and you learn to be helpless many times. You just aren’t expected to be able to get yourself out many times and there’s always people there to help you.

The adaptation into the role of psychiatric patient is vividly portrayed by Genevieve’s comments. Two days prior to her admission she was a health professional managing a large client load, working in a valued role where her opinion was respected and remunerated accordingly. Upon Genevieve’s arrival and getting a room in a secure ward: “it was just wander around like a psych (sic) patient – up and down the ward” (Genevieve). The shift in role and expectation, once she was marked as a psychiatric patient, submerged all previous identity and capability. The change in role that accompanied being marked or labelled was not a transitory activity. The mark of ‘madness’ could transfer and stay with her in future times and contexts, which were unable to be predicted. Even though she was discharged from this recent admission, she would never be discharged from her diagnosis. The diagnosis lived on in records independent of the judgement of the persons who made it and the health states currently experienced by the Participant. But how were these judgements made and what effects arose for the Participant when they disclosed? It seemed something important was taking place involving the ‘what’ and ‘how’ of *disclosure*. These aspects were involved when talking to a psychiatrist and are examined next in greater detail.

¹⁴ Robert was recently reassessed. He was found to have a thyroid deficiency in addition to his head injury, and has been phased off all psychiatric medication.

Talking to a psychiatrist during an appointment necessarily involved the *eliciting* of verbal information about their psychiatric disorder. *Disclosure* with a psychiatrist had the quality of revealing one's own knowledge and actions by opening themselves up to the knowledge 'gaze' of others. *Disclosure* was a performative act to an audience, where the boundaries of how much or how little, what was good or bad, right or wrong performance, disappeared. There were no limits to the range of performance values. Thus not disclosing, poor disclosing, misleading *disclosure*, very competent *disclosure* could all create value cues for any decision-making by a psychiatrist. Everything was indicative of something that related to their psychiatric health profile.

The questions asked by psychiatrists were usually not of an "empathic or dialogic or everyday intent" (Edmond). The language used incorporated terms drawn from assessment, diagnosis and medication 'talk'. This talk indicated to both parties what the psychiatrist's indices of psychiatric health were, and how they were progressing according to these indices. There could be apprehension and *uncertainty* prior to, and during, the consultation.

The apprehension was, "will I be categorised?" or "labelled" (Edmond) and thus seen as a "label" and put in a 'box' (Robert). An underlying concern was: "will I be asked about what is happening for me?" so that discussion co-constructs in a dynamic and meaningful way client answers to: "how to manage my life, when am I going to be over this, if I could be over this, if it is a lifetime thing - forever and ever amen "? (Edmond).

The language of diagnosis and assessment could increase *uncertainty*. Questions using this linguistic form predetermined discussion. Usually either questions proceeded from or to a diagnostic categorisation (label). Clients discerned that this intention to categorise was at the expense of integrating their experience in their own words with the knowledge of the consultant:

Edmond: They don't really let us explore these ideas you've got – very defeating ... Could never ever get me an answer that I was comfortable with ... Not knowing is the *uncertainty*"[author's emphasis].

Their *disclosure* to people who were experts in mental health could leave them with perceptions that it resolved nothing. If this occurred with a group of people who have privileged knowledge and experience about psychiatric health, it could heighten *uncertainty* about *disclosure* to lay people. The form and reach of questions could anchor in attributions of:

- illness permanence (nothing changes, reduced hope of recovery),
- an overt illness focus (there is nothing else about self important enough to be discussed),
- an illness identity (known only by their illness), and
- limited human attributes (becoming ill equalled becoming less human).

It was by repeated interaction with an overt illness focus, that their previous identity was subsumed into an illness identity. This *reconstruction* of *identity* gave rise to the *haunting*. The boundary of withdrawal into a psychiatric service, the boundary of communication, the boundary of appropriateness, the boundary of wellness, the boundary of the real, the boundary of identity and the boundary for service exit, were shaped by the mark of ‘madness’ and the *uncertainty* it engendered. People were how they communicated with their world. Being and identity were interactively and reflexively formed during conversation. Participation in conversation and *disclosure* during service use developed a repertoire for *disclosure* with others that paralleled adaptation into the role of a “psych patient” (Genevieve).

Such activity of *disclosure* built little initiation into flexibility with *disclosure*. There were clear sets of probes, which both parties expected to be asked. Transfer of such *disclosure* practices to a workplace could be detrimental. Participants learned that they were expected to disclose when asked questions concerning their health, not just their mental health. This was especially so in evaluative contexts and when being interviewed by a person of higher work status, such as an employer. Such disclosure could be very inappropriate to the task of getting a job. An overt focus on illness (e.g. stabilise, assess, manage, discharge to community support/care) cultivated an illness identity whose concerns were primarily with illness for both staff and client. This could create considerable confusion. The person may be ‘well’ enough to leave a psychiatric service - in other words, had

learned what was necessary to be discharged. But rarely had Participants learned or been prepared for how to face up to the demands of everyday life. Yet this was often the biggest question mark in their minds:

Reg: ...coming back from hospital was like returning home after World War 2 and being lost - kind of the old boundary. The old familiar surroundings were not quite there and meantime I had sort of experienced quite a sort of a battle field during that time in hospital ... The biggest question mark in my mind as I came out ... was what did this [bi-polar disorder] mean for my work life from now on? What does this mean for me? What can I do? What cannot I do? What are your suggestions? And really nobody - none of the psychiatrists - could really offer me anything.

The *uncertainty* around the course of their disorder, vulnerability, psychiatric service use, length of stay and post-crisis life course, framed a particularly challenging task; a task they were reminded of when Participants were asked to disclose to a non-consumer audience. Apart from psychiatric and support staff, some of the first instances of *disclosure* involve *disclosure to consumers*.

Consumers

Participants were likely to spend more time talking to other consumers within a service than to staff. Other consumers were usually the first group of non-staff people the Participant had consistent interactions with. Their interactions with other consumers were likely to involve *disclosure*, as within a mental health service mental health was a high priority topic. Participants also received advice from other consumers about what to do and say, in order to survive their treatment. They learned what outcomes ensued from what they had disclosed to which staff. Learning these things could maximise reciprocity with their disclosures. At the same time it could reduce adverse events occurring due to misunderstanding, staff retribution or lack of interest. Moreover there is now greater transparency with staff decision-making. Consumers have access to their personal records. They can see how staff have interpreted or misinterpreted what they have said and how this has led to their course of service response. The informal and formal acquiring of information during and after *disclosure* was instrumental in learning the 'get well game'.

Participants could develop a wariness and *uncertainty* in disclosing about their psychiatric disorder. This could extend to other consumers within a service.

Genevieve: There were some really sick people there ... so I didn't have much communication at all ... All I wanted to do was get out. So I wasn't going to talk to them about any problems I had.

Participants were faced with the contradiction that they were trying to get well in the presence of the 'madness' and 'mad' people around them. When other people were unwell there could be a risk of the same thing happening to them.

Evan: I have reached the point now where I make my own judgement about who is mad. I don't believe that madness is not contagious. I know strictly in the medical sense it probably isn't contagious but, using the language loosely, I know that it is contagious.

Disclosing to, and associating with other people who were 'mad' could exacerbate their own disorder. Thus, *disclosure* had aspects of both creating and resolving *uncertainty*. The difficulty was that in such an environment it was hard to know what boundaries for appropriateness, recovery and reality were. There was an *uncertainty* around how people could get well enough to make sense of their world and themselves, when surrounded by and interacting with other clients.

Sada: I think I'm making sense, aye. But you try and tell a crazy person he's making sense - even a crazy person thinks he's making sense. How does he know? How do I know I'm making sense?

Thus the journey to recovery and 'making sense' was fraught with ambiguity and *uncertainty*. Participants often talked about psychiatric disorder in this context from a first-person perspective. Thus this talking involved disclosing about their disorder. These *disclosures* could act as sensitising and empathising actions with other consumers. They established familiarity with drugs, places, activities, organisations, professionals and people whom they had known as a result of using psychiatric services. But it was hard to get experience of regular interactions with people outside the 'system' when the *uncertainty* of *disclosure* ensured a comfort with 'system' insiders:

Mary: I feel comfortable around other psych (sic) survivors. I am often resentful of people without emotional disorders because they do not understand how we feel. They do not understand us. But anybody with an emotional disorder knows what it is like to go through the hell of it all. So I feel comfortable with people with psychiatric disorders.

Talking about their psychiatric disorder and experiences associated with it could form a large part of conversation with staff and people. There were implicit social pressures to do this; and implicit social consequences around not disclosing could

lead to reduced conversation opportunities with people. The activity of regularly engaging in *disclosure* talk about their disorder could lead to feeling that it was okay to do so. This position could rapidly change after adverse experiences when *disclosure* occurred outside mental health care. Strategies were used by Participants, either deliberately or inadvertently, to actively test out *disclosure* acts through everyday activities. Moreover, at the same time the experiences of *disclosure* then sensitised the Participant to relearning the rules of social engagement, as a person who had experienced psychiatric disorder. However, the *uncertainty* around *disclosure* acts was never completely resolved for self and others. *Uncertainty* could be magnified in role-based and highly evaluative situations that occurred within the workplace.

Disclosure in the workplace

Disclosure in the workplace was different to disclosure elsewhere. It combined elements of disclosure in:

- Psychiatric and support services - in that there were role-based disclosures, hence there was a power differential present.
- Friendships – as informal disclosures occurred and relationships at work could often lead to friendships.

In addition to these features there were other elements:

- work provided a primary status and social location;
- work provided economic gain or sanction;
- selection and retention of employment was competitive and therefore involved evaluation;
- outcomes from work promoted health across a range of dimensions; and
- work was a primary source of social inclusion and participation in everyday life.

Thus the workplace was often an intersection for values, judgements, prejudgements, power relations, social participation and personal worth. It was an area enmeshed with expectations, rewards and considerable consequences if loss of employment occurred. Employment was valued and coveted equally by those who were employed, those who were trying to be employed and those that were not. Entry into employment and retention of employment entailed an *uncertainty* that while there is much to gain there is also much to lose. For Participants,

disclosure in the workplace could lead to both productive and negative consequences.

In discussing *disclosure* Participants characterised the normative aspects by 'shoulds' and the *uncertainties* as 'what ifs'. For instance, 'should I disclose to an employer and when should this happen?' 'If I tell a workmate, what will they tell others?' 'If others are told what will they do with this information?' 'If others are told, what will they think of me?' 'If I do not tell others, what happens when I become unwell?' 'When I become unwell should I disclose or just take sick leave'? When Participants disclosed about their psychiatric disorder in the work place, they did not come to the act of *disclosure* in a naive manner. Rather *disclosure* was an activity that had been learned in previous contexts, notably while using mental health and support services. Here the act of disclosure was often viewed as an essential pre-requisite to each of seeking, entering and exiting these services. It was value laden (in terms of ensuing outcomes), expected to be authentic (no subterfuge involved), helpful, and to happen frequently. This experience of *disclosure* and its outcomes could be the converse of what was required to take place during job seeking and working. For instance Tane did not want to disclose, but felt that probing was a surreptitious way of eliciting information during a job interview. When he was 'put on the spot' about his past experiences, he did not want to lie. Disclosure was to reduce *his uncertainty*:

... I asked him if there was a job for me and he said "oh have you done the training?". I said, 'yeah I done the training'. I didn't tell him that I went to hospital. You see, it was just the fact that they said, "are you familiar with places like [prison Z] and [hospital X]?" I said, "why is that for?". He said, "just in case you have to transfer patients/ clients from [prison Z] to [hospital X]". That hit me, aye. I didn't know what to say, aye, I thought they were putting me on the spot. Well, I didn't know if they were or not. I said, 'yeah I'm very familiar with them, I was an ex- I was an ex-client of [hospital X]. Well they said, 'oh sorry there's no jobs'. So that was a slap on the face (Tane).

Participants, when 'put on the spot' about their health, were faced with the social demand of responding to people in authority. The template to such *disclosure* could be past experience with psychiatric service personnel. Previous acts of *disclosure* from these situations do not transfer well to the workplace. Nor do the inferences concerning self-identity, personal power and confidence that position people during *disclosure*. They encourage a sense of self, hope and possibilities of

very limited scope. Examining this more closely, the main guide a person had to the 'shoulds', 'what ifs', 'whens', and 'hows' of *disclosure* activities were from the outcomes of past experiences in different contexts and the *uncertainty* around these outcomes. For instance they could range from:

- the very productive - people clearly know about their disorder and support the efforts made to cope and be productive in the work place, to
- the disappointing - a job interview that was going to lead to employment, upon *disclosure* now leads to unemployment, to
- outright persecution - where there is frequent and sustained harassing by other workers.

These were not trivial outcomes for Participants. When strongly evaluative contexts (like job interviews) combined with adverse outcomes, this fed back into the high salience of *disclosure* activities for many Participants. When *disclosure* had taken place, it could not be taken back, nor could negative or positive unintended consequences be calculated in advance. As such there was a degree of risk and *uncertainty* involved. Participants sought resolve by developing strategies for different people and contexts, which were then modified according to new experiences. These strategies could increase appropriateness and positive consequences. They might give some measure of confidence to their and others' responses.

First I will examine *inadvertent disclosure* - where information was inadvertently or wrongfully disclosed and acted upon by third parties. Next the selective strategies – 'tell-you-straight', 'if needed', *no disclosure* - which Participants used in *resolving uncertainty* about disclosing are covered.

Inadvertent disclosure

Despite the best efforts by Participants not to disclose, *inadvertent disclosure* could occur. This was when information relating to their psychiatric status, illness experiences and past associations with mental health care was disclosed without the Participant intending to do so. When this happened most instances fell into two different groups – *disclosure slips* and *wrongful disclosures*.

Disclosure Slips

Disclosure slips occurred when clues about their psychiatric experiences were accidentally revealed. Sometimes the *vigil* for detection of ‘*mad*’ signs was ineffective. When this happened, *disclosure slips* could take place.

Evan: Anything to do with the head - if you disclose problems to do with your head, whether it be physical and/or mental - then there is an incredibly strong taboo towards people with such problems. Something I have learnt very painfully not to do, much. Sometimes I still let it slip.

At work, some Participants occasionally displayed bizarre behaviour or behaviour that was out of character. However, such behaviour could be seen as an intermittent or transient thing; in which case they had recourse to such explanations as: “overworked”, “overstressed”, “family difficulties” or “health difficulties”. Despite using such explanations *disclosure slips* could require a Participant to fully disclose or leave their job if:

- their behaviour was still affecting job performance or public responsibilities,
- workmates could not account for what was happening, compared with what they had known of the person previously (e.g. increasing suspicions),
- their explanation did not fully account for the range of personal difficulties experienced at work, or
- ‘work difficulties’ did not resolve within a period of absence or leave taken.

Other instances could be during a job interview. A person might indicate a long break in their employment history or an interrupted education. When the Participant did not explain because they did not think it was important they could find themselves receiving employer probes about it. Finding themselves unexpectedly having to account for that time and wanting to be honest, information could slip out about their psychiatric history.

People who had been entrusted with private knowledge of the Participant’s psychiatric history could also make *disclosure slips*. When this trust or confidentiality was broken then *wrongful disclosure* could occur.

Wrongful Disclosure

Wrongful disclosure occurred when other people, without the Participant’s intention or permission, disclosed information about the Participant’s psychiatric experience. Such instances usually contravened the Privacy Act and could be

remonstrated through the courts. But this did not change the impact and *outing* that had taken place.

Genevieve: ...the reason they found out was the manager of psychiatric unit X wrote to my employer to say I was in hospital and that I would need support when I came back to work.

Genevieve could no longer work within the health profession she had trained for.

Genevieve: They have personal files - they stuck a note on my file to say that I had been in a psychiatric ward and that my services were no longer required. They never got over it or once you have been a psychiatric patient you are always marked as a psychiatric case, and you need to be able to get over it.

Taking successful legal action over the breach of confidentiality alienated her even further from service organisations that might have employed her. In addition to being a psychiatric patient, she was now perceived as a ‘trouble maker’ because of successful legal action against her employer. This forced her to retrain and work in another field, where her past legacies would be less likely to haunt her working relationships. It also further consolidated her position to never disclose. But not everyone had such adverse experiences. While *inadvertent disclosure* could occur, some Participants adopted strategies of choice about when and when not to disclose. These strategies – ‘*tell-you-straight*’ and ‘*if needed*’ - are discussed next.

‘Tell-You-Straight’ Approach

When adopting this approach Participants intentionally disclosed aspects of their psychiatric history. The context for this could be in a job interview, with people of higher work status (e.g. employers or managers) or with their current workmates. The conditions could range from a deliberate probe about their ‘health’ to engaging in a discussion about ‘nutters’ and ‘axe murderers’ during a work break. Consequences could be either:

- productive - a resolving of *uncertainty* about ‘mad’ people who have been in ‘mad’ places and have done ‘mad’ things, or
- unproductive – increasing *uncertainty* about having a ‘nutter’ in a workplace.

The *tell-you-straight* approach usually involved cost-benefit considerations.

Digger: I did the job interview and they said ‘what ya been doing’. And I said “well I’ll tell you straight. I’ve had schizophrenia but I feel I’m all right to get back in the work force”. And they went out and had a talk about it. The upshot

was they offered me the job. I thought it's a waste of time trying to bullshit about it. If they've got a problem with it, it's their problem. And I found them ok about it.

This did not mean volunteering information but neither did it involve side-stepping inquiries or considerations about 'madness' and 'mad' people.

Digger: You tell employers at job interviews or when you get a new boss, but only if they ask ya (sic) how what ya (sic) health's like you know.

It was a considered and resolute approach that involved *disclosure* in many situations but not immediately with all people in all situations. For instance when their *disclosure* could invoke fear and *uncertainty* in others with whom they were required to relate, then the Participant might wait until a more suitable moment occurred to disclose. This approach could be quite liberating, as the Participant no longer had to hide their past and withdraw from situations because of *disclosure slips*. Nor had they to be so vigilant about *disclosure slips*. They could engage in help-seeking earlier as there was no fear of *disclosure* and they were more likely to stay 'well'. I begin this section by first examining some causes of the *tell-you-straight* approach.

Participants might start out being oblivious to *disclosure* and its effects. Rarely did this persist as everyday encounters outside of psychiatric services disabused Participants of this notion fairly quickly. When their own experiences from these encounters corresponded with information they received through other consumer experiences, the act of *disclosure* was usually viewed with *uncertainty* and trepidation. As a result of adverse experiences, they then might move to a *no disclosure* or an *if needed disclosure* strategy. What caused Participants to adopt a *tell-you-straight* approach, given the prevailing negative perceptions around madness, was directly outcome related. There was a definite cost/benefit ratio considered. For Piha *disclosure* was a way of explaining the origins of her appearance: "I used to always tell people because that was almost a way of apologising for the way I looked and what I was". It was better for others to think she was not personally responsible for character and overweight appearance (benefit) as they were due to the diagnosis and medication side-effects (cost). The benefit outweighed the cost of disclosing her psychiatric status. Participants

usually took time to acquire diverse experiences before they could resolve the *uncertainty* of what benefits for which costs.

Digger: Well you got to realise I've had over twenty years of practice in talking about having schizophrenia to people. So I feel quite comfortable talking about it. At first probably I didn't.

Participants sought to resolve *uncertainty* over *disclosure* by deliberate *disclosure* in no uncertain terms. What caused Participants to adopt this approach could be:

- secrecy - no longer wanted to hide significant current or past experiences,
- *vigil* – wanted to decrease the internal pressure and attention demands of the *vigil*,
- suspicion – wanted to decrease the social risk of someone *outing* them and *disclosure slips*,
- withdrawal – wanted to participate in social situations with fewer restrictions,
- identity – wanted to publicly embrace 'madness' label as there was nothing to hide and wanted acceptance for the way they were,
- daily pragmatics – once *out* they could enlist support, ensure realistic work loads, promote understanding, or take leave to get well instead of leaving their employment.

Disclosure could be a real 'stumbling block' to employment when it created *uncertainty* over outcomes from job seeking.

Neil: I'm a person I will not lie to them. I tried for a couple of shipping jobs overseas working on the boats. I felt that was the stumbling block - that I'd had a breakdown, and I felt that was why I didn't get any of those jobs.

Digger used a *tell-you-straight* approach to disclosing about his psychiatric disorder when seeking employment. He believed that employers would take him on his merits and that most people were 'pretty decent'.

I'm pretty positive about most people. I think most people basically are pretty decent you know. And if you explain to them, yeah I've had schizophrenia but I'm back in the work force. I'm working. I'm supporting myself. I'm stable on my medication. I think most people would be prepared to give you a go.

- even when this approach had previously cost him an employment position:

Digger: ...at the end of the phone interview the guy said, "it all sounds pretty good to me. We will get you up for an interview", and he said, "by the way, how is your health?". I said, "Well, my health is good apart from the fact that I've got schizophrenia". And I heard a voice in the background say, "Well we don't want

any lame ducks". And the guy said, "Well, we will call you". And they never did, so I think being honest about that cost me a job.

By having no secrets Digger experienced genuine reactions and stereotypical views about madness, 'mad' people and 'mad' places. Having this out in the open meant he could explain an insider's view about schizophrenia that was based on facts rather than fear.

Digger: ...after coming out of the mental hospital I worked in a factory and I didn't make any secret of the fact that I had schizophrenia and people's reaction were, 'oh who did you think you were' and things like that, and I explained that it wasn't like that, but I didn't really find any sort of stigma from the people I work with. When the guys there found out I had schizophrenia they were pretty alright about it.

A *tell-you-straight* approach meant being *out* about their psychiatric status and past experiences. Being *out* could mean employers took them into their employ, fully cognisant of who they were.

Neil: I will not lie to people. I actually told them that I had a breakdown. I feel it's better to tell them and they can take you on the way you are then.

For Participants this meant embracing an illness identity in a very public way but with the benefit of not having to hide or fearing any *disclosure slips*. Their reduced hiding, secrecy and fear of *disclosure* helped in *resolving uncertainty* about incorporating a devalued illness identity into a valued social/employment identity. Participants did not have to worry and deal with the *uncertainty* of who knew and who did not. They could say what they liked and request assistance that related directly to their psychiatric disorder. A *tell-you-straight* approach could resolve *uncertainty* others might have before it occurred. *Matching* occurred when expectations of rejection matched occasions of experiencing rejection based on stereotypes and the negative characteristics of 'madness' and being 'mad'. When this happened the myths became the truths. Joan's *tell-you-straight* approach was very effective in resolving uncertainty about this.

Joan: ...they were scared that their lobbying point wasn't going to be got through strongly enough ok. And I said, "for those of you who don't know I happen to operate under the cloud or I suffer from a mental illness, which means that my emotions are only just below the surface". I said "I would ask that you bear that in mind when you ask me to represent you". And I have no problem with that because I guess as an educator my position enables bringing things to people's attention all the time.

For her work colleagues, this resolved *uncertainty* about her competence and how much psychiatric disorder affected her work role. While *disclosure* could be preventive it also could be used to empower Participants to defend themselves. As the Participant was open about their diagnosis they could also be open about the prejudices and misunderstandings of others around them.

Digger: I tell them I've got schizophrenia. I don't go around shooting people and just try and sort of stick up for me and the other people.

Hamish: How do they take that?

Digger: Oh it's quite funny actually. They all just shut up and don't say anything. It's just as if they're embarrassed to talk about it once you've said that you're a got schizophrenia yourself. But the people you're close to at work, I've never really felt any real antagonism from them. I have not felt that they sort of look at me as an outsider.

The emotional impact of a *tell-you-straight* sudden *disclosure* meant it could be used as a 'shocking strategy' to create *uncertainty* in others. In creating *uncertainty* in others, it forced people to resolve the discomfort they felt and could make them receptive to the Participant's plausible explanation.

Joan: ...to be up front. Some times that shocking strategy works really well.

Hamish: How do they react?

Joan: "Usually with gob smacked silence. Yeah, it is. Because, you know, nobody in our sort of touchy-feely-nicey-icy (sic) work place wants to appear to be the one that's insensitive. I mean behind the scene it might be different but to my face then every one is pretty good really.

At the same disconfirming self-expectations.

Sal: They say "Oh, I didn't know that. I thought you were just [laugh]. OK. I thought there was nothing wrong with you". It's like they didn't see me as any different from anybody else. And I sort of expect them to think I was this really crazy strange person [laughing]. It does it sort of makes me feel a bit better. It makes you think, well, maybe I'm actually imagining that they actually do think any different [laugh]. And it does make you feel a bit better about yourself when you realise that they don't actually realise that you are any different.

One of the biggest concerns was that when there was an onset of symptoms or raised stress levels then the Participant could seek time off to recover. Not having to hide meant that the seriousness of a situation was fully appreciated and reasons for absence were seen as genuine. This could result in help-seeking occurring much earlier as the Participant did not need to hide what was happening. Nor did they have to wait until they became very unwell and could not work in order to cease work. Instead of having their workmates thinking they were 'losing the plot', by disclosing they were resolving *uncertainty* around misinterpretation of their behaviour. Workmates who may have thought the Participant was 'losing the plot' before, now realised that they probably were. They could then cover and

assist, because there was some certainty that this was not a trivial event or malingering.

Digger: I should have told you, I got schizophrenia. And he said, “Oh shit. Didn’t know that”. And he said, “Look, is there anything I can do”? And I said “I think I better go and see the doctor”. And he said, “Look, I’ll cover up for you. I’ll say you came in”. He said, “I’ll say you got the flu” He was going to cover up for me, which I thought was pretty good.

Not all work places were ‘safe’ work places to adopt a ‘*tell-you-straight*’ approach.

Lass: I felt there was a stigma. I felt that unconsciously people in the workplace were seeing me as a ... I had a bit of stigma I thought. Their feelings produced a stigma towards me because everyone knew I had a breakdown.

The *tell-you-straight* approach could shift to an *if needed* strategy of *disclosure*.

‘If Needed’ Disclosure

The *if needed* approach involved a cautious and discretionary use of *disclosure*. Participants might not want to disclose but if they believed the situation warranted it, then they would. In some instances this might involve literal *disclosure* of the diagnosis (e.g. schizophrenia) or it might involve the use of discretionary terms (e.g. nervous breakdown) or expressions (e.g. psychiatric problem). When *disclosure* occurred even in a limited way, Participants still faced the *uncertainty* of who knew and who did not, and what effects this could have. Effects could be productive – when this approach reduced *uncertainty* in others and improved working relationships. It could also be unproductive – when Participants failed employment selection procedures. I begin by presenting some of the causes, contexts and conditions in which Participants chose to use an *if needed* strategy of *disclosure*.

A Participant may have found that openly disclosing their psychiatric history in an interview introduced *uncertainty* regarding their employability.

Reg: ...then it came down to the part of the form where it says ‘do you suffer from any known conditions?’. I put down bipolar condition. Never heard a whisper from them and I never placed any follow up calls to find out where my application went - because I felt that was a mistake. I went away thinking I should never have done that.

For Reg, *disclosure* was such an error of judgement, that the situation could not be retrieved. There was tacit co-operation between the stigmatiser and the stigmatised, that such an identity was stigmatising. His “I should” indicated the implicit social rules and sanctions that were present. His transgression was irretrievably his fault. *If needed disclosure* was contingent on the situation and its demands. In other employment situations, when Reg received a direct probe about being in hospital, he did not ‘spell it out’.

...I don't necessarily tell them anything ...I might explain the situation is that I have been in hospital and I have come out again. I may tell them that I have been unwell in the past. They might look for gaps in my CV but I still don't have to spell it out - there is discrimination; there is no doubt about that. I even wondered about how I was going to react to the interview question of “How do you handle stress?”, and I don't think it is totally necessary to sort of spell out your hospital record. It is a question of applying the lessons that you have learnt and saying “Well, this is what I do for a hobby. I kick the cat - I don't take it out on the kids, I go for a walk.

Despite the discrimination that Reg expected to occur, other Participants said, “...it is best to be honest right from the beginning”(King) while others preferred to wait and see how their work situation unfolded. “I guess some employers I wouldn't tell straight away. I'd like to actually see how I went first and then tell them”(Sal). The *if needed* approach did not involve hiding their psychiatric status. Rather it was about discretionary use of this information. Participants were discrete because of the:

Reg:...many misconceptions about psychiatric illness - I could be just an axe murderer as the next person, and may look quite conservative to anybody else. But if you read the Truth; if you watch 60 Minutes, there are many exposé on people with psychiatric conditions who will shoot their family. If that is all you have been exposed to, and that is your understanding of what a psychiatric illness does to anybody, then you will grow up misunderstanding the condition that I might have, in my experience.

When there were misunderstandings and negative expectations about ‘madness’ and ‘mad’ people, then the Participant's psychiatric status could invoke negative sanctions. They were fully aware of the unintended consequences that could occur, and therefore sought to limit these while at the same time being as honest as they could be. Thus there was *if-needed disclosure* rather than *no disclosure*. One way of *resolving uncertainty* about fulfilling the need to be honest and yet not incur negative sanctions, was to be discrete about *disclosure* and use discretionary terms when they did.

Reg: I have information about myself that I will use at my discretion. It may be necessary at times to offer that information but there are always ways of explaining something without necessarily spelling it out in black and white.

Not 'spelling it out in black and white' involved choosing what terms they would use in their *disclosure*. They had to be selective.

Digger: You don't just say, 'Hi my name's Digger, I've had schizophrenia, how ya feel about that' sort of thing? you know [laughing]. Yeah, I think you got to be a bit choosy in who ya tell.

Some Participants like Mary used the term 'schizophrenic' while others had: "...learned to remodify explanations of where I had been and what I was doing or why I needed help" (Robert). The term 'nervous breakdown' was frequently used to describe psychiatric disorder and in preference to any psychiatric terms or associations.

Robert:... the term nervous breakdown I think is quite a good one. If people ask me how this or that, I like the term nervous breakdown. It's an old term but I have felt less adverse reaction to that term than to any other when I have had to explain how come I went into hospital. "Couldn't cope - had nervous breakdown".

Laura used the term 'nervous breakdown in association with attending psychiatric services.

Laura: That is what I tell them. 'I know about psychiatric institutions, I've been in one. Why ... 'I have a nervous breakdown' ... that's it. I don't tell them anything else. That's what they know.

This had a reasonable outcome for some Participants (e.g. Reg) and not for others (e.g. Lass). The problem with this term was it could create *uncertainty* about whether it was situation dependent (e.g. overworked) or personal weakness (e.g. cannot cope). Robert suggested not: "to mention anything to do with the psychiatric arena ... because it just automatically closes doors". When Participants found a discretionary term to use which was less likely to invoke sanctions they still had to contend with the *uncertainty* over who knew and who did not: "I was always worried whether or not they had been told behind my back or what the story was and I was a bit edgy about that at times" (John).

Negative facts about Participants had a way of spreading beyond the immediate situation and audience. A Participant might tell their manager, who in turn told

their supervisor. Once *disclosure* was out Participants lost control over both what was said and who it was said to: “the manager knew and told the supervisor, which was meant to be confidential but she was a gossipy sort of a bitch and she told the whole world” (Laura). The effect of this in the workplace was that unintended consequences could occur. Other people made decisions based on what they had heard from someone else and the Participant had little or no input into the decision. It might be made for them in their best interests. Discrete *disclosure* was no guarantee that it would remain discrete. This caused problems in employment for some Participants.

Neil: “I still have times when I find that it [*uncertainty* about someone finding out] keeps coming back. It’s affected my work in a lot of ways ‘cause I feel I don’t know who knows and who doesn’t know.

Sometimes other people finding out to a limited degree could create a sympathetic reaction. Instead of *uncertainty* creating distrust and fear it might result in productive helping. But sometimes it did not, especially when *disclosure* invoked stereotypical expectations about Participant behaviour and their ‘need’ for help.

Laura: If it comes into the conversation and people say not very nice things about people being in psychiatric institutions, I say, “Well, I’ve been in one”. But I certainly don’t participate in conversations about it. It depends on the person’s attitude because there’s just a lot of people where I just feel as if it doesn’t really matter what I say. The minute I say it, they change. They start trying to tell me how to live my life. I have all these very helpful people come along and tell me that ‘you’ve got to be very careful or you’ll burn out’. They don’t ask permission to give me advice about my life because the minute they know where I’ve been ... they don’t see this girl has survived all these things, so obviously she’s got a few clues as to how to live her life. They start thinking that I need advice all the time. I get advice about my relationships. I get advice about people ... and they think they’re being [helpful]... and I just find it very patronising.

However, not all *if needed disclosure* produced unhelpful helping. Sometimes there could be a sense of trust with a fellow workmate and a need to tell them as they may work in close proximity. There might be a sense of inevitability, that as they were in close proximity they were probably going to see the Participant have some ‘rough’ days. Rather than create *uncertainty* with no explanation the Participant might disclose only enough information to explain what was occurring. When this happened their work colleague could gain an appreciation of the efforts required from the Participant just to get through the day. They had some understanding and expectations as to what was required for their working relationships. Such a person could become a *monitoring partisan*: a person who

was seen to be on their side, yet able to give independent views when needed and whose reasons for association were based on mutual respect and friendship.

Participants learned *disclosure* from the outcomes of past *disclosure* experiences. This not only involved what to disclose, but how to disclose, when to disclose, who to disclose to and why they should do so. *Disclosure* was an activity that could invoke negative sanctions in some situations and not others. Participants first learned to disclose to themselves (e.g. accept diagnosis) before they chose *no disclosure* or *disclosure to others*. When *disclosure* to others occurred, the *uncertainty* and fear it created could lead to increasing surveillance and *monitoring*. When this happened, people who monitored solely because of the Participant's association with madness, 'mad' people or 'mad' places, could become *monitoring others*.

No Disclosure

No disclosure was refusing to reveal information about psychiatric diagnosis, status, experience or associations, in any form. Adopting *no disclosure* as an explicit strategy could incur both productive and undesirable consequences. On the productive side, others did not mark Participants as 'mad' and therefore vulnerable to stereotypical expectations and treatment. On the undesirable side, Participants were concerned that others would find out and this would incur negative consequences. Instead of *no disclosure* reducing concerns, it could increase attention on psychiatric health because it needed to be kept secret. I start this section by examining the uncertain effects of *no disclosure*.

Uncertain Effects

Not disclosing to your workmates, and starting to have difficulties in the workplace, created intolerable levels of tension and *uncertainty* for some Participants. The querying of their actions by others, who made erroneous assumptions about why they wanted time off, further increased their sense of incompetence. Due to not disclosing, they were denied the opportunity of explanation. Without explanation, they could be seen as lacking competence to resolve the situation. Not explaining could be interpreted as hiding something which could further raise suspicions by others and increase the frequency of their

inquiries. The *uncertainty* about what to say in reply could elevate levels of stress to a point where escape was the only possibility of relief:

Claude: Yeah, I knew what I was doing, but I couldn't grasp the things that I thought were common place. So I said "Oh I'll go home". And they looked at me and sort of said "Well, why are you going home?" And I said "I feel ill" and they looked at me. "You don't look ill, what's the story here? You know, what's going on here?" and I sort of said, "I don't know. I've got to go home". So I was getting ready to go home and one of the factory hands [said] "Some of us cannot afford to go home. Some of us, you know, we've really got to work to make our money. Why are you going home?" And I couldn't answer him, so I did go home.

As a consequence of this *no disclosure* approach, Claude faced challenging events without recourse to an explanation that could have maintained a valued and respected identity. In response Claude shut down and withdrew; a defensive tactic which minimised audience cues and gave attentional resources to his most urgent need – escape to cope with what was happening. He felt there was nothing he could say to retrieve the situation when faced by audience disbelief and misunderstanding. Onset of symptoms was not visible to his workmates in terms of being "ill" (e.g. like the coughing and sneezing with onset of a cold). His increasingly bizarre behaviour could be seen as an extension of everyday behaviour (e.g. having a bad day) or personal idiosyncrasies (e.g. 'always been like that'). But they were not. Without past recognisable 'illness' cues for his audience and no comments forthcoming from him, his workmates were uncertain what to make of his actions. Moreover, in this context they viewed them as evidence of malingering - he was imagining or faking illness just to get time off work.

This further undermined his confidence and competence. His illness was not seen to exist, the symptoms he was experiencing that prompted this course of action were not seen as important and his concerns were not likely to be respected or believed. *Disclosure* for Claude would have increased his *uncertainty* regarding audience response, and his not disclosing magnified further *uncertainty* in others as to his motivations. Claude never returned to this workplace despite having the opportunity to do so. He would have had to confront perceptions by others of his previous behaviour. That probably would have entailed some explanation regarding his psychiatric disorder – something he did not want to do (also a particularly difficult activity when he was also becoming unwell). He left

employment, thereby avoiding the stress of a workplace and the ‘outing’ that took place regarding his psychiatric disorder.

Passing

Sometimes Participants like Sal would wait and see how they went in their job (*passing*) and whether they wanted to stay (i.e. ‘testing the waters’). If they were planning to stay then there was an investment in the job which could offset some of the uncertainties that arose upon *disclosure*:

Sal: ...some employers I wouldn’t tell straight away. I’d like to actually see how I went first and then tell them ... You hide the fact that you’re different ... That I guess you’re a little bit crazy.

Essentially *no disclosure* was telling the truth. At that moment in time, the Participant may not be experiencing a psychiatric disorder:

Reg: ...it is like people saying I have diabetes, therefore I am diabetic - I mean as far as I am aware I have a condition that may sort of flare into - but it doesn’t make me a manic depressive.

For Reg his condition ‘might’ ‘flare’ up, but should he disclose, others would expect it would flare up because he was a ‘manic depressive’. To other people the person was the illness – he was a ‘manic depressive’. The prospect of being collared with a stereotype of ‘madness’ and expectations of ‘mad’ behaviour was a risk he was unwilling to take. Reg, in *passing*, did not disclose: “I still maintain that I will never go into a job interview and say that I have got a psychiatric illness”. If gaps were found in his CV during a job interview, Reg would say he had been ‘unwell in the past’. This created a picture of sickness or illness that was transient – it occurred for a period of time after which he recovered and recommenced work again.

Reg: I really need to get to know people well before I do or say anything [*disclosure*] like that, and I think that is important because until you develop a trust with somebody else that you might have a discussion with, then you are really taking your life into your own hands.

The critical aspect in Reg’s comment was that upon *disclosure* he was taking his life in his own hands. The *uncertainty of disclosure* could induce a sense of peril about the course of events from that moment on (*haunting*). But this was only with people outside the mental health system. Those who had been users of mental health services or ‘insiders’, were accorded *partisan* status:

Sal: It's about the 'us and them'. You see yourself in different category to people who don't have a mental illness ... there's some people that are ok and some people who aren't.

With 'insiders' there was a reduced experiential distance of living with the mark of 'madness' and a shared sense of the threat that occurred by *disclosure*. Expectations of acceptance and understanding upon *disclosure* could be brutally thrust aside when *disclosure* only made things worse:

Laura: ... it's the same thing as tech. When I'm at work, I'm anonymous. People don't know where I've been and I have a created identity, and people know nothing about previous eating disorders, bikers, drugs, things like that. I just don't bat an eyelid. I just act as if I know nothing about it and I don't tell them anything about myself. I go in and I do my work. I participate in small talk and that's it. I used to have this wild urge to run around and tell people because it's like ... I'll prove their stereotype wrong. But what I found was it just didn't change their perception of me. They didn't go, "Oh maybe those people, in psychiatric institutions and everything aren't what I think they are" ... because they [didn't see] me, this person who held down three jobs and got straight A's. They instantly stopped seeing that, and changed and put me into the stereotype. So I don't bother. What's the point?

There was an abruptness and finiteness of change in other people who viewed the Participant through stereotypical expectations associated with 'madness' and 'mad' people. It reified the sense of hopelessness from being grounded in an illness identity. But these expectations also matched occasions within individual experience. The sense of *uncertainty*, peril and threat around *disclosure* was built up by personal experience and consequences. Recollections of these events could become 'horror' stories that were shared with other 'insiders'.

Consequences of Being Found Out

Despite every personal effort not to disclose, just being in a mental health service informed someone of their psychiatric status. Service people, acting on best intentions and believing others should be informed, could breach privacy conditions. For instance, Genevieve did not disclose under any circumstances to employers, and was very cautious about who she disclosed to within mental health services. Her past experiences of not disclosing were extremely unsatisfactory. Despite receiving assurances that *no disclosure* would occur to her employer, it happened. While away on sick leave, information about her admission and treatment were communicated to her employer without her knowledge or consent. This *disclosure* to a third party terminated her career in her profession and to this

day has prohibited her return. The unintended consequences of this *disclosure* have been enduring, whilst financially and professionally disastrous. It has required her to retrain for another profession and at the same time the mark of ‘madness’ could never be completely erased from public or professional memory.

What happened with Genevieve indicated how uncertainties could load into any situation where *disclosure* had happened. The negative consequences from past *disclosure* encouraged her to take the position of *no disclosure*. But working in a profession as a health worker could create its own contingencies. New Zealand is a small country and professional groups are even smaller in terms of their memberships. It can be very difficult to keep a psychiatric hospital visit secret; even when travelling to another part of the country to use one. As Genevieve found, “word got out”:

Genevieve: I think what actually happened, word got out that I had been in a psych (sic) hospital and my supervisor was aware of that. When talking together about cases I was always conscious of the fact that I had been hiding the fact that I had been a psych (sic) patient.

The *uncertainty* of who knew and who did not now haunted interactions when *no disclosure* was employed. Some explanation had to be given when Participants needed time off to recover. As a health worker, Genevieve was usually overworked and someone had to stand in and cover her caseload. Therefore a plausible explanation had to be found to account for her absence:

Genevieve: I didn't tell them that I had been in psychiatric ward or anything like that. I kept that completely out of it and just explained that I had some time off to deal with deaths in my family, and that was the way I got around it.

When an explanation was found to explain an absence, there was always the prospect that she could be found out. *Passing* required the maintenance of *secrecy* about past psychiatric events. This could be particularly difficult when your clients have known you when you were ‘mad’ and might identify you:

Genevieve: Just the sheer fact that I had to keep it secret; that was like being marked ... I made sure that nobody knew that I had been in a psych (sic) hospital. I did not talk about that part of my life ... I kept well away from psychiatric patients because I thought that they would find out that I had been in a psych (sic) hospital.

Similarly, it was very difficult to work with colleagues who knew her as both a colleague and a client. While formal boundaries exist between staff and clients to maintain unbiased practices, the informal relationship between staff can confuse this relationship when staff become clients.

Colleagues as Clients

Work colleagues could be sure of what they would say and do with a client but were very unsure what to do and say when staff were clients. Sometimes they just did nothing:

Genevieve: Well now I know that she knew that I was having a breakdown. But she just didn't approach me with the fact; say, "Look here, Genevieve, you are unwell. We need to do something about it". There was nothing like that. It was like she was waiting for me to fall, and I certainly did.

Moreover, despite having all the provisions of care for clients, they may not be extended to staff when they become clients. There was an implied set of boundaries for what was acceptable 'sickness' or 'deviancy' at work. Approach those boundaries too closely, or step over them and it was 'not alright'. As Genevieve suggested, professions were hardest on their own members because boundaries of professional practice were not seen to incorporate 'madness'. You could not be 'mad', just a little 'mad' or occasionally 'mad' and generally still be seen to retain the professional identity of a health worker. 'Madness' introduced an *uncertainty* into professional identity which was hard to manage for colleagues and even more so for the Participant. Perceived and actual sense of rejection matched stereotype with experience. The discomfort of trying to maintain a professional 'face' when it could be pulled away introduced an *uncertainty* that thrived on social avoidance:

Genevieve: Places such as social situations where I knew that people were going to be talking about their jobs; I didn't want to tell people that I had virtually got the sack, so I would withdraw from social situations and I would withdraw from friends because I didn't want to burden them with the fact that I had been a psych (sic) patient. And they just didn't understand what being a psych (sic) patient was like - it was really hard to explain that.

The act of *disclosure* rarely involved closure. The difficulty was how to explain something which could only be seen from the inside. No amount of *disclosure* could fully explain to others what it was like to be a psychiatric patient and therefore understand what she had been through in her job. This created a tension

- of wanting to talk about a significant feature of her past and current experiences, yet at the same time having to ignore it because it could not be communicated. The possession of this knowledge invited a social distance and isolation from those who have never had similar experiences:

John: With the cleaning job there were people that I wouldn't tell that I had a mental illness in the past. I was always worried whether or not they had been told behind my back or what the story was, and I was a bit edgy about that at times.

There could be a guarding of information relative to psychiatric status and a *vigil* to ensure that it was not revealed or inadvertently communicated. This non-*disclosure* was held in check by *secrecy* of an identity marked by mental illness and *distancing the past* associated with it:

Mary: ...once a schizophrenic came into the front desk ... and she said, "Oh, I am a schizophrenic and I would like some part time work, please. Would you consider my application form?" And H said "Yes" ... and as soon as she walked out the door H said, "I would never employ anybody with a mental disease." And I had a quiet laugh to myself because - I mean - I had had all this mental disease myself and I felt like kicking her in the bum actually. But I never said anything to her.

By *passing*, Mary experienced first-hand the negative perspectives and discriminating behaviours of others. The probable consequences for her, should she have disclosed, consolidated her intention of *no disclosure*. *No disclosure* in this instance resolved the prospect of *uncertainty* in her employer relationship and ongoing employment opportunities. But the underlying reason for her *no disclosure* was the shame she felt about her illness and being 'sick':

Mary: I was told that I had good insight. And I do actually recognise when I am getting unwell and I do now reach out. You see, before I used to be ashamed of my illness and I used to go up to [hospital Y] when I got sick.

When Mary got 'sick' she used to leave work. To maintain *no disclosure* and *pass* she used to exit employment and leave town for treatment: "and then I got so sick that I couldn't get up there but I had to be treated in [hospital X] and now I am treated in [hospital X] and I couldn't give a stuff who knows". Similarly, Leila thought an employer was going to find out at some stage, as a person 'will get sick'; but unlike Mary she still would not disclose. When Participants disclosed it precluded other forms of 'sickness'. By adopting *no disclosure* other forms of sickness or indisposition could be put forward as probable explanations.

Sometimes Maori were more inclined to *no disclosure* with those outside their ethnic group: “I think I didn’t tell too many of my European mates. Yeah. But I’d tell the Maori because they’ll always be Maori and close to Whanau - yeah.” (Tane). One aspect of *no disclosure* could be ‘cultural fit’. Certain aspects of individual experience within one world view (Maori) may not transfer and fit into another (Western medical) without attributions of pathogenesis. Given this prospect a Participant might not disclose certain aspects of their experience as they did not have a safe ‘cultural fit’ with their audience.

No disclosure could also be a sign of personal strength. A Participant might no longer feel ashamed about their psychiatric disorder, and use it to explain things about themselves to others all the time. Only sometimes: “I got to the stage where I learnt not to tell people. Because it wasn’t necessary. I sort of feel that I don’t have to tell people today anyway, really” (Piha). Perhaps the last word on *disclosure* is best explained by Achilles:

... it's a choice. The person has to make that choice. Personally, I disclose, but I am fairly robust in that direction now. In the early days, certainly, I didn't disclose because I didn't want to be singled out. There is an awful lot of people in my experience who never identify themselves and are working successfully, especially in creative and artistic positions. A lot of people get stalled and stuck in dependence around it by being on a benefit for years. A few failures in various aspects of their lives, and they are struggling along on the benefit but they are making it. The feeling of stigma, the feeling of hostility when they enter a strange place or a work place, which may or may not be a function of their illness; it doesn't matter; their feeling is that it is alien to them. They would rather associate with other people. Perhaps they don't associate with anybody very much at all, but they will not make that step to risk, because they have lost so much in the past, another loss like that is too much. So it's not really easy to generalise with people out there.

Disclosure was a choice that depended on appraisal of threat and the personal strength to manage untoward consequences, should they occur.

Summary

Disclosure within a psychiatric service was necessary for Participants to exit their service. Here, any staff interaction was a performance of, and disclosure about, their mental health. When social interactions took place in the workplace they entailed similar concerns about mental health for the Participant. What was at stake for Participants during workplace interactions was not just their hopes for a

future work trajectory, but their hopes for recovery. The process of deciding about *disclosure* evoked an *uncertainty* that could erode social confidence and provide unease. Irrespective of whether *disclosure* was forced, inadvertent or voluntary, this activity created an *uncertainty* over ensuing consequences that were felt personally and faced socially. Participants experienced both positive and negative consequences upon *disclosure*. On the one hand, *disclosure* resolved the *uncertainty* about other people finding out about their psychiatric history in the workplace; on the other hand, it made Participants vulnerable to discrimination by others. Rejection during interviews and adverse comments in the workplace created further *uncertainty* about disclosing again. Disclosure could cast a shadow of *uncertainty* over the Participant that lived on in other peoples' minds and within public records.

In the next chapter on Uncertainty in the Workplace, analyses from the previous chapters converge and are applied to a real-life setting - employment.

CHAPTER 8 - UNCERTAINTY IN THE WORKPLACE

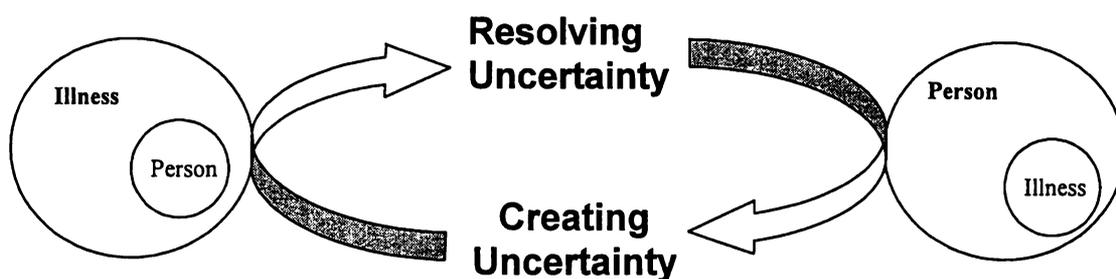


Figure 1. Basic Social Process

Monitoring of Participants by co-workers, or those more senior, was a characteristic of most workplaces. *Monitoring* involved both observation and evaluation. Its focus was to resolve *uncertainty* about Participants and their activities. Resolving workplace *uncertainty* was not an activity uniquely focussed on the Participants. In any work place, people monitor a person at the start of a new job to evaluate competence, role and status. What often intruded in work place *monitoring* of Participants was *uncertainty*. *Uncertainty* was a key feature in workplace difficulties for Participants. These difficulties arose from internal Participant processes and external interactions with people in the workplace. *Uncertainty* could amplify to an extent, where it could not be resolved in the workplace, and the Participant achieved resolve by leaving. In a new job, workplace *monitoring* entailed a primary process which I have called *job sorting*.

Job sorting

Job sorting takes place in any occupation and is used by employers and fellow employees to discern the employee's fit to their job and to the workplace. Both employers and employees use informal and formal processes to evaluate both technical and social proficiencies. The twin function of *job sorting* was discerning (e.g. a colleague's social fit and work ability) and resolving (e.g. *uncertainty* associated with performing these things). The basis for *job sorting* was usually the behavioural norms in the workplace and the Participant's ability to fit in. Abilities

to meet social norms as well as work norms were interwoven. Difference from work norms indicated difference from social norms. Participants knew their degree of 'difference' when they experienced social distance and unease during social interactions. Outcomes from this process endured and could mark Participants in a temporary or permanent manner.

Participants used the type (e.g. negative outcomes that would be unlikely to occur for other non-consumer employees), frequency and duration of their *job sorting* experiences when compared to those of their colleagues, as the main yardsticks to discern normative workplace experiences from those that marked them as 'different'. In addition to being 'different', when work colleagues perceived this 'difference' as a sign or label of 'madness', it further altered *job sorting*. Participants found it both an unfair process and outcome when *job sorting* happened that was different to that experienced by work colleagues. However, when *job sorting* occurred that appeared similar to what other employees experienced (e.g. whether or not they could just do the job, with social norms being irrelevant), Participants did not feel that they were marked. Participants described this as a "so what?" perspective about their psychiatric problems, that could help *job sorting* and build Participant acceptance. However, when work colleagues perceived their mental health considerations as unimportant, Participants could be led to adopt the same disregard for any mental health considerations, sometimes at the expense of their own well being.

Positive outcomes could lead to practical interest and support, with a focus on a Participant's work instead of on psychiatric competence, and ultimately job retention. Experiencing a positive outcome or a shared difficulty at work usually involved working alongside someone else. Such a person could develop into a *monitoring partisan*. The positive outcomes from informal *job sorting* depended on whether the Participant could prove himself/herself fit for the workplace. Participants who were accepted in the workplace had gone through a negotiation process of *proving yourself alright*.

Proving yourself alright was an especially important outcome for Participants - it meant effective psychiatric illness management, obtaining status and acquiring a

valued workplace identity. This outcome moved beyond just unemployment or employment and built an acceptance that helped resolve *uncertainty*. However when there was ambiguity or unfairness about *proving yourself alright*, *uncertainty* was created. Increased *monitoring* by others could occur that appeared to be more frequent and for longer periods than for other employees. When this was perceived to have occurred because of their psychiatric disorder, their *uncertainty* about self-management was increased. That this appeared to be happening for them and not others reconfirmed their own suspicions that they were not coping. Internal attributions about the source of these difficulties were pernicious. Participants perceived their differences from other employees as personal failings rather than contingencies that flux and wane, for anyone, on a daily basis.

Their *uncertainty* in comprehending *job sorting* was exacerbated by problematic interpretation of others' emotions, thinking and extrinsic motivations. Hence some did not know whether the feedback they were getting from others was genuine, their perception was appropriate, or whether their memories of events, actions or interactions were real or imagined, and therefore whether using these experiences as a base for future action or interaction was suspect. This was perceived to have created feelings of *uncertainty* or suspicion for both sides. On the other hand, once you had *proved yourself alright* and had become accepted, any feelings of stigma could disappear. When this did not happen Participants perceived themselves *marked* as 'mad' and saw this as a likely reason why they were unable to *prove themselves alright*.

Marked

When Participants were *marked* as 'mad' and had failed to *prove themselves alright*, *monitoring others* were seen as increasingly vigilant towards the Participant. What had started out as a *monitoring* of their difference while undergoing *job sorting* now intensified. The beginning of this marking someone out as different was an extension of processes regularly employed by an audience to monitor out-group difference.

Digger: ...difference from the group: that's how I feel the stigma is. Like you've got something that they don't know about. Like you're a schizophrenic or

whatever. And they think, “Oh him: he’s a schizophrenic”. So therefore ‘click’: “You must be different”. Let’s watch him to see what he does”, sort of thing.

But unlike other group differences based on gender, ethnicity, class or age, this difference is linked to a group membership whose characteristics are associated with *uncertainty* and peril. The person with these characteristics is not a ‘nobody’ in the newspaper or on TV. They are a ‘somebody’ in their workplace who was also sitting down beside them in their tea break: “like sitting around the smoko (sic) table and ... there’s been, like, the Raurimu massacre and they might say ‘Oh they should lock up all these nutters (sic)’” (Digger). When Participants had not disclosed in the workplace, *disclosure* could happen in an involuntary manner that immediately marked the person.

Lass: I broke down at work one day ... at work I completely - my mind was split. Someone contacted one of my sons for me. And a couple of women on the staff and my son took me to the GP at the time, who then said that she’s going to [hospital].

When Participants returned to work, their previous confidence in the workplace could disappear. It now had associations with loss of mental health and the fearing of what others might think about them. The presence of *uncertainty* within Participants’ approach to work could affect their job performance:

Lass: I was too scared to go to work. And when I did get to work I couldn’t perform because I was really scared of the people there ... Their feelings produced a stigma towards me because everyone knew I had a breakdown and been in the mental health system. I felt that their regard was that the lesser intelligent is who succumb to it.

Just as being less able fed into appearing less able, so appearing less able fed into being less able. Thus a person might appear less ‘intelligent’ than before and validate aspects of ‘mad’ stereotypes. Similarly aspects of ‘mad’ stereotypes could specify or indicate which target behaviours to evaluate for ‘mad’ signs. For Lass an important value or norm within the workplace was “intelligence” and being perceived as intelligent. The values that were important for inclusion could also act as the basis for exclusion. Hence the way that disfavour and status change was conveyed was by devaluing her “intelligence”.

Monitoring others could want to resolve their *uncertainty* about the Participant’s stability by asking about their efforts at maintaining their mental health: “every

now and again ... the manager of the place would or someone else would come and ask if I'm taking my medication. Yeah! Are you still taking your medication"? (Lass). But at the same time, it reminded and marked the Participant with *uncertainty* about their psychiatric health. The old concerns about 'madness' and 'mad' Participants felt were reaffirmed by the *uncertainty* it created in *monitoring others*. Their reasons for asking about medications were: "I might go wild again. I might break out. I think their fear - I think the ... old fear of mental illness..." (Lass). In other instances the marking could be quite subtle and difficult to detect, but it was perceived. These concerns were not affected by age or gender or ethnicity. The mark of psychiatric illness was a mark of *uncertainty*. It was initiated and reciprocated by *monitoring others* and *scrutiny* was required to co-exist with this.

Scrutiny

I use the term *scrutiny* to capture the activities in which *monitoring others* were perceived to engage. Additional to this 'watch' and 'ward' that both parties engaged in, *monitoring others* tried to resolve their *uncertainty* by adopting precaution. The precaution that *monitoring others* were perceived to employ involved *testing* the Participant. This was not a neutral activity as it involved direction and accusation. Thus while *scrutiny* entailed a defensive aspect (*on guard*) it also incorporated an offensive tactic (*testing*).

The context for *scrutiny* by *monitoring others* involved employees of similar or lower work status and happened irrespective of age, gender or ethnicity. The conditions under which *scrutiny* was perceived to have intensified were during occasions of evaluation. The words often used to describe this were: "keeping an eye on you" (Digger) or "checking you out". However this activity involved more than just looking on and watching the Participants' moves in the workplace. The functions of *scrutiny* were perceived by Participants to be to guard, regulate and provide information about the Participant. Being *on guard* with the Participant was a defensive strategy and *monitoring others* used an offensive tactic of *testing* to elicit information and reduce *uncertainty*.

On Guard

By being *on guard* with the Participant, *monitoring others* were perceived to be prepared should the Participant 'lose it'. *Monitoring others*' fears were perceived to lead to very inappropriate behaviour on their part. Displays of uncertain behaviour in the workplace by other people, and *uncertainty* about what to do when Participants "lost it", could lead to misunderstanding and inappropriateness. Rarely were other people able to be *on guard* without appearing so. Thus their actions and interactions - or lack of them, in varying from what typically took place with other employees, indicated and pronounced difference to the Participants.

When *monitoring others* were *on guard* for signs of psychiatric illness it introduced a sense of *uncertainty* for some people. As *monitoring others* tried to resolve their *uncertainty*, further *uncertainty* could be created for the Participant. This raised questions regarding the effectiveness of their own *vigilance*. The mere fact that they were doing this indicated difference. Perhaps no one else in their workplace received the same level of scrutiny or the same bias when interpreting events for that person. They were late for work or leaving early because of their mental illness and not just a bad day that anyone could have. It could infuse a sense of distrust and *uncertainty* into workplace interactions and raise Participant concerns, such as -

- Why would they be *monitoring* me if there was not a good reason?
- Will others think there is a good reason for *monitoring* because it is happening already?

When not able to satisfy these questions, Participants implicitly felt there was a lack of trust and that the activity of *monitoring* assumed a lack of capacity for independent action. The presence of *monitoring* and people being *on guard* beyond a probationary period could acquire a life of its own, where its presence served as a justification for its continuance. Such *scrutiny* and being *on guard* (e.g. you've got to watch so and so) could encourage suspicions that people already had. When the Participant disclosed, perceptions of people *monitoring* them heightened their self-consciousness. Their self-consciousness amplified so that the Participant's internal *vigilance* increased and they became increasingly

uncertain and uneasy about the perceptions of others. Participant *uncertainty* escalated, reducing the ease of interaction with others, who in turn perceived target behaviours that promoted their own unease and *uncertainty* with the Participant.

When interactions became uneasy, both parties in wanting to increase their own ease might reduce the frequency and duration of interactions. In reduced interactions, the linguistic padding people used to background the key points of their comments or instructions were often left out, leaving very bare information being transacted. Trying to grasp bare information without its background can lead to misunderstanding about reasons for the information; especially the ‘why’ of instructions and the motivations of people involved. It became easy to misunderstand and misattribute upon receipt of such information and this was further exacerbated by suspicions both parties might harbour.

With reduced occasions for interaction, the Participant could over-emphasise the interactions that did take place, as any interaction became important. There was no larger pool of interaction moments or contents to provide a perspective on them. In some cases Participants just withdrew and continued their withdrawal to its conclusion with job exit, as a way of coping with the *uncertainty of monitoring other’s* behaviour. Finding flaws in their mental health could make the Participant vulnerable to *monitoring others’* finding flaws in other directions. Moreover, from the Participant’s view, it was further evidence that other people were behaving unfairly or unreasonably towards them. Despite their *disclosure*, Participants were trying not reveal anything that could indicate stereotypical traits of ‘madness’, as any accusations of impropriety could substantiate perceptions of mental illness behaviour. The *on guard* process that *monitoring others* were perceived to have used began by informal testing of the Participant.

Testing

Monitoring others could engage in *testing* Participants out in specific ways. Ways that this could occur were through spontaneous or planned opportunities, and by covert or overt means. *Monitoring others* could test by *presence, inquiry, instruction* and *activity*. *Testing* was often perceived as testing Participant

psychiatric health status and competence. Although similarity to *testing* of non-consumers permitted work colleagues to suggest that this was no different, it had a subtle underlay of *uncertainty* that manifested itself in quite different ways for Participants:

- (1) If the Participant was not *marked*, *monitoring others* did not experience a disruptive *uncertainty* with them and nor did the mark provide the means for accepting or rejecting them.
- (2) If the Participant was *marked*, the *scrutiny* would be sustained in a manner that led to their receiving *close scrutiny* and being *set apart*.

The outcome from the above item 2 was that *testing by monitoring others* placed the Participant *on probation*. This normally took place in any *job sorting* of employees, but for Participants the perception of being *on probation* never quite came to an end and the activities of *monitoring others* seemed to confirm this perspective:

Digger: ...after coming out of the mental hospital I worked in a factory and I didn't make any secret of the fact that I had schizophrenia. And people's reaction were, oh, "who did you think you were"?, and I explained that it wasn't like that, but I didn't really find any sort of stigma from the people I work with, but I felt ... I was pretty much on probation as far as the employers were concerned.

Testing and probing could take place just by other people being present.

Testing by Presence

Testing by presence refers to presence of *monitoring others* who attend to the Participant, usually in a discreet manner. Their method and intention of approach to Participants can be different from what they would employ with others. *Monitoring others* would sometimes approach but not engage in conversation or activity with the Participant. There might be discreet observation where others occasionally tested Participants, in a way that did not intentionally offend the Participant. It was covertly done and difficult to discern from regular evaluation that took place with any employee.

Hovering

At other times there could be *hovering*. This was when *monitoring others* kept lingering in the vicinity of the Participant. There was a sense that *monitoring*

others were waiting for something to happen, not knowing quite what could happen and thus wavering in an indeterminate or irresolute state. *Hovering* occurred when Participant job performance:

- was very visible – such as at start and stop times during the day, or
- could reflect poorly on colleagues and the business entity. E.g., Participants noticed that people were hovering around them when they were on the phone or when they were at reception talking to the public.

Monitoring others might not engage, but needed to be close enough to monitor. This was more overt than *incidental* or *surreptitious checking*. The Participant felt like they were being tested or checked constantly, without a visible reason or explanation being given. Usually, the Participant slowly became aware of *hovering* when they noticed that routines by others started to accompany performance of their tasks, in manner very different to before. *Hovering* had no pretence of assistance and was markedly different to what happened with other employees. Overt *hovering* could increase so that every time the Participant made a mistake they turned around and felt “like the whole world is looking at them” (Laura) - or was pretending not to. When *hovering* became entrenched, as opposed to just an initial probationary tactic, the impression of no change in degree of acceptance and respect reduced comfort in continuing with current employment. Even when Participants believed *hovering* was taking place they still had to sort through their *uncertainty* about perceptions. While *testing by presence* did not involve verbal interaction, *testing by inquiry* certainly did.

Testing by Inquiry

Inquiry was the action of seeking information about the Participant. It was testing by examination. Its object was to elicit information about the Participant’s mental health. This could be done:

- overtly – through direct and explicit questioning about the Participant’s mental health, or
- covertly – by disguising questions about Participant’s mental health in everyday greetings.

Participants perceived monitoring others as being *uncertain* about their ability to do a job. This did not relate to their job skill but to their mental health skill. *Monitoring others* had a need to ‘check in’ by disguising a covert probe into their mental health state in an everyday manner. Often this probe would happen prior to making a request. At other times the act of enquiry by *monitoring others* presumed a closeness within a relationship that was not warranted or agreed to. *Monitoring others* might want to obtain mental health information in a covert way. They would not ask directly but indirectly. There was a sensitivity that resolved *uncertainty* about how the Participant was going to behave and thus how they were going to work with them.

Digger: ... when I started working for X corp, when I came up here, he’d ask me things like, ‘You feeling ok about this?’ and, you know, ‘You don’t mind doing this?’[author’s emphasis]

Other covert approaches were often disguised in everyday words. One greeting/inquiry was, “How are you”? The words might appear innocuous but the inflection that accompanied them was not. Participants had usually received the same inquiry within psychiatric care and their response became used as an evaluation for their psychiatric health. Outside of psychiatric care the same inquiry could also be used as a covert probe of their psychiatric health or their coping with the moment. “How are you” carried a subtext of “How are you – *really*?”. Similarly with the inquiry of “You’re alright?”:

John: people ... sort of keep a distance from me. They’re not too sure of how to approach me ‘cause they think, “Is he sick? Is he still mental or is he mad still?” You know, they think I’m mad all the time so they - Like I was I met one friend one time and he said, “Oh you’re alright?”. I said, “Yeah”. He said, “Are you sure?”

Hamish: So how do you react to that when people say that to you?

John: I just say, “Yeah, I’m alright. I’m not mad - not right now, anyway”. You know ... And I find it annoying when people ask me that, but most people ... They don’t want to talk to me. Don’t want to know me.

Alternatively, inquiry about the Participant could be done through other people in the workplace rather than inquiring directly. It could increase the group of *monitoring others* as Participants never knew who was watching, or whether they were *monitoring* the Participant for someone else:

Elijah: ... sometimes you get the boss, who may be aware of my illness, might say to one of your colleagues, ‘Oh, how’s he going?’ and sort of disclosing it to them, and sort of keeping tabs on you type of thing.

When *monitoring others* had viewed or heard of symptomatic behaviour in the workplace it could make the Participant's illness appear as a public concern or risk. In order for colleagues to alleviate their concerns and reassure themselves, people would ask the Participant about their symptoms or medication. This action presupposed that they had a right to do this:

Lass: ...it could have been seen as constructive ... But the other woman who ... sidled up to me every now and again, said, "Are you still taking your medication?". It was a wee bit derogatory sometimes, the way it was said ... I was reduced to more of a childlike thing that I had to be reminded to take my medication.

Hamish: How long did this keep going on for?

Lass: For several months.

Because illness symptoms were associated with uncertainty about risk, distress and predictability, and were not readily visible, people took it upon themselves to check out their uncertainties with the Participant. The Participant felt the uncertainty and risk they posed was often unfounded and provided a warrant for people to open up a very personal part of their life to public view. Inquiry could force disclosure and any disclosure became grounds for further, and often more invasive, inquiry.

On occasions when Participants had worked in mental health organisations as a consumer representative (where having a psychiatric disorder was required for the job), then everyone knew. However *testing* by inquiry still occurred, and some cases were more invasive, as more personnel had access to more personal information. There could be resultant difficulties in making friends, as workplace rules seem to preclude it:

Elijah: ...because of the ethics involved in that industry, it's hard to make friends here ... Ethics... like, workers are not allowed to have relationships with people that are clients, and I'm sort of a client and worker so I cannot make friendships with the workers because I'm a client, and I cannot make friendships with the clients because I'm a worker.

Once Participants had disclosed, others usually wanted to find out more, irrespective of whether they had a prerogative to do so by courtesy or by law. On the other hand, Genevieve was asked about everything except her psychiatric difficulties:

Hamish: But did she [supervisor] pick up on your unwellness at all?

Genevieve: Yes, she did.

Hamish: How did she broach that with you?

Genevieve: Well, she didn't.

Traditionally, in New Zealand work places, humour has been employed as a way of talking about topics that harbour social deviancy and prohibitions. *Monitoring others* used joking as a way of *testing* the Participant and as a specific type of conversational inquiry. While these moments were intended as humorous, they could also be acts of covert information gathering that formed the basis for others to learn from Participant experiences in a non-stereotypical way:

Digger: ... working as an underground miner, it was all sort of up-front, like... you know. Somebody would say something about nutters (sic), 'Oh you got schizophrenia have you?'. I'd say, 'Yeah', and they said, 'Oh, who did you think you were?' sort of laugh. I'd say, 'No, it's not like that', and they'd just say, 'Oh, what is it like?' and they'd just ask what it's like and they might make a joke about it sometimes, and you make might make a joke back, you know. And I found it was in ya (sic) face. And what's more, they'd listen.

By raising a stereotypical belief about schizophrenia (e.g. split personality), others could check the veracity of this belief and the Participant's warrant for membership of the "nutters" group. Their beliefs might remain, but at least they were assured that their stereotypical beliefs did not necessarily apply to the Participant. Even when people enquired with the best of intentions, the fact that other people thought it was important to do so anchored the significance of the mark in interpersonal relations. Often *inquiry* could be a pre-cursor to *instruction*.

Testing by Instruction

When *monitoring others* gave *instruction* there could be *uncertainty* as to whether the Participant would respond in a positive way. As a way of reducing *uncertainty*, *monitoring others* might begin *instruction* with *enquiry*. Their *uncertainty* with detecting 'mad' signs when there were no visible marks could be resolved by soliciting Participants' self-states. This then acted as a guide to likely compliance with a request. At the same time, it permitted a person tactfully to withdraw. Notice that the emphasis of the above inquiry to Digger was not on his ability to do the task, but on his ability to manage himself. The *uncertainty* *monitoring others* felt concerning social predictability with the Participant was visibly different from that of Diggers' workmates: "whereas with other people he just said, 'Oh, just do that will ya', and 'Can ya have that by Monday?', and, well, with me he seemed a bit more cautious" (Digger).

The assumptions on which *monitoring others* were operating seemed unable to be disconfirmed or warranted by the Participant's workplace behaviour. The Participants noticed that the ease and assumed outcome that took place with others did not take place with them. There could be *uncertainty* about whether other people were just being considerate or something else. There could be an assumption that Participants not only had a mental disease, but had a mental deficiency, such as reduced intelligence. Just because a Participant had disclosed they had been: "mentally ill, it doesn't mean that they are dumb as well, because intelligence is not synonymous with mental illness" (Veila).

It raised questions for the Participant around:

- *uncertainty* - "Why do they seem so uncertain about me even when I am feeling ok"?, "Are they seeing things I do not"?
- overcompensation (e.g. over explanation of request assumes a fragility);
- marking the person out as different (e.g. different interactional style and social distance compared with other employees); and
- frustration (e.g. 'why don't they just get on with it?').

Instruction usually happened with people of a higher workplace status. On an everyday level there was *activity* by workmates.

Testing by Activity

Activity refers to how Participants engaged with others and their job. It was dependent on the *inquiry* and *instruction* they received from others. *Activity* with others was necessary to the job, but the act of *activity* also carried some risks to the Participant. In some instances, *activity* with Participants was used to collect information that could be used against them - either to verify the Participant's membership of a group stereotype or to undermine them. Such an activity, while transparently malicious, was not unusual. It was more likely to happen in work situations that were very dependent on character reference (e.g. professions, public service, health). In such positions Participants were more vulnerable to status threats. Attacking the person's character by innuendo and maligning them outside their presence could alter others' perceptions. The mere fact of suspicions occurring could be grounds for being suspicious, and when these suspicions were

raised about psychiatric health they tended to persist. In this situation work colleagues could use *disclosure* and suspect performance attributed to psychiatric disorder to discredit or undermine a Participant's work status. This happened differently for people of different social status:

Digger: ... "with people I've worked with in management and technical jobs ... I've noticed quite a bit of back stabbing in a lot of those sort of jobs I've been in ... some of the educated people have a sort of a sensible attitude to it and think, 'Ok. The guy's stable on his medication. He's held down a responsible job - he should be alright. But we'll probably keep a bit of an eye on him. We will not tell him" sort of thing. But other people (are) crawlin' (sic) their way up the corporate ladder, or use any device what-so-ever to stab me in the back. And I have been told that this has happened to me".

Work colleagues could find ammunition for manipulation, and to advance their own cause, in any sort of difference perceived as transgressing norms of behaviour, of which psychiatric health might be just one possible cause: "I think any minority or any people that are perceived as outside the norm of society are going to be treated that way" (Digger).

In selection for professional employment, selection committees often look for reasons to discount a prospective employee, rather than select them. Once *disclosure* had happened, the Participant had no way of knowing what bias was given to information as it circulated through employment networks. As a high percentage of professional appointments are sourced through personal and social networks, negative connotations about their psychiatric status can reach into these networks with adverse effects. The Participant may never know why they were never accepted or favourably reviewed for advancement; they may only learn of this sometime later through third parties.

This knowledge could give *monitoring others* a lever of control that they did not have with other colleagues. Unintentional as it might be, casual inferences about the Participant's psychiatric disorder reminded Participants of something they had tried to put behind them. These comments could pull Participants back into an illness identity again. The continued *haunting* constantly demanded *constructing identity* in response to being marked again by their psychiatric disorder. *Monitoring others* might expect less performance. By not wanting the Participant to perform as others would in a similar position with the same skills, the

Participant and those around them were informed that they were not as competent as their peers. Similar wages but disparate task expectations were more likely to receive negative evaluations from colleagues and the person might face comments like: “You’re not up to it”, “Weak as...”, or “What is so special about you?”. Or, in the reverse, similar task expectations by employers who paid dissimilar wages could have a corrosive effect on motivation:

Claude: Consequently I thought my work was substandard. I thought to myself "Why is he not paying me the amount of wages that I'm really due? I think my work must be substandard, I don't think that I'm working to the full potential". And I went on working like that for about two years, and I started to get despondent.

Sometimes Participants needed to take a short break to get through the day, which could confirm stereotypical views of Participants as somehow, permanently weaker than others:

King: ...the stigma is sort of seen that, if you’re looking for more of a full time job, that the employer might see you as more of a part timer. You might just need to take a break because you just need a break. For no other reason. Sometimes it might be seen as not always being able to provide a high function of activity or work.

Monitoring others could present very incongruent messages to the Participant on their work ability. Underlying this incongruence might be genuine mistakes, but even these lent themselves to a negative interpretation - giving sufficient licence that the Participant could be treated any way the employer wished. At the same time the incongruent messages could be perceived as a covert lack of trust in the Participant’s judgement, which only came to fruition in evaluative contexts that had salient consequences for *monitoring others*. For instance:

Joan: ...there was innuendo that I was going to be incompetent in my presentation of staff view points, and that I was going to misrepresent or understate the points of view of certain staff members.

When *monitoring others* engaged with the Participant, both the process and outcome could seem as though the Participant was *on probation*. The *scrutiny*, where *monitoring others* were *on guard* and *testing* Participants, could produce information and experience that mediated the effects of being marked as mad. When Participants were “checked out” and “proved “alright”, the *scrutiny* might reduce and switch to *practical support* or *disinterest* – the Participant just ‘gets on with it’. When this did not happen, processes of the *scrutiny* endured and intensified. The actions of *close scrutiny* and *setting apart*, which were shadowed

in *guarding* and probes by *monitoring others*, solidified to become concrete and explicit interpersonal behaviours. Different experiences by *monitoring others* could often polarise the positions of their work colleagues. Some could be on the Participant's side, or at least not against them. This was in contrast to others who at worst wanted the Participant to cease employment, or at best were just unhappy with the Participant and never satisfied with their work. It was the latter group of *monitoring others* who engaged in further *close scrutiny* and *setting apart* of the Participant, which is examined next.

Close Scrutiny

An essential part of *scrutiny* was the watchfulness that was kept by *monitoring others*. What changed *scrutiny* from watchfulness to intrusiveness, was its becoming *close scrutiny*. *Close scrutiny* had two key parts. Firstly, it involved inquiry. Secondly, it involved attention in a manner that attracted notice and was particular about detail, so that inspection was done closely and intently. *Close scrutiny* was not perceived to be a productive activity whose rationale was consistent with workplace norms. Rather, it became intensified *scrutiny* due to a continuing *uncertainty* on the part of *monitoring others* that they were unable to resolve through *job sorting*, *guarding* and *testing*: "I got the job and I knew that ... I'd be under close scrutiny"(Joan).

What differentiated *close scrutiny* within employment was that its frequency, duration and intensity were overtly different from that which took place with equivalent workplace colleagues. This activity was transparent and unambiguous in its prosecution.

Hamish: Do you think that people became over-observant of you once they find out?

Genevieve: "Oh yeah ... They are watching for signs and symptoms of madness.."

Close scrutiny was visible to both *monitoring others* and Participants as it directly intruded into workplace interactions, and *monitoring others'* interpersonal behaviour was intrusive because of their *close scrutiny*. It was self-righteous, because the need for it was viewed as implicit and obvious, and therefore no subterfuge was necessary. *Close scrutiny* placed a Participant's workplace behaviour under a very fine lens, unlike those applied to other employees.

Achilles: Someone reported me as not coping in court. And I 'd say, "Well, in what sense not coping?" I went with the required number of files and didn't miss a trick ... they were making subjective judgements ... I tended to dress in a less formal way than most. Or that in the writing and expression of the courts I was much more tolerant around people who had mental ill health than perhaps some others might be, so my report and recommendations were seen as being liberal.

Close scrutiny could cease to be a defensive strategy and become offensive. Ambiguity or misunderstanding in workplace behaviour or non-workplace activity might be interpreted as disqualifiers for job performance or retention. There could be an overt effort to look for ways to 'let someone go' instead of retaining their services:

Achilles: I became manic for a period of about 3 days and ended up in hospital for 3 days. Again nothing particular to draw attention to myself except being manic, extravagant, unwell. And the Department of course knew of this, so when I came out, the suggestion was that I would like to resign. And I said, 'No, I would not'.

When signs of 'madness' happened in the workplace *uncertainty* was created. When others had no prior knowledge or experience with such events, all they had to fall back on to inform their perception of events and resolve their *uncertainty* were culturally shared ideas about 'madness' and 'mad' people. When Participants did not act and behave according to their stereotypes, rather than the stereotypes being disconfirmed, they could be solidified and polarised. Having caught Achilles out as "mad", *monitoring others* 'naturally' assumed he'd accept that he could not continue in his work. They then expected him to resign. The assumptions were that 'madness' was permanent and crisis could occur at any time, permeating negatively all future work endeavours. These were precisely the same illness attributions that could *haunt* the everyday life of Participants. Moreover such a position was incompatible with Achille's continuing employment: "The administration basically hated me. The older people, who couldn't accept that someone could be - and the word 'psychotic' was always there - and work" (Achilles). Put simply - 'mad' people cannot and do not work:

Achilles: Yes, they did not believe that a person could manage an illness and not let it interfere with work, and I am quite sure I demonstrated that ... I withdraw after early signs for a period and return when things are ok again.

This scrutiny Achilles received was pernicious, resolute and insoluble to repair. It neglected the position that the Participant was not 'mad' 24 hours/day, 365 days

of the year. Moreover, when Participants were unwell, it was for short periods that could fit into allotted leave and existing entitlements. “In the last twelve years I’ve had manic depression less than what people get the flu for, which would average out one week a year” (Elijah).

Sick leave appeared to be only for people who were ‘sick’ and could ‘recover’ to resume employment. Thus by not permitting this as a reasonable option, no recovery of the work role and competence was seen as likely, or desirable. The Participant’s continuing presence was resented. *Close scrutiny* could be a means used by *monitoring others* to camouflage their own *uncertainty*. When that *uncertainty* ensued from beliefs and expectations about ‘madness’ and ‘mad’ people, then Participants had no means to disconfirm such positions. Consequently ‘in situ’ evaluation of their performance was not salient or relevant. The judgement had already been made. Alternatively, *close scrutiny* could have an implicit threat of: ‘Do not play up as we are watching you’. The control by scrutiny was a way of controlling the outbreak of ‘madness’. *Close scrutiny* might be seen as being in the Participant’s own interest and that *monitoring others* were really there to support them, hence making the *close scrutiny* necessary. But if work performance and behaviour was satisfactory, then Participants perceived that the grounds for its continuance were that it was unnecessary and faultfinding:

Genevieve: It was like power and control issues She wanted to know absolutely everything that I was doing. Which was fine. I mean, I had that responsibility to tell what I was doing. But she ... criticised me in the way in which I worked, so I felt really put down by her.

The closeness of their scrutiny raised a suspicion about their own competence - being able was seen as being independent of supervised care. Being in supervised care (i.e. *close scrutiny*) could link with experiences undergone when they were not able and dependent. Hence being under *close scrutiny* once more meant that Participants could infer that they were less competent. On top of this there could be an overlay of difficulties. It could be difficult for Participants to know whether this *scrutiny* was justified or merely served to escalate feelings of suspicion and thereby contributed to pre-cursors of becoming unwell. *Close scrutiny* for anyone could make them feel as though they were under the spotlight at the very time when they wanted to feel that they could and were fitting into their work environment. In other instances the *close scrutiny* receded but did not go away. It

got accepted as part of their job, even if the Participant was unable to resolve it or had no events occur that warranted it:

Digger: Just over the years I felt like times that employers have been sort of keeping an eye on me to make sure I didn't do anything sort of funny or something like that you know.

In this situation Digger received *close scrutiny*, but was *not set apart*. However, the outcome of *close scrutiny* can be that the Participant was *set apart* in some way that was visible to others and to themselves.

'Set Apart'

Close scrutiny created a sense of unease and *uncertainty* in interactions. This *uncertainty* could be partly resolved by *testing* and the responses to it. However the assumptions perceived as being made about the Participant, before, during and after *testing*, were what distinguished their *testing* from that applied to anyone else in a workplace:

John: "Yeah I am, yep, pretty isolated because of this stigma that's surrounding me. People look at me. They think, 'Oh, there's that mad person'. They don't know how to approach me ... they think I might be dangerous or that I might be infectious".

These and similar assumptions informed by stereotypical beliefs about 'madness' and 'mad' people were perceived to underwrite the *uncertainty* that *set apart* Participants. They might observe no one else in their workplace having that degree of *scrutiny*. Someone always seems to be lingering nearby (e.g. checking, not trusting). The lack of confidence others might have in Participants could promote their need to maintain a *scrutiny*, either out of self interest (e.g. fear) or work interest (e.g. job responsibility) or *uncertainty* (e.g. suspicion). While there might be only a few people who were really keeping an eye on Participants, the need to do that in a manner different from what was done to others could easily be adopted by a wider group. When Participants had not disclosed in the workplace, the sense of difference they might feel was heightened by the need continually to observe others, to see if they were being watched for some reason. Suspicions by others could become suspicions for the Participant.

The consequences of managing suspicions could be social *uncertainty*. When suspicions were thought to be extreme or had a measure of personal threat/fear, people could behave in a very restricted manner when they interacted. In not

wanting to cause offence or provoke eruption, they might avoid and not engage or interact. In some ways, by avoiding the Participant they were also avoiding their own fears and *uncertainty*. The feeling of being avoided could create in Participants a sense of “is there something wrong with me?” (i.e. internal attributions which related to psychiatric health status). When *close scrutiny* occurred and Participants were *set apart*, the act of being set apart could be concealed within workplace practices. Such practices of probation or trialling employees before their position is confirmed have widespread currency. It legitimated their *scrutiny* of the Participant and permitted termination of their employment. People were not sacked; they just failed to complete their probationary period. Or, in the situation below for Achilles, the conditions for restarting employment after sickness did not involve resumption but reinstatement. In seeking reinstatement (which involved a probationary period that was more than that usually required), he faced conditions of employment that were more severe than when he first obtained his employment:

Achilles: I was put on 18 months instead of 12 months probationary status. And that's where the stigma really started, because half the staff were supportive of me returning and half the staff wouldn't because I was a mad bastard. They were totally polarised.

His need both to be reinstated and to pass a probationary period implied a very different trajectory to that of someone who has taken ‘sick’. It brought attention to him and set him apart in a very unambiguous way. There was considerable conjecture around his employment and this had the effect of ‘polarising’ staff support.

Achilles. It was not well accepted by individuals ... some of them found it very difficult to accept and wanted to stay away from me - ostracise me socially - and really saw me as being really dangerous, if you like, and different and strange. The other half didn't. Again, it is always a 50/50 split, it seems.

Achilles adopted a very robust approach to *resolving uncertainty* with his employment and being *set apart*, but he did have support from at least half of his workmates. Sometimes there is no support or fellowship with work colleagues:

Lass: It was more a case of being excluded. And really, really by the time that I got back to the workplace, I found myself excluded there. [People] just generally avoiding me and ... so my reaction then was to shy away from other people and [this] recreated a sense of inadequacy and more shyness.

When Participants were being excluded by colleagues, they were excluded from casual everyday interactions, not regularly participating in everyday interactions. Moreover, when interactions did occur it was because others had to rather than wanted to, which could lead the Participant to avoid interactions as much as did others. Sometimes when people were set apart and did not fit in, the language and behaviour of others marked them out. They got called: “a psycho, nutter (sic), crazy. A lot of people wouldn’t talk to me anymore ... got picked on a lot and well, I mean, I didn’t like it”(Laura). The potential for getting ‘picked on’ during interactions could make contact an unpleasant activity, fraught with *uncertainty*. Avoiding interactions reduced the frequency of contacts, but not the need for person contacts.

Digger: I was feeling I was desperately unhappy, you know. I really was. And, you know, I found that a real strain to, like, not having any one I could confide in. ‘Cause at that time I was working as [a national inspector of a primary industry].

Wanting to have someone they could share with, while at the same time not being able to do so, could lead to a sense of inadequacy or reduced competence and feeling so alone. When Participants were not confident, did not feel competent and sensed that others were avoiding them when they engaged in social interaction, they were both being *set apart* by others and being *set apart* by their own efforts. As the person was perceived to be *set apart*, they set themselves apart:

Genevieve: I think they were, yes, they were picking up the fact that I looked a mess, that I wasn’t doing the job properly. I had multidisciplinary meetings. I wasn’t going to meetings, yes, ‘cause I couldn’t face anybody and I knew I was going down the tubes.

Similarly, needing different work practices and then getting them, marked Participants and set them apart from their fellow workmates: “...I would get very tired and go and lie down in the back room. That was okay. Which I thought was odd” (Claude). The Participants themselves recognised that their behaviour was unusual, and that having their ‘odd’ behaviour accepted set them apart from those who did not. When Participants resumed work after being sick, it might not be possible to resume the same the level of trust and respect that had been enjoyed there before. The *uncertainty* experienced by *monitoring others* meant not quite knowing who was turning up for work today: Is it going to be the ‘real’ Participant or someone else?

Mary: Well, once I went back to work at Org X and everybody knew I was a manic-depressive. They treated me differently. They used to say, “You are noisy today. Is that the real Mary, or are you the quiet Mary that we used to know before? Is this noisy Mary that we know now the real Mary? Or is the quiet Mary that you were before the real Mary?” And I had to say both.

Hamish: How did you make sense of that?

Mary: They were discriminating against me because I have got a mental illness.

This occurred within a workplace for mental health workers. A group who had been trained and were experienced in sorting through the difficulties of psychiatric illness still faced *uncertainty* in determining competence in their work colleague. While Participants’ interactions with others could mark them and set them apart, so could bodily movements that occurred as side effects of medication. Even in the workplace where people got to know the Participant, the visibility of the ‘shakes’ invited questions and attention from others:

John: They want to know what it’s caused from, or what it is, but it set me apart from the rest of so-called normal people. I didn’t like it at all it ... at work they were pretty good about it. But, you know, I still felt set apart from the rest of society when I was experiencing the shakes like that.

Over politeness, excessive instruction, lack of ease, solicitation of self-state; all, despite best intentions, indicated that Participants had not proved themselves ‘alright’. In other words if you were ‘alright’ you would be treated the same way as other people. Hence there appeared to be a different set of expectations held for Participants. Communication could be felt to be a risk-taking activity as they lacked confidence or certainty about how the other person was going to react. It could reveal communicative incompetence (e.g. baby talk), social *uncertainty* (e.g. are they going to blow up?), lowered expectations (e.g. keep it simple) and publicly marked the person as different. Confirming Participants as being outside the norm permitted them to be treated that way and there were usually no half measures, for people were:

Achilles: ...either with you or against you, and I was not fortunate in my immediate boss, but very fortunate in my immediate co-workers, because it took me 3 months to be functioning properly again, and I even got to the stage of getting merit gradings and did the job with ease.

When Participants had been *set apart* from others within the workplace, they struggled to make sense of why this was happening. As discussed, Participants made inferences from *monitoring others’* behaviour and disposition towards them, with regard to their competence, agency and psychiatric status. The origins and

expectations of *monitoring others* in their *close scrutiny* could be portrayed as a by-product of being in the workplace. However when Participants used their performance in the workplace as a guide to interpersonal relations with *monitoring others*, an incongruence appeared. *Monitoring others'* interactions about a Participant's work could conceal probes about their psychiatric health, so that work performance was psychiatric health performance. Psychiatric status and job competence started to be viewed by Participants as a central concern, process and outcome of employment, even when they were 'well'.

Keeping Going

Participants all talked about the efforts they made to *keep going*. *Keeping going* was the struggle, persistence and resolute efforts Participants made in the face of the demands and difficulties they experienced in employment. For some, the workplace and its inhabitants became an aversive experience:

Evan: I have experienced from other people such shocking mutual consideration, bad manners, unreasonable expectations ... that I am actually very happy to be on the invalid's benefit.

What was hard for Evan was not necessarily the work he was attempting to do, but what passed for normal behaviour in the workplace. The effort it took and the threats it made to his wellbeing, made *keeping going* in the face of 'normal' workplace behaviour an unendurable experience. The only way for Evan to *keep going* was to exit employment generally and try to return to a selected work environment. *Monitoring others* were perceived to have an expectation that Participants knew the unstated behavioural norms of workplace behaviour. In adopting this position, transgression of such norms could be seen as intentional (deviant) rather than incidental to altered thinking and perceptual processes. It could be difficult to know what were the "right things" in 'normal' social interactions when prior social interactions had been with 'mad' people. The baseline for the 'what' and 'how' of normal interaction had to be re-established:

Mary: When I got my job it ... I had to try harder to be a normal person because I was not on medication.

Hamish: What were you trying to do, when you say "be a normal person"

Mary: You try harder to do all the right things. You try much, much harder to do all the right things.

In order to do the "right things", Participants had to find out what they were and develop confidence in their interpretation of what others were doing and saying

to them. This was not an easy task when a Participant's thinking and emotion could be tracking in a very different way to those around them. As with a significant percentage of the non-consumer population, it was easier for Mary to be 'normal' when medicated. Going off medication could reduce Participant scrutiny as the medication side-effects could recede. This was not a trivial matter. Medication side-effects could alter Participants in both visible and discreet ways.

To *keep going*, an often-used tactic was to withdraw from employment. But for this to happen, a certain type of arrangement with the employer was sought:

Laura: Quite often I would take time off work. The Manager was really good. I mean, I'd go to him and say 'Look I just cannot ... I cannot cope with this', and take a week off work ... I'd worked for six weeks and then I just wouldn't be able to ... cope with all the hassling and things like that ... and I'd stay at home and lie in bed all week, feel sorry for myself and then I'd just sort of go back.

Keeping going could go either way; it rarely sat comfortably on a middle ground. Participants usually either succeeded or they did not. *Keeping going* could lead into developing responses to and alliances with others (e.g. a *monitoring partisan*) that were adaptive for them. Alternatively, Participants could find themselves *keeping going* from the workplace to hospital or from employment to unemployment. Just as important was their internal processing of what was taking place. Inferences and attributions about self-worth, self-confidence and social ease were sometimes more important than job ability and competence. Though both contributed, it was difficult to separate out whether job performance was mental health performance or mental health performance was job performance. *Monitoring others* and Participants alike conflated work performance with mental health performance, when it came to assessing progress. Yet it was when Participants moved from viewing their psychiatric disorder as their main focus within and about themselves, to viewing it as a subset of considerations amongst other personal/social considerations, that *keeping going* became a positive adaptation. Similarly, as *monitoring others* started to perceive and interact with a wider spectrum of social and personal expectations (e.g. less marking), so too did the Participant. What hastened *keeping going* was change in the attitudes and efforts of workmates and their employer. These efforts are discussed next as *practical interest*.

Practical Interest

When *monitoring others'* interest in the Participant was no different to other workmates or was supportive, then this was called *practical interest*. It might be discreet or, if overt, not enough to be invasive like *close scrutiny*. When it was overt it was only sufficient to permit others to know some of the achievements and difficulties the Participant had faced, and was expressed in an everyday manner.

Digger: ...a number of the office girls were saying, "Like, you feeling alright now, Digger? We heard you been sick." and all that, and I think they genuinely meant it, you know. So it it's fairly supportive, really, yeah.

In this instance *monitoring* could also be a strategy of concern and support. Staying in touch with the person reduced the ambiguity of experiential interpretation, built a sense of communicative competence or ease, and demonstrated publicly that talking to and being with this person was 'alright'. When open social interaction was seen to be 'alright', then that could act as a basis for others to predict that it would be 'alright' for them. Another important aspect was that by being open and honest with *uncertainty*, Participants were able to discuss with others their difficulties in a way that sought resolution rather than apology. Often Participants could be surprised at the positive response they received.

When some Participants were open about their psychiatric difficulties with an employer who had known the Participant for some time, the employer could be very flexible with their working arrangements. Moreover, such support, despite repeated absences, could run over many years and admissions, for Participants who were hard workers:

Toa: ...and within those 6 years I had about another maybe 4, 5 admissions. ... I rang up the boss first and told him I wasn't feeling very well. ... I told him that I was going back into [hospital] and he said "Oh, well, you know your job will be still here when you get back." He used to say that all the time ... I think they realised that I was a good worker and ... a couple of times that I did go in there voluntary I always seemed to get back, yeah.

On occasions the support could be very practical and meet the Participant's need to rest or withdraw during the course of the working day: "they were very good to

me, very open minded. I'd go to sleep and it would take me an hour and a half to have a lunch hour. They accepted that" (Claude).

Sometimes however, despite support, employers could see that while the Participant was in their employ they were not addressing more important health issues. Sometimes there was a reduction in hours first, before getting termination of employment. At other times it became a 'make or break' situation, where there was no further room for manoeuvring around work difficulties: "...I told him, 'Why?', and he said, 'Look, you've got to do something, and I cannot keep covering for you like this.' And yeah, so I got the sack"(Laura). The support that some Participants required was breaking the job down into workable parts. When this happened, it not only provided a way to achieve tasks but also a clear way to evaluate or assess their progress. Sometimes the best support could be from people with whom Participants had worked: "I think they just used to say "Oh, you're alright now, aye, bro (sic). You're alright now." Yeah, that was their attitude towards that, which was good support, I suppose, mm..." (Toa).

Their honest appraisal and positive attitude could help resolve the Participant's *uncertainty* while in the workplace about whether they were 'alright'. In some ways this statement was a pronouncement that what had happened was behind them and at the same time it was also querying whether that was really so. Such a comment from *monitoring others* could build an expectation and therefore almost a pressure to agree. The best support could occur when Participants had been unwell and they wished to return to the workforce. Having someone who was realistically aware of their ability and wanted to support their return could be hard for the Participant. They might want to return fully to their prior position, yet they were required to demonstrate that they were able to do so. It could be difficult to find a way to facilitate return that did not undermine the motivation and status of the Participant. Moreover the criterion had to match their current ability to do the job, and not risk the quality of the service they were required to deliver.

At the same time, presenting job tasks they could achieve and seeing the way forward to a position similar to the one they had achieved prior to leaving work instilled hope. In some professions in which Participants had worked (e.g.

teaching, social work, mental health), which had a shortage of practitioners, employers might be more considerate and motivated to have people return to their workforce. In other forms of employment where there was a glut of prospective employees, employers might not want to make this effort. To overcome the dependence on employers for jobs, some Participants became self-employed. In self-employment, there was no need to disclose. Unlike paid employment, which involved statutory terms, conditions and responsibilities for employers; in self-employment the customer had no such lien on them. Customers could cease their relationship at will and with no recognisance. However, when Participants had to stop work, either due to symptom onset or crisis and admission, there was no one to step in and cover for them. Participants then were required to give some explanation to their customers of why they had stopped work, if they wished to retain them upon restarting business again. *Practical interest* and a solid Participant work ethic can result in self-employment where:

King: ... even though I am doing work for them, and they are aware of where I have been, they are very supportive by continuing to employ me to do their work, and even talk openly about their experiences.

Sometimes *practical interest* and support could develop in the course of employment; at other times *practical interest* and supports were required before Participants could enter the workplace.

Joan: ...I applied for it ... and I was really lucky in that. The day hospital staff advocated really really supportively and superbly on my behalf. And I think without them at that stage I probably wouldn't have got the job... and I've been in it - this is my third year.

What greatly assisted *practical interest* and support within the workplace was the presence of a *monitoring partisan*.

Monitoring Partisan

A *partisan* was a person perceived to be in league or allied with the Participant for mutual support or joint action. The *partisan* had access to more private knowledge of the Participant and reduced social distance when talking. A *partisan* could become an independent source of feedback concerning self-state and event interpretation. This functioned as a triadic tactic, triangulating information between the event (and any third parties involved), the *partisan* and Participant.

Triangulation permitted resolving *uncertainty* around events in terms of their reality (real vs imagined), reference to norms (appropriate vs inappropriate) and mental health status (well vs unwell perceptions).

Digger: Oh I could talk to them about things I've talked and say, 'Look I think so and so, and this is happening'. They say 'Oh no, I don't think it is, Dig'. Like, 'Take it easy', you know. Your friends can be a good reality check for you.

As Digger suggests, disclosure could be a 'reality check' and used to determine what was quite normal.

Monitoring others could become *monitoring partisans*. This shift in role and social distance usually developed over time with people who were of the same sex and equivalent work status. It was a relationship marked by openness with expression and a trust that the person would give an independent view even when the Participants might not agree with it. The *monitoring partisan* enabled effective support (e.g. where people would cover for you) to take place as well as being an accurate source of feedback on the Participant's performance in both social situations and job functioning. It was like having someone on your side who would go into bat for you, particularly when you were not around. What made the *partisan* so important and desirable was:

- the basis and ongoing presence of the relationship was not a paid one (e.g. unlike a support worker),
- the relationship had occurred in an everyday manner, as it did with other people, and with those who usually were not mental health users, and
- it was an outcome of their own personal attractiveness to, and shared interest with, others.

The relationship with a *monitoring partisan* was usually developed over time and through shared experience. Having a *monitoring partisan* was the best predictor of sustaining employment. Work became a social and an economic activity. Difficulties could be resolved by their own efforts and without mental health staff intervention, thereby fostering confidence, problem solving and resilience. Participant's personal and social *uncertainty*, involving other people, could be viewed independently. For Laura it was someone she knew both within and outside of work. The *partisan* was willing to seek resolution of difficulties that Laura faced.

Laura: My flatmate ... worked at Org X, and she was also very staunch and she basically threatened to beat up quite a few people if they didn't lay off. She went and complained before I got back to work. She heard the supervisor going around saying things when she went in, complained to the manager and the supervisor got it sorted out. But it didn't stop it, it just quietened it down".

When John worked in a mental health service, he had *monitoring partisans* who could provide an independent view and mental health advice:

John: If I do become a little unwell it will be snapped up quick: They will be able to recognise the signs. They all know my signs 'cause I have let them know this what happens to me when I start going haywire. Like someone will tap me on the shoulder and say "Hey, John. How about taking a few days off?" or, this is my doctor, "How about taking a few extra pills for a few days?"

Whereas Achilles relied primarily on his wife, though he did have workmates who could also assist:

Achilles: I have lot of networks who feed back to me. I have got people - my wife is a mental health worker, but she is certainly very capable of feeding back to me niceties of life - behavioural and mental states - and she can do it in quite an objective way. But also with work mates here.

Having a *monitoring partisan* was a very effective strategy for *keeping going* in the face of personal and social *uncertainty*. However, an ideal situation for Participants was to have disclosed and yet not find themselves *marked* by their psychiatric disorder.

Not Marked

When Participants disclosed at work, other people monitored them because of their *disclosure* about their psychiatric disorder. In addition to Participants' labels that went with their diagnosis, the manner in which others monitored and interacted with the Participant also *marked* the Participant and set them apart. The extent to which a Participant was marked by their psychiatric disorder through the activities of *monitoring others* usually reflected the extent to which a person was monitored by others. However as a result of *job sorting* and *scrutiny*, others within the workplace might cease their *monitoring*, because the mark no longer created *uncertainty*. Although others were still aware of the Participant's psychiatric condition, it ceased to be a pivotal feature of workplace interaction, social inclusion and evaluation:

Toa: Well, the boys treated me quite good. They were trying to help me as much as they could. I think the biggest thing they did was just - they didn't talk about my sickness. They knew I was a quite a sick person.

All Participants had engaged in work that had reduced entry requirements before they moved into more demanding work that challenged their abilities. In such forms of employment, they joined others who did not 'fit in'. Employers were perceived only to be interested if they could do the job. Consequently, provided personal difficulties did not interfere with doing their tasks, any significance attached to their psychiatric disorder disappeared:

Achilles: I had a big label and a large load of medication, so the jobs that I took were jobs where labelling sharpness or intellect are not required. Like, I was sweeping floors and working in various places like boundaries, boatyards and doing jobs which, in application for it, if you said you were mentally ill it wouldn't matter anyway. They would just say, "Ho hum, can you do the job?"

When Participants were not *marked* it could lead to their being seen as an everyday employee. Their psychiatric disorder was there, but it did not become a pivotal feature to consider when working with the Participant. The Participant perceived that they were *not marked* when they were treated in an everyday manner by their workmates. Just as importantly, the expectations that were held for their job performance were not contingent on them managing their mental health, but on managing their social health and functioning at work. Deviancy from workplace norms did not incur sanctions because prior experiences and practical strategies gave a measure of predictability to their job performance. Participants might become 'unwell' or 'fall over', but this happened within the context of general work, sickness or accident. In particular, the choice of employment type (e.g. flexible working hours, afternoon/evening shift work), medications with less side effects, workplace and non-workplace supports, created a scene in which the Participant could function at their best. When this happened there were fewer opportunities for marking to occur and better resilience when it did.

Summary

Constructing identity required considerations of psychiatric illness that could mark out a Participant's life trajectory with reduced expectations and outcomes in employment. In the workplace, *haunting* created *uncertainty*, which *vigilance* was

employed to resolve. *Passing* was a strategy that Participants used to avoid discrimination during interviews and daily workplace interactions. However, *passing* could intensify concerns about impression management, so that Participants were hyper-vigilant to both their *inadvertent disclosure* and how other people perceived them. The social demands of workplace interactions could heighten suspicions about personal competence in a manner that made it difficult to sort them out from normal workplace evaluation. Were they having a 'bad day', like anyone else, or were they beginning the slide towards crisis? Misunderstandings, poor communication and loss of employment could amplify *uncertainty* about what was *appropriate, real* and non-*illness* mediated events. Yet Participants acutely felt the value of employment. It was an activity that indicated to them and those around them, that they had rejoined the 'world' and were a person, again.

The discussion in chapter nine will bring the previous analysis chapters (4-8) together and provide a theoretical framework for considering psychiatric stigma as *uncertainty*.

CHAPTER 9 - DISCUSSION

Introduction

Psychiatric stigma, in this context, is the stigma that occurs as a result of a person having used a psychiatric service. This project examined the stigma experienced by people who have used psychiatric services and have sought or maintained open employment. Psychiatric stigma was found to impact most on people when they exited psychiatric services and faced the challenges of everyday life. Everyday life inaugurated a social identity that was prone to stigma after using psychiatric services. Thus first person accounts of psychiatric service users were examined for processes, which occur within a psychiatric service, that then transfer to another action scene - employment. A theory of psychiatric stigma was developed from psychiatric service use and then refined using the experiences reported by Participants when seeking or maintaining employment.

The focus of this project was the stigmatised person's experience of psychiatric stigma and its role and effects within employment. In order to arrive at employment Participants had to traverse a range of mental health and support services. People who have experienced mental illness show the poorest employment outcomes across all disability groups (Kydd, Mahoney, & Turbott, 1997; MHAC, 1999; O'Hagan, 2000; Rutman, 1994; Statistics New Zealand, 1998;). Hence this low employment participation suggests something structural is operating that results in this exemption or exclusion over time (MHC, 1999a; MOH, 1997; Nuthall, 1997). People who experience psychiatric illness are more likely to return to hospital than to work (Anthony & Blanch, 1987; MacKenzie, et al., 2000). When phenomena are likely to be structural they are easier to research, as they have a relatively consistent and stable form, as opposed to phenomena that are transitory or ambiguous. As these phenomena have been around over time they are also likely to have a history and can therefore be fitted into a historical landscape of social life.

The action scene of employment was chosen because it was a locale that had clear outcomes for the Participant - either they were employed or they were not.

Secondly, employment is a key facet of everyday life for many people without mental illness. Thus there was an opportunity to examine a significant practice of everyday life that is shared by people without mental illness. Thirdly, the audience of employer and fellow employees provides interactions, views and values that are likely to be independent of the mental health service culture. Thus Participant work experiences can occur with an audience naïve to their psychiatric history. Fourthly, employment is a site for the intersection of social practices that relate to citizenship, gender, class, ethnicity, socio-economic status, and power (Marinelli & Orto, 1991). The outcomes from employment spread beyond material gain to personal and social gain in a manner that is visible to others and inclusive to community life. For these reasons employment was chosen as a locale in which to apply a theory of the operation of psychiatric stigma and specific attention was paid to the experiences of Participants in their journey through support and service organisations.

A grounded theory of psychiatric stigma was developed from Participants' trajectory through psychiatric services. The theoretical framework was further refined through theoretical sampling of Participant experiences when seeking or maintaining employment. Thus preliminary conceptualisations about psychiatric stigma were stabilised only when they could handle new evidence of similar events (stigma) from different action scenes (employment). The core category, which captured most of the variance within the data, was *uncertainty*. The basic social psychological process Participants employed in managing everyday concerns about uncertainty was *resolving/creating*. Thus a theoretical framework for psychiatric stigma was developed from first-person accounts that uniquely captured its core feature, and the processes that either created or resolved its presence. What distinguishes this theory is its focus on employment and the use of lay terms that describe complex processes simply.

In the next section I develop a theory of psychiatric stigma and later show how this works by applying it to a relevant area – employment. How does this theory help our understanding? To answer this question I will revisit major points covered in the introduction and relate them to issues raised by the Participants. This will demonstrate how the theory can predict an employment situation

involving psychiatric illness and demonstrate the contribution this theory can make to existing knowledge about psychiatric stigma.

Theoretical Framework

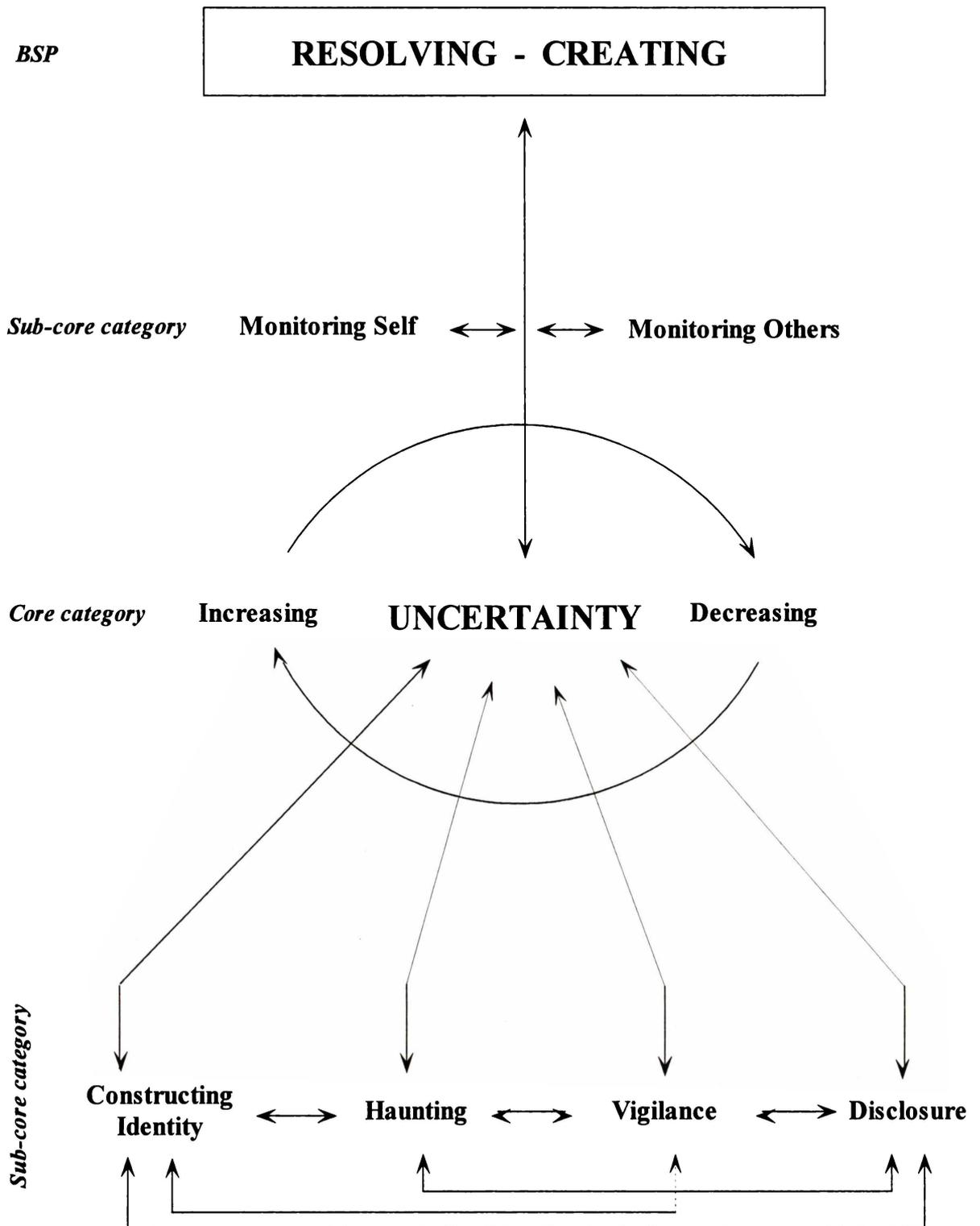
In bringing the previous conceptual categories together, I present in Figure 2 on page 248 an integrated model of the Participants' approach to managing psychiatric stigma. The three dimensions within this model of psychiatric stigma as *uncertainty*¹⁵ were the core category: (1) *uncertainty* – increasing and decreasing; and the sub-core categories (2) *monitoring* – self and others, and (3) the emergent stages – *constructing identity*, *haunting*, *vigil* and *disclosure*. The basic social process (BSP) of *resolving-creating* that Participants used to manage psychiatric stigma integrates the previous conceptual categories – *uncertainty*, *monitoring* and *stages* – into a working model.

Core Category

Psychiatric illness primed uncertainty within intra-personal and interpersonal processes. To the extent that this happened, uncertainty became a mark of psychiatric illness. It marked out social, spatial and internal practices by the self. In doing this it left marks in its movements that interwove with the practice of everyday life; marks which became psychiatric stigma. This stigma infused everyday life, to a greater or lesser degree, with a vicarious tenure - a substitution of an illness for a person. This could subsume a person into the marks of their illness; marks that arbitrated perception and experiencing and imbued them with uncertainty. What made uncertainty uncertain was the property of vicariousness. At any moment it was possible for events to substitute a person for the marks of their illness. Exactly when uncertainty was present or absent was itself uncertain. Uncertainty entailed reaction. Its presence was not neutral, as uncertainty either increased or decreased. It predisposed actions, thinking and emotions by disrupting continuities with these activities. Continuities were dependent on discerning a cause and effect relationship. Uncertainty interceded by introducing probability between causes and effects. Uncertainty had negative features that incurred personal and public sanctions.

¹⁵ All conceptual categories in this chapter are first presented in italics and then appear as standard text

**Figure 2. Theoretical Framework:
Incorporating the Basic Social Process (BSP), Core and Sub-core Categories.**



People could limit daily life to reduce the discomfort associated with uncertainty. Living a reduced life excluded people from economic and social activities. However, uncertainty had positive aspects. Being uncertain about personal trajectories, internal and external processes lowered the threshold for disappointment. At the same time it could be a realistic and pragmatic appraisal and expectation of outcome.

Basic Social Process

The basic social process (BSP) people employed to handle uncertainty was in part resolving uncertainty. However the act of resolving uncertainty led to creating further uncertainty. Hence the BSP consisted of resolving-creating uncertainty. Uncertainty was never fully resolved, either by internal processes, social processes or personal trajectories. A set of conditions, which amplified the valence and salience of uncertainty, was found in employment. The social and personal value of being in employment rendered paid work as an indicator of return to an everyday life. However the prominent outcomes and evaluative nature of being an employee intensified self-monitoring and amplified concerns about monitoring others. Thus participation in employment could resolve uncertainty about a devalued identity and social or economic exclusion, but alternatively it created uncertainty about exactly the same things. How Participants resolved uncertainty within the workplace by disclosure could mark them just as easily as creating uncertainty by not disclosing. Co-operative and evaluative demands of the workplace placed the Participants in a unique situation from which to theorise stigma. The proposed theory of psychiatric stigma hinges on interactions that take place between the three dimensions that are broadly described next.

Sub-Core Categories - Monitoring

In resolving-creating uncertainty, people with a psychiatric disability developed a *monitoring self*. The monitoring self was initiated during the therapeutic journey required to depart from psychiatric and support services. The internalisation of monitoring as a self-directed activity retained the same culture of influence from where it was acquired, to be applied to actions in future endeavours. It was the process of monitoring within psychiatric services that rendered feelings, thinking, and behavioural states as characteristic of psychiatric status. There was a shift from the regime of being monitored by psychiatric staff to installing monitoring as

a self-directed activity. The need to monitor was based on uncertainty regarding intra-psychic processes and interpersonal congruence in social situations. Monitoring the signs or marks of their illness independently was needed to manage living independently of staff care. This then enabled departure from psychiatric care. However it set up a dependent scenario of monitoring self and monitoring others. One did not occur without the other being present or intended.

The activity and dynamics of monitoring transferred to other evaluative situations like employment. There, people who observed the Participant could easily slip into a role that was perceived to mirror that of *monitoring others* (people who monitor only because of the Participant's psychiatric status) within a psychiatric service. That is, talking, actions and comprehension were a display of mental health. Failure with actions, talking and comprehension were a failure of mental health. Hence the need to monitor other people for signs of not *making sense* and the need to monitor self to limit *awkward moments* that could indicate a lapse in mental health competence. The association between monitoring and stigma is that monitoring instituted the marks of psychiatric disorder into internal cognitive and perceptual processes. How the Participant viewed and interpreted themselves, others and their world now had internal referents to the marks of their disorder. Monitoring others took on a slightly different role beyond therapeutic care but the social demands and sanctions employed were consistent with psychiatric service experience. This BSP explains the relation between the person with psychiatric illness, the psychiatric services that they have used and their experiences of psychiatric stigma.

Sub-Core Categories – Stages of Uncertainty

Resolving-creating uncertainty was both an interpersonal process with monitoring others and an intra-personal process for the monitoring self. There were clear emergent stages: constructing identity, haunting, vigil and disclosure. Staging was not linear. Movement between stages was contingent on uncertainty and a BSP of resolving-creating uncertainty. Thus each stage interwove according to the extent and salience of these two contingencies. Constructing identity primed the haunting, which in turn gave rise to vigil and disclosure. These were necessary for the monitoring self to negotiate everyday life. These stages were as much adaptive

as reciprocal responses to the presence of monitoring others and a monitoring self. They existed both independently of and interdependently with the presence of monitoring others.

For example, increasing uncertainty from constructing identity after changes in life course due to illness could lead to attempts to resolve it by withdrawal. However withdrawal could create further uncertainty about ease in social situations, which then created further constructing of an identity that could comfortably *pass* in the company of others. The importance of illness and identity created the haunting prospect of illness re-occurrence, and the significance of this intruded into everyday life. Given the prospect and intrusion of haunting, the monitoring self used vigilance to resolve the uncertainty this created. In resolving the uncertainty of vigilance, people may disclose to reduce the tension of impression management; however this can create further uncertainty as knowledge of their psychiatric disorder can induce fear and unease in others. This theory can explain and predict what impels people to resolve stigma and how it also contributes to its negative outcomes.

Next I compare Participant experience with existing interpretations in the literature. This will show this study's consistency with previous research around stigma but also highlight an under-theorized aspect of the illness experience – uncertainty – and its absence within psychological research on stigma. A theoretical approach that develops psychiatric stigma as uncertainty can offer a practical and innovative method for reconciling disparate accounts within the literature.

Comparisons with Existing Literature

Stigma and Social Distance

Participants, as members of the general public, held stereotypical views of people who have used psychiatric services. This was similar to findings in New Zealand (Blizzard, 1969; Business Research Centre, 1997; Disley, 1989; Green, McCormick et al., 1987; Green, Walkey et al., 1987; MOH, 1997; Ng et al., 1995; Patten, 1992; Romans, 1995) and overseas studies (Bhugra, 1989; Cumming &

Cumming, 1957; Johannsen, 1969; Kreisman & Joy, 1974; Lamy, 1966; Nunnally, 1961; Olmsted & Durham, 1976; Rabkin, 1972, 1974; Sarbin & Mancuso, 1970; Weinstein, 1983). However, they experienced actual occasions of rejection that matched expectations of rejection (Link & Cullen, 1983; Link et al., 1987). It was not something that happened to other people; it was happening to them. Stereotypes around madness, 'mad' people and 'mad' places had the capacity to intoxicate social interactions with unease and to exorcise other personal attributes (Crocker & Quinn, 2000; Link et al., 1989; Link et al., 1997; Link & Phelan, 1999b; Link, Phelan et al., 1999; Link et al., 2001). Interpersonal behaviour and its perception indicated a personal attribute that could be linked to negative stereotypes (Jones et al., 1984). Stigma provided the link and marked interactions with uncertainty, and uncertainty marked interactions with stigma that encouraged a social distance.

Stigma and Stereotyping

Stigma interacted with stereotypes (Biernat & Dovidio, 2000) and prejudice (Miller & Major, 2000), and became a self-fulfilling prophecy (Jussim, 1986; Jussim et al., 2000). Stigma as a sign signalled the intention, direction and valence of adverse reactions. These reactions by a general public were expected and held as Participant beliefs that were self-evident after Participants had used psychiatric services (Link, Mirotznik & Cullen, 1991). Central to perceived public fears were dangerousness and the continued threat of psychiatric disorder that persisted in the absence of symptomatic behaviours (Link, Andrews & Cullen, 1992; Link, Phelan et al., 1999; Phelan et al., 2000). Stigma evoked not only a personal challenge to self but a specific set of characteristics that was assumed to exist among people of that category (Brewer & Brown, 1998; Crocker et al., 1998). As found in international studies, other people paid more attention to negative information than positive information (Skrowonski & Carlstone, 1989).

Stigma and Social Categorisation

Social categorisation involved information reduction and elaboration (Tajfel & Turner, 1986). Robert's comment "I am in a crazy house, I must be crazy" theorised his new identity and his membership of a social category (Allport, 1954). It could sort their social world into 'us' and 'them' (Tajfel & Turner, 1986). Information was rejected about his specific attributes but the category

allowed for assumption of the range of qualities characteristic of the group - crazy (Mackie et al., 1996). Categorisation developed congruence to a group prototype ('crazy' person) and similarity with other members of that group (Hogg & Hains, 1996). This was not a neutral activity. It subsequently affected how information was processed, stored and retrieved (Park & Rothbark, 1982; von Hippel et al., 1995); and how it was interpreted and explained (Hewstone, 1990; Pettigrew, 1979). Research has suggested that when self-esteem is threatened stereotypes are more likely to be activated. Under threat, stereotypes access information in a biased way by causing selection of information to confirm the stereotype. The more negative the emotional valence, the more negative is the processing of this information. Thus both perceiver and target access and process information that is more likely to reproduce stereotypical behaviour than disconfirm it (Claire & Fiske, 1998; Fiske, 1998). Categories gather diffuse information and imply more beyond the information given in a situation. They entail expectations, a strong feeling of inalterability, inductive potential and explanations that appear 'natural' (Biernat & Dovidio, 2000). In Chapter 4, Constructing Identity demonstrated how this happened from a Participant's perspective.

Stigma Congruence

Participants were particularly attuned to the potential negative implications of stigma for their lives. The chapter on haunting vividly portrays how this happens. Experiences can match lay perceptions of psychiatric disorder, so that the 'myths of madness' can become the truths. At work the Participants adopted *caution* and *vulnerability* because of attributions about their disorder. These attributions and coping methods could lead to *problems of their own making*. Overt focus on problems and difficulties rather than strengths and abilities was amplified by the co-operative and evaluative demands of the workplace. *Job sorting*, the *scrutiny* of other employees and how they *tested* the Participant could lead to increased *scrutiny* and feelings of being *set apart*. This heightened perception that there was something 'wrong' with the Participant. It further increased negative self-inferences and attributions. Participants either resolved this uncertainty - which could lead to practical interest - or the uncertainty increased so that Participants exited their employment. The process of creating-resolving uncertainty fully captures the tension that Participants experienced.

Stigma and Labelling

Participants talked about how their use of a psychiatric service could label or mark a person. The mark can endure beyond psychiatric service use and has the potential to intrude in future situations because of formal record keeping and associations present in personal biography. In attending hospital for a general admission, their psychiatric records could be accessed, so that a health visit became a psychiatric health visit. Similarly, when accounting for past employment, gaps in Participant curriculum vitae and employment choices could lead to questions about reasons why they were not in the workforce. On these occasions Participants could be pulled back into an illness identity that held them captive to negative stereotypical associations and expectations. It was a 'master status' that over-rode all other status considerations and was perceived to reduce the bearer of the mark to a 'tainted' or 'discredited' person (Goffman, 1963). This was subjectively experienced as uncertainty and could induce feelings of shame, unease and discomfort. Presenting in such a manner could be seen as confirming stereotypes about psychiatric disorder, which then justified the adverse reactions of others. Thus there could be tacit co-operation between both parties in the social uncertainty induced by stigma from disclosure and the reifying of stereotypes.

Once Robert and the other Participants became known as psychiatric patients, public responses in evaluative situations could be based on the label, and the label was the person. Evaluating the Participant through expectations associated with the label only confirmed the salience of the label. The label in the absence of bizarre behaviour caused rejection (Link & Phelan, 1999a; Farina, 1998). The label as a mark and therefore stigma of psychiatric disorder was perceived as a threat to social interactions (Blascovich et al., 2000). It involved an internal struggle (Smart & Wegner, 2000) where lapses in performance could lead to 'awkward moments' (Hebl et al., 2000). The existence of stigma and sensitivity towards encounters that stigmatised produced stigmatisation (Farina, 1998). In support of labelling theory, the significance of the label varied in terms of audience reaction, suggesting it is something that attaches to the person and can be removed. Stigma did occur the more the Participant tried to move from being a patient to being a citizen. However, contrary to labelling theory, the label did not behave as a label for the person. The label incurred an 'inscribed stigma',

something that entailed changed ontological commitments and wove itself into the personal fabric of their knowing and being (Scambler, 1984).

Stigma as Threat

Stigma, by itself could become a threat - and not just because of stereotype activation (Crocker et al, 1998; Jones et al., 1984). Stigma evoked affective cues, including unlearned ones that elicited threat directly (Blascovich et. al., 2000). Threat occurred for the Participant when their evaluations resulted in personal resources not meeting their situational demands. Treating stigma as a threat (Stangor & Crandall, 2000) created 'demand evaluations' (Blascovich et al., 2000). These concerned perceptions of 'danger' and 'uncertainty' and the 'required effort' to managing these items for personal performance (Blascovich et. al., 2000, p. 310). Evaluations had affective (e.g. feeling) and cognitive (e.g. semantic) processes (Zajonc, 2000). Conscious and unconscious appraisals can inform each other and may occur in parallel. This can be an iterative process. When the situation and Participant performance was not static, the Participant could re-evaluate the situation and adjust their performance accordingly. Stigma could act as an evaluation cue to others and to the Participant (Blascovich et. al., 2000). The processes described in the Chapter on Vigil showed how this happened and what consequences could ensue.

Maintaining vigilance due to the potential threats of stigma led some Participants to disengage from domains where they were vulnerable (Major & Schmader, 1998), such as employment. The perception that Participants were being treated differently because of their psychiatric disorder was hard at times to differentiate from the normal evaluation that takes place within the workplace. It created a disagreeable uncertainty. For instance, the type, manner and intention of precaution perceived to be directed toward the Participant was seen as different from that directed at other employees. This indicated, (a) that actions originate from a direction, so that precaution necessarily entails prior assumptions about the Participant; and (b) that these acts of precaution indicate a future direction. Thus precaution extends from expected norms of behaviour, but is employed because of expectations of non-normative behaviour (Vickers, 1997; 2000).

These expectations can take shape as suspicions that are not neutral. They involved an accusation that imputed something about the Participant, to the Participant, during interactions. These imputations could regulate and control the types of interactions Participants had but they could also shape future ways of knowing, for both parties. While the suspicions and accusations implicit in *scrutiny* could spring from uncertainty about the Participant, they also functioned both to reduce and increase uncertainty. In charting the direction of monitoring others' suspicions, Participants developed a guide to resolving the uncertainty they experienced. Conversely, the direction of scrutiny for Participants could act as an explicit feature of uncertainty for monitoring others and at the same time became an evaluation point for others to resolve their uncertainties with the Participant. However, when no resolving of uncertainty was perceived to occur for monitoring others then the accusation implicit in scrutiny could be confirmed for the Participant.

Stigma and Social Role

The Participant Robert did not talk about thinking he was crazy; he talked about being crazy. 'Crazy' had colonised his life world. He found himself by default matching the stereotypes and expectations about madness, 'mad' people and 'mad' places. When he entered treatment, beliefs about how most people treated psychiatric disorder took on new meaning (Link et al., 1989). The insidious nature of negative stereotypes is that their eliciting can become as automatic as their associations (Devine, 1989). Stigmatising attributes are associated with stereotypes when the attributes are confounded with social role (Eagly, 1987). The social role of 'being crazy', 'mad', 'nutter' or 'lunatic', and the role of psychiatric patient fused sickness with madness. Madness like sickness needed to be controlled. However, with sickness it is the illness that is out of control. With madness it is the person who is out of control. Thus attributions about personal responsibility inhabited ideas around madness whereas sickness could happen at any time to anyone. People recovered from sickness in a manner that expected them to return to their former social roles. The expectation that psychiatric patients would not return to their former social roles suggested something irrevocable had occurred once people experienced psychiatric disorder. The permanence of this change was mirrored when people were discharged. When

they tried to return to everyday life the stigma of psychiatric illness could act as a social sanction to keep them in the patient role (Scheff, 1990). *Haunted* by prospects of psychiatric disorder, Participants adapted by living a reduced life to minimise discomfort and uncertainty.

Stigma and Media Influence

Media accounts were viewed as promoting and anchoring negative characteristics of all people who experience psychiatric disorder (Allen & Nairn, 1997; Hyler, 1988; Hyler, et. al., 1991; MOH, 1997; Wahl & Lefkowitz, 1989; Wilson, et. al., 1999), and not just the very small percentage that achieve public infamy for violent acts. Media portrayals could serve as a base for other employees' ideas about 'mad' people (O'Hagan, 2000). Stereotypes might not be true but that did not stop them being used (Fiske, 1998). Some Participants were able to use their current work status to disconfirm such views as the exception rather than the rule. Some Participants experienced a sense of fair play on some occasions. For instance, in employment, disclosure about their psychiatric disorder could be either regarded as irrelevant or at least not problematic provided they could demonstrate that the disorder was managed (Vickers, 2000). This would minimise the causal associations between stigma and outcomes (Miller & Major, 1998). However the general perspective on disclosure was that it should only occur in response to a need-to-know situational demand (MHAC, 1999). This was usually based on their previously adverse experiences when disclosing (MHC, 1999a). The chapter on disclosure demonstrated how Participants employed different strategies to manage this within the workplace.

Stigmatisation

Goffman (1963) discussed the process of stigmatisation where the threat of discovery lodged into personal frames for referencing self, but he did not articulate this as uncertainty. There were strong similarities between Goffman's (1963) account of what happens when people incur a devalued identity and the strategies that they then employ to negotiate everyday situations. However, it was not just the discrediting, but the threat or potential of discrediting, which had the most impact for Participants. This threat or potential threat that fed into conceptions of self and the dynamics of social intercourse induced an uncertainty. The uncertainty occurred because the boundaries for discrediting were the marks

or signs of their psychiatric disorder that could be invoked at any time. They experienced an uncertain and vicarious self in that using signs to mark their illness also marked out their self and life trajectories. While stigma has been seen as the linking of personal attributes to a stereotype (Goffman, 1963; Jones et. al., 1984; Crocker et. al., 1998) by the perceiver, it was different for the target (Swim & Stangor, 1998). Their internal processes continued this activity so that it integrated into perceptual, emotional, cognitive and behavioural practices. Stigmatisation was an intra-psychic, interpersonal and spatial activity (Goffman, 1963).

Stigma and Illness

Charmaz (2000a) put it simply in her discussion about what changes after major illness – life is uncertain. Learning how their life is mediated by illness can be a ‘shocking’ experience when people learn how others will view and value them (Charmaz, 1999). Unlike most other illnesses, people do not have to learn how others will treat someone with psychiatric disorder - they already come primed with cultural beliefs and expectations. It was still ‘shocking’ to learn how adverse public beliefs and expectations about psychiatric disorder were. Attempts to reduce occasions for discrimination and ‘enacted stigma’ could lead to strategies of concealment (Scambler & Hopkins, 1988). However efforts at concealment magnified the importance of psychiatric disorder so that it intruded more into self-concept and meanings of identity. It disrupted peoples’ lives by forcing new and unwanted ways of conceiving self, relationships and situations (Charmaz, 2000a). This created disunity between the certainties of the past and the uncertainties of the present that required Participants to think how they were living and who they were becoming. New indicators of capacity had to be acquired that then created a stark contrast with who they had been and what they were capable of before. This can lead to pragmatic strategies for coping (Charmaz, 2000a). Such strategies could entail an *on guard process* to sort products of their disorder within everyday experience and a process for *making sense* of their subjective experiences. The chapter on *vigil* showed what these strategies were and how they were employed.

Illness and Uncertainty

According to Mishel (1988), uncertainty occurs when people are unable to determine meaning from illness events. Psychiatric service intervention can help

people make sense of their experiences. At the same time it can reduce understanding because the linguistic practices around psychiatric disorder can lead people to think about themselves in ways that are inconsistent with their personal meanings. The disjuncture between a cultural schema, a professional schema and a personal schema of their subjective experience can lead to an incomplete appraisal of illness events. In Mishel's view this creates uncertainty and reduces personal mastery in situations when uncertainty occurs. This was precisely what occurred for Participants both in situations where they felt stigmatised and also when they did not. Thus Mishel's definition of uncertainty provided a similar theoretical capture of the understandings that emerged from Participant experience. As Makal's (1999) phenomenological study of mental illness shows, "Participants no longer enter the world of others with ease. The world has become a place of uncertainty" (p.2952). However, this study extends the concepts of uncertainty and illness, by linking them to stigma, coping and daily living. It further grounds and demonstrates the course of uncertainty in intrapsychic and interpersonal operations within the key life situation of employment. The processes of resolving and creating uncertainty that were used to resolve the daily shifts in feeling and function states and reintegration of identity explained how this took place, while negotiating a stigmatised identity.

Theorising Psychiatric Stigma as Uncertainty

Up to this point, previous conceptions of stigma and stigmatisation appear to share similarities with Participant perspectives and my theoretical account. The views of Link and Colleagues, Goffman, Farina and Colleagues and Jones et. al. can be summarised thus. Stigma (1) marks people out as different, (2) sets people apart, (3) and links personal attributes to negative characteristics or associations, which (4) result in negative consequences. These negative consequences occur because there are (5) culturally induced expectations of rejection, which (6) match experiences of rejection that (7) people make efforts to cope with. The social reaction model suggests discrimination and status loss occurs. The psychological reaction models suggest internal processes bias information selection and processing. Both are correct yet they do not effectively account for the experience of illness itself and how that problematizes existential concerns for the Participant. Illness challenges a Participant's subjective knowing and being. It was from

theorising about first-person experiences of illness and their core concerns that the primacy of uncertainty both appeared in the literature and within Participant narrative (e.g. Makal, 1999). Psychiatric disorder marked cognitive, emotional and behavioural activities with uncertainty. Thus stigma as a mark was a mark of uncertainty. Uncertainty was likely to produce the very reactions that could be seen as stigmatizing by others and subjectively experienced as personal discomfort and disability.

I will now use the model to address undeveloped considerations of psychiatric stigma in the literature that were raised in the introduction and have not received specific attention so far.

The social and psychological reaction models of stigma that provide in-depth description of parts of processes involved with stigma are not sufficiently integrated to provide an adequate description of the complete process.

This study has addressed a major gap in the literature about self-perception of stigma. Previous studies have attributed the perception of stigma to the psychological deficits of psychiatric disorder and have used this perspective to reject the concept and effects of stigma (e.g. Crocetti et. al., 1972; Gove, 1980; Torrey, 1994). The perception that others were excluding Participants, and that this was a shared activity, could easily be seen as (1) evidence of paranoid ideation or delusional thinking; and (2) outcomes of socially deviant behaviour. Alternatively, in accepting the concept and effects of stigma, studies have acknowledged, but paid little attention to, the psychological deficits of psychiatric disorder (e.g. Link et al.). Thus there has been little research into the proposition that both psychological deficits and stigma were indicative of everyday experience for those who have experienced psychiatric disorders. First-person accounts of psychiatric disorders and the theorising of illness experiences have frequently suggested that there are interactive effects between illness, intrapsychic and interpersonal processes and experiences. The proposed theoretical model brings together information from previously disparate studies by developing a social, psychological and personal reaction model of stigma. Unlike previous studies, this model now has congruence with first-person accounts of psychiatric disorder because it is grounded in Participant experience.

The distinctiveness of psychiatric stigma and its effects have noticeably different outcomes from other stigmas and conditions.

The Participants' increase and decrease of uncertainty about psychiatric disorder involved intra-psychic processes, illness induced cognitive deficits, social interaction and salience of historical prejudices. The discrediting that occurs from psychiatric stigma is more severe because of associations with dangerousness and unpredictability with its course. It was not just the threat, but the uncertainty with the threat of a more aversive reaction from others, increased social distance and negative consideration of their individual ability at work. Other international (Ezzy, 1993; Farina et al., 1973; Link & Phelan, 2001) and local studies (Harris, 1995, 1997; MHC, 1999a) mirror the official outcomes within employment in New Zealand for people with psychiatric disorder (Statistics New Zealand, 1998) and the experiences of consumers (Consumer Employment Group, 1997; MHAC, 1999). As noted by Olshansky, Grob and Malamud (1959), Participants, in holding similar views as the general New Zealand public (BRC, 1997; O'Hagan, 2000) shared the same beliefs about 'madness' and 'mad people' and their unsuitability in the workplace as did other employees, even if they did not always act on them. The disposition to stigma was suggested by stereotype priming for both the Participant and their workplace audience, which raised concerns about trust, fear and predictability. Punitive sanctions (Susman, 1994), social contagion (Forgas, 1985), awkward moments (Hebl et al., 2000), existential discomfort (Vickers, 2000) and fear (O'Hagan, 2000) found in other studies undergo an intensification within employment. The evaluative nature of employment creates not only a threat to 'production' and the 'relations of production' but magnifies uncertainty with expected social and economic contracts and the roles they oblige. This study demonstrated how and why this took place.

There is a key role of uncertainty in psychiatric illness and the need to incorporate uncertainty into accounts of psychiatric stigma.

This research demonstrated how the dilemma of uncertainty that most people faced without a psychiatric disorder in social interaction was amplified by psychiatric disorder. What this created for the Participant were multiple possibilities for interpretation without an 'Archimedian point' of reference. The

haunting prospect of psychiatric disorder left marks of uncertainty in personal and social functioning. When Participants used a vigil to manage their disorder and make sense of their experiences, any monitoring of self increased their attunement to the marks of their disorder. Whether disclosing or passing, each provided further impetus to impression management. Social or personal lapses that could happen to anyone were experienced as a mental health failure by both Participants and their audiences. Consequently, what was at stake during any social, personal or workplace performance were risks to Participant's mental health and the prospect of a devalued identity. Uncertainty with this prospect could intrude into cognitive and emotional processes and affect personal and social identity. The meanings inherent within everyday activities underwent a transformation, because uncertainty was precisely about meaning. Altered meanings were characteristic of uncertainty. Uncertainty was as much a product as a cause in psychiatric disorder. Hence psychiatric disorder can reasonably be viewed as marked by uncertainty and through extension stigma can be seen as uncertainty. This provides an insight into psychiatric stigma that is congruent with first-person accounts of psychiatric disorder.

There are strong similarities between the effects of uncertainty on coping with general illness states and how people cope with psychiatric stigma.

The potential threat of stigma (e.g. uncertainty) leads to an increased appraisal and vigilance for it (Blascovich et al., 2000). As in other studies, whether stigma was impending or absent, Participants still coped in a manner similar to that employed when it was directly experienced (Stangor & Crandall, 2000). Thus coping appears integral to understanding the experience of stigma. Coping is based on what people have done, not just what people intend to do. Link et al. (1991) signalled the importance of coping strategies with psychiatric stigma. Such strategies were found to reinforce a view for their Participants and others that they were flawed and not competent at managing their own affairs. Thus my study provides a cogent explanation of why and how this happens. Being watchful and vigilant to stigma cues in the workplace required constant thinking about them. This can result in unwarranted thought intrusions (Carver & Sheier, 1993) about stigma and psychiatric disorder, as described in haunting. As haunting both predicts and creates uncertainty, so vigilance is required for internal and

interpersonal processes to clarify meaning in a situation by resolving uncertainty. The creating of uncertainty (and accompanying arousal) necessitated vigilance as a form of self-regulation (Krohne, 1993). Monitoring included vigilance and other aspects that were needed for coping. It enabled control over Participant actions and the modulation of affect by resolving uncertainty (Miller et al., 1993). Thus the discussion of monitoring in this project extends the analysis of Miller et al. by showing how resolving uncertainty also leads to creating uncertainty. Uncertainty involved more than self-regulation; it was crucial to the production of meaning about subjective experience. In this study psychiatric stigma and coping were shown to interweave and the consequences that ensued for interpersonal operations and conceptions of self were explored.

There is a relationship between stigma and illness intrusiveness in psychiatric disorder, the potential of stigma to pre-occupy daily thinking and how people cope with this.

This study predicts both that haunting creates the perceived prospect of psychiatric disorder re-occurring and that this intrudes into intra-psychic and interpersonal processes. Participant consequences were attributions about their disorder and adaptation to social expectations about 'madness'. The effects of these were reductions both in life chances and in the ability of self to engage in opportunities to improve life. Devins et al., in a study of illness intrusiveness highlighted the same features of haunting (1996) and showed how illness intrusiveness was intensified by stigmatising conditions (1994). However, psychiatric disorder and illness intrusiveness were distinctly different from other medical conditions (Antony et al., 1998; Beiling et al., 2001). My study furthers knowledge of illness intrusiveness by developing a conceptual framework for how intrusiveness is understood and managed in lay terms with psychiatric disorder. Participant accounts vividly described how illness intrusiveness disrupted self-esteem and emotional wellbeing. Within employment, the haunting would load interaction moments and employee evaluation with an existential uncertainty, as found in Vickers' (2000) Australian study. My study moved beyond previous general taxonomies of stigma and unseen illness (Vickers, 1997, 2000) and specified the nature of psychiatric disorder and stigma from an insider's view.

This study showed how talking about psychiatric disorder made Participants prone to the adverse reactions of others. Once disclosure had taken place at work it cast a shadow over future endeavours. Passing enabled Participants to draw attention away from their stigma and sustain non-stigmatised interactions. This enabled them to experience '*life without labels*' and interactions with others that were based on acceptance and independence. Identity was based on ability rather than disability. However a consequence of *passing* was that Participants experienced the adverse comments of others about psychiatric patients (*looking from the outside in*). The need for impression management in passing further attuned Participants to the demands of stigma. On the one hand it resolved uncertainty about negotiating social interactions with a discrediting identity. On the other it created further uncertainty because the demand for concealment and evaluation of proficiency in passing heightened vigil and haunting. Thus the basic social psychological process people employed entailed both resolving and creating uncertainty.

As Dindia (1998) found, disclosure was not a mutually exclusive phenomenon of disclosure–concealment. It was contingent on a range of factors that were pre-existing, present and changing within a disclosure situation. *Open disclosure (needed, if needed and tell-you-straight approaches) wrongful disclosure, inadvertent disclosure and no disclosure* were all possibilities, although Participants usually had a dominant mode they preferred. *Disclosure* affected the conceptions Participants had about themselves as noted by Fishbein and Laird (1979). It involved risk and vulnerability to such an extent that in order to resolve the uncertainty disclosure created, Participants had to balance disclosure against the uncertainty of concealment (Petronio, 1991). Managing disclosure was important for managing boundaries of impressions, meaning and existential comfort as suggested by Petronio (2000). However managing boundaries of meaning could create as much uncertainty as it resolved (Wegner et al., 1993). This study showed the ironic tension present within any endeavour that could create as much of a problem as a solution.

The concepts of felt stigma and enacted stigma require further investigation within the context of psychiatric disorder.

Whilst all Participants had experienced discrimination (either when accessing or in maintaining employment), this did not happen all the time. As noted in previous studies on epilepsy (Scambler, 1984; Scambler & Hopkins, 1988) ‘enacted stigma’ did occur, and Participants would usually try and avoid occasions where it could occur, because it was so unpleasant and damaging to self-esteem. What Participants learnt from enacted stigma was the ‘shocking experience’ of how other people now viewed them as described in constructing identity. Enacted stigma partly drove the uncertainty about what to tell, when to tell, who to tell and how much, in the “calculus of telling” (Charmaz, 2000a, p.285). More frequently, Participant experience mirrored felt stigma. This involved fear (e.g. being found out), shame (e.g. being brought down to a degraded social status) and guilt (e.g. a failure) (Jacoby, 1994). Maintaining felt stigma to avoid enacted stigma enlarged the importance of psychiatric disorder and the need to maintain secrecy. The cost to this was that it disrupted people’s lives.

This study enlarges our understanding of felt and enacted stigma by focussing on psychiatric disorder. It was not just social reaction (e.g. enacted stigma) that affected uncertainty about disclosure. In the process of constructing identity the person acquired linguistic appraisals of themselves from psychiatric services. The uncertainty was not just about ‘telling’ but whether any act or talking could disclose, because both were a performance of mental health. Failure to do so in an appropriate manner frequently entailed attribution of psychiatric disorder, for themselves and others. Thus in passing in the workplace, construction of identity, haunting and vigilance all interwove as intra-psychic operations, in addition to any contingency of negative reinforcement.

Grounded Theory

Grounded theory has been used to account for the experience of chronic illness before (e.g. Charmaz, 1990; Schreiber, 1996) and this study continues in a similar vein. Its method produces comprehensive and rich theory that is conceptually accurate because it fits, works and is relevant to Participant experience. In theorising a basic social psychological process, individual experiences were linked by the shared task of resolving their concerns in everyday life. What

concerned Participants and what they tried to resolve was uncertainty. It was through the emergent process of Grounded Theory that the category of uncertainty was discerned and sustained as consistent with Participant experience (see Appendix G for a review of the entire thesis by a person who has experienced living and working with mental health services). Alternative methods may well have reified existing notions of psychiatric stigma, rather than encourage an inductive process that leads to innovative knowledge in a productive and thorough manner.

Qualifications

This study only examined the perspectives of the stigmatised person. Thus exactly what and how things were taking place for others present in situations in which stigma occurred were not canvassed. There may be a discrepancy between the perception and actual intentions and actions of others. Examining the views of others would obtain multiple perspectives and thus enrich the understandings that were taking place for the Participant. The recruitment of Participants was such that only those who were seeking or maintaining themselves in employment were interviewed. This might have excluded people with chronic disorders and fewer occasions or shorter duration of being 'well'. They may have had a very different perspective to those with milder disorders. However the age range of Participants was such that it included those who had experienced severe and persistent psychiatric disorders but had recovered and were in employment.

There was a gender imbalance with proportionately more males than females. This could have affected the range of experiences in employment (e.g. more negative), as females in international studies receive less harsh reactions from friends, families, other employees and employers. Males tended to experience more severe disorders, greater periods of hospitalisation and less inclusion back into everyday life. Thus this study, with its higher proportion of males, was more likely to encounter the adverse experiences of people living with psychiatric disorder.

An interview is an interactive process that requires a degree of comfort both with presence and linguistic form. An interviewer who was of similar ethnicity to

Maori and Pacific Island people may have received different information because of this. However to the extent that these people used mainstream psychiatric services and sought open paid employment there was a strong similarity both within and between different ethnic groups.

Future Research and Significance

Further research might examine these concepts of uncertainty, constructing identity, haunting, vigil and disclosure in more depth. They are everyday concepts with complex meanings that clearly explain Participant experience. The literature on coping with stigma suggests that it is under-researched. Yet this is the most important aspect for people in managing everyday life. The literature would be improved when theoretical accounts that are grounded in everyday experience of people are able to demonstrate how they resolve stigma. As Stam (2000) has indicated, health and illness have been under theorized in psychology. Even less psychological research has examined how health and illness are maintained by people in life domains that are critically important to social, psychological and economic prosperity, like employment.

In order for this theory to be applied within interventions across different settings, it needs testing. Consequently, in further research the core process of resolving and creating uncertainty could be operationalized by utilising the stages – constructing identity, haunting, vigil and disclosure – as dimensions for the construct of uncertainty. The rich descriptions within these dimensions offer ample scope to develop a taxonomy, and fine grained measures for testing the theory's predictability within both individual experience and between groups. Testing would develop and refine the core concepts for application across workplace settings, ethnicity, age groups, social status and gender.

The theoretical significance of this study is that it demonstrates what psychiatric stigma is, how it works, why it occurs, in what circumstances and with what consequences for those seeking or maintaining employment. The theory brings together personal concerns, sociological and psychological processes in a practical and innovative manner.

The social significance of this research is that comprehending psychiatric stigma as uncertainty suggests methods for its reduction. Understanding the intersection between social, historical and cultural forces that create 'myths' which become 'truths', indicates a site for intervention. Considering uncertainty within clinical encounters would lead to the development of subjective accounts of psychiatric disorder to reduce it. The linguistic and professional practices that encourage a disjuncture between subjective and clinical knowledge could be improved. Understanding how uncertainty intrudes into personal, social and life processes, and the detriment it brings, gives opportunity for preventative action during clinical encounters. This would entail addressing psychiatric disorder and the experience of having psychiatric disorder as two mutually interactive activities, both of which require attention. From the service user point of view, it is always the experience of living with psychiatric disorder that creates the biggest uncertainty, threat and challenges. Developing coping strategies based on resolving uncertainty could be extremely productive. However the larger questions still remain. Why does difference create uncertainty? Why is it that disorders that have to do with the mind are treated and responded to in such an inequitable fashion compared with other physical complaints? The first inequality is social and the second inequality is personal. Both can result in social, economic and existential exclusion. It is the irony of psychiatric treatment that, while it can help your psychiatric health, it can also take away a life that you enjoy. People who believe and act according to this position can make the uncertainty of psychiatric disorder, uncertain. This needs to change.

APPENDICES

Appendix A - Notes from a Pre-Research Meeting with a Community Organisation

A pre-recruitment meeting with a host organisation was a valuable and useful exercise. Most of the people had experienced first-hand the issues that can arise in conducting research within the field. As an example, one early discussion at Hauora Waikato raised these research and methodological issues:

1. Research methods should use verbal and not written interviewing. For example, Ms Rei Wirihana (CEO) conducted a survey of forensic mental health users and found that when talking to consumers and asking them to complete questionnaires, many did so, because it was to their advantage to do so (e.g. demonstrates reading). However, Rei found that many could not read and were so used to giving interviewers' what they wanted (e.g. response bias), that another approach was needed. This was dress appropriately, simple language, develop friendship/trust, repeated checking and keep everything oral.
2. The person becomes the patient/diagnosis. This can be both desirable and undesirable for the person. This can be desirable for the person as being a certain "type" of patient or diagnosis, is directly linked to the level of Mental Health Service (MHS) care and monetary support they receive. This can be undesirable when people are admitted for an acute episode, get over the episode, but not the diagnosis and/or medication addiction/adverse reactions. Further issues arise from this:
 - Misdiagnosis - In the latter situation some Maori are admitted for events that are explainable and resolvable through *kaumatua* consultation, yet bio-medical assessment pathologises such events as symptoms and uses pharmaceutical / restraint intervention. The person concerned may then spend the rest of their life on an institutional (e.g. clinic or prison) revolving door, and require further / continuous intervention to get over the initial assessment/treatment, that was not appropriate in the first place.
 - "Addiction to the mental health system" – in the former situation the person is wedded to the MHS. This way of being-in-the-world renders 'positive discrimination' as normal, appropriate and desirable. People can desire to be patients as this increases their resources (e.g. MHS access, entitlements); positions them in hierarchy (e.g. level 2-5 accommodation) and gives them identity (e.g. I am a level 2); and enhances self-esteem (e.g. I am a high functioning schizophrenic).
 - Underwriting this position is an insidious power relationship. Thus patients are not people who have needs of identity, self-esteem, family, housing, employment but are positioned as 'patients who need treatment' or 'consumers who need care or support'.
3. We had interesting discussion about what to call psychiatric illness. Is it psychiatric or mental illness, or disorder or disability? Ms Wirihana's position was that the phenomena (my word) should be viewed in terms of its effects not causes. Primarily what faces most people, is that the phenomena results in a disability. What pathologises this phenomena is psychiatric knowledge, assessment and treatment. Hence the phenomena should be known as psychiatric disability. Mr Bob Elliot gave an interesting example. As a former head psychiatric nurse at Tokanui, he bumped into an associate ('A') who was going through admission procedures to a psychiatric ward. Mr Elliot asked him what he was here for. 'A' said he was here for depression. Mr Elliot then asked what was he really here for. 'A' mentioned that his grandmother had appeared to him in his bathroom over in Sydney, and chatted with him that

someone had died. Returning for the *tangi* he was quite distressed about what had happened. Bob advised him to not say anything about his having a chat to his dead grandmother, just mention that he was depressed over the death of a close family member. This 'A' did, was treated, discharged and to Mr Elliot's knowledge has not used a MHS again. Quite easily 'A' could have been diagnosed as having schizophrenia, and spent the rest of his life being psychiatrically ill/in remission, and dealing with medication addiction / adverse effects.

4. People (mixed ethnicity, though predominately Maori) who experience psychiatric disability and use Hauora Waikato's services are not referred to as patients or consumers or survivors but as *whanau*/family of Hauora Waikato. Hence people are recognised as embedded in a social/historical world, where dislocation from this position and subsequent re-embedding could be conceptualised as psychiatric disability and healing. That is to be made whole or become people (*kaupapa/whanau*) again. In providing this service, Mr Elliot said, "the footprints we leave are not our own" (I understood this to mean, that past/present/future descendants have an obligation/expectation/dedication/entrustment of service and to walk in this life hand-in-hand with those who have gone before - ancestors).
5. Psychiatric stigma and discrimination exists amongst other stigma/discrimination. It is not just psychiatric stigma that needs consideration but other features of social life that result in "layers of stigma" occurring. For Reis' interviewee's, 96% felt it was features other than mental illness that's important.

Mental illness
Maori
Low SES
Low education
Unemployment

(I felt that understanding psychiatric stigma in this way raises an important issue for my research. Does psychiatric stigma matter or matter as much for Maori? Can I reasonably consider psychiatric stigma divorced from other stigma's? Will this result in an overpowering loss of richness, context and complexity?)

6. Limitations of being Pakeha in an interview situation with Maori Participants which may alter empathy, rapport and linguistic understandings.

Discussions should focus on personal experiences of psychiatric stigma and under no circumstances stray into *whakapapa* (oral genealogy).

Appendix B - Information Sheet

PSYCHIATRIC STIGMA AND EMPLOYMENT PROJECT

Telephone: (07) 838-4466 ext. 8922
Email: hcm@waikato.ac.nz
Principal Researcher: Hamish Mackenzie
Doctoral Supervisor: Dr. Michael Hills

Psychiatric Stigma: its role and effects for people with experiences of mental illness who seek or maintain employment

GENERAL INFORMATION FOR PARTICIPANTS

About the Project

You are invited to participate in the 'Psychiatric Stigma and Employment' research project. The researcher is interested in gathering from people their personal stories of having experienced mental illness whilst seeking or maintaining their employment.

Personal accounts from people (Maori and Non-Maori, men and women) will be documented through one or more interviews. I hope to interview a variety of people from all walks of life.

People's stories recorded on audio tape will be examined in a number of ways. I will be looking at the origin, role, process and effects of psychiatric stigma on employment from the perspectives of Consumers. I am particularly interested in how, and why, Consumers are participating in open employment and key themes that arise from this across interviews.

Participation

Through meetings with community members and their organisations, and using contact people to invite others to participate, it is hoped a diverse group of people will take part in this project. It is important to note that contact people do not disclose any Participant details (including your name) until you agree to allow your name and telephone number to be passed on to the researcher.

The researcher will fully explain the project, the information sheet and consent form. You will have the opportunity to take this information away and consider what has been said. You have the right to be fully informed about this project and have your questions answered to your satisfaction at any stage.

Your participation is voluntary. You have the right to withdraw from the research project at any stage or for any reason. This right includes the opportunity to change, or have erased any part or whole of the interview(s) or transcripts at any stage. A decision to participate or withdraw will have no effect on your access to any health or community services or any benefits or entitlements.

You are most welcome to have a support person present. If you wish to use a translator or speak with an interviewer whose personal characteristics you are more comfortable with, I will endeavour to meet this need. Only after feeling satisfied that you have had all your questions answered, should you agree to participate in this project and return your consent form to the researcher.

I am asking for your involvement in an interview which usually takes less than one (1) hour [and no longer than one and half (1.5) hours]. Should further interviews be applicable, these are usually less than one (1) hour. The interviewer may ask questions to guide you through the telling of your story on your experiences of mental illness and employment. You do not have to answer the questions and you can stop an interview at any time. I would like to have the opportunity to contact you after an interview to see if there were any things you would like to discuss further.

Confidentiality

All interviews and survey information will remain confidential. After completing an interview the audio-taped recordings or questionnaire responses will be written out (transcribed). The only people who have access to this information are the Participant, researcher and the transcriber. Transcripts from interviews will be returned to Participants for their comments. The transcripts will then be edited to remove any information that may identify you. Edited transcripts may be viewed by Doctoral Supervisors. Organisations who have research supervisory bodies will have access to a general summary of those transcripts. No material which would personally identify you will be used in any general summaries from interview transcripts or questionnaire responses, or reports from this project.

Your contact name and telephone number, interview tapes, completed questionnaires and all material relating to interviews, will be stored in a locked room. All material will be held until three years after publication of the research and then the tapes will be erased and transcripts with any identifying material destroyed.

Results

This project will lead to a better understanding of psychiatric stigma within employment for people who have experienced psychiatric illness. There will be publications arising from this project of scholarly articles, reports and a short book prepared for the local consumer support and advocacy service, Centre 401. Information from the project will be presented at conferences and may be used in some educational and training materials. A newsletter on the projects progress will be sent to participating organisations on request. If you would like to receive copies of the research reports and/or continuing information about this project, please let the interviewer know and you will be put on a mailing list.

Ethical Commitments

This project has been approved by the University of Waikato Psychology Department Research and Ethics Committee; and by the Waikato Ethics Committee. Both the project researcher and supervisor are bound by and committed to following standards established by the New Zealand Psychological

Society's Code of Ethics. The project's design and process has a commitment to the Treaty of Waitangi in relation to health, partnership, participation and equity.

Concerns and Complaints

Any questions or concerns you may have about the project will be addressed by contacting in the first instance:

Principal Investigator: Hamish Mackenzie Ph (07) 838-4466 Ext. 8922

Doctoral Supervisor: Dr. Michael Hills Ph. (07) 838-4466 Ext. 8296

Should the need arise for a formal complaint to be made about this project please contact:

Head of the Psychology Department, The University of Waikato:

Dr. Paul Taylor Ph. (07) 856-2889 Ext. 8662

Chairperson, Research and Ethics Committee Convenor:

Dr. Bernard Guerin Ph. (07) 856-2889 Ext. 8268

Secretary of Waikato Ethics Committee

Ms Dianne Lawson Ph. (07) 846-1539

If you have any queries about your rights as a Participant in this project you may wish to contact the Health and Disability Services Consumer Advocate. Their freephone number is 0800 801 482.

Please Note

This project involves no physical risks, as it consists of participation in an interview or answering a questionnaire. However, it could be distressing for you to reflect on your past experiences of mental illness and employment. If you find that the interview has caused distress, please, do phone Hamish Mackenzie (07 838-4466, *Ext.* 8922). I am required to inform you that any mental health injury resulting from participating in this project is not covered by A.C.C.

Thank you for your interest in participating in the project.

Kind Regards

Hamish Mackenzie

Principal Investigator

Appendix C - Consent Form

University of Waikato, Psychology Department

CONSENT FORM

PARTICIPANT'S COPY

Research Project: Psychiatric Stigma and Employment

Name of Researcher: Hamish Mackenzie

Name of Supervisor: Dr Michael Hills

I have received an information sheet about this research project or the researcher has explained the study to me. I have had the chance to ask any questions and discuss my participation with other people. Any questions have been answered to my satisfaction.

I agree to participate in this research project and I understand that I may withdraw at any time. If I have any concerns about this project, I may contact the convenor of the Research and Ethics Committee.

Participant's
Name: _____ Signature: _____ Date: _____

=====

University of Waikato, Psychology Department

CONSENT FORM

RESEARCHER'S COPY

Research Project: Psychiatric Stigma and Employment

Name of Researcher: Hamish Mackenzie

Name of Supervisor: Dr Michael Hills

I have received an information sheet about this research project or the researcher has explained the study to me. I have had the chance to ask any questions and discuss my participation with other people. Any questions have been answered to my satisfaction.

I agree to participate in this research project and I understand that I may withdraw at any time. If I have any concerns about this project, I may contact the convenor of the Research and Ethics Committee.

Participant's
name: _____ Signature: _____ Date: _____

Appendix D - Preliminary Questions

(1) The beginnings of illness

- Perceptions of background causes of the problem
- Recognition
- Help seeking (formal and informal)
- Naming the problem
- Reactions of partner, family/whanau, friends, employment colleagues/career and the impact of this.
- *Did being Maori help or hinder your understanding of the problem?

(2) Becoming well and becoming unwell

- What happens, what influences this, what do you do, reactions of others, impact on others.
- Did being Maori help or hinder your becoming well or unwell?

(3) Illness and wellness

- What happened, how long it lasts/lasted, descriptions of experiences, symptoms, feelings, expectations, resolutions, management
- Expectations, encounters, consequences with mental health and support services
- Impacts on partner and friends and family
- Impact on employment colleagues/employment/career.
- *Did being Maori help or hinder the course of your wellness or illness?

(4) Recovery

- Processes of recovery e.g. what, how, why, advice
- Illness affects - pluses, positives, regrets, disappointments, limitations, responsibility
- Precautions, recurrence, forward planning
- Attitude towards diagnostic term
- Detection of illness and wellness – e.g. “how do you know you are having a bad day like anyone else as opposed to illness onset”?
- Degree of comfort in talking to others about experiences - Who do you: tell/don't tell/hide from; what do you hide/why; and who talk to comfortably?
- *Did being Maori help or hinder you recovery?

(5) Employment and unemployment

- Perceptions, expectations, experiences, benefits, disappointments, difficulties, impact/reactions of others.
- *Did being Maori affect your experience of employment or unemployment?

(6) The effects of items (1) – (4) on the Participant experience of employment and unemployment

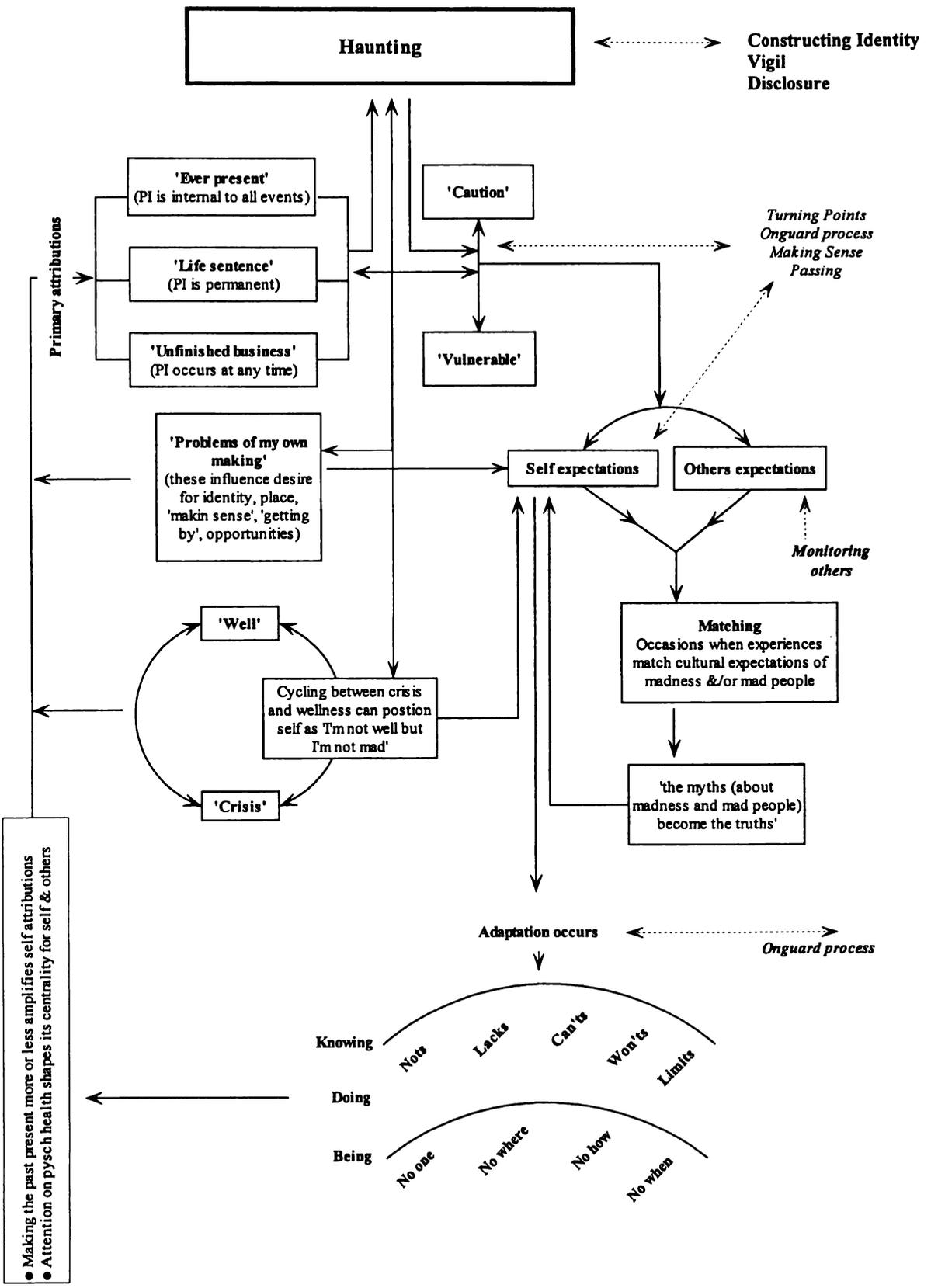
- What happened?
- What did you do/didn't do?
- Why did things turn out the way they did?

- What helped/hindered?

(7) Experiences of the process towards employment and unemployment

- What did you do/didn't do?
- What happened/helped/hindered?
- What was needed for you/would you do differently?
- Did being Maori help or hinder the process towards employment or unemployment?
- Experiences and perceptions of people and organisations involved with Consumer access to and retention of open employment
- The future. Where to now?

Appendix E - Example of Mapping a Sub-Core Category



Appendix F – Memo’s on terms referred to in ‘*Problems of my own making*’

Narrowing	is when Participant’s range of personal adaptability shrunk. For example: emotional range could narrow, especially on certain medications (pulling down the highs and pulling up the lows) which reduced personal comfort in novel situations or with those who did not share a similar experience (e.g. general public). The diversity of stress levels experienced could narrow so that stress was avoided/minimised, losing opportunities to disconfirm self-expectations around stress in novel situations (e.g. employment). Social interaction range could narrow as Participants only felt comfortable around others of similar shared experiences (e.g. consumers)
Withdrawal	of self as a way to cope with an increasing range of physical and social situations that fell outside of their narrow range and induced <i>uncertainty</i> . A shrinking of personal adaptability and reduced flexibility with responses to novel stimuli promoted withdrawal as a practical strategy to resolve uncertainty in present and future times.
Suspicion	is where the <i>uncertainty</i> over perceptual and cognitive processes carried a tag of suspicion over events and their interpretation. Nothing had an ‘a priori’ given-ness, and could be a product of the slide into madness. Suspicion then became an impetus to differentiate the mad signs from the everyday. However, suspicion about some things could swiftly extend to all things and people, until confirmed otherwise. Having increased and pervasive suspicions could be a sign of things getting worse.
Scared	is what Participants felt when things started to slide into the ‘bizarre’ and personal efforts to pull things back became desperate and ineffective. When the slide began there could be an inexorable certainty that this was going to end in crisis. The sense of personal responsibility for this ate away at self-esteem and confidence. Feeling scared of activities and situations, and avoiding them, could safely prevent opportunities for escalation of psychiatric illness. Yet if this became a

	<p>persistent manner then it further narrowed opportunities for personal and social reward; and opportunities for disconfirming self-expectations in those situations or activities. <i>Uncertainty</i> was scary.</p>
Scarring	<p>is when a person no longer recovered from personal and social hurts but instead the wounds lay open beneath a protective layer of reduced emotion, that thickened as time went by reducing the richness of emotional range. Scarring amplified narrowing and immobilisation.</p>
Bottle-necking	<p>occurred when unresolved hurts from one source of abuse (e.g. family, sexual, physical, employment) bleed into one from another source eventually formed one overarching sense of hurt. The effect was to lower the threshold for hurt to re-occur and raise the limit on accepting more hurt again in the future.</p>
Mis-interpretation	<p>could happen due to <i>uncertainty</i> with affective, perceptual and cognitive processes, so that things could accelerate in their head extremely quickly with precipitous outcomes, that then had to be faced when things 'straightened out'.</p>
Motility/ compartment	<p>difficulties were accelerated by certain medications, so that a person's sense of body shape and movements influenced the way they participated in and travelled through public space. The undesirable change in body shape/movements could lower self-esteem, increase isolation through reduced self-presentation in everyday life and create a sense of being an object - a 'thing' or 'it' that is only 'done to'. The lifestyle of sitting around, smoking and not doing further exacerbated health problems which created considerable tension and contradiction – the medications which were meant to improve mental life were also responsible for destroying physical health and social opportunities.</p>
'Trapped'	<p>is what it felt like when the revolving door of inpatient-outpatient admissions seemed to preclude the possibility of getting back to an everyday life <u>and</u> being able to enjoy it. Making the same mistakes with the same unpleasant outcomes undermined the possibility of hope and increased the hopelessness that went with being trapped.</p>

<p>'Rescued'</p>	<p>is how Participants felt when services responded to their immediate needs in situations of emergency. This was very useful. However repeated rescues could lead to a dependence on others for assistance without the fostering of self-assistance and abilities to manage. Services had to respond to emergency yet were not able or could not respond to personal crisis or pre-crisis. Yet it was crisis and pre-crisis management that reduced escalation and absence of this fostered rescuing because service intervention was emergency focussed.</p>
<p>Secrecy</p>	<p>is the tactic used to maintain knowledge of their psychiatric status within social boundaries. This tactic reduced the <i>uncertainty</i> which occurred when others knew about their psychiatric status. With <i>secrecy</i> went the considerable effort of keeping their 'secret' a secret. This could exacerbate <i>narrowing</i> and <i>withdrawal</i> as such activities reduced opportunities for the secret to get out. It increased the social capture of Participants within consumer only groups as with these groups there was no <i>uncertainty</i> about disclosure, no secret to hide and therefore increased ease of association.</p>
<p>'Bolt'</p>	<p>is what Participants did to resolve overwhelming <i>uncertainty</i> in social situations. By fleeing the situation they were able to reduce their feelings of discomfort to a suitable level of ease. But the prospect of it happening again was never entirely removed. Having to return to the situation they had bolted from, with some explanation, usually entailed a 'loss of face' and further reminded the person of their inability to cope. Sometimes the prospect of returning to account for what took place was just too much and Participants never returned.</p>

Appendix G – Consumer Thesis Review

Hello Hamish,

Thank you for forwarding your thesis. I received it early last week and spent 3 days reading, thinking, pondering and considering the theme. I must say I found it very compelling and insightful.

Chapter 1 was very enlightening. I had never paused to consider the origins and history attached to mental illness.

Reading the participant's history was a profound journey through the past. I felt as if some if not all had taken the words from my mouth or they had a glimpse through a window to my soul. Being made aware that others had travelled the same path and that they were prepared to share the depth of their pain and the massive struggle to recover and make sense of it all was very moving. To be honest at times it brought a lump to my throat and tears to my eyes.

Your synopsis of the process we all went through was right on the button. It mad a lot sense to my journey. I could almost tick off each step as I progressed as I recognized many of the stages you described.

The chapter headings intrigued me, especially *The Haunting* and *The Vigil*. They were great, they echoed exactly the mood and feeling at that stage my recovery. As soon as I saw them I had an immediate sense of what the chapter was going to describe. I only wish that I had had an opportunity to read a text like this as part of my recovery process.

In saying that I urge you to produce your thesis in some sort of booklet form much like the Kia Mauri Tau narrative, as I feel it would be invaluable to people that have suffered a disorder. It would show that the light at the end of the tunnel is real and it is bright and you can lead a (normal) life that is rewarding and fulfilling. All to often the feeling is of hopelessness and despair and no future except on the benefit.

Get your work out to the mental health community please. I feel your conclusions and insights are accurate and would of great value to the professionals as well as the patients. You will make a difference.

Thanks for taking the time and effort to talk to the participants. Like Kia Mauri Tau, the mere fact that someone out there could see something that needed addressing and was prepared to put time and effort into the project has done a lot of good for myself and I am sure the other participants a great deal of good. We can share our stories with one or two and offer some help, but this thesis can touch a lot.

Thanks again for sharing your time and your work, I wish you well in the future. If you at any time wish to contact me I give my permission to do so via Rose Black at the Psychology Department for my details.

Kind regards
Paul Evans-McLeod

BIBLIOGRAPHY

- Abbott, M. (1983). *The development of community mental health services in New Zealand*. Auckland, NZ: Mental Health Foundation of New Zealand.
- Abroms, K., & Kodera, T. (1979). Acceptance hierarchy of handicaps: Validation of Kirk's statement, 'Special education often begins where medication stops'. *Learning Disabilities*, 12, 15-20.
- Adams, J. (2000/2001). 'Criminal lunacy' 1882-1912. In B. Brooks & J. Thomson (Eds.), *'Unfortunate folk': Essays on mental health treatment 1863-1992* (pp. 66-82). Dunedin, NZ: Otago University Press.
- Albrecht, G., Walker, V., & Levy, J. (1982). Social distance from the stigmatized: A test of two theories. *Social Science and Medicine*, 16(14), 1319-1327.
- Alison, K. (1998). Stress and oppressed category membership. In K. Swim & C. Stangor (Eds.), *Prejudice: The target's perspective* (pp. 145-170). San Diego, Ca: Academic.
- Allen, R., & Nairn, R. (1997). Media depictions of mental illness: An analysis of the use of dangerousness. *Australian and New Zealand Journal of Psychiatry*, 31, 375-381.
- Allport, G. (1954). *The nature of prejudice*. Cambridge, Ma: Addison-Wesley.
- Allport, G. (1968). The historical background of modern social psychology. In G. Lindzey & E. Aronson (Eds.), *Handbook of Social Psychology Vol. 1* (pp. 1-80). Reading, Ma: Addison-Wesley.
- Anells, M. (1996). Grounded theory: Philosophical perspectives, paradigm of inquiry, and postmodernism. *Qualitative Health Research*, 6(3), 379-1360.
- Anthony, W., & Blanch, A. (1987). Supported employment for persons who are psychiatrically disabled: An historical and conceptual perspective. *Psychosocial Rehabilitation Journal*, XI(2), 5-23.
- Antony, M., Roth, D., Swinson, R., Huta, V., & Devins, G. (1998). Illness intrusiveness in individuals with panic disorder, obsessive-compulsive disorder, or social phobia. *Journal of Nervous and Mental Disease*, 186(5), 311-315.
- Armstrong, K. (2000). *The battle for God*. New York: Alfred Knopf.
- Baker, C., Wuest, J., & Stern, P. (1992). Method slurring: The grounded theory / phenomenological example. *Journal of Advanced Nursing*, 17, 1355-1360.
- Barham, P., & Hayward, R. (1995). *Relocating madness: From the mental patient to the person*. London: Free Association Books.
- Barrowclough, C., Haddock, G., Lowens, I., Connor, A., Pidliswyi, J., & Tracey, N. (2001). Staff expressed emotion and causal attributions for client problems on a low security unit: An exploratory study. *Schizophrenia Bulletin*, 27(3), 517-526.
- Barry, C. (1998). *Choosing qualitative data analysis software: Atlas and NUD*IST compared*. Sociological Research Online. Available: <<http://www.socresonline.org.uk/socresonline/3/4.html>> [2001, December].
- Bartlett, P. (1999). *The poor law of lunacy: The administration of pauper lunatics in mid-nineteenth-century England*. London: Leicester University Press.
- Beaglehole, E. (1950). *Mental health in New Zealand*. Wellington, NZ: New Zealand University Press.
- Beck, C. (1990). Qualitative research: Methodologies and use in pediatric nursing. *Issues in Comprehensive Pediatric Nursing* 13(3), 193-201.
- Bennie, G. (1996). Critical issues for supported employment in New Zealand. In G. Bennie (Ed.), *Supported employment in New Zealand* (pp. 1-9). Levin, NZ: Network Publications.

- Bennie, G. (1997). *Supported employment programmes emerge as cost effective*. Paper presented at the Association for Supported Employment in New Zealand, Hamilton.
- Benoliel, J. (1996). Grounded theory and nursing knowledge. *Qualitative Health Research*, 6(3), 406-428.
- Bhugra, D. (1989). Attitudes towards mental illness: A review of the literature. *Acta Psychiatrica Scandinavica*, 80(1), 1-12.
- Bieling, P., Rowa, K., Antony, M., Summerfeldt, L., & Swinson, R. (2001). Factor structure of the Illness Intrusiveness Rating Scale in patients diagnosed with anxiety disorders. *Journal of Psychopathology and Behavioral Assessment*, 23(4), 223-230.
- Biernat, M., & Dovidio, J. (2000). Stigma and stereotypes. In T. Heatherton, R. Kleck, M. Hebl, & J. Hull (Eds.), *The social psychology of stigma* (pp. 88-125). London: Guildford Press.
- Bishop, D., & Beynon, C. (2000). *Poles apart: A touch of madness*. Wellington, NZ: Steele Roberts.
- Blake-Palmer, G. (1962). *Honest prejudices and unnecessary deviations: their influence on the form of mental health programmes*. Thomas Cawthron Memorial Lecture, No. 37. Nelson, NZ: Stiles.
- Blascovich, J., Mendes, W., Hunter, S., & Lickel, B. (2000). Stigma, threat and social interactions. In T. Heatherton, R. Kleck, M. Hebl, & J. Hull (Eds.), *The social psychology of stigma* (pp. 307-332). London: Guildford Press.
- Bleicher, J. (1980). *Contemporary hermeneutics: Hermeneutics as method, philosophy, and critique*. London/Boston: Routledge & Kegan Paul.
- Blizzard, P. (1968). Public images of the mentally ill in New Zealand. *New Zealand Medical Journal*, 68(438), 297-303.
- Bloomfield, J. (1979/2001). Dunedin Lunatic Asylum 1863-1876. In B. Brooks & J. Thomson (Eds.), *'Unfortunate folk': Essays on mental health treatment 1863-1992* (pp. 21-34). Dunedin, NZ: Otago University Press.
- Blum, A. (1970). The sociology of mental illness. In J. Douglas (Ed.), *Deviance & respectability: The social construction of moral meanings* (pp. 31-60). New York: Basic Books.
- Blumer, H. (1966). Sociological implications of the thought of George Herbert Mead. *American Journal of Sociology*, 71, 535-544.
- Blumer, H. (1969a). Collective behaviour. In A. Lee (Ed.), *Principles of Sociology*. New York: Barnes & Noble.
- Blumer, H. (1969b). *Symbolic interactionism: Perspective and method*. Englewood Cliffs, NJ: Prentice-Hall.
- Blumer, H. (1980). Mead and Blumer: The convergent methodological perspectives of social behaviorism and symbolic interactionism. *American Sociological Review*, 45, 409-419.
- Brewer, M., & Brown, R. (1998). Intergroup relations. In D. Gilbert, S. Fiske, & G. Lindsay (Eds.), *The handbook of social psychology*. Vol. 2 (4th ed.) (pp. 554-594). New York: McGraw-Hill.
- Brooks, B. (1987). *The early days of the Seacliff Asylum: The admission and treatment of patients*. Paper presented at the First New Zealand Conference on the History of New Zealand and Australian Medicine, Hamilton, NZ.
- Brown, R. (1995). *Prejudice: Its social psychology*. Oxford: Blackwell.
- Brunton, W. (1972). If cows could fly. *Australian and New Zealand Journal of Psychiatry*, 6, 46-51.
- Brunton, W. (1983). Hostages to history. *New Zealand Health Review*, 3(2), 3-6.
- Brunton, W. (1985). Citadels - some factors in the survival of psychiatric hospitals. *Health Review*, 5(2), 3-7.

- Brunton, W. (1987). *The New Zealand lunatic asylum: Conception and misconception*. Paper presented at the First New Zealand Conference on the History of New Zealand and Australian Medicine, Hamilton, NZ.
- Brunton, W. (1997). *Sitivation 125: A history of Seaview Hospital, Hokitika and West Coast mental health services, 1872-1997*. Hokitika, NZ: Seaview Hospital 125th Jubilee Committee.
- Business Research Centre. (1997). *Public knowledge of, and attitudes to, mental health and mental illness* (BRC project number: 1486). Wellington, NZ: Ministry of Health.
- Buston, K. (1997). *NUD*IST in action: Its use and usefulness in a study of chronic illness in young people*. Sociological Research Online, Vol. 2(3). Available: <<http://www.socresonline.org.uk/socresonline/2/3/6.html>> [2001, December].
- Butler, T. (1985). *Mental health, social policy and the law*. Basingstoke: Macmillan.
- Canadian-Mental-Health-Association(Ontario-Division). (1994). *Mental health anti-stigma public education strategy. An unpublished report*. Toronto: Author.
- Carver, C., & Sheier, M. (1993). Vigilant and avoidant coping in two patient samples. In H. Krohne (Ed.), *Attention and avoidance: Strategies in coping with aversiveness* (pp. 295-319). Toronto: Hogrefe & Huber.
- Catholic Encyclopedia. (2001). *Mystical stigmata*. New Advent Catholic. Available: <<http://www.newadvent.org/cathen/1429b.htm>> [2001, June 13].
- Chalmers, A. (1982). *What is this thing called science?: An assessment of the nature and status of science and its methods*. Milton Keynes: Open University Press.
- Charmaz, K. (1991). *Good days, bad days: The self in chronic illness and time*. New Brunswick, NJ: Rutgers University Press.
- Charmaz, K. (1990). Discovering chronic illness: Using grounded theory. *Social Science and Medicine*, 30, 1161-1172.
- Charmaz, K. (1994). Discoveries of self in illness. In M. Dietz, R. Prus, & W. Shaffir (Eds.), *Doing everyday life: Ethnography as human lived experience* (pp. 226-242). Mississauga, Ontario: Copp Clark, Longman.
- Charmaz, K. (1995a). Body, identity and self: Adapting to impairment. *Sociological Quarterly*, 36, 657-680.
- Charmaz, K. (1995b). Grounded theory. In J. Smith, R. Harre, & L. van Langenhove (Eds.), *Rethinking methods in psychology* (pp. 27-49). London: Sage.
- Charmaz, K. (1999). Stories of suffering: Subjective tales and research narratives. *Qualitative Health Research* 9(3), 362-382.
- Charmaz, K. (2000a). Experiencing chronic illness. In G. Albrecht, R. Fitzpatrick, & S. Scrimshaw (Eds.), *The handbook of social studies in health and medicine* (pp. 277-292). London: Sage.
- Charmaz, K. (2000b). Grounded theory: Objectivist and constructivist methods. In N. Denzin & Y. Lincoln (Eds.), *Handbook of qualitative research* (pp. 509-535). Thousand Oaks, Ca: Sage.
- Charon, J. (1985). *Symbolic interactionism: An introduction, an interpretation, an integration (2nd ed.)*. Englewood Cliffs, NJ: Prentice-Hall.
- Cioffi, D. (2000). The looking-glass self revisited: behavior choice and self-perception in the social token. In T. Heatherton, R. Kleck, M. Hebl, & J. Hull (Eds.), *The social psychology of stigma* (pp. 184-219). London: Guildford Press.
- Claire, T., & Fiske, S. (1998). A systemic view of behavioral confirmation: Counterpoint to the individualist view. In C. Sedikides, J. Schopler, & C.

- Insko (Eds.), *Intergroup cognition and intergroup behavior* (pp. 205-231). Mahwah, NJ: Lawrence Erlbaum Associates.
- Clausen, J. (1981). Stigma and mental disorder: Phenomena and terminology. *Psychiatry: Journal for the Study of Interpersonal Processes*, 44, 286-295.
- Cloerkes, G., & Neubert, D. (1984). Cross-cultural and historical variations of the social reaction towards disabled persons. *International Journal of Rehabilitation Research*, 7(3), 339-340.
- Cody, T., & Woolley, C. (1997). Renegotiating meanings: A grounded theory of core factors in healing shame in adult survivors of sexual abuse. In G. Habermann (Ed.), *Looking back and moving forward: Fifty years of New Zealand Psychology. Proceedings of the 1997 Annual Conference of the New Zealand Psychological Society* (pp. 9-15). Palmerston North, NZ: Massey University Printery.
- Coffey, A., Holbrook, B., & Atkinson, P. (1996). *Qualitative data analysis: Technologies and representations*. Sociological Research Online, Vol.1(1). Available: <<http://www.socresonline.org.uk/socresonline/1/1/4.html>> [2001, December].
- Coleborne, C. (1997). *Reading madness: Bodily difference and the female lunatic patient in the history of the asylum in colonial Victoria, 1848-1888*. Unpublished PhD thesis, LaTrobe University, Melbourne.
- Compas, B., Connor, J., Saltzman, H., Thomsen, A., & Wadsworth, M. (1999). Getting specific about coping: Effortful and involuntary responses to stress in development. In M. Lewis & D. Ramsay (Eds.), *Soothing and stress* (pp. 229-256). Mahwah, NJ: Lawrence Erlbaum.
- Consumer Employment Group. (1997). *Mental Health Consumer Employment*. Wellington: Author.
- Corrigan, P. (2000). Mental health stigma as social attribution: Implications for research. *Clinical Psychology: Science and Practice*, 7(1), 48-67.
- Corrigan, P., River, L., Lundin, R., & Uphoff, W. (2000). Stigmatizing attributions about mental illness. *Journal of Community Psychology*, 28(1), 91-102.
- Crandall, C. (2000). Ideology and lay theories of stigma: The justification of stigma. In T. Heatherton, R. Kleck, M. Hebl, & J. Hull (Eds.), *The social psychology of stigma* (pp. 126-152). London: Guildford Press.
- Crocetti, G., Spiro, H., Lemkau, P., & Siassi, I. (1972). Multiple models and mental illnesses: A rejoinder to "Failure of a moral enterprise: Attitudes of the public toward mental illness" by T. Sarbin and J. Mancuso. *Journal of Consulting and Clinical Psychology*, 39(1), 1-5.
- Crocker, J., Major, B., & Steele, C. (1998). Social stigma. In D. Gilbert, S. Fiske, & G. Lindzey (Eds.), *The handbook of social psychology* (pp. 504-553). New York: McGraw-Hill.
- Crocker, J., & Quinn, D. (2000). Social stigma and the self: Meanings, situations, and self-esteem. In T. Heatherton, R. Kleck, M. Hebl, & J. Hull (Eds.), *The social psychology of stigma* (pp. 153-183). London: Guildford Press.
- Crowther, M. (1982). *The workhouse system, 1834-1929: The history of an English social institution*. Athens, Ga: University of Georgia Press.
- Csordas, T. (1994). The body as representation and being-in-the-world. In T. Csordas (Ed.), *Embodiment and experience: The existential ground of culture and self. Cambridge studies in medical anthropology* (pp. 1-26). Cambridge: Cambridge University Press.
- Cumming, E., & Cumming, J. (1957). *Closed ranks: An experiment in mental health education*. Cambridge, Ma: Harvard University Press for the Commonwealth Fund.
- D'Andrade, R. (1984). Cultural meaning systems. In R. Schweder & R. Levine (Eds.), *Culture theory: Essays on mind, self and emotion* (pp. 88-119). New York: Cambridge University Press.

- Das, V. (2001). *Stigma, contagion, defect: Issues in the anthropology of public health*. Available: <<http://www.stigmaconference.nih.gov/DasPaaper.htm>>30/10/2001].
- Davis, A., & George, J. (1993). *States of health: Health and illness in Australia*. Sydney: Harper Educational.
- de Certeau, M. (1984). *The practice of everyday Life*. Berkeley & Los Angeles, Ca: University of California Press.
- Deegan, P. (1993). Recovering our sense of value after being labelled mentally ill. *Journal of Psychosocial Nursing and Mental Health Services*, 31(4), 7-11.
- Deegan, P. (1996). *There is a person in here: A keynote address*. Paper presented at the TheMHS (The Mental Health Services) Conference, Brisbane, Australia.
- Denzin, N. (1989). *Interpretive interactionism*. Newbury Park, Ca: Sage.
- Denzin, N. (1991). *Symbolic interactionism and cultural studies: The politics of interpretation*. Cambridge, Ma: Blackwell.
- Devine, P. (1989). Stereotypes and prejudice: Their automatic and controlled components. *Journal of Personality and Social Psychology*, 56(1), 5-18.
- Devins, G. (1994). Illness intrusiveness and the psychological impact of lifestyle disruptions in chronic life-threatening diseases. *Advances in Renal Replacement Therapy*, 1, 251-263.
- Devins, G., Beanlands, H., Mandin, H., & Paul, L. (1997). Psychosocial impact of illness intrusiveness moderated by self-concept and age in end-stage renal disease. *Health Psychology*, 16(6), 529-538.
- Devins, G., Stam, H., & Koopmans, J. (1994). Psychological impact of laryngectomy mediated by perceived stigma and illness intrusiveness. *Canadian Journal of Psychiatry*, 39(10), 608-616.
- Devins, G., Styra, R., O'Connor, P., Gray, T., Seland, T., Klein, G., & Shapiro, C. (1996). Psychosocial impact of illness intrusiveness moderated by age in multiple sclerosis. *Psychology, Health and Medicine*, 1(2), 179-191.
- Digby, A. (1989). *British welfare policy: Workhouse to workfare*. London: Faber.
- Diggins, D. (1994). *The promise of pragmatism: Modernism and the crisis of knowledge and authority*. Berkeley, Ca: University of Chicago Press.
- Dindia, K. (1998). "Going into and coming out of the closet": The dialectics of stigma. In B. Montgomery & L. Baxter (Eds.), *Dialectical approaches to studying personal relationships* (pp. 83-108). Mahwah, NJ: Lawrence Erlbaum.
- Dingwall, R. (2001). Notes toward an intellectual history of symbolic interactionism. *Symbolic Interactionism*, 24(2), 237-242.
- Disley, B. (1989, December). Stigma: An overview. *Mental Health News*, 6-12.
- Disley, B. (1997). An overview of mental health in New Zealand. *Mental health in New Zealand from a public health perspective: Public health report No. 3*, 3-37.
- Donoghue, P., & Siegel, M. (1992). *Sick and tired of feeling sick and tired: Living with invisible chronic illness*. New York: Norton.
- Dooley, D., Prause, J., & Ham-Rowbottom, K. (2000). Underemployment and depression: Longitudinal relationships. *Journal of Health and Social Behaviour*, 41, 421-436.
- Dovidio, J., Major, B., & Crocker, J. (2000). Stigma: Introduction and overview. In T. Heatherton, R. Kleck, M. Hebl, & J. Hull (Eds.), *The social psychology of stigma* (pp. 1-30). New York: The Guildford Press.
- Duck, S. (1990). Relationships as unfinished business: Out of the frying pan and into the 1990's. *Journal of Social Personal Relationships*, 7, 5-29.
- Durie, M. (1998). *Whaiora: Maori health development*. (2nd ed.). Auckland, NZ: Oxford University Press.

- Eagly, A. (1987). *Sex differences in social behavior: A social-role interpretation*. Hillsdale, NJ: Lawrence Erlbaum Associates.
- Eagly, A., & Chaiken, S. (1998). Attitude structure and function. In Gilbert, D. & Fiske, S (Ed); et-al. (1998). *The handbook of social psychology, Vol. 1* (4th ed.). (pp. 269-322). New York, NY, US: McGraw-Hill
- Edwards, D. (1998). Types of case study work: A conceptual framework for case-based research. *Journal of Humanistic Psychology, 38*(3), 36-70.
- Elias, N. (1994). *The civilizing process: The history of manners, and State formation and civilization* (E. Jephcott, Trans.). Oxford: Blackwell.
- Ellis, G. (1991). *Chronic schizophrenia and coping with employment: A descriptive study of significant factors*. Unpublished Master of Social Science thesis, University of Waikato, Hamilton, NZ.
- Ernst, W. (1991). The social history of Pakeha psychiatry in nineteenth-century New Zealand: Main themes. In L. Bryder (Ed.), *A Healthy country: Essays on the social history of medicine in New Zealand* (pp. 65-85). Wellington, NZ: Bridget Williams Books.
- Ezzy, D. (1993). Unemployment and mental health: A critical review. *Social Science and Medicine, 37*(1), 41-52.
- Fabrega, H. (1981). Concepts of disease: Logical features and social implications. In L. Caplan, H. Engelhardt, & J. McCartney (Eds.), *Concepts of disease and health: Interdisciplinary perspectives* (pp. 485-492). London: Addison-Wesley.
- Fabrega, H. (1990). Psychiatric stigma in the classical and medieval period: A review of the literature. *Comprehensive Psychiatry, 31*(4), 289-306.
- Fabrega, H. (1991). The culture and history of psychiatric stigma in early modern and modern Western societies: A review of recent literature. *Comprehensive Psychiatry, 32*(2), 97-119.
- Fabrega, H. (1992). The role of culture in a theory of psychiatric illness. *Social Science and Medicine, 35*(1), 91-103.
- Farina, A. (1981). Are women nicer people than men? Sex and the stigma of mental disorders. *Clinical Psychology Review, 1*(2), 223-243.
- Farina, A. (1998). Stigma. In K. Mueser & N. Tarrier (Eds.), *Handbook of social functioning in schizophrenia*. (pp. 247-279). Needham Heights, Ma: Allyn & Bacon.
- Farina, A., Allen, J., & Saul, B. (1968). The role of the stigmatized person in affecting social relationships. *Journal of Personality, 36*(2), 169-182.
- Farina, A., & Burns, G. (1984). The effect of uncertainty as to whether others believe that one has had a mental disorder. *Journal of Social and Clinical Psychology, 2*(3), 244-257.
- Farina, A., Burns, G., Austad, C., Bugglin, C., & Fischer, E. (1986). The role of physical attractiveness in the readjustment of discharged psychiatric patients. *Journal of Abnormal Psychology, 95*(2), 139-143.
- Farina, A., & Felner, R. (1973). Employment interviewer reactions to former mental patients. *Journal of Abnormal Psychology, 82*(2), 268-272.
- Farina, A., Felner, R., & Boudreau, L. (1973). Reactions of workers to male and female mental patient job applicants. *Journal of Consulting and Clinical Psychology, 41*(3), 363-372.
- Farina, A., Fischer, E., Boudreau, L., & Belt, W. (1996). Mode of target presentation in measuring the stigma of mental disorder. *Journal of Applied Social Psychology, 26*(24), 2147-2156.
- Farina, A., Fischer, E., Sherman, S., Smith, W., Groh, T., & Mermin, P. (1977). Physical attractiveness and mental illness. *Journal of Abnormal Psychology, 86*(5), 510-517.

- Farina, A., Fisher, J., Getter, H., & Fischer, E. (1978). Some consequences of changing people's views regarding the nature of mental illness. *Journal of Abnormal Psychology, 87*(2), 272-279.
- Farina, A., Gliha, D., Boudreau, L., Allken, J., & Sherman, M. (1971). Mental illness and the impact of believing others know about it. *Journal of Abnormal Psychology, 77*(1), 1-5.
- Farina, A., & Hagelauer, H. (1975). Sex and mental illness: The generosity of females. *Journal of Consulting and Clinical Psychology, 43*(1), 122.
- Farina, A., Holzberg, J., & Kimura, D. (1966). A study of the interpersonal relationships of female schizophrenic patients. *Journal of Nervous and Mental Disease, 142*(5), 441-444.
- Farina, A., Murray, P., & Groh, T. (1978). Sex and worker acceptance of a former mental patient. *Journal of Consulting and Clinical Psychology, 46*(5), 887-891.
- Farina, A., Thaw, J., Felner, R., & Hust, B. (1976). Some interpersonal consequences of being mentally ill or mentally retarded. *American Journal of Mental Deficiency, 80*(4), 414-422.
- Farina, A., Thaw, J., Lovern, J., & Mangone, D. (1974). People's reactions to a former mental patient moving to their neighborhood. *Journal of Community Psychology, 2*(2), 108-112.
- Farina, A., Wheeler, D., & Mehta, S. (1991). The impact of an unpleasant and demeaning social interaction. *Journal of Social and Clinical Psychology, 10*(4), 351-371.
- Fennell, S. (1981/2001). Psychiatry and Seacliff 1912-1948. In B. Brooks & J. Thomson (Eds.), *'Unfortunate folk': Essays on mental health treatment 1863-1992* (pp. 137-152). Dunedin, NZ: Otago University Press.
- Fine, M., & Asch, A. (1988). Disability beyond stigma: Social interaction, discrimination, and activism. *Journal of Social Issues, 44*(1), 3-21.
- Finnane, M. (1985). Asylums, families and the State. *History Workshop, 20*, 134-148.
- Fish, S. (1989). *Doing what comes naturally: Change, rhetoric, and the practice of theory in literary and legal studies*. Durham, NC: Duke University Press.
- Fishbein, M., & Laird, J. (1979). Concealment and disclosure: Some effects of information control on the person who controls. *Journal of Experimental Social Psychology, 15*(2), 114-121.
- Fiske, S. (1998). Stereotyping, prejudice, and discrimination. In D. Gilbert, S. Fiske, & G. Lindzey (Eds.), *The handbook of social psychology* (pp. 357-414). New York: McGraw-Hill.
- Forgas, P. (1985). *Interpersonal behaviour: The psychology of social interaction*. Sydney: Pergamon.
- Frable, D. (1993). Being and feeling unique: Statistical deviance and psychological marginality. *Journal of Personality, 61*, 85-110.
- Frable, D., Hoey, S., & Platt, L. (1998). Concealable stigmas and positive self-perceptions: Feeling better around similar others. *Journal of Personality and Social Psychology, 74*(4), 909-922.
- Frame, J. (1961). *Faces in the water*. Christchurch, NZ: Pegasus Press.
- Garfinkle, H. (1967). *Studies in ethnomethodology*. Englewood Cliffs, NJ: Prentice-Hall.
- Garton, S. (1988). *Medicine and madness: A social history of insanity in New South Wales, 1880-1940*. Kensington, NSW: Renwick Pride.
- Gerbner, G. (1993). Dreams that hurt: Mental illness in the mass media. *Journal of the Californian Alliance for the Mentally Ill, 4*, 17-20.
- Gergen, K. (1985). The social constructivist movement in modern psychology. *American Psychologist, 40*, 266-275.
- Gergen, K., & Gergen, M. (1991). Toward reflexive methodologies. In F. Steier (Ed.), *Research and reflexivity* (pp. 76-95). Newbury Park, Ca: Sage.

- Glaser, B. (1978). *Theoretical sensitivity*. Mill Valley, Ca: Sociology Press.
- Glaser, B. (1992). *Basics of grounded theory analysis: Emergence vs forcing*. Mill Valley, Ca: Sociology Press.
- Glaser, B. (1994). *More grounded theory: A reader*. Mill Valley, Ca: Sociology Press.
- Glaser, B. (Ed.). (1996a). *Gerund grounded theory: The basic social process dissertation*. Mill Valley, Ca: Sociology Press.
- Glaser, B. (1996b, May 8-10). *Edited transcript of proceedings of a grounded theory workshop conducted by B. Glaser*. Christchurch, NZ.
- Glaser, B. (1998). *Doing grounded theory: Issues and discussions*. Mill Valley, Ca: Sociology Press.
- Glaser, B., & Strauss, A. (1967). *The discovery of grounded theory: Strategies for qualitative research*. New York: Aldine Publishing Co.
- Gluckman, L. (1971). The royal touch in England; a theory of origin derived from observations in the New Zealand Maori. *New Zealand Numismatic Journal*, 1(49), 13-18.
- Gluckman, L. (1976). *Tangawai: A medical history of 19th century New Zealand*. Christchurch, NZ: Whitcoulls.
- Goffman, E. (1963). *Stigma: Notes on the management of a spoiled identity*. Harmondsworth, England: Penguin.
- Goldin, C. (1990). Stigma, biomedical efficacy, and institutional control. *Social Science and Medicine*, 30(8), 895-900.
- Gove, W. (1980). Labelling and mental illness: A critique. In W. Gove (Ed.), *The Labelling of deviance: Evaluating a perspective* (pp. 53-109). Beverly Hills, Ca: Sage.
- Grant, S. (1998/2001). A separate world? The social position of the mentally ill, 1945-1955. In B. Brooks & J. Thomson (Eds.), *'Unfortunate folk': Essays on mental health treatment 1863-1992* (pp. 235-254). Dunedin, NZ: Otago University Press.
- Gray, T. (1959). *The very error of the moon*. Ilfracombe: Stockwell.
- Green, D., McCormick, I., Walkey, F., & Taylor, A. (1987). Community attitudes to mental illness in New Zealand twenty-two years on. *Social Science and Medicine*, 24(5), 417-422.
- Green, D., Walkey, F., Taylor, A., & McCormick, I. (1987). New Zealand attitudes to mental health. *New Zealand Journal of Psychology*, 16(1), 37-41.
- Gregoire, P. (1990). The phenomenology of psychiatric hospitalization: The patient's experience and expectations. *Acta Psychiatrica Scandinavica*, 82(3), 210-212.
- Grob, G. (1973). *Mental institutions in America; Social policy to 1875*. New York: Free Press.
- Groz, L. (1994). *Volatile bodies: Towards a corporeal feminism*. Sydney: Allen & Unwin.
- Guba, E., & Lincoln, Y. (1989). *Fourth generation evaluation*. Thousand Oaks, CA, US: Sage Publications, Inc.
- Guba, E., & Lincoln, Y. (1994). Competing paradigms in qualitative research. In N. Denzin & Y. Lincoln (Eds.), *Handbook of qualitative research* (pp. 105-117). Thousand Oaks, Ca: Sage.
- Hage, G. (1998). *White nation: Fantasies of white supremacy in a multicultural society*. Sydney: Pluto Press.
- Haig, B. (1995). *Grounded theory as scientific method*. Philosophy of Education. Available: <http://www.ed.uiuc.edu/EPS/PES-Yearbook/95_docs/haig.html> [2001, April].
- Haines, H., & Abbott, M. (1985). Deinstitutionalisation and social policy in New Zealand: 1: Historical trends. *Community Mental Health in New Zealand*, 1(2), 44-56.

- Hammersley, M. (1989). The problem of the concept: Herbert Blumer on the relationship between concepts and date. *Journal of Contemporary Ethnography*, 18, 133-59.
- Hannan, L. (1990). *Stigma, felt identity and the chronically mentally ill: An ethnographic study of the chronically mentally ill in an Australian community*. Unpublished PhD thesis, University of Sydney, Sydney.
- Harasymiw, S., Horne, M., & Lewis, S. (1978). Age, sex, and education as factors in acceptance of disability groups. *Rehabilitation Psychology*, 25(4), 201-207.
- Harris, C. (1995). *Employment options: A review of employment opportunities for people with long term mental illness*. Auckland, NZ: A Churchill Fellowship Report.
- Harris, C. (Undated). *Rehabilitation/recovery: An integrated focus for mental health services in New Zealand: A report to the Mental Health Commission*, Wellington, NZ: Author.
- Hayes, T. (2000). Stigmatizing indebtedness: Implications for labeling theory. *Symbolic Interaction*, 23(1), 29-46.
- Health Research Council of New Zealand. (2000). *Mental health outcomes research in Aotearoa*. Paper presented at the Mental Health Outcomes Research in Aotearoa, Wellington, NZ.
- Heatherton, T., Kleck, R., Hebl, M., & Hull, J. (Eds.). (2000). *The social psychology of stigma*. London: Guildford Press.
- Hebl, M., Tickle, J., & Heatherton, T. (2000). Stigma, threat and social interactions. In T. Heatherton, R. Kleck, M. Hebl, & J. Hull (Eds.), *The social psychology of stigma* (pp. 301-333). London: Guildford Press.
- Heidegger, M. (1962). *Being and time*. New York: Harper & Row.
- Henwood, K., & Pidgeon, N. (1992). Qualitative research and psychological theorising. *British Journal of Psychology*, 83(1), 97-111.
- Henwood, K., & Pidgeon, N. (1995). Grounded theory and psychological research. *Psychologist*, 8(3), 115-118.
- Hewitt, J. (1997). *Self and society: A symbolic interactionist social psychology (7th ed.)*. Neddham Heights, Ma: Allyn & Bacon.
- Hewstone, M. (1989). *Casual attribution: From cognitive processes to collective beliefs*. Oxford: Blackwell.
- Hewstone, M. (1990). The "ultimate attribution error"? A review of the literature on intergroup causal attribution. *European Journal of Social Psychology*, 20(4), 311-335.
- Hogg, M., & Hains, S. (1996). Intergroup relations and group solidarity: Effects of group identification and social beliefs on depersonalized attraction. *Journal of Personality and Social Psychology*, 70(2), 295-309.
- Holland, J., Holyoak, K., Nisbett, R., & Tharbard, P. (1987). *Induction: Processes of inference, learning, and discovery*. Cambridge, Ma: MIT Press.
- Holloway, J. (1991/2001). 'Unfortunate folk': A study of the social context of committal to Seacliff 1928-1948. In B. Brooks & J. Thomson (Eds.), *'Unfortunate folk': Essays on mental health treatment 1863-1992* (pp. 153-167). Dunedin, NZ: Otago University Press.
- Hurst-Turner, A. (1990). *Researching community care options: Representing consumer perspectives*. Unpublished Master of Social Science thesis, University of Waikato, Hamilton, NZ.
- Huxley, P., & Warner, R. (1992). Case management, quality of life, and satisfaction with services of long-term psychiatric patients. *Hospital and Community Psychiatry*, 43(8), 799-802.
- Hyder, S. (1988). DSM-III at the cinema: Madness in the movies. *Comprehensive Psychiatry*, 29, 195-201.

- Hyder, S., Gabbard, G., & Schneider, I. (1991). Homicidal maniacs and narcissistic parasites: Stigmatization of mentally. *Hospital and Community Psychiatry*, 42(10), 1044-1048.
- Irurita, V. (1996). Hidden dimensions revealed: Progressive grounded theory study of quality care in the hospital. *Qualitative Health Research*, 6(3), 331-349.
- Jacoby, A. (1994). Felt versus enacted stigma: A concept revisited: Evidence from a study of people with epilepsy in remission. *Social Science and Medicine*, 38(2), 269-274.
- Joas, H. (1985). *G. H. Mead: A contemporary re-examination of his thought*. Cambridge, Ma: MIT Press.
- Johannsen, W. (1969). Attitudes toward mental patients. *Mental Hygiene*, 53(2), 218-228.
- Jones, E., Farina, A., Hastorf, A., Markus, H., Miller, D., & Scott, R. (Eds.). (1984). *Social stigma: The psychology of marked relationships*. New York: Freeman.
- Jones, K. (1972). *A history of the mental health services*. London/Boston: Routledge & Kegan Paul.
- Jussim, L. (1986). Self-fulfilling prophecies: A theoretical and integrative review. *Psychological Review*, 93, 429-445.
- Jussim, L., Palumbo, P., Chatman, C., Madon, S., & Smith, A. (2000). Stigma and self-fulfilling prophecies. In T. Heatherton, R. Kleck, M. Hebl, & J. Hull (Eds.), *The social psychology of stigma* (pp. 374-418). London: Guildford Press.
- Karmel, M. (1969). Total institution and self-mortification. *Journal of Health and Social Behavior*, 10(2), 134-141.
- Kelle, U. (Ed.). (1995). *Computer-aided qualitative data methods and practice analysis: Theory, methods and practice*. London: Sage.
- Kelle, U. (1997). *Theory building in qualitative research and computer programs for the management of textual data*. Sociological Research Online, Vol. 2(2). Available: <<http://www.socresonline.org.uk/socresonline/2/2/1.html>> [2001, June].
- Klein, D. (1960). *Mental hygiene*. New York: Henry Holt.
- Kreisman, D., & Joy, V. (1974). Family response to the mental illness of a relative: A review of the literature. *Schizophrenia Bulletin*, 10, 34-57.
- Krohne, H. (1993). Attention and avoidance: The two central strategies in coping with aversiveness. In H. Krohne (Ed.), *Attention and avoidance: Strategies in coping with aversiveness* (pp. 3-14). Toronto: Hogrefe & Huber.
- Kydd, R., Mahoney, J., & Turbott, S. (1997). *A survey of the needs of users of mental health services who require high support, prepared for North Health*. Auckland, NZ: Department of Psychiatric Behavioural Medicine, University of Auckland.
- Lamy, R. (1966). Social consequences of mental illness. *Journal of Consulting Psychology*, 30(5), 450-455.
- Landrine, H. (1987). On the politics of madness: A preliminary analysis of the relationships between social roles and psychotherapy. *Genetic, Social, and General Psychology Monographs*, 113(3), 341-406.
- Lane, J., & Wegner, D. (1995). The cognitive consequences of secrecy. *Journal of Personality and Social Psychology*, 69, 1-17.
- Lattas, A. (1987). Savagery and civilisation: Towards a genealogy of racism. *Social Analysis*, 21, 39-58.
- Lazarus, R. (1974). Psychological stress and coping in adaptation and illness. *International Journal of Psychiatry in Medicine*, 5(4), 321-333.
- Lee, R., & Fielding, N. (Eds.). (1991). *Using computers in qualitative research*. London: Sage.

- Lefley, H. (1990). Culture and chronic mental illness. *Hospital and Community Psychiatry, 41*(3), 277-286.
- Lehman, S., Joy, V., Kreisman, D., & Simmens, S. (1976). Responses to viewing symptomatic behaviours and labelling of prior mental illness. *Journal of Community Psychology, 4*, 327-334.
- Leibrich, J. (1999). *A gift of stories*. Dunedin, NZ: University of Otago Press/Mental Health Commission.
- Lieban, R. (1992). From illness to symbol and symbol to illness. *Social Science Medicine, 35*(2), 183-188.
- Lindesmith, A., Strauss, A., & Denzin, N. (1988). *Social Psychology (6th ed.)*. Englewood Cliffs, NJ: Prentice Hall.
- Link, B. (1987). Understanding labeling effects in the area of mental disorders: An assessment of the effects of expectations of rejection. *American Sociological Review, 52*(1), 96-112.
- Link, B., Andrews, H., & Cullen, F. (1992). The violent and illegal behavior of mental patients reconsidered. *American Sociological Review, 57*(3), 275-292.
- Link, B., & Cullen, F. (1983). Reconsidering the social rejection of ex-mental patients: Levels of attitudinal response. *American Journal of Community Psychology, 11*(3), 261-273.
- Link, B., & Cullen, F. (1986). Contact with the mentally ill and perceptions of how dangerous they are. *Journal of Health and Social Behavior, 27*(4), 289-302.
- Link, B., Cullen, F., Frank, J., & Wozniak, J. (1987). The social rejection of former mental patients: Understanding why labels matter. *American Journal of Sociology, 92*(6), 1461-1500.
- Link, B., Cullen, F., Struening, E., Shrout, P., & Dohrenwend, B. (1989). A modified labeling theory approach to mental disorders: An empirical assessment. *American Sociological Review, 54*(3), 400-423.
- Link, B., Dohrenwend, B., & Skodol, A. (1986). Socio-economic status and schizophrenia: Noisome occupational characteristics as a risk factor. *American Sociological Review, 51*(2), 242-258.
- Link, B., Mesagno, F., Lubner, M., & Dohrenwend, B. (1990). Problems in measuring role strains and social functioning in relation to psychological symptoms. *Journal of Health and Social Behavior, 31*(4), 354-369.
- Link, B., Mirotnik, J., & Cullen, F. (1991). The effectiveness of stigma coping orientations: Can negative consequences of mental illness labeling be avoided? *Journal of Health and Social Behavior, 32*(3), 302-320.
- Link, B., Monahan, J., Stueve, A., & Cullen, F. (1999). Real in their consequences: A sociological approach to understanding the association between psychotic symptoms and violence. *American Sociological Review, 64*(2), 316-332.
- Link, B., & Phelan, J. (1999a). Labelling and stigma. In C. Aneshensel & J. Phelan (Eds.), *Handbook of the sociology of mental health* (pp. 481-494). New York: Kluwer Academic/Plenum.
- Link, B., & Phelan, J. (1999b). The labeling theory of mental disorder (II): The consequences of labeling. In A. Horwitz & T. Scheid (Eds.), *A handbook for the study of mental health: Social contexts, theories, and systems* (pp. 361-376). New York: Cambridge University Press.
- Link, B., & Phelan, J. (2001). Conceptualizing stigma. *Annual Review of Sociology, 27*, 363-385.
- Link, B., Phelan, J., Bresnahan, M., Stueve, A., & Pescosolido, B. (1999c). Public conceptions of mental illness: Labels, causes, dangerousness, and social distance. *American Journal of Public Health, 89*(9), 1328-1333.

- Link, B., Struening, E., Neese, T., Asmussen, S., & Phelan, J. (2001). Stigma as a barrier to recovery: The consequences of stigma for the self-esteem of people with mental illnesses. *Psychiatric Services*, 52(12), 1621-1626.
- Link, B., Struening, E., Rahav, M., Phelan, J., & Nuttbrock, L. (1997). On stigma and its consequences: Evidence from a longitudinal study of men with dual diagnoses of mental illness and substance abuse. *Journal of Health and Social Behavior*, 38(2), 177-190.
- Linn, L. (1968). The mental hospital from the patient perspective. *Psychiatry: Journal for the Study of Interpersonal Processes*, 31(3), 213-223.
- Lofland, J., & Lofland, L. (1984). *Analyzing social settings (2nd ed.)*. Belmont, Ca: Wadsworth.
- Longmate, N. (1974). *The workhouse*. London: Temple Smith.
- Lonkila, M. (1995). Grounded theory as an emerging paradigm for computer-assisted qualitative data analysis. In U. Kelle (Ed.), *Computer-aided qualitative data analysis: Theory, method and practice* (pp. 41-51). London: Sage.
- MacKen. (2000). *10 years of TheMHS, 10 years of Centre 401, in 10 minutes*. Paper presented at the TheMHS Conference, Adelaide.
- MacKenzie, H. (2000a). *Psychiatric stigma and employment: Do they exist for people with psychiatric disability?* Paper presented at the Association for Supported Employment in New Zealand Conference 2000, Christchurch, NZ.
- MacKenzie, H. (2000b). *Psychiatric stigma: Is this why employment considerations are often not present within discharge planning?* Paper presented at the TheMHS Conference 2000, Adelaide.
- MacKenzie, H., & MacKen, K. (2000a). *Hearing voices, hearing changes: An evaluation of 'Hearing Voices that are Distressing' workshop*. Paper presented at the Association for Supported Employment in New Zealand Conference 2000, Christchurch, NZ.
- MacKenzie, H., & MacKen, K. (2000b). *Hearing voices, hearing change: A summative evaluation of 'Hearing Voices that are Distressing Workshops'*. Paper presented at the TheMHS Conference 2000, Adelaide.
- MacKenzie, H., Manley, D., Warriner, R., Lange, M., Harvey, J., Carreon, E., & Deynzer, J. (2000). *Rehabilitation in mental health: where does employment fit in?* Paper presented at the National Mental Health Conference 2000, Wellington, NZ.
- Major, B., & Schmader, T. (1998). Coping with stigma through psychological disengagement. In J. Swim & C. Stangor (Eds.), *Prejudice: The target's perspective* (pp. 219-241). San Diego, Ca: Academic Press.
- Makal, M. (1999). The experience of living with the stigma of mental illness: An empirical phenomenological investigation. *Dissertation Abstracts International: Section B: The Sciences and Engineering*, 60(6-B), 2952.
- Margolis, J. (1986). *The persistence of reality 1: Pragmatism without foundations: Reconciling realism and relativism*. Oxford: Blackwell.
- Marinelli, R., & Orto, A. (1991). *The psychological and social impact of disability, (3rd ed.)*. New York: Springer Publishing Company.
- Markowitz, F. (1998). The effects of stigma on psychological well-being and life satisfaction. *Journal of Health and Social Behavior*, 39(4), 335-347.
- Marrone, J., & Golowka, E. (1999). If work makes people with mental illness sick, what do unemployment, poverty, and social isolation cause? *Psychiatric Rehabilitation Journal*, 23(2), 187-193.
- Marsden, M. (2001). Maori illness and healing: Mental health - a case for reform. In M. Henare (Ed.), *Te Ao Pumau: Standards and foundations of Maori society*. (pp.7-24). Auckland, NZ: Mental Health Foundation of New Zealand.

- Mason, K., Johnston, J., & Crowe, J. (1996). *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, NZ: Author.
- Mason, K., Ryan, A., & Bennett, H. (1988). *Report of the Committee of Inquiry into procedures used in certain psychiatric hospitals in relation to admission, discharge or release on leave of certain classes of patients*. Wellington, NZ: Author.
- McCandless, P. (1981). Liberty and lunacy: The Victorians and wrongful confinement. In A. Scull (Ed.), *Madhouses, mad-doctors, and madmen: The social history of psychiatry in the Victorian era* (pp. 489-562). Philadelphia, Pa: University of Pennsylvania Press.
- McClellan, V., & Warren, J. (1996). *Stakeholder perceptions of the strengths and weakness of mental health services: A report prepared for the Ministry of Health*. Wellington, NZ: Centre for Research Evaluation and Social Assessment.
- Mead, G. (1934). *Mind, self and society*. Chicago: University Press of Chicago.
- Mead, G. (1938). *The philosophy of the act*. Chicago: University Press of Chicago.
- Mechanic, D., McAlpine, D., Rosenfield, S., & Davis, D. (1994). Effects of illness attribution and depression on the quality of life among persons with serious mental illness. *Social Science and Medicine*, 39(2), 155-164.
- Mehta, S., & Farina, A. (1988). Associative stigma: Perceptions of the difficulties of college-aged children of stigmatized fathers. *Journal of Social and Clinical Psychology*, 7(2-3), 192-202.
- Mehta, S., & Farina, A. (1997). Is being "sick" really better? Effect of the disease view of mental disorder on stigma. *Journal of Social and Clinical Psychology*, 16(4), 405-419.
- Melia, K. (1996). Rediscovering Glaser. *Qualitative Health Research*, 6(3), 368-378.
- Meltzer, B. (1959/1972). The social psychology of George Herbert Mead. Kalamazoo: Centre for Sociological Research, Western Michigan University. In J. Manis & B. Meltzer (Eds.), *Symbolic interactionism: A reader in psychology (2nd ed.)* (pp. 4-22). Boston: Allyn & Bacon.
- Meltzer, B., Petras, J., & Reynolds, L. (1975). *Symbolic interactionism: Genesis, varieties and criticism*. London/Boston: Routledge & Kegan Paul.
- Mental Health Advocacy Coalition. (1999). *Real jobs for real pay. A report on the First National Employment Forum to identify opportunities and obstacles facing people who experience mental illness*. Wellington, NZ: Author.
- Mental Health Commission. (1997a). *Discrimination against people with experiences of mental illness*. Wellington, NZ: Author.
- Mental Health Commission. (1997b). *New directions: International overview of best practices in recovery and rehabilitation services for people with serious mental illness*. Wellington, NZ: Author.
- Mental Health Commission. (1998a). *Blueprint for mental health services in New Zealand: How things need to be*. Wellington, NZ: Author.
- Mental Health Commission. (1998b). *Critical mental health service improvement reports:*
- No. 1 - *Present state of clinical risk management in mental health services*.
- No. 2 - *Present state of discharge planning in mental health services*.
- No. 4 - *Changes to the level of service provision for people with co-existing mental health and alcohol and drug problems*. Wellington, NZ: Author.
- Mental Health Commission. (1998c). *A travel guide for people on the journeys toward equality, respect and rights for people who experience mental illness*. Wellington, NZ: Author.

- Mental Health Commission. (1999a). *Employment and mental health: Issues and opportunities. A discussion paper*. Wellington, NZ: Author.
- Mental Health Commission. (1999b). *A competency framework for the mental health workforce*. Wellington, NZ: Author.
- Mental Health Commission. (1999c). *Developing the mental health workforce*. Wellington, NZ: Author.
- Mental Health Commission. (1999d). *Housing and mental health: Reducing housing difficulties for people with mental illness*. Wellington, NZ: Author.
- Mental Health Commission. (1999e). *New Zealand's national mental health strategy: Review of progress 1994-1999*. Wellington, NZ: Author.
- Mental Health Commission. (2000a). *Mental health consumer participation in crown health agencies: A review, February-April 1999*. Wellington, NZ: Author.
- Mental Health Commission. (2000b). *Four Maori korero about their experience of mental illness: Mental Health Commission recovery series 1*. Wellington, NZ: Author.
- Mental Health Commission. (2000c). *Pacific people in New Zealand talk about their experiences with mental illness: Mental Health Commission recovery series 3*. Wellington, NZ: Author.
- Mental Health Commission. (2000d). *Four families of people with mental illness talk about their experiences: Mental Health Commission recovery series 4*. Wellington, NZ: Author.
- Mental Health Commission. (2000e). *Realising recovery - through the education of mental health workers*. Wellington, NZ: Author.
- Mental Health Commission. (2001a). *Recovery competencies for New Zealand mental health workers*. Wellington, NZ: Author.
- Mental Health Commission. (2001b). *Report on progress 1998-2000 towards implementing the Blueprint for mental health services in New Zealand*. Wellington, NZ: Author.
- Miller, C., & Kaiser, C. (2001). A theoretical perspective on coping with stigma. *Journal of Social Issues, 57*(1), 73-92.
- Miller, C., & Major, B. (2000). Coping with stigma and prejudice. In T. Heatherton, R. Kleck, M. Hebl, & J. Hull (Eds.), *The social psychology of stigma* (Vol. Guilford Press, pp. 243-272). New York.
- Miller, K. (1984). *Kathryn*. Rotorua, NZ: Tancred Press.
- Miller, K. (1987). *Injustice*. Rotorua, NZ: Tancred Press.
- Miller, S., Combs, C., & Kruus, L. (1993). Tuning in and tuning out: Confronting the effects of confrontation. In H. Krohne (Ed.), *Attention and avoidance: Strategies in coping with aversiveness* (pp. 51-69). Kirkland, Wa: Hogrefe & Huber.
- Ministry of Health. (1996). *Towards better mental health services: The report of the national working party on mental health workforce development*. Wellington, NZ: Author.
- Mishel, M. (1981). The measurement of uncertainty in illness. *Nursing Research, 30*(5), 258-263.
- Mishel, M. (1984). Perceived uncertainty and stress in illness. *Research in Nursing and Health, 7*(3), 163-171.
- Mishel, M. (1988). Uncertainty in illness. *IMAGE: Journal of Nursing Scholarship, 20*(4), 225-232.
- Mishel, M. (1995). Response to "Adult uncertainty in illness: A critical review of research". *Scholarly Inquiry for Nursing Practice, 9*(1), 25-29.
- Mishel, M., & Braden, C. (1988). Finding meaning: Antecedents of uncertainty in illness. *Nursing Research, 37*(2), 98-103.
- Mishel, M., Padilla, G., Grant, M., & Sorenson, D. (1991). Uncertainty in illness theory: A replication of the mediating effects of mastery and coping. *Nursing Research, 40*(4), 236-240.

- Moliner, P. (1995). A two-dimensional model of social representations. *European Journal of Social Psychology*, 25(1), 27-40.
- Moliner, P., & Tafani, E. (1997). Attitudes and social representations: A theoretical and experimental approach. *European Journal of Social Psychology*, 27(6), 687-702.
- Monahan, J. (1992). Mental disorder and violent behavior: Perceptions and evidence. *American Psychologist*, 47(4), 511-521.
- Moscovici, S. (1984). The phenomenon of social representations (S. Rabinovitch, Trans.). In R. Farr & S. Moscovici (Eds.), *Social representations* (pp. 3-55). Cambridge: Cambridge University Press.
- Mullen, P. (1991). The fear of the mentally ill: Is this public attitude justified? *New Zealand Medical Journal*, 13, 104(907), 90-92.
- Mullins, L., Cote, M., Fuemmeler, B., Jean, V., Beatty, W., & Paul, R. (2001). Illness intrusiveness, uncertainty, and distress in individuals with multiple sclerosis. *Rehabilitation Psychology*, 46(2), 139-153.
- Mulvey, E. (1994). Assessing the evidence of a link between mental illness and violence. *Hospital and Community Psychiatry*, 45(7), 663-679.
- Ng, S., Martin, J., & Romans, S. (1995). A community's attitudes towards the mentally ill. *New Zealand Medical Journal*, 1, 108(1013), 505-508.
- Nisbet, J., & Hagner, D. (1988). Natural supports in the workplace: A re-examination of supported employment. *Journal of the association for persons with severe handicaps* 13(4), 260-267.
- Nunnally, J. (1961). *Popular conceptions of mental health: Their development and change*. New York: Holt, Rinehart, and Winston.
- Nuthall, J. (1997, July). *Relationship between low socio-economic status and use of health services*. Paper presented at the Public Health Association New Zealand Conference 1997: Collaborating for health. Pathway to the future, Hamilton, NZ.
- NZ Herald. (1997, August 20). The trouble with social acceptance. Mental breakdown - a Herald series. *NZ Herald*, pp. A11.
- NZ Herald. (1999, September 2). Community care: A step to far. *NZ Herald*, pp. A11.
- Oaks, P., Haslam, S., & Turner, J. (Eds.). (1994). *Stereotyping and social reality*. Oxford: Blackwell.
- Ogonowska, C. (2000). *Have no shame = Kaua e whakama: family stories of living with mental illness*. Christchurch, NZ: Schizophrenia Fellowship New Zealand.
- O'Hagan, M. (1999). *Realising recovery: Six challenges to the mental health sector - Keynote address at the Realising Recovery Conference*. Available: <http://www.mhc.govt.nz/Conference%20Papers/Papers/CP1realising_recovery.htm> [2002, February].
- O'Hagan, M. (2000). *Bridging the troubled waters: An investigation into Workbridge and the bridge to employment for people with experience of mental illness*. Auckland, NZ.
- Olmsted, D., & Durham, K. (1976). Stability of mental health attitudes: A semantic differential study. *Journal of Health and Social Behavior*, 17(1), 35-44.
- Olshansky, S., Grob, S., & Malamud, I. (1959). Employers' attitudes and practices in the hiring of ex-mental patients. *Mental Hygiene*, 391-401.
- Opie, A. (2001). *The use of computing packages in qualitative research: Recent literature in the field, Part 2 of two reports on 'Computing packages in qualitative research software'*. In D. Thomas (Ed.) Health Research Methods Advisory Service, Newsletter 49, Health Research Methods Network. Available: <<http://www.auckland.ac.nz/mch/hrmas.htm>> [2001, June].

- Outhwaite, W. (1975). *Understanding social life: The method called verstehen*. London: George Allen & Unwin.
- Oyserman, D., & Swim, J. (2001). Stigma: An insider's view. *Journal of Social Issues*, 57(1), 1-14.
- Packer, M., & Addison, R. (1989). *Entering the circle: Hermeneutic investigation in psychology*. Albany, NY: State University of New York Press.
- Padilla, G., Mishel, M., & Grant, M. (1992). Uncertainty, appraisal and quality of life. *Quality of Life Research: An International Journal of Quality of Life Aspects of Treatment, Care and Rehabilitation*, 1(3), 155-165.
- Page, S. (1977). Effects of the mental illness label in attempts to obtain accommodation. *Canadian Journal of Behavioural Science*, 9(2), 85-90.
- Page, S., & Day, D. (1990). Acceptance of the "mentally ill" in Canadian society: Reality and illusion. *Canadian Journal of Community Mental Health*, 9(1), 51-61.
- Parry-Jones, W. (1971). *The trade in lunacy: A study of private madhouses in England in the eighteenth and nineteenth centuries*. London: Routledge & Kegan Paul.
- Patten, D. (1992). *Public attitudes to mental illness. A report for the Mental Health Policy Section prepared by Health Research Services*. Wellington: Department of Health.
- Pearson, A. (2001). *Critical issues for people with a mental illness pursuing higher education*. Paper presented at the Massey University Disability in Education Conference: Progress Through Partnerships, Albany, NZ.
- Peirce, C. (1965). *Collected papers of Charles Sanders Peirce. Vol. V: Pragmatism and pragmaticism; Vol. VI: Scientific metaphysics*. Cambridge, Ma: Belknap Press Harvard University Press.
- Penn, D., Kommana, S., Mansfield, M., & Link, B. (1999). Dispelling the stigma of schizophrenia: II. The impact of information on dangerousness. *Schizophrenia Bulletin*, 25(3), 437-446.
- Penn, D., & Nowlin-Drummond, A. (2001). Politically correct labels and schizophrenia: A rose by any other name? *Schizophrenia-Bulletin* 27(2), 197-203.
- Pennebaker, J. (1989). Confession, inhibition and disease. In L. Berkowitz (Ed.), *Advances in experimental social psychology* (Vol. 22, pp. 211-244).
- Pescosolido, B., Monahan, J., Link, B., Stueve, A., & Kikuzawa, S. (1999). The public's view of the competence, dangerousness, and need for legal coercion of persons with mental health problems. *American Journal of Public Health*, 89(9), 1339-1345.
- Petersen, A. (1994). *In a critical condition: Health and power relations in Australia*. Sydney: Allen & Unwin.
- Petronio, S. (1991). Communication boundary management: A theoretical model for managing disclosure of private information between marital couples. *Communication Theory*, 1, 311-335.
- Petronio, S. (2000). The boundaries of privacy: Praxis of everyday life. In S. Petronio (Ed.), *Balancing the secrets of private disclosures* (pp. 37-122). Mahwah, NJ: Lawrence Erlbaum Associates.
- Pettie, D., & Triolo, A. (1999). Illness as evolution: The search for identity and meaning in the recovery process. *Psychiatric Rehabilitation Journal*, 22(3), 255-62.
- Pettigrew, T. (1979). The ultimate attribution error: Extending Allport's cognitive analysis of prejudice. *Personality and Social Psychology Bulletin*, 5(4), 461-476.
- Phelan, J., Bromet, E., & Link, B. (1998). Psychiatric illness and family stigma. *Schizophrenia Bulletin*, 24(1), 115-126.

- Phelan, J., Link, B., Stueve, A., & Pescosolido, B. (2000). Public conceptions of mental illness in 1950 and 1996: What is mental illness and is it to be feared? *Journal of Health and Social Behavior*, 41(2), 188-207.
- Pidgeon, N., & Henwood, K. (1997). Using grounded theory in psychological research. In N. Hayes (Ed.), *Doing qualitative analysis in psychology* (pp. 245-273). Hove, England: Psychology Press/Erlbaum (UK) Taylor & Francis.
- Pinel, E. (1999). Stigma consciousness: The psychological legacy of social stereotypes. *Journal of Personality and Social Psychology*, 76(1), 144-128.
- Piner, K., & Kahle, L. (1984). Adapting to the stigmatizing label of mental illness: Foregone but not forgotten. *Journal of Personality and Social Psychology*, 47(4), 805-811.
- Quadagno, J., & Antonio, R. (1975). Labeling theory as an oversocialized conception of man: The case of mental illness. *Sociology and Social Research*, 60(1), 33-45.
- Rabkin, J. (1972). Opinions about mental illness: A review of the literature. *Psychological Bulletin*, 77(3), 153-171.
- Rabkin, J. (1974). Public attitudes toward mental illness: A review of the literature. *Schizophrenia Bulletin*, 10, 9-33.
- Reed, A. (1993/2001). Taming the brain storms. In B. Brooks & J. Thomson (Eds.), *'Unfortunate folk': Essays on mental health treatment 1863-1992* (pp. 49-65). Dunedin, NZ: Otago University Press.
- Reichenbach, H. (1949). *The theory of probability* (E. Hutton & M. Reichenbach, Trans.). Berkeley, Ca: University of California Press.
- Rennie, D. (1998). Grounded theory methodology: The pressing need for a coherent logic of justification. *Theory and Psychology*, 8(1), 101-119.
- Rennie, D. (2000). Grounded theory methodology as methodical hermeneutics: Reconciling realism and relativism. *Theory & Psychology*, 10(4), 481-502.
- Rice, G. (1988). Report of two conferences, indicating future directions. *Society for the Social History of Medicine*, 409-414.
- Richards, L., & Richards, T. (1991). The transformation of qualitative method: computational paradigms and research processes. In R. Lee & N. Fielding (Eds.), *Using Computers in Qualitative Research* (pp. 16-37). London: Sage.
- Richards, T., & Richards, L. (1994). Using computers in qualitative research. In N. Denzin & Y. Lincoln (Eds.), *Handbook of Qualitative Research* (pp. 445-462). Thousand Oaks, Ca: Sage.
- Richardson, L. (1993). Interrupting discursive spaces: Consequences for the sociological self. In N. Denzin (Ed.), *Studies in symbolic interactionism: A research annual* (Vol. 14, pp. 77-84). Greenwich, Ct: JAI.
- Richardson, L. (1994). Writing: A method of inquiry. In N. Denzin & Y. Lincoln (Eds.), *Handbook of qualitative research* (pp. 516-529). Thousand Oaks, Ca: Sage.
- Riessman, C. (1990). Strategic uses of narrative in the presentation of self and illness: A research note. *Social Science and Medicine*, 30, 1173-1186.
- Rock, P. (1979). *The making of symbolic interactionism*. London: MacMillan.
- Rosen, G. (1968). *Madness in society: Chapters in the historical sociology of mental illness*. London: Routledge & Kegan Paul.
- Rosenberg, M., & Turner, R. (Eds.). (1981). *Social psychology: Sociological perspectives*. New York: Basic Books.
- Rosenfield, S., & Wenzel, S. (1997). Social networks and chronic mental illness: A test of four perspectives. *Social Problems*, 44(2), 201-215.
- Rosenhan, D. (1975). On being sane in insane places. In S. Dinitz, R. Dynes, & A. Clarke (Eds.), *Deviance: Studies in definition, management, and treatment* (pp. 279-291). London: Oxford University Press.

- Roskin, G., Carsen, M., Rabiner, C., & Marell, S. (1988). Attitudes toward patients among different mental health professional groups. *Comprehensive Psychiatry*, 29(2), 188-194.
- Rossi, A., Jacobs, M., Monteleone, M., Olsen, R., Surber, R., Winkler, E., & Wommack, A. (1986). Characteristics of psychiatric patients who engage in assaultive or other fear-inducing behaviors. *Journal of Nervous Mental Disorders*, 174(3), 154-160.
- Rutman, I. (1994). How psychiatric disability expresses itself as a barrier to employment. *Psychosocial Rehabilitation Journal*, 17(3), 15-35.
- Sainsbury, A. (1947). *Misery mansion: Grim tales of New Zealand asylums*. (4th ed.). Otahuhu, NZ: A. Sainsbury.
- Sarbin, T., & Mancuso, J. (1970). Failure of a moral enterprise: Attitude of the public toward mental illness. *Journal of Consulting and Clinical Psychology*, 35(2), 159-173.
- Sayce, L. (1998). Stigma, discrimination and social exclusion: What's in a word? *Journal of Mental Health UK*, 7(4), 331-343.
- Sayce, L. (2000). *From psychiatric patient to citizen: Overcoming discrimination and social exclusion*. New York: St Martin's Press.
- Scambler, G. (1984). Perceiving and coping with stigmatizing illness. In R. Fitzpatrick, J. Hinton, S. Newman, G. Scambler, & J. Thompson (Eds.), *The experience of illness* (pp. 203-226). London: Tavistock.
- Scambler, G., & Hopkins, A. (1980). Generating a model of epileptic stigma: The role of qualitative analysis. *Social Science and Medicine*, 30(11), 1187-1194.
- Scambler, G., & Hopkins, A. (1988). Accommodating epilepsy in families. In R. Anderson & M. Bury (Eds.), *Living with chronic illness* (pp. 156-76). London: Unwin Hyman.
- Scheer, J., & Groce, N. (1988). Impairment as a human constant: Cross-cultural and historical perspectives on variation. *Journal of Social Issues*, 44, 23-37.
- Scheff, T. (1966). *Being mentally ill: A sociological theory*. Chicago, IL: Aldine de Gruyter.
- Scheff, T. (1984). *Being mentally ill*. Chicago: Aldine.
- Scheff, T. (1990). *Microsociology: Discourse, emotion and social structure*. Chicago: University of Chicago Press.
- Scheff, T. (1998). Shame in labeling of mental illness. In P. Gilbert & B. Andrews (Eds.), *Shame: Interpersonal behavior, psychopathology, and culture* (pp. 191-205). New York: Oxford University Press.
- Scheff, T., & Retzinger, S. (1991). *Emotions and violence: Shame and rage in destructive conflicts*. Lexington, Ma: Lexington Books/DC Heath & Company.
- Schneider, J., & Conrad, P. (1980). In the closet with illness: Epilepsy, stigma potential and information control. *Social Problems*, 28, 32-44.
- Schreiber, R. (1996). (Re)Defining my self: Women's process of recovery from depression. *Qualitative Health Research*, 6(4), 469-491.
- Schutz, A. (1967). *The phenomenology of the social world* (G. Walsh & F. Lehnert, Trans.). Evanston, Ill: Northwestern University Press.
- Schwandt, T. (1998). Constructivist, interpretivist approaches to human inquiry. In N. Denzin & Y. Lincoln (Eds.), *The landscape of qualitative research: Theories and issues* (pp. 221-259). Thousand Oaks, Ca: Sage.
- Scull, A. (1981a). The social history of psychiatry in the Victorian era. In A. Scull (Ed.), *Madhouses, mad-doctors, and madmen: The social history of psychiatry in the Victorian era* (pp. 5-34). Philadelphia, Pa: University of Pennsylvania Press.
- Scull, A. (1981b). Moral treatment reconsidered: Some sociological comments on an episode in the history of British psychiatry. In A. Scull (Ed.),

Madhouses, mad-doctors, and madmen: The social history of psychiatry in the Victorian era (pp. 105-120). Philadelphia, Pa: University of Pennsylvania Press.

- Seidel, J. (1991). Method and madness in the application of computer technology to qualitative data analysis. In R. Lee & N. Fielding (Eds.), *Using Computers in Qualitative Research* (pp. 89-106). London: Sage.
- Siassi, I., Spiro, H., & Crocetti, G. (1973). The social acceptance of the ex-mental hospital patient. *Community Mental Health Journal*, 9(3), 233-243.
- Signorelli, N. (1989). The stigma of mental illness on television. *Journal of Broadcasting and Electronic Media*, 33, 325-331.
- Skinner, L., Berry, K., Griffith, S., & Byers, B. (1995). Generalizability and specificity of the stigma associated with the mental illness label: A reconsideration twenty-five years later. *Journal of Community Psychology*, 23(1), 3-17.
- Skowronski, J., & Carlston, D. (1989). Negativity and extremity biases in impression formation: A review of explanations. *Psychological Bulletin*, 105(1), 131-142.
- Skultans, V. (1975). *Madness and morals: Ideas on insanity in the nineteenth century*. London/Boston: Routledge & Kegan Paul.
- Skultans, V. (1979). *English madness: Ideas on insanity, 1580-1890*. London/Boston: Routledge & Kegan Paul.
- Smart, L., & Wegner, D. (1999). Covering up what can't be seen: Concealable stigma and mental control. *Journal of Personality and Social Psychology*, 77(3), 474-486.
- Smart, L., & Wegner, D. (2000). The hidden costs of stigma. In T. Heatherton, R. Kleck, M. Hebl, & J. Hull (Eds.), *The social psychology of stigma* (pp. 243-272). London: Guildford Press.
- Smith, R. (1981). The boundary between insanity and criminal responsibility in nineteenth century England. In A. Scull (Ed.), *Madhouses, mad-doctors, and madmen: The social history of psychiatry in the Victorian era* (pp. 363-377). Philadelphia, Pa: University of Pennsylvania Press.
- Snow, S. (2001). Extending and broadening Blumer's conceptualization of symbolic interactionism. *Symbolic Interactionism*, 24(3), 367-377.
- Socall, D., & Holtgraves, T. (1992). Attitudes toward the mentally ill: The effects of labels and beliefs. *Sociological Quarterly*, 33(3), 435-445.
- Somerville, A. (1996/2001). Ashburn Hall (1882-1904). In B. Brooks & J. Thomson (Eds.), *'Unfortunate folk': Essays on mental health treatment 1863-1992* (pp. 83-103). Dunedin, NZ: Otago University Press.
- Sorrentino, R., & Roney, C. (1990). Uncertainty orientation: Individual differences in the self-inference process. In J. Olson & M. Zanna (Eds.), *Self-inference processes: The Ontario symposium, Vol. 6. Ontario symposium on personality and social psychology* (pp. 239-257). Hillsdale, NJ: Lawrence Erlbaum Associates.
- Spiro, H., Siassi, I., & Crocetti, G. (1972). Public contact with the mentally ill: Who's kidding whom? *Mental Hygiene*, 56(2), 36-38.
- Stafford, M., & Scott, R. (1986). Stigma deviance and social control: Some conceptual issues. In S. Ainlay, G. Becker, & L. Coleman (Eds.), *The dilemma of difference* (pp. 77-90). New York: Plenum.
- Stallworthy, K. (1958). *The facts of mental health and illness*. (2nd ed.). Christchurch, NZ: N.M. Peryer.
- Stam, H. (2000). Theorizing health and illness: Functionalism, subjectivity and reflexivity. *Journal of Health Psychology*, 5(3), 273-283.
- Stangor, C., & Crandall, C. (2000). Threat and the social construction of stigma. In T. Heatherton, R. Kleck, M. Hebl, & J. Hull (Eds.), *The social psychology of stigma* (pp. 62-88). London: Guildford Press.
- Statistics New Zealand. (1998). *Disability counts*. Wellington, NZ: Author.

- Stern, N. (1994). Eroding grounded theory. In J. Morse (Ed.), *Critical issues in qualitative research methods* (pp. 212-223). London: Sage.
- Strauss, A. (1964). *George Herbert Mead: On social psychology*. Chicago: University Press of Chicago.
- Strauss, A., & Corbin, J. (1990). *Basics of qualitative research: Grounded theory procedures and techniques*. Newbury Park, Ca: Sage.
- Strauss, A., & Corbin, J. (1994). Grounded theory methodology: An overview. In N. Denzin & Y. Lincoln (Eds.), *Handbook of qualitative research* (pp. 273-285). Thousand Oaks, Ca: Sage.
- Strauss, A., & Corbin, J. (1998). *Basics of qualitative research: Techniques and procedures for developing grounded theory (2nd ed.)*. Thousand Oaks, Ca: Sage.
- Strike, K. (1987). Toward a coherent constructivism. Cited in T. Schwandt (1998). Constructivist, interpretivist approaches to human inquiry. In N. Denzin & Y. Lincoln (Eds.), *The landscape of qualitative research: Theories and issues* (pp. 283). Thousand Oaks, Ca: Sage.
- Susman, J. (1994). Disability, stigma and deviance. *Social Science and Medicine*, 38(1), 15-22.
- Swim, J., & Stangor, C. (Eds.). (1998). *Prejudice: The target's perspective*. London: Academic Press.
- Tajfel, H., & Turner, J. (1986). The social identity theory of intergroup behaviour. In S. Worchel & W. Austin (Eds.), *Psychology of intergroup relations* (pp. 7-24). Chicago: Nelson.
- Talbot, F., Nouwen, A., Gingras, J., Belanger, A., & Audet, J. (1999). Relations of diabetes intrusiveness and personal control to symptoms of depression among adults with diabetes. *Health Psychology*, 18(5), 537-542.
- Tattan, T., & Tarrier, N. (2000). The expressed emotion of case managers of the seriously mentally ill: The influence of expressed emotion on clinical outcomes. *Psychological Medicine*, 30(1), 195-204.
- Teichman, Y., Bazzoui, W., & Foa, E. (1974). Changes in self-perception following short-term psychiatric treatment. *Journal of Psychiatric Research*, 10(3-4), 231-238.
- Tennant, M. (1987). *The sick poor and medical relief under New Zealand's charitable aid system*. Paper presented at the First New Zealand Conference on the History of New Zealand and Australian Medicine, Hamilton, NZ.
- Thayer, H. (1968). *Meaning and action: A critical history of pragmatism*. New York: Bobbs-Merrill.
- Theriot, N. (1993). Women's voices in nineteenth-century medical discourse: A step towards deconstructing science. *Signs*, 19, 1-31.
- Thoits, P. (1985). Self-labeling processes in mental illness: The role of emotional deviance. *American Journal of Sociology*, 91(2), 221-249.
- Thomas, A. (2000). Stability of Tringo's hierarchy of preference toward disability groups: 30 years later. *Psychological Reports*, 86(3), 1155-1156.
- Torrey, E. (1994). Violent behavior by individuals with serious mental illness. *Hospital and Community Psychiatry*, 45(7), 653-662.
- Tringo, J. (1970). The hierarchy of preference toward disability groups. *Journal of Special Education*, 4(3), 295-306.
- Trope, Y. (1979). Uncertainty-reducing properties of achievement tasks. *Journal of Personality and Social Psychology*, 37(9), 1505-1518.
- Trute, B., Tefft, B., & Segall, A. (1989). Social rejection of the mentally ill: A replication study of public attitude. *Social Psychiatry and Psychiatric Epidemiology*, 24(2), 69-76.
- Tucker, G. (1887). *Lunacy in many lands*. Sydney: Charles Potter, Government Printer.

- Tuffin, K., & Danks, J. (1999). Community care and mental disorder: An analysis of discursive resources. *British Journal of Social Psychology*, 38(3), 289-302.
- Vickers, M. (1997). Life at work with 'invisible illness (ICI): The 'unseen', unspoken, unrecognized dilemma of disclosure. *Journal of Workplace Learning*, 9(7), 240-252.
- Vickers, M. (2000). Stigma, work and 'unseen' illness: A case and notes to enhance understanding. *Illness, Crisis & Loss*, 8(2), 131-151.
- von Glaserfeld, E. (1991). Knowing without metaphysics: Aspects of the radical constructivist position. In F. Steier (Ed.), *Research and reflexivity* (pp. 12-29). Newbury Park, Ca: Sage.
- von Hippel, W., Hawkins, C., & Narayan, S. (1994). Personality and perceptual expertise: Individual differences in perceptual identification. *Psychological Science*, 5(6), 401-406.
- von Hippel, W., Jonides, J., Hilton, J., & Narayan, S. (1993). Inhibitory effect of schematic processing on perceptual encoding. *Journal of Personality and Social Psychology*, 64(6), 921-935.
- Wahl, O., & Harman, C. (1989). Family views of stigma. *Schizophrenia Bulletin*, 15(1), 131-139.
- Wahl, O., & Lefkowitz, J. (1989). Impact of a television film on attitudes toward mental illness. *American Journal of Community Psychology*, 17(4), 521-528.
- Walmisely, G. (1997). Workforce issues arising from psychiatric community support initiatives. *Mental Health News*, 8-10.
- Wang, C. (1992). Culture, meaning and disability. *Social Science and Medicine*, 35(9), 1093-1102.
- Warriner, R. (1996). Supported employment for people who experience psychiatric disability. In G. Bennie (Ed.), *Supported Employment in New Zealand* (pp. 30-41). Levin, NZ: Network Publications.
- Wegner, D., Erber, R., & Zanakos, S. (1993). Ironic processes in mental control of mood and mood-related thought. *Journal of Personality and Social Psychology*, 65, 1093-1104.
- Weiner, B., Perry, R., & Magnusson, J. (1988). An attributional analysis of reactions to stigmas. *Journal of Personality and Social Psychology*, 55(5), 738-748.
- Weinstein, R. (1979). Patient attitudes toward mental hospitalization: A review of quantitative research. *Journal of Health and Social Behavior*, 20(3), 237-258.
- Weinstein, R. (1983). Labeling theory and the attitudes of mental patients: A review. *Journal of Health and Social Behavior*, 24(1), 70-84.
- Westbrook, M., Legge, V., & Pennay, M. (1993). Attitudes towards disabilities in a multicultural society. *Social Science and Medicine*, 36(5), 615-623.
- Williams, W. (1987). *Out of mind, out of sight: The story of Porirua Hospital*. Porirua, NZ: Porirua Hospital.
- Wilson, C., Nairn, R., Coverdale, J., & Panapa, A. (1999). Constructing mental illness as dangerous: A pilot study. *Australian and New Zealand Journal of Psychiatry*, 33(2), 240.
- Wineman, N., O'Brien, R., Nealon, N., & Kaskel, B. (1993). Congruence in uncertainty between individuals with multiple sclerosis and their spouses. *Journal of Neuroscience Nursing*, 25, 356-361.
- Young, I. (1990). Throwing like a girl. In *Throwing like a girl and other essays in feminist philosophy and social theory* (pp 103-112). Bloomington: Indiana University Press.
- Zajonc, R. (2000). Feeling and thinking: Closing the debate over the independence of affect. In J. Forgas (Ed.), *Feeling and thinking: The role*

of affect in social cognition. Studies in emotion and social interaction, (2nd Series) (pp. 31-58). New York: Cambridge University Press.
Zanna, M., & Olson, J. (Eds.). (1994). *The psychology of prejudice*. Hillsdale, NJ: Lawrence Erlbaum.

LUCEO NON URO