"Kia Mauri Tau!"

Narratives of Recovery from Disabling Mental Health Problems

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Report of the

UNIVERSITY OF WAIKATO
MENTAL HEALTH NARRATIVES PROJECT

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Acknowledgments

WHAKATAUKI

Kia pono ki ta te wairua,
Hold fast to that of the spirit,

Ka mahu ko te kikokiko.
Comes a healing of the body.

This whakatauki tells of the strength and powers of ones spiritual elements that can and will show the way to good physical and mental well being.

MIHI

E nga maunga tiketike, kei nga Rangatira,
To the high mountains, to you the esteemed people,

tena koutou katoa.
I bid you greeting.

Ka tika te mihi arorangi atu ki te hunga ka moe,
It is appropriate at this time for us all to acknowledge those who have passed on,

ka ngaro i te pa ihu, i te mahana paparinga,
whom we no longer have the privilege to hongi, and have their warm cheeks against ours

haere ra koutou katoa.
farewell to them all.

E rau rangatira ma,
To the esteemed,

Whai ake nei ko nga korero ka taaria a nga tangata whai ora
The following are stories told by consumers

ka takoto hei panuitanga ma koutou.
about their experiences.

ma koutou ra hei wananga te ahutanga o nga whakaaro kei roto i enei korero.
You the reader can learn from the messages contained in these precious stories.

Tena koutou katoa.
Greetings to you all.

Foreword

Early in 1996 I went to a meeting in Auckland with several mental health leaders to discuss priorities for new mental health research funding. As we sat around the table brainstorming, I threw in my concern that a lot of the questions mental health research sought to answer were of little relevance to people with mental health problems. The research agenda has been set by academics and professionals who value so called objective evidence over subjective experience. They have developed elaborate frameworks for understanding mental illness but they barely acknowledge the process of recovery. I went on to say that there's one crucial but simple question service users want answers to, but professionals and researchers often don't think to ask it. That question is – what keeps people well?

Our brainstorm influenced the Health Research Council's priorities for mental health research. One of the priorities they created was 'pathways to wellness', with an emphasis on the perspectives of people with mental health problems.

A bicultural research team at the University of Waikato successfully applied for funding from the Health Research Council to do a qualitative research project in the area of 'pathways to wellness'. They interviewed 40 people who defined themselves as recovered, about their lives before, during and after their experience of mental health problems. To my knowledge this was the first New Zealand based research on people's recovery experiences funded by a government agency.

Hilary Lapsley, Linda Waimarie Nikora and Rose Black presented the preliminary findings of their research to the Mental Health Commission in 2000. Their findings on people's experiences of mental health problems amply reflected my own experience and knowledge. But it was their findings on people's recovery experiences that really riveted me. Their descriptions of the themes of recovery, and of the barriers to recovery, did more than echo my own experiences; it confirmed my belief that they were shared by many and diverse others in loosely predictable ways.

The Mental Health Commission has decided to publish *Kia Mauri Tau!* because we want the whole sector to benefit from this groundbreaking research. You hold in your hands one of the best thematic accounts of mental health problems and recovery I have ever seen. It is accessible and easy to read. It is a bicultural project based in New Zealand, when most recovery literature is written by white people from other countries. It honours the experience of the people who told their stories by taking them at their word. And its findings shed new light on the tempestuous and triumphant journeys of many thousands of New Zealanders. That is why everyone with an interest or involvement in mental health issues should read it.

Mary O'Hagan
Commissioner

Starting Points

This chapter is the point of embarkation on our research journey to find stories of Maori and non-Maori women and men who recovered from disabling mental health problems. Here we state the aims of the Mental Health Narratives Project, and then we introduce some of the ideas about recovery, narrative research and mental health which set our waka moving. In the last half of this introduction we describe the methods we used in the Mental Health Narratives project.

AIMS

The Mental Health Narratives Project set out to gather forty narratives of mental ill health, recovery and life after recovery by interviewing Maori and non-Maori women and men who once had a disabling mental health problem. We aimed to describe journeys to mental health, identify key themes in accounts of the recovery process and describe the impact of the experience of mental ill health on life after recovery.

As a bicultural endeavour, our research team was comprised of Pakeha and Maori investigators and interviewers and we interviewed equal numbers of Maori and non-Maori participants. We incorporated Treaty of Waitangi principles into our research partnership and in our data analysis, and compared Maori and non-Maori accounts of illness and recovery, as well as specifically examining cultural contributors to recovery in the narratives of Maori participants.[1]

The theoretical orientation of the project led us to use thematic and narrative analysis techniques to investigate themes and journeys; these are described more fully in the later section on data analysis. We paid particular attention to constructions of self and identity in mental health narratives and further investigations from the project team will focus on how these constructions are framed by social discourses on mental health, including discourses involving gender and ethnicity.

BICULTURAL RESEARCH IN MENTAL HEALTH

Our research waka and the subject that it conveys inevitably demands that stories of recovery from mental ill health be viewed and investigated in the fullness of their social, economic, political, spiritual and emotional environments. These environments are essentially bicultural, even in some instances multicultural, and sometimes monocultural. Rarely do they involve only Maori.

The stories, the heroes, the villains, the triumphs and the disappointments, the joys, and the betrayals, occurred mostly within the broader context of Aotearoa/ New Zealand and its myriad ecologies. To understand and appreciate these stories, and to honour the storytellers, there must be fluidity of voice reflecting the social, ethnic and cultural ecologies of the lives of those we spoke with.

Many of the locations, experiences and narratives flow into and out of a commonality, a sense of being here – in Aotearoa/New Zealand. By professing a bicultural approach, this study locates its material – the stories of Maori and non-Maori men and women who have recovered from disabling problems – in a world defined and shaped by more cultures than one. In recognition of this, the study actively and rightfully engages in a bicultural methodology.

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[1] Several other pieces of work from our project also examine cultural contributors to recovery. They are H. Lapsley, L.W. Nikora, & R. Black, "Women's narratives of recovery from disabling mental health problems: A bicultural project from Aotearoa / New Zealand." In J. Ussher (ed.), *Women's Health: Contemporary International Perspectives* (London: British Psychological Society Books, 2000) and C. J. Ansley, "From Negotiations of Threat to Strategies of Identity: Men, Mental Health Problems and Masculinity", M.Soc.Sci. thesis, University of Waikato (which does not use data from the project, but does utilise similar approaches). A forthcoming thesis from Rosanne Black will examine cultural contributors to recovery in the non-Maori women's narratives using data from the project, and Jan Wilson, using data she collected herself, is examining women's narratives of recovery from depression for a PhD project.

RECOVERY IN MENTAL HEALTH

Most narrative research in the health field has focused on stories of illness rather than stories of recovery. Recovery must take a more central place in research on mental illness stories, since an orientation towards recovery and away from illness is at the heart of a whole paradigm shift in mental health policy and practice. Today, the recovery vision now guides the development of mental health services in New Zealand.[2]

A recovery focus in mental health counters the myth, too often dominating service provision, that a diagnosis of mental illness means a life sentence. Researchers are concluding that while many mental illnesses are persistent, long-term recovery rates for the 3% of the population who experience severe mental health problems are better than most people imagine. Moreover, mental illness is very common, with symptoms of mental ill health significantly affecting perhaps 20–30% of the population at any one time. It touches everybody's lives, whether through their own experience or that of those around them. The toll taken by mental illness can be alleviated by good health treatment and care. Even more importantly, this toll can be alleviated by fostering life circumstances that enhance wellness and by removing obstacles to recovery, such as discrimination and social exclusion.

New Zealand's recovery orientation in mental health originated in worldwide mental health consumer movements, and through developments in psychiatric rehabilitation and the populist self help recovery movement.[3] This approach places the tangata whaiora, or service users, as key players in service development and expects services to foster self-determination, a sense of hope and meaningful lives for people who experience mental illness. A recovery orientation would enhance social participation and combat social exclusion.

Recovery orientations are compatible with Maori mental health models, in that a balance is sought between the body, person, whanau, and the environment and ecologies within which they exist. At the base of all Maori mental health models (irrespective of whether this is explicitly stated) is the firming and grounding of mauri across all dimensions of a person's life. This is a basic premise recognised by Maori writers such as Mere Balzer, Bob Elliot and Stewart Price; Mason Durie; Moana Jackson; and Rangimarie Rose Pere.[4] A secure identity, both personal and cultural, is integral to this "balancing".

The fonofale model, illustrated by a house (fale) with its roof, posts and foundations, was developed by Fuimaono Karl Pulotu-Endemann to understand the health needs of Pacific peoples. Its holistic nature also sits easily with a recovery approach and is used in recovery education.[5]

Many of the writings of the international "recovery movement" are experientially based, making personal accounts central to their exposition. They have much to say about recovery as a personal process, as well as a mental health ideology. Patricia Deegan, for example, emphasises the importance of understanding recovery via the "lived experience" of people who have been through it. She sees it as a process emerging from within, rather than imposed by mental health professionals, its goal being to "meet the challenge of the disability and to re-establish a new and valued sense of integrity and purpose within and beyond the limits of the disability. The aspiration is to live, work and love in a community in which one makes a significant contribution."[6]

Recovery is not a one-dimensional process. William Anthony, in making the point that recovery does not necessarily mean being entirely symptom-free, comments that it "is a deeply personal, unique process of changing one's attitudes, values, feelings, goals, skills and/or roles. It is a way of living a satisfying, hopeful, and contributing life even with limitations caused by illness." To the person who has recovered, the illness is "no longer the primary focus of one's life".[7] The Mental Health Commission defines recovery even more broadly, as "living well in the presence or absence of illness."[8] To the mental health professional, recovery

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[2] For a wide selection of New Zealand and international studies on the recovery orientation in mental health, which substantiate the points made in this discussion, see Mental Health Commission. *Mental Health Recovery Competencies: Teaching Resource Kit* (Wellington: MHC, 2002).

[3] A good resource on the international recovery movement is L. C. Curtis, *New Directions: International Overview of Best Practices in Recovery and Rehabilitation Services for People with Serious Mental Illness* (Vermont: Center for Community Change, 1997). *Psychiatric Rehabilitation Journal* is a leading resource in this area.

[4] M. Balzer, B. Elliot & S. Price., "The living colours". 14th Australian Congress of Mental Health Nurses Conference (Sydney, 1988); M. Durie, *Mauri Ora: The Dynamics of Maori Health* (Melbourne: Oxford University Press, 2001); M. Jackson, "The mentally ill offender: A Maori perspective", *Community Mental Health in New Zealand*, 1988, 4(1), 45-51; R. Pere, *Te Wheke: Whaia te Maramatamga Me te Aroha* (Gisborne: Ako Global Publishers, 1991).

[5] The fonofale model is explained in Ch.3 of Mental Health Commission, *Pacific Mental Health Services and Workforce: Moving on the Blueprint* (Wellington: MHC, 2001).

[6] Cited in L. C. Curtis, *New Directions*, op. cit., p.13.

[7] W.A. Anthony, "Recovery from mental illness: The guiding vision of the mental health service system in the 1990s", *Psychosocial Rehabilitation Journal*, 1993, 16(4), 11-23), p.14.

[8] Mental Health Commission, *Blueprint for Mental Health Services in New Zealand: How Things Need to Be* (Wellington: MHC, 1998), p.1.

might mean absence of symptoms, whereas to the person with mental illness recovery might mean regaining one's life.

Using a narrative perspective, the metaphor of recovery as a journey is readily evoked. This journey metaphor has been widely used in writings on recovery, including in the Mental Health Commission's plan for the elimination of stigma and discrimination.[9] The term "pathways" is also frequently used in the recovery literature, which emphasises that the process is unique for each individual, as is their destination.

NARRATIVE PSYCHOLOGY: RESEARCHING EXPERIENCE THROUGH THE STORIES WE HEAR AND TELL

Stories are a fundamental way of understanding and communicating. When people converse, write, sing, chat on the phone and e-mail, they often tell stories about themselves and the people they know. The stories we hear and tell impose order and meaning on our lives, weaving the natural disorderliness of our experiences into a fabric of personalities and events which we arrange into time sequences.

This process of constructing stories out of our experience is part and parcel of everyday life. It includes "telling our day", gossiping, boasting, explaining ourselves, making humour out of ordinary events, entertaining an audience with our exploits, illustrating a point, telling how we solved a problem, moralising, seeking sympathy, and recounting the fortunes and misfortunes of others with disapproval or amazement and sometimes relish.

We often use the term "story" to mean something fictional or made-up, but in narrative psychology "story" means any account that has a narrative shape (that is, comprised of events ordered into a sequence over time). [10] Creating "made-up" stories is indeed at the heart of story-telling, myths, novels, films and television drama. Such fictional stories, to find an audience, must "ring true", bearing some relation to

human desires, experiences and emotions even if the events they narrate did not actually happen.

However, the stories we tell about ourselves, although we devise them in order to communicate meaning, do convey what happened, or at least, our perspective on what happened. Of course, people may lie, exaggerate, brag, indulge in fantasising or distortions to entertain us via their stories, but as an audience we have sophisticated ways of understanding the intentions of the communicator. Using "story" to describe one of the primary means of human communication should not imply that what is being described is fictional or untruthful. It does, however, indicate that communication about experiences is socially constructed through meaning-making processes.

CULTURAL STORIES

Culture has a powerful influence on the stories we tell. Stories about ourselves stem from personal experience, but we impose structures on them which we have learnt from all the stories we have heard. We order events into beginnings, middles and ends and we create characters – ourselves and others, heroes and villains. Our narrative accounts take dramatic shape around embarassments, conflicts, misfortunes, rivalries, dilemmas and coincidences, and our stories often fall into the genre of comedies or tragedies. We usually place ourselves as the hero, or chief character, in our stories and we often use stories to communicate a moral stance towards a person or event.

Most stories occurring as part of conversations are fragmentary rather than fully developed. Conversations are interactive and it is not seen as polite for one speaker to hold the floor for too long. In conversations, stories are often co-created rather than thought out beforehand or rehearsed. Telling our experiences to others helps shape them, incorporating feedback from others as well as our own structuring. Ultimately, the social story-telling we engage in shapes how we understand ourselves and the events in our lives. As much as we are shaped by culture, so too are our stories.

NARRATIVES IN PROFESSIONAL AND MENTAL HEALTH SETTINGS

Stories play a key role in our interactions with professionals and agencies. We narrate a series of events to a lawyer, we give a doctor an account of how our symptoms arose, and in order to obtain a welfare benefit, we are expected to tell stories about

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[9] Mental Health Commission, *A Travel Guide for People on the Journeys Towards Equality and Respect and Rights for People Who Experience Mental Illness*, (Wellington: MHC, n.d. [1998]. For an excellent guide to discrimination issues in mental health, see L. Sayce, *From Psychiatric Patient to Citizen: Overcoming Discrimination and Social Exclusion* (Basingstoke: Macmillan, 2000).

[10] Useful sources on narrative psychology include T.R. Sarbin (ed.), *Narrative Psychology:The Storied Nature of Human Conduct* (New York: Praeger, 1986); and M.L. Crossley, *Introducing Narrative Psychology: Self, Trauma and the Construction of Meaning* (Buckingham: Open University, 2000). The series of books edited by R. Josselson, A. Lieblich et. al, *The Narrative Study of Lives* (Newbury Park, CA.: Sage) is also useful.

events impacting on our health, family or employment situation. In mental health settings, the stories patients and family members tell about what has been happening are part of the process leading towards diagnosis and treatment.

Therapeutic story-telling is a special kind of narrating, distinctive to mental health settings. Psychotherapy and counselling rely on people's ability to relive their experiences emotionally as they talk about them. Therapeutic conversations provide a setting for the emergence of stories which we may not wish to tell elsewhere – stories of guilt, shame, loss, failure, disability, deep hurt, betrayal and abuse. A confessional mode of story-telling is at the heart of "talk" therapies.

The newly popular narrative therapies claim that people "story their lives", drawing on widely recognised cultural stories, embedding in them such themes as success and failure, strength and weakness, responsibility, personal dilemmas, mental illness and so on.[11] Narrative therapists tell us that people experiencing mental distress construct negative and self-limiting stories about themselves which have a powerful influence on their thoughts, feelings and actions. Therapeutic interventions guide clients towards creating more affirming, life-enhancing stories, allowing them to move forward and at the same time to resist cultural stories defining them negatively and restrictively (e.g., "I'm an alcoholic" or "I'm a failure").

As well as therapeutic story-telling, which takes place in the counselling room, there is another narrative form well known in mental health. This is the "case study", located at the conference or in professional books and journals. Although the patient or client is the focus of attention, it should be pointed out that their role is not as the central protagonist. In the case study, the client is not the one who makes things happen, in other words, is not the one with agency. The hero of case studies is the mental health professional who guides the patient towards recovery by providing therapeutic inter-ventions, whether medical or psychotherapeutic. We will return to this point throughout our study, because it forms a key difference between the stories we obtain in narrative research and the "case study" stories which predominate in the mental health literature.

WHOSE STORY IS IT?

Accounts of illness based on the experience of the sufferer have become a popular genre and are the stuff of memoirs, films, television dramas, documentaries and talk shows. They have become so common that they could be said to form part of a literary genre: the illness memoir.[12] This is not a new phenomenon, but the huge growth in interest recently suggests that there is a ready audience for "illness stories", in contrast to earlier times where suffering in silence was seen as appropriate.

Moreover, in societies where medicine dominates views of health and illness, sick people are not seen as having expertise – in other words, as saying anything worth listening to – on their illnesses. This has been especially the case in mental health. Traditionally, users of mental health services have been stigmatised, regarded as unreliable sources, and denied a voice in the literature of mental health.[13] Linking mental illness (or madness or lunacy) with unreason, excess, incapacity and unreliability are historically entrenched attitudes in Western societies. These attitudes sit alongside the growth of power and expertise in the medical and helping professions which have led to the denial of a voice for clients/consumers in treatments for both physical illness and mental illness.

Consumer movements in recent decades have helped the clients of mental health services to gain a public voice. Stories of confinement stimulated public outrage, and stories of suffering have elicited sympathy and understanding. Mental health organisations have encouraged the publication of accounts of mental ill health as part of public education campaigns to increase sympathy, decrease stigma and normalise mental illness. An increasing focus is on stories of recovery, for example, the New Zealand collection, *A Gift of Stories.*[14]

These accounts of illness, as told by those who have experienced it, redress a historical imbalance and allow the "heroic" role to be taken up by the person with

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[11] An excellent New Zealand text on narrative therapy is G. Monk, K. Crocket, D. Epston and J. Winslade (eds.), *Narrative Therapy in Practice: The Archaeology of Hope* (San Francisco: Jossey-Bass, 1997). See also A. Frank, *The Wounded Storyteller: Body, Illness and Ethics* (Chicago: University of Chicago Press, 1995).

[12] The most recent notable example is the Oscar-winning film, *A Beautiful Mind.* For an academic approach to autobiographical accounts of illness, see G. Thomas Couser, *Recovering Bodies: Illness, Disability and Life Writing* (Madison, WI.: University of Wisconsin Press, 1997).

[13] For a historical perspective on mental health memoirs, see R. Porter, *A Social History of Madness: Stories of the Insane* (London: Weidenfeld and Nicholson, 1987).

[14] J. Leibrich, *A Gift of Stories* (Dunedin: University of Otago Press/ Mental Health Commission, 1999). Another excellent anthology is J. Read and J. Reynolds (eds.), *Speaking Our Minds: An Anthology of Personal Experiences of Mental Distress and its Consequences* (London: Macmillan, 1996).

first-hand experience of mental illness, or tangata whaiora, as well as the professional.[15]

NARRATIVE METHODS IN THE HUMAN SCIENCES

Since stories are central to human thinking, it may seem surprising that they have been systematically neglected in the social and behavioural sciences. The scientific study of human behaviour has been characterised by an emphasis on objectivity, a distrust of experiential knowledge and the application of quantitative, experimental and observational methods. This approach has worked outstandingly well in the natural sciences, and this has been the justification for applying it to the study of human beings and their societies. By using this approach, over the last century a vast fund of knowledge about human behaviour and culture has developed. However, some social scientists have been concerned that the emphasis on empirical and objective methods seems to strip human behaviour of its meaning, agency, purpose and social context.

Structured interviews, questionnaires, surveys and other similar methods arising from objective traditions are frequently used techniques to explore how people think and feel. These techniques allow generalisations to be made about populations, yet they also detract from a full exploration of subjective experience. Large scale surveys ask everyone the same question and provide a limited range of responses for people to choose from, thus engaging with people's analytical rather than narrative modes of thinking. Although they are highly useful techniques, they share with experimental and observational studies the same tendency to undervalue meaning, purpose, agency and context, because they ignore narratives and their central importance in creating meaning and conveying experience.

Interpretive, phenomenological, experiential, psychoanalytic, discursive, humanistic, postmodernist, qualitative, hermeneutic and narrative – these are some of the technical terms which describe systematic and scholarly approaches to understanding people and cultures which emphasize the investigation of language and meaning, rather than quantifiable and observable behaviour. Although most are not new – and many such approaches have a more comfortable home in, for example, sociology and anthropology than in psychology – they are now gaining ground right across the human sciences. Increasingly, computerised techniques for qualitative data analysis come to their aid, allowing for highly systematic investigations of the complexity of subjectivities, including those expressed through personal narratives.

UNDERSTANDING ILLNESS STORIES

Recently there has been a surge of interest in narrative studies of illness in social science-oriented health research. Taking its place alongside related approaches such as phenomenological and discourse studies, narrative health research examines the language of illness and the meanings people make of their illness experiences in social and cultural context. Narrative studies usually involve the systematic collection, analysis and interpretation of illness stories, usually gathered by researchers through open-ended interview.[16]

Arthur Kleinman, a leading narrative health researcher from the United States, explains that narrative, in common with other social science approaches to health studies, understands illness as a human and social situation, and more than a disease or medical/biological event. Ill health, mental or physical, involves not only a disorder of body or mind, but is a troubling personal and social circumstance. Severe ill health and disability impacts on everyday life, one's sense of self, understanding of the world, relationships with others and pathways through life.

Moreover, the experience of ill health is not necessarily wholly negative in its impact. It is potentially transformative, and disabling illness can profoundly alter the ways in which people understand their lives. As Kleinman says, in coming face to face with disruption, disability and the possibility of death, people are forced "to reconsider our lives and our world. The possibility for human transformation ... sometimes begins with this disconcerting vision."[17]

Through telling stories of illness people give meaning to their experiences of suffering and dislocation. The process of making meaning can, in itself, have profound

[15] See Sue E. Estroff, "Whose story is it anyway? Authority, voice, and responsibility in narratives of chronic illness." In S. K. Toombs, D. Barnard and R.A. Carson (eds.), *Chronic Illness: From Experience to Policy* (Bloomington, IN.: Indiana University Press, 1995) for an astute discussion of "voice" in research documents.

[16] Two methodological resources are: E. G. Mishler, *Research Interviewing: Context and Narrative* (Cambridge, MA: Harvard University Press, 1987) and C. K. Riessman, *Narrative Analysis* (Newbury Park, CA., Sage, 1993).

[17] A. Kleinman, *The Illness Narratives: Suffering, Healing and the Human Condition* (New York: Basic Books, 1988), p. 55. Other useful resources for narrative and theoretically similar studies of illness include the journal, *Qualitative Health Research.*

effects on the course of illness, and Kleinman emphasises the healing power of stories and the therapeutic importance of health professionals bearing witness to people's stories of suffering. He argues that if health providers focus solely on the biological foundations of disease and neglect the role of meaning in the bodily and psychological experiences of illness and recovery, they may stimulate processes that are illness enhancing. Moreover, a biological focus neglects potentially restorative social and cultural resources available to people in their networks. Nowhere, perhaps, is this truth more apparent than in mental health, where the deleterious impacts of stigma, institutionalisation and physical treatments with profoundly incapacitating side effects have been well documented.

NARRATIVE RESEARCH ON RECOVERY

Narrative methods of investigation should be a very appropriate research tool to support the recovery vision in mental health, with its emphasis on incorporating the experience of service users/tangata whai ora. Yet as we have pointed out, most narrative health research still focuses on illness rather than recovery.

In the early days of conceptualising this project, we found encouragement from research conducted outside the field of mental health. In particular, Julie Leibrich's study of desistance from crime was inspirational because, as with our proposal, it examined a "problem" from the point of view of people who had surmounted it.[18] In contrast to most criminal research, which focuses on current offenders, Leibrich's research involved interviewing people with a criminal past, examining their journeys into "going straight." Although crime is a very different area from mental illness, the success of Leibrich's methodology gave us the confidence we needed to embark on a study of people who were once mentally unwell and were now recovered.

Another helpful line of research was the work of American psychologists Richard Tedeschi and Lawrence Calhoun, who have extensively researched transformative impacts in the life history of individuals who have experienced severe reversals of fortune through serious illness, bereavements, accidents and other trauma. The negative psychological consequences of such events have been well documented, but this research programme has been innovative in its focus on psychological growth in the aftermath of suffering.[19] Unfortunately, their research neglects the potentially transformative impact of experiences of mental ill health. These studies provided a justification for our decision to include a research focus on life after mental ill health.

As we have noted, our project began at a time when there were few other research studies using narrative approaches to mental health topics, but it has acquired some companions along the way. In particular, Catherine Garrett's Australian narrative study of recovery from anorexia is a thorough and imaginative investigation of recovery stories.[20] Other useful material from a narrative perspective includes Harvey's work on loss and Rappaport's on community narratives.[21] Moreover, some recent studies using thematic or statistical rather than narrative analyses come close to our research area, e.g. the U.K. Mental Health Foundation's research into "people's strategies for living with mental distress" and MIND's survey Roads to Recovery. [22]

In this section we have outlined the theoretical considerations and research perspectives that informed our research, particularly in its developmental stages. The next section of this chapter outlines the project's research methods.

THE MENTAL HEALTH NARRATIVES PROJECT

Project Funding

The project began with a seeding grant from the Health Research Council, followed by a full grant to the Principal Investigators, Hilary Lapsley and Linda Waimarie Nikora, which allowed the present study to begin in 1998, with the appointment of Rosanne Black as Project Researcher. The investigators were based in the Department of Women's Studies and the Maori and

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[18] *Straight to the Point: Angles on Giving Up Crime* (Dunedin: University of Otago Press, 1993).

[19] R.G. Tedeschi and L.G. Calhoun, *Trauma and Transformation: Growth in the Aftermath of Suffering* (Thousand Oaks, CA: Sage, 1995). See also G. Becker, *Disrupted Lives: How People Create Meaning in a Chaotic World* (Berkeley, CA.: University of California Press, 1997).

[20] C. Garrett, *Beyond Anorexia: Narrative, Spirituality and Recovery* (Cambridge: Cambridge University Press, 1998).

[21] J. H. Harvey, *Embracing Their Memory: Loss and the Social Psychology of Storytelling,* (Needham Heights, MA.: Allyn & Bacon, 1996); J. Rappaport, "Community narratives: Tales of terror and joy," *American Journal of Community Psychology,* 28(1), 2000, 1-24.

[22] Mental Health Foundation, *Strategies for Living: A Report of User-Led Research into People's Strategies for Living with Mental Distress* (London, MHF, 2000); MIND, *Roads to Recovery: How People with Mental Health Problems Recover and Find Ways of Coping* (London: MIND, 2000).

Psychology Research Unit of the Psychology Department, University of Waikato. The university provided administrative and academic resources, collegial support and additional funding for the study.

Consultation Processes

During the initial phases of the project, consultation was undertaken with mental health service users, providers and policy-makers, consultants, researchers and academics, and Maori communities. The purpose of consultation was to obtain feedback on the research design, to inform and consult with relevant communities about the proposed research, and to enlist their help in achieving an ethical, culturally safe and soundly based research process. The networking involved in consultation also fostered contacts with potential participants in the study.

Groups and organizations consulted included the Mental Health Commission, the Mental Health Foundation and the Health Research Council, as well as local and regional organizations including Lakeland Health, Midland Health, Hau Ora Waikato, Te Whanau Poutirirangi a Papa, Te Puni Kokiri in Hamilton, Centre 401, Pathways and New Progress Enterprises.

A community psychologist was contracted to carry out Maori consultation in Rotorua. This identified key people, introduced them to the proposal, obtained feedback on ethical and procedural aspects of the project and identified sources of participants and support.

Ethical Issues and Ethical Approval

Ethical issues identified as needing protocols included confidentiality, privacy and safety of participants, and culturally appropriate selection and interviewing procedures. The decisions we made around these issues are described in the section on Research Methods.

Ethical approval was obtained from the Human Research Ethics Committee of the University of Waikato and the Waikato Ethics Committee. The Bay of Plenty Ethics committee asked us to seek support for the project in their area from Te Whanau Poutirirangiora a Papa, an iwi health network. We met with them at one of their regular hui to discuss the project, and then approval for this region was also granted.

Research Methods

Interview development

A comprehensive set of interview questions was developed and piloted during the first few interviews. Building on this experience, a shorter interview guide was developed and used as the basis for all further interviews. Because the interviews were relatively unstructured, aiming to obtain a coherent narrative of mental ill health, recovery and life afterwards, interviewers were not required to follow a strict schedule of questions; rather, they needed to understand the aims of the project and be aware of themes that the researchers were particularly interested in, so that they could put questions around areas which had not been covered as the interviews progressed. Obtaining a good narrative flow was considered to be more important than ensuring that all 40 interviewees responded to each question on the schedule.

Interviewers

In addition to the Principal Investigators and the Project Researcher, we employed eight extra interviewers. This enabled us to provide participants with a choice of interviewer, particularly in relation to sex and ethnicity. Most, though not all, the extra interviewers were graduate students, mainly in psychology, and all of them had relevant prior experience, in community psychology, counselling, and mental health services. Some had experience of mental health problems themselves, and all, we felt, were people with whom others would be willing to share their life stories.

Interviewer Training

We ran an intensive three day training programme for our project interviewers. Topics for the training sessions included:

- a thorough explanation of the project, its theoretical orientation and research procedures;

- a profile of mental health problems in the New Zealand population;

- mapping our own experiences of mental health problems within our family and personal networks;

- exercises in interviewing skills with a counsellor;

- a presentation, with exercises, on cultural diversity in interviewing, focusing on the question "What are the qualities and behaviours we would like to have in a person who was going to interview us?";

- a discussion of consumer issues in mental health with an invited speaker;

- an in-depth examination of a videotaped pilot interview, with interviewer and interviewee present to answer questions about the process;

- practical and technical aspects of the interview process, including signing of consent forms, using the recording equipment, the interview schedule and debriefing;

- hands-on interviewing practice involving interviewing each other about a chosen topic.

The training session received highly positive evaluations from the interviewers and its in-depth nature enhanced team-building on the project.

Selecting Participants

Locating suitable participants: Forty participants were sought, ten in each of four pre-selected categories: Maori women, Maori men, non-Maori women and non-Maori men. Our initial selection criteria were that they needed to:

- once have suffered from a disabling mental health problem;

- consider that they now had recovered;

and they should

- not have made use of mental health services during the last two years;

- no longer be using psychiatric medication.

We also wanted to select for diversity, as well as filling our pre-arranged categories. In particular, we wanted to ensure that a range of mental health problems and illness experiences was included in the experiences of people who volunteered, and that people were varied across age, occupation, ethnicity (within the non-Maori group) and educational achievements. It was not possible to select systematically over these characteristics, given the size of the sample, but we did try to achieve variety. This meant that the selection process was easier in the earlier stages of the project and became more difficult in later selections as we tried to ensure diversity.

The strategies used to find participants were:

- "word of mouth": talking about the project to family, friends and colleagues recruited a number of participants;

- media publicity: following an article in the *Waikato Times,* around twenty people called the office;

- contacts through mental health health workers: this was a less effective strategy than we imagined, as it became clear that mental health workers usually lose contact with people who have recovered, unless they are in their family, friendship or workplace networks;

- consultation processes: these produced several volunteers.

It was easier to find women than men and initially easier to find non-Maori participants. Towards the end of the interviewing period we were turning down numbers of volunteers, but still searching for Maori men who met the criteria. At that point we employed one of the Maori interviewers to engage in further networking to find suitable participants, and this was a very successful strategy.

Pre-selection procedures: Potential participants were asked a number of pre-selection questions, usually by telephone, in order to determine whether they met the selection criteria, i.e. whether they qualified for the project, whether there were still places in the categories we were trying to fill and, as time went on, whether their characteristics enhanced diversity amongst our participants.

In most cases the pre-selection interviews were discussed by at least two of the researchers before selection was confirmed. Altogether around twenty people who volunteered to take part in the project either withdrew at the pre-selection stage or were not accepted to be interviewed. Turning down volunteers was the most awkward aspect of the selection procedure, as most were keen to be interviewed and disappointed to be told that there was not a place for them in the project. We made sure to carefully explain the project rationale and selection procedures to them and to indicate our appreciation of their willingness to be interviewed.

Controversy about selection procedures: While we were looking for participants, a controversy arose in the local mental health community about our selection criteria. This was the result of our declining to interview certain volunteers who did not meet the criteria we had set. In most cases this was because they still made use of psychiatric medication and were therefore still in contact with the mental health system, even though they had otherwise made a good recovery and had overcome the disruption that mental ill health had made in their lives.

Some service users and health workers charged that we had defined recovery in a narrow manner and that

our declining to interview people who saw themselves as recovered might operate as a restigmatizing process. Our project title "Success Stories" seemed to enhance this perception, because it is a highly attractive self-description. It was suggested that people who were not chosen as a "success story" might then see themselves as a failure. In putting a different perspective on recovery, the analogy was made that someone who had a mental health problem but who now lives normally with the help of medication is akin to a person with diabetes who does not experience limitations from the illness as long as they take insulin. The Mental Health Commission's definition of recovery, "living well in the presence or absence of illness", also supported that perspective.

We were initially taken aback at the controversy, because no such problems had emerged in our widespread consultation and very positive comments had been made, especially from Maori communities, about our project title, "Success Stories." We were reluctant to change the criteria because one of the innovative aspects of the research was that we wanted to interview people whose experience of mental ill health had occurred some time in the past, and who would be able to reflect back on this experience and its impact on their life during illness, recovery and afterwards. We did not ever see the project as focusing on current service users/tangata whaiora, although we saw this group as an important part of the consultation process.

Moreover, we did not consider it a local project, although we were required to obtain ethical approval from local health ethics committees. Even though most of our participants would be local, for reasons of convenience, we knew that often their experiences of mental ill health would have taken place elsewhere.

Confirming our initial research decisions, some of our early interviewees indicated that recovery may occur over a very long period of time and that, as one participant put it, one may learn very little during an initial episode of mental ill health about preventing further episodes. We were committed to interviewing people who had years of experience of dealing with ups and downs and had recovered, not in the sense that they felt invulnerable to mental ill health, but that they no longer saw themselves as likely to be disabled by it in the way that they had been formerly.

This controversy caused us considerable concern. We took care to develop an ongoing relationship with consumer representatives and to explain ourselves at a meeting of mental health sector representatives and

in a project newsletter. Most especially, we did not want anyone who did not meet our criteria to think of themselves as a failure, so we had thoughtful discussions about how best to explain our rationale for turning down volunteers. Moreover, we did relax the selection criteria so that the project does contain interviews with several people who still use psychiatric medication regularly or occasionally, but whose experience of disabling illness was quite some time in the past and who had overcome its disruption to their lives. In the end, the project contained seven participants who made continuing or occasional use of medication, but they emphasised that it was very much their decision.

The controversy involved a learning process for us. We learned more about public relations, about the power of psychiatric stigma, and about the aspirations of those who are currently in contact with mental health services. We also came to realize just how highly charged the term "recovery" is in mental health circles.

We learned about the importance to service users and providers of local mental health research. We found that the mental health community's perception of research derives from their understanding of quantitative methodologies, so we needed to explain very carefully how our project involved selection for diversity, not random sampling. Also, it became clear that there is a strong need for our community to hear the "success stories" of those who live rich and satisfying lives, despite an ongoing mental health problem – but that would be another project.

The Interviews

Once a person agreed to take part, the interview process and interviewer options were discussed with them. Project information and consent forms were posted out for them to consider, and then the selected interviewer was given their details so that interview arrangements could be made.

Maori consultation had established that it was appropriate for interviewers of Maori participants to be Maori (although we found that in several cases, Maori participants expressed a preference for one of our non-Maori interviewers); and that individual rather than group interviews would be preferred, although individuals could have a support person present. Interviews, it was advised, could take place at homes or community centres.

Also, all of the women participants were interviewed by women, though the men were interviewed by either men or women, depending on their preference.

At the beginning of interviews, the interviewer went through the information and consent forms and checked whether the person had any questions or issues around who might hear or see the material, how it would be archived and how long interview materials would be kept for. Some of the interviews were to be transcribed by University Secretarial Services staff; if this was likely to be the case, interviewees were informed and asked if they agreed. This was also mentioned as a possibility on the consent form. Once consent forms were signed, the interview could begin.

Interviews were carried out in a number of different settings, including people's homes, workplaces or the researcher's office. Some took place in Dunedin, Wellington and Auckland, but for the most part they were carried out in the Hamilton, Rotorua and Bay of Plenty areas.

Of the 41 interviews that took place, 34 were audiotape recorded, with a pilot interview being videotaped as well. During the later phases of the project, when it was proving especially difficult to obtain interviews with Maori men, it was found that some were willing to participate if not tape recorded. Accordingly, several interviews were conducted with the interviewer taking notes on her laptop computer.

We budgeted for counselling should anyone become distressed as a result of the interview, but no one requested this. Early in the process it was decided that it would be better to contact people after the interviews, as a matter of procedure, instead of telling them to contact us if they were distressed. (All in all, the Project Researcher had an average of around eight contacts with each interviewee over the course of the project, with the exception of most of the Maori men, who were located and interviewed by one of the Maori interviewers.)

Although no one wanted counselling as a result of the interview, quite a few told us that they found it unsettling or at least thought-provoking. Distress was sometimes obvious at particular times during the interview, but everyone who was distressed wanted to continue. We mostly had very positive feedback about the interviews from participants. In fact, interviewers were often quite moved and sometimes a little shaken after interviews, owing to the impact of hearing stories which incorporated loss, trauma and sadness. The Project Researcher played a debriefing role for interviewees and interviewers.

Interviewers or Secretarial Services (University of Waikato) transcribed their interviews and saved them on disk; the Project Researcher then stored them on her computer. Audiotapes, disks and hard copies were stored in a locked filing cabinet, along with signed consent forms and notes from the pre-selection stage.

Transcripts were returned to the interviewees, unless they expressly stated that they did not wish to see a transcript. There was a copy for them to keep and one for them to return with any alterations or additions.

Pseudonyms were given to participants, after consulting with them about what name they would like to be called by. Some participants were happy to use their own name, but it was decided that all names used would be pseudonyms.

Only one participant withdrew after completion of the interview, since he decided that he still had some way to go towards recovery.

Participant Characteristics

The final number of useable interviews was 40, as planned, with groups nearly even in size: 11 Maori women, 10 Maori men, 10 non-Maori women and 9 non-Maori men. Of the non-Maori women, one saw herself as part-Maori, one was from the Pacific and another woman told us that her mother, but not her father, was a Pacific Islander. All the non-Maori men were of European descent. All Maori were born in New Zealand. Of the non-Maori, one was born and raised in the Pacific, two in the United States, two in England and one in Australia.

Data on other characteristics of the participants was not gathered as systematically as it would have been with a structured questionnaire. However, we have information on age, occupation and family status from nearly all participants; where this information was not recorded, it was often clarified in the text of the interview. Ages ranged from 26 to 66, with most being in their 30s and 40s. Twenty-nine of the 40 were in paid work, five were students, two were homeworkers and two were retired. Only two were unemployed, meaning that our group had a lower level of unemployment than the New Zealand population as a whole. There was a wide range of occupations, including professional (psychologist, nurse, academic, student support), sales personnel, real estate agent, manager, builder and seasonal worker. Where the group differed from the population as a whole was that far more of them worked in helping occupations, particularly in mental health, as nurses, psychologists, consumer advocates and staff of voluntary organisations.

Twenty-nine currently had a partner and sixteen were single. At least 27 participants had children.

The mental health conditions experienced and the treatments received will be detailed in the appropriate chapters. The most common diagnoses given at some stage to participants were depression, followed by schizophrenia and related disorders. There were also participants diagnosed with bipolar disorders, anxiety disorders, anorexia, personality disorder and alcohol and drug dependence. We have not presented these in tabular form, as it will become apparent from later discussion that often conditions were not easy to categorise accurately. Participants received a variety of diagnoses, and some rejected diagnostic labels as inappropriate descriptions of their experiences. What is important to note here is that the mental health experiences were all self-defined as disabling, and the severity of disability varied quite widely. Some lost years of their life to mental ill health and most were unable to work or carry out expected duties during their periods of ill health. Around two thirds had spent time in hospital, with most of the others receiving treatment in community settings; in contrast, a few had received no treatment for their disorder during the period that it was disabling. Three, all non-Maori women, had some or most of their experiences of mental health interventions outside New Zealand.

Data Analysis and Theory Development

Firstly, tapes were transcribed (some running as long as 40 pages of text) and checked, then prepared for importation into NUD*IST (Non-numerical unstructured data indexing), our qualitative data analysis software package. Next, each transcript was printed out with line numbering and we were ready to begin the initial processes of analysis. After most of the interviews had been completed, we organised a feedback and analysis session with the interviewers. We asked each of them to present a short summary of the participants' stories from the interviews they had carried out, including a suitable title, a brief description of the person, and the story of their mental health problem and recovery. After hearing the stories, we brainstormed in order to generate questions and categories for analysis.

This procedure stimulated the researchers to develop categories that would reflect the common sequence of events we heard from the stories. We had organised the interviews around a simple sequence of three stages: problem, recovery and life after. Our new categories described eight stages: origins, onset, the experience of mental ill health, consequences, three stages of

recovery and life afterwards. These formed the basis of our initial coding of all interview content in the software programme, a procedure which was very time-consuming but well worthwhile. One of the great strengths of our software programme was that it allowed the same piece of text to be coded under more than one heading. For example, a participant might refer to a childhood event, which would be coded under "origins", but the same text might also involve reference to a recovery process which involved coming to terms with that event, so it could also be coded under one of the recovery stages.

These eight stages have proved robust, and form the basis of the organisation of this report. They also allowed us to develop our "pink pages", brief written notes attached to the front of the interviews which refer to key events or themes in each stage, and provide an outline of the participant's story. The "pink pages" proved handy when we wanted to look at the whole context of a sequence of text that we were examining.

Once the initial coding had been done, work proceeded on coding of sub-categories for each stage. Whereas the eight categories formed a narrative sequence, coding within each stage was thematic. For example, within the "consequences" stage, categories and subcategories were developed around consequences for career, for family (subcategories were children, partners, family of origin, etc.), for economic status, etc. Basically, a sub-category would be developed whenever there was too much material in a category for it to be described easily. Altogether, we used around 150 categories, and many chunks of text were coded under a number of different categories. However, the categories were not developed all at once; rather, they were interwoven with the analysis and writing process. NUD*IST software allows for the integration of data analysis and report-writing. Over the long period of analysing and writing up results, coding was a time-consuming but once again rewarding element.

The usual approach when beginning to analyse one of the "stages" was to read over all the material pertaining to that stage, develop initial categories, and begin coding. As coding proceeded, categories could be changed, refined or amalgamated, an easy process using our software. The software also allowed for "memos" to be written and attached to each category. These memos (usually summarising all the "mini-stories" to be found in a category) assisted the draft writing process.

We became aware that carrying out our data analysis using NUD*ST meant that the project was proceeding

considerably more slowly than if we had been using conventional methods of analysis such as coding by marker pen, or cut and paste. However, we stayed with our process, even though it meant that the project went considerably over time, because the benefits of working this way were so great. It meant that the data was systematically and reliably organised, could be shared amongst the researchers, could be readily checked, and could be re-analysed and theorised. For example, a Maori graduate student did the initial coding of the data on "cultural contributors to Maori recovery" from Maori participants.

The quality of the analysis, we felt, was far higher than if more "hit and miss" approaches had been used, as it was relatively straightforward to prepare a highly accurate description of the text in each category. Moreover, having the data in such an organised form will make it easier to do further analysis of data for other papers which will be prepared from the project.

Overall, we were very pleased with the interviews we carried out and with the systems we used for coding and analysing data, although our attention to detail meant that the project ran considerably over time. However, these processes did mean a very satisfying research journey.

PART**one**

Journeys Into Mental Ill Health

Journeys Into Mental Ill Health

The *experience* of mental ill health plays a central role in autobiographical narratives written by or recorded from people who have suffered from mental health problems. They are usually motivated to tell these stories, painful as they are, to make sense of their own experience and to improve public understanding of the plight of people with mental illness.

Given that the focus of our particular research project is on *recovery* from mental ill health, we were reluctant to allow the "mental illness story" to dominate the interview time. We pressed people to cover the territory of mental ill health – background, onset, experience and consequences – within the first half of the interview, so as to allow sufficient time for their stories of recovery. Yet their stories of ill health provided a rich resource, making it clear that we needed to understand the illness stories fully before we could analyse the themes in the recovery stories.

To understand the illness stories, we found it useful to ask the following question: *What was it that people with a mental health problem needed to recover from?* This overriding question informed our description, in the following chapters, of the stories of mental ill health told by our participants.

The journey into mental ill health divides into four stages, each with its characteristic "plot":

- Firstly, the origins of the mental health problem in earlier experience:

  "There was always something the matter, but I managed to get on with my life."

  (Only a minority of participants had felt comfortable about themselves before the mental health problem arose.)

- Secondly, the onset of the mental health problem:

  "I found myself in a difficult situation, something very stressful occurred and I just could not cope any more."

- Thirdly, the experience of mental ill health, including encounters with mental health services:

  "The mental health problem took over my life."

- Fourthly, the consequences of mental ill health:

  "Its consequences were highly disruptive."

The next three chapters portray stages of the journey into mental ill health. Then come two chapters outlining diagnosis, treatment and consequences of mental ill health, followed by a concluding section.

CHAPTER | **one**

Origins of the Mental Health Problem in the Past

For most participants, aspects of the past contributed to the mental health problems they experienced as adults. A few described family *legacies,* but most references were to circumstances or events from *childhood* or *adolescence* which they associated with their later mental ill health.

LEGACIES

Given that all those we interviewed considered themselves recovered, it is not surprising that few participants made references to their experiences of mental ill health as being genetically determined. One who did emphasize genetics was *Denis,* who saw his tendency towards mood disorder as inherited, and as no different from a physical condition such as diabetes. Having learnt to stabilize his moods with the help of lithium, he is now able to lead a normal life.[1]

Several referred to historical or family troubles which had set them up for later mental ill health, even before they were born.

Frank's father, traumatised by his war experiences, was unable to tolerate family life. The atmosphere in *Jane's* family was heavy with secrecy about incest in her mother's generation. *Jack* had tried to make a living on land that had been cursed; and *Rawiri* came into the world with "a lot of illness about me, physically, mentally and spiritually".

CHILDHOOD

Many people told us about childhood contributors to mental ill health, but not all of them came from unhappy or troubled families. For some who lived in happy families, traumatising events, such as *Kim's* sexual abuse by a babysitter and *James'* humiliation by his teacher, were seen as the instigators. Three participants said that being over-protected by their parents caused difficulties later on.

Altogether, just under half of the participants (17) spoke of troubled family life, marked by abuse, parental separation or bereavement. For the others, family background was presented as ordinary (12) or happy (7). Three participants made no reference to their childhood. There were no clear differences between Maori and non-Maori participants in accounts of childhood; however, women were more likely than men to see childhood circumstances as contributing to later mental ill health.

The three major themes identified as childhood contributors to later mental health problems were:

- *abuse* (physical and/or sexual, mainly within the family, but also at school)
- *loss and abandonment* (mainly in relation to parents, due to separation or death, lack of parental warmth, or feeling abandoned)
- *feeling different*(especially in relation to other children, because of factors such as illness, disability, sexuality, educational failure or ethnicity).

Abuse

Abuse was mentioned in the narratives of close to half of the participants. Eleven women and seven men told us about abuse during childhood.[2] A third described physical abuse and a third sexual abuse; many experienced both physical and sexual abuse. Nearly half the women (nine) recounted sexual abuse, compared with three of the men. There were no significant numerical differences between Maori and non-Maori participants.

[1] As we noted in the introductory chapter, several participants continued to use psychiatric medication.

[2] Participants were free to tell their mental health story as they chose. Stories of abuse were volunteered, rather than involving responses to direct questions.

Some of those abused in childhood described further abuse during adulthood. A few, mainly men, reported that they themselves had been abusive as adults.

Among those who spoke of abuse, some did not elaborate, but many gave graphic descriptions. In the worst cases, abuse was repetitive, covered the spectrum of physical, sexual and emotional abuse, and occurred in the context of an unhappy and disrupted family environment. Some participants witnessed their mothers and/or other family members being abused. For others, abuse (usually sexual abuse) was perpetrated by one particular person, mostly a known family member or friend, in the context of a more secure family environment.

Abuse within the family

Nine of our 40 participants referred to abusive fathers or stepfathers, including four whose fathers/stepfathers perpetrated sexual abuse. These people had particularly grim memories of growing up:

> "I still see him today pounding my mother, my mother lying on top of me protecting me from the hidings he would give me. He hit me so hard one time he drove my head right through the wall." *(Tua)*

> "[After she had told her mother about her father raping her] I could hear her sobbing by the fireplace, filling up the water and lighting the fire and she's just sobbing, and I thought, 'I've made my Mum cry, I've hurt my Mum' ... I heard her and Dad argue, fight over me ... I just decided not ever to talk to my Mum again.'" (*Ataimihia,* who described the rapes as continuing throughout her childhood)

> "My father said that one good bash like that would make me into a man and I would never, ever want to be a sissy any more after he had finished with me." (*Tom,* gang-raped by his father and mates for dressing in his sister's clothes)

> " ... I would be lying on the bed and I would hear yelling, shouting, bashing of things and voices and thuds and mother would come tearing into the bedroom and slam the door and he would be bashing on the other side and screaming and then he would disappear." (*Frank,* whose father twice put his mother in hospital from beatings)

Physical abuse or punishment from mothers was mentioned by a few, though these stories were not of horrific abuse. In some stories perpetrators were other family members. *Pare* told us about abuse from an older brother, which made it even more difficult for her to

deal with the rape which made her pregnant as a young woman. *Tua,* as a young teenager, was seduced by an auntie, which left him feeling used and affected his attitudes to women.

Some participants who referred to repetitive abuse in childhood did not name the perpetrator, but indicated that it occurred in a family context. *Cathy,* who contacted us after the interview had taken place specifically to tell us about abuse, said: "I really believe that it was because of my childhood and the abuse, verbal, emotional and sexual abuse that I suffered, that made me what I am today."

Abuse at school

Five participants mentioned being bullied at school (with *Alan* describing his school environment as a "reign of terror"). *Tua* was beaten for speaking Maori and *James'* humiliation by a teacher for writing sexual words provoked a lasting sense of shame and wrongdoing which developed into a mental health problem. For *Tasimauri,* the schoolmaster's house, where she was sent after her mother died, was a place of abuse and neglect.

Abuse from outsiders

Several women referred to abuse during childhood or adolescence from non-family members. An abusive babysitter, *Kim* told us, "affected all my relationships with guys and hindered forming healthy wholesome relationships". Two women had experienced violent sexual attacks, *Huia* at age 12, and *Amy* at 16.

Loss, Abandonment and Lack of Love

Themes of loss and abandonment figured in many of our childhood narratives, especially in relation to parents. Events which shaped the childhood landscape included loss of a parent through death or separation. Pervasive feelings included being unloved, unprotected and emotionally abandoned.

Two participants spoke about the death of their mothers. *Tasimauri* explained the impact on her:

> "I felt unique and I felt treasured [and] when my mother died I lost all of that, because there was nobody to sustain that for me."

Several participants, all Maori, referred to the death of grandparents as a severe loss.

Maternal separation made a deep impact on *Joan* and *Mako,* whose mothers, suffering from mental health problems, were not able to act as caregivers. Mako

also experienced stigma on account of her "mad" mother wandering about in the local community.

Frank's father as well as his mother had mental health problems. His father was mostly absent and was abusive when he was around; his mother was hospitalised for depression from time to time, when Frank would be sent to foster homes, health camps or to his grand-parents.

Children whose fathers left home usually grieved for them, even if they had been abusive. *Huia,* as a pre-schooler, became ill when her father left, and *Liz* told us that throughout her life, "I had a major problem with why my father didn't love me." *Johnny,* on the other hand, told us that though his father left when he was a child, this did *not* contribute to his later drinking problem.

Some children felt abandoned even in the presence of their parents, especially those whose mothers had failed to protect them from abuse by fathers or stepfathers – such betrayals were deeply felt. Several others felt unloved and emotionally abandoned by their mothers.

Protectors

Having someone special, a bright light or protector, can increase resilience in the face of ill-treatment or misfortune. Mothers figured in the narratives of childhood as the most loved figures, but overall, stories of childhood contributors to mental ill health often featured parents causing harm rather than fostering resilience.[3]

Another bright light, the kuia/grandmother, featured in some narratives of childhood (five altogether, all Maori) as a source of warmth, protectiveness, wisdom and uncomplicated love. Other elders who had the potential to protect – older siblings, teachers, aunts and uncles – were scarcely mentioned in the narratives.

Tangi/funerals and the opportunity to grieve

Liz and *Ataimihia* (both Maori) experienced severe grief reactions after being kept from attending a grandparent's tangi. *Sylvia* (Pakeha) at age 11 was kept away from her mother's funeral because she was thought too young for the distressing event; she said she was years into adulthood before she could properly grieve. *Mako's* experience was different. She had hardly

known her "mad" mother, yet she was summoned to the tangi, told to sit next to her mother's body and pay her respects. After she had "fulfilled her cultural obligations", she was sent back to her adoptive parents (matua whangai), feeling the rejection from her biological family deeply. She developed "a massively muddled view of who I was and where I belonged".

Feeling Different

Childhood illnesses and disabilities, along with disfigurements and other personal oddities, feature surprisingly prominently in accounts of childhood contributors to mental health problems. These afflictions, such as a heart problem, epilepsy, lameness, asthma and speech impediments, caused isolation and feelings of being different from other children, as well as leading to being treated differently. Even apparently minor afflictions could have a big impact: *Mary* dated the beginnings of her depression, a time when she began to feel cut off from the world, to wearing glasses from the age of 11.

For several children, disabilities led to over-protectiveness from parents. However, in *Jen's* case her partial deafness probably arose, she thought, from her stepfather hitting her; he also told her she was unattractive compared with her sisters.

For others, mental health symptoms led to being treated differently. *Hare* made the mistake of revealing to his family that he heard voices; they thought he was "porangi" and sent him away to live with relatives. *Lee's* family thought she was strange, too, because of her "black moods" which lasted for days. The most horrific experience of difference was told to us by *Tom,* who loved dressing in women's clothes and was punished in a horrifying way, which has already been mentioned.

Feeling different also came about from educational underachievement, although not all of the eleven participants who said they did badly at school considered this relevant to their later mental health problem. Racism also led to experiences of feeling different at school – for *Huia,* living in a largely Pakeha rural community, and *Tua,* beaten at school for speaking Maori.

Overall, stories about "being different" involved feeling ashamed and inadequate with one's peers and sometimes being teased or bullied by them. The earlier themes of abuse and loss were also marked by shame, feeling different, and feeling negatively valued or picked on, usually by family rather than peers. "Feeling different" when young uncannily echoed the stigma of

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[3] This may have arisen from the narrative structure of the stories, which focus on accounting for the later mental health problem. The childhood stories contrast with stories of recovery in adulthood where, as we shall see, parents often played an important role. However, those parents were not usually the ones who had caused childhood harm.

ADOLESCENCE

In presenting material on abuse, loss and feeling different, we included data from adolescence, as well as childhood. When abuse or trauma was experienced in adolescence, some of the consequences were different. When *Amy* was violently raped by a man she met when she was out drinking without her parents' knowledge, she described that evening as "the end of my childhood".

In troubled family situations, adolescents moved to leave behind the dependencies of childhood. Recklessness and risk-taking was a theme in some of the narratives around adolescence. Though such behaviour helped to relieve a difficult or abusive family situation, it was not always seen as contributing to the later mental health problem. However, drug-taking and heavy drinking, later contributing to mental ill health, were patterns established early in adolescence by some.

Huia was admitted to hospital with alcohol poisoning at the age of 13. *Frank* began his career as a drug addict by raiding his mother's medicine cabinet and then went on to burgle chemist shops, develop a drug addiction and eventually serve a term of imprisonment.

Recklessness was one way of responding to troubling problems, but lack of confidence, especially around sexuality and friendships, and a struggle for identity were equally strong themes in narratives of adolescence.

SYMPTOMS OF MENTAL ILL HEALTH IN CHILDHOOD AND ADOLESCENCE

Many participants experienced symptoms of mental ill health during childhood, although others did not. It was not unusual, though, as the previous material shows, for later mental health problems to be linked with earlier childhood and adolescent situations. Where there were these links, those who experienced difficult and unhappy feelings or manifested troublesome behaviour were not usually labelled as suffering from mental ill health until a crisis occurred in adulthood.

Some indicators of stress have been mentioned already in the accounts of childhood illness, disability and difference. Stuttering, hearing voices, manifesting tics and experiencing black moods may have elicited concern from parents, but were seldom dealt with. Only two participants mentioned being given professional mental health assistance: *Frank,* who was told during the 1950s that he had an inferiority complex, and *Liz,* who was sent to a psychiatrist after the death of her grandfather. More often, mental health symptoms during childhood and adolescence accentuated feelings of difference and sometimes led to scapegoating. Experiences such as dissociation or depression were not necessarily noticed by others. Substance abuse, developing in later childhood or adolescence, was sometimes noticed, though none mentioned effective responses to their behaviour.

Suicidal impulses and actions during childhood or adolescence were mentioned by several participants. *Ataimihia,* aged only six, lay down at the edge of the water after being abused, wanting the tide to take her away. *Frank* said that from the age of five or so, he was:

> "just so lonely, so much pain inside ... I couldn't see any point in living, I had no hope and I was suicidal even before I was at an age to comprehend being able to kill myself."

CONCLUSIONS

This chapter highlights the fact that for many participants "there was always something the matter", in terms of their mental health. Only a few attributed later mental ill health to genetic predisposition, whereas many pointed to events or circumstances during childhood and adolescence, particularly abuse, loss and feelings of difference. Quite a number of participants manifested some symptoms of mental ill health during childhood, but these were seldom investigated.

The Onset of the Mental Health Problem

Stories about the onset of a mental health problem usually spoke of stressful circumstances becoming increasingly hard to bear. During this time it was common for a critical incident to occur, acting as the last straw and precipitating a mental health crisis. The shape of "onset stories" was: "I found myself in a difficult situation, something very stressful occurred and I just could not cope any more."

Those participants who had experienced difficult and disrupted childhoods – "there was always something the matter" – had entered adult life ill-equipped to make good choices around relationships and careers. Some, mostly those with backgrounds of severe abuse, got into lifestyles involving excessive alcohol use, illegal drugs, gangs or prostitution, and these lifestyles exacerbated their psychological problems. Others did their best to put together an ordinary life, but were haunted by underlying unhappiness.

Of those who had normal or happy childhoods, some, as adults, found themselves in situations where they could not maintain mental health, such as living with an abusive partner. For others, the requirements of growing up or coping with a severe disruption later in life led to the onset of mental health problems.

In this chapter we look firstly at accounts of *stressors* present at the onset of mental ill health, which nearly all participants mentioned. This is followed by an analysis of *"critical incident"* stories, that is, accounts of dramatic events which either precipitated a mental health crisis or made it very clear that a crisis was building up. Around half the narratives describe a critical incident. Most accounts refer to the first occasion of mental ill health, though some refer to later occasions.

STRESSORS

The *breakdown of a partner relationship* was mentioned by nearly a third of participants, usually involving rejection by a partner. For several this came out of the blue after a long marriage, while for others the painful rejection occurred in a teenage or young adult relationship. *Frank's* rejection was perhaps the most forceful – his wife stabbed him in the chest with a kitchen knife. In nearly half the breakups, a particularly wounding aspect was infidelity on the part of the partner. For several of the women, the relationship ended because of violence from their male partners.

A quarter of participants described *lack of supportive social networks* as a stressor. For some this occurred because they had moved away from familiar places. *Kim,* as a mother of young children, shifted with her husband many miles away from her home town. For others, such as *Tom* and *Matua,* it was not so much geographical distance that was hard to handle, as alienation or pressure from family/whanau.

Other stressors, mentioned by between three and six participants, were:

Stressful work circumstances: Four referred to high stress work situations; for two others, isolating work was the problem. As an example of the latter theme, *Jen* found that working in a darkroom in the X-ray department of a hospital made it more difficult for her to keep away intrusive thoughts.

Bereavement: The deaths of kuia, a boyfriend, a sister and best friend, and a horse were mentioned as precipitating breakdowns.

Unemployment or financial troubles: Four participants had such problems, two as a result of business failure and two from unemployment.

Physical health problems: Four participants referred to physical injuries or illnesses as implicated in their mental health problems. Being unable to work or participate

socially seemed to be the problem, rather than the actual experiences of ill health.

Sexual identity issues: Three of the five participants in the project who identified as lesbian or gay – *Mako, Tom* and *Lee* – were stressed by sexual identity issues at the time their mental ill health problems reached crisis point.

Poor relationships with father: *Joan,* who had not felt loved by her father, was very stressed by his long illness from a wasting disease. *John,* whose father was a bully, became depressed while working on the farm with him after leaving school. *Tom's* father, as we mention later in this chapter, utterly humiliated him in front of his whanau.

Educational stress: Feeling alone or alienated at school or university was mentioned by two. *Denis'* first episode of mental ill health began when he froze during a University Entrance exam and was unable to complete it.

Other categories of stress, receiving one or two mentions, were: *unwelcome pregnancy with pressure to adopt,* or *being pressured into abortion; failure to find a boyfriend; stress within an ongoing relationship* (perhaps surprisingly, this hardly figured at all, compared with relationship breakdown); and the *stress of caring for children* (but it is interesting to note that although many mothers referred to difficulties in looking after children while they were unwell, only a couple of them regarded the stress of caring for babies or young children as in itself a major factor in becoming unwell.)

Looking over the circumstances which were mentioned as stressful, the central themes were:

- *isolation, loneliness and lack of support* (from wider social networks, after partnership breakdown, or because of illness and unemployment);

- *loss* (partnership breakdown, loss of family support, bereavement, loss of job, loss of health);

- *identity conflicts* (including sexual identity, work identity, transition to adulthood);

- and, less frequently, *responsibilities which were too demanding* (at work, parenting).

CRITICAL INCIDENTS

Although some participants described their mental health problem as developing gradually against a background of stressful circumstances, many could point to an upsetting event which served as a "last straw". For some it was an incident, such as a suicide attempt, which made it clear to themselves (and others) that they were in crisis. The critical incident often precipitated hospitalisation.

Stressors and *critical incidents,* in the way we have categorised them, overlap occasionally; so the analysis of critical incidents that follows has been organised around their psychological impact, rather than the actual sources of stress.

Shame, Humiliation, and Sense of Failure

The most frequently described critical incidents were those that provoked a devastating sense of shame, humiliation or failure, which then triggered the mental health problem. One such was described by *Tom,* whose father, along with his mates, had raped him. As an adult, Tom had cut off from his family and was going off the rails. Despite his respectable day job, he was working at night as a prostitute, using drugs heavily and sometimes beating up his male clients. Hostile to men and unresolved about his own homosexuality, when his beloved kuia died he tanked himself up with drugs and went home to the tangi. As he told it:

> "I looked down at my kuia and I was too far gone to even cry. My sister said that I just stood there like a dummy, staring at our kuia, asking her to take me with her. I just wanted her to take the pain away and the hurts, to forget them ... It was the poroporoaki and my dad more or less trashed me in front of the whole hapu and whanau. From there I just went straight downhill. I didn't belong anywhere, not with my whanau, hapu and my kuia had gone, so there was really no reason to live ... After the tangi and the last bit of dirt had been shovelled over my kuia I went back to [the city] and just went crazy."

Similarly, *Hare's* kuia died and everything went wrong for him. He took to selling drugs, and the voices that had been with him since childhood became more troublesome. When someone accused him of killing her brother, who had died of a drug overdose, he "lost it":

"Everything just went black and next thing I'm tripping out in the psych ward."

Partner breakups could provoke shame and humiliation, as well as a cocktail of grief, jealousy and anger. This is described by *Edward,* whose wife told him she was having a relationship with his brother, and to make matters worse, that his brother was really the father of their young son. When Edward talked to his parents about it, they sided with his brother, always his mother's favourite:

"I looked at my parents and I thought, fuck the lot of you. My boy was asleep at the time, so I kissed him and said it was just too much and left."

He no longer turned up to his job, started drinking and taking drugs "big time" and did virtually nothing else but sleep, the beginning of a "real deep daze" which lasted for two years.

Other humiliating incidents which triggered mental ill health included freezing in an exam and botching a first sexual encounter.

Reactivating Earlier Trauma

James, who had been shamed in the classroom over sexual matters, had that trauma reactivated when his wife told him of her earlier sexual experiences. When *Amy* had to put down her horse, intrusive memories of her rape nine years earlier, at the age of 16, were revived. *Liz* found she could not form relationships with men after her ex-boyfriend broke in and raped her; the mistrust she later experienced at the possibility of a relationship developing led to a state of tension that became a mental health problem.

Tom, Steve and *Ataimihia* all had histories of childhood abuse which played a role in critical incidents. Tom's shaming at the tangi has already been mentioned. *Steve* confided in an "auntie"; when she tried to draw him into a sexual relationship, as a previous auntie had done, his reaction was that he was just a "fucking machine" and that idea fed into a developing mental health crisis. Ataimihia tried to "cross the river to rejoin her Nan" after being raped in an attack by several men.

Physical Health Crises

Cathy stopped taking psychiatric medication and became unwell. On the other hand, *Lee* was given a high dose of steroids after a really bad asthma attack; she "just flipped" and found herself in the secure unit at Lake Alice. *Pare's* breakdown occurred soon after the birth of her baby. She was on "a high", couldn't sleep and wanted to spend every moment with the baby. Not getting on with her husband made things worse, and when his relatives came to stay, she was so busy looking after everyone that she could not catch up on sleep. The physical depletion, she felt, led to her breakdown.

Lack of Control Over One's Life

Mary was having problems with depression when she became pregnant unexpectedly. Her husband and a doctor arranged an abortion for her and she felt she had no say at all. This tipped her over the edge into an incapacitating depression. Some of the other incidents, such as those involving partners' leaving, also fostered a feeling of not being able to control the important things in one's life.

Suicide Ideation and Attempts

Fourteen participants described suicidal behaviour at the onset of their mental health problem (altogether, 27 participants discussed issues around suicide at some point in their interviews). Suicidal ideation or attempts were expressions of internal crisis and alerted the person themself, and often other people, to the severity of the problem. It was at this point that distress was often identified as a mental health problem.

It has sometimes been suggested that suicide attempts are a "cry for help". However, for our participants they signified deep emotional wounding and/or depression and despair. Rather than manipulating someone else into providing help, the incidents sometimes led participants to seek help. For example, *Katie* felt desperate after her husband left her. Driving her car to the top of a steep hill, she thought about letting off the brakes. But her children depended on her and she felt her husband would have "won" if she killed herself, so she drove back to town and went immediately to the doctor's. Likewise, *Liz* went to a counsellor when she was tempted to run her car into a power pole, and *Joan,* finding herself "standing on a London underground wanting to throw myself under a train", immediately went and told her nursing supervisors.

For some, suicide attempts brought attention from health professionals. *Jen* and *Susan,* as young women, took overdoses and were hospitalised. Both found it difficult to say exactly why they overdosed (Susan referred to suicide as "romantic", "dramatic" and "bohemian"). *Jen* resisted offers of help and concentrated on getting out of hospital, whereas *Susan* sought out treatment for "neurosis". Others who made

suicide attempts (e.g., *Annie, Ataimihia* and *Huia*) found themselves admitted to a psychiatric facility as a consequence of their behaviour.

This chapter has described the themes that emerged in an analysis of stressors and critical incidents, which were involved in the onset of mental ill health.

Being Mentally Unwell

Having a mental health problem involves experiencing symptoms of mental ill health and, usually, encounters with the health system, whether it be primary health care or specialised mental health services, for diagnosis and treatment.

The characteristic "story" for this phase of the journey was: "The mental health problem took over my life." Since there was so much interview material describing this part of the journey, we divide our coverage of it into two chapters. The first focuses on the experience of being mentally unwell, and the second on health care.

GENERAL DESCRIPTIONS

Language used around mental health is often negative and disparaging, so it was interesting to note the words participants used to described their own experiences. General descriptions of mental ill health were identified in thirty transcripts and fell into the following categories:

Illness: often expressed in terms of improvement or deterioration, such as unwell, getting better, getting worse, deteriorated, "something majorly wrong" and "problems".

Suffering: as in "emotional affliction", "nightmare", "ugly", "a big black hole", "shattering".

Not managing everyday life any longer: the most common phrase used was "not coping"; a similar one was "not functioning". Not managing was seen as arising from emotional states which could not be mastered, whether they involved excessive expression of emotions, e.g. "crying all the time", or depressed mood, which meant that the person could not summon up the motivation to carry out normal daily activities.

A milder term, used as a signpost on the road towards not managing, was "stressed". For more serious instances of not managing, the terms "breakdown" or "nervous breakdown" were also used. Phrases which evoked more dramatic or sudden "not managing," that is, everything coming to a halt, included "collapsed", "burnt out", "completely cracked up".

Madness: Some terms summoned up strange states of mind and out of control behaviour, as in conventional understandings of mental illness. Quite a few terms were slangy, though hardly anyone described themselves as "loony" or "mad". "Nuts", however, was used by one or two; other terms which cropped up in the interviews once or twice were "funny", "feral", "off", "screwed up", "going a little insane", "a madness", "fucked in the head" and "off my head".

Personal identity and awareness supplanted by strange and alienated states of mind: Many suggested a loss of personal identity to the point of unknowingness, using terms such as "gone", "lost it", "scattered", "dislocation", "out of it", "real deep daze", "blurb time", "blank in my mind", "consumes you", "oblivion"; or a strange and alienated state of mind, such as "spaced out", "a zombie", "tripping out". One phrase used by several, which suggested the chasm between normal life and becoming mentally unwell, was "lost the plot". Less evocative was the phrase "went into a state". Some phrases emphasised a lack of control, as in "losing it", "flipped" and "totally lost the plot".

The sheer awfulness of the experience of mental ill health was striking in participants' accounts. It involved distressing symptoms, acute emotional pain, terror and loneliness. Moreover, for most people it involved a considerable variety of dysfunctions, including problems with sleep, mood, appetite, thoughts, feelings about the self, feelings about others, optimism, physical health, experience of one's body and more.

These wide-ranging impacts are often overlooked in the way society understands mental health problems, probably as a result of the specific labels we use, such as eating disorder, mood disorder, depression, and psychosis. Labels such as these tend to bring to mind specific symptoms and lead us to ignore facets of mental ill health not associated with the label.

SYMPTOMS OF MENTAL ILL HEALTH

In the rest of this chapter we try to convey the wide-ranging nature of the disturbances people experienced as a result of their mental health problems.[1]

Thoughts of suicide and/or suicide attempts:Two-thirds of participants referred to suicidal thoughts and wishes, arising from desperation about situations that seemed painful and insoluble (including despair about getting good mental health care). Attitudes included: "life is just absolute crap" (*Liz*), not being able to cope any more, losing hope, or "having nothing to live for" (*Pare*). Over a quarter mentioned making suicide attempts and others described resisting the wish to take their own life.

Ataimihia had a different perspective, telling us that "I didn't see it as despair when I did it [jumped out of a building]...It was Nan, let me come across the river."

Depression:This state of mind, with its accompanying feelings of sadness, emotional pain, hopelessness, and lack of energy, was mentioned by more than half of the participants. They used terms such as "badly depressed", "deep sorrow, soul destroying sorrow" and "clinical depression". People referred to not being able to get out of bed, "nothing mattered", "numbness", being a "zombie", as well as "real, deep emotional hurt", anguish, being in a "black hole" and crying a lot.

Disordered sleep patterns:More than half the participants also mentioned these. For some, particularly those who had experienced bipolar disorders, going for several days without sleep, accompanied by hyper-activity, was a feature of the early stage of an episode of mental ill health. For others, difficulties in sleeping were a long term problem. Those who *could* sleep for long periods, sometimes with artificial assistance, prescribed or otherwise, found it a refuge, and some described staying in bed for much of the day over a period of weeks or months. Dreams and nightmares were seldom mentioned, although *Hare* resisted sleeping because the voices that plagued him were worse at night.

More than a third of participants mentioned the following symptoms as part of, or accompanying, their mental health problem:

Anger and aggression:" Irritable and ugly and snappy" and "angry, uptight and agitated" were how two participants described their state of mind. Around a third spoke of aggressive feelings, volunteering that at times they had wanted to engage in violence, though most did not act on their thoughts. Aggressive behaviour was, on occasions, part of the constellation of events leading to hospitalisation (as in "losing it"). For a few, mainly men with abusive fathers, violence was not so much part of the experience of mental ill health; instead, it was an aspect of a lifestyle they had taken up, involving drinking, drugs and crime.

Anxiety, panic and phobias: Some spoke of being plagued by anxiety, "nerves," tension, fear, inability to relax, being "uptight" and agitation. Severe anxiety, panic attacks and agoraphobia featured in several accounts.

Alcohol and substance abuse: This was an issue for quite a few participants, but was usually seen as separate from the mental health problem, though arising from the same underlying psychological pain ("anaesthetising" and "self-medicating" were practices one man referred to in relation to his use of illicit drugs). Two participants had been admitted to hospital in drug-induced states of mental ill health, and it seems likely that for some others, substance abuse worsened the mental health problem.

Negative or disordered feelings about oneself:Poor self-esteem, lack of confidence, being disgusted with oneself, comparing oneself unfavourably to others and blaming oneself – such feelings were often reported. Some felt their whole identity and self-knowledge were in question and reported "putting on an act" to pass as normal to others. The most disturbing feelings around self involved disruptions right at the heart of who one is. *Mako* had developed "all these invented people who would go out and take care of things". Under the stress of an unexpected pregnancy, she no longer "had any grip of my various realities. They were everywhere. I could not cast my net and hook them all back in."

Loneliness and social withdrawal:Loneliness and self-preoccupation were mentioned by a number of participants. "It was like being in a place all by myself. Everything was going on around me, but I wasn't part of it" (Fiona). Some actively sought silence or solitude, including two men who became what they described as "hermits", and a survivor of sexual abuse who was hospitalised and spent years of her life in silence.

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[1] A reminder here is important: this study did not use questionnaires. People were free to describe their mental ill health as they wished and the amount of detail given varied from one participant to the next. If a "checklist" approach had been used, the numbers acknowledging each specific symptom would almost certainly have been higher.

Perceptual disturbances, including voice-hearing: Ten participants referred to voice-hearing. For some it was unusual, happening only during a period of severe distress; others were more familiar with the phenomenon, but found that it intensified as their mental health deteriorated. Several Maori participants mentioned conversations with a kuia who had passed on; hearing her speak words of comfort or advice from beyond the grave did not trouble them and was not seen as an aspect of mental ill health. Hallucinatory images were mentioned by several, but less frequently than voice-hearing. *Lee,* with psychoses induced by asthma medication, had "… the full range [of hallucinations], auditory, visual, tactile, taste, everything, so my world was a shambles." Other perceptual disturbances included trance, and depression so deep that the sufferer was oblivious to the outside world.

Cognitive disturbances, including irrational thoughts: Strange and obsessional beliefs were mentioned by a few who experienced them at the height of mental ill health. These beliefs were mostly centred around religion or politics, like *Tasimauri* who had "delusions of grandeur". Others were bothered by "stupid thoughts," such as worrying that they were being watched. Other impacts of mental ill health on cognitive functioning included confusion, disorientation, problems with racing thoughts ("my mind would not shut off... it went tick, tick, tick all the time", as someone put it) and inability to concentrate enough to do even ordinary household tasks. Memory problems were mentioned by several in relation to the events immediately preceding, or in the early period of hospitalisation, though, in contrast, one person said that she remembered the traumatic events around hospitalisation in heightened detail.

Disturbing behaviour: Some told us of incidents of behaviour that, to an outsider, would seem irrational. To the participants themselves, looking back, their behaviour seemed foolish or shameful, though they usually understood what had motivated them at the time. Some odd behaviour felt obsessional to participants, such as *Jen's* constantly taking baths and *Mako's* peeping in windows to view domestic scenes; whereas other behaviour was just odd, like *Jen's* enjoyable conversations with the fridge. Behaviour during psychosis could be extremely upsetting, even frightening, such as *Jack's* big spending spree and *Cathy's* trance-like state which led to her frightening the children in her care, and assaulting one of them.

Low energy and lack of motivation: For the most part, those who described this type of problem saw themselves as having been depressed. Fatigue was mentioned, and lack of motivation could involve not looking after themselves, not eating properly, not getting up in the morning and not getting dressed.

Around a quarter of participants mentioned the following aspects as part of, or accompanying, their mental health problem:

Manic states/overwhelming restlessness: Unpleasantly high energy levels, manifesting themselves in constant restlessness, or at their peak, in a manic state; these were distressing experiences involving unremitting tension and nerviness, not sleeping or eating, having racing thoughts, not being able to sit still, pacing up and down, or talking non-stop. About half of those who referred to hyperactivity saw themselves as having had a bipolar disorder. Several participants mentioned how disturbing it was to have mood swings, from manic states through to intense depression.

Eating problems: Undereating was not uncommon, and often associated with hyperactivity, though for some it was linked with depression. For *Tasimauri,* fasting to perfection was part of her obsessional religious thinking. *Hirini* suffered from anorexia, which involved induced vomiting and taking "benzos" to suppress appetite. *Kim* and *Ataimihia* mentioned overeating, Kim taking "solace" in food and Ataimihia hoping to make herself unattractive to men.

Unusual bodily experiences, physical sensitivities and illnesses: For quite a few, the mental health problem had bodily effects, mostly unique to each person. Mentions were made of stammering, shaking, and "robotic movements"; Georgie had to be helped with walking when she was at her worst. One felt her head expanding, another her arms expanding and Bruce thought he was losing his sight. Hirini experienced the distorted body perceptions often associated with anorexia. Several others experienced all sorts of physical discomforts and minor ailments.

PERSONAL REACTIONS TO THE EXPERIENCE OF MENTAL ILL HEALTH

Mental ill health experiences, with all their disruptions to normal states of mind, body and well-being, had a strong impact on people. Fear was the predominant reaction, and lacking an understanding of the problem added to this fear. As *Denis* put it:

> "I just wasn't coping, you know, with normal things and the more I couldn't cope with normal things, the more I got frightened. Because I did not understand what was going on."

Not knowing how long these distressing states would continue was itself distressing, and for those who were troubled by suicidal thoughts, the lack of a time perspective made matters worse. Fear of "going crazy" was also a concern for some, with "crazy" representing a frightening, out of control and possibly permanent state even worse than the one being experienced.

Others were puzzled: "This isn't me," as *Amy* put it. Confusion was another common reaction, especially for those who experienced more intensely unusual states of mind, such as psychoses.

"I was so totally confused about everything that went on, I mean, I didn't know what was happening to me, I was in shock." (Cathy)

In the next chapter we continue our account of the "mental illness" stage of the journey, moving from this description of the experience of ill health to an examination of stories of encounters with health services.

Mental Health Interventions

In this chapter we deal firstly with accounts of being diagnosed with mental illness, and then with accounts of mental health treatment.

Our participants, who, it will be remembered, were chosen on the basis of having recovered from disabling mental health problems, nearly all experienced mental health interventions. One might think that since participants had recovered, their mental health treatments must have been effective. This is far from the case. Disturbingly, many stories describe damaging aspects of mental health treatment. When diagnosis and treatment was experienced as unhelpful, the recovery process involved recovering from mental health treatment itself.

Negativity was far from the universal theme in accounts of diagnosis and treatment, although it was surprisingly pervasive, especially in accounts of hospitalisation. Of course health care does not need to be enjoyable to be effective. But illness is a social and not just a physical experience, and becoming ill inevitably puts the sufferer into health care situations that may introduce new stresses and add to the burden of recovery.

On the other hand, there were also many accounts of sympathetic and effective interventions, where the sufferer was introduced to environments and treatments which gave respite from problems, promoted recovery or were even life-saving.

The relationship of mental health treatments to recovery is explored in Part Two of this report. In this chapter the focus is on describing, from participants' narratives, the experience of encounters with mental health care and treatment.

DIAGNOSIS

In the previous chapter we examined the ways in which people experienced being mentally unwell. We highlighted the language they used to describe their experiences and the fear, lack of understanding and confusion around what was happening to them.

Developing insight into what was going on would, one might have thought, be a central theme in accounts of psychiatric diagnosis. However, accounts emphasising gaining understanding were overshadowed by accounts revealing how diagnostic processes were intertwined with hospitalisation, medication, labelling and stigma.

Reactions to Diagnosis

Being diagnosed with a mental health problem produced a variety of reactions in people, including relief, outrage, shame, despair, fatalism and bemusement. Perhaps the most uncomfortable aspect of diagnosis was when a prognosis was included in the information given to the person – notably, when a prediction was made that the disorder would be lifelong.

Accepting Mental Health Labels

All our participants saw themselves as troubled and all reported symptoms of mental ill health. Not quite all saw themselves as having had a mental health problem, even though this self-description was a criterion for participation in the study. As it turned out, several participants, mostly Maori, believed that the terminology of mental ill health should not have been applied to them and were suspicious of any kind of diagnostic labelling. *Hare* referred to his disorder as "mate Maori"; *Rawiri,* a mental health worker, preferred to understand his troubled times in a holistic way; and *Ataimihia* explained her behaviour, which involved years of silence in hospital, as a strategy she had devised for dealing with the overwhelming psychic pain resulting from her abuse as a child. *James,* a Pakeha man, told us that mental illness is a myth.

Multiple Diagnoses

For some of the others, diagnosis was problematic, particularly for those who had been hospitalised a number of times and received a multitude of diagnoses. *Matua* was asked if anyone had told him what was wrong with him, and replied:

> "Oh yeah, manic depressive, bipolar, paranoid schizie or, like that, if they didn't know what was wrong with me they would make up one. No honest, that's what I actually think of the system, they don't know what's wrong with you, they'll make up a name."

Lee had received many diagnoses, but eventually was satisfied with an explanation that made sense – steroid-induced psychosis (as a result of medication for her chronic asthma) combined with post-traumatic stress disorder (following on from childhood sexual abuse). She once asked to see her hospital records and recorded the nine different diagnoses given to her during her career as a psychiatric patient. She brought the list along to the interview and after saying, "I thought this was really funny," read them out:

> "Chronic depressive state, major depressive illness, depressive illness secondary to corticosteroid therapy, chronic hallucinations, psychotic illness non-specific, paranoid schizophrenia, borderline personality disorder, post-traumatic stress disorder, and multiple personality."

"So you can take your pick," she concluded.

Schizophrenia

Every single one of the ten participants who told us they had been labelled schizophrenic believed that their diagnosis was incorrect. Schizophrenia is linked, not entirely accurately, with chronicity and the spectre of deterioration. Our interviewees had contradicted that prognosis by recovering, despite psychotic symptoms. Initial reactions to a diagnosis of schizophrenia included "doom," "hopelessness" and "nowhere to go". It was a stigmatising, even punitive label. *Alan* said, jokingly, "One time I went in depressed and came out with schizophrenia. I was looking for a diagnosis that would give meaning and a way out, but there was not much hope with schizophrenia at that time."

Kim told us said that the psychiatrist told her the reason he knew she was schizophrenic was "because I wasn't happy about taking medication". And in an unusual diagnostic move, *Annie* was told that if she stayed with her violent husband, her schizophrenia-like disorder would keep recurring and worsen.

Tasimauri, one of the few in the study still receiving help from mental health services, told us that she had rejected the label of schizophrenia for social reasons, as well as believing it to be inaccurate:

> "If people ask me why I'm not working [in my professional career] ... I just explain that I had a nervous breakdown and I usually say bi-polar ... .[I]f I said paranoid schizophrenic, they'd be scared immediately, think I have a gun hiding somewhere and I'm going to shoot them or something ... "

Bipolar Disorders

For other participants, diagnosis was helpful, or at least made sense – and so it could facilitate appropriate recovery strategies. A diagnosis of bipolar disorder (known as manic depression in the accounts of people diagnosed some time ago) was more likely to be accepted than schizophrenia, although still rejected by some. A downside, however, was that those who received this diagnosis were told that they would never be well and would always have to rely on medication.

Cathy, Denis and *David,* all diagnosed as having a bipolar disorder, were amongst the few participants in this study still using medication. Cathy had found it difficult to accept the advice that she would need drug treatment for the rest of her life, but with an experience of hospitalization after not taking her medication, she changed her view. David felt that because he was not diagnosed with bipolar early on, he had picked up additional problems, in the form of anxiety and panic disorders "along the way".

Denis, undergoing a second breakdown in his 20s, recalls asking a psychiatrist why he was unable to stop crying:

> "I was sane enough to understand what he was telling me ... about affective bipolar disorder and manic depression and once I had an understanding that it wasn't ... totally emotional weakness, my self-esteem started to come up."

However, *Jack* was told by his doctor that he had manic depression: "That's not a label that I really think is me, you know". *Ataimihia* said "I got myself into deep depression, manic depressive, that kind of shit and I know it wasn't."

Depression

Depression was the most common diagnostic category referred to by our participants. For around one-third it was the name which had been given to their disorder. For many others, depression was a prominent feature of a disorder with a different label. Participants who described their disorder as depression usually felt comfortable with the label, and this term was preferred by several others who did not agree with the diagnoses they had been given. It was seen as a less stigmatising, more accurate description of emotional pain, and offered more chance of recovery. However, it should be noted that depression, as described by our participants, was mostly very severe; for around two-thirds it involved hospitalisation, and at its worst was accompanied by psychotic features.

One who was unsure whether the term "depression" really applied to her was *Susan,* who received voluntary inpatient treatment for depression and "neurosis" (in the days when psychotherapeutic wards were more in vogue). She felt that it was more accurate to say that she was unhappy and having some problems in growing up (she had made a suicide attempt). As she put it, "Depressed is quite a safe word, isn't it? Depression covers a multitude of stuff."

Other Diagnostic Categories

For participants placed in other categories, the diagnosis was often relatively unproblematic. *Hirini* suffered from anorexia, *Tom* had a personality disorder, and *Tua* had a drug-induced psychosis. *Amy* accepted that she was suffering from post-traumatic stress syndrome, though she was angered at the suggestion that she would never be well again.

Mako played up to her diagnosis, schizoid, which she was given during a period when she was young, suicidal and distraught: "[It] fitted into my self-image at the time, very neatly. It gave me a huge buzz – I know it sounds stupid." The label described her at the time, since "each day [the psychologist] saw me there was a different person sitting in her office." She laughed at this, but said that no diagnosis really fitted her; she described herself as "off," with no way of understanding what was the matter. Treatment given on the basis of her diagnosis was, she found, culturally inappropriate and no help at all.

Some self-diagnosed, for example *Sylvia,* a graduate psychology student, who did not receive treatment for her agoraphobia. *Bruce,* a psychiatric nurse, diagnosed

his own anxiety disorder, though he did organize treatment. *Johnny,* reluctant to label himself as an alcoholic, instead thought he drank too much, and recovered without treatment.

Jen speculated: "It would have been much easier if I had a diagnosis, eh? You know, if I went to the doctor's and he said you're a schizophrenic or a manic depressive or whatever they do – they change the names of everything." However, her conclusion was that it's "good just being nuts."

One odd situation was that of the person who was hospitalized and diagnosed *after* he was well on the way to recovery. *Steve* had taken off into the bush for several years in order to cope with overwhelming emotional pain; when he emerged, unused to society, his relatives were concerned about him and he agreed to a hospital admission in order to please them. He was diagnosed with agoraphobia and social isolation.

As some of these stories demonstrate, finding out what was the matter could be a task fraught with difficulties.

TREATMENT

In this section we do not analyse all accounts of treatment, since some of these accounts more appropriately form part of recovery stories, explored in Part Two of this report. The focus here is on how interventions helped to shape the *experience* of mental ill health, with a particular focus on hospitalisation.[1]

We begin by looking at accounts of General Practitioner visits, usually the first port of call in distress. Next, we look at hospitalisation – the most dramatic of interventions – experienced by 28 of our 40 participants. Then we look at treatment in community mental health settings, and finally, at those who received no treatment.

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[1] It must be remembered that the purpose of our study was not to evaluate the effectiveness of mental health services or treatments (which often took place quite some time in the past), but to portray the experience of illness, recovery and life after mental ill health. For this section, it is beyond our scope to analyse all accounts of non-hospital treatments. Hospitalisation had the most profound impact amongst those who experienced it and tended to be the focus of those narratives, even when people had received forms of community treatment, especially via community mental health or GPs. The recovery chapters later in this report return to accounts of treatment, looking at the ways in which therapies, medication and supportive professionals assisted recovery, as well as examining how some interventions acted as barriers to recovery.

General Practitioners

Sometimes people went to General Practitioners (GPs) on their own initiative; others went at the behest of family members. GPs made initial diagnoses, prescribed medications and acted as gatekeepers, arranging hospitalisation or recommending other treatments.

A good relationship with GPs or other primary health professionals was an important factor in recovery for some, as Part Two shows. It is interesting that there were virtually no complaints about GP interventions from the participants. Unlike hospital and community mental health services, contacts with GPs did not lead to people feeling powerless, trapped or deprived of their rights.

Not everyone made matters easy for their GP. *Jen,* who did not want anyone to think she was mad, told her doctor that she suffered from headaches. He did not challenge her story, but the medication he prescribed, she believes, was for anxiety. Nevertheless, she didn't take it because she didn't have headaches!

The most substantial issue relating to GP contacts was around medication and side effects. Some found that prescribed medications improved or stabilised them. There could be difficulties, though, in finding appropriate medication, managing side effects, managing drug interactions and withdrawal strategies. People who had mood swings seemed to find getting the right medication particularly difficult, though they often reported benefits.

Some seemed particularly sensitive to medication and found the side-effects "compounded the problem". *Kim* could not cope with the "terrible grogginess" and uncoordinated motor activities that had her eyes rolling around in their sockets when she was trying to drive the car. Later, she was to choke on her tongue after an injection from a district nurse and nearly die. Once a competitive squash player, she became unable to hit a ball.

For *Katie,* medication helped at first and then started to get in the way of recovery; being "levelled off", as she put it, could get in the way of addressing underlying problems. In a couple of instances, unwanted medication was sold on. Others, like *Huia,* found it addictive. It was also used in suicide attempts; for example, *Frank* said he was too depressed to take his anti-depressants so he took them all at once.

Hospitalisation

Being hospitalised

Most participants gave indications as to how often they had been admitted to hospital and the length of time spent there. Four groups of more or less equal size emerged from these accounts. The group with the most lengthy experiences of hospitalisation had each spent at least several years, in some cases up to a decade, in and out of hospital. The second group experienced several admissions and would each have spent considerably more than six months in total in hospital. A third group mainly had shorter hospitalisations, on two or three occasions, totalling several months in all. And lastly, another group had only one hospitalisation, with durations ranging from a couple of weeks to a few months.

Around half of those hospitalised told us they were voluntary patients; around a quarter told us that they had been committed; and a further group did not emphasize their legal status, but referred to their mental condition as the reason for their hospitalisation. Some readmissions were voluntary and some participants were repeatedly "sectioned in".

A number sought out hospitalisation because of fears about their state of mind or that they might commit suicide. With others, voluntary status was something of a myth, because it resulted from relatives applying pressure – as *Matua* said, "I would do anything to please my Mum and my Dad" – and in some cases arranging admission. *Alan* drove himself to hospital, accompanied by his wife, who was separating from him. He wanted to drive so that "I would still have some sort of dignity". With part of his mind, he thought it might be an adventure, an illusion that was soon dispelled. It was not uncommon to pick up from the accounts a sense of passivity and inevitability about hospital admission, whether or not it was voluntary.

A few had very little recall for that period of time, e.g. *Hare* said, "everything just went black and next thing I'm tripping out in the psych ward". On the other hand, *Annie* remembered it all in heightened detail, including being strait-jacketed at her home and put in an ambulance.

Overall attitudes to hospital

The most common experience of hospitalisation, reported by around half of the participants in the whole study, was highly negative. For them, hospital was seen as unpleasant, often unwanted and could work against recovery. Their conclusions included sentiments such

as "incredibly devastating" and "a real bad trip". Those who spent considerable periods of time in hospital had particularly unpleasant memories.

A further small group experienced hospitalisation as unpleasant, but nevertheless felt that they had received the care they needed.

Around a third of those who spent time in hospital, mostly those who had experienced relatively short stays, had more positive experiences. They emphasised safety, not having to meet other people's expectations and sometimes enjoying the company of other patients; in other words, they experienced hospital as a refuge. Those who were positive had usually been in a specialised group therapy ward detached from the main hospital, a kaupapa Maori unit, or a psychiatric unit attached to a general as opposed to a psychiatric hospital.

In terms of their time in hospital, one frequent theme was of having little memory or awareness, especially of the early days, because of a distressed state of mind or high levels of medication. Quite a few reported sleeping a lot, others just being in a blank state. *Hirini* said he "walked around like a drongo" for two or three years, and *Ataimihia* veiled herself with silence. One or two complained about boredom, though *Amy* found it hard to get enough rest.

Daily life

The daily routines were unappealing to most, with the occasional exceptions such as *Susan* who was one of the "elite", having been in a special villa for "neurotic" patients on the grounds of a large hospital; however, she did find her first day at the hospital, on the admissions ward, terrifying. *Denis* emphasised the ordinariness of life on the psychiatric ward of a general hospital, and said his visitors were surprised at how normal everything seemed.

Given the daily contacts, surprisingly few reported friendship with other patients, though in a couple of instances, the camaraderie of others helped with recovery. These stories are told later.

Feeling controlled or being bullied was the fate of some. *Matua* told us that even the prisoners who had tried to get out of jail and onto a psychiatric ward usually only lasted a couple of weeks, because of the terrible conditions there.

Confinement

Everyone who spoke of locked rooms and isolation – a common part of the hospital experience – made it clear that this was a fearful aspect. *Lee,* spending two months in seclusion and not even allowed into the games room, was grateful that nurses sometimes put their jobs on the line to take her for a walk. *James* was often put into confinement, with only a mattress on the floor. There he suffered from "dreadful torture of the mind", and though staff would sit with him, "they could not understand the concentrated torture".

Annie's story was the most vivid account of confinement, experienced in another country. She was in a completely bare room, with grey walls and a metal door with a frosted glass window. Her glasses had been removed and she often could not tell if it was night or day. In this situation she experienced "regressive" behaviour, exposing herself and urinating in the drain that went through the middle of the cell.

Matua, who could respond aggressively when goaded, saw seclusion as a racist practice, saying:

> "It takes Maori twice, at least twice, three times, four times as long to get out than it does Pakeha ... Stuff like that just sucks ... Because, to me, we've just got too much spirit, which is not a bad thing, it's just that they don't acknowledge it."

Tua was the only one who found lockup in any way helpful. For him, it was a salutary lesson about where he did not want to be:

> "I remember looking outside and seeing the fence, even the rooms next door, they all had bars on them. There were people inside them and they were looking out at me and they were rocking back and forth in the windows and I was thinking, 'Shit, what the hell have you done?' Ah yeah, and I really worked hard in there [on detoxifying]."

Treatments received in hospital

In the accounts, treatment in hospital consisted mostly of drugs. Some mentioned ECT and a few referred to group sessions on the ward. It seems that there were usually few opportunities for individual therapeutic sessions.

Narratives concerning drug therapies in hospital were far more negative than accounts of drugs prescribed by GPs. The most frequent themes were lack of choice, high doses and side effects. People spoke of being incapacitated by drugs, using terms such as "zonked out", "drugged up" and "doped up"; *James* said that

"they gave me enough drugs to kill a horse." *Lee* said that she was given extra drugs to counter side effects: "They had me on just about every medication there was."

Medication was seen by *Matua* as a form of behaviour control:

> "I was on eight or nine pills three times a day ... there was a point where I couldn't stand up, you know, that's how they wanted me to be. Just floppy, couldn't talk."

and by *Hirini* as a form of neglect:

> "The psychs are saying to you, 'How are you feeling today?' You know that they don't give a shit, just pop the meds into you and you'll be fine. It don't work like that."

Annie felt even more isolated as a result of drugs. She said:

> "I do tend to communicate with people about my feelings and about my view of things and I expect them to talk back to me. I think the loss of all that created a very great alienation in me, and this was exacerbated by the medicine that they poured down me in the hospital."

She also said that the drugs meant that she had a hard time separating dreams from what was going on around her. *Jane* became forgetful and apathetic, "walking around like a zombie". Bodily effects were also mentioned, in particular, distressing and strange body movements, putting on weight and becoming unfit because of a lack of incentive to exercise.

One or two reported being taken off drugs when they were admitted, e.g. *Denis,* who "literally went cold turkey" from prescription medications.

However, some had welcomed the opportunity to sleep or calm down, aided by medication. *Amy* said she hadn't been able to sleep for a year, but with a week of sedation she slept 14 hours a day; and *Cathy* said she was "stabilised on medication". *Jack,* who had resisted hospitalisation, said he:

> " ... went crazy at the hospital and next bloody thing I'm drugged up on this sedative, Mogadon or something, and just always asleep. Didn't really want to wake up 'coz I was in debt big time."

Seven participants mentioned having received ECT and most reactions were negative. *Matua* saw himself as a guinea pig; shock treatment "blew me away and from there I just wasn't recovering". *Kim* found shock treatment "devastating" and it "never did any good for me whatsoever". For *Ataimihia,* "I lost the memory track of numbers rather than the memory of why I was there." *Mary* had had over two hundred shock treatments for depression. Only *Denis* was positive about ECT, saying that "there is a lot of hoo-ha about it ... but it did the trick for me".

Therapy and professional encounters in hospital

Several mentioned group therapy in the ward; two who were in a special "neurosis" unit found this, along with the ward activities, helpful, as did several who had been in a unit run in a kaupapa Maori way, or those who had a kai awhina who visited to run groups. Those who were in general wards had nothing positive to say about talk therapies. *Hirini* said:

> "And I hated those therapy sessions. Took me back to that movie, you know, with Jack Nicholson, bloody sitting in a circle saying how we feel each day and sharing your story with people who are just, well, not there, some of them, others don't have the choice ... there's this expectation that just because you've nutted you've all got things in common. What it did, well, for me it sort of sent me more and more back into myself."

Talk therapy with health professionals seems to have almost never been available in the hospital setting. Though there were several positive mentions of a particular nurse, psychologist or psychiatrist, it was unclear from accounts how systematic and available these therapies were. There were sometimes comments on the absence of these approaches which could have been helpful.

In general, stories about encounters with health professionals in hospital were mixed, with the negatives outweighing the positives. Stories about professionals who were seen as very special and who assisted in recovery feature in the next chapter. Those who had negative experiences included *Matua,* who said that he was never able to communicate when he was taken to see a psychiatrist:

> " ... because they would bring in Germans, Indians and Japanese and ... you can hardly understand them when they question. And you say 'Uhh!' and to them that's a negative, so they put a cross by your ... and when you ask, 'What's that for?', they say 'Oh, you're over-reacting' or 'You're getting violent.' I say, 'I can't even bloody understand you' and they go, 'Oh no, no, no, get him out,' and you know, straight away you're stuck there for another three months."

Being passive was an easier option. *Matua* said, "I used to act like a dumb Maori, that's what they wanted me to be." And *Steve,* also Maori, said of his encounters with doctors on the ward, "It was like you were this non-brained person ... who couldn't think for yourself."

On the whole, the sentiments conveyed about interactions with professionals referred to not being treated as an individual, the problem not being carefully investigated, not being listened to, no one really wanting to know how you felt, and being given medically-oriented treatments which seemed to make ward management easier but did not address the mental health problem. Nurses were the day-to-day caregivers and surprisingly little that was specific was said about them, comments ranging from "lovely" to "prison wardens". *Annie,* reflecting on her traumatic time, emphasised the importance of health professionals realising what a profound effect they have on people in their care.

Community Treatment Settings

Many had experienced counselling or been referred to a psychologist or psychiatrist. Most encounters with health professionals outside of hospital settings were positive, and those who were able to undergo a therapeutic process mostly found it rewarding; their stories appear in later chapters on recovery.

Many people lacked the opportunity to undergo counselling or therapy, and there were only one or two stories of negative experiences with counselling involving inappropriate treatment. In *Mako's* case, she was young and the treatment from Pakeha counsellors was culturally inappropriate and damaging; whereas *Matua* said his initial contacts with local Maori counsellors made him feel worse.

There were few stories about *community mental health services. Amy's* "turning point" story, as we shall see later, involved taking a look at a community housing service at the end of her brief stay in hospital and being jolted into turning her life around on her own. She disliked the idea of others managing her money and putting rules around her lifestyle. *James,* too, felt that having special accommodation "probably exacerbated the problem because the presumption was that I wasn't well and needed help".

A couple of people experienced halfway houses overseas and had nothing positive to say about them. *Tasimauri* had at first enjoyed a halfway house where she stayed in New Zealand, but then found the prohibitive rules annoying, such as not being able to have a shower every day. A few people went to specialised treatment settings or communities, which were helpful, and another two had a rest in a convalescent home.

Georgie preferred to go back to the Maori cultural unit to see people there who had helped her, rather than be helped by the community team. In the recovery section and in the Maori cultural supports section there is more detail on Maori treatment settings and practices, which mostly were experienced as very positive.

Not Seeking Help

Five participants used alternative strategies, instead of mental health services, for their mental health problems. As mentioned previously, *Steve* was hospitalised *after* he had largely recovered from trauma and emotional pain, which he had dealt with by living as a hermit in the bush for several years; concerned relatives persuaded him to go into hospital after he emerged and was in the process of adapting to society again.

Sylvia, a psychology student, self-diagnosed and self-treated agoraphobia. Her approach was ineffective during her first bout, which diminished over time; but when it resurfaced, she put into practice effective self-help techniques. She was better placed to deal with it the second time around, because as a result of her earlier experiences, she had gone into psychotherapy for general life issues and had then begun a long-lasting self help therapy group.

Paddy received no treatment for the depression he experienced as the result of a severe head injury. He was ashamed of his depression and spoke only to his wife about it.

Jen did seek help after years of severe mental health problems when she went to GROW, a support group, but she had no contact with regular mental health services. She and her family did not want to experience the shame of mental health treatment, and the family tolerated and normalised very unusual behaviour from her over a long time. When she joined GROW, she wanted to learn how to behave like an ordinary person.

Fiona, although she was in contact with her GP, "treated" her depression by dropping out of polite society, into what was for her a safe space with the other "lost" people in the alcohol/drug scene.

Consequences of Mental Ill Health

"It completely changed my career options, completely wrecked my family life, completely lost all my friendships bar one ... [If] you didn't work for five years and it was a time when you were probably in your prime for setting up ... it completely stuffed me up." (Alan)

This chapter explores the immediate consequences of a mental health problem, in terms of its impact on a person's relationships, career, living circumstances and other important aspects of life. It will be recalled that the research question for this part of the project is "What is it that people are recovering from?" The impact of mental health problems on people's lives is often highly disruptive. Part of the recovery process will involve coming to terms with these disruptions and, for many, beginning over again.

The long term impact of having had a mental health problem and having recovered from it is different in nature from the more immediate consequences of mental ill health. That issue is dealt with in the chapter dealing with the final stage in the mental health journey, "Life Afterwards".

THE IMPACT OF MENTAL HEALTH PROBLEMS ON FAMILY/WHANAU AND FRIENDS[1]

Relationships with Partners

For partners, living with someone with a mental health problem was seen as a considerable strain and as stretching to the limit their ability to be supportive. *Bruce* said it was "very difficult" for his wife, as they had five children and he was working as well as studying when his anxiety problem manifested itself,

but she was "very good" and he was able to share everything with her.

When *Kim* went to hospital, her husband had to put the children in daycare, cope with his job, look after the house and visit his wife several times a week. On her third admission, he "was getting to the end of his tether" and was asked not to visit, for the sake of his own health. At a low point he drafted a letter to Kim's parents saying that he would have to send her back to them as he could do no more for her, though in the end he did not send the letter.

Others found the strain too much, especially if the relationship was in a bad way (and as we have seen in discussing onset, relationship breakdowns often acted as a trigger for mental ill health). *James* commented that "it was not much fun" for his wife, with whom he was experiencing conflict at the time. *Denis'* wife was "supportive up to a point" but left him because she did not know how to handle the situation. They did get back together and "she gets angry, but she's been really good". *Mary's* husband felt guilty, and tried his best, but "had to let go" when he could see no way to help after Mary continued to go in and out of hospital over the years.

Alan felt especially rejected when his partner, who was planning on leaving him, arranged for him to be committed. At a hospital meeting they were told that they should not have children, since he would always be mentally ill: "It completely wrecked my family life," he concluded. Perhaps most dramatically, *Frank* ended up in the emergency department with a knife in him, after an assault by his wife.

Some participants left their partners to create space to deal with their problems. *Tua* ("I went to get some milk one day and I didn't come back for five years") and *Steve* left suddenly, without explanation, leaving their partners to deal with the children.

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[1] This section includes material about impact on those close to the participant. In interpreting it, bear in mind that it involves the participants' perceptions. If this research had included the perspectives of family members, different issues may have been raised.

Relationships with Children

Participants who had children often spoke of unfavourable consequences for them. Such accounts often involved failing the children in some ways and loss of relationship with them.

Two of the women gave up babies, as a result of being emotionally vulnerable as well as young and single.

Sylvia's children had to put up with unexpected cancellations of plans and missed out on holidays because of her agoraphobia. *Jen* said that her son, who was "little when I was nuts", had to "put up with a lot of nonsense". *Huia* said she had failed her children periodically, and *Denis* said that he had caused "worries" for his daughter.

Kim found it difficult to continue with the daily chores of looking after house and children when she was in a deep depression. She lay in bed late in the mornings and found it difficult to motivate herself. Once when she felt she could manage no longer, she drove off in a panic, leaving the children on a street corner near her sister-in-law's home. She believed that she caused some harm to them by "not being there and not being present for them".

Fiona described staying in bed and not looking after her children as "ugly". She let the kids make a mess in her normally tidy house: "I mean, the fact that I left the kids to their own devices, that shows you where my state of mind was at ... all I could do was just cry."

Caring for children put an extra strain on participants. *James* could not tolerate his children crying. *Jen* and *Jane,* both solo mothers, heard voices telling them to harm their children, though they managed to ignore these.

In some cases, the harm was apparent. *Annie* said that at the time of her breakdown she was "disorientated to a dangerous extent. I was dangerous to myself. I was dangerous to my family." When she came out of hospital she had to deal with her children's behaviour problems. They were "in quite a traumatic state" and wetting the bed a lot. "Some of my children's earliest memories are watching me strait-jacketed and put on the stretcher and taken back to hospital."

Cathy described a very frightening incident which occurred soon after she had begun caring for her new partner's children:

> "I started having these thoughts that the children were evil ... and it seemed like the voices were telling me to beat the evil out of them."

It was the middle of the night, the four children had woken up upset, and she made them sit in a circle around an altar she'd made. They were crying, and every time they tried to get up, she'd make them sit down. The five year old was on her knees:

> " ... and the voice told me to put the bag over her head and squeeze the life out of her. Inside I felt all filled with turmoil and not sure whether I was doing the right thing, but I did what the voice told me and I put the bag over her head and I closed my hands around her throat and it was telling me to squeeze tighter and tighter ... I said to God, "Please, God, help me, I don't want to do this!" and straight away my hands were released ... I pulled the bag off the child's head and I held her in my arms and I cried."

Blood was pouring from the child's nose and the other children were watching "in shock". When their father woke and came downstairs, he immediately called the police and had Cathy committed. As he was unable to care for them himself, the children were sent to foster care.

Men, especially, often lost contact with their children. *Tua* acknowledged the painful effect of his years of absence on his relationship with his children. He has continuing conflict with "my little one ... because I never had the time to nurture her, to spend time with her as a child and when I came back she was a young lady".

Denis and *Edward* were both annoyed by their partners' use of their mental health problem to block access to their children. Denis "misses his kids" and became involved in a protracted custody dispute.

Some stories about consequences in relation to children were more positive. For some of the Maori women, such as *Fiona* and *Pare,* sending children to live with their kuia while they took much needed time out was not seen as disadvantageous to the children. For Katie, having to look after the children was a "saving grace" because it was a responsibility she could manage despite her difficult emotions and her agoraphobia. About her three year old, she said, "I needed him to keep me going". For Jane, it was a turning point when she left her parents' house and took her son with her, and managed on her own.

Children occasionally took action as their parents became more and more embroiled in their own problems. Two participants' turning point stories (described in a later chapter) revolved around an older child insisting that they get their lives together.

One or two other participants spoke of children learning resilience and tolerance, in living through the experience of having a parent with a mental health problem.

Relationships with Parents and Wider Family/Whanau Networks

With partnerships often strained or breaking at a time of crisis, intervention was often sought or offered from the wider family/whanau. The process of interacting with family was an unexpected opportunity for participants to discover strengths – or failings – in their networks.

Parents' reactions are mentioned in around two-thirds of the narratives. Some were incredibly supportive,[2] some were involved but conveyed a critical attitude, and others were rejecting. Practical support included, for example:

- taking care of their grandchildren, sometimes for months at a time;

- sorting out practical and financial problems, e.g. *Jack's* parents paid the debts he incurred after a wild shopping spree, even though they had to mortgage their home;

- allowing participants to come back home to live, as an alternative to hospitalisation;

- providing regular contact, love and listening, e.g. *Denis* would phone his mother in tears at 6 a.m. every morning; *Cathy's* parents immediately flew to Australia to be by her bedside.

When parents were supportive, their help was appreciated, and recovery was often attributed to receiving such help. However, sometimes concerns were raised about becoming more dependent on parents, and in that way coming to feel less competent. *Georgie,* for example, appreciated the way her parents took over the family when she had a breakdown, but when she was recovering found it difficult that she had to ask their permission before she did anything with her own children. But things got sorted out when she complained to them. "We didn't know how to talk to you," her parents said.

Often parents were very upset at the state of affairs. "Mum and Dad were desperate," *Kim* said. *Susan* cried during the interview as she told us that, "The day my parents drove me to Kingseat must have been one of

the worst days in their life." In contrast, *Cathy* told us that her very supportive parents did not reveal their feelings to her, as their focus was on her getting better.

Uneasy relationships continued to be uneasy: *Pare's* mother was always ready to look after the children, but Pare had to put up with blame and criticism in return. *Tasimauri* developed further problems when she went to live with her father and his new wife. *Alan's* parents were concerned, but mystified, "trying hard to be nice" but also saying, "pull yourself together".

Relationships with parents could become worse, especially if unpleasant facts came to the forefront. *Liz* had a stand-up fight with her mother about going to counselling:

> " ... and she's going, 'What are you saying about me?' and I said, 'The truth, that you're a fucking old bitch. And you know you made me feel like this, you did this to me, so how does that make you feel? It hurts, and you're more pissed off about some counsellor things. You should be worrying about how I feel.'"

In contrast, *Tua's* father, who beat him when he was young, went through some life changes and apologised to his son about his earlier treatment, and tried to be supportive. *Jane,* who also raised the issue of family abuse, said:

> "It rocked my family ... like, it was a reflection of what they did, you know, and I was angry with them ... Eventually we ended up going to see Dr X. and they just took me up the ward and that's where they left me."

However, when she became hapu (pregnant) they were very protective, although overly so, since they doubted whether Jane would be able to manage the baby.

The most devastating reaction from parents was when they were ashamed and followed through with isolation and rejection.

Hare's parents, who had sent him away as a child because they thought he was porangi (mad), did not react any better when he became mentally ill as an adult. Visiting him in hospital:

> "My old lady looked at me, man, like I was shit. Knew she felt whakama about being in the loonie ward, all the cuzzies [who worked there] seeing her there."

Hirini also felt his parents were ashamed of him, and *Lee's* mother would not visit her; she "would meet me

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[2] For more details on how parental support contributed to recovery, see Chapter Eight of this report, under the heading "Experiencing Social Support".

at the bus stop on top of the hospital hill because she wasn't going into 'that place'".

Amy needed to phone the crisis team when she was staying overnight at her parents' house. A hospital admission was arranged, but she told her parents that she was being admitted because of her epilepsy. When they later learnt the truth, her mother was "devastated"; and her father, she said, was "just not into that" [i.e., mental illness].

Relationships with the wider family/whanau involved similar dynamics, though a little less intense in their disappointments, guilts and resentments. On the other hand, those few who were stigmatised, scapegoated or rejected by the total family/whanau experienced great pain.

Katie said that her Maori family "thought that they were all entitled to poke their noses in ... [and] you nod and say, yes aunt, yes aunt, OK, fine and although you're not really believing it, you go away and you think maybe they're right because they're older".

Mary's family was "real embarrassed about the whole thing" and by the time she had been a number of years in hospital they no longer had any contact with her. *Amy's* cousin worked at the hospital but did not come to visit her: *Matua's* family would not visit him, either, after they had "put him away".

Georgie's parents ran a regular stall at a local market day:

> "And as the whanau go past, there's always this massive hui on the street. Then my Mum will say, 'Here, this is my kotiro', and then one of them will say, 'Oh, are you the one ... ' and she'll just dead stop. I'll just look, and I know I want to finish, that kind of thing. So yes, I think the whanau have still got their concept of whakama when you have someone different."

Tom, like *Amy* with her parents, refused to let hospital staff inform his whanau of his whereabouts, because he was alienated from them and felt ashamed of his behaviour: "I was already an outcast." And for *Edward,* who went off the rails after his brother went off with his wife, the ensuing conflict "tore the whanau apart".

Relationships with Friends

Friendships were also affected. *Jane* and *Lee* remarked that the illness made it difficult for them to make friends. Others experienced disruptions to friendship networks, making such comments as "friends faded". *Denis* said,

"I didn't share it so friends don't really understand", and *Paddy,* who also kept to himself, said "the illness lost me friends". *Georgie* found that her church friends "looked at me differently". *Alan* had friends who tried to help, but they wore themselves out, "and it destroyed our friendship in two weeks" – he told us that he "lost all his friends, bar one". Likewise, *Amy* lost a friend "who tried to be the ambulance".

Some friends emerged as wonderfully supportive. *Ruiha* said, "I certainly found out who my friends were." *Denis* said that those who stayed by him will be "friends for life". *Tasimauri* commented on the friend who "always accepted me for who I am, rather than for my illness, so my illness hasn't clouded his view of me as a person".

WORK AND CAREER CONSEQUENCES OF MENTAL ILL HEALTH

Hardly any of the participants continued with work as usual when their mental health problem manifested itself. The amount of immediate disruption varied immensely, though, and over the short to medium term, impact on career and working life was also quite varied. In what follows we elaborate on the patterns of consequences of mental ill health for work and career, particularly in the short to medium term. Long term impacts are revisited in the final section on "life after mental ill health".

Those Whose Careers (or Potential Careers) Were Severely Affected

More than a quarter of the participants spoke about severe impacts on career or potential career. *Tasimauri* was near to completing her graduate professional requirements, but was unable to finish. *John* left social work training because of emotional issues it raised for him; then he found probation work too stressful, though he did find other work and was proud that he only ever had a month of unemployment.

Alan experienced painful periods of unemployment – five years of living "off the state" and periods in hospital meant precious time wasted, as he saw it, in building a career and financial stability. For *Mary,* who developed severe depression before graduating, and spent a decade in and out of hospital, no career development was possible.

The way in which mental health problems put an end to *Joan's* nursing career was one of the saddest stories. She had a breakdown nearing the end of her training,

but her colleagues were supportive and a few months later she was able to resume. She enjoyed a varied career centred around people, involving nursing, work as a police officer, psychiatric social work, further training, and nursing in various specialties. In her 40s, a further breakdown following overwork saw her take some time off work and take up short-term, sometimes low status jobs. This coincided with a period of high unemployment nationally, and jobs became harder to come by. Overwork and a job in a nursing situation that didn't suit her led to another breakdown, this time resulting in a four month spell in a psychiatric unit. There she rested up and got better, but when the time came to leave she was told she could not go back to nursing. "And I never got a job again," she said. Joan told us that when she found out about Winston Churchill being manic depressive, "I thought that if he could lead England through the Second World War without the aid of modern drugs, … well, I felt I could continue with nursing with the aid of modern drugs."

Several others described losing or leaving their job as the mental health problem worsened. *Matua* was a train driver and when he became ill, "it wiped out my career". His employers said, "We don't want someone like that driving trains." He became a cleaner instead.

Employers were sometimes understanding, but not infinitely patient. *Lee* was a primary school teacher, and was experiencing more and more symptoms, including hallucinations. She had a period of inpatient treatment and the job was kept open for her, but she didn't perform very well when she got out. "I'd had ECT the day the principal came to see me and I didn't know who he was (laughs), which was a bit embarrassing really, and he just said that they were going to have to let me go." For the next decade, it was a mixture of hospitalisation, being on a sickness benefit and relieving teaching until she embarked on graduate study after her recovery.

When *Edward* went on a drinking binge and into a period of deep depression, he stopped turning up at work. His boss gave him a few weeks off but then said, "'Bro, hurry up and get it together. If you don't stop drinking and get back to work, I'll have to get someone else.' I just didn't bloody care." *Fiona,* in a similar situation, threw in a high paying job in the computing field.

Those Already Living on the Margins

Seven of the participants described lifestyles on the margins of society before the mental health problem reached the crisis point. Two of the women worked in prostitution (as did one of the men, though he had a regular day job); all seven were involved with illegal drugs, and several with other criminal activities. In other words, they earned their usually irregular living from marginal activities (although for one, this involved a lucrative career). Six of these seven had suffered abuse and/or family disruption in childhood – mostly of considerable severity – and the seventh had suffered a traumatic rape during her adolescence.

For this group, who included *Frank, Tua* and *Ataimihia,* it was not really a question of a mental health crisis disrupting their careers – their careers had taken this direction in their late teens and 20s, because of mental health problems which had evolved through childhood and adolescence. All described considerable emotional pain as part of daily living. The mental health crises they experienced, in all cases, led eventually to personal changes that resulted in them moving out of their marginal lifestyles.

Those Whose Working Lives Already Involved Changes of Occupation or Work Commitments

For many of the participants, particularly those who were mothers of young children, it was difficult to discern the impact of mental ill health on careers. The women who were at home with the children may have engaged more fully in the paid workforce if they had not been struggling with mental ill health; but some in this group, such as *Pare,* had strong family, business and community involvements despite periods of postnatal exhaustion and breakdown.

Some of those in their 20s at the time of mental ill health had already made several changes of occupation and were unsure of their career direction, a not uncommon pattern for that age group. Once again, it is difficult to say how the mental health problem impacted on careers, except that immediate time out was often needed.

Those Whose Work Capacity Was Affected, Though They Continued in the Same Line of Work

Women at home looking after children often reported that they were unable to perform their domestic activities adequately. If the situation came to a crisis, sometimes they were relieved of their commitments by family intervention or by hospitalisation, and after time out, resumed them again later.

Some men mentioned doing their work badly for a period of time, but being protected by their workmates or their position in the organisation. *Paddy* was told to "take a hike" when it was clear that he was not working well, but managed in another job to organize work around his levels of tiredness.

Participants who were students sometimes just took longer to achieve their goals than they would have otherwise. In the case of *Sylvia,* agoraphobia meant turning down a junior academic position in favour of a doctoral scholarship which in the long term actually enhanced her career.

Positive Effects on Career

For many, as the chapter on life afterwards shows, mental ill health and recovery led to changes in life direction, which often involved further education and career changes in a positive direction. But not surprisingly, mental health problems did not have immediately positive effects on careers.

FINANCIAL CONSEQUENCES OF MENTAL ILL HEALTH

Surprisingly few of the participants referred directly to the economic consequences of their mental health problem, but most probably experienced lack of earnings. *Amy* prided herself on getting a flat as soon as she got out of hospital, and managing to earn enough to keep it. *Jack,* on the other hand, had his breakdown when his business failed, and then he went on a spending spree. His parents bailed him out and suffered financially to do so. *Fiona,* who had "a lovely healthy bank balance", spent all her savings during her time out.

There were references to the financial aspects of living on benefits. *Joan,* who had established herself to some extent, had to sell off her furniture when she was on a sickness benefit, because she could not pay storage bills.

OTHER CONSEQUENCES

A number of other consequences were mentioned, ranging from distressing to life-shattering. Several mentioned getting out of shape physically or losing sporting prowess. A few acquired criminal convictions which would stay with them.

SOCIAL STIGMA

Being socially stigmatised was a pervasive consequence of mental ill health. In the accounts, already described, of experiences with mental health services, and the impact of mental ill health on family, friends and career, stigma and discrimination often featured. Stigma had an internal shape, too. Many participants were ashamed that they had become mentally unwell, especially if they were marked out by having spent time in hospital. Shame lowered self esteem and impeded recovery.

Kim told us she was:

> " ... convinced that people could tell just by looking at me. It was like I had a band across my forehead saying 'been to Tokanui' ... Each time I'd come back into the community with more and more stigma ... attached to me."

Mako referred to the shame as being "hard" and *Steve* said that it made him "worse ... having to tell people that I had spent some time in the unit". Several Maori participants mentioned feeling ashamed because people they knew who worked at the hospital had seen them inside. *Jane* said she used to be "real whakama" walking down the street, "thinking the cleaner's seen me at [the] unit".

Jen mentioned that people were awkward with her: "You have to be careful what you say to her, you might tip her over the edge."

Fiona was pleased she had spent time on the streets rather than seeking help for her problem, because she had not wanted an "ugly" label. She said, "I get the feeling that if people had gone through that process, you're stigmatised for a long, long time." And *Annie,* whose treatment in hospital was "very, very brutal", recognised the links between external stigma and stigma within, when she said, "I understood that was the way mentally ill people were treated and part of me thought it was fair enough."

Further discussion of stigma as a barrier to recovery is in Chapter Ten.

In conclusion, the immediate consequences of mental ill health were negative, involving loss, disruption, harm to career and personal relationships and stigma. Positive consequences were few, although some, in testing the strength of family networks, found that they were richly supportive.

The chapter began with a quote from *Alan,* who said, very passionately, that mental ill health "completely stuffed me up". But *Amy,* in her late 20s, who told us that "it completely shattered my life at one time," went on to say wryly, "But three years in 28, what's that?"

PART two

Journeys Towards Recovery

Journeys Towards Recovery

From exploring accounts of the journey into mental ill health, we gained a better idea of what recovery must involve. The journey does not simply involve an "illness" or a "mental health problem", but rather a severe disruption to one's life, both in the present and in prospects for the future. Even the past is up for reshaping through therapeutic journeys. The end-point of this journey into mental ill health might aptly be called, "losing the plot".

From the narratives, we heard that recovery needs to occur across a number of dimensions. People need to recover from:

- *what had always been the matter* (family legacies; childhood losses, disruptions and trauma; feelings of difference);

- the *stressful situations that led to the onset* – or identification – of the mental health problem in adulthood;

- the s*ymptoms of mental ill health,* which, for most people, no matter how their problem was named, involved disturbance across a wide range of personal functioning;

- *fears and anxieties* surrounding the symptoms and their possible recurrence;

- *treatments* received for the problem, some of which were unpleasant, frightening and even traumatising (especially those involving hospitalisation, drugs, ECT);

- the *consequences* of the mental health problem and also of its treatment, which often involved major disruptions in personal relationships, employment, and education, and could lead to isolation, joblessness and poverty;

- *destruction of self-esteem, trust, optimism, hope and faith in the future;*

- the *stigma* associated with mental ill health, experienced within oneself as shame and from other people as social exclusion and discrimination.

In Part Two of this report we examine journeys towards recovery. When we first tried to identify the sequence or "plot" of mental health narratives, we assigned one stage only to recovery stories. However, on scrutinising the interviews as we gathered them, it became clear that recovery stories could be divided into three stages.

The most dramatic aspect of recovery narratives was the *turning point,* often a rapid event or sequence of events whereby people took charge of their situation, gained hope, developed insight and a new sense of direction.

We first thought of turning points as marking the transition between mental ill health and recovery. However, it became clear that for nearly everyone, positive changes had occurred prior to the turning point incident. What had gone on beforehand was an undercurrent, sometimes barely discernible, which laid the foundations for the turning point. We named this first stage *glimpses of recovery.*

Once the second stage, the turning point, had been reached, the battle was far from over. In some ways, it had only just begun. Taking charge meant utilising available help, putting into practice strategies which were proving effective, and undertaking significant change, often at the core of personal identity. This third stage of recovery we named *the road to recovery.*

The participants' journeys through these three stages are presented in Chapter Six.

Chapters Seven and Eight describe the model of recovery we developed after analysing the themes common to all three recovery stages. We named this model RECOVER+HEART.

R E C O V E R refers to *strategies* which participants found helpful in recovery. We grouped these under the following headings:

- **R**eading, researching, and learning from others about mental health

- **E**motional growth

- **C**hange of circumstances

- **O**thers – experiencing social support

- **V**irtues – practising them

- **E**tceteras – additional recovery strategies

- **R**epeating strategies that work and realising that recovery takes time.

Each individual drew together recovery strategies they had learnt, often by trial and error, into a unique blend. Grouped together, their strategies form a huge pool of insight and expertise which can inspire others. However, they are not prescriptions for how to recover, and should not be seen in that light.

Moreover, discovering helpful strategies was not enough. Participants also had to *want* to put strategies to use. In effect, they had take charge of their health, develop an investment in recovery, and find within themselves the motivation and courage to enact recovery strategies.

So at the heart of recovery were *fundamental processes of change* in individuals. We grouped together these processes, which we called H E A R T:

- **H**ope

- **E**steem

- **A**gency

- **R**elationship and connection

- **T**ransitions in identity.

In our analyses we have presented Maori and non-Maori stories together, sometimes identifying ethnicity, sometimes not. The recovery journey and the recovery model derived from it are bicultural, having developed out of the stories of both Maori and non-Maori participants. In Chapter Nine, however, we single out *cultural contributors to recovery* amongst Maori, examining those aspects of Maori narratives which drew on unique cultural strengths.

Finally, in Chapter Ten, we look at *barriers to recovery,* of which stigma and discrimination were the most prominent.

Recovery Journeys

Journeys towards recovery can be described as progressing through three stages, which we have named *glimpses of recovery, turning points* and *the road to recovery.* In this chapter we describe the progression towards recovery through each stage. We place an emphasis *on turning points,* which are the most dramatic moments in these narratives of recovery. Although the first and third stages contain more interview data on recovery, they are discussed only briefly in this chapter. The reason for this is that in the following two chapters we present a more detailed analysis of recovery themes from all three stages, presenting them in the form of a model, RECOVER + HEART.

GLIMPSES OF RECOVERY

The first stage of recovery is often barely perceptible, an undertow gathering strength before the tide turns. Recovery begins in the bleakest times, when people are held in thrall by mental ill health, losses and disruptions are many, and hope seems distant. As *Alan* put it:

> "The beginning of recovery is a total stripping, emotionally and physically. We seem to lose our possessions and lose our relationships and lose – challenge and lose – ... our notions of traditional success."

For a number of participants this "stripping", as Alan called it, resulted from negative experiences with mental health services, especially hospitalisation. For others, the movement towards recovery began more with the despair felt at the depths of misery caused by living with a mental health problem.

At "rock bottom", fundamental processes of change began, propelled by a sense that a choice must be made between life (moving forward, overcoming problems) and death (stagnation, a living death in the institution, or even suicide). Leading up to the crisis of the turning point, people developed a feeling that they simply *could not* continue their journey further into mental ill health. They started to sense something within themselves that made itself known in the worst of despair – some survival instinct, stubbornness, or glimmer of hope.

Although rock bottom is a lonely place – and not every journey got as far as that place – at the beginning of the recovery process the support of others was overwhelmingly important. Support often came from family and friends. As *Paddy* said of his wife, "When I ... hit rock bottom she was there as a shoulder for me ... to cry on ... That's basically been my strength, is my wife, yeah." For *Tasimauri* it was the Pacific Island community in her town, for *Bruce,* a group who prayed for him, and for *Rawiri,* "my tupunas never gave up on me". *Matua's* friend in hospital, a "lifer", helped him see how the system worked, to "see things as they were ... he gave me the strength".

Mental health workers who conveyed hopefulness could ignite the recovery process. A psychiatrist and a social worker from the hospital where *Annie* had been committed had faith in her recovery, despite her initial diagnosis of schizophrenia. Counsellors provided a safe place where some could express themselves emotionally and begin a journey of self-exploration. *John's* psychotherapist, who insisted in every session that John make an agreement not to kill himself before the next appointment, steered him towards his turning point. Maori counsellors helped some to identify cultural supports and take pride in their Maori identity.

A healing place was crucial for many at this time. For *Katie,* admitted to hospital for a physical illness, rest and time out from problems at home was helpful. For *Cathy,* it was returning from overseas to her homeplace, which was quiet, peaceful and undemanding and where she received unqualified support from her parents. *James,* despite his supportive family, found that he needed to be somewhere else to begin recovery, and that place turned out to be a Christian community.

There he found friendship and the opportunity to do physical work outdoors:

> "Having found myself in a place without family or friends, the family having done all that they could to try to help me, I could start afresh ... the greatest help was being in a new situation."

Several others found an environment to foster the beginnings of recovery in groups or communities; sometimes these were part of the health system, but seldom the standard psychiatric ward. Rather, our stories told of therapeutic communities, kaupapa Maori wards and places for convalescence.

Supportive people and environments enabled participants to begin making behavioural or lifestyle changes to help them through recovery. Recognising their problems, learning more about them, understanding how they had got to this point and beginning to forgive themselves were all important. So was learning to deal with failure, learning to appreciate their own company, giving time for grief to heal, understanding and tolerating unruly emotions. Some needed to give up the use of substances, such as alcohol, illegal or prescription drugs, which deadened their feelings and their will to move forward. Finding their own voice in relation to mental health treatments was crucial for many.

As recovery began, some made new, achievable commitments, perhaps a course of study or part time voluntary work. Often the beginnings of *identity transitions* lay in this period. Glimpses of hope for the future appeared, but for a different future than the one that had been envisaged before the mental health problem. There grew a sense that recovery from some of the difficulties that life had thrown in their path might just be possible. Also, the sense that it might be possible to feel comfortable with oneself, as a grown-up, as Maori, as a woman or a man, as gay or lesbian – as a unique individual, rather than a repository of family and role-bound expectations.

TURNING POINTS

Descriptions of turning points were the dramatic moments of stories of recovery. The incidents or occasions described were many and varied, yet turning points could be identified in nearly all narratives. Occasionally a person's story featured more than one turning point, but usually just one event was described.

Turning points normally involved a sudden, almost instantaneous change of direction. However, for some people a less sudden movement towards recovery could be described as a turning point; in these cases, it was not so much a moment of insight or decisiveness, but a relatively short period of time (compared with the duration of the mental health problem) during which profound change occurred.

Our analysis of turning point stories showed that they were organised around identifiable themes. These were, in order of frequency:

- taking charge (of one's illness, one's recovery process, or one's life generally)
- interventions from others
- insight or self-acceptance
- a spiritual experience
- a "rude awakening"
- deciding to live
- a sudden shift in identity.

Most stories incorporated more than one of these themes. Sometimes a nasty shock *(rude awakening)* precipitated people into *taking charge;* for others, it was making a *decision to live* or undergoing a *spiritual experience* which encouraged them into the driver's seat. *Interventions from others* sometimes removed people from desperate situations and put them firmly in charge. *Insight or self-acceptance* could lead to *sudden shifts in identity,* as could *spiritual experiences.*

In what follows we explore a number of turning point stories, pointing out the central themes as they appear.

Kim told us she learnt nothing at all from her first experience of mental ill health, a brief breakdown when she was a young woman. Time healed on the first occasion, but nothing fundamental changed, she told us, leaving her vulnerable to mental health problems later on. When her husband got a job in a distant town she and their three young children went with him, shifting away from the place she had lived all her life and where her parents still lived. Despite her husband's encouragement, Kim found herself increasingly unable to manage the household and children. She was prescribed psychiatric drugs, and reacted adversely, and then she was hospitalised on several occasions. In hospital she was given more drugs, a diagnosis of schizophrenia and electroconvulsive therapy.

Each time Kim came home "with more and more stigma attached to me because of where I had been":

"Life was just not worth living. I wasn't getting any better, I couldn't see any hope. I was becoming a chronic depressive, I couldn't see any answers. I had a lovely family, three beautiful children, lovely husband, but I was depressed."

At the height of despair she left her young children on the corner of the street near her sister-in-law's and drove off, not knowing where she was going. She was tempted to take her life, but a strong Catholic upbringing and a fear of hell prevented her from doing this. Eventually she arrived at her sister's place hundreds of kilometres away: "Next day she drove me home with my tail literally between my legs and then I had another spell in [hospital]."

A cousin who once had a breakdown and had been helped by the self help organisation, GROW, told Kim's family about its group meetings for people with mental health problems. She gave it a try, though at first the weekly meetings were "very strange" and she could not sit still, because of the side-effects of her medication. But as the weeks went on, she began to appreciate the little nuggets of wisdom she found there, as well as the fact that "no one ever said pull your socks up". GROW was Kim's turning point: "I can literally say I was loved back to health ... It was my turning around, of gaining the resources to be able to change my thinking [from having] the 'poor me's' in such a devastating way." The self help group enabled her to take charge of her symptoms of depression. She stopped comparing herself with other mothers, became more independent of her own mother and started to take responsibility for her life, without feeling blamed or criticised.

Other participants, like Kim, told us of despair about mental health treatment activating their turning point. *Mary* had spent far longer in hospital and her turning point was a more sudden and decisive act of taking charge. Suffering from severe depression with psychotic symptoms at times, she had spent most of her 20s in and out of psychiatric hospitals in another country. She had been given shock treatment on many occasions and continuous drug treatment. Periods outside hospital were mostly spent in halfway houses, her husband and family having eventually given up on her. Only two people seemed still to care about her: her mother-in-law, who was supportive, and her psychiatrist, who took a special interest in her case and had written about her in a medical journal.

Mary got to feeling that she would die if she stayed in hospital:

"I felt like a zombie and I, I was in this black hole of despair and I couldn't figure out what part was me and what part was the drugs ... I don't really know why, I know that somewhere inside of myself I knew that if I didn't get away from that psychiatrist, I wouldn't survive."

She decided to stop all her drugs and leave the hospital. Startlingly, when she told her psychiatrist she was leaving he confessed that he was sexually attracted to her. He warned her that she needed medication because she was a "mental diabetic".

Mary nevertheless plucked up her courage and walked out of hospital, taking a bus to a city a thousand miles distant, where she knew no one. She got a job in a bar and she did survive, though it was tough. She was lonely, still very depressed and dealing with the effects of sudden withdrawal. She would phone the Samaritans when things seemed very grim, but resisted any suggestions of returning to medication.

A New Zealander she worked with encouraged her to move to New Zealand, where she met her husband and had a child. These changes did not banish depression – it remained a problem for many years. However, the decision to reject the help which was preventing her from participating in life marked the beginning of the long haul of recovery.

Cathy and *Jane* were also in hospital when things began to turn around for them. Cathy had been transferred to the long stay ward: "That put me into shock, eh, there was no way I wanted to be in there forever ... It was a joke, that ward, it was dark and dungey like you see on TV. " Up till that time she had only been pretending to take her medication, but now she decided to cooperate and within a few weeks she improved and was moved "up" to the Maori cultural ward, "the most healing part" of the hospital. Cathy decided to be patient and she stayed in that ward long enough to become "really well" so that when she left there would be no need to return.

Jane had become apathetic and forgetful as a result of her medication, and "that became the beginning of going there [to hospital] whenever I needed support". But during one of her stays she began to feel particularly trapped "and I just wanted to get out of there so I became hapu (pregnant)". Her parents were worried that Jane might not be able to look after the baby and that it might be taken away, but after the baby was born, against their wishes, she organised a state house and moved out on her own. Times were tough, but she managed and slowly recovered.

Alan, Georgie, Lee and *Amy* also made decisions to stay away from hospital. Alan made a "secret pact" with himself that he would not go in again; he had "had enough" of hospital staff's pessimism about his future. Georgie received excellent therapy and support from the Maori unit at the psychiatric hospital near where she lived. After her discharge, instead of accepting help from the community mental health team when things got difficult, she preferred to visit the ward. However, she reached a point where she recognised that she should not keep returning. "This has got to stop," she told herself, "and I have never been back as a client."

Lee was in a particularly difficult predicament. Even though it had been established that her dramatically psychotic experiences, which had so far led to more than a dozen hospitalisations, resulted from asthma medication, nothing at all changed. Her psychiatrist told her she would just have to learn to live with psychotic breakdown and hospitalisation. What sort of life could that be? Lee moved back to her home town to live with her mother. She saw a respiratory specialist, who confirmed the psychiatrist's view that she would never be able to live without the medication. She had adrenal suppression and had been on steroids for too long. However:

> "I just said I was going to get off them and I did. It took me about eighteen months and it was pretty traumatic."

Lee risked her life to break the pattern of psychotic crises and hospital admissions and the risk eventually paid off.

Amy, in contrast, had experienced only one hospital admission, lasting about three weeks. When her discharge came up, she was told that she was not fully recovered and that she should move into supported accommodation. She inspected some facilities and disliked what she saw. People were not allowed to drink and they were not allowed friends over. Most offensively to her, their money was managed by the organization and they were given what was left from their benefits after expenses had been deducted. "Nothing against [the organization]," she said, but "how do you know that [it] isn't scamming off you?"

It worried Amy that being in supported accommodation might make rehospitalisation more likely. She decided to "head for the hills while I've still got a chance". Her frank opinion on the mental health services: "You guys are a bunch of clowns and I thought, surely I've got a mind and I'm going to start using it." She rented a flat

and when "they sent someone around to my flat" she told the woman "Thank you for calling!" and sent her on her way. Before leaving the health visitor said discouragingly, "I will keep your file open." Amy, however, was determined to recover using her own resources – and she did.

Annie's story featured a rescue, rather than coming to her own decision to put the mental health system behind her. In another country she had been hospitalised for a breakdown during her marriage to a violent man with long-term mental health problems. With his suspicious attitudes and frequent shifts of location, he had isolated her from social supports, including her relatives who were more than a thousand miles away, and she had young children to care for. When Annie's mother heard her daughter was in a mental hospital, she packed a gun and flew into town, bringing Annie's uncle along for support. Never for a moment thinking her daughter might be "mad", she had her assessed by an independent psychiatrist.

As the hospital psychiatrist came to accept her mother's view, that Annie's severe symptoms were caused by her desperate home situation, he cooperated in her mother's escape plan. Stretching professional ethics beyond the limit, he made an appointment for her husband and gave him a heavy dose of sedatives exactly at the time of Annie's secret departure. Back home Annie's mother had organised the tickets and contacted authorities to make sure Annie and her children would arrive safely at the airport and board the plane early. Although Annie had her own misgivings about returning to dependency on her mother, she recognizes that being rescued in this dramatic way began the process of turning her life around.

Hospital treatment was not the only kind of mental health treatment featuring in turning point stories. For *Katie* and *Huia,* stopping prescription drugs signalled taking charge of their health. Huia had a history of addiction, readily becoming dependent on prescription drugs; she came to the conclusion that she needed to explore holistic health care. Katie realised that she could stay calm without drugs, just by accepting that what she had done for the day was "OK". *Pare,* who had found anti-depressant medication helpful when she eventually accessed it, felt that it was a turning point when she was able to make a choice to avoid mental health help at a stressful time. Now when depression seemed lurking in the shadows, she was able to decide "not to go there".

For a number of participants, the challenge to move out of mental ill health came from others. For *Ataimihia,*

the turning point was when her son was taken away from her. Lost in her own troubles for years and addicted to heroin, she said that her son was the "only thing in my whole world that I simply loved". A moment of tremendous shock, when her son said "I hate you", led to "an awakening". *Katie's* son told his mother that she was " a whining, snivelling coward" and then went on to say, "I love you, you're our mother ... and do something about it." Katie was shocked into deciding she didn't want "a drunk" (her ex-husband) getting custody of her children and "so I sort of kicked my own backside".

Edward had his backside kicked, literally, by his father, who came into the pub where he was drinking as usual, during his period of completely blotting out the world:

> "My Dad came looking for me, I remember. I was totally wasted in the pub and next thing I'm on my arse. He's only a small guy, solid though."

Edward was taken to see his auntie, who told him that he was depressed, and then to a tohunga:

> "I don't think I had any choice but to go with my Dad. My youngest sister, K., she was bawling her eyes out real hard, like, and that got to me, yeah, seeing K. howling."

The tohunga took him to a river:

> "I'm in the mouth of the river getting blessed and dunked and freezing my arse off, then I slept for a long time. I still don't really know what happened in that water, but when I came out I wasn't cold and that water was freezing. Having my Dad and K. was a, well, it made me not feel like I was a crazy. I went home with my sister. I didn't want to see my Mum, but when I went inside my boy B. was there. Big tangi tangi, my boy he got scared first, then my Dad said something to him in Maori, yeah. That's about how it was, big buzz seeing my son, yeah, it was OK."

This helped Edward "get his shit together"; visits to the tohunga "got easier and I didn't feel so ashamed of admitting I was a bloody nutter. The big thing with [the tohunga] was getting in touch with my taha Maori."

Fiona was also called back from immersion in a lifestyle of alcohol and drugs by her family, who were gentler than Edward's had been. They had taken over the care of her children when she was too depressed to look after them properly. As she said, "I needed some space and I got that." But at one point she realised that "I was either gonna get worse or I was gonna come back."

Her decision to turn back:

> "had a lot to do with my family. They were giving me the space but they expected me to come back ... It was like a grieving time, it really was, you've had your time to grieve, you have responsibilities that require you to see to them, come back and do it! It was as simple as that. I could have at that stage said no, turned my back on it, but I didn't."

Consciously saying yes to life – life without illness, with its freedoms and responsibilities – was a feature of most of the stories of leaving illness behind. *David,* for example, decided this on the day after his suicide attempt: "I decided then, that's it, I'd had enough ... and I just wanted to live the rest of my life and just enjoy it, the hell with anyone else."

John had also been wrestling with suicide. In his late 20s, he had been seeing a psychotherapist for a year or so, after becoming more and more depressed. He liked the therapist, but his state of mind was worsening. He experienced frequent rages, which resulted in spells of impulsively dangerous driving, and he had stopped sleeping: "Night after night I'd be awake, you know, things just racing around in my head." John got to the point where after four or five nights of virtually no sleep, "I felt physically and mentally just a write off". What happened next was hard to explain:

> "After about maybe the fifth night, this is going on – between three and four in the morning, I think it was, I had a sensation like, almost like a palpable and audible click in my head – and it stopped and I went to sleep. I knew at that point, instantly, it was fine, everything was OK."

John told the interviewer that in the 20 years since that "click in the head" he had not suffered again from depression, except on rare occasions when it was appropriate to the situation. He believes that his therapy, by enabling him to explore his feelings about his father, got him to the turning point. But the "click in the head" remains unexplained. John is unusual in his "turning point" stories, in that recovery was so rapid. Mostly at turning points, recovery becomes a chosen direction, but nevertheless takes time and hard work to accomplish.

John's "click in the head" was not a spiritual experience, but it certainly was mysterious. Several turning point stories, especially from Maori participants, did feature spirituality, as we have seen with Edward's story of the tohunga blessing him. *Pare's* uncle came to her unbidden, because of his dream, and performed karakia

for her, allowing her to move on. *Jack* allowed his mum to take him to a tohunga, despite his reluctance:

> "I kept thinking she was a load of crap trying to get me to do that buzz ... and this humming starts, well, what seemed like humming, and it's the old koroua chanting these prayers over me. That just about freaked me out. Water's getting thrown over me. I think I had to go back a few times, but the – it got lighter."

Bruce and *Ruiha* were turned around by others praying for them. In Bruce's case, the particular moment was when he had an anxiety attack while driving on the motorway:

> "My wife was sitting in the car with me. And I asked her to pray for me and I was just kind of out of control and I was very intense. And, um, so she just laid hands on me and started to pray and I just had a sense that this, yeah, this anxiety went through the top of my head ... and it, uh, just kind of went to nothing."

Unlike John's "click in the head", Bruce's sudden sense of the problem departing was not final, but the experience had a "profound effect" on him. When he was overwhelmed by anxiety on later occasions he would ask people to pray for him and it would usually work. His experience was a turning point along the way to recovery.

Mako also received spiritual assistance at a time when her life seemed hanging in the balance. She had been mixing with drug users and had an overdose, passing out in an old shed:

> "I was sick, vomiting, shaking, deathly deathly cold. Frightened. Sliding in and out of my body. Pain. Sort of curled up and shaking, shaking, shaking. And all these fuckin' shoes, rags and dirty towels, ripped pillows, used underpants, old socks, raincoats, cigarette butts, pie packets and all this shit ... I suddenly felt like I was being kicked. Like someone was belting me and kicking me. I looked up bleary eyed and there were these four figures. They were huge, all the way to the ceiling ... Kei te mau kakahu ratou. Mau moko. Mau rauhuia ... They were magnificent, their eyes ... they were spitting and the voices saying things like 'Na wai koe, kei te aha koe? Mahi taurekareka.' They actually said, 'Clean yourself up, girl.'... I woke up [four days later] clean, clear, absolutely clear."

She told the interviewer, "I actually think my body was cleaned, was purged by those koroua." Leaving the drug

lifestyle behind her, she got back on track with her studies. However, she discovered shortly afterwards that she was unexpectedly pregnant, and the events that ensued threw her off course again.

Joan had been diagnosed with manic depression. Although her career in nursing and psychiatric social work meant she was thoroughly familiar with medical approaches to mental illness, her strong Christian faith led her to seek a different solution. She went to a healing service conducted by a well known evangelist and requested exorcism. The ceremony made no difference to her, and she remained acutely suicidal. The following year Joan discovered through her reading that spirits might not come forth during an exorcism if called by the wrong name. "And it was just as if a light went on inside me", Joan said. God had spoken to her some time before, telling her to "deal with the mania and the depression will take care of itself"; suddenly, it all made sense. She should try to have the mania, not manic depression, exorcised.

It took Joan two years before she was ready to act on this insight. She was reluctant to tell the evangelist that he had used the wrong term. But eventually she went again and asked to be exorcised of the spirit of mania; he did so, and asked her, too, to tell the spirit to go. Joan said of this occasion:

> "I didn't feel any different. I never have emotional feelings with the religious experiences. You know, people have converted and they're full of joy and they're baptised in the holy spirit and they speak in tongues [laughs]. Well, I never do any of these things."

But she became more and more sure, with the passing of time, that this second exorcism had been successful. She had no more manic periods and her depression alleviated.

James was also Christian, though his turning point came about from repentance rather than exorcism. His shaming by a teacher when he was 12 for writing sexual words in class has already been described. At this time James had not connected the earlier trauma with the long period of mental ill health during his 20s. But when he came to an understanding of how deeply the experience had affected him – particularly after a psychiatrist had made him feel like "an emotional cripple" – he began to understand his character better. He realised that defending himself, as a 12 year old, from what had seemed an unfair attack had got him into a persistent attitude of self-justification ("no, I'm not wrong!") which had persisted and "determined the

course of my life". When it struck him that, as a boy, he could have accepted the reprimand and acknowledged that he had done something wrong – for as he said, "there is nothing wrong in writing the words, but the context was inappropriate" – everything began to turn around:

> "I admitted I was wrong and that was the key to my changing. I was wrong. When I thought about it, this repentance I talked about, I collapsed in the shower. I said ... 'I'm sorry' to God, 'My life is not what you intended. It could not have been.' So things changed from then on."

James' repentance happened 25 years after his shaming over sexual matters. His mental health problems as an adult had been triggered by his partner talking about her previous sexual experiences, but he had not linked that to the earlier trauma. However, he argues that "it wasn't sexual in the end, it was attitude ... It's not what happens to us, it is our response in that regard ... I mean, you know how most people operate – they operate on the basis of performance – blame, shame and approval. Now, once you get rid of those, you can actually be free."

Gaining insight into one's own patterns of behaviour, reconciling with the past and starting journeys of profound change featured in other turning point stories, too. For *Sylvia,* a turning point was reached in realising how tightly she locked up her emotions. Her agoraphobia was not in the foreground at the time she went to see a psychotherapist to help her deal with a marriage breakup. With the therapist using techniques which promote emotional expression, her usual self-containment broke down and her feelings came out in a flood. During the process it became clear to her that there was a connection between the anxiety associated with agoraphobia and the emotional rigidity she had developed after her mother died when she was young. She had learnt never to ask anyone for help and to contain all her feelings to the point of scarcely being aware of them. After this therapeutic encounter, Sylvia initiated a self help therapy group which was to be of lasting benefit.

For *Denis,* self-acceptance came when he stopped being so afraid of what his mental illness implied about him as a person. When a psychiatrist took the time to explain to him about the biological basis of bipolar illness, Denis felt respected as someone "sane enough" to understand. To him it was a huge relief that his mood swings were not a sign of "totally emotional weakness" on his part (Denis was the man who described himself as like a "ladies' blouse" when he'd been on a crying

jag). With his self-esteem rising, he was able to profit from group therapy in hospital, where he felt comfortable mixing with people "from all walks of life", including those whom he would have thought of as strong people – "big hulking strong farmers, a traffic cop". It was also a relief to him that "even though I was a bloody nutcase at the time", his family "understood that it was a passing thing."

Tasimauri found that a survivors' group was a key to the self-esteem boost she needed to change her direction. "I had been so used to being on the dumping heap of society after mental illness, going to halfway houses and people just treated you like objects." But this time a care worker who was "different" pointed her in the direction of the survivors' group and after three months of hesitation, she "went up and I found it was just the right place for me". Tasimauri spoke of coming to terms with her situation in life and feeling able to use the skills and resources she had gathered both before and during her illness: "it was just having the confidence and self esteem to use them, and when people are interested in your welfare, then the self esteem grew from that."

Developing self-belief was also part of *Matua's* turning point, though in his case it was in spite of rather than because of the mental health system. When he was just out of hospital he went to watch his sister playing in her band, and a woman approached him. He did not remember who she was, because shock treatment had given him "a lot of memory blanks", but she introduced herself as a nurse who had looked after him when he had first been admitted to hospital.

> "I said to her, 'That place really fucked me up.' And what she said made me really sort of realise ... she said, 'You're lucky you got out when you did, that place would have really fucked you up.' And that was coming from a nurse ... She said when I was there ... she had no power because she was only a nurse, it was up to the doctors and psychologists, psychiatrists, whatever. And she said to me, 'You were only trying to be yourself, but everyone was telling you what to do ... ' Which sort of snapped me out. I knew I was right because at the time people kept telling me what to do, so I started listening and it made it worse. I'd say something, I pretty well trust my own judgment."

Insight and self-acceptance often mark a shift in identity, from the person one is expected to be to the person one feels oneself to be. As *Rawiri* put it, "I guess the turning point came for me when I realised I didn't know myself ... I asked myself who I was and what I was."

These processes of personal change took time, but turning point stories often point towards the changed direction. *Frank,* for example, describes his experiences with fellow patients in a psychiatric ward as a turning point for him:

> "I realised, sitting there in the acute ward ... amongst all the other loonies in there, I actually felt safe and comfortable, first time in my life that I could remember, as an adult. I could be myself, I could be a mess and no one minded, no one was putting me down, the other patients accepted me as an OK person even though I was a total fuckin' mess. And this was like a revelation ... I needed this and it was so good to have."

Frank later joined Psychiatric Survivors, like Tasimauri, finding support there for being himself, despite being poor, not having a job or "flash clothes", as well as the political activity which he loved. The survivors' movement gave him an identity.

Other turning point stories which revolve around identity change include the themes of retrieving Maori identity and discovering gay identity. Sometimes identity change was linked with spirituality, as in Tua's story of a "spiritual awakening". When he was in hospital he had met a man who:

> " ... was talking about God, and I said, 'I don't want to know about that bastard'. I was brought up a Baptist. I remember cutting Jesus out and sticking him on bits of paper when I was a kid ... And I said to P., 'What is this God bullshit, what are you talking about?' ... P. said, 'It means Good Orderly Direction ... In your life right now you have no direction, it's totally chaotic'."

This made an impact on Tua, and later, when he had moved out of hospital and into a treatment centre, he began working with a carver who was now "clean" and who came in every day. Tua came to respect the man, and enjoyed learning to carve as he had always loved drawing. The turning point came when he asked the carver how he had found God:

> "He looked at me and said, 'That's easy, bro. Jesus is a Maaori.' I just went, 'Wow', yes, because I had looked at a picture of Jesus and he was dark, long hair, olive skin and I could imagine that topknot with the hair, moko on his face. I said yes and I grasped onto that. From there my creativity started to be Maaori motifs – I don't know where they were coming from, they were just appearing in my artwork."

Tua's father and mother had been at odds, and he had been coming from a place where gangs and drugs predominated. He saw as part of his turning point therapeutic work with a woman who was at ease biculturally, and who helped him feel easier about his masculinity, convincing him that "I am half wahine, half tane and that I can't lie within my mother's womb for nine months and not have her in me."

Jack, whose story of receiving a blessing was told above, also linked his turning point with identity. For him, "I think it was the coming to terms with my Maori and Pakeha side of me, you know, not having to be one or the other, especially with the treatment."

Tom was conflicted about his Maori identity, abused drugs, and was aggressive towards men he encountered as a prostitute, as well as towards anyone who suggested he might be homosexual. He said that:

> "My recovery came when I met my partner in the hospital. He used to come along and do workouts with the men. He's Pakeha, and I used to think to myself, I'm not gonna let this baldhead tell me what to do. I just resisted his good intentions at the time and it took about two months before I felt comfy with him, and from there we developed this amazing relationship ... I have never really looked back."

The "most empowering thing" for Tom (who said humorously, "yes, I use all these counselling words") was taking his partner home to meet his mother: "She freaked out, and then she came right because he's such a softie, you just can't but not like him."

For Mako, recognising her attraction to a woman soon after she had given into pressure to get married, "It was like I had come home. I just knew that this is who I wanted to be. This was what I wanted to be."

THE ROAD TO RECOVERY

In the first stage of recovery, people at their bleakest times experienced glimpses of a way ahead. Many reached rock bottom, and all were profoundly shaken by their experience of mental ill health, with its shattering of the taken for granted aspects of everyday life and its detrimental impact on people, their social networks and their livelihoods.

Turning points established a direction for recovery, rather than making everything better right away. There were a couple of exceptions, as in John's case, where the turning point event marked the end of people's

troubles with mental ill health. However, for the most part, once the impetus for recovery was established, there was still a long way to go, even years, though hope and optimism now accompanied people on their journeys.

As they made their way to recovery, after turning points had clarified their direction, people learned to enact mental health promoting strategies and to place themselves in environments which were health promoting. The support of others, crucial at the beginnings of recovery, remained of key importance right through the process. After their directions had become clear, people developed a better ability to make use of support and to recognise what kinds of support were actually helpful.

All these processes, taking material from each of the three recovery stages, are discussed in Chapter Seven, which describes the "RECOVER" framework.

During this process people also underwent profound personal change. The tools and circumstances and support from others, described in the "RECOVER" framework, helped them on their journey, and were intertwined with their changes. They began to see themselves differently, coming to understand their strengths and vulnerabilities, what helped and what harmed. Their self-esteem recovered. The profound experience of mental ill health altered forever their understandings of how they and the world around them functioned. This process of change in self, identity and relationships is covered in Chapter Eight on "HEART".

Personal change, we found, resulted from support and practical strategies; but support and practical strategies could often not be used unless personal change provided the motivation to use them. These processes were neither cause nor effect, but represented a holistic interaction between "doing" and "becoming".

The Recovery Framework: RECOVER

READING, RESEARCHING AND LEARNING FROM OTHERS ABOUT MENTAL HEALTH

"I went searching for what helped ... I tried many things and different ideas." (Alan)

More than half the participants told us that finding information about their mental health problem helped with recovery.

Research and Reading

Quite often participants mentioned books they had found helpful, and some put considerable effort into reading and researching information about their mental health issues. *Pare,* for example, who had been given a profound insight into her problems by attending a lecture on postnatal depression, was able carry out a research project on the topic for a course she was taking.

Jane, who is Maori, reported that her investigations were discouraged. She was told by an English psychiatrist that she should not be reading psychiatric literature in the hospital library.

Hirini, who had spent several years in hospital, was a poor reader and was ashamed of it. His girlfriend helped him and then, as part of a Maori mental health programme, he received literacy tuition and learned to use the library. As a result of his reading, he decided that it was time to give up the medication he had been taking for years:

> "My mum, she didn't like that I wasn't going to take the meds, ... you know, the old people still think the doctor's God, well, that was me reading ... I've been off those meds ... four years going on five, so that tells me I'm well."

Huia told us that she researched local services thoroughly, so that wherever she lives, she knows how to access the best free counselling or "time out" residential retreats.

Learning from Others

Other people – friends, family or professionals – were useful sources of knowledge about mental health. A turning point for *Edward* was when his auntie told him that what he was suffering from was depression. *Denis* experienced "a big turnaround" when his psychiatrist talked to him informatively about bipolar disorder.

Bruce, who worked as a psychiatric nurse in a kaupapa Maori ward, learned much about his problem and recovery processes from patients and colleagues:

> "I've worked with people who have had some vision for their life and I've seen some amazing people do some amazing things and I guess that has helped with my healing."

Support groups were another source of useful information, with particular praise from several for GROW, which provided practical advice about how to deal with distressing symptoms. *Jane* learnt distraction techniques for dealing with voices, *Kim* learnt techniques for overcoming her inability to get up in the morning and carry out her daily tasks, and Jen learnt about "normal" behaviour.

Learning to Recognize the Signs of Ill Health

One useful kind of knowledge, mentioned by many participants, involved learning to recognise signs in themselves of impending illness. This self-knowledge enabled them to take appropriate steps to prevent a relapse, moving over time from avoidance of relapse to recovery.

David's account of learning about bipolar illness shifted him from being unable to control the effects of emotional stress to being able to self-monitor and seek appropriate treatment. After he had learnt about his health problems, he moved to a new town and signs of illness started to build up again. He went to his new

GP and told her:

> "'I've got manic depression' and she said, 'Oh well ... we'd better go and get you on to the experts because I'm no good at this sort of thing.'"

David was sent to the local psychiatric service:

> "and I walked in there and I said, 'This is the deal, I've got manic depression and I want lithium.' 'Look we can't just do it like that,' [they said] and I said, 'Yes you can,' I said, 'I want it,' and I said, 'You just start off in slow doses and just build it up, and that's it,' and that's basically how I got on lithium. I wasn't prepared to go on antidepressants again, no way, there's just too many side effects."

Beforehand, David saw himself as "struggling along with manic depression", but investigating and learning about the disorder has changed his attitude to the point where he takes pleasure in knowing himself:

> "I think that's where I enjoy it more than a lot of people because I learnt about it myself and I went looking for information."

EMOTIONAL GROWTH

Around half of the participants told us that processes of emotional growth were central to their recovery. For some, this was a process undergone as part of their life journey, coming to terms with emotional factors, sometimes from childhood, which had contributed to their illness. Learning to express anger, sadness or other emotions ("getting in touch with my feelings") were mentioned by some; others referred to a more general process of "working things out", "getting rid of baggage" or learning acceptance.

For one participant this process was carried out entirely alone. *Steve* went bush for a number of years, and in his solitude he was able to recover from the impact of horrific sexual abuse from his stepfather; the same experience had led to his sister's suicide. *Steve* told us that in the bush:

> "There was no dope, nobody, just nobody with me, no memories was the best part, no bastards touching me, just me and the rain, wind and cold. You ever just been away from anything? It's like a whole world opens up to you, you get to smell and learn what not to eat. For the first time in my life I was alive and safe. I knew my kuia was looking over me, I never really felt alone ...

> I found time to think about the shit things that had gone on in my life and I suppose 'cause I had to live off my wits, I stopped mutilating myself ... A lot of the excessive baggage I carried around about my folks and whanau is still being dealt with. It's a slow process."

Mostly, however, contact with others was necessary for such an intensive process. Nearly half the participants described a therapeutic context for emotional growth, some with a mental health professional and others in therapeutic group settings. Here are two of their stories.

Hare's therapeutic process was guided by a Pakeha man who was a regular visitor at the hospital:

> "[He] used to spend a lot of time talking to me and reckoned I should look at my nightmares. Shit man, ... well I told him to get real. Now that's when I knew I had gone to the pictures. But man, he had me eating and talking to the other patients. I was taught how to look at my feelings when the voices started ... Well, some bloody amazing stuff came out of that work, there was stuff that looked like The Exorcist, ha, ha ... nah, not really, but there was, um, mainly it was outlines of old men."

Once, when Hare was causing a disturbance and "screaming like a crazy man" because someone had challenged him about a sensitive issue, his "mate" came in and "got ... me to look at what was going on":

> "I don't know if it was the first look or the second that had a story about my father and my eldest brother and this little wee fella in the back, I think on a football field. It was always, oh, [my brother] was the greatest, he ran the fastest, swam like a shark and the, yeah, umm, well I was never really good enough ... Yep, it was the old self esteem thing."

Hare saw this therapeutic process as a turning point, after which he moved on towards recovery.

Lee, whose psychotic episodes were found to be steroid-related, had decided she must learn alternative ways of dealing with asthma. But recovery was complicated by the fact that sexual abuse and other family issues from childhood had led to a constellation of reactions which fitted the description of post-traumatic stress disorder. A psychiatrist led her through a three year therapeutic process:

"That relationship was tremendously healing because ... I was convinced I was as mad as a meat axe and nothing was ever going to change ... and since she was the first person after, what, three and a half years, to tell me I actually wasn't crazy, that what I was experiencing was normal ... "

The psychiatrist helped her get off medication and deal with her issues, and though the process " ... still got pretty messy at times," it proved to be the pathway to recovery.

Overall, the benefits from counselling and therapy included:

- learning to deal with difficult behaviour patterns;
- recognising how family background had shaped the person's present character;
- helping with the expression of inhibited emotions;
- coming to terms with abuse;
- reframing distressing circumstances.

In groups, people experienced emotional growth through support and challenge from others. *John* spoke of a Christian therapeutic community, *Francis* of a psychodrama group, *Sylvia* of feminist self help therapy. Several Maori participants referred to the importance of their experiences on mental health programmes which focused on culture and identity.

CHANGE OF CIRCUMSTANCES

For more than half the participants, a significant change in life circumstances was part of the recovery process. Mostly these changes were initiated by participants, although sometimes others intervened. Early in the process, changes leading to recovery were often those which lessened stress and responsibility; further down the path, recovery-enhancing change often meant picking up new challenges and responsibilities.

Two types of change were most frequently mentioned: change of residence, and becoming involved in more demanding daily activities (specifically, getting a job or taking up further education).

Change of Residence

The kinds of change of residence which fostered recovery in its early stages sometimes involved going somewhere familiar, living in circumstances where people were understanding and accepting, or just taking time out in some way. *Cathy's* parents took her home

to the coast when she was well enough to leave hospital:

"It really was a healing time for me because Te P. was a place that you could walk around dressed in anything and nobody would give a damn – you know – it was relaxing, it was quiet, it was peaceful and nobody expected anything of you."

A few, though not many, participants mentioned the circumstance of living in a mental health facility as conducive to recovery (while a number of participants made reference to positive aspects of hospitalisation, only a few found the environment itself helpful). For *Frank* it was because the other patients accepted him for himself and he did not have to prove anything. *Susan* reported similar feelings. *Hare* and *Georgie* enjoyed the daily routine of a Maori-run hospital ward, with their cultural observances. *Pare* and *Huia* welcomed respite stays in a home which took in women in need of a break from domestic responsibilities. *Katie* found that being hospitalised for a physical problem gave her the rest she needed. Three people mentioned the benefits of time spent in Christian living/healing communities.

In contrast, *leaving* the mental health system and going to live in a more normal environment was a key part in the recovery of several participants, as we illustrated in the section on turning point stories.

Making a New Commitment to Employment or Further Education

Around a quarter of participants told how a new job assisted their recovery.

James, for example, put in a year of hard physical work, which helped him achieve a much better mental state. Some told of the boost it gave them to cope with increased expectations; for example, *Sylvia* found herself able to meet the demands of an academic job. Some used their personal knowledge to begin working in the mental health field, which was especially rewarding.

There were also those who took up study; interestingly, all seven of those who stressed how important tertiary study was in their recovery were women (though several of the men, too, were currently studying when interviewed). Self esteem blossomed with their academic success, especially for those "first in the family" students whose relatives doubted their ability to study. Others took the opportunity to embark on career-oriented higher degrees.

New Family Responsibilities

These seldom featured in recovery stories, though for a couple of women, a pregnancy resulted in changed life circumstances and provided the impetus to take charge. Similarly, when *Jen's* mother died she was expected to take on more and to behave more normally; she responded well to the challenge.

Responsibilities and Recovery: More or Fewer?

There is an ebb and flow around the theme of personal responsibility in the narratives. At the onset of illness, life became chaotic, responsibilities were not fulfilled, and in many cases, a new environment, often the hospital environment, meant less responsibility for people. For some, as we have seen, a less demanding environment helped with recovery, though for many, the hospital environment imposed additional stresses. Further down the track, it was time to take on new responsibilities; these were sometimes imposed by external circumstances or family pressures, or were the result of a bold choice. It is unclear how participants could sense that the time was ripe for new responsibilities, as sometimes the next step seemed a matter of chance.

Fiona's story shows, better than most, the process of letting go and returning. After her partner (who had been abusive and unfaithful) was shown the door, Fiona had a breakdown. She resigned from her well-paid job, and her parents stepped in to look after the children, because she was clearly no longer managing. Fiona was able to have "some space". She went off to the beach for a while, and then came back to her home, where she proceeded to get "rotten drunk." For a year or so she was "just basically wasted", using up her savings.

She did drugs, picked up a criminal conviction and mixed with a new crowd: " ... this little community of lost people and it's like they're ... we're all in the same boat for whatever reason." After more than a year, her family felt she had had enough time out and called her back. For Fiona, it was a major decision to come back into normal life, because she had felt in a "safety zone" with the down-and-outs, free of the family expectations, which sometimes her sisters laid on her quite heavily. But she looked around at her little group of "lost people", and decided she did not want in ten years' time to be the "local drunkard, druggie, spaced out person". She took what was for her the hard option, and with the special encouragement of her kuia, weaned herself off her addictions, left her newfound

friends and came back to work and to look after her family again. Interestingly, as Fiona describes the process, it was her time out in a far from healthy lifestyle which enabled recovery. Returning to normal life was made possible by having had her "grieving time". She regarded her choice as preferable to being institutionalised and marked with the stigma of mental ill health.

Fiona's story has some similarities to that of Steve (described in the last section). Both described a recovery process which, to outsiders, might have looked more like an illness process. Steve left his responsibilities to partner and children and "went bush" where he healed his emotional wounds on his own. However, his return to take up his life again was impeded, because when he came back, more or less recovered but somewhat unconfident in society, his relatives persuaded him to go into an institution. There he was diagnosed with agoraphobia and social isolation and gained a new raft of problems.

OTHERS: EXPERIENCING SOCIAL SUPPORT

Help from others was, to an overwhelming degree, the most frequently mentioned theme in accounts of recovery.[1] All 40 participants, in describing the recovery process, referred to assistance from other people. Family and mental health workers were the most common source of help, and each was mentioned by over half. More than a third mentioned friends and partners. Only a few referred to people from their workplace.

Support did not come only in the form of help from family, mental health workers or individuals. Over half the participants referred to help received from groups – most commonly support groups, but also therapy groups, psychiatric survivors, other patients on the ward, and residential communities. This section covers each category of supportive others in turn.

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[1] Another methodological reminder: since this was a narrative rather than a questionnaire-based study, frequency of reference to different categories of support indicates only how many participants raised that topic in an open-ended interview. For example, though over half mentioned family/whanau, even more might have done so if the whole sample had been questioned directly about family support. It is also important to note that this section focuses on the role of others in relation to *helping recovery*. Both positive and negative references to the impact of others were made in accounts of ill health. In particular, in an earlier chapter on consequences, we discussed the impact of mental ill health on relationships with others. Mostly we documented negative impacts; however, during recovery the picture that emerges is the important role of other people in providing support. The later section on hindrances to recovery also documents some instances of unhelpful behaviour from others.

Family/Whanau Assisting Recovery

Families provided support for recovery in a myriad of ways. Certain themes emerged from our analysis, which we characterised as "presence", "faith", "active support" and "challenge in the context of support".

Presence

When *Cathy* was hospitalised in Australia, her parents flew over to be at her bedside:

> "The thing I remember the most about being in the hospital ... was that when I was feeling really stiff and stressed and I couldn't talk or do anything, we'd sit in the chairs and ... Mum would hold one hand and Dad would hold the other. I could feel their positive feelings coming – the aroha coming into me and taking ... away all that negative stuff I was feeling at the time. It was a huge part ... of my recovery."

Others described the importance of having family in their lives, for conversation, to listen, or just to convey a sense of support.

Some reported that fear of mental illness in the family had to be overcome before the usual interactions resumed. *Jack* said that support from his whanau was "choice", but that when he first came out of hospital "some of them were funny ... but now they just treat me as their bro and that's all that matters to me". *John* found that gradually, from one Christmas to the next, he and his brothers and sisters were able to talk more openly about what it was like for them growing up, and that helped.

Sometimes a family member decided independently that their presence was needed and arrived at just the right time. *Pare* told us:

> "My 70 year old uncle had a dream that something was wrong and he drove from his home to see me. I was in bed, really low, and he spoke to me about the sexual abuse and to let it go because he could see how badly it was affecting me, and my whanau. My first response was to think, I can't let go. As he was talking he shared a similar experience with me. After a few quiet moments I thought, just maybe I could let go. My uncle's sharing of his story, his strength and his closeness had a peaceful effect on me. And in my head I was able to let it go.
>
> He did a karakia over me and sprinkled the water. Then he went outside my house and did another karakia. I started to pull myself up because he just

didn't go to see people unless for the purpose of karakia. He just knew he was sent to me. He just knew he had to help me. That's when I went to seek help at rape crisis."

Another form of presence mentioned by some Maori participants was of those who had passed on. We heard several powerful stories about the effect of kuia who had been close to the participant as a child, and who remained a presence, giving love and advice, after their death. As *Steve* put it, when he was in the bush, "I knew my kuia was looking over me, I never really felt alone." He then remarked to the interviewer, "I suppose you wouldn't really know what I mean, eh?"

Faith

Families could powerfully convey hope (or despair) and being believed in was important to recovery. *Denis* valued the support of his family: " ... even though I was a bloody nutcase at the time, they understood that it was a passing thing." *Mary,* who had spent ten years mostly in institutions, had lost the support of most of her family, including her husband, but her mother-in-law never seemed to judge her for anything: "she was just there." *Ruiha* reported that her in-laws gathered as a group and prayed for her recovery, conveying a powerful feeling of hope.

Huia's whanau provided her with a sense of being valued when she was at a very vulnerable time in her recovery:

> "I was seen by a psychiatrist and he wanted me to go to Tokanui. And I said, 'No, no, no, all I need is loving. All I need are good people around me to listen to me.' Now ... I wasn't brought up in a traditional Maori whanau ... situation. However, at this particular time one of my uncles died, and he was a young man, so nearly all of the family gathered on a marae for about four days and during that time I had the best healing. Spirit was really present. I was an integral part of the family's grieving process. After that I [was] rung by my mother and told by members of the family that they will be looking to me for spiritual guidance in the future ... I didn't tell anybody that I was recommended to go Tokanui ... [While I was on the marae] just being around my family and their loving, and the communal lifestyle, and all of that sort of thing, and the singing and just the karakia and all that sort of stuff, my family gave me my mana back and put me back together."

Active support

Participants made many mentions of active support from family – helping to look after the children, making a home available, paying debts, and many other forms of help. *Cathy* said about her parents bringing her home to the coast:

> "And like I said, if it wasn't for Mum and Dad coming and getting me at that time, I would probably still be there now. You know, I wouldn't have recovered as well. It would have been an even longer and harder struggle."

It was good, too, when families were sensitive about the movement towards recovery. *Georgie's* whanau provided a lot of help when she was unwell, but they learnt to back off as she got better, trusting her to be able to look after her family.

Challenge in the context of support

Occasionally, family support involved dramatic challenge as well as support. We have already mentioned *Fiona's* family calling her back from her life with the down-and-outs and *Edward's* father knocking him down in the pub and taking him to a tohunga, which gave him "no choice" but to begin the healing process. Also, after *Katie's* eldest son had "called her bluff", he was supportive towards her during the recovery process. *Annie's* story of being rescued from a violent husband by her mother has also been told.

Partners

Having a mental health problem clearly put a strain on partner relationships. But the opposite was true too – having a partner can put a strain on mental health. For around a quarter of participants, the mental health problem was triggered by a relationship breakup.

Given this context, fewer participants mentioned partners than family/whanau as crucial to recovery. For half of those who did, they were referring to a new partnership. There were notable differences between women and men here: a partner mentioned as helpful in recovery was far more likely to be female than male.

Sometimes a partner was very devoted, as in the case of *Kim's* husband, who dealt with his job, the household of young children and visiting his wife in a hospital some distance out of town. But she had some issues of her own, to do with growing up and learning to take responsibility for herself, and these could not be solved through his help, though the marriage lasted.

Support described as coming from partners was mostly in the line of tolerance and understanding; and some partners very actively helped to seek solutions. *Paddy,* who had depression following a head injury, was able to confide in his wife but no one else, not even his adult daughters. He sought no mental health support and was deeply ashamed of his condition. The injury had occurred while they were overseas and by the time they returned, their business was in strife and he was not well enough to make decisions. Paddy's wife took over, sorted out the books and sold the business; then she went to Income Support and enrolled him for a sickness benefit, another step which he had found impossible on his own. When Paddy felt ready to return to work, yet was unsure whether he had staying power and was worried about losing the benefit, his wife returned to the workforce, so that if he did not cope she would be able to support him. These actions constituted major changes in a conventional marriage which had previously been based on male-as-breadwinner. Paddy's wife handled these changes, which in some ways were liberating to her, with delicacy and consideration.

Some partners, one would have to say, were long-suffering. *Steve* said he was going down the road and did not come back for four years; his wife raised the children and accepted him back when he returned. *Tua* came and went, had other girlfriends, arrived on the doorstep injured after falling off his motorcycle and was nursed back to health. Despite his checkered life, marked by alcohol and drug problems and a drug-induced psychosis, his wife remained there for him over the years. When he was rehabilitated he was able to rejoin his family and become a father to his children again.

New partners provided a stimulus for recovery, understanding and love which may have been lacking in the previous relationship. They were sometimes formed with people who had also experienced mental health problems and who were therefore able to offer a special kind of understanding.

Friends

Half the participants mentioned friendship as playing a significant role in recovery. Friends were able to listen, and to offer companionship, encouragement and support. Friendships were less likely to be marked by the tensions that were often present in a partner relationship. Friends were also less likely to feel deeply the acute stresses and disappointments often

experienced by partners and family/whanau when their loved ones' lives went off the rails as a result of mental health problems. Not being as close to personal situations, friends could often maintain faith in the person more steadily than could partners or family. However, stories about friends who helped with recovery were less detailed than stories of family or mental health workers, perhaps because of this less intense involvement.

Mental Health Workers

More than half the participants discussed the ways in which health professionals or support workers played a role in their recovery. Counsellors were by far the most commonly mentioned as helpful in recovery. They were mentioned by 11 participants, followed a long second by psychiatrists and GPs (3 mentions each), nurses (3) and psychologists (1).[2] Mental health workers were also often mentioned without their profession being identified, for example, when someone referred to the staff of a particular unit or a support team. The profession of some significant individuals was unclear; several may have been voluntary workers.

What did mental health workers offer that was seen as helping recovery? The accounts show four main themes: (a) a counselling process; (b) quality of relationship with the health providers; (c) learning from health providers; and (d) the cultural emphases of Maori health providers.

Health providers as counsellors

Seventeen participants described interactions with a mental health provider (most often a counsellor) who used a counselling or psychotherapeutic approach which was significant to their recovery. Some description has already been given of the emotional processes in counselling which helped recovery (see the previous section on "Emotional Growth").

Quality of relationship

Health providers who appeared in stories of recovery were often seen as as having a special quality of relationship with the participant. Being easy to talk to was mentioned, as was trust, feeling equal, being

supportive and helpful, and being respectful. *Amy,* for example, said, "If I went to my GP tomorrow she would give me Aropax like that ... But we choose to do it a different way." *Pare,* describing a nurse, said, " ... it was like she lifted down and pulled me out of a black hole, just being there". Several mentioned health providers who believed in them and didn't see them as "mad".

There were stories of providers who went the extra mile. *Lee's* psychiatrist continued with her therapy despite shifting cities, driving back once a week especially for the session. *Ata's* district nurse set up a methadone programme for her, and helped to the extent of shifting into the house to be with her during this period, even arranging for her own husband to take Ata's child for the duration. *Hirini* told us how the support person for a voluntary agency always made her flat available for anyone to call in, and was always happy to talk and provide kai. *John's* psychotherapist was very insistent on having John make a pact not to commit suicide, and would keep returning to the topic, even if it took half the session before John would agree. And one of the more dramatic stories, already told, was about *Annie's* psychiatrist, who as part of Annie's escape plan actually sedated Annie's husband.

Health providers as teachers

The section on "Research, Reading and Learning from Others about the Mental Health Problem" contains some appreciative references to health providers who taught the participant something helpful about their mental health problem, enabling effective recovery strategies. Other forms of learning, too, were sometimes helpful. In particular, a number of Maori participants described learning from health workers about Maori culture. This strengthened their Maori identity, helped them resolve some conflicts, and increased their pride and self esteem. *Tua's* "spiritual awakening" through a teacher of carving in a mental health facility was described in the "turning point" stories.

Health providers creating an appropriate cultural setting

Many of the Maori participants paid tribute to Maori mental health workers and traditional healers who provided an appropriate cultural model which assisted in recovery, for example, a whanau setting in a mental health facility. For *Matua,* who was secluded because he was aggressive, it was just a Maori face which helped him calm down ("because you know that at least they've got that aroha, they've got the wairua"). Cultural contributors to recovery are discussed in more detail in a separate section of this report.

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[2] Nearly all participants had made use of health services during the course of their mental health problems. Other references to professionals as helpful (or otherwise) are to be found in the illness stories, in the chapter on mental health interventions. The figures used in this chapter refer to help featuring in recovery stories. It should be remembered that recovery, for some participants, advanced dramatically when they decided to leave mental health services behind (see turning point stories).

Support Groups

The support of others in group settings was a significant factor in nearly half the stories of recovery. In most instances this came in the form of organized support groups, but for some this support was from other patients in a psychiatric ward, particularly in Maori mental health settings. (In some of the stories, in contrast, there was no sense of kinship with others in hospital, but rather, a deep sense of alienation.)

Francis found the company of other professional people in hospital and this helped his self esteem. *Frank* found a sense of kinship with other patients. *Cathy* said:

> "I had the support of the staff you know, and the clients – it was a whanau situation and a marae situation. It really, really was a bond for me and a longing that I never had because I never had that sort of thing when I was younger."

Matua was fond of his fellow patients. He said that they were:

> " ... some of the most beautiful people you could meet. Like, I felt that I had an identity with them because we had all been through the same things. Like when we used to sit around and tell each other about how we used to commit suicide, that was a real buzz, ha, ha. You know, that's pretty morbid, but when you're in a morbid place, you've got to have something to crack you up, have to have a sense of humour."

GROW was crucial to the recovery of three participants. *Jen* told us about going with a friend to her first GROW group "to help us with our confidence":

> "We went into this room and there was like twenty-four people there, which was amazing. I am sure that was the biggest GROW group ever in history. It was really lovely ... Tania said the same thing – Tania is a very shy person – it was one of the first times where we both walked into a room and didn't feel funny or strange – any of those kind of things. It really was ... quite lovely and like that was the major turning point there. I remember them giving us this bloody little blue book – us taking it home and we'd discussed it all the next day and she wasn't too sure. 'You don't know about them mad people,' Tania says. I said, 'Oh no, no, it will be alright, we'll just go and before you know it, we will have our confidence back and we'll just be fine.'"

She went on to explain the principles of support groups:

> "It really was a very humbling experience for me because I tend not to share a lot of what is going on with myself emotionally unless it is happy. But the bad things I don't. I ... didn't often say, God I feel miserable or whatever. So it was a humbling experience and it was good to be able to be honest with people about how I was feeling and knowing that I needed the help, and it is that mutual help process. Because as we give other people the experience of our knowledge and understanding, and they are doing it back – you have to practise what you preach, eh?"

Jen told us how she learned the GROW principles by rote so that she could apply them without looking up the book. She applied the "principle of ordinariness" to getting a broken window fixed (she normally avoided speaking to strangers) and the same principle helped her break the urge to take baths frequently throughout the day. The "principle of regard" helped her to stop losing her temper. When, six months after beginning with GROW, she started hallucinating spiders again, she desperately searched in her mind for a solution: "Oh God, what would Barb [a fellow GROWer] tell me to do?" "I'll go by what I know, not how I feel", was what came into her mind. Jen said:

> " ... that was the turning point ... I haven't had that again since, except once when I was in bed one night and I could feel the spiders crawling on my legs and I was thinking, 'Oh God, here we go again.' But when I actually had a look, it was a moth (laughs) and it was real and it was there and it was moving."

GROW was the turning point for *Kim,* too. It helped her learn strategies for dealing with depression, and it also gave her friendship and the experience of being loved for herself:

> "I can literally say that I was loved back to health. And this feeling of self esteem when somebody does love you and believe in you and things like that and personal value, which is the first GROW principle. No matter how bad my physical, mental or spiritual condition, I am still a human person, loved by God and a connecting link between persons. I am still valuable, my life has a purpose, and I have my unique place and my unique part in God's work. And so they made me read this and I thought I don't believe this. And they said don't worry about it. Just read it and in time you will come to accept it."

Jane belonged to GROW for five years. It was "hard work", and initially she wondered what she was doing there, but hearing testimonies from other people who heard voices, too, made her feel less on her own.

Organising in groups as users of mental health services provided an important source of group support for some. *Frank* went on from feeling totally accepted in the hospital ward to become a pioneer of the consumer movement. *Lee* and *Tasimauri* became consumer advocates. *Matua* enjoyed the Maori "psych survivors" group he belonged to.

Other types of helpful groups included support groups for people with bipolar illnesses, AA, feminist self help therapy, Maori women's groups, residential communities and a psychodrama group. Support groups generally provided a sense of collegiality (being with others in the same boat), supportive others, humour, useful advice and strategies, increased self esteem and an end to shame and isolation – all in all, a very powerful mixture for some participants.

Miscellaneous Helpful Others

Several participants mentioned supportive bosses or work colleagues as helpful in recovery. One mentioned her cat and her horse. One referred to role models. A couple mentioned the spiritual presence of others, in one case, embodied in a protective taonga, and for another, the ghosts who brought her out of a suicide attempt. Steve told us of a complete stranger while he was a hermit in the bush, who sat waiting patiently for him to make contact, finally luring him into human company with the smell of sausages cooking.

To conclude, the kinds of support from others which facilitated recovery included:

- a kind, friendly, accepting presence;
- loving inclusion (in groups, such as whanau/ family and support groups);
- faith in the person's ability to recover;
- showing the way (people who had been there already);
- providing the tools for recovery in a way which facilitated learning and allowed for negotiation and choice (health professionals and support groups);
- providing practical help which enabled the person to achieve the conditions necessary to recovery.

VIRTUES – PRACTISING THEM

Altogether, 34 participants talked about fostering healthy attitudes and practices to help them move towards recovery. We named this section "Virtues", as it describes a set of good health practices which potentially provide some advice on how to live the good life during recovery from mental ill health. The "virtues" have been categorised into:

- good general health practices;
- keeping away from situations and stressors known from past experience to worsen mental ill health;
- recognizing warning signs of impending mental health problems and taking preventive action;
- using medication thoughtfully and in a considered way to maintain recovery;
- emotional release;
- psychological/cognitive techniques to overcome thoughts and behaviour symptomatic of ill health;
- spiritual practices;
- pushing at the limitations that have arisen as a legacy of the mental health problem.

Good General Health Practices

Looking after general health was important in recovery. Keeping in good shape, not getting run down, looking after oneself – these were ways of describing the value placed on health overall. Five participants, four of them men, said that physical exercise or working outdoors helped them stay mentally healthy. Others referred to the importance of good eating habits and dietary supplements, such as vitamins. Still others mentioned the importance of enough rest and sleep.

Some found alternative health remedies good for general health, or for the relief of stress and depression. Bach flowers, St John's Wort, massage, reiki healing, rongoa, mirimiri and relaxation techniques were all mentioned.

Several said that dealing with a physical health problem was important in mental health recovery. For *Jen,* getting a hearing aid helped her to engage in normal social interaction instead of avoiding people; and for *Lee,* learning alternative techniques for dealing with asthma was crucial to her plan to avoid psychosis-inducing cortico-steroids.

Avoiding Known Triggers and Stressors

Avoiding alcohol and drugs

Avoiding alcohol and recreational drugs, particularly when they had been used abusively in the past, was a theme for a number of participants; and giving up smoking tobacco was mentioned by one. Participants had sometimes made use of alcohol and/or drugs to dull the emotional pain which was the background to the mental health problem. For some, alcohol and drug abuse were intertwined with their experience of mental ill health.

During the recovery stage, *no* participants felt that heavy use of alcohol or drugs was warranted; some avoided these substances entirely and some used them much more cautiously. Only *Johnny,* recovered from out-of-control use of alcohol, felt OK about using marijuana regularly. He said it had helped him during the period when he was determined to stop "going out and getting wasted".[3]

Avoiding prescription medication

For some participants, avoiding prescription medications, even when recommended by their health practitioner, was important to recovery. Previously in this report we pointed out that many had disliked psychiatric medication for reasons such as weight gain, inactivity, feeling like a "blob", inability to concentrate, becoming a "zombie" or "all spaced out".

In some instances, the rejection of psychiatric drugs was deeply felt, and the result of a brave and difficult decision. *Mary's* flight from a decade of drug prescriptions and hospitalisation is an example.

Avoiding stress

The importance of avoiding stress, overwork, over-commitment or taking on too much responsibility was emphasized, since these were factors sometimes implicated in the period leading up to the mental health problem. "Knowing my own limits" was a phrase used.

Miscellaneous

Other stressors or situations to avoid, mentioned by a few:

- "poor me" type of thinking;
- impulsiveness;
- abusive or negative people, and people who discouraged your chosen recovery strategies;

- peer pressure;
- financial risks.

Recognizing Warning Signs of Impending Mental Health Problems and Taking Preventive Action

"Researching, reading and learning from others" told of learning to recognize the signs of incipient illness. Good mental health practice meant acting on this knowledge. As *Mako* said, "I know when I'm going to lose it. Now I know what to do." *Matua* told us how he used to let things build up until "they just blew"; now he knows the importance of talking things out.

Many mentioned warning signs such as several sleepless nights, not eating, or high stress levels. For those who heard voices, increased activity from those sources was a sign. Once people had become familiar with these signals, they were in a position to take action to prevent things from getting worse, by avoiding stressors or using some of the mind management techniques described later in this chapter.

Using Medication Thoughtfully

The initial selection criteria for this project stated that participants should no longer be using prescription medications. This requirement was modified as the selection procedures developed, so that we could include stories from people who had recovered dramatically from lives disrupted by mental ill health, but who nevertheless still made use of medication. In the end, seven participants referred to continuing or occasional use of medication, but they emphasised that it was their decision.

One or two were completely comfortable about "following doctors' orders", as they had learnt from painful experience that they could not have recovered without their prescription drug regime. The others had learnt by trial and error, often in cooperation with their doctors, what circumstances warranted a prescription and which medications were appropriate. If medication was ongoing, recovery usually involved lower dosages than during the illness period.

For example, if *Matua* did not sleep for two nights, he needed to take quick action. Medication to help him sleep on the third night would mean that he got sufficient rest and stopped going downhill. As he put it, it's " ... just a matter of accessing those systems to get the medication without all the big interviews and the SS interrogation".

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[3] Johnny was the only participant in the study whose central problem was alcohol abuse, which differentiates him from the other participants.

David's story about telling new doctors exactly what his problem was and what drugs were needed was mentioned earlier. For *Bruce,* anti-anxiety medication was a "last resort", but it was helpful that he could access it if needed.

Emotional Release

The previous section on "emotional growth" described self-discovery processes undertaken as part of the journey towards recovery. Some techniques needed to be used in an ongoing way:

- to release emotional stress
- to deal with painful emotions;
- or as a continuing process of self-development.

People referred to relaxation, keeping journals, analysing dreams regularly, or writing poetry, stories and songs.

Another vent for troublesome feelings was talking about them with someone. For those who were unused to talking freely about their emotions, this had to be learnt.

Psychological/Cognitive Techniques to Overcome Thoughts and Behaviour Symptomatic of Ill Health

Many participants were taught – or discovered for themselves, through trial and error – how to maintain mental health and diminish symptoms of ill health, using psychological strategies. Although there were no descriptions from participants of the currently popular cognitive-behavioural interventions, it is interesting that some people managed to discover such techniques for themselves. Others were able to access them through support groups, notably GROW.

Some tried to organize their thinking patterns so that troubling thoughts did not dominate. *Paddy,* who recovered from depression, learnt to "channel my thoughts in a different direction", not "dwell on unhappiness" and "head it off before you get to the point of no return". *Amy,* who had a breakdown when thoughts of an earlier trauma became intrusive, used self talk to ward off unpleasant thoughts:

> " ... if I'm thinking something that isn't right and if I don't catch myself out then that's going to lead to another thought and that's going ... you know ... what fills up a bucket? You know. One drop after another. And then you've got it overflowing ... "

Simply forgetting about things was *Jack's* strategy (he couldn't recall some of the shameful things he'd done during his mental ill health). *Jane* tried to keep herself busy. *Johnny* used realistic thinking and honesty with himself to avoid peer pressure to drink heavily. He learned to moderate his intake by using self-talk, such as "I'm going out to have a few to relax" instead of "I'm going out to get smashed." He set himself motivational goals and regarded his cutting down as similar to training for a marathon.

For *Katie,* having had a period of being "totally emotional" allowed her to learn how to control her impulsiveness and become "cold and rational" about what she was doing. Gradually she learnt to think before she acted; but she told us that it was having emotional release that gave her the breathing space to do so. When she allowed herself to get really angry with her husband, who had left her for another woman, she gave him two black eyes. Katie told us she felt much better for it, but perhaps we shouldn't be describing this action as a "virtue"!

Alan needed to set goals to motivate him to be "a human being":

> "[I]t could be as pathetic as getting up and getting dressed, making a decision to live today – phone up a friend – or it could be as significant as going to help someone who has asked for support."

Lee spoke to herself sternly after she became extremely distressed during a gynaecological examination (she had been sexually abused as a child):

> " ... it actually flipped me into a whole pile of stuff and I handled it wrong. And, I mean, looking back on it I should have talked myself through it, instead I just went away, and I sort of exited somewhere. And that was, looking back I think, well, in three years' time when you gotta go through this again, you don't leave, you stay and talk to yourself."

Sayings, affirmations and proverbs (whakatauki) were helpful to some in maintaining an optimistic outlook, or in encouraging them to act in a certain way. *Sylvia* learnt self help techniques from a book on fears and phobias, which taught her to walk right through the feared situations by telling herself that "jelly legs will carry you through". She described the advice as summed up by the phrase, "feel the fear and do it anyway".

Participants who had found GROW helpful usually mentioned the maxims they had learnt there, which helped them "train their thinking". *Jen's* use of maxims to guide her behaviour in situations where she was tempted to behave abnormally was mentioned in the

earlier discussion of GROW as a support group. What was useful to her and to others were sayings such as "your thoughts can compel your actions", "go with what you know, not how you feel", the principle of regard for others and the principle of being ordinary. *Kim,* whose life was turned around by GROW too, said that at least "nobody told you to pull your socks up"; instead, they offered tried and true techniques in a supportive atmosphere.

GROW techniques also helped *Jane,* who heard voices:

"There was a time when I didn't know any better that I may have harmed my kid, because he was crying and I was tired and he was sick and I didn't have Mum here. There was a pair of scissors sitting on the windowsill and this voice just came from nowhere and said, like, "Just stab him and then you'll be fine," and it really just threw me. Because if I didn't know any better I might have done it, but because I was, you know, just there, I actually got the scissors and threw it up out of sight and just went about doing my work or whatever I had to do.

I learnt in GROW that if the voices come in you just have to distract yourself by doing other things. You can acknowledge that they are there, but you just distract it by doing other things, not hooking into the head things that are going on. How do you do that? Ahh ... not go along and act it out. If it says, 'Go out the gate and go down the road and go and get some money from the money machine, sixty thousand dollars', (laughs), you don't act on it because in reality you haven't got sixty thousand dollars (laughs). But this is what voices can do sometimes, ah, just takes control so you actually learn to control that and debunk it, yeah. And you talk it out with your friends or you can take it to the group. The group is held regularly, for two hours every week, it has to be every week so that you're practising a program to change your way of thinking, your way of coping. So it's not unhealthy coping, so that you stay in reality."

Hare, who had heard voices since childhood, reported using similar techniques to deal with them. He said:

"I don't hear or, well I'm not frightened of the voices anymore, they're just security sirens to keep me on track ... I just have to monitor myself ... If I hear a voice telling me to go and rob the bank I say, 'Which one won't have the alarm or video?' Nah, seriously, when I get overtired of trying to do, you know, bloody lots of things, I just have to say no."

Lee told us that she sometimes feared a return of psychotic symptoms or severe depression when she noticed little signs. Her solution was to "normalize" such signs instead of pathologising them:

"Like, if I wake up in the morning and I feel really down, or just can't be bothered getting out of bed ... , I have to normalise that and say, 'Heaps of people wake up in the morning. They don't want to get out of bed, you know, bed's a comfortable place", and normalise that ... Coz what used to happen when I initially, in '95, which was my first year with no admissions since '88, I'd wake up in the morning and I'd feel like that and I'd be absolutely petrified that I was getting sick, I'd be absolutely beside myself and that, you know, sort of compounds on itself, really."

Humour could also be a lifesaver; and some people also referred to techniques which promoted mental relaxation.

Spiritual Practices

Spiritual or religious practices were mentioned by some as aids to recovery. These included meditation, prayer, karakia, calling to mind religious sayings or proverbs, and following religious discipline. *Francis* found that taking his Catholicism seriously helped. *Sylvia* discovered that Quaker meetings, with their meditative practice, were strengthening. *Tua,* who experienced a spiritual awakening in hospital, was told by someone there that he needed God, and when he protested, he was told that God meant "Good Orderly Direction", which was indeed what he needed to recover from his chaotic lifestyle and drug-induced psychosis. *Rawiri* discovered his "inner wairua" and became his own best counsellor.

Other spiritual practices included *Pare's* description of going to have a "reading" where she was encouraged to carry out a ceremony which "released into the light ... a lost soul" who had been abusive to her, which set her mind at rest. *Joan,* whose story is told in "Turning Points", had an unsuccessful attempt at exorcising her manic depression, and then spent a period of time considering, through prayer and bible study, what might make another attempt succeed – and it did. *Ataimihia,* whose childhood was abusive, learnt from her kuia how to remove her body from the physical world. After her kuia's death she was able to enter that realm and take comfort from her.

Solitude and quietness

Many spiritual traditions emphasize solitude and quietness. For some participants, a period of solitude was part of the recovery process, though it did not necessarily have a spiritual basis. Solitude allowed for a sorting out of emotions, recovery from stress and a mustering of personal resources. The two most dramatic stories of solitude have already been mentioned: those of *Steve,* who became a hermit for several years, and *Ataimihia,* who literally stopped speaking for eight years. *Tua* found his partner sympathetic when at times he just needed to cancel work commitments and stay in his room for a day or two; and *Huia* found that people understood that she wanted to be by herself when "the loneliness birds" arrived.

Sylvia, suffering from agoraphobia, found the silence of Quaker meetings strengthening:

> "I went to Quakers to ... seek a bit of grounding and spiritual strength, to see if there was something within me that would allow me not to chicken out [of a forthcoming trip]. And I found that process of the hour's silence was, yeah, it did give me strength, it was amazing. [It helped me say to myself] get your priorities sorted, you really want to do this, it's a matter of importance. And, you know, there is help. Not necessarily a higher power or anything like that, but within you, you have the resources to help yourself."

Pushing at Limitations

Some participants said that it was important, in recovery, to push themselves beyond the limitations imposed by illness. For *Georgie* this meant avoiding the tendency to seclude herself and practising reading again after losing her concentration. For *Jen, Johnny* and *Sylvia,* it was being able to face their behaviour with honesty, avoiding rationalisation and being open to hearing other's views. For *David,* it was important to face up to failure.

The "virtues" described in this section were many and varied, and a little difficult to categorise. In a related project on recovery from depression,[4] a participant mentioned that she could list more than 30 techniques for getting off to sleep. This remark made us aware of the multitude of possible techniques there could be for dealing with the variety of symptoms that can be part of a mental health problem. A larger group of participants would no doubt have produced many other

creative ways of dealing with particular situations. So, this list of good mental health practices derived from our participants' stories should be seen only as indicative, not comprehensive.

ETCETERA

Some miscellaneous contributors to recovery, mentioned by one or two participants, are not covered by the above categories. In particular, several participants mentioned money. For example, *Francis* felt that a key factor in his recovery was getting together enough money to buy a house that he loved. "I don't care what anyone says", *Alan* said, "Money helps ... It's easier to get sick, physically or mentally, if you haven't got money." Financial resources were, of course, highly important, even if not singled out for mention as a recovery technique. The chapter on consequences made it clear that mental ill health had a strong financial impact for many participants.

REPEAT STRATEGIES THAT WORK AND REALISE THAT RECOVERY TAKES TIME

Participants frequently emphasized that recovery is a trial and error process. It takes time and requires vigilance and the repeated use of helpful strategies. *Alan* said he " ... went searching for what helped and ... tried many things and different ideas". His advice was, "Try it out – if it works, good, and if it doesn't work, well, try something else." What especially worked for him was each day affirming his decision to live. Then, "there just came a day when I woke up and I realised that I hadn't done it for some time – and it surprised me ... I don't know when that was – I couldn't put a date on it – recovery started here, if you know what I mean."

Becoming reconciled to taking the time needed for recovery was important for many. *Denis* said he felt better when he recognised that his illness was "a passing phase in my life that wouldn't destroy me; it would upset me for some time but I would get through it". "It takes as long as it takes", said *Katie.*

On the other hand, *Kim* said of an early experience of mental ill health that "time is a great healer" but that one may learn nothing to equip one for the future if recovery has been solely due to the passing of time. For *Sylvia,* her first episode of agoraphobia involved gradual recovery over time, but she did not learn effective techniques for dealing with the problem until it recurred several years later.

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4 A PhD project by Jan Wilson, presently underway.

As *Johnny* put it, "So you're on the journey. You've started the journey and that's the thing, the starting is the hard part. It gets easier as the journey goes on."

The Recovery Framework: HEART

HOPE

Some states of mind are hard to put words around, but are important for many on the road to recovery. These include hope, faith, a sense of direction, a belief that one's life has meaning and purpose, a faith in something outside of oneself, and the feeling that one is meant to live, that one has something to contribute. Some express these ideas through their religious faith, while others have different frameworks.

It is clear that having others believing in you kindles optimism and hope. "People believed in me", "people had faith in me", "people gave me hope", said participants. *Tasimauri* said, of her return to her Pacific homeland, that it was:

> " ... very positive to be around people who were so supportive of me and so concerned for my well-being and it gave me a lot more joy and a lot more spark for the future."

Others emphasized their recognising something fundamental within themselves that emerged at a life-threatening time. For *David,* whose wife had left him, recovery started the day after he tried to commit suicide. He decided:

> "That's it, I'd had enough more or less and I just wanted to live the rest of my life and just enjoy it, to hell with anyone else."

For *Denis,* it was:

> " ... the indomitable spirit in me, and that might come from family support and everything else – but even though I see a light at the end of the tunnel, and a lot of the time it is a friggin' train coming the other way and it clobbers me – ... there is a little flicker of flame inside me that will refuse to give up."

Developing a belief that life has meaning and purpose was part of the recovery transition for *Alan.* He struggled

with suicidal wishes for a long time, and found himself getting better when he got angry and challenged "prognoses of doom" from the mental health system.

After covering up his mental health history, he got onto an Access Programme where he was able to do creative work alongside others. This was a turning point:

> "I certainly felt a lot better when I got a job and I started recovering a lot more effectively, when I had meaning and purpose in terms of work."

He also got himself a cat:

> " ... the most meaningful thing can be to help something grow, so I got a pet cat and then it became one more reason why I couldn't die, because who would feed the cat? I know it sounds ridiculous ... "

He concluded:

> "I am okay – there is a part of me that wants to live – and I was very fragile outwardly and yet, what people didn't understand was how robust I was inwardly."

For some participants, hope and faith came in the form of religious beliefs. *Joan's* story of exorcism is told in the section on turning points, as is *James's* story of repentance. *Tasimauri* injected a note of caution about religion, saying she used to use God as a crutch, and sometimes during her illness she had religious delusions. For a while she became:

> " ... very fundamental in my beliefs and now I've come out of that because I was looking for all the answers and I thought the answers had to be black and white, but it's not like that. I've still got my faith, but I haven't found that it's given me an automatic key to success, happiness and love."

Bruce and *Ruiha,* though, felt immensely strengthened and gained hope from the prayers of their spouses and their church groups.

ESTEEM (SELF ESTEEM)

Restoring or gaining self esteem was implicit in most accounts of recovery and was mentioned explicitly by more than half the participants.

Denis made the point that having a mental health problem "destroys your self esteem" and for him, coming to understand his mood disorder as not "totally emotional weakness" meant that he was able to see himself more positively again.

Achieving new goals and picking up again on previous activities helped restore self esteem for some. Involvements mentioned included yacht racing, enjoying a friendship, taking up study, getting a job again, coping with family responsibilities, getting a house or moderating drinking.

When low self esteem had contributed to the problem to begin with, achievements boosted self esteem. *Katie,* for example, had always been told by her family that she was "dumb". When she enrolled at university, despite their ridicule, she earned a really high grade in her first assignment and she felt much better about herself. Educational achievements were a theme in a number of narratives.

Some participants spoke of increased self esteem making them less dependent on the approval of others. *Kim,* for example, said that comparing herself unfavourably with other mothers had contributed to her depression, but through GROW she found "this feeling of self esteem when somebody does love you and believe in you and things like that".

Hirini, recovering from anorexia, told us that sharing his story with other young men boosted his self esteem:

> "Yep, that was about the biggest wow thing for me, you know. At first it was hard facing all those young tane and their firm bodies and the taiaha, man, once I held that, my life took on another meaning. I remember the first time holding the taiaha and thinking, am I really a worthwhile person to tell these young men how to be proud? I looked at my not too firm body and I really wanted to cry, but once I held onto that taiaha things really did, well, they changed big time."

Alan summed it up: "Recovery for me meant coming to value myself for who I was."

AGENCY

Having agency means believing that one can control, or at least influence, the circumstances of one's life. Even though our lives are affected by external circumstances, believing one does have some control is important to mental health. Alternatively, feeling helpless is inimical to mental health.

Agency is a key element in narratives of illness in recovery, because it is integral to the most dramatic moment of narratives, the turning point – when participants truly become the heroes of their own lives and cease to be victims of circumstance or controlled by others, including health professionals. Although support and intervention from others was crucial too, it was important that support stimulated personal initiative, rather than creating dependency.

Because turning point stories have already been examined in detail, there is no need to discuss agency at length. But it is important to emphasize that achieving agency is one of the most important processes of personal change during the recovery process. In a very real sense, it is at the heart of recovery.

Also, it is worth analysing themes arising under agency. With *taking charge* as the key theme, the *ways* in which people took charge showed some variation.

The most dramatic turning point stories, such as *Mary's* leaving hospital and the care of her psychiatrist after a decade of mental health treatment, or *Lee's* giving up the steroids which caused her psychoses yet prevented asthma crises, involved a *defiant or decisive act* of taking charge. Such an act set the participant on a different path from the timeless zone of the mental health system, where agency had been stripped away, onto a pathway which would lead eventually to recovery, despite the doubts and fears of others. Many of these defiant/decisive actions involved rejecting mental health treatments. However, in *Jane's* case it was a matter of deciding to make use of treatments which had been spurned – when she found herself heading for the back ward after pretending to take her medication.

Other decisive actions revolved around taking charge of one's life circumstances, rather than mental health treatments, such as *Katie's* decision to get better so that she could regain the respect of her children, and so that the ex-husband who had rejected her would not have "won". Giving her husband a black eye when he turned up with his new woman symbolised, to her, taking control of her own life.

Some *decisions in favour of health* were less dramatic, but still involved taking charge, such as enrolling at university, or deciding not to drink or abuse drugs – all those small acts of personal courage involved in undertaking good physical and mental health practices. Having learnt about the pattern of one's illness also helped increase agency. *Lee,* who had achieved recovery and was getting on with her life, nevertheless recognised a point where she had become in danger of getting ill again:

> "I was sitting on the front doorstep one night with my partner and it just suddenly, it clicked that I had a choice, that I could let this progress and end up in hospital and have undone all the good stuff that had been worked through ... I was ... saying, well, ... that would be really nice to go into hospital and be looked after and ... it clicked in my head somewhere that I actually did have a choice, I didn't have to ... go down that road."

Finding a voice, making one's own decisions, having the courage to be oneself – these competencies grew gradually and were fundamental to taking charge. They were often related to transitions in identity which we discuss later. Some emphasised the importance of making their own decisions, as opposed to doing what others thought best:

> "[The family] just got used to telling me what to do. And when I started saying no, I don't want to do this any more, well, it took them ages to actually allow me to be in charge of my own destiny." *(Matua)*

> "I make my own decisions now, all of them, not just some. I've achieved that and really, if I feel like I want to be in a crowded room and stick to myself, I do it. I don't feel bad about it. And when I'm ready to leave someone's company, if I've had enough, I don't think that I have to excuse myself, I leave." *(Georgie)*

> "I said to myself, I would not allow myself to be stood on, so I made a commitment that I would communicate with every single person [in the family] even though inside of me it was tearing me up. I think the thing was, I have made these choices, no one has made these choices for me, and that's the strength I have." *(Tua)*

Lee talked about how therapy had made her realize that "I had rights, that I had a voice, that I have a right to say things and not say things, a right to say yes and no". *Jen* described "learning to set my own standards for myself". She remarked that when you are breaking

down, people tell you what to do, but that it's important to get out of that pattern and make decisions in your own best interests, not in order to please or impress others.

Annie, describing a relationship after she had recovered, said:

> "I was stronger. I was able to talk back better and I gained a voice ... I have realised ... that my voice in certain circumstances becomes very fragile. And having a voice is crucial to my mental health."

Getting into the driver's seat was also helped, for some participants, by *having a goal* that they really wanted to achieve. *Sylvia* decided to fight her agoraphobia with determination when she was offered a job which involved a lot of travelling. The desire to keep their children motivated *Katie* and *Ataimihia* also to tackle problems which previously had been defeating them. *Annie* was overjoyed when a scholarship application to graduate school was successful:

> "It was wonderful, it was absolutely wonderful and I felt such a sense of agency. I had decided what it was I wanted. I went for it and I got it."

Determination, strength of mind, self-responsibility or willpower – all strategies which involve trying to wilfully overcoming the symptoms of mental ill health – were usually a hopeless task when one was in the grip a mental health problem. Mental ill health seemed to fracture the will, and being told to "pull one's socks up" by well-meaning friends and relatives usually made participants feel worse. However, at or after the turning point, with a better understanding of the shape of the problem and a strong incentive to leave the problem behind, determination became an ally.

Kim found the very specific advice given out by GROW, with its supportive group atmosphere, helped to alleviate the paralysis induced by depression. The little wisdoms such as "I can compel my muscles and limbs to act rightly" helped her to get out of bed in the morning and enabled her to become more reliant on reasoning, rather than feelings: "I'd given in to my feelings and when you're disturbed you can't rely on your feelings anymore."

Johnny prided himself on health and fitness. After an occasion when he coughed up blood and worried about "killing myself slowly physically", he became determined to do something about his drinking. He compared giving up drinking with training for a marathon, focusing on step by step progress:

"At the end of the day it's a control thing, it's self discipline. You know deep in yourself what your limits are or what you really want out of your life ... [T]he only person who can solve a problem that you have is yourself."

Spiritual assistance featured in a few stories as helping to strengthen determination. *Sylvia* told of gaining strength from the silence of a Quaker meeting, where she had asked for help to overcome agoraphobic symptoms so that she could undertake a difficult task which was morally important: "And you know, there is help, not necessarily a higher power or anything like that, but within you, you have the resources to help yourself."

Tasimauri, when she walked over the land of her ancestors, realized that "I couldn't live my life going from one mental institution to another ... I knew that I had these experiences for a reason and ... maybe God's plan for me was that he would put me through as much as I could take and then I would recover from that and use that to help other people."

RELATIONSHIP

As we have seen, the support of others is the most frequently mentioned factor in recovery. In this section, we focus not so much on how participants accessed support from others, but on changes during the recovery process in relationships to others. Here we discuss different kinds of relationship change.

Change in existing close relationships could mean moving away from family, so as to be free of their expectations, or alternatively, spending more time with family for comfort or support. Stories on this topic included *Huia's* account of finding herself in a leadership role among her family at a tangi and feeling loved and strengthened as a consequence. *Fiona* told us about her grandmother's teachings on whakapapa, which helped her understand that her actions affected not only herself as an individual, but also her whole whanau's past and future.

New and sustaining relationships were a stimulus to recovery for several: for *Francis,* it was a new love relationship; for *Amy,* another horse replaced the one whose death had precipitated a mental health crisis. *Hirini* and *Jane* emphasized learning to make connections to others through friendship.

Some participants developed a whole *new outlook on relationship and connection. John's* experience in a community helped him with more responsible and open ways of interacting. *Annie* came to understand that broadening her networks would mean that she would never again allow herself to be dependent on just one person. *Jen* valued the lessons about relationship which she learned from GROW – that you had to have regard for others despite your own feelings.

Moving towards helping others rather than receiving help was another significant theme. Both *Kim* and *Jen* were influenced by GROW. *Kim* now saw herself as a connecting link between people, and *Jen* referred to the principle of mutual help – that if you help someone else, you also let them help you. Some emphasized the importance of voluntary work. Others said that telling their story to others was a way of offering help and also played a role in their own recovery, through having the confidence to expose their own vulnerabilities. *Bruce,* working in mental health, told us:

"Over the years I have been privileged to hear other people's stories and I know that they have had a real impact on my own life ... I think probably the greatest healing for me is that I have a story and it is important to share it and I have done so in many situations."

TRANSITIONS IN IDENTITY

Many people, having learnt to fit comfortably into their lives as adults, have no need to question their identity. However, the experience of mental ill health unsettles much about life that had previously been taken for granted. It thus provides the impetus for a process which often leads to transitions in identity. Other profound experiences, such as disabling physical illnesses, may have a similar impact.

Many participants, though, told us that they had felt ill at ease with themselves *before* their mental health problem took over. As they took charge, during the recovery process, the need to be clear about who they were and where they felt "at home" became strong.

Identity change can be a long process, beginning during recovery and continuing into life afterwards. In this section we discuss identity stories told to us during talk about recovery. Further material on this topic is analysed in a later chapter, on life after mental ill health.

Identity in adults is built on investigating "Who am I?" "Where do I belong?" "What makes me unique?" and "How am I connected with others?" Within psychology, the notion of identity is a complex construct involving a number of dimensions, personal, social and cultural.

Identity transitions, although they could begin suddenly, seldom meant the dramatic adoption of entirely new identities. Rather, they involved the reorganisation and revaluing of problematic, discounted or suppressed identities and shifts of group allegiance. Sometimes it was a matter of resisting family/whanau or social expectations that had been experienced as damaging. Throughout recovery, participants came to understand themselves better and to accept their individuality, at the same time exploring shifts in family, social or cultural allegiances.

During the recovery process, this reorganization could involve rejecting a permanent illness identity for oneself, yet still feeling connected with others experiencing mental ill health and affiliating with consumer organisations. Quite a few began an enduring link with the field of mental health. Dedication to alleviating the suffering of others, whether through association with consumer movements, voluntary work in mental health or a career transition into the mental health field, was a feature of reshaping identity around the experience of mental ill health which continued into life afterwards.

In what follows we cannot do justice to the complexity of the narratives; rather, we briefly describe and illustrate some central themes.

Personal Identity

Learning to value oneself as an individual and resist the expectations of others, particularly family members, was important in a number of the stories. *Georgie,* a Maori participant, said, "My family were really eager to have me be who I was before I went to hospital." She described how she had to fight for her own individuality.

Alan talked about "creatively constructing a new personality". *Matua* said:

> "It was hard that no one could really understand me for me. You know, you're so and so's son or you're so and so's brother ... and to me it's, 'So, what about me, don't you want to know me?'"

For some participants this assertion of self was seen as part of maturing. "I was growing up ... I was quite unsure of myself", *Sylvia* said about her late 20s. *Susan,* talking about herself around the age of 20, referred to "a growing up process that was taking place despite itself". For *Mary,* after having spent her 20s in and out of psychiatric facilities, it was a matter of getting a life of her own.

Women, particularly, had to assert their individuality against the expectations of traditional roles for women. "Something within me wanted to broaden my horizons", *Sylvia* said. *Ruiha* said that becoming unwell was:

> "all about trying to ... please people ... rather than have a vision of whatever it is and concentrate on doing something and just going ahead ... I'd be living, you know, I've done this for my husband, I've done this for my children ... I was trying to convince people that I was what I wasn't."

Katie, recovering from a breakdown after her husband had left, said: "I was my father's daughter, I was my husband's wife and now I want to be just me for a while." For *Annie* it was more about regaining what she had lost during her abusive marriage. She had been highly regarded in her family of origin as "the person they came to for advice ... So it was getting back that view of me which turned out to have had a lot to do with my identity, I suppose ... it was the regaining of that identity that fed into my recovery."

Not so many men spoke of having found masculine identity constricting and relating to their illness. *Frank* was an exception. In prison he had become a "hard man". Later on, as he came to accept his vulnerabilities, he decided that masculinity "is just a whole lot of shit, you have to be a human being first". *Tua,* with a gang background, told us how a counsellor:

> " ... instilled in me the belief that I am half wahine, half tane and that I can't lie within my mother's womb for nine months and not have her in me. As well, my father is part of me too ... she offered me these taonga."

Maori Identity

Maori identity issues formed the strongest theme relating to identity and recovery. For around half of the Maori participants, Maori identity was taken for granted before experiencing mental ill health. Recovery, therefore, was not centred around Maori identity issues for these participants, though they often realised the importance of valuing that identity. Their own experiences of mental ill health often engendered an enhanced commitment to developing support systems appropriate to Maori, especially if contact with monocultural services had made matters worse. *Matua,* for example, told us:

"I think, like, having my Maori identity was the big one. It wasn't until I got [to the hospital] that I found out that there was a lot of people, lot of Maori in there, who had no knowledge of their Maoritanga. And they were coming and asking me and I thought – it made me realise ... what I did have compared to others and that I was able to help them."

But for the others, enhancing Maori identity played an important role in recovery. Quite a few, particularly men, told us how increased pride in themselves as Maori was important.

Edward said:

"The big thing ... was getting in touch with my taha Maori. Man, I never used to be proud of being Maori ... thought saying Kia Ora was for spoons, not now, did Ataarangi and never looked back."

Hirini told us his girlfriend:

" ... was doing Ataarangi at the time and she used to share the myths and legends about our people and that blew me away."

Doing the Ko Wai Au? programme led him into profound change:

"See, I never ever thought about who Hirini was, I only saw myself with my dad, brothers and uncles, nobody ever asked me who I was. We started off with this wharenui and one of our lessons was to fill in the blanks with whanau and you had to put yourself in the middle pou.

 Man, that [was] just awesome, ... stoked me good and proper. [I]t was the first time I really saw me. The next little whare, well that was all about me and where I wanted to go. You know girl, that was one time I knew that I would never go down that self destructive path again, it really spooked me."

Jack told us that his reluctant visit to a tohunga, described in "Turning Points", brought about profound change. He attributed his recovery to:

"... coming to terms with my Maori and Pakeha side of me, you know, not having to be one or the other, especially with the treatment. See, when I stopped fighting the Maori treatment it all sort of fell into place. My partner, now, she reckons I just needed a balance. It must sound porangi to you, ah!"

Tom, who was struggling against acknowledging a gay identity, spent time in a taha Maori unit. This was not his initial choice, because:

"I had always blamed my Maori side for the horrible things that had happened to me in my life ... Because in my mind, it was only Maori men who had inflicted pain on me, so doing Maori things always repelled me. I also have a lot to be thankful for to M. [at the ward], she just helped me out so much. The aroha and the manaaiki, that's what make me paddle backwards."

Rawiri described a search for identity *within* a taken for granted framework of being Maori. He said that his turning point came about "when I realised I didn't know myself. The more I asked myself who I was and what I was." These questions initiated a journey of self-discovery: "The more I got to know myself, my tangata, the more I was able to reach into the realms of my being." This led to a recognition of himself as a "matakite" or "tohunga wairua":

"People have called me a success story ... I think the success comes down to, is the knowing, the more you get to have a relationship with yourself, the more successful you become in your being, being who you are."

For a few, identity issues during recovery were focused around Maori politics. *Huia,* for example, said:

"I discovered that I didn't have to be oppressed. I discovered that there were other people out there that knew what I knew and were feeling what I was feeling. About patriarchy, about inequality, about racism, and all of that sort of thing. And that empowered me a lot."

Tua spoke of understanding decolonisation as "a large part of my recovery". *Pare* spoke of wanting to be around Maori women who understood oppression.

Maori recovery is explored more fully in the next chapter, and Chapter Eleven, on "Life Afterwards", takes up the analysis of Maori identity further.

Cultural Identity (Other than Maori)

Tasimauri, as a Pacific Islander, decided that:

"The cure can lie in the family if everybody is prepared to work together and to come to an understanding and that the problem I had came from there, but the solution can come from there as well."

So she went back to her country, walked her land and visited her mother's grave. Her trip was a cause of both sorrow and joy, but she felt that she was around people who were "supportive, joyous, robust and who savoured every moment" and she gained a lot more "spark for the future".

It was rare for Pakeha people in the project to speak of Pakeha identity as having any relevance to their mental health problem. An exception was *Alan,* who spoke of illness as a process of loss and being stripped down, of testing his beliefs, and then that:

> "... the whole idea of recovery for me, is to develop my own sense of what my own culture was and give that some value, some meaning. And then the next goal from that is to find some other people who have similar ideas – so that I have some validation or, and company about that – you know, I need some sense of society or community."

Achieving Lesbian or Gay Identities

Four of the women we interviewed identified as lesbian, and one man identified as gay. For all of them, the achievement of a secure and positive sexual identity was intertwined with the recovery process.

Tom's story, it will be recalled, was of a child who enjoyed dressing in his sisters' clothes, and who was beaten and raped by his father and other men, ostensibly to teach him a lesson about masculinity. He rejected his whanau as a young man and led a respectable working life by day, while by night, as a male prostitute, he found an outlet for his sadistic impulses towards men. In his early 30s, after periods of hospitalisation, revaluing his Maori identity was important to his recovery, and so was coming to accept himself as homosexual:

> "That's what helped me with healing myself, coming out of the closet ... I had tried for so long to think that I was a girl in the body of a man, it was killing me. I went in and out of hospital and back to the Taha Maori unit more times than I can remember.
>
> ... [M]y recovery was when I met my partner in the hospital. He used to come along and do workouts with us men. He's Pakeha and I used to think to myself, I'm not gonna let this baldhead tell me what to do. I just resisted his good intentions at the time and it took about two months before I felt comfy with him and from there we developed this amazing relationship. I felt sorry for my partner because he had to give up something important for this Maori boy. But, hey, it was worth it cause we are both very happy and I have never really looked back."

Tom's taking his partner home to meet his family was "the most empowering thing for me".

For *Mako,* the recognition of lesbian identity was instantaneous:

> "I heard this noise and I turned and looked into the courtyard. And there was this woman in khaki shorts and khaki shirt ... She had long curly curly brown hair ... That was Elle. It was like I had come home. I just knew that this is who I wanted to be. This was what I wanted to be. In a way, the recovery or the bits coming back together again, started happening at that point – seeing Elle."

Huia's adoption of a lesbian identity was accompanied by political revelation. In an unhappy marriage in her early 20s:

> "I was given some feminist books and that's what helped me make the decision that I was lesbian, and I had to leave the relationship. And I just found it really empowering knowing that there was such a thing as sexism. And I had an analysis for my sexual abuse. I was really able to apply that to racism as well."

Sylvia and *Lee* placed less emphasis on lesbian identity in their stories of recovery, but it was there in the background. Lee thought that her "craziness" was a curse from God for having a relationship with another woman in her church. But later she came to terms with being lesbian and during her recovery the support of her partner was a key factor. For Sylvia, becoming lesbian was part of the process of becoming more confident in herself, which enabled her to tackle agoraphobia effectively.

Leaving Behind Illness Identities

Experiencing mental ill health over a long period of time could lead to the incorporation of illness into one's identity. This process was facilitated by diagnostic categories which could lead people to call themselves, for example, bipolar, anorexic and so on. It must be said, though, that many participants resisted illness identities. One feature of recovery involved reshaping identity around one's experience of mental ill health. This process continued into life after mental ill health and will be discussed more fully in that section. However, some themes from talk around recovery are discussed here.

The rejection of mental health treatment, discussed in "Turning Points" and "Agency", was a central part of the recovery process for some participants. Drastic action of this sort involved a rejection of the idea of shaping one's life around being mentally ill. During the recovery process, aspects of oneself which had previously been seen as symptomatic of illness were reconsidered and integrated into identity in a different

way. *Lee* makes the point that:

> "When you're sick, everything you do is a sign of being sick … [I]t's like all your behaviour is interpreted through the lens of, this person has got A, B, C. It's like having to take that lens off myself and say well, actually, I'm fine, thank you."

Being part of the consumer movement or support groups such as GROW offered an identity which could serve the transition to wellness. *Frank's* becoming part of Psychiatric Survivors allowed scope for his political interests and encompassed him in a group where he felt accepted for who he was:

> "I felt like I had come home, it was the first time I really felt like I belonged. So that started a journey that lasted many years."

Lee said:

> "Being well was really scary, having to pay my own bills and cook my own meals, and the normal daily living stuff … go down the road, catch a bus, stuff like that initially was really just scary … [T]he consumer stuff gave me a bridge back into (pause). I don't know how to put that, really. It was a safe place to experiment with being well, I suppose."

Later she left the groups because she felt that she needed to "let go of the safety of that". Likewise, *Hirini* left GROW after two and a half years because he felt he needed to think for himself and become more independent. Also, "I wanted to feel like I could be part of the normals instead of the crazies."

Cultural Contributors to Maori Recovery

Throughout the report so far, Maori stories have been presented alongside non-Maori stories. Analyzing both groups of narratives together meant that we have produced, so far, a bicultural account of recovery. This approach is unusual in mental health research in Aotearoa/New Zealand, where research including Maori tends either to be based on data in which Maori participants are a numerical minority, or the data is specifically Maori. For Maori participants, unsurprisingly, recovery involved many of the same kinds of events and processes found in the non-Maori stories. At the same time, there were also aspects of recovery which seemed unique to being Maori. We felt that it would be useful to examine these aspects in this separate chapter.[1]

This chapter is organized under five headings, representing different influences on Maori recovery: manaakitanga o te whanau; understanding mental illness within a Maori cultural frame; Maori healing processes; cultural contributors within general mental health services; and Maori mental health services.

MANAAKITANGA O TE WHANAU – WHANAU CARE

Whanau intervention was crucial to recovery for many. Supportive whanau interventions are discussed under four headings: cultural teachings in the whanau; locating traditional healers; practical support, such as providing shelter and child care; and general supportiveness from the whanau. Finally, in this section, we discuss some of the ways in which whanau hindered recovery.

Cultural Teachings in the Whanau

Four participants told us of cultural teaching, usually by a kaumatua such as a kuia or koroua, as an aid to recovery. For some, it was teaching during childhood. *Ataimihia* told us how her "Nan" taught her "to get out of my body so that if it was being abused that I could just go and that what was what my world of silence was about". As she progressed through her journey of healing from abuse, though her kuia was no longer alive, her teachings continued:

> "There were no services available at that time to even begin to understand that, begin to understand my Nan was teaching me. So she taught me out of spirit, not in this world, in another place ... These teachings included the use of rongoa (Maori medicine) and exploring the spiritual realm."

As an adult who had "lost the plot", *Fiona* was given detailed instructions by her grandmother in fundamental principles about life, death and tikanga Maori. Fiona's grandmother told her that she would be protected from "bad spirits" by her tupuna:

> "You know, those things where people were trying to hurt you, it would never come from your own. Your own would do their utmost to protect you and I believe that wholeheartedly."

Mako, as a young girl, was told stories by her kuia about "really X Files stuff" that related to her understanding of herself as matakite. As she got older, she underwent training with a koroua, who taught her about whakapapa and how to "handle all the things that I was seeing".

Locating Maori Healers

Making use of Maori healing methods is described below. Here it is important to note that it was usually whanau who initiated contact with the healer. Some participants were willing to submit to these processes. Others were initially reluctant and only went along at the insistence of their relatives, usually their mother.

Edward's story of being knocked down in the pub by his father and forcefully taken to the tohunga was perhaps the most dramatic family intervention. He concluded, though, "Without their tautoko I'd be a goner, for sure."

Practical Support

Practical support from the whanau included looking after the participants' children, financial support, arriving to help with the household, providing a home to come back to and negotiating with health providers.

Several of the women mentioned that their parents looked after the children when they were unwell. *Fiona's* parents "recognised that something was happening quite markedly" after her sister had told them what was happening. They took the children away to stay with them and "they just let me have my time". *Pare,* who suffered from postnatal depression, said "I didn't have to do anything", as her whanau, especially her mother, came to the house and helped out; and at other times she took the children when Pare needed a break.

Georgie saw herself as "very fortunate that I had a supportive family". As a result of her depression, when "nothing really mattered to me", she went to a Maori unit for three months, and the family "moved into the home and backed up. They were good."

Men who were parents sometimes deserted their families and spent time on their own, which they needed for recovery. They did not view the children as their sole responsibility in the way women tended to, so it was not so much a matter of accessing support from their partners, but rather expressing gratitude later that their partners had managed in their absence. *Tua* mentioned how his whanau would often come to stay with him when he was in a bad state, including after suicide attempts. His father, who at one stage apologized for beating Tua when he was a boy, would:

> " ... just turn up on the doorstep and say, 'I'm here, son' and go into the lounge and he'd set his bed up and he would stay with me."

His family's support meant that he avoided hospitalization on a number of occasions.

Practical support while in hospital was appreciated, too. *Cathy's* family flew to Australia, stayed at the hospital while she was there and brought her back home to the coast where she spent a "healing time".

General Support

Just being around supportive whanau and experiencing their aroha was a key to recovery for some. It was not just practical support that *Cathy* experienced when her parents flew to Australia, but also love:

> "Mum would hold one hand and Dad would hold the other. I could feel their positive feelings coming ... the aroha coming into me and taking away the negative ... It was ... a huge part of my recovery and ... if it wasn't for Mum and Dad coming and getting me at that time I would probably still be there now ... They knew I could get well with their help and you know, and they were there for me and they gave me hope."

Huia's presence at a family tangi was a recovery experience:

> "I wasn't brought up in a traditional Maori whanau sort of situation. However, at this particular time one of my uncles died, and he was a young man, so nearly all of the family gathered on a marae for about four days and during that time I had the best healing. Spirit was really present. I had the best healing from my family ... just being around my family and their loving, and the communal lifestyle, and the singing and just the karakia and all that sort of stuff, my family gave me my mana back."

For several participants, tupuna provided a supportive presence. Huia speaks to her grandmother "as part of my healing process", going to her grave and talking to her. Participants who recalled grandparents instructing them in tikanga Maori and nurturing techniques, such as *Ataimihia,* were comfortable around speaking to and being spoken to by tupuna.

Fiona's taonga provided her with the symbolic presence and strength of her whanau, which was comforting:

> "[It] is really old and when I get nervous or uptight or things like that, if I have to go into something new, especially at work I'll actually wear that taonga so that I don't go by myself. And that's the way I look at it, I'm not alone and I've got all this support behind me."

Overall, whanau support was "choice" *(Jack).*

Whanau Hindering Recovery

The early chapters of this report showed that for a number of participants, there were childhood hurts to heal in relation to whanau. Some had difficulties with whanau which contributed to the onset of mental ill health in adulthood. For some, the illness process also involved tensions with whanau. Around a quarter of participants referred to whanau members hindering the recovery process. Being blamed, isolated, cast out, ostracized, being seen as shaming the whanau – these attitudes and actions arose from mental illness stigma. Some whanau also showed unrealistic expectations or a lack of understanding about their relatives' circumstances.

Rawiri told us:

> "At the time when I went into Carrington, a lot of my whanau, my whanaunga, my relations actually didn't come around anymore. [There was] a sense of, they didn't want to know me or they didn't want to understand and I was isolated."

Jane said:

> "Yeah, I think it was my parents not understanding, in fact ... my mother got quite resentful and ... even called me hatana [Satan]."

Tom, who had been shamed at his kuia's tangi, found himself in hospital soon afterwards:

> "From there I just went straight down hill, I didn't belong anywhere, not with my whanau [or] hapu and my kuia had gone, so there was really no reason to live ... I wouldn't let the nurses or doctors inform my whanau that I was in hospital, I was already an outcast ... I wanted to die on my own away from my whanau."

Matua said:

> "Yeah, the disappointments are in my own family for me ... and that they didn't want to know me first, then when I started getting, gee, you actually can do a lot of things, then they all wanted to know me. Then it got to the stage where they started using me ... They just got used to telling me what to do. And then when I started saying no, I don't want to do this anymore, well it took them ages to actually allow me to be in charge of my own destiny. They were too busy wanting to control it."

Sometimes people felt compared unfavourably with others. For example, Georgie's sister had also experienced a marriage break-up but it had not precipitated mental illness. The family were ashamed of her and also to expected her to cope:

> "Your sister's husband left her and she didn't end up in here ... she went through this and so and so done that, and so why can't you do it?"

Similarly after a marriage break-up, Katie's family told her to get over it :

> "I didn't know how to get over it and I kept this feeling of it being my fault. [This] was reinforced by others around me, not by friends but by family and being Maori. I think that had a lot to do with it because they all thought that they were entitled to poke their noses in, they were all entitled to give me the benefit of their great insight and that really brassed me off."

UNDERSTANDING MENTAL ILLNESS WITHIN A MAORI CULTURAL FRAME

Many Maori participants saw themselves as having experienced mental illness although, as with a number of non-Maori participants, they often rejected particular diagnoses given them and developed their own understandings that aided them during recovery. However, around a third of them rejected the idea that they had been mentally ill, viewing their experiences within a Maori cultural frame that allowed them to see their experiences as normal rather than as a sign of illness. This contributed to recovery and averted the harmful effects on self esteem of mental illness stigma.

For example, *Ataimihia* told us that she did not believe that she had ever been mentally ill, and that her behaviour was misinterpreted by psychiatrists. For example, what seemed like a suicide attempt to mental health professionals, to her did not mean obliterating herself, though it did involve moving away from life in her body. She wanted to go "across the river" to a place she had often visited with her beloved kuia, "a place I know where I had spent years of happiness and beauty". As a child trying to deal with sexual abuse, she had been taught by her kuia to visit that "safe and healing place". After she jumped from a building, she was taken to a psychiatric hospital and spent years in silence. She did not see her muteness as pathological, either, but as a deliberate strategy to retreat into "my world of silence".

Jack viewed his "bipolar" symptoms, not as the result of a biochemical disturbance, but as stemming from an "illegal" transference of land by his whanau several

generations back. This provided the background to his agricultural business failing, and he commented, "If I had've listened in the first place the bad buzz might not have happened".

Communicating with those who had passed on was a frequent experience and was never seen as a sign of mental illness, although for some, hearing unidentified voices was problematic. *Mako,* however, saw her experiences as meaning that she was clairvoyant or matakite:

> "I was a child that heard voices, that saw people that weren't there, that talked to the kehua, the dead people. And that was a real presence in my life as a child ... I was always told by my mother and my kuia and those people who bought me up that [matakite] is something you just don't talk about. That it was a gift that you held close."

Another participant viewed his mental illness as deriving from an imbalance of the spiritual, mental and physical realms of his being. "Now, they treat the imbalance with chemicals, with psychiatric drugs [but] what I'm saying is the cultural holistic knowing and being is the healing factor." *(Rawiri)*

MAORI HEALING PROCESSES

Nearly two-thirds of the Maori participants mentioned that they engaged in some form of traditional Maori healing process. Most of these functioned to provide the participants and/or their support people (usually whanau) with a degree of comfort and peace of mind.

Quite a few engaged in the practice of karakia (prayer) and whakawatea, a clearing technique usually involving water. *Cathy* told us:

> "My dad said a karakia over me and sprinkled water over me and I felt instantly better straight away. I felt calmer straight away, even though the turmoil was still there and the confusion."

When in the Maori unit of a hospital, she found the marae situation "really, really healing for me because we used to do a lot of karakia and you know, a lot of talking and sharing". *Matua* also appreciated the karakia and waiata in the Maori unit. *Pare's* story of her uncle arriving unexpectedly, as the result of a dream, to conduct a healing ceremony has already been told.

Mirimiri (massage) and rongoa (Maori herbology and healing processes) were mentioned by some as helpful.

Steve told us that he continued to use rongoa, or, as he put it: "Every now and then when I feel overloaded, like doing too much, I have a swig of the old rongoa."

Several participants were reluctant to participate in Maori healing procedures. Hare complained about his kuia "always praying over me ... and sprinkling water". *Edward* resisted being "blessed and dunked and freezing my ass off" in the river, but it did begin recovery for him. *Jack* gave into pressure from his "old lady" even though he "kept thinking she was a load of crap trying to get me to do that buzz". He told us that he was "freaked out" at the prospect, but after karakia and whakawatea, things "got lighter". When the rest of his whanau got involved, too, it was a turning point for him:

> "See, I think the tipuna, they were waiting to have us all done, not only me blessed, that is. Well, I turned to the Lord then, joined the church my mum was in, went from being no good to really thinking about my spirituality."

Tohunga

Five participants had accessed the assistance of a tohunga. *Edward* told us of his reluctance:

> "My dad took me to see ... the tohunga and next bloody morning I'm in the mouth of the river, blessed and dunked. It felt sort of weird first time but each time I had to go see him it got easier and I didn't feel so ashamed of admitting I was a bloody nutter. The big thing with [him] was getting in touch with my taha Maori."

Jane said:

> "I was quite fearful of the voices in my head and I think I got into a bit of paranoia ... I used to wake up with panic attacks and go and ring X, he was sort of like a healer, a faith healer, I used to ring him up in the middle of the night, I used to think that he was the answer to everything."

Pare had her first good night's sleep after the tohunga her mother called in told her what to do.

> "So in the end I did ring mum because I just couldn't cope anymore, I was getting bad, really bad. And she rang a tohunga and she and I spoke to him about it. And then he told me what to do at home and I did that and it slowly and it stopped the sucking feeling and I was able to sleep, that was the first good sleep I had had for ages."

GENERAL MENTAL HEALTH SERVICES AND RECOVERY

Experiences with mental health services and mental health workers have already been covered in a previous chapter. For Maori participants, the overall picture was not very different from that for the whole group:

– Most stories about GPs were brief and neutral in tone: they were mainly the first port of call, giving an initial diagnosis, prescribing drugs, referring to counselling, and organizing hospital admissions.

– Narratives about *mainstream hospital services* were, for the most part, highly negative, and this included accounts of psychiatrists and nursing staff. Main themes were being treated without respect (including being treated as ignorant), not being listened to, and receiving treatments and practices (drugs, ECT, seclusion) which they felt made them feel worse.[2]

– There were largely positive descriptions of mental health services in *community settings,* such as counselling, district nurses and support agencies and support groups. These featured strongly in recovery stories.

This section examines in more detail negative and positive experiences of Maori within general mental health services, in relation to recovery. One negative theme which cropped up in at least three stories was being treated as stupid. *Steve* said:

> "It was like you were this no-brained person ... who couldn't think for yourself ... like a kid having to be spoon fed all the time ... Man, if you read a book about your illness the Doc and staff would come down on you real heavy, like you couldn't read or simply that you don't know squat."

Jane's experience was similar; she was told she should not be using the hospital library. *Hirini* learnt to read better and to use the library, where he researched his condition; he had also complained about being made to feel "dumb" by Pakeha staff.

Matua reported that as a Maori man, violence was expected of him. The other patients thought he was from the Mongrel Mob because of the town he was from. The foreign psychiatrists, when he had difficulty understanding them, were quick to label him as violent:

> "I was on ... eight or nine pills three times a day ... there was a point where I couldn't stand up, you know, that's how they wanted me to be. Just floppy, couldn't talk."

Matua also complained that Maori spent longer in seclusion than Pakeha.

Quite often Maori participants expressed the feeling that because they were Maori, they felt particularly alienated from the system and not recognized according to their cultural background or context.[3] *Georgie,* when she left a Maori unit, tried the local community mental health team, but did not like it "because it was going from Maori perspective back to European". *Ataimihia* said, "There were never ever any for Maori by Maori [services] on their own outside of Pakeha set ups." Matua, who found only one Maori staff member in the whole hospital where he went, said:

> "What I found out in the mental health system is that they know everything about the tinana, and the hinengaro but they don't know, acknowledge the wairua, which to Maori is a big thing."

He told a story about helping a fellow patient improve by conversing with him in Maori, despite being told by staff that the patient did not speak Maori.

Mako, who as a young woman received counselling which made things worse, said:

> " ... these so called professionals ... had no idea of Maori anything. They treated me like some sort of interesting and unique opportunity to experiment with ... there wasn't even the remotest recognition of the fact that I was Maori from a tribal community."

Positive, recovery-facilitating experiences with the general mental health services were mostly similar to those for non-Maori. Some have been described in the chapters on experiencing mental health treatment, and more extensively in Chapter Seven's section on mental health workers supporting recovery. These experiences included being treated with respect, held out hope for, listened to, comforted, and provided with good professional assistance, good counselling processes and practical support.

There were not many descriptions of positive experiences with general services which were particular to being Maori, with the exception of pleasure at

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[2] Eight of the ten Maori men had been hospitalized and six of the eleven Maori women.

[3] It should be remembered that often the experiences described were some years back. We are not implying an evaluation of current services. What these experiences do show is the impact of neglecting kaupapa Maori in mental health services.

encountering Maori staff (Matua said of going into hospital, "It wasn't until I saw a Maori face that I calmed down.") The only negative spin on Maori staff involved the "cuzzies" phenomenon, mentioned by two or three, who felt that their relatives on the staff would spread the word around and add to the stigma they felt about being in hospital.

MAORI SERVICE PROVIDERS

Half the Maori participants discussed encountering Maori health service providers, and this generally had a positive impact on them. They enjoyed being with other Maori staff and patients, usually found the treatments they received appropriate, and appreciated learning from staff. They also found cultural practices, such as karakia and waiata, comforting, and they thrived on opportunities to participate in cultural learning and events. The following three quotes give examples. *Cathy* said:

> " ... within about four weeks, I was moved up to X, which is the most healing part of [the hospital] itself. I had the support of the staff you know and the clients, it was a whanau situation and a marae situation ... It was really, really healing for me because we used to do a lot of karakia and you know, a lot of talking and sharing. And we would have Uncle X ... used to come out and take us for blessings down at the river and it was really reconnecting with the earth and what was around us and stuff, that really helped. It helped me immensely."

Georgie:

> "I went into X which I found was the best ward out there for Maori ... There were more health workers than health professionals in that ward and they were good for me, good therapy to have Maori people there ... they were good for you as company, as safety, as keeping your identity of being Maori."

Matua on a Maori ward:

> "We were able to do things the Maori way, we had Kaumatua coming in, we had powhiri for people, we'd welcome other people in, you know, things like that ... run along like a marae, I suppose."

Particular Maori mental health workers, some in hospital and some in the community, received praise. "I've got this choice Maori counsellor," *Edward* said; "one onto it lady" *(Hare);* "she was off the wall but she really made me laugh" *(Hirini).*

Only two made negative comments, in one case about a Maori ward which the participant felt was being run in an orthodox way, and another because he did not appreciate being in that context when he was struggling to recover from ill-treatment by his whanau.

Maori education providers figured in some stories of Maori recovery, too. Participants were sometimes linked with them through mental health services. They included literacy services, courses teaching Maori culture and Maori self esteem courses. *Edward* put it very distinctively:

> "Man, I never used to be proud of being Maori ... thought saying Kia Ora was for spoons, not now, did Ataarangi and never looked back."

In speaking of Maori health providers, Fiona concluded:

> "Maori health providers have been knocked so much because they don't meet this and they don't meet that, but the fact is, what they do they do so damn well that nobody can refute it."

Stigma and Other Hindrances to Recovery

The focus of the recovery section of the interview was on the story of recovery, with a particular emphasis on what helped. The recovery stories, then, focused on the positive. However, implicit in many of the accounts of the experience of mental ill health was an identification of factors which, by being productive of illness, hindered recovery. Moreover, many of the participants were explicitly asked to reflect on the main hindrances or barriers to recovery.

Just as the support of others was the most commonly identified factor in facilitating recovery, it was the attitudes and behaviour of other people which were far and away the most common hindrance to recovery. What got in the way of recovery was other people's fears, their stigmatising behaviour, their lack of understanding, and their rejecting behaviour in relation to mental ill health. People had to cope with stigma from family, whanau, workplace and "society".

Jen's family were so frightened of mental illness and hospitalisation that they tolerated years of strange behaviour from her without comment. *Katie* turned to Pakeha friends because she found that other Maori in her town were not used to talking about "psychological hangups".

Georgie said that "coping with stigma" was "the hard thing, really hard":

> "I look around, my parents even now are still very careful how they describe Tokanui and they are very careful, ... you know, like when they are having normal conversation and they are laughing. You know what it's like in a marae sort of situation with the whanau and then somehow mental illness always seems to be part of a joke. I know that they stop themselves and that's because I'm sitting in the room."

Virtually all of those who identified family rejection or lack of understanding as the main barrier to recovery were Maori. In interpreting this, it is once again necessary to recall the logic of this research process.

The non-Maori participants spoke of family rejection frequently in their narratives, too, but Maori were likely to identify this as the main factor when questioned about the major barriers to recovery. So this finding does not necessarily mean that Maori families were any more rejecting of members with mental health problems than non-Maori; what it does imply is that for those who, as adults, were suffering from a mental health problem, whanau or family of origin were even more important to Maori than to Pakeha. In other words, the differences identified may say more about cultural differences in family life than about cultural differences in attitudes towards mental health problems.

The workplace featured only occasionally as a significant factor in recovery, but it did feature more often in accounts of barriers to recovery. People mentioned difficulties in getting a job if it was known that they had mental health problems, or workmates not being understanding. One mental health professional interviewed said that even though he participated fully in his professional association, he felt like an outsider because of the "prejudice" of his colleagues.

A number of people entered the mental health workforce after their experience of mental ill health. Although that experience may have been considered a positive factor in their application (e.g. for a position involving consumer representation), it could also make them susceptible to discrimination in the workplace. *Tua* said, "I had to tame my korero" in talking to those in power as "it can put me in a susceptible and vulnerable position". *Ruiha* said:

> "How should I describe it? Different ones used to make comments. One comment was if this person was on the interviewing panel for me to come on board to be a team in the mental health services, they would have never have chosen me. And another person just said to me, you know, 'You're thankful you were a nut otherwise you wouldn't be in this position' and that's happening all the time."

The mental health system was also the site of discriminatory attitudes. These were more fully explored in accounts of illness, earlier. In speaking of what hindered recovery, *Denis* referred to the "lack of understanding" that he encountered in his first hospitalisation. *Amy* reflected bitterly on the lack of belief in her recovery that led to her being offered supported accommodation; her own consciousness of stigma meant that she did not want "to be known by the next door neighbours as living in that house".

For a few participants, difficult behaviour from people (usually family or ex-partners), rather than stigma itself, was named as a barrier to recovery. For example, *Matua's* family told him that he had to give up drinking, but he had to stand around and watch as they partied. *Fiona's* parents and grandmother were understanding, but her sisters "hassled" her to fulfil her family responsibilities at a time when she needed "grieving space". And when *Jane* confronted her whanau about incest, everyone was hostile towards her and her koroua told he that he dreamt about her head coming home in a box.

Coming a long second after stigma, in responses to the question of what hindered recovery, were references to personal flaws, most commonly one's own lack of understanding, attitudes or fearfulness about the illness.

Thirdly, a few cited the mental health services they received (or failed to receive) as the main hindrance to recovery. *Amy* thought that the ward was "the ambulance at the bottom of the cliff that pumped you full of medication to get you to a point where you could step out into a facilitated outfit", whereas she thought that counselling services would have helped her recovery more. People's difficulties with medication have been mentioned already, but two thought it was the chief barrier to recovery. As *Matua* put it, "Medication, yeah, ... that's the biggest one. Getting off the medicine, if you can't get off those you're pretty well stuck in the system." And *Kim* said that what hindered her was:

> "The drugs, because they only ever fogged me up, the terrible side effects of the medication was then something that you had to contend with which compounded the problem, so the medication totally, totally hindered. And the shock treatment was devastating and was never ever helpful."

PART three

The Onward Journey

The Onward Journey

Recovery is not the end-point of journeys through mental ill health. In this project we were interested in the impact of mental ill health on life after recovery, which is why we chose participants who had experienced mental ill health and recovery some time in the past.

During the final part of the interview participants had the opportunity to reflect on the impact of mental ill health on their lives. For all, it had been a life-changing experience, from which they had learned a lot about themselves and others. They had had the opportunity to test and develop their personal resources and sources of support. They knew who they were and what they needed in order to thrive. They were more empathetic and understanding towards others. Most had developed a perspective on mental health services and many were now involved in helping others with mental health problems. Having "lost the plot" at some time in their journey through life, many now had a deepened understanding of the social norms and expectations which surround life journeys; for many, this meant that their views of society had changed.

In reflecting back, surprisingly few expressed bitterness about the troubles they had been through. Though some had regrets, these were usually tempered by reflections on the positive benefits of their journeys. Overall, people were extraordinarily positive about the changes that their journey through mental ill health had brought into their lives.

Life After Mental Ill Health

In this chapter we firstly examine how mental ill health influenced people's life paths (following on from the stories in Chapter Five, on the more immediate consequences of mental ill health). We next report participants' views on how stigma and discrimination currently affect them. Then we examine what people said about what they had learnt about their mental health problem. We go on to look at how the experience of mental ill health changed them as people.

Spirituality was a topic which arose frequently in this phase of the interview, so this topic forms a section. We then examine how the experience of mental ill health changed people's understanding of mental ill health and society and encouraged them to contribute towards helping people who are mentally unwell. Finally, we look at some comments which encapsulate peoples' views on their experience of mental ill health, recovery and the effects of the whole experience on their life.

HOW MENTAL ILL HEALTH INFLUENCED LIFE PATHWAYS

Work and Career

The interviews did not involve a full life history, so we did not obtain detailed information about the course of people's lives following their period of mental ill health. However, participants gave us at least some information on this topic.

Chapter Five, on the consequences of mental ill health, discussed immediate impacts on people's lives. It made it clear that for many those consequences, such as relationship breakdown or loss of career or educational opportunities, had a persisting impact.

In terms of careers, a few of those we interviewed had continued with their successful career trajectories relatively unchanged, or perhaps even enhanced, by

their experience of mental ill health. They included academics, mental health professionals and people in sales, and some of them were outstandingly successful. In contrast, another minority carried with them a sense of deep regret at career possibilities which, in their view, had permanently vanished. One said, "I would probably be working in a downtown law firm now", and another, "if you didn't work for five years in your prime it completely stuffed you up".

Those who experienced their mental health problems in young adulthood, or who had disrupted childhoods, usually experienced delays in taking up careers. Some of these were now availing themselves of educational opportunities, which were usually enjoyed. Quite a few participants had compensated for the work changes which mental ill health had led to, and were now satisfied with their current work. In fact, changes of direction were often looked on very positively and in some cases had led to a passionate commitment to the new work. For example, *Mary* said, "I know now what my work is and ... I'm not sure how I'll do it for the rest of my life, but I know I will do it."

Of those for whom mental ill health led to career changes, many moved into mental health work ("making a career of my history", as one said). A few found career opportunities there which exceeded their former expectations. People doing mental health work, whether they began before or after their experience of mental health, made beneficial use of their personal knowledge. Many others in all kinds of work settings found that their experiences came in useful in relating to others. A number of people also said that the self knowledge they developed from their experience contributed to their work. Issues around stigma and discrimination in relation to work are discussed below.

As was pointed out in the participant profiles, our group had a very high rate of employment participation; some were in education, homemakers or retired, but few were unemployed.

Family, Partners and Friends

Family/whanau relationships had sometimes come badly unstuck before and during the experience of mental health problems. Looking back, some still felt strains within the family. "I'm the black sheep," said one; another, who told us that his problem "tore the whanau apart", said that it had never been the same since. Others had tested the strength of their family networks and now knew how much they appreciated them. For a few, coming to forgive family members who had been unsupportive or abusive towards them was important. *John* said that he forgave his father when he realised what his father had lost out on, and told us that he was a different father to his own children; and *Ataimihia,* who suffered the most appalling abuse from her father when she was a child, said simply that "it was a joy to forgive him", and that this was part of her healing.

As pointed out in the "Consequences" chapter, difficulties in partner relationships were often implicated in the onset of mental health problems. In the long term, some still held disappointments about broken relationships, while others appreciated their partners for their support. Some had made new and better partnerships, while others found it difficult to find new partners.

As the participant profiles showed, more of our participants were single than is usual for New Zealand adults, and a number expressed wariness about intimate relationships. As one who has suffered severe childhood abuse put it, she is not "good material" in terms of a sexual relationship, but celibacy had helped her "find my wairua self".

Several of the women regretted missing the opportunity to have children, or to have another child.

Finally, a number of people pointed out how important social networks, including friendships, are, for supportiveness and pleasure in life.

STIGMA AND DISCRIMINATION

Many of the participants acknowledged stigma around mental illness as still relevant to their lives after recovery. There were few references to stigma from family members after recovery. However, some felt that their families still did not really understand. One or two felt uncomfortable talking about their experience even with a close family member, such as their partner.

Only a few still felt shame about the experience – "It's not something to be proud of" *(Paddy).* Some said that

those close to them discouraged them from talking about it. *Hare* said he did not talk to very many people about it as "it took a big chunk out of my life". *Alan* resented the fact that the experience had "created part of me I hide away". *Tom* said that he never spoke of it; in fact, he said to the interviewer, "You're the first and last."

Most of the discussion relating to stigma centred around the issue of disclosing one's past to people who did not know about it. Negative consequences were envisaged for disclosing past mental ill health in the workplace, or when applying for jobs. *Mako,* a professional, put it frankly: "Madness puts your job at risk." *Alan* said that in New Zealand it is "not cool to have had a mental illness experience". Several said that they would definitely not refer in their CV to having had a mental health problem; as one said, that would mean it would be "the first CV to get chucked in the bin". On the other hand, *Kim* said, "I've always fully disclosed and it hasn't been held against me."

Over time, many people came to feel more comfortable about telling people. Jane said, "I used to be real whakama", but now she has learnt to talk about herself. Those who seldom told others still found it could be an upsetting experience. As Jack said, "The old puku gets a good clean out when you talk about it."

There was still cautiousness about the circumstances of disclosure, even when people would rather talk freely. Sometimes there were uncomfortable outcomes; for example, *Francis,* working in the helping professions, felt that his experiences set him apart from his colleagues. *Edward,* who talked about himself at an AA meeting, felt that they then looked at him as different: "too many baldheads waiting for the nuttiness in you to come out". *Jen* said she wouldn't want people to treat her "with kid gloves" if they knew about her past.

People were most likely to self-disclose to other people with mental health problems, when they felt that talking about their own experience could be helpful. Many of those who worked in mental health had developed the courage to tell their stories as part of facilitating healing in others. As *Rawiri* said, he shares the truth, but it's for the benefit of others, not himself. *Bruce,* who sees himself as a private person, nevertheless shares his experiences with others. *Tasimauri,* a consumer advocate, said of telling her story, "it's part of my job description".

People also spoke a little about the reasons for stigma. *James* felt that mental illness "challenges people because they don't know how their minds work". *Mary* said that she thought " everyone has a deep down fear of going crazy".

WHAT PEOPLE LEARNT ABOUT THEIR OWN MENTAL HEALTH

As a result of experiencing a disabling mental health problem, people learnt a lot about themselves, their needs, and their strengths and limitations. The previous chapters on recovery described the actions people took and how they themselves changed on the road to recovery. What was learnt during recovery was taken into life after mental ill health.

Many emphasised the importance of *keeping up good physical and mental health.* They make use of techniques for dealing with stress, keep physically healthy, watch out for fatigue, and engage in relaxing pastimes such as gardening.

Participants who had been vulnerable to alcohol and drugs now avoid them. The few who know they need to take prescription medications use them appropriately. Herbal, alternative and Maori health remedies were mentioned as useful by several. *Edward* said, "When I feel overloaded, like, doing too much, I have a swig of the old rongoa."

For many, good mental health is closely linked with *good emotional health.* Some said they valued having learnt to recognize and express their emotions. As *Steve* said, "I would never have got in touch with my deep feelings if I had not experienced the self-mutilation and living in isolation." *Frank* called this being "real".

Their emotions provide a guide and a reality check for some. *Annie* put it, "I have to operate from the centre of whatever my emotional life is, whatever my feelings are." However, others are cautious about being misled by emotions. *Jane* recalls the GROW advice: "I go by what I know, not how I feel." *Jack* still has some loss of memory for painful events around the time of his disorder, and said that this probably helps him survive.

Those who have made the commitment to emotional self awareness explain that it is not possible to avoid troubling feelings. *Huia* said that instead of taking medication, "I choose to stay with the [emotional] pain, or stay with the experience of it and observe it and try and detach, and to develop some tolerance of it."

Frank's view was that:

> "A lot of us have suffered real grief and pain, a lot of us have ongoing states of grief and it's only when you come to the point of resolution of the grief that you come, well ... some grief can never be resolved."

Taking care of one's mental health means *knowing one's limits.* The experience of ill health had provided most with a good understanding of what they can tolerate and what they can't. *Bruce* said:

> "There is a white line and if ... I walk over that white line I'm looking for trouble. Before this happened ... I didn't sort of realize there was a white line in my life, but ... I respect it and I ... don't play around with it."

Steve told us he feels uncomfortable in some situations, such going to tangi, as "crowds do still sort of make me feel queasy ... But I have this monitoring system that tells me not to be afraid to listen to my integrity, I simply go to tangis on the second day."

Annie knows that "it's very dangerous for me to be in a situation where I can't talk about my feelings and where I can't let them count ... There are reaches of alienation that I can't or won't go to."

As *Fiona* put it:

> "I'm actually my most important person ... No matter how strong your family is, you always look to yourself first ... Very selfish, but it's not selfish when you think about it, I mean, I can't be there for anybody else if I'm not there at all. Believe me, I've learnt that the hard way."

Knowing limitations came out of having developed, through bitter experience, a good *understanding of the shape of one's disorder. Kim* found that this can take time: at first "you run away from yourself, but you take yourself with you, so it ... doesn't work". Now she is no longer depressed, but:

> " ... everyone has days and circumstances come upon them which will test your mental health ... I know that if I wallow or have the 'poor me's' for any great length of time I will end up back in hospital, but I know that I will never ever end up in hospital because I've now got the resources."

Some recognize that they remain predisposed to particular forms of mental ill health, but now that they understand the nature of the problem, they are no longer ruled by it. On the whole, they just see it as part of their human uniqueness. For example, *Ataimihia* sees herself as an addict, but doesn't use drugs; *Hare* still hears voices, but they are not especially troubling since he has techniques for dealing with them. *David* is "always going to be on lithium" and "I still suffer from manic stages" but "it's in my nature to sort of overcome that, so people don't notice it". David and *Denis* both said that they harnessed the energy from the "manic

phase" for their work; as Denis, a prize-winning salesman, put it:

> "Sometimes your mind can work very fast and very quick and you think you can conquer the world, part of the manic phase, which I don't get a lot of, but I use it as a tool within my job because I can cope a lot better with multiple stresses and pressures and function quite well."

Knowing themselves and their limitations well, people were able to enact *strategies to keep themselves safe* when confronted with stressors or situations of special risk. Most people seemed to feel that they would never return again to the very worst state they had been in, even if subjected to the same stresses.

A few people commented to the researchers that reflecting on their lives – on the worst times in their lives – for the interviews was unsettling. For example, Steve said that after the interview had been arranged, "I had a lot of time to think about this and I thought it had, well, been resolved, but I had to take time out even before I could talk to you."

People usually felt confident that even if life were to deal them more hard knocks, they had developed the tools they needed to prevent problems compounding. *Alan* said he no longer hooked into negativity. *John* said that he could now turn negative feelings into something constructive. *Sylvia* had learnt to face her fears so that they no longer got out of hand. *Paddy* knew that though he would continue to experience depression, he would be able to "head it off" before it became disabling.

Two or three commented on the negative possibilities of ignoring safety strategies. They noted that while it only took a short period of time, in certain circumstances, to become unwell, recovery would take much longer. Some commented that now they were *more comfortable about seeking help* when appropriate, either from friends and supportive networks or from mental health services.

In contrast, a number of participants made it very clear that *disabling mental ill health would never be part of their future.* For example, *Jen* said that she did not ever fear another breakdown, *Ruiha* knew she would never be readmitted to hospital, and *Fiona* said that her previous problem was not part of her life any more.

Having enacted successful recovery strategies, people were now in charge, taking responsibility, acting optimistically, with a sense of a future and a vision for their lives to sustain them. *Fiona* said, "the positive thing

about it is that I know where I don't want to go, I've been there and it's an ugly place". As *Huia* put it, "If I get a bit down, I don't actually get right down anymore because I know there is hope, I know I've got power".

PERSONAL CHANGES RESULTING FROM THE EXPERIENCE OF MENTAL ILL HEALTH

Many participants told us of personal qualities they had developed as the result of their experiences.

Strength, courage, determination: *Fiona* said, "I'm a lot stronger for having been there and come back". *Francis* told us, "What I think I learnt ... was that I ... had immense determination". *Liz* recounted to us that her family thought that mental health problems mean that you're "weak", but "it's actually made me stronger, so I'm not weak at all". And *Matua* was proud that he had found he was resilient as a result of his experiences. When his mother died, "the whole family was devastated and I was the only one who sort of, you know, just carried on".

Confidence, feeling good about being oneself and the courage to be real: "I have a sense of myself", "I'm a good person" – these were typical comments. *Georgie,* at the end of her interview, wanted to emphasize that:

> "Even though I was a person that had to rely on someone else to help me find out who I was again and to strengthen myself, I was never any less the person I was before I started there ... You are still who you started off being."

"I'm so proud of where I am", *Amy* said.

A sense of being in charge, in control, taking responsibility and being resourceful: Many referred to having more of a sense of control about where their lives were going, as well as an ability to take responsibility for their life direction. *Annie* claimed that this was essential for mental health. As she put it, "a sense of agency is very important in the retention of my mental health".

Clarity, a sense of direction, an understanding of things and people, a philosophy of life/values have been explored and established: *Johnny* said, "I look towards the future with a lot more clarity". Similar remarks were made by a number of others. Values had often changed. *Frank* told us that he had become "content with the real things that have real value" even though he regretted lost opportunities. *Georgie* said:

"A lot of my values are ... being tested and a lot of the things that I've been taught have since been revalued ... I don't ... take things too lightly anymore. At the same time, nothing shocks me much."

Rawiri had thought deeply about his journey towards a holistic balance of hinengaro and wairua. He believes that mental illness often relates to people having no forms of protection which would allow them to deal with painful experiences from the past. His explorations of Maori philosophy have enabled him to know himself and his place in a whole web of relationships, past, present and future, "which allows me to be me." This knowledge, he argues, is a "protection shield."

Tolerance, empathy, compassion, understanding of others based on one's own experiences: *Georgie,* who said that nothing now shocks her, talked about how she interacts with people she knows who have mental illness: "You sit down and you treat them like an ordinary person and you will see the real thing coming forward. That's something that's very hard to understand for someone who hasn't been ill ... it's very hard, unless you've been there yourself." She feels better able to understand the impact of disrespectful treatment of people with mental health problems.

A number of those who are now mental health workers make use of their own experience. *Huia* said, "I have an empathy for [the people I work with] because it grows out of my own awareness of this sort of condition."

Lee said:

"It's made me a lot more tolerant of people, a lot more accepting of people, a lot more non-judgmental, a lot less quick to jump to conclusions ... I suppose it's made me a lot more compassionate and caring ... I don't tolerate fools easily, that's a contradiction when I say I'm more tolerant! But things like arrogance and prejudice and cruelty and injustice ... I'm really intolerant of that sort of stuff now, whereas I don't think I ever saw it before."

Having something to offer others: Many who went into working with people with mental health problems saw their choice in terms of giving something back. *Mary* said: "I'm really convinced that my experiences have given me a way of thinking that ... makes me feel like I can do something ... It makes me feel I have something to offer, and that's what makes me feel OK about myself."

Being more happy, carefree, and spontaneous: Some people emphasized how much happier they are with life after mental ill health than they ever had been beforehand. Several mentioned that with less anxiety or depression to contend with, they were more carefree and spontaneous. "Now I enjoy surprises", said *Sylvia.*

Negatives: Very few people referred to negative personal qualities they had developed as a result of mental ill health. Those who did usually mentioned more positive qualities. However, *Paddy* had lost his confidence, *Frank* was more sensitive to shocks and *Alan* had lost some trust in himself.

SPIRITUALITY AND MENTAL ILL HEALTH

In reflecting back on their mental ill health, many participants spoke of spirituality, a theme which is an increasing focus in discussions of recovery. Participants' talk covered a number of themes.

Spiritual faith and practices as important during illness and/or recovery: Some referred to the importance of prayer, spiritual protection and the power of God. *Cathy,* for example, felt that when she frightened her new stepchildren:

"I was being pulled from either side ... the evil voices were trying to get me to actually hurt this girl, kill this girl. And it was the good voice that actually came out in me, asking God to help ... me. The whole experience was like a spiritual experience – like a good spirit and a bad spirit torn between, inside me ... I felt later that it brought me to a crossroad in my life about which path I needed to follow."

Bruce said:

"You know, in the Bible there are proverbs. Maori talk about whakatauki ... those are the kind of things that ... when I have been going through really difficult times, those are the only things that I have to hold on to ... "

Spiritual beliefs changed as a result of mental ill health: *Pare* had developed a very strong faith in God, while others mentioned getting in touch with or redefining their spirituality as a result of the experience of mental ill health. Kim told us how she found GROW's emphasis on spirituality difficult at first, but she came to share their philosophy.

Spiritual beliefs central to present philosophy of life:
A number of participants referred to the importance of
spirituality in their understanding of the world. Whether
it was "the Catholic thing", believing that "we are God",
expressing the idea of holism and balance in life, or
emphasising the importance of wairua and the spirit
within us, many participants let us know how central
spiritual beliefs were to their present philosophy of life,
which had been informed by the experience of mental
ill health.

***Spiritual gifts are sometimes confused with mental
illness:*** A couple of participants told us that, in their
opinion, spiritual gifts are sometimes confused with
mental illness, and that they learned to be careful not
to publicize their gifts, for instance, matakite, or second
sight.

Mental ill health may have spiritual origins: Another
few participants, in reflecting back, referred to spiritual
origins to their illness. *Frank* referred to having "lost
my soul" and *Huia* said, "I know enough about my
illness now, or my unwellness now, to know that it's
nothing more than me separating myself from God."
Joan described her illness as resulting from the evil spirit
of mania and being cured through exorcism.

However, *Lee* told us earlier about believing that her
illness had come about because she had been cursed
by God for her involvement in a lesbian relationship;
later she completely rejected this idea.

Mental illness seen as a test or as part of God's plan:
Tasimauri: "It's like the path that God leads you down
and he doesn't put obstacles in your way that are too
great for you to overcome ... and you learn from them."

MENTAL ILLNESS AND SOCIETY

The experience of mental ill health led to profound
personal change for most of the participants. As well
as change of life direction, and change at a personal
level, people changed their views of mental illness and
the way it is treated. In many cases, they developed a
commitment to bettering the lives of people who now
suffer. In a sense, many people were radicalised in their
views as a result of their experiences.

As people came to understand their own experiences
better, mental ill health was demystified. They were
able to recognise and understand mental ill health
among other people they knew, to reflect on ways in
which systems of mental health care could help or
hinder, and sometimes to offer appropriate help or
advice. Sometimes it was a matter of being more

understanding in a personal situation, such as at work.
For example, *Paddy* said that he was more charitable
in his opinions. Many mentioned having more empathy,
understanding and feeling comfortable with people
with mental ill health. *Susan* said that when people
spoke about someone they knew who had committed
suicide, she was less shocked.

Others felt a bond with other service users and
committed time to consumer movements, or moved
into the helping professions themselves, taking their
new values with them. People mentioned things such
as the privilege of hearing other people's stories; the
importance of letting people make their own choices
(*Mary:* "We can be there for other people, though we
can't take responsibility for them"); and treating other
people in an ordinary way, as you would like to be
treated yourself. *Matua* said that everyone knows
someone who has been through mental ill health, and
that they were "some of the best people I've ever met".

Attitudes to the mental health system were largely
distrustful and critical. These attitudes were often based
on a view that mental health professionals pretended
to know more than they actually did, yet withheld
information they did have, for example, about the
effects of medication. Labels could be dangerous and
stigmatising, the likelihood of recovery was often
underestimated, and professionals could be controlling
and insensitive to people's individual needs and to their
wairua. There was a feeling by some that "people who
haven't experienced it can't help you".

However, *Alan* said that despite it being "fashionable
to slate them", mental health services "kept me alive"
and also that mental health services are improving. In
contrast, *Fiona* said that if her children were to have
mental health problems, she would rather they did what
she did (drop out) than go to Western-style mental
health services, because of the power of stigma.

In terms of broader social attitudes, the following
themes occurred: questioning of one's own values; the
importance of respecting difference ("there isn't a place
in the world for some people", as *Mary* put it); the
repression of emotions in society; and hypocrisy around
drugs and alcohol.

HELPING OTHERS WITH MENTAL HEALTH PROBLEMS

Most showed a desire to help others understand mental health and deal with mental health problems in their own lives. People spoke of helping their children, other family members, friends and people at work. Sharing their story was the most commonly mentioned form of helping. But even those who were reluctant to publicly disclose their own history looked for ways they could help. *Paddy,* who was perhaps the most secretive about his past, said "I'd like to help other people if I could". *Tom* would have liked to "give back", but he found it too stressful to talk about his experiences.

Some participants had dedicated their lives to helping. *Kim,* for example, did voluntary work for decades and became the National President of a voluntary mental health organisation. *Tasimauri,* who was involved in consumer advocacy, felt that although she regretted the impact of mental ill health on her promising professional career, it was part of God's plan for her to help people in this way. *Fiona, Tua* and *Ataimihia* were among several participants who had worked with determination – in either a voluntary or a paid capacity – to make changes for Maori in health, and Tua had visited jails and schools as part of his work with a consumer agency. He said, "When I see somebody hurting I can say, 'Kia ora man, I know what you're going through'." Other stories were told in the earlier section on careers.

Lee reflected thoughtfully on the meaning of her illness and the ability it has released in her to help others. She expressed her feelings about it in the form of a parable:

> "[I]n the Bible there's a story, it's after Jesus' resurrection and he's standing in some room and Thomas comes up to him and ... says to Jesus, I won't believe until I can put my hands in your wounds, and Jesus lets him do that ... In the church that story is often taught as Doubting Thomas, that he should have believed without the experience, so he shouldn't have needed to put his hands in a wound.
>
> And ... the other day we were talking about woundings in life and, I mean, I'm not comparing myself to Jesus (laughs) but ... this experience has given me wounds that makes me maybe accessible to people, that people who haven't got the wounds aren't accessible. Does that make sense?"

FINAL THOUGHTS: RECOVERY, REGRETS AND THE GIFT OF MENTAL ILLNESS

How did people sum up their experience of mental health problems and their journey through mental ill health, recovery and beyond? Firstly, they had some thoughtful comments to make about the recovery process. *Alan* described it as the action of grace in his life. *Amy* said in a poem she gave us that "if you hang on long enough, sunrise will come". *Huia* saw recovery as a metamorphosis: "It's a journey and you will embody history and scars."

Others, like *Rawiri,* also used the metaphor of a journey, "the person's journey of being who they are". As *Matua* put it, it's "only because I've worked my way through it I don't have to go back". *Hirini* used the story metaphor, claiming his own version: "It was my story, not theirs, that's how I coped, it was hard though."

Jack and Jane expressed huge relief about where they had got to. *Jack* said he does not "need the doctors and all those boxes they put you in, I just want to be known as me". *Jane* rejoiced: "I'm not mad, I'm not under their thumb, I'm getting a life."

Matua was typically philosophical in his response to a question about whether he had any regrets. He said:

> "Yeah, heaps, but too late for that, why worry about it? Oh well, shit happens, that's life. Life goes on, don't let it get to you ... The world is not going to stop because you're sad."

Frank felt that his life had been ruined, though he did mention the many ways in which he had grown as a person as the result of mental ill health – as he put it, he had softened, not hardened as a result of the experience.

Amy said, with her usual street-wise humour, that she regretted her time as a prostitute, "but it's a great talking point over dinner".

Others regretted "lost years" but used metaphors to express a philosophical attitude to them, like "taking a ride on the sea of life". *John* referred to the "years of locusts":

> "Who knows what difference [not having a mental illness] might have made to my whole life, in terms of career and all sorts of other consequences or choices. But that's not what happened, and as a Christian, I believe scripture says something somewhere about the Lord repairing the damage

done by the years of locusts ... Even if I'm not earning as much as I might have been ... it doesn't matter. I have still got enough. It's not all up to me. I don't know if that makes much sense to you."

When *Lee* said, "I could get all bitter and twisted, or use it as an advantage", and *Tasimauri* said "It's taken a huge chunk out of my life but it's contributed to who I am today", they were expressing the most common attitude: that going through the journey of illness and recovery brings benefits in the long term.

Many participants described incorporating the experience of mental ill health into their sense of themselves and using it as a growing point. As *Alan* said, "Illness is in a sense life saving – it stresses and challenges people." For him, it had a huge impact and was " the major psychic experience of my life". *Lee* was stumped when asked if she could envisage what her life would have been like if she had not had to contend with psychotic illness. She concluded that she would have been dead. Her illness was so overwhelmingly disruptive that she was forced to deal with all sorts of personal issues, and this led her into therapy for the abuse she had suffered as a child. Without that, she believed that her more ordinary depression might have led to suicide.

Many waxed philosophical about the relationship between mental ill health and life's journey. "I am my mental health," said *Huia.* A number, whether religious or not, expressed the view that their experiences were not meaningless. "Nothing ever just happens, it all happens for a reason," said *Amy. Joan* and *Tasimauri* told us that they believed that God will not allow you to be tested above what you're able to bear and that you learn from the obstacles that are put in your path. *Johnny* said his whole life is a journey, so "there's no rush".

The notion of illness as a gift or a blessing was expressed by a number of participants, who believed that their journey had been a crucial opportunity for learning about life. When *Mary* was asked by a puzzled interviewer to explain what she meant by referring to depression as a gift, she laughed and said ironically, "I feel really lucky that I had those grey years of misery." She went on to explain that:

> "I feel like it's given me, um, an understanding of the world beyond the understanding of other people ... of people, of how to be with people."

Kim put it in this way:

> "My mental breakdown was a breakthrough to a better way of life ... If I hadn't had the breakdown and subsequently found GROW I would have probably always lived at a very low existence level ... We can cruise along in life and unless we are faced with some sort of crisis, we won't ever be able to know how to deal with it."

Many participants told us how proud they were about where they had got to; their attitudes were summarised in *Jack's* remark that if it were not for the mental illness, "I wouldn't be the person I am today." They referred to enjoyment of life, to being in charge, and to being better people because of their experiences.

Tom, whose childhood and young adulthood involved appalling abuse and emotional pain, said:

> "I didn't really want to die and I am so pleased that none of those suicide attempts were successful. Ooh, I have to cringe when I think I may have been six feet under. No, girl, I am alive and I enjoy my life, life at the moment is wonderful."

Conclusions

This narrative study followed the journeys of people who at one point in their lives lost their way, through the experience of a disabling mental health problem.

Their journeys through mental ill health, recovery and into life after mental ill health, we found, could be divided into eight stages:

A typical journey into mental ill-health

1. There was always something the matter, but I somehow got on with my life
   - Not many felt okay about themselves before the mental health problem arose, though some did

2. Then something very stressful occurred
   - I found myself in a difficult situation
   - I just could not cope any more

3. The mental health problem took over
   - The experience of mental ill-health
   - The experience of diagnosis and treatment

4. The consequences were highly disruptive
   - Loss of job or dropping out of study
   - Family and relationship problems
   - Experiencing stigma and rejection
   - Shame, loss of self esteem and despair

A typical journey towards recovery

5. I glimpsed the possibility of recovery
   - One or two good things happened
   - I learnt some useful strategies
   - I experienced flashes of hope but the mental health problem remained or kept recurring

6. I reached a turning point
   - Something dramatic occurred
   - I vowed to leave mental ill health behind
   - I took charge of my situation
   - I realised that I was worthwhile and that I would recover

7. I travelled on the long road towards recovery
   - I made use of effective strategies
   - I found useful resources and supports
   - It was a difficult process and there were often setbacks
   - I discovered who I really am
   - I experienced strengthening or altering of my identity.

A typical journey beyond mental ill-health

8. My experience of mental ill-health has changed me
   - My position in life is now different in relation to work, family and friends, partner
   - I know my strengths and limitations
   - I'm "sadder and wiser"
   - I know who I am and what really matters to me
   - I have more understanding and tolerance
   - I'm willing to use my story to help others.

The first part of our report, describing the journey into mental ill health, examined the question, "What is it that needs to be recovered from?" and answered this by establishing that recovery needs to occur across a range of dimensions, from:

- what had always been the matter;
- the stressful situations that led to the onset;
- the symptoms of mental ill health;

- fears and anxieties surrounding the symptoms and their possible recurrence;

- treatments received;

- the consequences of mental ill health;

- destruction of self esteem, trust, optimism, hope and faith in the future;

- the stigma associated with mental ill health.

All of the participants recovered, and they described recovery as a process. They glimpsed the possibility of recovery in the midst of mental ill health. Turning points, those dramatic moments in participants' narratives, marked a leap forward, putting people in charge of their process. Finally, they needed to undertake the long hard work of recovery.

The recovery framework we developed (RECOVER + HEART) was our way of organising the significant themes emerging from the data which described the variety of experiences, imaginative actions, hard work and profound changes of heart and identity contributing to recovery.

Coming out the other side of mental ill health and recovery, participants had changed profoundly. They had become more resilient, yet accepted their limitations as well as understanding their strengths. They had got to know and like themselves better – now they knew who they were. Their relationships with others had changed too, as illness and recovery had given them the opportunity to test the resilience of their social networks. They had come to understand how invaluable were connections with supportive people – family, friends, workmates, health workers, fellow tangata whaiora – and they also understood what it was like to experience lack of support, as well as stigma and discrimination.

This was a bicultural study and we paid particular attention to cultural contributors to the recovery of Maori participants. We found that recovery for Maori and non-Maori involved many of the same kinds of events and processes, but that there were also aspects of recovery unique to Maori, which we examined in Chapter Nine.

Throughout the project, we paid attention to the ways in which people tell stories about their mental health experiences. Their texts of illness, recovery and life afterwards are social texts, informed by ethnicity, gender and other social markers. Their stories are shaped by deeply personal and unique experiences, at first isolating and frightening, though later enriching. The stories are also shaped by the cultural resources participants drew on to speak of themselves, their networks and their relationship to mental health services.

People who have experienced disabling mental health problems have much to teach us about suffering, about life's journeys, about wisdom and about the importance of knowing who we are. Mental health services, although they feature strongly in stories, are not their central focus: services help or hinder, but do not usually provide the defining moments in recovery, because recovery rests largely on personal as well as cultural resourcefulness.

Like all tellers of personal stories, people's narratives of mental health journeys place themselves at the centre – they are the heroes of their own lives. By listening to them, we come to an understanding of and respect for their journeys.

Glossary of Maori Terms Used In This Report

aroha	compassion, love		*rongoa*	herbal or healing remedy
hatana	Satan		*taha Maori*	Maori way of doing things
hinengaro	thoughts		*tane*	man
iwi	tribal grouping		*tangata*	people
kai	food		*tangata whaiora*	mental health service users (people seeking health)
kaiawhina	helper			
karakia	prayer		*tangata whenua*	indigenous people
kaumatua	elder		*tangi*	funeral; weep
kaupapa Maori	Maori philosophy		*taonga*	treasure
kehua	ghost		*tautoko*	social support
kia ora	informal greeting, hello		*tikanga Maori*	Maori customs
ko wai au?	Who am I?		*tinana*	body
koroua	male elder		*tohunga*	healer, specialist
kotiro	girl		*Treaty of Waitangi*	founding treaty of NZ as a nation, 1840
kuia	female elder			
manaaki	care		*tupuna* [also *tipuna*]	ancestors
manaakitanga	process of caring		*wahine*	woman
marae	gathering and meeting place		*waiata*	song
matakite	second sight		*wairua*	spirit
mate	illness		*waka*	canoe
matua whangai	adoptive parents		*whakama*	shame
mauri	life force		*whakapapa*	genealogy
mihi	greeting		*whakatauki*	proverb, maxim
mirimiri	massage		*whakawatea*	a cleansing or freeing ritual or process
poroporoaki	farewell			
pou	physical support		*whanau*	extended family
puku	stomach		*whanaunga*	relative

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