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Recovering Voices
in mental health, families and anthropology

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2009

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Abstract

This essay discusses some experiences of families, carers and people with experience of mental ill-health and recovery in New Zealand, focussing on 'recovering moments' in social exchanges, families, mental health settings and in anthropological research. It draws comparisons between phenomenological approaches in anthropology and practices promoted in recent mental health recovery philosophy, with a particular focus on the production and exchange of particular local expertise, much of which resists academic appropriation or definition. The value, currency and relevance of these 'recovering voices' relates to their being privileged, validated and transmitted in ethical exchanges in a range of social settings that exemplify aspects of Marcel Mauss' discussion of the act of giving, receiving and repaying (1980:34).

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Introduction

This essay presents something of a journey of recovery and discovery within an *archipelago of the mind* – a field that emerged, for me, through my participation in a range of mental health recovery-related events and exchanges. In it I discuss a series of encounters that I refer to as ‘recovering moments’ – points of interaction and discussion that involved my and other people *recovering voices*. The title of my essay refers both to an ethnographic act of recovering voices, and to the *recovering* status of those who participated.

In this sense, my essay is mimetic both of the fieldwork process, and the recovery journey – an eclectic process that gradually unfolds within and from continuing social exchanges, reflection and narration – a form of praxis (Knauff 2006). My discussion of this ‘recovering moment’ in mental health is not definitive but rather, explorative and adaptive. I discuss processes and exchanges rather than defining or describing recovery as a destination or static condition (Lapsley *et al.*, 2002). I have sought to *evoke* a sense of the field and my subject without explicitly defining, and thus confining the bounds of their experiences and potential. This essay challenges a sense of *institutional* ‘definitions’ and ‘bounds’ of what an essay is, or should be in that it responds more to the nature, ethics and experiences of the field in which I took an active part.

And in contrast to many academic and scientific research endeavours, I argue the validity of *not knowing* as a way of *being* in research, I myself repeatedly returning to this condition with a willingness to *find out*. Where Jackson suggests that Helene Cixous “sees definition, categorizing, rationalizing, and enclosure as masculine traits [...and] celebrates instead a passive and open attitude toward life in which language is entered into rather than exploited” (1996:43), I emphasise the *act of exchange* as being of prime importance in this recovering moment, more than the ‘object’ or ‘condition’ being offered, observed, categorised or defined in the research/treatment process. I position myself as an ‘experimental subject’ – anthropology offering a way of facilitating and mediating exchanges, my method being to *enact* a journey of recovery, and to share in its ongoing transmission. My approach in research and writing resonates with that of Cixous’, where

“This mode of passivity is our way – really an active way – of getting to know things by letting ourselves be known by them. You don’t seek to master. To demonstrate, explain, grasp. And then to lock away in a strongbox. To pocket part of the riches of the world. But rather to transmit: to make things loved by making them known.”(1991:57).

Part One of this journey presents something of a long introduction explaining my way of “getting to know” the field through a series of encounters. It traces, in a roundabout way, the discursive formation of my thesis, aims, theory, methodology, ethics, subject and findings, each developing in relation to the other – blending, merging and interacting within and in relation to an “ever emergent ethnographic field”.

This field – an *archipelago of the mind* – formed through, and from recovering voices, both privileged and marginalised, and in chapter two I discuss my own shifting awareness of the politics of inclusion and exclusion within this ‘recovery’ narrative, and the ongoing legacy of New Zealand Pakeha institutions.

In chapter three I discuss aspects of the “Recovering Moment”, describing my subject and participants not in terms of ‘status’, but identifying them through our shared practices. I discuss my “fellow travellers”, that include people with experience of mental ill-health, carers, support workers, family and other supporters – “we” who participated in various events.

In chapter four I explain my phenomenological approach that involves partaking in the lifeworld of my participants by getting beyond privileged ‘academic categories’ of observation. Thus, in “Voices beyond words” I privilege other less documented aspects of experience that may fail to register in academic discourse whilst being of major importance in my participants’ lifeworld.

In chapter five, I discuss this ever emerging field, looking at some “Changing perceptions in a fractured system”, discussing the diversification of our local concepts of being, and perspectives of wellbeing, as they shift away from dichotomous models. I consider some of the challenges these shifts present to the mental health institution,

suggesting those with power have an obligation to develop responsive, flexible and inclusive practices and perspectives to meet the needs of their constituents.

In chapter six I look at how constituents navigate, map, and plot a course through this ever emerging *Archipelago of the mind*, suggesting that knowledge of the self, family and the system form through, and from, ongoing social exchanges. I look at the ways in which some of my participants work to develop a sense of unity of self, family and institution by mapping personal/familial needs as they relate to the mental health system.

In Chapter seven, “Signposting experience”, I circle and fixate on some of my participants’ thoughts and experiences around the medical model and diagnostic labels. In mind of the relationship between institutions, individuals and families, I consider the implications of my own deployment, uptake or rejection of such labels, and the medical model, in my research practices. I discuss my research dilemma, contemplating how I might ‘define my subject’ without imposing, perpetuating or privileging limited or problematic institutional assumptions or categories. Eventually, I consider the possibility of using strengths and goal-based approaches to break free of these markers in research, and treatment settings.

Seeking “Ethical exchanges”, in chapter eight I discuss the reflexive process of developing practices in a collaborative manner with participants. I explore the benefits of enquiring about my research participants’ ethical concerns that reveal insights into their personal needs, values and perceptions when mediating the boundaries of personal and public, familial and social domains.

In chapter nine, I discuss my experience of “Engaging interviews”, comparing my ethnographic practices to others looking to affect and partake in *recovering moments*, practicing the social art of engagement and exchange within this *archipelago of the mind*.

Part One of this essay resembles something of the “messy baroque” in anthropology (Marcus 2007), in evoking a more diverse, eclectic sense of the field that forms somewhat chaotically through an expansive range of varied encounters. My

navigation between these voices suggests a form of “anthropology in the middle” whereby I mediate various strands of experience and voice in attending to the ‘recovery’ task at hand (Knauff 2006). Having traced the development of my methodology and practices as they responded to my experiences in the field, I suggest something of an *ethnographic inversion* takes place within my *archipelago of the mind*, as I consider my encounters with various informants who resemble what Marcus described as “paraethnographers”(2007) – local experts involved in knowledge production in, and of, the field.

Taking this line of reasoning further, in Part Two I look at local stories, narratives and knowledge production in various ‘recovery’ settings, expanding on the notion that in this recovering moment, the *form* of exchange is of equal or greater significance than the *content*, or *object* in itself. I focus primarily on ‘consumer’ or ‘first-person’ narratives of mental ill-health, voice-hearing and recovery, emphasising the “Local expertise” of participants, and discussing aspects of world and self-making in recovery.

In Part Three, “Being as Family”, I return to my original question regarding the relationship between “mental ill-health” and “family life”. To do so, I take another journey through various domains, discussing the experience of bodies and objects moving through and between place and space. I look at a diverse range of recovering moments occurring both with the family home, and between families, individuals and the mental health institution. In chapter eight, I conclude by discussing my recurring motif of the “The gift” that I suggest offers far more potential in how we perceive, practice and experience these recovering moments within this *archipelago of the mind*.

Part One Recovering Voices

1. An Archipelago of the Mind

I ventured, a little over a year ago, to find out “how might relationships affect and be affected by the experience of mental illness?” A little way into my journey I realised that my question led to others regarding assumptions about what mental illness is or isn’t, who does or does not *have it*, or *experience of it*, and who has the *right* to decide and define such matters. I wondered, in who’s authority, and consensus, shall I/we trust? How can we tell what affect *it* does or does not have, on a person, and in relationships? What are *its* bounds, and how can we really say what affects the experience of *it*? My initial question assumed certain, simplistic dichotomies that, through my ethnographic engagement with people in complex lived realities, I now see as part of the ‘*problem*’. In a phenomenological and ethnographic fashion I sought to get behind such assumptions, to enter a site and state of ‘not knowing’, and to discuss some of the process of ‘finding out’. This essay presents the story of my research – a journey of exploration and discovery – a multi-sited recovery project in what I came to experience as an *archipelago of the mind*. As such, my arguments, insights and discussions unfold throughout this essay in a manner that reflects the evolving and sometimes labyrinthine nature of the field, both for researcher and participants.

This intersubjective field formed through my engaging with the voices that wait within these pages. As metaphor, this ‘archipelago’ ties closely into a lived reality involving journeys and encounters within, and about the field of mental health recovery – a place about mind – the bounds, categories and population of which were often illusive and ill-defined¹. The significance of this metaphor “lies in its disclosure of the interdependency of body and mind, self and world [... where metaphors] thus reveal or realize unities; they are not figurative means of denying dualities”(Jackson

¹ Hatfield explains, “Unfortunately we do not know what proportion of people with mental illness can be said to be in recovery. The problem is complicated, as Lefley points out, by the fact that there is no agreed-upon definition of what constitutes recovery. [some] argued for viewing it as a process rather than an end point. This suggests that we need to define milestones in this process by which to assess the individual”(1997:255, citing Lefley 1997). My essay presents a journey, quest, or intersubjective project where a sense of *being recovered* is reified in a *recovering moment* through *recovering voices*.

1996:9)². The journey of mental health recovery involves both an exploration of the self and the world, and the relationship between the two. Recovery – a living project of navigating, charting and mapping and interacting within the *archipelago of the mind* – ties into every aspect of being and relating, where

“mind is viewed here as something that ‘extends beyond the skin’ in at least two senses: it is often socially distributed and it is connected to the notion of mediation”(Wertsch 1991:14, citing Bateson 1972; Geertz 1973).

Lapsley, Waimarie Nikora and Black (2002)³ propose some common aspects of mental health recovery derived from research with forty New Zealanders. Their recovery journey, which became something of a model for my own, involved:

- Research, reading, and learning from others;
- Emotional Growth, and learning about myself;
- Changing my circumstances and taking on responsibilities;
- Experiencing social and familial support;
- Practicing virtues and positive strategies.

(2002:57-69)⁴

On this recovery journey, I drew a map resembling the Trobriand Islands pictured in Malinowski’s *Argonauts of the Western Pacific* (1961), between which circulated precious gifts in the Kula Ring⁵. Where Malinowski situated himself within the ‘native’ village, partook of village life, and developed an understanding of the Kula progression from this central position, my own work involved moving about between

² Jackson observes that these metaphors “of journeying and storying simply convert this habitual sense of moving to and fro in the world into spatial temporal terms”(2002:32-33), suggesting that “stories possess a ‘spatial syntax,’ partly because they encode the correct itineraries and protocols governing movement within a social environment, partly because they provide ‘delinquent’ and tactical clues as to how boundaries may be infringed, gulfs crossed, and movement varied”(ibid:32).

³ Lapsley *et al.*’s research “*Kia Mauri Tau*” *Narratives of Recovery from Disabling Mental Health Problems* (2002) describes and outlines the transformative aspects of New Zealander’s recovery journeys that resembled my own experience of immersing myself in my anthropological research project.

⁴ They also discuss “HEART”: working with Hope, on self Esteem, practicing Agency, working on Relationships, and Transitions of identity (2002:71-78).

⁵ The Kula refers the circulating gifts moving within the network of islands in the archipelago in different directions, conducted by high status representatives in a reciprocal manner, one function of which was to forge and maintain ties between groups and individuals.

various meetings, support groups, and points of exchange at mental health related events⁶. Where the asylum and the traditional ethnographic site might once have been perceived as distant, separate and other to the gaze of the observing culture, my anthropological field formed within and from multi-sited encounters (Marcus 2007). This reflects the fractured nature of the mental health system in New Zealand, and the movements of some of its constituents since the shift to reintegration and community care following deinstitutionalisation (Brunton 2004, Gawith & Abrams 2006).

These ‘sites’ of mental health recovery encounters involve service providers, service users, carers, family and whānau, researchers, support groups, non-government organisations and so on. They take place at community centres, Marae, homes, halls, libraries and public spaces. They include courses, meetings, interviews, conferences, summits, discussions and support groups⁷. Like the Kula, this recovering moment “welds together a considerable number of tribes, and... embraces a vast complex of activities, interconnected, and playing into one another, so as to form one organic whole”(Malinowski 1961:83). The gifts circulating this system often take the form of stories (Leibrich 1999; Lapsley *et al.*, 2002). We who partake in the formation of the field are *recovering voices*. In this field, “ethnography [...presents] itself as mediational, as situated among its multiple sites [developing...] coherent positions of cultural critique from these contexts” (Marcus 2007:1133).

Thus, the field (both of research, and mental health recovery) was ever emergent, mediated through various encounters. It began to form when I started speaking of my recovery project – when I disclosed my position and intention, paid membership fees, got on mailing lists, joined libraries, asked questions, participated in discussions and requested assistance. I partook in a manner comparable to other ‘family members’, involved in the exchanges made available to us. Like others present, my participation

⁶ The proper conditions for ethnographic fieldwork, for Malinowski “consist mainly in cutting oneself off from the company of other white men, and remaining in as close contact with the natives as possible, which really can only be achieved by camping right in their villages”(1961:6). Similarly, Brunton (2004) observed the ‘cutting off’ of patients, and staff, from the rest of New Zealand society in remotely located asylums.

⁷ For a list of the mental health related events, meetings and courses I attended, see the appendix. Some of the groups with which I became associated include Supporting Families in Mental Illness (S.F), The Hearing Voices Network Aotearoa (HVN), Connect Supporting Recovery (Previously AMHS), The Mental Health Foundation, and Psychiatric Survivors. Yet there are a vast range of groups who organised events.

holds parallels with the radical empiricist practice of ethnography involving reflexive observation, enquiry and engagement (to varying degrees), where we were each, in relation to the other, “drawn into the lifeworld as participant”(Jackson 1996:29).

We each enacted aspects of a recovery journey through and from which we formed this *archipelago of the mind*. This involved developing an awareness of self in relation to others, and to the system as a whole, through mindful participation in various relationships. The recovering moment is akin to phenomenological anthropology where participants sought “to recover the sense in which experience is situated *within* relationships and *between* persons [so that the] lifeworld may be explored as a field of intersubjectivity and not reduced to objective structures *or* subjective intentions” (Jackson 2002:26).

I was faced with the question of how, without making or perpetuating possibly problematic assumptions, and undermining people’s sense of self-definition and determination, could I define my research group in this recovering moment? I resisted imposing established and privileged *categories* of being and experience to locate participants, instead encountering “engaged reflexive subject[s]”(Marcus 2007:1133) with varied perspectives and experiences, who “cannot be mere informant or subject of research [but...] become involved in its intellectual work and scope”(ibid). Thus, the recovering moment within this *archipelago of the mind* can be seen as a “multi-sited arena of fieldwork as networked knowledge sites[,] the ethnography of which is both thick and thin, and is patterned by very politicized relations of collaboration; and ultimately the inclusion of reception itself”(ibid). The ‘status’ of participants is of secondary importance to the relationship in and through which it is taken into account, established, challenged and maintained.

Thus, I entered the field and engaged with those who registered interest. I situated myself within something of a *family* of perspectives – speaking with parents, siblings, partners and adult children who held various and sometimes multiple roles as carers, support people, mental health ‘consumers’, professionals and researchers – all insightful participants within their varied relationships. And my research and writing formed organically, taking part in “the performance of mediations of found perspectives in multi-sited space amid reflexive subjects capable of their own

paraethnographic functions”(Marcus 2007:1133).

2. Privileged Voices

I have, as a matter of course, privileged certain voices in a manner that reflects something of my experience of, and encounters in the field⁸. My early encounters were almost entirely with Pakeha, and being that I was unfamiliar with the system I was exploring, and that I had a limited scope and timeframe to make enquiries, my twelve interview participants were representational of my early encounters in the field⁹. Non-Pakeha groups were often underrepresented at the events I attended, and I considered a range of factors involved in privileging or marginalising voices.

I am from a working class Pakeha family living on Auckland's North Shore – a relatively well catered for community. I had access to adequate and affordable accommodation. Through ongoing interactions with educational and other institutions I have become somewhat familiar and practiced in *using* the system as opposed to being subject to it. I expect to be heard and understood, have become accustomed to 'yes' responses, and to having a variety of options and alternatives. As a student, I have access to libraries and a database of articles in my native language, and to the voices and assistance of professionals practiced in the workings of Pakeha institutions. I have access to an internet connection. The scholarship money I received allowed me to spend a year doing 'recovery work' without having to work long hours,

⁸ I follow Wertsch's argument, with regard to matters of privileged voices in my essay, where the "reason for using privileging rather than domination is that the latter is often implicitly associated with some kind of stasis, whereas privileging is assumed to be more dynamic. It is dynamic in part because sociocultural settings do not mechanistically or unilaterally determine mediated action; in many settings it is at least possible for participants to define the situation in new, unexpected, or creative ways. Thus, there is a degree of dynamic negotiation involved. A major source of this dynamic derives from the fact that patterns of privileging are accessible to conscious reflection and hence, to self-generated change"(1991:124).

⁹ The terms by which mental health issues were almost uniformly addressed in my encounters were Pakeha, Western, and spoken of in English. That is not to say that I did not seek or hear Maori and other non-Pakeha perspectives, both in my reading and in discussions. Recovering the voices of an arguably privileged group about difficulties and suffering may go some way to locating experiences that might be amplified for minorities, the marginalised and less privileged voices in mental health relationships. Despite rhetoric and discourse that might suggest otherwise, the mental health system in New Zealand is based on and born out of Western models and systems (Gawith & Abrams 2006; Brunton 2004). Groups like AMHS/ Connect are involved in amplifying traditionally marginalised voices. Non Pakeha voices and perspectives in the day-to-day exchanges received little acknowledgement. I felt recovering non-Pakeha voices and having access to Maori ontology, concepts of well-being, family and whānau, illness and recovery could be beneficial and enriching both minority and privileged 'stakeholders' alike, and the system as a whole. Peterson *et al.*, 2006,2008; Lapsley *et al.*, 2002; Barnett and Lapsley 2006a, 2006b and other New Zealand researchers recover the voices of Pakeha and non-Pakeha groups somewhat proportionately.

weekend or evening shifts. I don't attend to children, nor do I have a substantial 'carer' or 'service user' role, nor do I feel particularly burdened. I have been relatively mobile – bicycling, bussing and borrowing a vehicle to move between daytime, evening and weekend meetings, interviews and so on. Relatives in other cities accommodated me when attending events and conferences. Registration fees for such events were discounted to students, and sometimes free to affiliates of various organisations, the membership fees of which were also discounted for students. Membership in such organisations ensured my inclusion on email lists pertaining to services, seminars, courses and meetings, and access to libraries, advisors and advocates familiar with, and holding a working knowledge of the system.

My voice and position, then, like those with whom I spoke, is relatively privileged in defining this *archipelago of the mind*. Consequentially I present a somewhat limited and limiting perspective that evolved through interaction and exchanges with others whose concepts of experience around mind, being and wellbeing I now see could be enriched through recovering a diverse range of voices. My research, though not centred on ethnicity, is poorer in perspective for the voices it fails to recover, where “we, each of us, injure the humanity of our fellow sufferers each time we fail to privilege their voice, their experience”(Kleinman and Kleinman 1996:187) and thus must “be careful of ‘narrowing the humanity of the other and thereby of ourselves’” (bid:180; citing Said 1978).

3. The Recovering Moment

Here, I wish to shift away from a ‘medical’ idea of recovery as a state of being without illness, to emphasise the verb form of *recovering* as a practical act, a way of being and relating in the world, an ongoing project that means different things to different people (Lapsley *et al.*, 2002:2-3). Like others I spoke with, Arana observed “we are all healing from something that happened in our lives” – we are all, from time to time, recovering. Despite attempts, no one with whom I spoke could define or describe with any certainty the absolute bounds, nature, beginnings or endings of mental illness, mental health or well-being – these were experienced, imagined and described intersubjectively.

When shared and exchanged, the richness and variety of peoples’ expert perspectives dissolves this assumed dichotomy of ‘mental health’ in opposition to ‘illness’. The mental Health Commission defines recovery on broad, accommodating terms as “living well in the presence or absence of illness”(1998:1). Patricia Deegan promotes the idea of “recovery as a journey of the heart”(1996) through which the individual tries 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” (1988:15). In this essay, I take up the journey metaphor, attending to Deegan’s assertion that the, “aspiration is to live, work and love in a community in which one makes a significant contribution”(ibid). In contrast to privileged western medical explanations of mental illness, I emphasise the social aspects of mental and emotional distress, and recovery, that are conceptualised, lived and felt, and enacted within communities (LMLM 2003¹⁰).

Focussing on the act of *recovery* that involves *recovering voices*, I commonly refer in this essay to ‘we’ who commune with a shared objective and practice, irregardless of diagnosis, status, profession or categorisation¹¹. Thus, I describe a group of ‘travellers’ better defined by a shared, mutually beneficial objective and set of

¹⁰ LMLM: Like Minds Like Mine, a non government organisation working to stop stigma and discrimination for people with experience of mental illness.

¹¹ I do acknowledge that often, observations of categories and divisions were made, and emphasised by groups who felt disempowered or marginalised – certain labelled ‘identities’ were taken up as a tool for drawing attention to a shared ‘class’ experience, and cause – the goal being to draw attention to perceived and socially assumed differences, distinctions and discrimination so as to dissolve them.

practices that necessarily involve the dissolution of an institutionally maintained sense of otherness, of ‘them and us’¹², in favour of ‘we’ involved in recovering voices – for in these exchanges, as Laing observes,

“both sides come more and more to resemble each other. [...] Shall we realise that we and them are shadows of each other? We are Them to Them as They are Them to Us” (1967:83)¹³.

Thus, in this recovering moment, groups such as Like Minds Like Mine work on deconstructing problematic dichotomies, emphasising a common humanity as being of primary importance, whilst normalising mental illness as a common ‘human’ experience to which we all might be susceptible¹⁴. They emphasise the need for humane, moral and ethical practices in all spheres of social interaction, observing that personal recovery and wellbeing is closely associated with systemic recovery (LMLM 2003). Like Appleton in her research of the social experience of mental illness,

“I was convinced that full recovery, social reintegration and overcoming of social stigma depended on finding a means of reducing and dissolving the boundaries between self and other, of normalizing both the experience and those who experienced it, in ways which would allow us to relate to them as like ourselves” (2006:15-16).

¹² Rosenham (1973) discusses the institutionalisation of both patients and staff in mental hospitals, relating this to the social pathology of focussing on, defining, and emphasising difference, employing those differences to validate a benevolent imbalance of power that is then perpetuated through physical and positional means, sanctioning inequality and disempowerment, and sacrificing humanity despite (or through) enacting ‘good’ intentions.

¹³ Laing, in this chapter of his book *The Politics of Experience* (1967) discusses experiences and notions of *Them and Us* - the above quote responding to American involvement in the Cold War, alluding to the cyclical perpetuation of these ‘opposing’ positions that from certain perspectives might be seen as one and the same.

¹⁴ Anne Appleton, researching the social experience of mental illness in a New Zealand town, observed that, “A solely biomedical approach was inadequate to address the diffusive nature of the suffering involved in mental illness experience. Secondly... that in the New Zealand context, the dualistic mind/body model of the person negatively influenced social perception of both mental illness and the person who was ill, such that their identity became essentialized”(2006:15-16).

4. Voices Beyond Words

My research, and this essay, partakes in this act of *recovering voices* through which we might share in this sense of journey, discovery, and recovery together. Yet these voices are not all spoken. To dissolve this ‘mind-body’ dichotomy further, and to emphasise both a common, and ‘whole’ humanity, I look beyond the institutional tendency to privilege that which has been described and validated in a discourse made up of utterances. My position of ‘not knowing’ resonates with Jackson and other’s discussion of phenomenology that is the scientific study of experience,

“an attempt to describe human consciousness in its lived immediacy, before it is subject to theoretical elaboration or conceptual systematising. In the words of Paul Ricoeur, phenomenology is ‘an investigation in the structures of experience which precede connected expression in language’”(Jackson 1996:2, citing Ricoeur 1979:127).

I was inspired by the examples of those like Arana Pearson – voice hearer, family man, Mad Pride advocate, writer, singer, and public speaker – who emphasises aspects of a common humanity, dissolving the division between so-called ‘sanity’ and ‘madness’, and the various diagnoses he received¹⁵. At the Supporting Families Summit in 2008, Arana played with the ambiguities, anomalies and contradictions inherent in mental health-related rhetoric, drawing my attention away from scientific categories and descriptions of experience, back to the local human relationships in which we play a part. Where “the tendency to isolate various dimensions of a phenomenon is precisely what is encouraged by the disciplinary fragmentation that characterizes so much of the contemporary scholarship in the social sciences and humanities”(Wertsch 1991:119), Arana’s discussion moved me to find a methodology or “unit of analysis that cuts across, or better yet, ignores existing disciplinary lines [...and] to relate technical detail to other aspects of a general picture”(ibid:121).

¹⁵ Arana has appeared on various television documentaries, and speaks publicly about his experiences, shares his feelings and beliefs on his website, does peer support work and tells his story openly. He appears, as he did in the field, at various times throughout this essay. I asked Arana if I might quote him and discuss his story in my essay. He agreed, explaining there was no need to disguise his identity – that his story was ‘public’ – his words, a gift.

Where Laing observes that “we seem to need to share a communal meaning to human existence, to give with others a common sense to the world, to maintain *consensus*” (1967:65), Arana demonstrated how this might be achieved by means other than verbal communication and cognitive expression. He suggests that where Western institutions privilege the written word, in our interpersonal exchanges we *relate* and *feel* more through speech tones and rhythm, movement, positioning, touch, mannerisms, expression, eye contact, laughter, and silence. In line with Jackson and others’ phenomenological perspectives, Arana proposed that non-verbal experience is concise in that it is irreducible and stands exactly for itself. Our bodies are entirely articulate as they act and feel, preceding verbal description. Arana emphasised a sense of lived experience that pre-exists health status, institutional labels and medical explanations. His recovery rhetoric attended to a fuller sense of humanity, emphasising bodies that move, dance, stand still, act and feel with their own corporeal expertise. His discussion of mental health recovery involves a physical performance, and where consensus may be sought in ongoing explanations, definitions and discussion, it can be achieved more readily in a shared intersubjective experience – in a moment of articulate silence.

Arana’s observation informed my perspective of life for those involved in this *archipelago of the mind* that goes beyond ‘brain chemistry’, and “extends beyond the skin” (Wertsch 1991:14). “In Western Culture,” he observed, “we ask ‘what do you do?’ We have become human *doings* – *functionings*.” Within this value system, certain among us tend to “see the mind as full of problems, observing ‘poor functioning’ or ‘problematic or abnormal behaviour’.” The emphasis, in Western society, on ideal ways of ‘functioning’ marks, for Arana, a loss of humanity, health and wellbeing. He explained, “Being is more important” – simply *being* can be enough.

And it was such a shift in perception that carers managed – I spoke, sometimes, with family members of people thought to be experiencing the ‘negative symptoms’ of schizophrenia, discussing the difficulty of rousing interest in doing things like ‘washing the dishes’ on their own accord. They observed, however, that when they asked for help with a task at hand, loved ones were often most willing – we considered the notion of ‘doing the dishes’ and the like, shifting from a purely

functional perspective of ‘getting things done’ to seeing it as an opportunity to collaborate, to share space and time, to be together, to commune through the suds, as it were. Family members often practiced shifting their perspectives, and renegotiating what was at stake in family interactions.

Arana explained, “The most important question when Maori meet is, ‘Where are you from?’” asking we consider the question “How did I get here? To this [physical] *place* and to this *place in my mind?*” – alluding to this sense that journeys within self and the physical/social world are experienced concurrently as we move about with other travellers, developing a sense of inter-experience through “mediated action”(Wertsch 1991). This form of phenomenology, as Laing observes,

“is the science of my own and others’ *experience*. It is concerned with the relation between my experience of you and your experience of me. That is, with *inter-experience*”(1967:27).

I navigated between various meetings and encounters on our recovery journey – change is affected by sharing in common acts – eating together, recovering voices, sharing stories and partaking in and attuning to an intersubjective and emotionally “interactive atmosphere”(Jenkins 1991:388). Participants in these exchanges enact something of an anthropological endeavour that as Jackson observes,

“brings us into direct dialogue *with* others, affording us opportunities to explore knowledge not as something that grasps inherent and hidden truths but as an intersubjective process of sharing experience, comparing notes, exchanging ideas, and finding *common ground*. In this process our social gumption and social skills, as much as our scientific methodology, become measures of the limits and value of our understanding”(1996:8).

In this sea of professionalized knowledge and assumptions I wish to emphasise and validate our instinctual and expert local human knowledge – where we practice and reclaim confidence in our social and personal ability to experience healing. I draw on the wisdom of my participants, like Arana who emphasises the Greek origins of “psyche” meaning “soul”, suggesting psychiatrists might *recover* their role as

“doctors for the soul” – and I am drawn to Arana’s notion of their discipline being “part art, part science”, where as he explained, “we don’t need complicated science – we need simple stuff – mental health is about building a relationship.”

5. Changing Perceptions in a Fractured System

Entering this archipelago of the mind, one may become somewhat disorientated and overwhelmed (Barnett and Lapsley 2006a,2006b). Some discuss the labyrinthine qualities of the New Zealand mental health system, in relation to which personal and familial journeys unfold. Where once a dichotomous view of sanity as opposed to madness, and mind as separate to body were maintained in a system in which ‘head stuff’ was treated in a space and place separate from the rest of New Zealand society (Brunton 2004), we may now observe and envision a far more complex, fragmentary reality in which established and assumed divisions have dissolved, shifted, or been upheld in relation to institutional power and perspectives (Gawith & Abrams 2006).

Although institutional and systemic foci tend to shift (if slowly) in relation changing social needs, in mental health provision, clinicians make a concerted effort to affect/facilitate corresponding changes within in their subject. Rather than simply treating the ‘mind’, more holistic views are reflected in the wide discourse around mental health as it relates to every aspect of our being. Beyond the ‘medical model’ we might now observe that “there is much that is physical in the so-called mental disorders, and much mental in the so-called physical disorders” (First *et al.*,2004:14), and much that is social about mental illness (LMLM 2003, Bentall 2004). Similarly, today’s mental health recovery may involve developing ‘life-skills’ just as a focus on mental illness-prevention might involve employing clinically developed stress management techniques such as Cognitive Behavioural Therapy in everyday settings. This marks a shift of ontology more akin to holistic indigenous and Maori models of being and wellbeing (Durie 1994)¹⁶. From various perspectives, the *archipelago of the mind* (this world of ‘mental health recovery’, both personal and social) is indistinct, interspersed within and indecipherable from society as a whole¹⁷.

¹⁶ Jackson writes: “We are now seeing a shift of emphasis toward indigenous truths, in which oral history is seen as sustaining the life of the living rather than keeping a record of the past. In her work on Maori oral narratives, Judith Binney speaks of the importance of this shift in making colonizers aware of what is imperative for the colonize – a necessary step in the dominant culture is to change its attitudes about its possession of the ‘truth’”(Jackson 1996:38, citing Binney 1987:17).

¹⁷ There are two main interrelated areas of contention where labels, static categories and dichotomous views are most often held and maintained – in professional settings, discourse, and institutions to help meet the needs of the industry, and in society in general, where they are often associated with stereotyping, stigma and discrimination (Peterson *et al.*, 2008).

With an appreciation of multicultural, heterogeneous subjects with both a shared and very diverse range of particular experience and needs, a sense of “them and us” gives way to the collaborative “we”. This is evidenced in the far more extensive inclusion of service users and family members in District health board roles, staff training, service design and policy work. As divisions dissolve and shift, and more voices are recovered, we see rapid systemic change (Gawith & Abrams 2006)¹⁸. We might observe a hierarchical system, with clinicians at the top on one side, and service users beneath, and on the other, being challenged – a whole range of services and groups now vie for funding, and voice, within the system.

Yet divisions persist between rhetoric, ideals, and lived realities in the field¹⁹. The system’s ability to represent its constituents depends on their voices being heard and acknowledged within a competitive funding system (Gawith & Abrams 2006; Walmisley 1998). Where connectivity and voice is associated with agency, empowerment and choice for families and service users, our sense and experience of this *archipelago of the mind* relates to whose voices are privileged. Those whose voices are least privileged, who have little contact with, understanding of, and power within the system may be isolated and least well served, perpetuating an experience of exclusion and division.

Throughout this essay I consider who has an interest in maintaining, challenging, or resisting shifts in power and voice within the system. Where Gawith and Abrams observe that “the task of facilitating recovery in partnership with consumers presents an ongoing challenge for mental health professionals [that...] may mean a substantial renegotiation of power and privileges (2006:146), Nick Argyle observes that in New Zealand “the positive development of consumers, the NGO and the recovery paradigm has unfortunately been accompanied by a pervasive negative attitude to clinicians”(2005:2).

¹⁸Various mental health related documents promote the inclusion of diverse voices, perspectives, skills and expertise at all levels of service provision, organisational change, policy making. See for example, MHAC (2008), MHC (1998, 2001, 2004), Ministry of Health (2000a, 2001, 2002a, 2002b), LMLM (2003); Lumb (2007), Cowan (2008).

¹⁹ Where Gawith and Abrams discuss the mental health funding system, where non government organisations must compete for funding whilst collaborating within the system to provide a holistic service (2006:246-7), we may see that the ‘staid’ established, inflexible and under funded structure sometimes undermines its own ideals.

Ever-shifting, particular, heterogeneous human needs present staid, inflexible, institutions with challenges. Where for decades, ‘service users’ have been asked to accept professional views, Wells challenges the mental health workforce to “be aware of their own life experience and culture[, to understand] discrimination and social exclusion[...], give us respect, rights and equality, [and, amongst other things...] learn about our service user or consumer movement”(2001)²⁰.

In this recovering moment, many believe that those with power have a civil responsibility to familiarise and align themselves with the social struggles, empowerment issues and voiced perspectives of those often marginalised – to step into their shoes²¹. To understand the recovery journey it is suggested that clinicians must have lived it – this involves losing and finding one’s way within this *archipelago of the mind* – and endeavouring to see through other’s eyes. We might ponder how the intensity of constituents’ feelings and emotions can be conveyed in rhetoric, written scripts and guidelines for best practice, and in this essay I suggest that phenomenological anthropology offers methodologies that might help affect such shifts in perception. Jackson suggests,

“To shift our focus from the privileged world of detached intellectual activity to the often underprivileged domains of the lifeworld is to reconstitute our notion of knowledge as something urgently of and for the world rather than something about the world”(1996:37).

My own shifting position on this recovery journey involved something of “a lateral displacement rather than an overarching perspective [the implication being...] that no cultural standpoint is central”(Jackson 1996:9)²² – developing a sense of unity from

²⁰ See also the Mental Health Commission’s *Recovery Competencies for New Zealand Mental Health Workers* (2001).

²¹ At one workshop I attended, participants wore a headphone with voices playing, whilst trying to partake in conversation with others, so as to gain a sense and feeling for the experience. Whether one understands or not, the *effort to find out* can be seen as an ends in itself.

²² I resist notions of information being actively and objectively ‘extracted’ from passive ‘subjects’, just as in the recovery model there is a shift away from a colonial perspective of passive patients being ‘treated’ by active authoritative doctors. I embrace a phenomenological approach that recognises experience as ‘intersubjective’ with parallels in the recovery movement that seeks to empower *all participants* by facilitating active engagement in relationships and ‘inter-experience’.

the fractured particulars of this *archipelago of the mind* involved actively recovering voices speaking from a range of perspectives. And I suggest that for those in positions of power, conducting an anthropological ‘recovery project’ may be helpful in adjusting perspectives and affecting personal change.

I developed some appreciation for people’s needs and experiences, their thoughts and feelings through their statements. Yet my *feeling* of the ‘emotional atmosphere’ of their lifeworld, my *sense* of what people felt, the urgency and intensity of their needs occurred less cognitively – wrought in physical expressions, voice tones and volume, movements and manner, through laughter and tears, signs of triumph, sadness and anger, expressions of anguish, frustration, weariness and exhaustion. Where written discourse so often fails to recover or convey the message of these voices beyond words, phenomenological anthropology “implies a methodological shift[...] since understanding this lifeworld entails reaching beyond ‘dialogue and discursive reality’ into participation and transference”(Jackson 1996:10, citing Devisch 1993:257). This transference dissolves perceived dichotomies and transcends fractured divisions, revealing and realising unities and connectedness.

The discussions that follow look at some of the ways participants on this recovery journey navigate, mediating their experience, sense of self, and sense of community through social interaction in a range of domains – my thesis being that through ritualised exchanges at various events, individuals and groups develop a sense of empowerment and obligation for those beyond their day-to-day world. I look to Mauss’ discussion of *The Gift* (1980), suggesting that attending to moral obligations around giving, receiving and repaying ensures both individual and social prosperity and wellbeing whilst uniting diverse groups. I discuss, in some depth, the transformative power of participating in events in which marginalised voices are privileged, where participation affects a sense of ‘other’ as spirit, flesh and blood, with emotions, strengths, hopes and needs.

6. Maps and Plans

Service users and family members spoke of their need to develop a sense of unity and connection within the system, and between the system and their own needs. At meetings between District Health Board representatives and family/whānau carers, the latter reported their concerns of feeling left out of the loop, and disrespected²³. Helen made evident the importance of people having access to maps and plans that help align services with particular, personal and family needs. In this chapter I discuss the formation of these maps and plans that correspond with the recovery experiences of constituents, and I argue that in this *archipelago of the mind* such ‘maps’ connecting the *social system/institution* to our experience of *being* must now be holistic, and socially and culturally inclusive.

I met Helen through Supporting Families. Some years back her daughter was having difficulties and was diagnosed with Schizophrenia. Like many first encounters with the mental health system, her induction was problematic (Barnett & Lapsley 2006a, 2006b; O’Hagan 1994, 2000a, 2006), in part due to the lack of support, and helpful information²⁴. Helen is articulate, educated, assertive and familiar with Western systems and institutions – in her own job she employs a “common-sense” approach to needs assessment, problem solving and service provision in attaining positive outcomes for young New Zealanders. She expressed determination and hope regarding her daughter’s treatment and the prognosis for her future, working hard to bring together the necessary conditions to improve the likelihood of recovery. Her daughter received good initial treatment and had ongoing meetings with a clinician in the public health sector – yet Helen felt that communication was poor, services were

²³ For extensive discussions and guidelines on Family inclusion and collaboration in service provision and recovery in New Zealand, see Trish Lumb’s *Participating in Partnership* (2007), Steinberg & Whiteside (2005) and Ministry of Health (2000a,). Outside New Zealand, see Mottaghypour and Bickerton’s *The Pyramid of Family Care* (2005). Others who emphasise family involvement in treatment plans include Hatfield and Lefley (1987, 1997), Marsh (1992) Hatfield (1990) and Barrowclough & Tarrier (1990).

²⁴ By many accounts of people I spoke with, the system and service provision has been improving rapidly in recent years, in accordance with objectives set out by the likes of Geraldine Strathdee (2008), the MHAC (2008), the MHC (1998,2004) and Mary O’Hagan (2006) around stepped approaches to care in primary healthcare settings, preventative and early interventions. Barnett & Lapsley (2006a, 2006b) and O’Hagan (2000a) suggest that services were often found lacking, or limited. Treatment providers with limited spaces responded to a sense of urgency and need, or a lack thereof, or to factors suggesting a high likelihood of positive outcomes with responsive clients. Some family members felt ill-informed, and others yet felt they were given too much information, and needed guidance to find the “useful” or “important stuff”.

withheld, and that information was not forthcoming²⁵. After two years, Helen felt her daughter's condition wasn't improving and that she needed practical help in problem solving, developing coping strategies and learning life skills to facilitate recovery and reintegration – a holistic approach. She explained,

you could see her socially unhappy..., and we had a lot of concern about that, and raised it with the psychologist, but he was dealing with her. And not prepared to step outside of that. [...] I know they were having great conversations [but...] it was all head stuff. And I kept saying to him, "Look, I think she needs more than just this", so he recommended someone who was private [...] and again it was all head stuff – about analysing. None of it was about strategies and coping, which I now know needed to be in place.

*...We asked, "Are there any other services we should contact to help her?"
"Huh?"*

They could say, "We don't know," and that would be fine. No one out there has got that experience to tell you, or they're not prepared to do it...

...We haven't had anyone tell us about Mind Matters – that would have been a great help. No one had told us about EPI [Early Psychosis Intervention] services, which were exactly right for her... We never had a key worker²⁶.

Helen felt that the professionals and the services provided were very good, but that there was a shortage and thus many people's needs went begging. Despite her assertiveness it took a long time and effort for treatment options and information to be forthcoming. This seemed to be due in part to changes in service delivery. That Helen's daughter felt safe with family, was bright and articulate, acknowledged and

²⁵ Both Waitemata and Auckland district Health Boards now have full time family mental health roles, as well as 'consumer/service user' positions aimed at better ensuing families are well informed of services, and services are informed of family and consumer needs. Supporting Families are considered a necessary first point of contact for families – though in 2008, family members were still turning up to family support meetings, complaining they had not been informed of the organisation's presence promptly enough.

²⁶ Helen continued: "For me the model that supporting families teaches you is the one that made the difference for us. The family needs to be there. There needs to be medication and there needs to be therapy, whatever that means. And they just say you've got to start. And that's all got to be in place before you can even begin to think that progress can be made. ... mental health services now have brochures saying they include family but in practice we weren't experiencing that at all. They were treating her and blocking us....We had to tell them, 'we know about this, now why can't we have it?' They didn't tell us about any service at any time that they had, which could have been beneficial to her."

showed insight regarding her illness, and took part readily in treatment, resulted in a lack of urgency in service provision. Holistic family and personal needs beyond “head stuff” weren’t given enough consideration.

For many, access to adequate, prompt care and assistance depended to a large degree on developing a recovery plan and a ‘map’ of the system – recovery involved a series of successful interactions between individuals, family and the institution.

For families and service users, safely navigating this recovery journey within this *archipelago of the mind*, involved close contact with an immediate support network, developing some understanding of the wider mental health system, becoming familiar with other social agencies and organisations, finding out about other’s experiences and connecting these with one’s own particular needs and experiences. A ‘map of being, experience, need and progress’ for individuals and families was aligned, and developed in correspondence with their mapped experience of available services²⁷. Those involved in this recovering moment became practiced in shifting focus from their particular experience of ‘mind’ to wider social and institutional conditions. As Kleinman and Kleinman observe of their anthropological practices,

“Getting at mediating psychological processes requires that eventually we shift to the view from afar – we cannot otherwise abstract universalizing processes from the particularizing content of ethnopsychological meanings – but to understand actual situations we must use both lenses.”(1996:172).

Similarly, where once, family members might be considered like Malinowski’s ‘natives’ not to have or need “any clear idea of the [system] as a big, organised social construction, still less of its sociological function and implications”(1961:83), we who become involved in this system found ourselves, like ethnographers, having to “*construct* the picture of the big institution” (ibid:84) by establishing and maintaining ties and ongoing exchanges with others doing the same – a sometimes onerous task. Through regular and ongoing exchanges between constituents, such a picture or map is constructed communally. Further, the way in which the system works, its structure

²⁷ The MHAC (2008), Parker *et al.*,(2007) and Strathdee (2008), suggest that primary healthcare settings need to be the first point of contact for people experiencing symptoms or mental distress, accessed before crisis occurs, and working as a ‘hub’ directing service users toward needed services.

and formation, and whom it supports, depends on participants' active engagement. I reiterate that my ability to successfully navigate and affect change within this *archipelago of the mind* was heavily dependent on my privileged position, my familiarity with Pakeha systems, and my status within them.

At the Supporting Families summit in Wellington, 2008, various among the workshop discussions dealt with matters of recovering voices²⁸. Representatives from Southland Mental Health Network who organised "Future Directions – weaving wellness into our future"²⁹, discussed their role in developing a map and directory of, and strong connections between, an expansive group of stake holders in the region – including general practitioners, primary health services, mental health workers, family representatives, schools, public health, Supporting Families, consumer groups, local Maori, Federated Farmers, the police and so on. This group partakes in an exchange of ideas, obligations, and goals. They explained that setting up a network, a village, uniting multiple domains, means that in this fractured system "we are all on the same page".

Individuals, families, service providers and organisations develop a living map. Those present have influence and are influenced, affecting obligations within the exchange – thus, the 'needs' of this living map can negotiate and interact in a personal manner with the 'haves'. This map, and the system are somewhat fluid³⁰, presenting challenges to service users, families and providers. By recovering voices regularly, institutions build flexibility, reflexivity and responsiveness into their organisational structure. Family and service user access to services depended on their access to current knowledge, which in turn depended upon participation in a social network. Groups like Supporting Families and AMHS play a mediatory role, working to maintain 'living' and 'feeling' relationships with services while developing an evolving appreciation of human need through ongoing personal interaction. Such

²⁸ A range of papers presented at this summit can be downloaded from <http://www.sfnat.org.nz/nationalMentalIllness.php> (January 2009).

²⁹ For a copy of the document and presentation, see: <http://www.sfnat.org.nz/documents/SouthlandMentalHealthNetwork.pdf>. (January 2009).

³⁰ Mental health-related organisations form, shrink, expand and disband, increase, diminish or change their function and processes, gain or lose funding, forge and sever ties – all in relation to a range of internal and external influences, all with systemic repercussions. Family and service user needs and experiences also change, depending on a range of factors – cultural, geographical, economic and so on.

groups facilitate ongoing exchanges in courses, support groups, fieldwork, and through peer support networks.

At the support groups I attended, where ‘recovery’ and ‘wellbeing’ were sought we plotted a course toward goals and charted personal progress within various domains. Wellbeing is conceptualised, experienced, mapped and maintained through intersubjective exchanges in a web of relationships – people partaking socially in a recovering moment. It arises at the interface between overarching institutional discourse and services, and the immediate and particular lifeworld of constituents. It develops when we are confident of our ability to transcend dichotomies and transgress institutional, social, conceptual and experiential divisions. Our mobility within this *archipelago of the mind* involves imagination, originality, and creativity – recovery involves every domain of exchange within New Zealand society. The enrichment of this system and its constituents, and the accuracy, currency of these maps (both of the system, and our experience of *being* within the system) is dependent on diverse, inclusive representation.

As Helen observed, to rely on singular claims of absolute authoritative certainty and knowledge risks peril. No single authority holds a full, current, dominion or universal comprehension regarding the *archipelago of the mind*. The efficacy of a system, and the wellbeing of its constituents depends on the circulation of information, stories, critique, experiences and shared obligations. Wellbeing, hope and faith occur not as ‘capital’ or ‘wealth’ held by professionals, nor in the ‘brain’, but emerge from a community’s ability and willingness to partake in ongoing, fair exchanges.

And so I venture a leap within this *archipelago of the mind*; those who are least represented in various exchanges, with a legacy of experiencing injustice, who have been marginalised within competitive or colonial systems, who have been separated from their language, their ‘expert knowledge’, their lands, whose communities have been divided, who have the highest occurrence of chronic, acute mental illness, whose needs are least often met, and who often have difficulties with Pakeha institutions – their voices are least recovered (Durie 2004; Kingi 2005).

7. Signposting Experience

An important part, for many, of this *archipelago of the mind*, are the diagnostic ‘signposts’ and the medical model that seem (amongst other things) to hypothesise an explanation of one’s condition, suggesting possible outcomes, whilst directing a path toward recovery³¹. At this phase of the journey I wish to circle, fairly extensively, these signposts, looking at some of the arguments, perceptions and experiences of those with a stake in their uptake, usage or dismissal. I begin by looking at arguments around their usage in some of the literature, and then in everyday language, relating this to our sense of ‘being, having, and experiencing’. I discuss in more detail some of the experiences of my participants, considering perceived ‘qualities’ of such ‘stable markers’ as they relate to changing lives. Finally I consider what is at stake for my research in acknowledging, adhering to or avoiding these authoritative texts – looking to strengths-based and goal-focussed approaches to help us move beyond their gravitational field.

Labels and Groups

At the outset of my research I was called to define my subject and research group, something I was reluctant to base on a medical model of ‘mental illness’. After my early encounters I came to question these assumptions and labels regarding human experiences. My information sheet explained that I wanted to talk with people in families where someone had experience of mental illness³², yet not everyone with diagnoses subscribe to the medical ‘illness’ explanation. Partaking in this *archipelago of the mind*, developing relationships with others going about *recovering voices*, looking to define my field and subject, I soon became aware of the dilemma of definition Lorna Murray refers to in the Hearing Voices Network annual report:

“One of the main causes of debate has been inclusion and exclusion from the network, committee and groups. There are inherent complexities in this discussion as the lines that we might use to include and exclude people are not clear. Not all voice hearers are service users, not all service providers are

³¹ I follow Stephen’s Shore’s assertion that at their best diagnostic labels “provide convenient carrying handles or summaries of a condition and... this can provide a key for needed services”(2008) for those who are seeking help.

³² For a copy of my research information sheet, refer to the appendix.

voice free and not all voice hearers are distressed by their experience. Opposing views are respected and heard, however it has been agreed that HVNANZ exists for and can be accessed by all people”(2008).

I followed Joan and Arthur Kleinman’s phenomenological approach, trying

“to become more self-consciously reflective about the human core of human experience [where...] a contextual focus on experience-near categories for ethnography should begin with the defining characteristics of *overbearing practical relevance* in the processes and forms of experience. That is to say, *something that is at stake* for all of us in the daily round of happenings and transactions” (1996:170).

Thus, my use of such labels responded to that of my participants. In the field, people presented a wide array of thoughts and feelings regarding what was at stake in the deployment, uptake and ongoing use of diagnostic labels. Those I spoke with and listened to often considered their experiences on terms other than, or in opposition to, psychiatric and medical models of illness – some making

“a fundamental critique of the psychiatric transformation of that irreducible existential quality of illness [where...] what is lost in biomedical renditions – the complexity, uncertainty, and ordinariness of some man or woman’s world of experience – is also missing when illness is reinterpreted as social role, social strategy, or social symbol... anything but human experience”(Kleinman & Kleinman 1996:169-170).

For some with whom I spoke, receiving a diagnostic label regarding their or a family member’s experiences was seen as a positive step – they felt it alleviated anxiety about their experience – by naming it they were able to externalise and define it, find supportive communities, talk about their experience using common language, and plot a direction and course of treatment (Kleinman 1978)³³. As a researcher I had similar

³³ Kleinman observes that “the healthcare systems of different cultures serve functions that are common to all. They enable individuals to communicate about their experiences; they sanction certain types of behaviour (for example, staying away from work when ill); they guide the choice of health

concerns – abandoning common (though not universal) categories I might struggle to find a research community and a common ‘code’ for dialogue. I risked losing my direction in a field without definition, distinction or bounds. Yet, the ethic behind this process of exploration validates my returning to, and even maintaining, a state of ‘not knowing’. Coming to terms with uncertainty is an important challenge for those partaking in this recovering moment. I acknowledged that the use of such labels occurred and saw their deployment, uptake and rejection as “‘Phenomena’ of human experience [where to...] deny such terms absolute explanatory power is simply a prelude to exploring their phenomenal power – the interests they serve and the transformation they affect”(Jackson 1996:12).

In New Zealand, most clinicians employ the American DSM-IV as a globally recognised guide to diagnosing mental illness and disorders³⁴. These labels offer a medical explanation and definition of a very personal, particular, subjective and heterogeneous experience to which outsiders have no access beyond observations of behaviour or disclosures of symptoms (MacDonald 1981). Mellsop *et al.*'s (2007) research found that New Zealand clinicians privilege this text for practical reasons – its common usage ‘promises’ consistency between practitioners, provides common, referable terms of reference directing practitioners toward treatment needs, and it is recognised by various institutions – service providers, welfare organisations, insurers and the state. Yet clinicians also pondered whether the model is always applied appropriately and as intended, questioning its relevance and applicability to non-Western patients and its efficacy in aiding recovery. They expressed concerns around a sense that receiving diagnosis potentially does more harm than good (ibid 2007). Lyn explained her ‘findings’:

I don't believe in categories – from what I've read and from what I've experienced. My daughter's had about seven diagnoses [...] but people end up thinking that they are the illness. I think self-stigmatising, internal stigma is much harder to break down than external stigma.

care interventions; and they influence health care practice *per se* (for example, the use of herbs, manufactured drugs or psychotherapy).”(1978:139).

³⁴ The DSM-IV: *Diagnostic and Statistical Manual of Mental Disorders IV* – (published by the American Psychiatric Association). Although this document ‘evolves’ it does so rather slowly in comparison to the conditions and experiences of those people it is meant to serve.

As mentioned earlier in this essay, many within this recovering moment are transgressing what is often perceived as a stigmatising dichotomous view of illness as opposed to health, to acknowledge a complex diverse and definition-elusive condition of being human. In his book, *Madness explained* (2004) Richard Bentall discusses the historical, cultural and institutional formation of concepts of mental illness and diagnostic labels, examining the propagation of a dichotomy based on assumptions around the nature of madness in opposition to sanity that has perpetuated a ‘them-and-us’ mentality and perspective within both the Western mental health model and Western societies in general. In part, this dichotomy relates to the privileging of an isolating reductive approach or vision in the sciences, an ‘either/or’, ‘cause and effect’ mentality and a failure of research and discourse to adequately situate, or ground methodology and findings within the context of the ‘lifeworld’ of personal experience – a part of which they claim to observe. Bentall suggests of this medical ‘narrative’, “What is required, after a hundred years or more of the dominance of an approach that is unsupported scientifically and unhelpful in practice, is a *balancing* stance rather than a balanced one” (2004:3). Let us look, then, at some of the discussion of these attempts to define and stake out a universally recognised claim within or *over* this ever-changing *archipelago of the mind*.

Debates around, and critiques of the privileged use of diagnostic labels and the medical model abound. Arguments are very often polemic – Parsons and Armstrong’s (2000) argument for the relevance of, and scientific rigour behind the DSM-IV and the use of psychiatric ‘benevolence’ responds to the work of Szasz (1960, 1987) who questioned profusely the medical model the ‘psychiatric power’ behind this ‘narrative’. John Read, a New Zealand clinician and researcher, along with Mosher and Bentall argue in *Models of Madness* (2004) that “Schizophrenia is not an illness” that can be biologically or genetically located or defined, questioning a range of assumptions relating to causes, experience, and the use of the diagnostic labels³⁵. In answer to this, another New Zealand clinician and researcher, Robert Miller, proposes that although Read *et al.*’s arguments may seem sound, we must shift our attention to

³⁵ In *Models of Madness*, Read, Mosher and Bentall argue against the notion that “mental illness is an illness like any other”, observing that it is “promulgated by biological psychiatry and the pharmaceutical industry, is not supported by research and is extremely damaging to those with this most stigmatizing of psychiatric labels”(2004:3).

what is at stake in the uptake or dismissal of such narratives where, “if taken uncritically, some of it has the potential to do real damage to good mental health services as they struggle to develop more humane and effective programs for treatment and prevention” (2008:13).

Arguments focus on perceived costs and benefits to service users, family members, clinicians and other stakeholders, as well as the accuracy, applicability or integrity of both the diagnostic process and the model it serves. Other writers are more discursive and less prescriptive, presenting different perspectives of individuals and groups that relate to their roles, needs, agendas and experiences in particular contexts and cultural settings³⁶. Some present alternative models that focus on strengths-based approaches to treatment (Blundo 2001; Rapp 1998; Saleeby 1997) and working without diagnosis (May 2008; Romme and Escher 1989, 1996; Bentall 2003)³⁷.

In New Zealand, Mellsoop *et al.*, (2004) discusses the perspectives of clinicians, whilst Peterson *et al.*, examine the experience of service users who sometimes relate the medical model and diagnostic labels to their experience of discrimination (2004, 2007) and, stigma, self-stigma and a reluctance to seek treatment (2008:16-17)³⁸. In their discussion of recovery, The MHAC³⁹ (2008) focus on states of “Well-being” as a goal for both individuals and communities that may or may not involve diagnosis. Randal and Argyle (2005) discuss accommodating spiritual models of ill-health, observing that “Clinician and patient may not have similar explanatory models; this difference is extreme if the patient's model is itself seen as evidence of psychosis by

³⁶ See for example: Corrigan (2007), Watson & Corrigan (2001), Nathan (2004), Floyd Taylor and Bently (2004), Kendell (1996), Estroff (1997), Maresella and Westermey (1993), Waxler (1981), Kleinman (1978, 1980), Joan and Arthur Kleinman (1996) amongst others.

³⁷ Today, in New Zealand, there is a greater emphasis on working with specific ‘concerns’ and without diagnosis – especially in early intervention services employing cognitive therapy to deal with specific experiences and distress, focussing on strengths and goals, without especial need to provide diagnostic labels – this relates, in part, to recognition of potential stigma and reluctance to seek help when diagnosis is given (See for example, May 2004; Parker, French, Kilcommons & Shiers 2007; Walsh 1997). We might discuss “mental ill-health” (Peterson *et al.*, 2008, MHAC 2008) and experiences of distress as opposed to “mental illness”.

³⁸ Peterson, Barnes and Duncan (2008:16-17) refer to discussions in literature that draw connections between diagnosis and self-stigma (Caras 2006), the reluctance to seek treatment (Watson and Corrigan 2001, amongst others), reluctance to disclose their diagnosis (Bromley & Cunningham 2004; Dinos *et al.*, 2004), and worsening symptoms (Risher and Phelan 2004, amongst others). Rather than trying to establish ‘directionality’ of cause and affect between diagnosis and self stigma, I explore what is at stake in the deployment or rejection of diagnostic labels in different settings and situations.

³⁹ Mental Health Advocacy Coalition (2008).

the clinician” (2005:2). They argue it may be “there does not need to be an either/or approach taken here, but that both/and explanations might help bridge the 'gap' between ‘explanation’ and ‘understanding’”(2005:2). In New Zealand, the state endorses recognition of non-Pakeha concepts of illness, health, wellbeing and being⁴⁰. There is an increasing body of literature discussing the beliefs, experiences and needs of Maori (Durie 2001, 2004a, 2004b; Kingi 2005; Webster & Bosman Watene 2003), Pacific Island (Lui 2003) and Chinese and Asian communities (Tse 2004; Tse *et al.*, 2006, 2007; Nayar & Tse 2006), often exploring how they compare with and contrast privileged Western models.

We can not assume that people should, or do recognise a singular mental health ‘model’ or explanation of experience within New Zealand, despite its predominance in clinical settings. Diagnostic labels delineate the intersection of personal experience and the social institution, yet the sense of division between these two domains widens when tried and tested labels and descriptions remain staid and unflinching in the face of personal and societal change.

Being, Having, Experiencing

What, or who is being defined or described by psychiatric labels, and how? Despite their intended uses, such labels are deployed interactively in relation to notions of social class, identity, personhood, illness experience, well-being, roles and responsibilities. Participants very often spoke in terms of being, having and experiencing. For example, attendees at family support groups expressed uncertainty regarding the bounds and extent of illness, personality, culture, habit or side effects with regard to their experience of another’s behaviour. Rebecca explained of her brother;

I think maybe it’s a combination of two things. Firstly, he’s a young Kiwi guy who doesn’t really know where he’s going or what he’s doing, but then on top of that he’s got his illness, so that’s making it doubly hard for him.

[...] I felt he was using his illness as an excuse to behave badly. He does do that; “It’s not my fault, it’s because of my illness.” And you’re like, “Your

⁴⁰ Various state funded documents include: Mental Health Commission (1998,2001,2004) , Ministry of Health (2001,2002a,2002b,2006), MHAC (2008), amongst others.

illness didn't [make you do that].” Other times he denies he's unwell. But then it's really hard to differentiate between what's his personality and what's the illness, particularly because he was so young when he was diagnosed, you know, he was seventeen or eighteen, so you're really not sure.

For families, the deployment and uptake of diagnostic labels and medical explanations for behaviour sometimes responded to their currency in day-to-day exchanges. Medical explanations sometimes afforded a “no-fault” perspective for service users (Parsons 1972), and for family members (Floyd Taylor & Bentley 2004). Certain significance and connotations could be flexibly and selectively emphasised or downplayed. As symbols, they were inscribed with all manner of inference depending on their usage by who about whom in what context and circumstances, in consideration of what was intended or implied, or what was *thought* to be intended or implied. There was a sense that where diagnosis was used as a tool to mediate power, this could be disruptive to their social cohesion. Furthermore, being ‘educated’ about diagnosis-related symptoms or outcomes might infer or reinforce potentially disempowering, self-fulfilling expectations or assumptions. I think the important thing for families and service users to recognise was that generally, diagnoses are of secondary relevance to the holistic particularities of being, having and experiencing.

We might trace a progression in the ways in which signposts explaining this *archipelago of the mind* have been deployed, illustrating shifts in people's sense and conception of *being, having and experiencing – identity, ownership and association*, in relation to social institutions⁴¹.

Someone stating, “He *is* a schizophrenic,” refers to an illness identity in the perfect tense assuming a permanent state of *being* that illness, and a class of subject. Under the medical model, we might observe a shift to *ownership* of illness or disease, in which one might “*have* depression”. Stating, “she *suffers* from psychosis,” assumes that suffering is necessarily implicated in this experience. Joan explained, “I am a voice hearer”, an identity emphasising a *human* experience independent of diagnosis.

⁴¹ We hear and employ a multitude of labels and markers used to describe people, states of being, experiences and so on – as a group, we might be referred to as consumers, service users, family members, patients, psychiatric survivors, wellness seekers, the mentally ill, voice hearers... and so on.

Others employed descriptive sentences such as, “he has *experience* of mental illness,” where illness is emphasised as an impermanent *experience* – rather than an indefinite possession or identity. “She had an experience commonly referred to as mental illness”, emphasises *association* with an idea over certainty and ownership, a more descriptive and comparative explanation, emphasising awareness of this intersubjective point of contact between the individual and the institution, between experience and discourse. Similarly, stating, “My brother *has a diagnosis* of schizophrenia,” draws attention to the institutional use of diagnoses without subscribing to, or ascribing its definitive power over personhood. Some told me, “I am mad,” re-appropriating (or *recovering*) a label abandoned by the institution, and inscribing it with aspects of their being, personal experience and personality, as a tool of empowerment⁴².

I suggest that this progression in the usage of labels reflects a postmodern appreciation of intersubjective experience of fragmentary, diverse, contested domains and discourses. Further, in this recovering moment we might observe that ‘ownership’ is contested, momentary, and fleeting – that ill-health, like recovery cannot be ‘accumulated’, but is experienced intersubjectively within ongoing exchanges (Kleinman and Kleinman 1996). We can observe in this *archipelago of the mind* a shifting awareness of the complex, particular and fragmented nature of *being, having and experiencing* in relation to somewhat staid, inscribed institutional notions and definitions.

My own appreciation of this contested arena developed through the process of recovering voices and perspectives, the bounds of my recovery project necessarily going beyond ‘illness’ to reflect a sense of the reality of the field and the lifeworld of those within it. For many, recovery involved making skilled meta-analyses of the implications of the medical model and psychiatric labels. Participants’ experiences and notions of *living, relating and being* developed both in response to and independently from psychiatric labels. The changing use and perception of psychiatric labels responds in part to recovery philosophies emphasising hope, the impermanence

⁴² Arana discussed his affiliation with the *Mad Pride* movement, something he compared to *Gay Pride*, and *Black Pride*, emphasising the valuable qualities of madness – a resource which he could draw on, and found empowering in the context of his life. Read for example, R. Dellar’s *Mad Pride: a celebration of mad culture* (2000).

of illness, and the value of self-determination and self-definition beyond illness identity (MHC 2001, LMLM 2003; Gawith & Abrams 2006). Thus, as Laing observes,

“In using the term schizophrenia, I am not referring to any condition that I suppose to be mental rather than physical, or to an illness, like pneumonia, but to a label that some people pin on other people under certain social circumstances. The ‘cause’ of ‘schizophrenia’ is to be found by the examination, not of the prospective diagnosee alone, but of the whole social context in which the psychiatric ceremonial is being conducted” (1967:103).

Convenient Labels?

In the field, we employed generalisations and diagnostic labels “as a way of mediating conversations and social relations”(Jackson 1996:19, citing Illich 1973) – often for lack of a better description, as a reference point on our journey, a shorthand for experience that invariably required elaboration. Interestingly, where family members were sometimes blocked in making enquiries about their loved one’s condition “because of the privacy act” (BOTPA)⁴³, clinicians were able to discuss aspects of an illness hypothetically and at length – giving examples of possible symptoms, likely outcomes, care strategies and so on, without mentioning a specific person. Yet, these ‘qualities’ relating to institutions privileging diagnostic labels also imbue a sense of permanence, stasis and universality presenting both benefits and costs to my participants.

Christine explained her experience of physical concerns, anxiety, panic attacks, and depression – she explained that, “not knowing what was going on” increased her anxiety. She quit her stressful job, was referred by her general practitioner to a psychiatrist, given a diagnosis for her symptoms, took up the advised treatment options, and received a good prognosis. Her anxiety was relieved further when she moved from an unemployment benefit to a sickness benefit, on which she “wouldn’t be harassed to find work.” The diagnosis allayed her fears and anxieties about her

⁴³ In support groups and at health board and other meetings, carers learned how to “ask the right kinds of questions” to find out about their loved one’s condition – when service users asked that their condition remain private, a degree of inference might be used in discussing a ‘diagnosis’.

condition, its causes and possible outcomes. Yet in hindsight she attributed her experience to a “Life-crisis – a spiritual awakening,” terms relevant to her sense of self, her history, and spiritual beliefs that were in turn accentuated through the experience. Publicly, she told few friends and kept her experience from potential employers, explaining that because of social stigma, “It was better to be unemployed than seen as having mental illness”⁴⁴. Years later she felt able to talk openly about her experience, it being subsumed into a more extensive personal life narrative. She acknowledged that the diagnosis of depression now has greater social currency, thanks to anti-stigma campaigns, seeing it as “not so strange after all”.

No longer in the midst of mental illness-related distress, Logan actively maintained and prolonged his ‘illness status’ with his doctor to maintain his sickness benefit. He situated an experience of serious depression and anxiety in his late teens within historical, social, familial, physical, spatial conditions involving poverty, within and over which he had diminishing control. Thus, responsibility for his condition was socially distributed. He related a chain of events over four or so years in his life that led him toward a serious depressive breakdown. After having his unemployment benefit cancelled, his condition deteriorated. At nineteen, on the advice of a visiting family member, he attained the sickness benefit for depression. Logan’s longer-term recovery involved making small steps toward improving his capacity to work at something full time whilst managing his levels of stress and anxiety. He recognised that to work or study full time would remove the beneficiary “safety net”, and diagnosis gave him some ‘currency’ in his exchanges with institutions, while his ‘student’ label was more appropriate in socialising.

Static Markers?

Recovery is difficult to define with any absolute certainty (Lapsley *et al.* 2002, Lefley 1997; Hatfield 1997). Some spoke of deploying labels in recognition of their institutional currency, affording the user some mobility and power within certain domains, demonstrating an appreciation for one’s agency within social and institutional bounds. With increasing power, mental health consumers now demand

⁴⁴ Peterson (2007) discusses the perception of risks associated with disclosure of one’s diagnosis or illness in: *I haven’t Told Them, They Haven’t Asked: The Employment Experience of People With Experience of Mental Illness*. (See also, Lapsley *et al.*, 2002; and Peterson *et al.*, 2008).

more say in how the system operates (MHAC 2008:8; Cowan 2008:34; Gawith & Abrams 2006:141-143). Yet where rhetoric, philosophies and practices might change, institutions tend to retain a grip, maintaining a stake in their subjects' definition within the bounds of existing frameworks.

Arana explained that his original diagnosis of schizophrenia was accompanied by troubling prognoses, the institutional assumption of the time was that he would not recover, nor would he work again. Consequently his partner left him, and he experienced intense distress and depression. Years later he told his doctor, "I did have that illness, schizophrenia, but I'm better now. I've recovered – Can you take it off my record?" The doctor couldn't. Recovery might occur in resistance to, in spite, or regardless of the psychiatric institution (Lapsley *et al.*, 2002). Where the inferences, prognosis and stigma around his diagnosis may have changed, and his own condition progressed to a point of 'recovery', the diagnosis of schizophrenia remains a permanent institutional identity. Deploying 'recovery rhetoric' demonstrated the relative lack of institutional power the recovery paradigm holds within and in relation to psychiatric discourse.

Although self-determination and definition are encouraged, and "recovery is possible" (MHAC 2008), taking something of the moral 'high ground' in relationships, certain aspects of experience and identity are staked out and remain, attesting to the power and will of the institution. The label remains, dismissive of the patient's self-image and terms of reference – a stable marker that speaks more of the institution than the individual's condition. As Kleinman and Kleinman observe, this "semiotic iteration of the [...experience] of lay men and women into the taxonomies of healing professionals is then shown to distort the moral world of patient and community" (1996:169). Arana's lived experience of recovering wellbeing stands in resistance to, and in spite of his diagnosis – he measures wellbeing by other means than symptoms or lack thereof, asking himself in his daily life, "Do I have a sense of humour? Do I have hope?"

Recovery, for Arana, involved subsuming psychiatric labels into his own 'privileged' narrative – in a way, diagnosing the institution. He played a defining role in asserting his title over experience, and his experience over title. He staked out a "Politically

Correct-free zone”, explaining his association with “Mad Pride”, a group involved with recovering voices, seeking empowerment through the reappropriation of those terms discarded by the institution – re-staking their sole claim over labels like ‘madness’ often deemed politically incorrect. Madness afforded Arana greater power – he took up stereotypical aspects of the label and used them to stake out a domain in which he had freedom to play, have fun, release tension and anxiety, and speak to strangers in elevators. As Lapsley *et al.*, noted of New Zealand recovery stories, “learning to value oneself as an individual and resist the expectations of others... was important” (2002:75). Arana’s story of resistance seemed to register with so many at the hearing voices meeting,

“Though stories emanate from personal experience, it is not the imprimatur of individual identity that gives a story value, but the imprimatur of a community [replacing...] ‘individual representations’ with ‘collective beliefs’ [and recasting] personal stories that make them ‘emblematic’ of all who suffered” (Jackson 2002:169, citing Bozzoli 1998:169).

Such stories “map out ideal itineraries (they ‘guide’), *and* they suggest how boundaries may be crossed (they ‘transgress’)”(Jackson 2002:26, citing de Certeau 1984:129). Thus, in this recovering moment, imagination and voice are keys to liberating oneself from, and transgressing the negative impositions of a system that seems to cheat some of their humanity – in this recovering moment, play, humour and wit provide the vehicle for defying one’s sense of proneness to the confinements and stigma of psychiatric language.

Experiential Flux

The life-world of my participants remains distant from that of the American Psychiatric Association and its *gift* of the DSM. The value of such benefactions depends on local recognition, the transformative nature of the ritual, and their positive currency in ongoing exchanges. Their meaning and significance forms through contemplation, interest, obligation and reciprocation (Mauss 1980). The challenge, then, for psychiatric clinicians in having their ‘gifts’ and ‘insights’ recognized as such is to focus on the exchange. To facilitate a sense of mutual obligation between individuals and the institution requires that those with power recognize, respond and

attune to the flux of local particular values, rituals, experiences and beliefs.

In their essay, *Everybody's Got a Little Mental Illness*, Estroff *et al.*, explore some of the ways that illness-related experience, externally applied labels, identity, and self-labelling correspond, explaining that the “sequence of individual responses to altered experiences of self, and the ideas and actions of others, work in a continuous reciprocal relationship, resulting at times in consensus and at other times in conflict between practitioner and patient, or individual and institution”(1991:332). They discuss self-labelling as a form of “illness-identity-talk” in such processes, finding that “Sociocultural factors have a stronger association with self-labelling than clinical factors such as formal diagnosis”(1991:331). In this study, and in my participant’s discussions, there were shifting resonances relating to people’s lived context-bound experience, their personal explanations, and the ‘external’ discourse. As Arana’s story demonstrated, “Labelling theory thus overestimates the importance of these formal biomedical designations, while failing to consider adequately how aspects of the person influence label acceptance or rejection” (Estroff *et al.*, 1991:361).

For many with whom I spoke, externally applied (or imposed) labels served a limited purpose and inadequately accounted for the depth, expanse and richness of their experience and identity. Yet through some infraction of vision, they came to overshadow the person, and their experiences. Where “experiencing mental ill health over a long period of time could lead to the incorporation of illness into one’s identity” (Lapsley *et al.*, 2002:77)⁴⁵, identity talk and identity work became an important aspect of recovery (Estroff *et al.*, 2001). Madness, or illness experience was not ‘other’ but an inherent aspect of their being and experiencing, and thus ever-shifting, evolving and responding to the elaborative process of action, thought, treatment, and discussion. Furthermore, the experience ‘diagnosed’ was never the same ‘illness’ between recipients, nor did the experience or behaviour remain static for individuals and family/whānau. Words fail to account for experiences. I asked Joan, a self-disclosed Voice Hearer, how I might write an essay without using the words “mental illness”. She explained:

⁴⁵Estroff *et al.*, (1991) observe that participants’ race, gender, context and circumstances, as well as the kind of diagnosis, and the kinds of illness-experiences, all play a contributing factor in willingness to acknowledge, or employ psychiatric labels in different ways.

There isn't a word. I haven't found myself a word - yet. And I think, "Is it because I'm so used to calling it an illness, in terms of this being labelled by others, that I find myself saying that?" And I find myself saying things like, "When I become unwell," but actually, that's not what happens. I'm currently writing something about psychosis, because I think of it more as Being Mad. There's something about being mad that appeals to me more. And I think of it much more as a human experience and a human dilemma, and as a response to the world. When you respond to things, we can dissect that and talk about neurochemistry and how our bodies respond... we can do all that, but it's real chicken and egg stuff, isn't it. And I'm not sure that the science at this point... I haven't seen the science actually help me. I'm not saying it's not useful. At the end of the day it doesn't actually help me.

As consumer-led movements and groups organise and their voices gain power, we might observe changes in the narratives, maps and explanations of being, having, and experiencing within (and shaping) this *archipelago of the mind*. Like Arana, Joan got beyond the medical dichotomy of illness as 'other' by actively exploring and describing her experience of voice hearing – something she explained, “wasn't done in mental health at the time”. She referred me to Bentall who privileges an explanation of voice hearing not as 'psychotic brain disorder' to be 'fixed' or eradicated. He suggests that “psychosis should be seen as just part and parcel of human variation rather than as an illness”(2004:96), where as they are experienced, “the boundaries between sanity and madness are indistinct and permeable”(ibid:115). Joan likened her voices to a gift, explaining that they came as both comfort and warning. I recall Joan speaking of her madness as a “survival technique” – a sometimes-enjoyable and indulgent state:

That's probably the side of madness that we don't talk about so much... is the seductive side of madness, where you are elevated to great lengths, where it's a physical... it feels almost euphoric and orgasmic to have that. That's hard to give up – the stuff where it grips you, and terrifies you, that's not so pleasant. But the other stuff, that's got a real lure to it. And one of the things I battled with, in terms of my voices, was that they could take me to that place. But I

can't go there now. But I can if I choose to. And in some ways I kind of think, it must be what it's like to be an addict. See, I can do it my head, but they do it through another medium, but I can actually do it in my head.

What was troubling for some was that this 'indulgent' or 'protective refuge' is itself driven into hiding. These voices are conceptualised as 'illness' and therefore other, devalued, alien, to be controlled or eradicated – yet they are a part of the real lifeworld of the person. Managing madness, in a sense, is one aspect of recovery. Joan talked less about mental illness than mental health, and I asked, "So would you think of yourself as recovering, or having recovered?" She staked out her claim:

I probably think of myself as living, as really living. Because this is what my life is, this is what my life is like. This is what living my life is...

A Research Dilemma

The above discussions explore experiences regarding the deployment, rejection and uptake of diagnostic labels in the medical model. Blundo (2001) discusses the significant difficulties diagnostic labels may cause in people's lives, and goes further to look at the intersubjective exchange, suggesting there are disparate positions inferred or implied between donor and recipient in the diagnostic exchange. These, he suggests, may reinforce feelings of inferiority and disempowerment for clients – herein lies my research dilemma.

I spoke with James and Anita whose son, Peter, had been diagnosed with Schizophrenia – an illness they felt he was unwilling or unable to acknowledge. I was uncertain how to proceed. I asked James to first consult with his son, who acknowledged his parents' wish to partake in interviews but expressed no interest himself. Yet I wondered, should I speak with family members when Peter didn't want to speak? Do we risk discounting his perspective by privileging theirs? How could we respect Peter's want of privacy around a possibly sensitive issue? In writing about their shared yet personal experiences, how might I avoid undermining Peter's self-image, self-definition, or self-determination, or reinforcing an externally imposed understanding of his position and experience? Could we acknowledge James' and

Anita's experiences and perceptions without focussing on illness?⁴⁶ I employ Mauss discussion of *The Gift* to explore aspects of exchanges between families, individuals and institutions.

James – who has himself experienced serious debilitating and chronic depression – explained his use of labels with regard to his son's experience, and in general:

I wouldn't ever call a person 'schizophrenic' or 'manic depressive', or any of those labels, because they are a person that has an illness that has those names. Sometimes there's not much of the person, and it seems like it's only the illness [...]. And it's really tragic, because I see the person as the well person who has a horrible illness, a very debilitating illness. And it's this terrible affliction that's causing them the difficulties that mental illness does.

Like other parents with whom I spoke, after sensing their son was having difficulties nearing adulthood, James and Anita received the diagnosis as something of a *gift* inasmuch as it offered insight and explanation, the acknowledgement and uptake of which involved both the relief of certain responsibilities and the beginning of others (Floyd Taylor & Bentley 2004). Yet Peter's reluctance to *accept* the label on others' terms suggests uncertainty about the implications and burdens of accepting or acknowledging such a gift where, as Mauss observed of Malinowski's discussion of the *Kula*, "to receive one of these gifts means that one is desirous of entering into and remaining in partnership"(1980:25-6)⁴⁷ – where this might be conducted between equals, this medical transaction between the powerful institution and the individual might be experienced on disempowering terms, where as Mauss points out:

“The hierarchy is established by means of these gifts. To give is to show one's superiority, to show that one is something more and higher, that one is

⁴⁶ In their research of New Zealand experiences of mental health recovery, Lapsley *et al.*, (2002) plotted a course in interviews that covered the lead-up to illness, illness experiences, the recovery process and life after recovery. In my interviews, narratives followed a similar progression. As James explained to me, “We all want the story to have a happy ending”.

⁴⁷ McCutcheon *et al.*,(2007) outline a range of approaches for clinicians trying to engage with reluctant young people – I offer Mauss' discussion of 'the gift' as a possibly helpful way of thinking about the nature of clinical, and other social exchanges – its relevance becoming evident in some of my latter ethnographic examples.

magister. To accept without returning or repaying more is to face subordination, to become a client and subservient, to become a *minister*” (ibid:72).

Where prestige is absent in diagnosis, so too is utility. On such terms, we might empathise with Peter’s disinterest, his reluctance to partake on such loaded grounds – where,

“In the distinctive sphere of our social life we may never remain at rest. We must always return more than we receive; the return is always bigger and more costly”(ibid:63).

On what or whose terms is this ‘gift’ of diagnosis, research, or writing, deemed of value? When we find ourselves the central figure of discussion whilst standing at the periphery in terms of having a defining role, I ponder, from where does one divine the meanings and connotations of ‘mental illness’ or the extent, definition or bounds of ‘schizophrenia’ in their lifeworld? What aspect of our being, self, identity, behaviour, strengths, hopes, dreams and experience might *not*, in light of such an all-encircling gaze (of the institution, science, research and treatment) cast a shadow resembling mental illness? Must we stand as involuntary participants in other people’s theses? Hannah Arendt observes, “the greatest injury which society can and does inflict is to make [the pariah] doubt the reality and validity of his own existence, to reduce him to the status of nonentity” (1944:114, c.f. Jackson 2002) – there are risks involved with speaking in alien terms of others in their absence. And so I asked Anita and James,

Should we be focussing on illness? Would it be more ethical to focus on strengths and goals – things aside from diagnosis and illness experience – both in this interview, and in home life? Would we still be here talking if not for this illness? Do we risk fixating on, and thus reinforcing that which Peter may find troubling?

Acknowledging Difficulties...

Often on my journey, the matter of someone not recognising or acknowledging their condition or diagnosis arose – especially where family/whānau might observe or

sense and experience strife. Speaking at a meeting for voice hearers and their supporters, Arana cited an Ethiopian proverb – “He who hides his disease cannot hope to be cured” – the clinch, it seems, being that wellness is dependent on some form of social recognition and validation of one’s expression, condition, voice and position⁴⁸. The risk for both the individual and the community is that that which remains ‘unspoken’ may become a fixation.

My discussion has circled a great deal varied considerations of these ‘defining’ diagnoses and labels. I have contemplated their part in mediating relationships at the interface between individuals and the social institution. I followed the narrative of my informants, enquiring after their ‘self-definition’, asking what was at stake in the deployment and uptake of labels. In an attempt to move forward with our journey I now look toward strengths and goals. For it is through changing perspectives that we liberate ourselves from a fixated, scotomised and mutually disempowering gaze.

....Approaching Strengths

We derive prestige from our ability to contribute of our strengths, and to see such gifts valued and recognised amongst our community (Deegan 1988). Blundo suggests that for social workers employing a ‘strengths’ approach, “the emphasis shifts from problems and deficits defined by the worker, to possibilities and strengths identified in egalitarian, collaborative relationships with clients”(2001:302). This perspective is suggestive of a phenomenological and ethnographic endeavour that “embraces the worldview of the client..., starting where the client is” (Saleeby 1997:197).

According to Blundo, this involves decentring one’s perspective and position and reflexively challenging one’s “habits of the mind” by privileging the voices of those with whom we work.

⁴⁸Recovering one’s voice in the form of disclosure, for some, took courage and involved contextualising and externalising an experience on one’s own terms in a creative manner for others to acknowledge. For some, naming an aspect of their experience, observing it, externalising and personifying it, recognising its nature and character, defining and confining its bounds could be empowering. New Zealander, Matthew Johnstone’s award winning book, *I Had a Black Dog* (2005), deals with his experience of depression in this manner, externalising it through personification and illustration, in writing and pictures, often with humour and lightness. He then co-wrote *Living with a Black Dog* (2008) with his wife, about those in supportive roles to people with experiences of depression. Sometimes, the separation of aspects of self into binary positions may be helpful. Kensella *et al.* cited a sibling’s advice: “separate the illness from the person and say it’s alright to hate the illness and it’s best to love the person”(1996:27, c.f. Jones 2006:972).

“When the ‘client’ is made the center of practice in a true sense, uncertainty and ‘not knowing’ take center stage. A truly mutual/collaborative dialogue ensues, resulting in unique outcomes unsuspected by the professional or the [...] student” (2001:303-4).

Taking strengths perspectives, regardless of the uptake or rejection of labels or diagnoses, seeks to ‘balance the books’. The *act* of engaging with and privileging others might be seen as an end in itself (Blundo 2001). Attending to strengths and values in the ethical act of *recovering voices* reifies an experience of *recovery*, facilitating a sense, if momentary, of *being recovered*. This is reinforced in the recovery of one’s voice, in the act of giving and receiving, in processes that challenge the notion that health (and wealth) can be given, taken, accumulated, and ‘owned’ like capital. In this manner, family members, service users, researchers and service providers move from a dichotomous ‘them and us’ perspective by investing effort in collaborative, mutually empowering relationships. Participation in this intersubjective process of *rendering experience* “involves not the assertion of power *over* others, but the vital capacity of people to work together to create, share, affirm, and celebrate something that is held in common”(Jackson 2002:40).

Maintaining an egalitarian, and open perspective remained at the forefront of my research ethics and recovery approach. Avoiding assumptions or inferences, I worked in consultation and collaboration with participants. When listening to people’s stories we journeyed together between identifiable waypoints, sometimes circling an idea or experience, surveying its significance in relation to the whole. These journey/stories reveal something of the patterns and rhythms of movement in the recovering moment within this *archipelago of the mind*. This involves balancing and shifting focus from matters at hand to the map as a whole – we trace our progress, take stock and assess our condition, deal with the doldrums and look to strengths, hopes and needs – reconsidering our intended destination we plot a course accordingly.

Discussion

For researchers, actively taking up a position of ‘not knowing’ relates in part to grounded, open-ended qualitative interview methodology from which new theory/understanding might arise. Yet, such an approach is limited and limiting if we

return again and again to observe, circle and reinforce an established, centred 'site' and 'subject' on the grounds of the commonly (and corporately) privileged, externally applied defining labels and models. Such sites are grounded within existing frameworks that assume these categories and diagnosis to be empirical 'facts' to which life conforms, something so many seeking empowerment within this *archipelago* challenge. Arthur and Joan Kleinman observe,

“We are far along in this process of inauthenticating social worlds, or making illegitimate the defeats and victories, the desperation and aspiration of individuals and groups that could perhaps be more humanly rendered not as representations of some other reality (one that we experts possess special power over), but rather as evocation of close experience that stands for itself.”(1996:187).

Generalisations made about the 'cohort' may serve to reinforce assumptions about a 'group' experience and may perpetuate self-fulfilling prophecies. By not challenging common, externally imposed terms of reference, descriptors of our subject such as “people suffering from mental illness,” we begin from and perpetuate an assumption regarding another's condition and potential of being, having and experiencing, in relation to a privileged and authoritative discourse. Some of us have, for so long, been the subject, passive donor to, and recipient of such research and discourse. Our experiences have been observed, compared and discussed, tabulated, graphed, examined, diagnosed and labelled, problematised and solved by those with a privileged and limited perspective. We often have the sense of being educated about our selves.

Despite the need to establish a point of 'entry' in research, decentering one's perspective may offer benefits to researcher, participants and recipients. This may involve facilitating collaborative or participant-led research practices, incorporating participant feedback into one's research process, developing reflexive, flexible

research parameters and processes that respond organically to the needs, experiences and terms of reference of a community, seeking participant guidance, working with focus groups and setting up dialogues between a range of voices around a locally relevant ‘inter-subject’, and following the dynamic aspects of changing systems through ongoing interactions and exchanges (as opposed to static experiences or unidirectional flows of cause and/or effect). We might work to privilege and recover voices of experience “beyond words”(Estroff 2008), independent of verbal exchanges. We might develop adaptive and reflexive research methodologies that respond to, reflect and partake in the flow of the ever-shifting, ever-emerging intersubjective field – partaking in the ‘lifeworld’ ourselves. Such approaches facilitate and validate other ways of seeing, being, and *recovering*, potentially widening and deepening our vision *and* appreciation of what is at stake on variant levels for participants. Anthropology’s focus on developing empowering and liberating ethical methodologies, and really questioning authoritative discourse, has much to offer in this recovering moment – both in research, and in everyday human exchanges.

Throughout this essay I explore some of the ways anthropology has been incorporated into the everyday lifeworld as a means of developing and sharing local expert knowledge, a way of being and relating. Curran (2008) explained his role as an Anthropologist in a London psychiatric ward:

“The key point is that anthropological theory and method move from being research into being incorporated into the diagnostic process [...where the] elicitation of a patient’s perspective is critical to culturally sensitive care” (2008).

He argues that anthropological methodology in itself is a useful tool, when it isn’t abused as a means of undermining the person with whom research or interviews are being undertaken, but to support their view, and understand and help them. If recovery involves a discussion, an exchange, then that which seeks to enforce and maintain an established, stable, unchanging paradigm or position may cease to contribute to the development of the collaborative recovery project. As medical and diagnostic models maintain power and privilege through state, and health-system endorsement, (evidenced in the institution’s refusal to accept Arana’s ‘recovered’

status), more than ever we see recovery being sought beyond the confines of psychiatric and mental health services (Lapsley *et al.*, 2008).

I went to places where people came together and shared stories relating to mental illness and mental health recovery, and I spent time with people *recovering voices*. I enquired after the terms and labels used by my participants regarding their experiences. I avoided making assumptions on the basis of diagnosis. I abandoned the need to comply with my sense of institutional expectations around the nature of the 'research subject' and a 'defined research population'. My theory, subject, aims, methodology and findings were established in and with the field, each in relation to the other. These responded to my shifting recognition of values, experiences, perspectives and needs in different domains and contexts. I took the labels of the established discourse as a leaping off point, after which I went with the flow of experience that signposts cannot direct. As Kleinman and Kleinman observe,

“ethnographers enter the stream of social experience at a particular time and place, so that their description will be both a cross-sectional slice through the complexity of on-going priorities and a part of the temporal flow of changing structures of relevance. That such structures are contested, indeterminate, novel and changing means that the ethnographer's descriptions are always about a local moral world that can only be known incompletely, and for which the relative validity of observations must be regularly recalibrated. Moreover, what the ethnographer experiences matches how individuals encounter the flow of experience. They do not dominate it, or invent it, but rather are born or thrown into the stream of lived interactions” (1996:171, citing Dewey 1957:269).

We shift “from standing *outside* or *above* to situating oneself *elsewhere* within the field of inquiry [that...] implies a shift from an emphasis on explanatory models to lived metaphors”(Jackson 1996:9). I sought the voices of those I felt might express some of the diversity, hope and potential of this recovering moment.

I frequently refer to myself, and others with whom I journeyed as “We”. I found that “for the most part human beings live their lives independently of the intellectual

schemes dreamed up in academe and that the domain of knowledge is inseparable from the world in which people actually live and act”(Jackson 1996:4). From within this ‘flow’, diagnostic labels and medical models were employed and pointed out as a momentarily recognisable reference point – a small aspect of a wider, flowing stream of experience. After some contemplation, we who enter into this recovery journey/story/exchange, who articulate and elaborate the particulars of our experience, eventually leave such static markers in our wake.

8. Ethical Exchanges

In anthropology, the ethicality of research and writing is of deep, underlying importance. I will suggest here that the challenge of behaving ethically, for researchers, extends to every aspect of their practice. In the recovering moment, I argue, researchers cannot presume to understand in advance the ethical needs or values of their participants, and there is much to gain in research by making ‘ethical conduct’ a central subject of the research itself.

Developing a shared appreciation of ethical concerns and practice was of fundamental importance in facilitating empowering and effective exchanges in this *archipelago of the mind*. In the meetings I attended, the value of stories and insights depended on their being acknowledged, transformed for personal use, and somehow transmitted further afield. Ethics play a mediating role in the exchanges between donors and recipients – between institutional and individual bodies and minds. Where disclosure and censorship might be considered in terms of purity and danger (Mary Douglas 1970), “it is the nature of a moral rule to be general, and its application to a particular context must be uncertain[... so that it can] never be reduced to something simple, hard and fast”(ibid:155). Practices varied greatly depending on the nature and context of the exchange, and the particular needs and values of different participants who in turn acted in mind of their own cultural institutions and families.

Concerns and contracts were stated explicitly, and within these bounds participants’ conduct affected and responded to an intersubjective sense of implicit values and expectations. At family support meetings, the convener explained we could share “learnings”, but not particular stories outside of the meeting, and that we respect each other’s voice, filter judgement or criticism, and offer positive responses. We *felt* our way instinctively, developing a sense for appropriate exchanges. From these meetings I discuss my “learnings” regarding the *feeling* and *nature* of these exchanges, and my developing sense of needs and concerns common to the community.

At some events stories were given from a stage to an audience in a public manner and I may quote these, yet need not identify *or* disguise the speaker. With Arana Pearson, a relatively public figure who has appeared on television, and who speaks about his

experiences publicly, and who is sometimes paid to do so, I enquired about quoting him and he affirmed that I should use his name. Where one's voice is privileged, or paid for, this involved some sacrifice of anonymity in the mediation of public and private domains.

At the Peer Support Volunteer course I attended with Supporting Families, we discussed a range of ethical issues around disclosure, privacy and safety, many of which were cited in policy, job descriptions and client/worker contracts. Again, within these protocols, the details and particularities of exchanges were negotiated, discussed and intuitively defined *in the field* – they developed intersubjectively between support worker and client, each navigating and responding to their sense of personal and shared boundaries and needs. This was very often an inexact process involving reflexivity and consultation, with tacit care, where ethical boundaries may only become apparent when trespassed.

These exchanges affect and respond to a sense of safety, secured in ritual, where a sense of agency might be attained through the sharing of insight between individuals and groups. In this archipelago, we disclose personal stories – the consequences of such an act may be far reaching – one's voice, restrained or recovered, runs deep – both in its origins and potential legacy⁵⁰. The following discussion deals mostly with ethical concerns around my interviews, complicated in that they have an intended written legacy, and by the depth to which such stories are rooted within intimate shared and personal family experiences.

The Legacy of Voices

Interviews and ethnographies transgress the regular sense of private and public domains (Jackson 2002). Participants and I weighed some potential benefits and risks associated with speaking about the self and one's social and family life, and with

⁵⁰ From the outset, there was a rapid and enthusiastic response to my research – It was for this reason that I was cautious in requesting participants – I proceeded with care, not advertising, my ethic being that to do so might be seen as an invitation involving further obligations. I was happy, however, to speak with people about my work – and discussions and exchanges were an ongoing, contributing aspect of my work.

taking part in qualitative research that in turn would be read by others⁵¹. Of poignant interest to some was this ‘research dilemma’ discussed in the previous chapter, regarding the possible impact of my speaking with James and Anita about their son – both in the content of what is told, and by implication, in the act of *telling*⁵². In our discussions we became aware of the tensions around speaking the self that involves *speaking of others*⁵³.

In interviews, we discussed such concerns, through which we established more detailed ethical boundaries and expectations particular to the exchange. These, in turn, were sometimes overlooked in the ‘heat’ of storytelling, yet referable in my writing up. By reflecting on ethics, needs and risks, we developed a sense of insight regarding the ‘given’ nature of particular family values, expectations and boundaries that often became apparent only when challenged, transgressed, censored or questioned. Discussing ethics as central aspect of how we mediate the interface of private and public worlds led to a richer appreciation of what was at stake and of value for participants and their families with regard to speaking out, or remaining silent. We considered, “Whose story is it anyway?” (Estroff 1995), getting at and then going beyond notions of personal ownership, each claiming to have a mutual ‘stake’ in the intersubjective experience of family life.

Lyn felt that in mental health research, setting inflexible and universal ethical bounds might result from, and perpetuate a “them and us” mentality – especially when they go too far in assuming, on behalf of a certain ‘group’, common experiences, universal needs, characteristics, qualities, vulnerabilities and concerns. In this recovering

⁵¹ I suggested that family members might want to be present during, or take part in interviews, and expressed willingness to discuss my research and questions openly with them. I suggested that participants might wish to consult and seek another’s ‘permission’ to speak about their relationship – yet acknowledged their right to privacy, and maintained the individual’s right to speak, regardless. Further, I acknowledged that some might not want others to know of their participation. I explained that identities would be disguised and names changed, but that participants and family members would conceivably be able to recognise themselves in the situations discussed. Yet, many participants felt the concerns raised by my university ethics board seemed somewhat exaggerated, or irrelevant to their situation. Participants suggested that they *spoke of others*, acknowledging their acceptance of others’ right to *speak of them*.

⁵² In my discussion of Anita and James’s situation in the previous chapter I contemplated the implications of doing family research in which another might be spoken of – and may even be seen as the focus of such research – and thus, is implicated whilst not participating.

⁵³ For some interesting discussions relevant to ethics of mental health research and relationships see Larossa, Bennett & Gelles (1981), Estroff (1995, 2004), Richards & Schwartz (2002), Lefley (1997) and Hatfield (1997).

moment, being oneself and attending to one's conscience, collaborating, consulting and making careful progress seemed to be of the essence, where "by and large the private conscience and the public code of morals influences one another continually" (Douglas 1970:154). James explained,

I find myself wondering, with some of the things you are asking, with regard to ethics, "is this the thing to do?" and, "Is this well meant?" And the word 'Ethics' becomes your name, 'Rowan'. Ask, "Is this the 'Rowan' thing to do?"

Participants maintained their right to speak as somewhat sacred, and took different measures to 'protect' family members. Yet, as Estroff observed, "When we convey this rich totality we may also unmask the person, reveal secrets, uncover hidden hopes and fears – to an audience of strangers, and sometimes to the person as well" (1995:78). Where practicable, some with whom I spoke chose to divulge their participation to family members as a sign of respect, and so as to acknowledge (and not discount) their shared state of *being-as-family*. Attending to ethics in my consultation, writing and editing processes, was of critical importance. Jasmine suggested,

...You'll write it in such a way that builds people's identities – you could write in such a way that doesn't undermine people's sense of self and sense of objectivity and subjectivity. You can write things in such a way as to build their capacity and capability. I mean, it should be something I could proudly say to him was for the cause – that I could say to him, "this is what I've done, you know, to give families a stronger voice in mental health, I've actually participated in this research. I've made issues with the system more apparent. I've shared in the same way that you share in it." I should be able to do that. I should be able to gift it to him, and quite proudly. And he should be able to read it and say, "Well done Mum."

The researcher plays a mediating role between individuals, families and institutions. Some employed the research process as a potential catalyst for positive change, personal validation, revelation and growth. This involved some degree of unburdening, and in transmitting these 'gifts' I have played a mediating role,

removing personal identifiers and adjusting identifiable situations, conscientious of both participating donor and the reading recipient – who may be one and the same person.

Joan and the Legacy of Silence

Peterson *et al.*, (2008), Lapsley *et al.*,(2002), and Barnett and Lapsley (2006b) found that in New Zealand, mental ill-health may be marked by restricted mobility, and a sense of isolation from society and loved ones – a sense of disconnection in which one may experience ongoing distress. Barnett and Lapsley (2006b) found that one of the major difficulties for young people experiencing first episodes of mental illness or distress related to a lack of safe situations in which they could speak of their experiences. My participants' descriptions of these isolating divisions between self and others, along with problematic social situations, sometimes seemed to reflect or resonate with their discussion of 'internal' experiences of distress. In this light, recovering voices and stories in an ethical manner, and renegotiating such divisions, may be seen as an aspect of recovery.

Joan explained that her voices operated at the intersection of private and public domains, mediating and censoring her part in social exchanges. They sought to dislocate, isolate, monopolise and control her at the cost of her social and familial needs and hopes. She hid her condition as best she could from those around her. Like others with whom I spoke, Joan's condition was marked by an increasing withdrawal from social situations, especially at times of stress. The isolation of madness offered a place of safety, but what seemed like an alluring escape was ultimately confining and constricting – she came close to ending her life. Choosing to live meant coming to terms with her situation, dealing with her anxiety and gaining some agency in her relationship with the voices – skills transferable to her social life. She reclaimed power by asserting her will to mediate these exchanges, employing what she referred to as “basic life skills” in all realms of interaction.

Joan's work, something she associations with her recovery, involved speaking publicly about her experiences of hearing voices. The gift of her story validated other voice hearers, challenged stigma, and showed one pathway to wellbeing – it enacted and performed important aspects of the recovering moment. Yet she had to consider

the concerns of others, explaining that although her children supported her move, her father struggled:

And I think, largely I suppose, it's generational. [...Perhaps] he saw that somehow it was his fault, that he was to blame for what happened to me, et cetera. So it was difficult for him. Because like I said... it's not the sort of thing that he wants to contend with, in his eighties. Especially when I'm doing so well – Why bring it up now? Etc. So it was really difficult for him. But my kids were really good about it.

The sense of implication and responsibility in family differs between generations. Yet as Jackson observes, “in enforcing ‘cleansing’ operations that divide the world into Us and Them, censorship may blind us to the ways in which contrasted domains not only overlap, but are, paradoxically, as necessary as they are inimical to each other”(2002:24-25) – Joan observed that her personal experience extends into other domains, regardless of whether or not she discloses it verbally. She continued, explaining that ‘ownership’ of experience was plural,

It doesn't just affect family, I think it affects the community, I think of how disabled I was, I think of my children's schooling, the neighbours, even, you know, “The crazy woman at number 22,” and how it impacted... You know, a variety of things that it impacted. So it's not just my story, as such.

Thus, to the question of ‘ownership’ of experiences and stories, we might turn again to Mauss' discussion of the Kula in Malinowski's *Argonauts of Western Pacific* (1961) to illustrate the value of these stories, as gifts, depends on their mediated movement and exchange between participants in the field. In theory, these valuable stories

“...never stop circulating [...] The gift received is in fact owned, but the ownership is of a particular kind. One might say that it includes many legal principles which we moderns have isolated from one another. It is at the same time property and a possession, a pledge and a loan [...] a deposit, a mandate,

a trust; for it is given only on condition that it will be used on behalf of, or transmitted to, a third person, the remote partner”(1980:22)⁵⁴.

Recovering one’s own voices was one seemingly essential aspect of personal recovery (Barnett and Lapsley 2006b). Yet in doing so, Joan’s public disclosure essentially transgressed social boundaries of what is ‘speaking’, which differed between her father and her children’s generation. It also transgressed the public/private divide that her voices had sought to monitor and control. Joan mediated her disclosure in mind of a range of implicated domains that including family and the wider community, and her disclosure broke silences within the media, freeing others to speak of experiences that were often relegated to silence through shame.

James and the Legacy of Voices

In response to the ‘research dilemma’ discussed in the previous chapter, James and I discussed the potential benefits and costs of talking about his experiences with his son. James acknowledged that the matter of our interview related to his son’s experience of mental illness, and that Peter would not be comfortable hearing us talk in this manner, and we discussed the symbiotic nature of their being-as-family in which experiences were inextricably shared. He observed that interviews involved disclosures akin to gossip, and suggested we risked affecting and reinforcing a narrow view of his son if we failed to acknowledge his ‘wholeness’. In light of these concerns, and in respect of his son’s feelings, James proceeded thoughtfully and reflexively. Yet what was conveyed and expressed in this process, beyond cognitive verbal statements, were the feelings and tones he spoke with, his movements and pause – these conveyed a *sense* of the depth of his thoughts. James suggested the need to convey in my writing something of the feelings and undertones behind the content of our dialogue.

Like other participants, there were things that James wanted his loved one to hear – possibly to read, and to know: that it was from a position of deep respect, love, and empathy that he spoke. The legacy of voices relates to the content of their message, to

⁵⁴ I reiterate here, all that occurred within the last year affected and contributed to my experiences of this *archipelago of the mind* – those words unquoted and stories unwritten, my part in yet-to-be articulated exchanges – all contributed to the sense, feeling and experience from, and about which I write. This essay partakes in mediating and circulating these gifts.

the importance of their subject, the context in and of which they speak, and the feelings and intention with and from which they are uttered. Ethnographic research that concerns itself with these aspects of being and relating beyond and behind content, or momentary thought, or the subject of discussion, may provide a richer more ethical sense of what people experience, and value, and of what is at stake in their lives. The legacy of voices goes far beyond words, involving mood, style and substance. As Joan and Arthur Kleinman suggest, “perhaps, one of the benefits of the ethnography of experience is that it challenges the ethnographer to search for an authentic voice that can match both the scholarly and ethical requirements of its subject”(1996:192). James spoke of my mediating role, where “storytelling enables us to create the ‘necessary illusions’ without which life becomes insupportable”(Jackson 2002:26):

James: *What we’re going to do is you will [in your writing], in a way cleanse – ethically. Does that make it right that we did do it?
[...] When I look back over what you and I have done here, that says that the ethics are in tact – that whatever I’m doing, that I ultimately want it to be for the good of Pete. And sometimes it seems that there is the discount.*

Me: *It goes deeper.*

James: *Yes, because to look at things from the adult ego state, taking the ‘observer’ view of what has taken place in the time that we have spent together... what I’m encapsulating here is that I don’t want to send Peter a limiting or a harmful message. I really do care how he feels and how he sees himself and how he assesses that I viewed him [...].*

Me: *It occurs to me that when writing, rather than saying, “James’s opinion is this,” I’m going to say, that it’s not just the opinion that matters, but all the thought processes and feeling and living that’s behind it, all the weighing up that he does...*

James: *Yes. When I think about this, and every now and again when we’re talking... I do pause, and I say, “how does this... what impact on Peter does this have?” Because I want Peter to thrive.*

Lapsley *et al.*,(2002) observe that for some New Zealanders, disclosure was helpful in their process of recovery, but personal stories were given mostly as a ‘gift’ to help others with similar experiences. Similarly, Peterson *et al.*, (2008) suggest that some found disclosing their condition helpful in battling stigma and self-stigma whilst acknowledging risks were involved. And we can observe that what is beneficial to one at some time in their life may, on the contrary, be problematic at, or to another. It was through discussing matters of ethical exchange, censorship and the right to speak, that I came to a deeper appreciation of what was at stake for individuals, families and communities mediating this interface between private and public worlds in their recovering moments.

9. Engaging Interviews

A Social Art

As with ethics, my methods responded to ‘recovery practices’ I encountered in the field. At the Supporting Families Summit in Wellington Arana Pearson explained, “The context of my life is the key to understanding me – Questions are the answer.” In a few words, he had confirmed and validated the motivation, theory, aims and method behind my *recovering voices*. I found many of those partaking in this *recovering moment* to be practicing something akin to McCarthy Brown’s observation of ethnography as “a form of relationship... a social art”(1991:12; c.f. Jackson 1996:36). In this section of my essay I explore some of the ways in which we, recovering voices, attend to matters of conduct in relationships – being mindful of our connectedness and separateness – becoming skilled in the practice of talking, asking questions, remaining silent and just *being*.

The central importance of this social art is spelled out in the research of Lapsley *et al.*,(2002), Peterson *et al.*, (2004,2008) and Barnett and Lapsley (2006a, 2006b), in which New Zealand research participants reiterate the valued position of people with whom they could relate on various levels, both in sickness and in health. Cowan suggests

“It is by telling our stories and having good listeners to help us that we make sense of our lives. By talking we learn how to act or behave in ways that better serve us as we move forward in life”(2008:64-5).

Barnett and Lapsley observe that for many service users and people with experience of mental illness in New Zealand, “their stories highlighted the importance of having emotional and practical support, and having access to peers and older adults who can listen to and validate their experiences, and who do not stigmatize mental health conditions” (2006b:88). They observed that the experience of mental and emotional ill-health and distress were closely linked with the absence of such conditions and were most pronounced when others’ conduct or reaction seemed problematic (Barnett and Lapsley 2006b).

In support groups, courses and various seminars, family members, carers and professionals worked on developing this social art. Often, attendees spoke of their struggle in caring for people whose illness experience had been serious, distressing and recurrent. We worked on deciphering and delineating different phases of illness-related experience – times of difficulty and distress, times of ‘acute crisis’ and serious illness, and times of relative stability⁵⁵. For many, this involved attuning to the condition of others – recognising signs of wellness, understanding possible symptoms and side effects of medications, and distinguishing between ‘intentional’, ‘compulsive’, ‘illness-related’ and ‘learned’ behaviours. We practiced active listening, and motivational interviews. We worked collaboratively on problem solving, seeking and reinforcing positive aspects of personality, and being and experience beyond perceived difficulties that arose.

Family members and carers often expressed a sense of unity and emotional connection, with potential benefits and detrimental affects. James explained,

...and what I realise is that there is this sort of symbiotic thing happening... you know a family is like a whole, I mean you're living together and things like that, so with Peter there's something similar taking place too, where the frustration that he's experiencing I'm also starting to experience some of it too.

Carers discussed being instinctively attuned to the emotionally “interactive atmosphere” (Jenkins 1991:388) of the home, discussing strategies on how to use this awareness whilst maintaining their own emotional bearing and composure⁵⁶. Joan and Vanessa, who had experienced serious mental distress, explained that seeing loved

⁵⁵ These ‘phases’ weren’t set in stone, but rather, were discussed as potentially helpful ways thinking about situations. Kleinman writes: “It may be difficult to distinguish the disease from the illness [where...] in such disorders, illness may exist when the disease is in remission, and recurrence of the disease itself may be due to the illness. Conversely, disease may be present with minimal or no illness. More usually, however, these two aspects of sickness undergo reciprocal changes such that they either worsen or improve together... There often is little or no time for the disease to be shaped into illness experience”(1980:74). Thus, Recovery was referred to as being able “to live well in the *presence* or *absence* of their symptoms”(Mental Health Commission 1998:1, italics mine).

⁵⁶ Much research has been conducted overseas, discussing the relationship between illness experience, recovery, family situations and ‘expressed emotion’. See for example: Leff & Vaughn (1985), Leff *et al.*, (1989), Leff (1989), Lefley (1989), Hatfield and Lefley (1987), Jenkins (1991), Barrowclough (2001), amongst others.

ones suffer was difficult – like others being cared for, they drew strength from seeing family and carers “staying strong” and maintaining their composure, routines, health, hopes, and wellbeing. Sometimes listening to troubling stories, I felt the need to manage my own sense of connectedness, permeability and boundaries – I took a reflexive, responsive approach akin to those practiced by family members in Karp’s discussions of family burden⁵⁷:

“Although any boundaries that human beings construct are subject to change and renegotiation over time, illness, because of its capacity to so thoroughly disrupt the coherence of daily life, demands ongoing assessments about the proper boundaries between family caregivers and patients. [...] The inevitable task that ‘well’ family members face is to honor the obligation and commitment they feel toward their sick spouse, parent, child or sibling without losing their own health and self”(2001:45-46).

Lyn, who has cared for her daughter and conducted mental health-related research, expressed a sentiment common amongst family members, service users and professional staff – “You’ve got to look after yourself first or else you’re no use to anybody else.” Thus, we who are involved in this *recovering moment* often engage in identity work, checking moods, thoughts and feelings, and consciously making adjustments in our lives. James discussed using transactional analysis (Byrne 1964) to monitor his moods and stress levels in the home in mind of his son’s experience of psychosis:

Now it has been happening, I can guess that, and I manage to get it in a cognitive realm, and I can go, “Hang on, I’m recognizing what is happening,” and that gives me more ability to use that adult ego-state to deal with the thing from a mature and sensible standpoint, to take action rather than be reacting.

⁵⁷ I avoid using such a *heavy* word as ‘burden’ to describe family experiences in this essay, in part responding to Lefley’s (1997) observation that ‘burden’ has been over emphasised in research that often fails to account for perceived benefits of caring. For overseas discussions of perceived burdens, and benefits associated with family caring roles, along with therapies, education and change, see Jones (2004); Karp (2001); Ostman, Hansson, *et al.*, (2000); Stueve *et al.*, (1997); Bulger *et al.*, (1993); Leff, Berkowitz & Shavit (1989); Hatfield and Lefley (1987); Hatfield (1983) Lefley (1989,1997).

This ‘adult ego-state’, often discussed in carer support groups and courses, bears resemblance to the ‘anthropologist’ involved in mindful, reflexive participation in relating to others. Family members and carers often took on dual or multiple roles – doing peer support, advocacy work, or working in mental health settings⁵⁸. Lynn observed of her roles as carer, mother, researcher and advocate: “I don’t really see the boundaries between those.” To be of help to her daughter, and to perform her work she explained, “I just had to try to remain who I was”.

Benevolent Roles

In times of crisis, some carers took on a benevolent, paternal, or parental role. They developed special responsibilities and exercised powers they might not have otherwise. It was through discussions about such matters that I become mindful of my own power, or lack thereof, to affect change – giving much thought to my motivations affecting how I took part in these exchanges. Where I monitored my involvement with participants, they too were aware of the need to be mindful of boundaries. Anita explained to me, “I don’t want to use this interview as a counselling session”, and I saw my *recovering voices* as non-invasive forms of mediation.

At support groups and various courses we discussed Transactional Analysis and practiced Cognitive Behavioural Therapy, working to manage stress and develop coping skills, understand grief processes, resolve conflicts, and reconcile differences. As ‘mediators’ we developed a necessary awareness of what power we had to affect change within our personal lives, relationships and wider social systems. Often someone would refer to the Serenity Prayer⁵⁹ – it was through such means that we established and challenged the parameters and extent of our agency, intentionality, power, affect and control over and within our personal and inter-personal lifeworld. We developed ways of relating to, acknowledging, affecting and accepting *things as they are* (Jackson 1996). Lynn discussed her mental health research:

⁵⁸ For a discussion of New Zealanders with various ‘mental-health’ related experiences in their private and professional domains, see Tara Scott’s *The Dual Role: Understanding the dual role experience of mental health professionals who are living and working with mental illness* (2007).

⁵⁹ The serenity prayer asks: “God, grant me the serenity to accept the things I cannot change, courage to change the things I can, and wisdom to know the difference.” Karp discusses a family support group mantra in the USA – *The four C’s* regarding a loved one’s illness: “I didn’t cause it. I can’t control it. I can’t cure it. All I can do is cope with it”(2001:23).

*Well, I enjoy doing it, but at the same time, you suffer too when you're doing research like that – because you feel... I get involved and feel for the people, and a lot of the time you feel quite helpless to change things. So, it's a blessing and a curse. Ha-ha-ha-ha-ha! There's just so much to be done!*⁶⁰

We (including anthropologists) participating in this recovering moment do what is within our power – sometimes just meeting to talk, listen, share a little time, food and thought, sadness or laughter. We led, where possible, by example. Together, we explored and described, exchanged information, but seldom prescribed – advice, when asked for, was given *advisedly* – allowing folk to be assertive in their own self-determined time.

Yet, during an acute crisis, carers and patients are faced with a dilemma of how to employ benevolent power that might have repercussions. James spoke about entering a “drama triangle”(Karpman 1968) in taking a paternal role in trying to help his son – he was weary of the risk of shifting from rescuer to victim. He discussed taking his son Peter, whilst very unwell, to the hospital where he was assessed and committed:

...afterwards he was in the secure part and he took medication because he had to, and he stabilized, and he went into the more general area and he didn't like the food down there, and I would be preparing him meals and taking him meals every day. [...] Now he managed to get in touch with the complaints authority and they got a lawyer for him and he was heard by the equivalent of a certain judge, and two days after... the finding was given that there wasn't sufficient grounds to hold Peter compulsorily, and so Peter came home, and it was difficult, and this is the point, because Peter believed that it was me, that I had somehow managed to get him committed.

[...] Peter experienced that moment in the way that he lived it, and so his recollection of it will always be how he perceived what was happening in that moment, and I think that's a really important thing for people who are living

⁶⁰ James expressed similar sentiments, and asked me as my research drew toward a close – had I gained, had I learned, was it beneficial? To which I replied that it was life, it was living, there was pain, and joy, and maybe I learned, but really I just did what was within my power, what felt necessary to do at the time. He commented on western notions of ‘gain’, ‘attainment’ and ‘accumulation’ of health, or knowledge as *capital*, that seems at odds with how things are experienced in this recovering moment.

with a person who has psychosis to accept, and this is that the person who has the psychosis – they have a reality, it's their reality, it's what they're experiencing.

Amador (2000) argues the necessity of carers employing institutional power during a crisis, despite potential problems⁶¹. Like other participants, James spoke of a “feverish state of delirium” in which he had to speak, or act, on Peter’s behalf – it was this dilemma of absolute dependence and ‘otherness’ carers sought to avoid. Both James and his son were deeply affected by this experience – and so we might consider how interactions between the family and the institution can affect intra-familial relationships. Recovering his relationship with his son was an important aspect of their being-as-family⁶².

Stigma, discrimination and social transactions

And I believe this social art can be extended in dealing with stigma and discrimination, where traumatic crisis may have affected our perspective, sense of otherness, and the power dynamics within families. At the interface of families and institutions we might observe certain ‘dilemmas’ and disrupted relationships that can affect disparities and a sense of division in the home – a limited and limiting perspective akin to stigma. In the recovering moment, aspects of reflexive, phenomenological anthropology and transactional analysis (Berne 1964) were employed in moving beyond ‘them and us’ perspectives. We got beyond a unidirectional sense of ‘cause and affect’ to see experiences as intersubjective and systemic, taking a relational perspective to observe “inter-experience”(Laing 1967:27). Rather than reacting emotionally and ‘blaming’ those expressing stigmatizing or discriminatory views (and potentially perpetuating them in the process), Helen took an adult-role, explaining,

⁶¹ O’Hagan (1994, 2006) discusses the problematic aspects of crisis treatment (of which she has personal experience), and the need to avoid it where possible, observing that it could be detrimental to individuals, treatment and family relationships. McGorry suggests the necessity of providing facilities designed specifically for young people with first experiences of psychosis, as “young adults are frequently traumatized by the experience of adult inpatient services, because those services are not designed around their needs, but instead cater to a group of older adults with severe and chronic mental health difficulties”(2004, c.f. Barnett & Lapsley 2006b:5).

⁶² At the Mental Health Service conference in Auckland, a group of family members and carers suggested that the most important (and sometimes most difficult) work involved recovering their ‘own life’ as much as possible, and the *old way of seeing* their loved one, overcoming the trauma that resulted in their ongoing sense of a loved one’s dependence and vulnerability.

... I feel that's because I haven't talked to them. I need to talk to them so that they feel more comfortable. I take responsibility for that. I don't blame other people. I don't really think we have discrimination for our own family, or for [my daughter], just maybe some people who don't know what it's all about. ... I think it's because of who we are as a family – we just laugh at discrimination, none of us would accept it.

Carers, anthropologists, family members and people with experience of mental ill-health all found especial cause to recognise what was at stake in dynamic exchanges where curbing impulsive 'reactions' involved reflexive meta analysis. Laing suggests that "[w]e act not only in terms of our own experience, but of what we think *they* experience, and how we think they think we experience, and so on in a logically vertiginous spiral of infinity" (1967:66). Helen demonstrated that checking the sometimes problematic aspects of this spiral, or cycle, perpetuated in stigma and self stigma (Peterson *et al.*, 2008) involves the empowering act of recovering voices, avoiding assumptions and considering other's perspectives.

James and Anita felt that despite their awareness of stigma and discrimination, they sometimes treated their adult son 'differently', due in part to their experience of his illness⁶³. Breaking this cycle, for some, involved recovering external voices. In James and Anita's case, their daughter returned from abroad and was able to share her perspectives of 'family needs', observing from the position of sibling, daughter, and independent adult. Her *being apart from*, and *being a part of* family helped in this light – she could play a mediating role (Marcus 2007, Knauft 2006). Another family recovery practice involved interviews – employed as a method of developing an understanding of social dynamics, to privilege voices, and to facilitate healing and trust.

⁶³ The sometimes traumatic initial experience of mental illness or distress could have further reaching consequences in family relationships. Peterson *et al.*'s research of New Zealanders with experience of mental illness; *Respect Costs Nothing* (2004) and *Fighting Shadows* (2008), revealed that much of the stigma and discrimination experienced by their informants occurred within families and the home.

Engaging in Interviews

In his book, *I am not Sick. I Don't Need Help!* (2000) Xavier Amador discusses how to 'help' family members reluctant to seek treatment. I refer to this book in part because of its extensive use by groups like Supporting Families. From an anthropological perspective, I contest Amador's suggestion that people with experience of psychosis and severe mental illness may have a lack of insight regarding their condition. This, he attributes to brain damage caused by severe illness, not unlike anosognosia, where "Pockets of unawareness and awareness often coexist side by side... they appear rigid in their unawareness, unable to integrate new information contrary to their erroneous beliefs"(2000:41)⁶⁴. These very same things might be said of those with power, of authoritative texts and privileged discourse (Wertsch 1991). I would emphasise not a 'lack' of insight *within* individuals but a lack of *shared* insight, emphasising experience "not as a subjective phenomenon – something that a single person 'has' – but as an interpersonal medium shared by, engaged in, and also mediating between persons in a local world" (Kleinman and Kleinman 1996:189).

However, Amador outlines a useful "four step process [...that] involves listening, empathizing, finding areas where the two of you agree, and ultimately forming a partnership to achieve the goals you share" (2000:55). Where a sense of division arises, researchers, carers, family and whānau all tried "to walk in their shoes to gain a clear idea of their experience of illness and treatment" (ibid:56). Taking this collaborative 'anthropologist' role, "asking questions rather than giving advice comes a lot easier"(ibid:58). And as this chapter has progressed I have tried to suggest similarities between the practices of various participants partaking in this recovering moment within the *archipelago of the mind* – each of us, from time to time, trying to walk in the other's shoes.

As we near the end of Part One of this essay, I should discuss my selection of participants. For ethical and practical reasons I sought those who seemed to me to be some way into the process of recovery. In my subjective judgement, they seemed

⁶⁴ Geekie observes of 'insight': "unfortunately, as the term is now used, it usually refers to whether the client agrees with the clinician's position rather than being truly concerned with the client's understanding" (2004:149) – it concerns me that such perspectives and assumptions only perpetuate perceived and actual divisions.

calm, articulate, and demonstrated some ability to mediate *emotional* distance between their current condition and previous or recent difficulties. Yet as we engaged, I soon recognised that I had sought and found local experts involved in analysing, producing and sharing knowledge and practices within the field. I was drawn to those who showed objective humour – often considered one of the most potent tools affecting, and resulting from recovery⁶⁵. Their experiences, and ‘social art’ informed my own practice of recovering voices.

⁶⁵ People would sometimes lament, “If you’re not laughing, you’re crying” – suggesting the need for meta-analysis of experience – in a sense stepping back from the situation to observe from the outside, as ‘other’, in a somewhat meditative manner - where appropriate, with humour.

10. Discussion

As we move toward Part Two, I wish to emphasise certain aspects of the journey/story that have some bearing on our course. I set out to partake in a recovering moment in mental health in New Zealand, focussing on the experience of mental illness as it related to family life. Entering the field as anthropologist and family member, I soon realised that where objectives were shared, and consensus formed, a sense of division, difference and ‘positioning’ often dissolved. Wellbeing arose from a sense of empowerment and agency within our lives, which others recognised and validated, facilitating a sense of unity within a diverse social system. I focus not on diagnosis, but on a shared practice of *recovering voices*.

My anthropological project of *recovering voices* brings us into this *archipelago of the mind*, an interactive space forming at the interface of private and public worlds, between individuals, families and wider social institutions. I refer to a space and place about mind that forms within and from the social exchanges of which we are a part. I challenge a dichotomous sense of mental health and illness, emphasising a common humanity with diverse experiences that respond, but don’t necessarily conform to institutional definitions and descriptions. Thus, I draw comparisons between the ‘multi-sited ethnographic field’ (Marcus 2007) that is ever-emerging through ongoing encounters and interactions between local participants, and a multi-sited mental health/social system, where ‘mental health’ is said to be “everybody’s business”(LMLM 2003). In my *mind*, the bounds of this field dissolve to absorb our entire human population.

My research was a collaborative process where thesis, aims, significance, subject, method, and findings evolve and unfold, each in relation to the other. These emerge at certain junctures between participants in local worlds, where we each partake in other people’s intersubjective experience. My *archipelago* represents a social system, an institution of relationships formed and maintained through ritual journeys and ongoing exchanges – my thesis being that it is through such ‘ethical exchanges’ and the act of ‘recovering voices’ that we come to experience ‘mind’ as social, and recovering. In various recovery settings we gift our story, its power and validity dependent as much on the *form* of the ritualised transaction, where burdens are

relieved and obligations taken, as the significance and meaning of the message and gift itself. Where the natural sciences might emphasise the primary importance of ‘facts’, ‘truth’ and ‘evidence’ regarding the subject of their narrative, in this recovering moment I have placed primary emphasis on the aesthetics and conduct of relationships and exchanges.

I found that in this archipelago of the mind, ethnographic theory and practice, and recovery philosophies each have something to offer the other. Going one step further, I propose that their primary attention to moral and ethical practices and exchanges are universally applicable, humane, and exemplary in that they seek and maintain a sense of social justice at the core of our human need. Thus, the *archipelago of the mind* extends beyond mental health. We might observe this in the dissemination of ‘professional knowledge’ into the wider community, and the inclusion of carers and ‘consumers’ in service, treatment, and research design and provision, and policy making. We might also observe this in the focus on recovering and validating marginalised voices, recognising expert local knowledge, and acknowledging non-Western ontology. Yet we may also observe distress and grief around systemic failure and problematic exchanges, where stigma and discrimination occur; where voices are censored, subdued, or fail to be recovered; where needs go unmet and assistance is not forthcoming.

I have suggested that our experience of mind forms communally, through interactions and exchanges, and “the basic goal of [...my] sociocultural approach to mind is to create an account of human mental processes that recognizes the essential relationship between these processes and their cultural, historical, and institutional settings” (Wertsch 1991:6). I have observed that my ability to ‘mediate’ voices and to play an active role, to learn and be heard in various domains, related to my privileged position and circumstances. I felt that in this *recovering moment*, our social system as a whole, and its individual constituents, would benefit from more extensive attempts at recovering less-privileged voices.

I suggest that in navigating this fractured system, participants were situated like Knauff’s anthropologist, somewhat “in the middle”(2006). No longer willing, or able to follow a single discourse, we mediate a range of voices to gain a sense of our

position, condition, desired destination and direction. In so doing, we developed complex understandings of the relationship between self and others, and the wider social system. We were called to assess the validity of a range of voices, some privileged above others by different means, for different reasons, by different groups. As Phenomenologists argue, we assess their validity less by claims of/on ‘authority’ and ‘authenticity’ than by their applicability within our particular lifeworld (Jackson 1996).

As this essay progresses I will illustrate further the role of anthropology in recovering voices *from the depths*. As a responsive, reflexive methodology, anthropology offers techniques of mediating between various voices, individuals, groups and institutions, but also between inner ‘personal/private’ experiences and wider social domains (Kleinman and Kleinman 1996). The recovering moment begins at the grass roots of experience, acknowledging and validating voices, and drawing connections between ‘personal’ events and dynamic social, political, historical and institutional contexts. Thus, in the remainder of my essay, I illustrate ways in which my participants employed paraethnographic practices (Marcus 2007) as a key to understanding the self and others, and mediating relationships within this social system.

In my research, I collaborated with reflexive, expert local participants invested and well versed in the workings of their community. Because they have had especial need to navigate journeys at the intersection of family life, inner worlds, and institutions, their stories offer insight into the relationship between such domains. In response to such expertise, Marcus and Homes devised

“the ready-made concept, or device, of the paraethnographic to assist in the more elaborate argument for the refashioning of what is to transpire in the scene of encounter in the contemporary ethnography and the ethnography of the contemporary. Its purposes have been to focus the attention of ethnography, with yet unknown consequences for its traditional genre form, back upon its conditions of fieldwork in an acute awareness of reflexive subjects...(Marcus 2007:1142).

The remainder of my essay responds to Marcus's discussion, as I trace junctures between anthropological practice and mental health-recovery. I discuss ways in which families, carers, service users, service providers and researchers each take from, contribute to, and share in developing expertise within "multi-sited terrains of knowledge production"(Marcus 2007:1143) as they navigate at the intersection of various domains. For me, this "generate[d] a fieldwork of found analytics that is deeply embedded in politics and arguments of graded, networked, and nested sites of knowledge production—expert and everyday" (ibid:1139). In the final two parts of this essay I explore some of the stories of these local experts in more detail.

Part Two Local Expertise

1. Recovering Voices

In this moment, many of us are recovering voices once consigned to the depths – where the denial of such voices, Oscar Wilde warned in *De Profundis*, risks a loss of humanity, both for individuals, and the wider society:

“To reject one’s own experience is to arrest one’s own development. To deny one’s own experiences is to put a lie into the lips of one’s own life. It is no less than a denial of the soul” (1986:916),

I propose that for many, our social and personal development is dependent on our recovering such voices *from the depths*. The expanse and depth of our experience of this archipelago of the mind is dependent on ongoing, inclusive exchanges where those voices most often marginalised, subdued, denied or rejected speak directly of and to our common human need. Their exclusion deprives all within the system, where isolation and distress reflect and affect deficits, imbalance, disconnection and disorder on variant levels. Anthropology, in this recovering moment, offers another *way of being and relating* that involves *recovering voices* with attention to ethics, fairness and justice that may facilitate a deeper, more expansive sense of human potential and wellbeing.

I first heard Arana speak at the Hearing Voices Network’s *Practical Tools for Wellness* event. A large audience of voice hearers, carers and supporters sat, captivated by his performance, his songs and stories. To me, he spoke more about life, living and relating than mental illness or madness. He presented a moving account linking his experience with voices into the context of his life story, and further into a social, cultural, and ‘human’ domain. He expressed a sense that in silencing people’s voices, our shared humanity had been purloined – denying us of an essential aspect of our being. In his narrative, he enacted and explored the ways in which we might re-appropriate our life story.

During the break I spoke with one of the women who helped organise the event – a long time advocate for systemic change involved in recovering marginalised voices. On hearing about my research, she asked what I thought. I confessed,

After reading about diagnosis, definitions, stigma, causes and treatments in mental health – all this listening and talking and thinking – I just don't know what it's all about. I've reached the point where I really don't know anything.

She replied,

That's good. I've been doing this work over twenty years and I still don't know what it all means.

In this field, one gets a sense of the process of self- and world-making, of finding out, of exploration and discovery. 'Not knowing', I learned, was an important starting point from which one might approach and come to know others – especially in a situation where so many speak of feeling cheated and deceived by another's authoritative claims of (and on) certain knowledge. In this *archipelago of the mind* we are careful not to misinform or misdirect – admitting uncertainty, and presenting honest accounts of personal experience gives one's story value and credibility.

In this part of my essay I discuss the growing recognition and validation of local expertise and experiential knowledge of 'service users' who are recovering their voices. I explore some literature discussing the importance of first person narratives being recovered in a range of settings. I discuss some instances where privileged voices have sought to control and contain, subdue and censor. My discussion compares the privilege and power of certain 'authoritative' voices, both in clinical and academic discourse, to my participants' experience of voice-hearing. From there, I explore how anthropological practices have been used to mediate, and navigate a course in relation to such voices. I draw on Marcus's (2007) discussion of paraethnography, exploring people's development of deep, expert knowledge of the relationship between personal 'private' experience and wider social systems. I argue that these local voices attest and demonstrate the primacy of attending to just, fair, empowering exchanges in all domains of sociality.

Recovery Discourse

The importance of first person narratives and narrating the self in recovery work is well documented⁶⁶. The MHAC (2008) argue for increased recognition of qualitative research in academic, clinical, and political circles, discussing the need to privilege first person accounts around mental illness, mental health and recovery. They argue for something of a phenomenological approach that looks “at evidence from the ground up, emphasising client-based evidence, practice and community-based evidence as well as formal research-based evidence” (ibid:48, citing Naquin 2007). These views respond to the observation that traditionally, first person narratives of schizophrenia, psychosis and other mental illness have been under-privileged and marginalised in clinical and academic discourse, especially in favour of external, ‘clinically trained’ observations (Geekie 2004, Estroff 2004)⁶⁷.

Sue Estroff identifies three main perspectives contributing to discourse regarding the experience of schizophrenia: First-person narratives of people with direct experience of schizophrenia, second-person accounts of family members and people involved in intimate or caregiver relationship, and third-person narratives produced by researchers, clinicians, reporters and others. She observes that the *privileging* of certain voices affects but does not necessarily reflect the lived experience of the subject:

⁶⁶ See for example, Wisdom (2008), Corin (1990), Estroff *et al.* (1991), Estroff (2004), Strauss & Estroff (1998), Geekie (2004, 2006a, 2006b), Mental Health Advocacy Coalition (2008), Cowan (2008). On narrative therapy, see for example: Eaken (1999), Epstein 1998, Parry & Doan (1994); and on narrative and discourse, Turner (1980), Tyler (1987), and White (1995) amongst others.

⁶⁷ At the time of writing this, I received word of Barbara Schneider’s (University of Calgary) recent work, “Mental Health, Homelessness, and Citizenship: A Participatory Action Research Project”. Her abstract talks describes an: “action research project on housing for people with mental illnesses that was carried out by a group of people diagnosed with schizophrenia. They chose the topic for the research, carried out interviews and focus groups with others like themselves, analyzed the data, and now are disseminating the research. The project advocates for the inclusion of people diagnosed with schizophrenia in three main areas—research about schizophrenia, decision making about medical treatment and housing for people diagnosed with schizophrenia, and public discourse about mental illness. Inclusion in these areas is a form of citizenship that enables people diagnosed with schizophrenia to take their place as full members in society with the ability and right to speak about issues that concern them, such as housing. The presentation will highlight the non-traditional, arts-based modes of dissemination that make it possible for the co-researchers to take part in disseminating their work. These include readers theatre presentations, a photo poster, a documentary film, a graphic novel, and a travelling exhibit”.

“the points of contrast, contestation, and convergence of these narratives have received insufficient attention from the various scholarly communities engaged in the study of schizophrenia... [where] disagreement and contestation about meaning, reality, and identity may represent the quintessence of schizophrenia” (2004:284).

She suggests that those with power might benefit all by recovering and privileging such marginalised narratives. She observes the imbalance of power between voices in academic and treatment domains perpetuates division, and that “the lack of common ground and understandings, of intersubjectivity, extends to the subject (the person and schizophrenia) and their subjectivities – their experiences with and understandings of schizophrenia and its treatment”(ibid:283). Where voices are dismissed, censored, ignored, under-funded or subdued, and others with power are privileged, personal distress has a very political dimension:

“At stake here is who has the authority to represent whom, upon what this authority rests, and what criteria are salient in the assessment of the divergent representations. Also at issue is access to the knowledge-producing landscape – that is, funding for services and research, professional journals, and the print and other media”(ibid:288).

Autobiographical accounts of experience have often been interpolated into predefined positions within psychiatric narratives that may serve to reproduce certain perceptions and perspectives of experience, for clinicians, service users and carers. Jenkins observes the making of subaltern subjects in psychiatric discourse and practices, where as Sherry Ortner explains, “cultural categories, historical subjects or forms of subjectivity are... made in that they are constructed by, and subject to, the cultural and historical discourses within which they operate” (Ortner 1996:1-2, c.f. Jenkins 2004:33-34). In some narratives, patient protest or critique may have been seen as “denial, lack of insight, transference, or evidence in direct contradiction to the narrator’s claims of validity” (Estroff 2004:285). Foucault observes something of a dichotomous relationship in which “the language of psychiatry [has been] a monologue of reason about madness” (1988:xi).

Yet Jenkins observes that there is no “natural” course of schizophrenia, “rather, the course of illness is inherently social and cultural, and a matter of intersubjective engagement [where...] any understanding of the problem however tentative or imperfect it might be, is invariably guided by Sociocultural models of illness” (2004:49, citing Jenkins 1988). Thus, deconstructing and reinterpreting problematic assumptions and inferences perpetuated within clinical and scientific discourse, and popular culture, was seen as an important aspect of recovery for some of my participants (Lapsley *et al.*, 2002; Peterson *et al.*, 2008). Yet the validity of such criticisms may not be satisfactorily acknowledged where “personal narratives of schizophrenia [represent...] experiential scenarios that cannot be accommodated within the prevailing paradigms of clinicians and researchers” (2004:283), because they seem to dissolve, or fail to observe, privileged academic and clinical assumptions and parameters regarding experience. We might trace parallels, then, between such disparities in academic discourse and disempowering relationships in clinical or treatment settings.

Privileging Voices

In the current ‘recovering moment’ in New Zealand, there is a shift toward privileging once marginalised voices and perspectives. Gawith and Abrams (2006), and more extensively, Cowan (2008), outline some of changes and progression resulting in and from ‘consumer’ voices gaining power in various institutional settings, both locally and globally. Consumers and carers are increasingly acknowledged as holding expert knowledge on self, system and their needs and strengths. The Auckland District Health Board hires full-time consumer advisors involved in educational programs for clinical and other mental health workers, and family members⁶⁸. Peer support is very often seen as a ‘given’ aspect of mental health recovery. New Zealand support and empowerment movements are often based on, and affiliated with groups operating in the United Kingdom and Australia. Connectivity and voice is greatly increased through internet networks⁶⁹.

⁶⁸ For a discussion with the Auckland District Health Board’s first consumer advisors, see O’Hagan (1990).

⁶⁹ Groups and individuals run websites and blogs that offer information, advice, discussion forums, testimonials, and references to discourse. See for example; <http://www.rufusmay.com>; <http://www.roncolemanvoices.co.uk>; www.madpride.co.nz; <http://hearingvoicesnetworkanz.wordpress.com/>; <http://www.intervoiceonline.org/>;

Also, in recent years there has been an increase in qualitative research, often ‘consumer’ led, seeking first person accounts of mental illness and distress, mental health, recovery, and experiences with services in New Zealand (Cowan 2008)⁷⁰. This grounded, ground-up approach emphasizes the importance of self-determination, attending to human rights, advocacy, and the ‘consumer’ voice in all areas that concern mental health service users (LMLM 2003; Cowan 2008; O’Hagan 2006). Such research emphasises the relationship between personal experiences and social conditions and has been directed in an inclusive manner toward an expansive audience where personal narratives may find increasing power.

Geekie (2004), Wisdom *et al.*, (2004), Rappaport (2000), Vanthuyne (2003) and Schneider (2003) discuss potential benefits both to patients and clinicians in recovering autobiographical accounts of experiences relating to mental illness, voice hearing and recovery. It is through such efforts that we might develop shared understanding about personal experiences as they relate to wider social and historical situations ‘beyond the brain’. This may facilitate a shared sense of empathy and trust, the idea being that those in positions of power might empower others through mutual investment in narrative production and testifier/audience collaboration (White 1995, Laub 1992, Parry and Doan 1994). Through my participation in various peer support meetings and recovery events where personal narratives are shared I gained a sense of the hopes of participants, and developed alternative perspectives, interpretations of experience, and potential courses of action. I argue that by participating in such ‘consumer-led’ events, clinicians and carers can play a supportive role, and become better attuned and aligned with needs, experiences, perspectives and criticisms of those they claim to serve (Wisdom *et al.*,2004; Rappaport 2000).

<http://www.keepwell.co.nz/>; <http://www.maryohagan.com/mental-health-service.html> ,
<http://www.connectsr.org.nz/>.

⁷⁰ For example: Peterson (2007), Peterson *et al.*, (2004, 2007, 2008); Lapsley *et al.*, (2002), Goldsack & Lapsley (2005), Barnett and Lapsley (2006a, 2006b), Leibrich (1999), Gibbs *et al.*, (2006) and O’Hagan (1990, 2000a, 2000b, 2006) have recovered first person accounts in highly effective qualitative studies.

2. Anecdotal Evidence

Rufus May, a voice-hearing psychologist, explained in an interview in 2008, “Madness is when people stop trying to understand you” – a view reiterated by a number of people with whom I spoke. Some suggested that in observing certain experience and behaviour as evidence of mental illness, deficit or disorder, the psychiatric gaze systematically displaces authority over personal narrative, biography and identity. Turning this gaze upon itself might reveal such tendencies as symptomatic of a legacy of hegemonic forms of institutional subjugation, inequality and discrimination⁷¹. In the discussions that follow, I look at how the stories of those partaking in this recovering moment can reveal insights regarding the workings of personal experience as it relates to the wider social institutions.

Arana’s Experience

At a seminar in Auckland, Arana related a personal account challenging a range of ‘taken for granted’ psychiatric assumptions around treatment, practices and discourse – a not-uncommon tactic employed by those discussing displacement of power at the interface of the individual and social institutions. Arana is a central figure working to affect change in the status of people with experience of mental illness, madness and voices hearing in New Zealand. His discussion at this event carried elements of protest, critique and resistance – about his treatment, the mental health system, and the wider social system in New Zealand. He discussed his first experience of hearing voices and his encounters with the mental health system.

Some decades back Arana was given his first of several diagnoses – Schizophrenia – along with a troubling (and depressing) prognosis. He described the affect of being given, at a difficult time in his life, a story about himself written by someone else. This unauthorized and projective biography/prophecy – a story spelling out difficulties, deficits and expected outcomes without mention of recovery or hope – was a like an imposed burden in which he found no value.

⁷¹ See for example: Like Minds Like Mine (2003); Geekie (2004); Read *et al.*, (2004); Bentall (2004); O’Hagan (1994, 2006); Peterson *et al.*, (2008); Cowan (2008); Rosenham (1973).

The ‘message’ of the institution, spelled out in its discourse and prognosis, was further evident in the language of space and place as a physical imposition. Seeking help whilst unwell, Arana was hospitalised and placed alone in a normal looking room⁷². Turning to see the door close behind him he observed it was lacking a door handle. The unspoken yet overwhelming message was of “no exit” – from the confines of the ward, his condition, and the dominant narrative. As I discuss in Part One of this essay, for those who have experienced mental illness and distress, place and space can both affect and come to stand for one’s sense of their personal condition, where experience may incorporate and yet shift beyond the limited bounds of verbal diagnostic explanations (Kleinman and Kleinman 1996, Desjarlais 1996).

As Mary Douglas suggests, “the more value people set on social constraints, the more the value they set on symbols of bodily control” (1978:xxxv). Mental health, hospital settings and some treatment relationships and situations reinforce the displacement of power between client and service providers, and the institution (Rosenham 1973; O’Hagan 1994, 2002). We might observe, in the use of place and space, and in controlled bodies, a voice that speaks of a social response to illness – evident in the quarantine of madness, censorship, and containment of voices and bodies. At the time when Arana was first treated there was a great deal more fear, shame, and loss of dignity associated with hearing voices, diagnosis, and mental illness in general. Voices were to be subdued, sedated and eradicated⁷³. For Arana and others this sense of shame that involved concealing one’s voices and condition from family and whānau, was in no way conducive to healing⁷⁴. In a sense, this social censorship was

⁷² David Case observes something of the Gothic in New Zealand photographs of “psychiatric hospitals [that] in the modern period were characterized by a medicalisation of madness that quarantined it on the public institutional side of a modernist division of labour between hospital and home.”(43-4). (See also Brunton, 2004).

⁷³ Vanessa, who has worked on the mental health crisis line, had experience of serious mental illness, used services, and has worked with carers and family members explained that there is much less shame and stigma around the experience of mental illness now than some years back. Yet the example, as shared by Arana, exemplifies wider social processes. Helen explained that it wasn’t until her parents’ death that she and her siblings were able to openly discuss and acknowledge their brother’s schizophrenia that had gone undiagnosed and untreated. She explained that in the 1970’s, social stigma and shame around mental illness meant that openly seeking treatment was unheard of – because of which, it became a silent illness – that which was unspeakable causing something of a disconnection in the family.

⁷⁴ For Joan, her visits to Carrington and Oakley hospitals weren’t mentioned by her family – she explained that when the voices arose and became problematic, she would disappear into ‘care’ without explanation. Being able to speak of these things was important to her recovery.

imposed on the person in discourse, treatment and physical constraint, where one's private condemnation relates to the social – as Jackson observes,

“the sense of shame that condemns one to remain silent about experiences that cry out to be told is a function of the impossibility of converting what is felt to be private into a story that has public legitimacy or social currency. Shame, in other words, is an affective measure of the socially-constructed and uncrossable line between private and public space”(2002:54).

Where Arana observed that “Sometimes the treatment is worse than the voices,” we can appreciate Estroff's observation that for people with diagnosis of schizophrenia,

“‘Symptoms of treatment’ are of one experiential piece with the symptoms of illness [where...] scholarly and scientific separations of these two domains... and the failure to recognize their essential entanglement, contributes to an enduring absence of agreement, not to mention accurate empathy”(2004:287, citing Estroff *et al.* 1991).

Decades on, Arana explained that regardless of his recovery work his doctor still wants him to comply - Cowan observing that in New Zealand, “the issue of compliance seems dominant; non-compliance with the medical regime is viewed as lack of insight on the part of the person being treated, which is deemed to be symptomatic of mental illness” (2008: 34). Although improvements are evident in service provision in New Zealand (Brunton 2004; Gawith and Abrams 2006; O'Hagan 2006, Kingi 2005), concerns arise that first person accounts are still acknowledged mostly under the rubric of illness, thus reinforcing a disenfranchising and disempowering perspective (Geekie 2004). Geekie suggests of recovery, “clients want to be active participants in this process rather than passive recipients of the clinician's model”(2004:158). Those who resist such powerful voices may find themselves in something of a double bind, as Joan's experience demonstrates.

Joan's Experience

Joan and I discussed parallels between her voices and kin, each made powerful because of their closeness to and knowledge of the subject. The 'method' employed by Joan's voices resembled something of Arana's discussion of the dominating, imposing and authoritative voice of psychiatric discourse. Joan's voices were skilled at isolating her within the walls of her home, placing her in a passive role and demanding compliance. They subsumed her pleas and arguments into their own dominating regime. They interfered and censored her when she tried to speak, reduced her social functioning, and shut her down. She observed the manipulative tactics they used to assert their power – they employed powerful insider knowledge of her sensitivities, anxieties and concerns. Joan explained that their tendency to point out *deficits* and *weakness, disorder* or *problems* was troubling:

They tend to know your deep dark secrets and everything about you, and they can go straight to the very core of what's likely to make you bite or jump. [...] They've got distinct tactics, but they are also quite strategic, so when I would come up with some sort of strategy to interfere or intervene in some way they often would pull back. [...but] the battle you're having is actually with yourself... there's no getting away from it because it's so internal. They go straight to the stuff that is going to hurt and humiliate, etc. And that's a powerful tool.

The troubling aspects of Joan's 'personal' experiences mirror, in her description, discussions of New Zealanders' experience of stigma, discrimination and mistreatment in various social and institutional settings⁷⁵ – these narratives discuss and describe systems in which participants feel oppressed and disenfranchised by powerful, confounding voices that resist being questioned, or challenged. Joan explained the frustration of dealing with so powerful a force,

I never argued with them, because when I argued with them they would always win, they always had a counter argument. And after a period of time

⁷⁵ See Frame (1980,1982,2004); O'hagan (1994); Peterson *et al.* (2004, 2007, 2008); Barnett & Lapsley (2006b), amongst others

it's soul destroying... it seemed like it was all day everyday that you were molested by them.

In Joan and Arana's stories we see evidence of problematic *relationships* where exchanges were marked by a displacement and ill-distribution of authority, personal agency and power. Distress resulted more from being subdued and censored in unjust exchanges and disempowering circumstances than the psychiatrically defined 'symptoms'. We might observe, in this recovering moment, anthropology offering one way of empowering marginalised voices within disempowering circumstances.

3. The Recovery Project

In telling his story, Arana described and *enacted* recovery, a project involving investigation, discussion, celebration, transition and change (Lapsley *et al.*, 2002). By employing metaphor, allusion, irony and pun to *perform* his story, he emphasised the power one has to reconfigure intersubjective meaning, significance, experience and value by engaging with voices in both a playful and serious manner. He drew strands of opinion and experience together, sharing biographical information and anecdotal and scientific evidence, proposing ideas, asking hypothetical, open ended questions, evoking images, leaving an occasional gap... allowing his audience to draw personally relevant interpretations along the way. He was attuned to the nuances and ambiguities of language, a wordsmith and evocative storyteller – traits common amongst those voice hearers I met⁷⁶.

From Arana's discussion of self and system, I derived an appreciation of Marcus's discussion of paraethnography – the “New ‘native point of view’ in the emergence of expert communicative spaces”(2007:1139). With and through his spoken word, Arana transgressed the line between public and private experience – an important step toward recovery⁷⁷. He developed (and now shares) his own expert knowledge, seeking autobiographical accounts of voice hearers throughout history. He compiled a library – a story that countered and challenged the psychiatric narrative of the time, and in fact venerated his experience. He developed empowering perspectives, attuning to those voices that resonated with his own experience, needs, and hopes and seeing through others' lenses. He described a kind of triangulation used to navigate a course in response to a selection of voices, drawing together strands of discourse and experience in a manner comparable to Knauff's discussion of praxis (2006)⁷⁸.

⁷⁶ Joan explained to me, “I’m a word person – a gap filler. A lot of us are natural gap fillers.”

⁷⁷ Wisdom *et al.*, suggest that “the dysregulation between the private and public self during severe mental illness creates a sense of crisis”(2008:490), discussing the benefits of reading, hearing, and telling stories about such experiences within life contexts where “the overarching aspect of recovery from serious mental illness is a redefinition of the sense of self, and the gaining of perspective that mental illness is simply one part of self”(2008:490 citing Corin 1990; see also, Lapsley *et al.* 2002) – but I argue that recovery also involves situating such experiences and narratives within wider social contexts.

⁷⁸ Caril Cowan refers to Paulo Friere's (1970) explanation of Praxis “to describe the cycle of acting in life, reflecting, finding new ways of acting or continuing with effective ways of acting, then reflecting again, and so on. It is by telling our stories and having good listeners to help us that we make sense of

Arana's approach resonates with Jackson's phenomenological methodology that "is above all one of direct understanding and in-depth description – a way of according equal weight to all modalities of human experience, however they are named, and deconstructing the ideological trappings they take on when they are theorized" (1996:2, citing Goldstein 1961:225-226). For Arana and others, this involves locating the person at the centre of the recovery project. From this position, Arana empowered himself to mediate and assess a range of voices. And his public storytelling renders and enacts this praxis – it "redeems us, not only through its power to convert private experience into general knowledge but through its power to confront, confound, and critique all received opinions by referring them back to lived experience and personal testimony"(Jackson 2002:64). His storytelling enacted and performed "a vital human strategy for sustaining a sense of agency in the face of disempowering circumstances" (ibid:15), his observations demonstrating ways of disarming troubling voices.

Setting up something of a dialogue between multiple perspectives, and experiences, Arana deconstructed the limited dichotomous psychiatric view of illness to evoke, and evolve, a fuller sense of human potential that includes, values and validates the experience of madness. Speakers like Arana, Patricia Deegan, Rufus May, Ron Coleman and Mary O'Hagan (1994) derive strength, skills, wisdom and value from madness and the experience of hearing voices, redefining experiences on their own terms.

Where Rufus May observes, "the diagnostic process converts someone's distress from a psychosocial problem into an individual problem – it takes the person's experience out of its social and historical context" (2008:1), Arana's narrative returns his experience to the social, environmental and historical context within and in relation to which it occurred. He quoted Marius Romme, explaining that "the writing of a life history is the single most important thing a voice hearer can do for themselves" – and it is with this life history, his narrative, laughter and song, movement and music that Arana interrupts the dominant discourse – that "all-knowing, all-powerful... force"

our lives. By talking we learn how to act or behave in ways that better serve us as we move forward in life."(2008:64-5).

(Deegan 1997). It is through his paraethnographic endeavour that he stakes out some space in which he, and others, might have some *say*.

4. Anthropology in the Middle

Research suggests that the experience of hearing voices may relate to previous traumatic experiences (Romme and Escher 1989; Geekie 2004). Arana, like other voice hearers, drew connections between hearing voices and troubling experiences in his youth. Narratives I heard at events, and my discussions with participants (including service users and family members) often dealt with a sense of social injustice, violence and physical transgression (LMLM 2003, O'Hagan 1994, 2006; Barnett and Lapsley 2006b). Arana explained, "we need to affirm people's reality – their lived experience, and offer to talk with people about their voices". Richard Bentall discusses Romme's support group, "Resonance" that

"encourages people to accept their voices as part of normal human variation rather than as manifestations of disease, and encourages independence from psychiatric services whenever this seems possible. This startling and quite deliberate attempt to move the boundaries of madness demonstrates that even the experiences normally attributed to schizophrenia *do not have to be* considered pathological" (2004:138, citing Romme & Escher 1989)⁷⁹.

Where Romme and Escher's research with voice hearers found that the "the non-patients saw themselves as stronger than their voices, whereas the patients saw themselves as weaker" (1989, c.f. Bentall 2004:138), many discussing their recovery spoke of the importance of recognising and mediating the relationship between their emotional experiences and social conditions (Lapsley *et al.*, 2002). The way in which Arana, Joan and other's affected a sense of power and agency in the face of various authoritative voices resonates with Marcus's (2007) discussion of the paraethnographer: they practiced self-actuation, developing expert knowledge of the self in relation to the wider social system through reflexive, reflective, active

⁷⁹ Anthony Morisson has suggested that "auditory hallucinations are normal phenomena that cause the distress and disability commonly experience by patients" (1999:298). Romme and Escher (1989) found that whether voices were problematic or not correlated with the hearer's sense of power over, or under them. Wahas & Kent (1997) found that rates of hospitalisation responded to whether hearers perceived voices as predominantly positive or negative. In all cases, experiences related to empowering or disempowering interpretations and perspectives, as Jenkins observed, "is not just an exertion of power against power, but also a meaningful metaphor of reappropriating one's own intentionality"(2004:39).

engagement and analysis of experience. Both Arana and Joan's approaches to recovery informed my own recovery journey – taking something of an ethnographic approach in dealing with their experiences, they affectively narrate a course *in mind* of a range of voices as they relate to and occur within the context of their lifeworld.

Arana demonstrated that different narratives need not negate each other, but may be implemented as required by those “in the middle” to reinforce their stake and power in their lifeworld⁸⁰. Arana, Joan and my participation in this recovering moment exemplify Knauff's observation of recent ethnographic trends, as our “articulations weave features of cultural and political economy to the project at hand rather than pursuing general theories or paradigms[, making...] creative and critical combinations through partial but suggestive connections” (2006:411). The content and enactment of these stories “open a wide middle ground for fresh combinations, explorations and authorship”(ibid: 413) that for Mary O'Hagan involved “the weaving of experience, ideology and practice” (1994:78) on her recovery journey.

Arana scheduled an interview appointment with his voices, working out a time and agenda that suited him. He named and profiled them, developing a sense of their character, kept a diary of their movements, their message, the triggers and conditions in which they arose, and the affect they had on him. He developed an awareness of the interactive relationship, of self and other, and self in relation to other, noting similarities between the voices and people he had known. He observed that the ‘project’ helped him recognise, understand and manage the anxiety around the voice hearing experience. We might observe the transformative and protective aspects of an ethnographic methodology that has the potential to affect one's relationship with others (and thus, self) through active engagement. This ‘project’ and methodology allowed him to mediate without feeling intimidated, and to stake out some ground within this *archipelago of the mind* on his own terms⁸¹.

⁸⁰ Geekie suggests that “if we [professionals] remind ourselves that there is not one but many professional perspectives on psychosis, and if we resist the temptation to adopt wholeheartedly one or other of these perspectives, this may make it easier for us to work with clients whose views do not correspond with our own”(2004:158-9).

⁸¹ Arana explained his first ‘arranged meeting’ with his voices – an appointment both he and they failed to attend, because he “had a date with a young woman,” and forgot all about it. From this he came to understand that he had some control over this ‘other’ – these troubling subjects, a position from where he started to gain some ground. What might now be considered ‘unethical’ practice in anthropology may in turn be helpful to those marginalised or disempowered.

In developing an understanding of the workings of his voices, Arana gained power in his relationship with them. In ethnographic fashion he sought to recover and demystify the voices, firstly for himself, and later for his audience – for family members, service providers, voice hearers, and the general public. Through this process, the stigma, shame, and power associated with these voices diminished. He explained that when he meets people who have been through such experiences he congratulates them – welcomes them – acknowledging the strength and resilience it sometimes takes to deal with these voices.

Joan's work with her voices also involved something of an anthropological approach. She acknowledged them, examined their nature, motivation and method. She explained they could be distressing, but as a community she did not wish to eradicate them – they had their uses, and she saw them as an *all too effective* coping mechanism. One 'character' in particular exemplified a supportive caring role:

She takes on that lovely grandmother role, in terms of... when things don't go particularly well she'll go, "Oh, they're only jealous darling, don't worry, you were by far the best," – you know, all the things your nana would say, that specialness that only nanas... sometimes your parents aren't able to give you but your grandparents can.

These voices provide clues as to the kinds of relationships that are helpful or unhelpful in treatment and family settings. In the anxieties and experience of voice hearers we might observe social anxieties and difficulties – social deficits that relate to a sense of injustice, violence and transgression, and the need to maintain borders and bounds. These voices, like madness, spoke of and from a sense of systemic failure. Like Arana, Joan found that taking a somewhat detached, objective and analytical approach allayed her anxiety around the voices. She took a year, without medication or psychiatrists, developing her own recovery project to disarm the voices. She explained,

Being able to maintain a level of control over my anxiety, I could manage the voices much better, because that's what they do – they feed on that anxiety.

You can learn to tolerate the voices [...]

I'm not sure if disassemble is the right word. When I tried to get an understanding of what they were about, and how they were affecting me, and how I wanted my relationship to be with them... I actually started to think about [the fact] that I was engaged in relationships with them, and then starting to gain a sense of power, as well. And that was very slow. I had to chip away at that. So trying to gain power that I had surrendered to them, that's really what made the difference... I took on the demons, and the demons were very much [the devil's] minions... and what I discovered from working with them was that the devil didn't really have any place any more... by pulling down the foundations he wasn't able to sustain himself in any sort of power.

Joan developed a form of Cognitive Behavioural Therapy that aided her recovery. What she learned by recovering voices she now shares with others. She developed interpretative methods, making positive readings of phenomena, focussing on what was at stake in various social exchanges. She took an active role, gaining understandings about relationships and her ability to affect change. Wellbeing related more to social issues than biology, medical definitions, neurological deficits or psychiatric treatments (Lapsley *et al.*, 2002, Bental 2004). Recovery was very much about managing one's engagement in the intersubjective field of experience, about self-actuation, about one's appreciation for social conduct. Joan explained,

I think it's a life-skill, in terms of; we're all usually engaged in a number of relationships and one of the things you develop when you mature is that ability to say there isn't room in your life for some people, and that's one of the things I had to do – [realise] that there isn't room for all these voices in my life.

I often think that while my issue is voices, I think that these are often just life issues. Mine just manifested itself in voices. So the skills that I required are pretty much just life-skills. So it's not about being crazy. It's about – I didn't have and I didn't develop the skills and I wasn't exposed to the skills that I

needed to deal with life. And that's nobody's fault. It just happened. And I didn't... I never took responsibility for that either.

This isn't mental health I've achieved... this is living.

5. Ritual Exchanges

I wish to return to matters relating to the privileging of voices in certain exchanges, discussing my experience and participation in ‘mental health-related’ events involving the production and exchange of local expert knowledge.

On my travels of New Zealand recovery settings – conferences, courses and summits – there was some evidence of a prevailing dichotomy – a sense of division between bounded groups such as people with experience of mental illness, carers, and mental health professionals⁸². The most heartening aspect of this journey, however, were efforts made by groups to be inclusive, where meetings and events involved all ‘supporters’ of the cause. When looking toward shared objectives and goals, and listening to people’s narratives, personal differences seemed incidental and each person was seen to have equally valid expert knowledge. These inclusive events redressed my sense of contrasting or incompatible points of view – privileging often-marginalised voices we all became peers *and* supporters.

At the *Practical Tools for Wellness* event, the organisation welcomed service users, voice hearers, family members, service providers, clinicians and supporters. Their motto borrowed a phrase commonly employed by a number of different groups and organizations, “Be the change you want to see in the world”. This message of Ghandi’s implies that the intentional enactment and practice of ‘living well’ may come to be mirrored in one’s social relations. It responds and stands in contrast to a sense of a paternal authority that instructs, prescribes and seeks to control. It asks that we look beyond illness, stigma, or social divisions and reinforce connections by enacting and observing strengths and goals and leading exemplary lives. Well-being, here, is presented as a personal project involving the development of power, agency and intentionality through positive action that may be reflected in an intersubjective field of experience. In this setting, people performed stories, poetry and a play –

⁸² Evidence of these divisions can be seen in the way in which ‘groups’ are identified and separated – for example, on the opening day of the Australian Mental Health Service conference in Auckland, participants had to choose between the ‘indigenous’, ‘family’, or ‘consumer’ events, some of us having been given free entry to one or the other depending on our ‘position’. Previously I have discussed the inclusive attitude of the ‘hearing voices network’, and the dissolution and challenging of once steadfast boundaries. My argument throughout this essay is that each might benefit from recovering the voice of, and intermingling with, the ‘other’.

performances addressing *all* participants. There was no movement toward blame or shame, nor use of ‘authoritative’ language.

Speakers at these events shared local expertise firmly rooted in experiential knowledge – the professional hierarchy was upturned and consumer/service user voices were privileged. This ritual ‘community’ structure provides a safe yet powerful environment facilitating disclosure, and challenges to the establishment. These gifts of stories were given with little of the ‘ceremony’ that surrounds academic discourse and publication. Rather than trying to *convince* recipients of their import, relevance, significance and value, Arana and his peers spoke somewhat casually of everyday things in an everyday manner. There was no move to market, sell or argue – these stories speak for themselves and make no claims of absolute or objective worth and understanding of matters beyond the self – the neoliberal ethic stands that people reach their own conclusions and assess and derive the value of items for themselves, based on local current needs and knowledge⁸³.

There is a sense of community, connectedness, support and encouragement, within which feelings may be shared – humour, sadness, anger and triumph – and in the spirit and energy of exchange, we move beyond difficulties toward hope, and a sense of promise. During breaks, attendees found their own voice in lateral discussions with others. We sought ‘like minds’ with whom to exchange stories, insights, queries, ideas and contemplations of these gifts – transactions that help to reinforce or enrich our appreciation of their value. Thus, other’s stories tie into our own. We take these gifts home – both in the form and message of stories and ‘learnings’, and in the *spirit* with which they were given, where “narrative, we might say, is a form of Being as much as a way of Saying”(Jackson 1996:39). The benefits are plural and realised by all – speakers share in and enact recovery, their own experience reinforced by audience/recipient recognition, attention and uptake. In this recovering moment recovery evolves in the interplay between self and other, flowing back and forth between personal and public experiences within this *archipelago of the mind*.

⁸³ Again, this contrasts some paternal aspects of psychiatric power and imposition.

I return again to the work of Geekie (2004, 2006a, 2006b); Vanthuyne (2003), Wisdom *et al.*,(2008), Romme & Escher (1989,1996), Kleinman & Kleinman(1996), and Estroff (2004), who, amongst others, argue for the privileging of such marginalized voices in academic and clinical domains – not just for their own sake, but for all. The ‘hearing voices’ meeting was something of an anthropological platform on which stories are lived and lives are storied. My discussion responds to and re-enacts my sense of the spirit of these events, where as Jackson explains, to “reconstitute events in a story is no longer to live those events in passivity, but to actively rework them, both in dialogue with others and within one’s own imagination” (Jackson 2002:15). These stories are exemplary of the field about which they speak, and from which they arise (Marcus 2007). Yet as Estroff observes, these first-person narratives receive the least funding, and page space, in mental health settings, the media and academic journals (2004:288).

In this recovering moment, those with power in the system are called to not only *acknowledge* once subdued, restrained and marginalised voices (British Psychological society 2000), but to *privilege, venerate* and *learn* from them. Arana and others’ speaking engagements, websites, articles, peer support, advocacy, research and other work all help to reinforce their authorial stake in the conditions of their personal identity, and this *archipelago of the mind*. They also stake out ‘safe ground’ for others to partake, detailing and defining aspects of shared terrain. Their stories dissolve the bounds between ‘symptoms’ and ‘treatment’ (Estroff 2004) whilst drawing connections between personal experience and the social environmental and historical conditions in relation to which they unfold (LMLM 2003, Durie 2004), reinvigorating our shared sense of living well. Furthermore, their stories are universally applicable – about our being human, dissolving clinical/medical perspectives and definitions.

6. Discussion

In her key-note address at a psychiatric research conference, Sue Estroff observed of the clinical situation;

“An argument can be made that we don’t need any more research about what to do. We know, and it’s pretty clear, and I think it’s up here. What we don’t know is how to do it; how to sustain it; how to change practices; how to fund it. It’s not rocket science. The people who I’m most familiar with need an enduring relationship with a multi-disciplinary team of people who are going to help them get resources, and there’s continuity of caregivers, continuity of care, so forth and so on. And I think we know what the technologies are” (2008).

Arana explained, “We don’t need high science, we need simple stuff – good talk, good relationships” – and so I return again to the *human* ethics around giving, receiving and repaying, and the *matter* of relationships and community. And to the fact that today, many of us struggle to deal with a sense of a sometimes unfair, unjust, intolerably immoral, stressful, competitive, degrading, disempowering, violent, dishonest and hypocritical system – many of us find ourselves grieving this social deficit. “Mental health”, Arana explained, “is about building a relationship” – about trust and honesty, openness, accountability, making positive readings and interpretations, reinforcing value and goodness in our intersubjective exchanges. Geekie maintains that “in a moral world, no one but the person in question has the status, the authority, under normal conditions, to decide what his experience means to him”(2004:149, citing Shotter 1981). Mary O’Hagan observes,

“Anyone who promotes community care as the great solution without tackling our society's historical tendency to abuse, neglect and limit the opportunities of mad people is being naive.

The sad reality is that while the mental health system is busy trying to provide better services our communities continue to abdicate their role in our well being”(1994:18).

By focussing on individuals in mental health, there seems to be a failure to observe intersubjective experience, and too little attention to wider systemic, corporate, and social issues. Voice hearer and campaigner Ron Coleman writes; “In Aboriginal culture when someone goes mad the whole tribe comes together to discuss what the tribe has done to cause the person to be mad” (2008) – yet he doesn’t foresee Western capitalist society ever responding to madness in this manner⁸⁴. From these perspectives we might derive some value from madness – challenging the privileged perception of madness as illness, and illness as other, re-inscribed “as anything but human experience”(Kleinman & Kleinman 1995:96, c.f. Jenkins 2004) – because the stories in this part of my essay illustrate the way in which madness may guide us toward a deeper, more expansive sense, appreciation and experience of our human potential and social needs. Jenkins observes in her research,

“that humanity is precisely what is at stake is well known among those who live with schizophrenia as a matter of first-person subjectivity and intersubjectivity in family contexts or clinical and research encounters [yet...] the suffering of persons with schizophrenia is substantially constituted by others’ (healthcare providers, employers, kin, neighbors, strangers in the community) [involving] cultural ambivalence and reluctance to grant them full ‘human’ status” (2004:43).

In essence, recovery rhetoric presents us with a state endorsed (though under-funded) vision toward developing a moral and ethical society. Although it stems from a neo-liberalistic shift to individual, family and community care and responsibility, those partaking in this ‘recovering moment’ now seek greater accountability from the state and other social institutions⁸⁵. This ethic is outlined, emphasised and directed by those with experience of mental illness and distress, heavily populated by marginalised and disenfranchised groups – local experts in human need – paraethnographers working at the interface of emotion and the institution in this archipelago of the mind. To contain, censor or censure these voices wont change the fact that they speak of, to and from our human need. Anthropology presents one example of this ethic, where with

⁸⁴ See: <http://www.roncolemanvoices.co.uk>

⁸⁵ As I write this, informants warn me that since the recent economic downturn early in 2009, and under the current centre-right government, funding is being siphoned away from preventative measures in healthcare in New Zealand, suggesting that these *recovering voices* may be further marginalised.

each new encounter we endeavour to begin from a point of not-knowing, with a willingness to find out, acknowledging that which is at stake for individuals and groups, where the personal is social, and political.

In a field where wellbeing, identity and personhood are at stake (Lapsley *et al.* 2002) it is no longer satisfactory that service users are ‘informed’ or ‘educated’ about a condition they are said to *have*, especially where these terms denote a downward, and unidirectional distribution of professionally authored information assumed to relate to one’s particular experience. Yet the institution privileges a powerful minority of ‘professional’ and ‘pharmaceutical’ voices. As one informant involved in amplifying Maori, Pacifica, service user and Family voices observed, competitive tendering for grants between non-government organisations can be problematic (Gawith & Abrams 2006, Walmisley 1998). She noted that where groups develop power and voice, conflict often occurs – and still, “A lot of support groups don’t have ministry funding”. People with whom I spoke on all ‘sides’ discussed the stressful aspects of service provision and treatment relationships, and the difficulties of implementing a moral, ethical vision and equal exchanges in a competitively *under* funded system.

Where, as I argue, personal and systemic recovery involves recovering marginalised voices, acknowledging and responding to their needs and hopes, and institutions provide the framework for this recovery, then empowerment depends heavily on whose voice is financed, authenticated and endorsed in a range of settings (Estroff 2004). And as Estroff observes of pharmaceutically funded and influenced endeavours (such as research, diagnosis, publication and medication), “there’s a disconnect between how we research and treat, and what people want us to know about what’s going on”(2008). First person accounts are least privileged in academia, and the media, effectively censoring *our* voice, and vision, and contributing to a sense, and experience, of disempowerment, subjugation and appropriation (Estroff 2004). Again, connections can be drawn between the ‘inner’ experience and social exchanges, where Dr Patricia Deegan’s discussion of her personal recovery might equally describe recovering one’s voice within and in relation to an authoritative system:

“I think frankly, after my studies and also through a lot of personal trial and error and learning experiences myself, that there really is enormous truth that [it’s] anything that promotes a sense of personal efficacy and power. That seems to be the key that, these voices which present themselves as these all-knowing, all-powerful, ‘we know everything,’ ‘we see everything you do,’ and on and on and on. To find that I can interrupt that powerful a force, really creates a space for me to have some power. And of course, this flies in the face of what much of modern psychiatry is saying. That people who are experiencing major mental illness are having ‘broken brains’ and can’t possibly take a stand towards what’s ailing them except to take medications. I feel we’re doing an enormous disservice in the United States in particular by saying that medications are the only answer” (1997; c.f. Jenkins 2004:38)⁸⁶.

Despite this notion of a neoliberal subject involved in personal, social and systemic recovery and self actuation, engaged in an ongoing dialogue on equal terms, playing an active role in generating knowledge in their local community, institutional structures and corporations play a powerful role in amplifying or silencing certain voices in relation to others. Where personal experiences are seen as relating to wider social structures, the responsibility of ‘recovering voices’ in a *humane*, community-minded manner is yet to reach the powerful, profit motivated corporation.

The power and agency of these recovering actors depends, to a large degree, on those with resources facilitating safe, supportive arenas for marginalised groups to speak. One well-established, highly ‘valued’ voice-hearing informant working to stake out ‘safe ground’ in this recovering moment explained his frustration at not being able to attain funding (and thus institutional recognition) to do so. Where a sense of wellbeing is equated with having a stake in the ‘big narrative production’ of this *archipelago of the mind*, reinforcing the validity of local, particular and immediate lived experience, voices are still disproportionately represented, perpetuating a

⁸⁶ Jenkins suggests that “Deegan’s trained capacity for self-awareness allows her to reappropriate her own reflexivity by insisting that the voices are part of herself. Deegan’s account also shows that orientation is not an effortless outcome, for resistance is encountered at the interface of subject and world. As with reflexivity, this effort, which is the taking up of a stance in the world, cannot be taken for granted by the patient. It appears as a moral uncertainty that is amplified in the voices’ accusation that the self is ‘bad.’ Assertion of moral goodness, literally the right to be in the world, is the surplus effort required for Deegan to become oriented in spite of her affliction” (Jenkins 2004:37).

polarising dichotomy. When a sense of injustice prevails, so to do polemic ‘them and us’ perspectives from which arise conflict, misunderstanding, loss of dignity and shame.

Arana acknowledges this polemic in his fight for empowerment, yet returns again and again to emphasise madness as one part of our common humanity. Assuming an anthropological role in this recovering moment, he works “to cultivate stronger and more active appreciation for diverse authorships at the same time [...] depolariz[ing] oppositions based on subject position or identity politics”(Knauft 2006:413) by emphasizing aspects of his particular story and our common, shared human experience. As Jenkins suggests of people diagnosed with schizophrenia, their voice

“can offer insights into human processes that are fundamental to living in a world shared with others. This is the case because the construction of shared meaning, usually taken for granted, can become fraught in schizophrenia. Their attempts to create shared meanings often entail a tremendous struggle, whereas for those who do not have schizophrenia, this is so often taken for granted”(Jenkins 2004:30)⁸⁷.

Arana’s own practice and insight encourages the primary importance of satisfactory exchanges at the interface between personal lives, family and social institutions. His narrative enactment compares with Knauft’s observations of anthropology “as a model of critical engagement with the world, rather than a distanced and magisterial explanation of the world” (2006:413), a way of emphasising connections and inter-experience before ‘otherness’. This ethnographic process, my “attempts to create shared meanings [also entails...] a tremendous struggle” (Jenkins 2004:30). Knauft writes,

“If the center of gravity in cultural anthropology is now most comfortable combining rather than separating moments that are, at turns, theoretical, objectivist, subjective, or reflexive, it occupies an increasingly middle ground

⁸⁷ Jenkins argues that “(1) the subjective experience of persons with schizophrenia is forged at the nexus of culture and agency, desire and attachment, none of which are annulled by disease process; and (2) the study of schizophrenia casts a bright light on our understanding of culture and subjectivity in general”(2004:30).

as well between academic pursuit and practical intervention”(2006:413).

The anthropological project, with its central emphasis on recovering voices, presents affective and flexible tools for those active in locating needs and affecting change within and between individuals, social systems and institutions. Phenomenological approaches shift attention from theoretical models to acknowledge lived experience, linking what is at stake for those on the ground with wider social processes (Jackson 1996, Kleinman & Kleinman 1996). “It is through re-appearance of this knowledge, of these local popular knowledges, these disqualified knowledges, that criticism performs its work” (Foucault 1980:82). The organic evolution of established institutional structures depends on their responding to and privileging marginalised voices. These tools are not only employed in developing awareness and understanding of ‘otherness’, but to emphasise, explain, and affect our shared intersubjective experience. They may also be employed by individuals, as Joan and Arana demonstrated, to mediate between particular personal or private worlds and the public realm, through active reflexive engagement, reflection and narration.

7. In Conclusion...

Throughout his talk, Arana moved around, sang, showed photographs of himself at different times in his life. “These tell an important story”, he explained. He employed multiple voices – emotional tones, body movement, music and laughter. Now and again he stopped, paused to think – to breath – to question, and to listen again to his own words. As Jackson observes,

“In storytelling events, the effacement of the boundary between private and public space is commonly *lived through* as a physical, sensual, and vital interaction between the body of the storyteller and the bodies of the listeners, in which people reach out toward one another, sitting closely together, singing in unison, laughing or crying as one”(2002:28).

Though limited by locale, these events transmitted so much more power than the written word – than articles and academic discourse. At the end of his talk, Arana picked up his guitar. The hall filled with song, everyone joined in to sing *Stand by Me*. The physical experience of being there, of listening and partaking, of meeting old friends and strangers, shaking hands, eating and singing together reached beyond the cognate, attending to our sense of being as one – we were moved to share, for a while, in this united voice. In this exchange, we each take something of the other, we move and are moved as a group. The boundaries open in this exchange – something deeply profound occurs beyond individual experience – we share in a sense of wellbeing.

There is a reason why the question is sometimes asked of an audience, “How many of us here are family? And service users? And clinicians?” Attending these meetings that privilege subaltern or marginalised voices, one cannot leave without developing some appreciation for our shared, lived needs and values – the lived expression of what matters now, to who, and how much. These are the ritual exchanges through which perspectives change. Attending these events reinforced my sense of “research as social justice”(Estroff), part art, part science (Kleinman and Kleinman 1996).

Part Three Being as Family

1. Introduction

In this part of my essay I return to my original thesis question regarding relationships between the experience of mental ill-health and family life. Rather than facing this question ‘head-on’, my discussion responds to the findings and theories developed with participants and outlined in Part One. I look again at those voices beyond words involving the movements and uses objects, bodies, place, space, and gifts through which a sense of wellbeing, and being-as-family is recovered.

As in the previous two parts of this essay, the stories in Part Three unfold, presenting a more holistic representation of my participants’ experience of being as family, being at home, and being apart within this recovering moment - my *archipelago of the mind* spreading ‘beyond the skin’ in an inclusive manner, incorporating a range of related domains. I emphasise the creativity and resourcefulness of families, people’s stories offering insight into the experience of familial, social, institutional and thus mental-health recovery. Their particular, day-to-day experiences reveal locally specific expertise and appreciation of human needs, insights the depth and expanse of which go far beyond those documented in ‘treatment-related’ discourse.

In discussing family, I take particular interest in people’s intersubjective engagement with the house, and ideas around the home. Again, I take up discussions around gifting that emphasise ethical and moral objectives in this recovering moment.

2. Recovering Families

The Mental Health Commission observe that “the lives of people with serious mental illness are inextricably involved with the lives of those they love and care for, and the lives of those who love and care about them”(1998:9) – this being especially apparent in the decades since deinstitutionalisation in New Zealand, and more recently, since the formation and implementation of the recovery vision in mental health (Gawith and Abrams 2006). The wellbeing of individuals is closely linked to their *being-as-family*, and although state funded discourse recognises that family members “act as the major caretaker and have a special emotional closeness” (Angermeyer *et al.*, 2003:602), institutional structures fail, at times, to account for dynamic intra and extra-familial relationships.

The MHAC and MHC outline a vast range of ideals, recovery rhetoric and plans that involve and implicate the state, service users, families, service providers and the wider public, suggesting that

“Families and whānau retain hope for their family member. They are supported and educated to enhance the recovery of their family member, as well as the recovery of the family unit, from the stresses associated with mental distress. All families have access to family peer support and recovery education. Mental health workers welcome their involvement, knowing that they can be part of the recovery journey” (MHAC 2008:34).

They suggest that a necessary transformation in mental health service provision requires a shift in focus where “service users, followed by families, need to be viewed as the primary stakeholders in the mental health arena”(ibid:54). As I have discussed elsewhere in this essay, the recovering moment in this *archipelago of the mind* must be holistic, taking a “whole population approach to mental distress and well-being in which the desired outcomes is for everyone to flourish”(ibid:14), where symptoms and difficulties might occur but with less widespread and long term damaging effects

(MHC 1998)⁸⁸. Yet in practice, recovery competencies are still confined to traditionally ‘mental health-related’ groups – people with experience of mental illness, families and service providers.

This recovery philosophy and vision situates mutual well-being as the foremost objective in every domain of social interaction and exchange. It is compatible with Maori models of health, where as Webster & Bosman-Wātene explain, “traditional Maori worldviews make no distinction between religion, science and medicine [and...] mental illness cannot be presented in isolation as Māori view the mental, physical and spiritual as a whole”(2003:9, citing Durie 1994). The MHAC observe that “Whānau ora – the foundation of Māori health policy – resonates with the recovery philosophy [and...] is defined as ‘Māori families supported to achieve their maximum health and well-being’”(2008:24, citing Ministry of Health 2002a). These values and needs resonate with those expressed by Pakeha with whom I spoke.

Where the MHAC suggest that “Whānau ora accentuates collective well-being, whereas recovery, with its western roots, tends to be more individualistic”(2008:24, citing MHC, 2001), my Pakeha participants all emphasised their sense of having a collective stake in each other’s well-being, suggesting that the institutional tendency to isolate and individualise patients related to structural and functional concerns as opposed to lived Pakeha cultural values. Where the transformation of the system “requires a whole new set of attitudes, values, relationships, explanatory theories, models of practice and organisational structures”(MHAC 2008:14), this must be mediated through ongoing consultation between individuals, families, service providers and the mental health institution.

Positive recovery stories featured successful mediations and exchanges between families and the institution, yet those discussed in my interviews were sometimes fraught with difficulties. These related to often-disparate practices, values, responsibilities and power structures between these groups, and issues of empowerment and authority of voice sometimes arose. When Vanessa became unwell

⁸⁸ This compares with the World Health Organisation’s conclusion that “health is a state of complete, physical, mental and social well being... [involving] full personal development and participation in balanced and independent social, economic and cultural life”(WHO 1947). Again, this ideal is suggestive of a necessary worldwide shift away from competitive, and toward collaborative exchanges.

with severe depression, the clinicians insisted she be hospitalised, challenging their family's stake in her recovery:

I couldn't talk, so he spoke for me. He told them, "If you take her out of her environment you will hurt her worse. If you take her away from her children and her home, how do you think she's going to get well? [...] You may be clinicians but this is my wife." [...] They wanted me to take lorazepam but he told them no, because he knew I liked to be in control, so putting me on lorazepam would be horrible for me. They said, "this is what's going to happen," and he said, "No, this is what we're going to do." Hearing him assert his knowledge of my needs with confidence, and to have this knowledge ultimately recognised by clinicians was incredibly helpful to me.

The success of Vanessa's husband's empowered stance and strength in advocating and negotiating on her behalf related to Vanessa's long-term involvement in mental health and family work, and that they had a plan in place in response to her previous experience of depression.

Yet most of those I spoke with had little or no previous knowledge of the system, their rights, or of the current recovery vision and competencies. At the meetings I attended, many carers expressed distress in response to the sense their being-as-family had been neglected and overlooked in the treatment of a loved one. To all those with whom I spoke, satisfactory exchanges in mental health depended on being familiar with the system, having connections with informed service providers, and/or rapid contact with Supporting Families. Distress arose when family members felt the social institution failed to recover or acknowledge the particular, yet taken for granted needs of their being-as-family. They felt the responsibility to consult rested, in the first instance, with those in a position of power (Lumb 2007).

Service providers might observe and acknowledge that one of the defining characteristics of families in this holistic recovering moment is the diversity of their heterogeneous experiences and needs. Despite service providers being familiar with the system, families most often are not – thus, those with power to mediate between

these two different social groups – the family and the institution – might benefit all by practicing something of an anthropological approach⁸⁹.

⁸⁹ In *Participating in Partnership*, Trish Lumb (2007) outlines extensive systemic procedures for incorporating family voices, strengths and needs into mental health service provision and policy in New Zealand. Vanessa, a participant who has used, and worked with mental health services for some time, explained that in recent years procedures have been changing rapidly, and for the better. Mary O'Hagan (2000a, 2000b) shares and explores some family stories, and like the Ministry of Health (2000a) and to a lesser extent The Mental Health Advocacy Coalition (2008), outlines guidelines and competencies for the inclusion of family/whānau as collaborators and contributors in treatment plans, service provision and policy. Steinberg & Whiteside (2005) discuss initiatives for including family members in training professionals, while Cowan (2008) outlines once clinical 'recovery' skills that can be employed by family members, and discusses family/carer-relevant aspects of the recovery paradigm, and the system. Goldsack *et al.*, (2005) discuss different perspectives (including family members, service users and staff) around home based treatment, as do Gibs *et al.*, (2006) regarding compulsory community treatment orders (CTO's). Peterson (2005) suggests the need to focus on power dynamics to understand stigma and discrimination in families (discussed in Peterson *et al.*, 2004), and alludes to the relationship between family members and service providers as a possible contingent factor. Kingi 2005; and O'Hagan (2006) discuss positive changes in the system, whilst observing areas that require ongoing improvement in service provision. Jones (2004) talks about the emotional and grief related needs of family members, while Mottaghipour *et al.*, (2005) discusses a five step pyramid of family involvement, and needs assessment, for clinicians to employ to best meet family needs. Slade *et al.*, (2005) discuss practices when service users don't consent to sharing information with carers. Various overseas research attributed to the likes of Leff, Lefley, Hatfield, Barrowclough (and their colleagues) are oft referred to in discussions of family experiences, needs, burdens, treatment, interventions and collaboration in mental health and recovery. We see quite a plethora of research discussing shifting perspectives about the relationship at the interface of family and health service systems.

3. Getting Beyond Words

In her keynote address at a psychiatric research conference, Sue Estroff discussed the need to develop awareness and appreciation in research for domains of experience and expression beyond the spoken word. She emphasised the potential benefits of attending to sensate realities, telling her audience, “I can’t *say* enough about getting beyond words”(2008). As Jackson suggests,

“If, as phenomenologists argue, knowledge of the mind is neither ontologically prior nor superior to knowledge of the body, then we have to accept that activity may be meaningful even when it is not couched in words, our gestures explicated in concepts, or subject to reflection. In other words, our gestures, acts and modes of comportment do not invariably depend on a *priori* cognitive understanding. Practical skills, know-how, a sense of what to do, are irreducible. The meanings of practical knowledge lies in what is accomplished through it, not what conceptual order may be said to underlie or precede it”(1996:34).

The implication of this argument is that to meet human needs we might push the bounds of recovery discourse beyond rhetorical structures, authoritative descriptions, scientific definitions and medical explanations⁹⁰, and attend to the *amorphous* bounds of our state of being and experiencing. Family members *know* their loved one’s needs, and can *sense* their condition. Yet, because of the tendency of relating cognition to speech that in turn may be transcribed, interpreted, translated and summarised, the purely articulate actions and experiences of bodies resist definition, and thus qualification in mental health discourse. The bounds of the academic conception of this *archipelago of the mind* are very much constrained by their privileging certain voices, and that which can be measured, quantified and described – the cognate over the sensate.

⁹⁰ I have already suggested that the bounds of ‘recovery’, ‘illness’, and ‘wellbeing’ are *ill-defined*, and that this ‘holistic’ recovery moment challenges its constituents to look beyond hegemonic western concepts of mind, illness and experience. These are not limited and confined to that which has been described in scientific and clinical discourse, or institutional policy, but go beyond the skin to include all domains and forms of human, social exchange.

Much of the current discourse in mental health provision centres on the need for family and service user voices to be heard and valued within the institution⁹¹. Yet clinicians have often found it difficult to incorporate enquiring after family needs, advice and information into their work (Gawith & Abrams 2006:146). Peterson (2005) discusses a range of international studies that suggest professionals sometimes perceive family members as irrational (Rethink 2003), uninformed about mental illness and treatment (Riebeschleger 2001), and to be contributors to their relative's illness⁹². They are thought to share in the discrimination and stigma around mental illness whilst being portrayed as having a burden (Peterson 2005). What stands between recovery rhetoric and practice, and between institutional and family perspectives, is a lack of accurate empathy and respect. Vanessa, who has worked with families for some years, pointed out that in some cases such *clinical* observations might be valid, but there is a failure to situate these within a wider intersubjective social context:

Family members see the signs, they know the person, and clinicians might think they are over-worrying, and they do worry sometimes. But if carers seemed a bit of a pain it was because of years of feeling not listened to, not heard. This would make family members very loud and aggressive because they don't know how else to be. The only way they knew how to get information was to stand there and yell for it. Staff would give information to get rid of them. But we have to remember there is a reason for this.

One aspect of this *recovering moment* involves shifts in professional perspectives away from 'textbook' observations of an 'other' to realign their view *with* those 'on the ground'. The stories of my participants illustrate the ways in which personal and familial distress relates to a sense of systemic failure (MHAC 2008), where institutions serve structural, functional and clinical purposes whilst sometimes neglecting human, family needs. Vanessa discussed the need to draw feelings and empathy into the exchange between families and the institution:

⁹¹ (See footnote 89).

⁹² Some family members and service users in New Zealand have suggested that professionals may be *too rational*, uninformed about families and recovery, and contributors to people's sense of disempowerment. Leff's (1989) research on family expressed emotion suggests problems in how we *treat* others may relate to how we perceive and research them.

The mental health team need to see you are a real person, not a diagnosis – a real person with a family, a full life, a history – a person before an illness.

More recently, the challenge for staff in mental health service provision has been to develop an appreciation for the physical and emotional fact of people's being-as-family – aligning themselves with local, particular knowledge and needs (Lumb 2007). Where much of research and discourse regarding 'competencies' emphasises the need for collaboration, partnership and planning within families and between groups, often discussing these relationships in terms of verbal encounters, little of the writing attends to equally significant and meaningful non-verbal exchanges – matters of ritual and routine involving bodies and objects moving in place and space. This sense of a division between mind and matter, the self-perpetuating dichotomy of mind over body, is stigmatised and limiting. The task, in this recovering moment following deinstitutionalisation, is to reinstate a fuller sense of, and empathy for, each other's humanity in clinical and institutional practices and settings.

As Arana observed, "so much of what we 'voice' in relationships is unspoken". Many with whom I spoke expressed a willingness and need to challenge assumptions, destabilise "and unsettle received ways of seeing the world, replenishing our sense of life's variety and possibility, [...]encouraging debate on the role of the intellectual [and authoritative scientific discourse] in a world of practical affairs"(Jackson 1996:4). The discussions and stories that follow regarding mental health policy and practices challenge those voices that speak "as if life were at the service of ideas"(Jackson 1996:2, citing Dewey 1980:291; Merleau-Ponty 1962:39). My approach draws from that of Desjarlais (1996), who in his essay *Struggling Along*, discusses how the day-to-day physical and emotional aspects of experience and relationships respond to and are affected by the structural systems, processes, policy and procedures of service providers at a drop-in centre he spent time in. He writes that where

“theoretical and medical formulations fail to account for the intensely felt personal dimensions of human life and suffering[,...in phenomenology] the emphasis is on felt realities rather than cultural categories, the near rather than

the distant, and the sensate over the semantic. The sensate begets immediacy which, in turn, begets authenticity”(ibid:72).

I argue further that phenomenological anthropology – a way of being, seeing and relating to others and the world – offers a method and ethic of encounter and exchange that lends itself to current “competencies” and objectives in this recovering moment. I wish to evoke a more holistic appreciation of family life that may develop through anthropological-type encounters, drawing attention toward those less privileged and discussed, and (according to my informants) most overlooked strengths, hopes and needs of our being-as-family. My thesis is that families already know much of what they need, and the role of the institution is to support them in exercising and strengthening this local expertise whilst ensuring their strengths are not undermined.

4. Entering Houses

“To hear voices, feel paranoid and think and act differently than others can have a tremendous effect on a person’s life, but the environment in which one lives determines so much more” (Desjarlais 1996:91).

As I argue elsewhere in this essay, recovering moments form through the interchange of once separate and segregated ideas, practices and bodies between families and the institution. Where the New Zealand house stands somewhat secure and insular – a place of safety, privacy and confinement – this recovering moment very often involves consumers and carers ‘opening up’ to external interaction and discussion. Family and consumer guidance is sought in managing institutional practices and policies. Family members attend support groups and other meetings on ‘neutral ground’, refreshing relationships, expanding their social network – overcoming stigma often associated with isolation (Peterson *et al.*, 2008). They look to bring others into their lives and homes that might affect positive transformation – sometimes welcoming field and support workers, the crisis team, an HBT⁹³ nurse or anthropologist. Once distinct and separate ‘professional’ and ‘friendship/whānau’ roles and practices may be seen as sharing overlapping bounds. Clinical therapies such as Cognitive Behavioural Therapy are now taught to family members and carers. Where power is balancing in this recovering moment, steadfast ‘definitions’ and ‘distinctions’ between roles and functions take second place to people’s immediate needs⁹⁴. Thus, of ongoing deinstitutionalisation we might observe an opening of the bounds between the house and the institution, between family expertise and professionalism, a shift away from an imposing institutional order.

Following Carsten & Hugh-Jones discussion of the “house as central institution”, looking at our society “through the house enables us to escape the constraints of

⁹³ Home Based Treatment

⁹⁴ Helen spoke of “catching up for coffee and a chat” with her Supporting Families fieldworker, and others sought in friends an ‘objective *professional* opinion’. What we see, in this recovering moment, is the need to attend to lived situations being placed before adherence to functional and structural formalities. These come into play only when issues of power are challenged, or displaced. As Hatfield observes, “there is evidence that people seeking help in our culture are highly subjected to the influence of nonprofessional advisors – family, friends, neighbors, and other informal sources, called the ‘lay referral network’ by Gottlieb [who...] observes that these nonjudgmental treatment modalities may serve as important alternatives for families”(Hatfield 1990:12, citing Gottlieb 1976).

conventional analytic categories” (1996:20). Visiting people’s homes to conduct interviews, I gained a sense of what Goldsack *et al.*’s research participants observed of the benefits of conducting Home Based Treatment (HBT), where “Visiting people in their homes, and the close relationship that develops[...], meant that HBT nurses felt that they expanded their understanding of mental illness and its meaning in people’s lives” (2005:26). The benefits went further than developing a more holistic, empathic appreciation of the other’s humanity – this situation benefited participants’ ‘professional’ relationship, and the individual’s recovery. One nurse observed,

“You’re not forcing someone into hospital, the power structure has gone. You do your best to work on that relationship”(ibid:31).

Such exchanges equalise power relations – obligations between host and guest are *felt* and *lived*, whilst remaining unspoken⁹⁵. The care and artistry involved in tentatively entering others’ spaces encourages an awareness of self and other – by having and being guests we stimulate our sense of being-as-family. Carsten & Hugh-Jones explain,

“It is only under exceptional circumstances [...] that we are forcibly reminded of the house’s central role and fundamental significance. Anthropological field research is another exceptional circumstance. To enter another culture is to stand nervously in front of an alien house and to step inside a world of unfamiliar objects and strange people, a maze of spatial conventions whose invisible lines get easily scuffed and trampled by ignorant foreign feet” (1996:4).

Home Based Treatment provided benefits for service users, workers and families (Golsack *et al.*, 2005). Clients felt safe, comfortable, and that their lives weren’t disrupted. Professionals developed a greater sense of people’s particular needs as they related to and through space, objects, family and the home. In changing the site of exchange, we can affect empowering relationships – so important in this recovering moment. One nurse explained,

⁹⁵ One participant observed that for their being-as-family, they only *spoke* of such matters when there was a problem, when boundaries had been breached.

“It’s about partnership as opposed to the [‘I’m a] nurse, I’m a professional, and you’re the client, and you’re going through something and I know what’s best for you...’ It is about working together, and it’s about mutual respect, about care and what we need to do ... we are more engaging. We do see people at their worst, and we see them at their best, but we are there for them and we are really real with people, and normal, as opposed to this textbook...” (ibid:26).

Nurses partook in the holistic life-world of their clients, coming to know their being-as-family, getting beyond words, looking beyond illness, developing empathy and gaining an appreciation of their shared humanity.

“Insofar as houses are continually transforming what passes through them, the hearth is both literally and figuratively the site where these transformations actually take place. [...It] is out of these everyday activities, carried on without ritual, reflection or fuss [...] that the house is built”(Carsten Hugh-Jones 1996:43-45).

These exchanges, ethnographic in nature, have transformative power. The ‘transformative’ recovery moment in mental health involves a greater degree of interaction between the institution and the home, and necessary shifts in the perspectives and perceptions of those with power. This anthropological practice of entering another’s place can involve something of a sensory psychosis. Conducting interviews in participants’ homes I gained an appreciation of their being-as-family – the walls, furniture, photographs, the taste of my tea, colours and smells, furnishings and fittings – all shared in the family voice. Objects came alive, became animate, physical, powerful, speaking to me of matters of immense importance spanning generations and running deep into the textured layers of the moment and their being. When we listen to people’s stories about home and family life, we might imagine or envisage something of our own. It is by participating in, and acknowledging the value of these exchanges that persons and institutions transform.

In privileging this physical experience, phenomenologists “intend an indictment of the

view that all experience is reducible to knowledge, and may be metamorphosed until it comes to resemble the objects of science”(Jackson 1996:3) – my discussion looks at ways in which the significance and meanings of objects and spaces relate to their use in people’s lives – the way they permeate or reinforce boundaries and facilitate exchanges between individual and social bodies, and minds. Emphasising these other voices I draw attention to the lived metaphors, narratives, ritual acts and routine practices inscribed upon and through place, space, bodies and objects⁹⁶.

⁹⁶ Dewey Writes, the “assumption of ‘intellectualism’ goes contrary to the facts of what is primarily experienced. For things are objects to be treated, used, acted upon and with, enjoyed and endured, even more than things to be known. They are things *had* before they are things cognized.”(1958:21; c.f. Jackson 1996:3) – we come to know family not from ‘rhetoric’ and a list of ‘competencies’ but through relationships and exchanges with people, through our senses, ‘things’, food, places and feelings beyond words.

5. Being at Home

Family members discussed the way in which their loved one's path to health or illness was spelled out in the evasion of or participation in shared space, time, meals and conversations. Occupants were aware of the language of the house – open and locked rooms, late-night noise, the use of public and private spaces, lights beneath doors, lapsed or enforced security, people's absence or presence, undeclared guests, objects moved or missing, smells and foods, running pipes and appliances, clean and dirty dishes, destruction and decay – these were the voices to which family members responded, emotionally and thoughtfully, establishing an understanding of others, and a sense of the condition of their being-as-family. Signs of ill and good health, changes and developments, were inscribed upon the house and body like *mise en scène*. Carsten Hugh-Jones observe that the house comes to reflect, affect, speak of and to a complex family being – dynamic entities that are born, age and die,

“their vitality comes from a number of sources – most obviously from the people who live in them but also from... life-giving rituals[...]Houses are far from being static material structures. They have animate qualities; they are endowed with spirits or souls and are imagined in terms of the human body” (1996:37).

Family members described ways of knowing and experiencing that ran deep into their condition of being, far beyond the confines of scientific or medical description or explanation. Attending to individual and family needs requires institutions develop an understanding of the local and specific conditions within and in relation to which experiences, including illness, unfold (Goldsack, *et al.*, 2005; Durie 2004). Home represented and embodied particular aspects of how participants' wanted life to be, ideals negotiated between individual family members, but also in response to external and historical forces. Home forms out of and partakes in the intersubjective experience of our being-as-family in relation to the wider society – it is a place about mind, both lived and imagined.

The house served as reminder and reinforcement of disparate realities between outer and inner worlds – between family and wider social institutions, between self and

other, and between private and public selves. Within its bounds, participants sought balance, respite, safety and comfort. How people managed their and others' comings and goings meant the bounds of the home could be experienced as nurturing, but also isolating, protective and/or restrictive. People with whom I spoke were emotionally, physically, and cognitively attuned and responsive to, and sensitive of, such movements. Thus, the experience of home was intricately linked with people's sense of individual, familial and societal values, and with their sense of ill-health, wellbeing, poverty and wealth. In this *archipelago of the mind* that goes beyond the skin, the movements of bodies in and between spaces and places, and the way in which we mediate either open or closed physical borders relates to our sense of the condition and nature of our mental and social bounds.

The Family Home

James designed and built his home in the 1970's, and it speaks of his beliefs about, and hopes for, his family and as such, participates in their experience of being-as-family. As Carsten & Hugh-Jones suggest, "If people construct houses and make them in their own image, so also do they use these houses and house-images to construct themselves as individuals and as groups"(1996:3). The care James placed in 'home' shows in the workmanship – He talked to me about the house:

*The house is symbolic – it is a metaphor – it is in a way the womb that is nurturing the inhabitants, which is the family and the system that exists inside the family, and that sort of stuff is just ingrained within us. And when that's disturbed, we're disturbed*⁹⁷.

James has a strong work ethic – yet he has experienced how debilitating mental illness can be. Like many parents and carers who I met at support groups, James wanted his adult son to work and strive as he has done, to find satisfaction, to live up to his potential and contribute of his qualities. He struggles with the idea of his son not having paid employment. Yet James laments for the younger generation a sense of fractured social expectations regarding 'appropriate' development, 'proper' work,

⁹⁷ Carsten & Hugh-Jones explain that. "An alternative language is precisely that of the house...[it is] 'about' kinship [...], joint subsistence, production and consumption [...and] common spaces"(1996:18). In James and Anita's case, the house speaks both of, and about, their personal and family values, qualities, needs, strengths and expectations.

family life, honour and respect. He explained his difficulty maintaining the home since his accident some years back that caused ongoing pain and was followed by severe depression – he finds himself, in many a sense, bound to it, and to his son's condition:

Because of the accident I wouldn't be able to do terribly much in a week or in a day, and so working from home cut down my commuting time and there was a possibility of giving me something to do, but it's disastrous. Where are the boundaries? Where is the workplace and where is the residence? You know, when people are commuting, the commute is the door, it's how they leave one and go through to the next... and the idea of making a transition – that you can leave one thing and go – so that you, 'the working man' and 'the family man' become more defined. Here we are this morning – he's sleeping underneath the floor where we're talking. There's a consciousness of that. It has influence⁹⁸.

For the families with whom I spoke, home became a social and physical site, an environment in and through which the manifestations of illness and wellness were experienced. As James observed, separation from the home provided a portal between identities and roles (Laing 1967). He lamented the dissolution of the rites of passage he knew as a young man – the socially endorsed and recognised shift into adulthood, individuality, and responsibilities often associated with leaving home – and he saw the modern world as stressful, with greater risks and challenges for young people to navigate. Thus, although a child's departure was often seen as fundamental to personal and familial development, the social institution did not necessarily support such transitions. When serious mental ill-health arose, family members often

⁹⁸ Laing observes the extent to which Western families are dynamically, and inextricably linked through individual bodies to the wider social system: "Each group requires more or less radical internal transformation of the person who comprise it. Consider the metamorphoses that the one man may go through in one day as he moves from one mode of sociality to another... These are not simply different roles: each is a whole past and present and future, offering different options and constraints, different degrees of change or inertia, different kinds of closeness and distance, different sets of rights and obligations, different pledges and promises [...] I know of no theory of the individual that fully recognises this. ... The tired family man at the office and the tired business man at the home attest to the fact that people carry over, not just one set of internal objects, but *various internalized social modes of being* from one context to another, often grossly contradictory"(1967:82) – yet these dynamics are shifting in the current recovery moment, since deinstitutionalisation, and in community care.

expressed a sense of grief around lost opportunities, changed expectations, and altered lives (Karp 2001, Jones 2004). Vanessa explained,

It's easy to say that it's not a downward adjustment, but when you've seen you're kid in uni, accomplishing heaps, really bright and smart, and to see that [now] their idea of a good day is to brush their teeth, know how to make a coffee and go for a walk, it's pretty hard to tell a family member that that's not downward. Realistically[...] It can be like a little death – death of the person, and sometimes people need grief counselling to let go.

Despite the recovery philosophy's emphasis on self-determination and living well (MHC 1998, MHAC 2008), parents sometimes struggled to adjust their values and expectations about home, family and their loved one, to align with this new situation – especially where the illness was particularly disabling. Thus, our being-as-family was affected by and dependent on our relationship to and position within the wider social institution as much as by the condition of individual family members. Where carers are expected to adjust to meet the needs of individual family members, in this recovering moment, the institution is called to employ their power in adjusting to meet the needs of our being-as-family.

Fragmented families

Yet the Pakeha families with whom I spoke were very often fractured – adult children were away flatting, living in other cities or abroad, and relatives lived separately. It wasn't always possible, or practicable, for extended family to 'adjust', play a caring role, and prosper. In a society where most adults work away from home during the day, the family's extended support network depended on mental health-related and other social services. Consumer and policy-led deinstitutionalisation involving shifts to community care have caused a displacement in how families where someone experiences mental ill-health function and develop (Brunton 2004, Gawith & Abrams 2006)⁹⁹. And still, the state often fails to attend to, and account for changing family needs.

⁹⁹ A sense of family 'burdens' and 'benefits' for families have been well documented abroad by Karp (2001), Lefly (1989,1997), Leff & Vagn (1985), Ostman and Hansson (2000), Stueve *et al.*,(1997), Bulger *et al.*, (1993) amongst others. In New Zealand, research has shown financial costs of caring

For home owning parents, the walls and confines of the house were sometimes used in affecting the development of their relationships with their loved ones. Leaving home involved a leap, for many, requiring money, a job, mobility and some understanding of institutional systems and process (Lapsley *et al.*, 2002). Some had the sense that ‘normal’ and ‘healthy’ familial development was hindered by illness-related experience. Yet there was often a struggle to find supported accommodation, and so the condition of the support network didn’t always cater to the needs of families, which in turn could affect behaviour and power relationships, and challenge values and expectations within the home – especially where there was a sense of danger or risk from without (Laing 1967). For example, while carers worked to recover and maintain their own lives, their ability to do so might be affected by challenges to power in their own home, that in turn related to the efficacy, philosophy, policy and availability of services¹⁰⁰, which could in turn affect their emotional state, and the “emotional atmosphere” (Jenkins 2004) of the home.

Embodiment therapy

As I mention elsewhere in this essay, one institutional response to the sense of familial symbiosis was to teach family members Cognitive Behavioural Therapy (CBT) – a form of re-embodiment¹⁰¹. This involved conscious observation and remediation of the relationship between five areas of affect – cognition, emotion, behaviour, physiology and environment. We practice shifting our focus from talk, rhetoric, and voices of the mind to attend to sensate aspects of being and relating – we practiced attuning to the physiological or emotional ‘voices’ of stress, for example, and in turn through physical action we might affect our emotions, thoughts, and make

(Supporting Families 2006) with some discussion of the family experience of caring and treatment (Goldsack *et al.*, 2005; Scott 2007, Mental Health Commission 2000).

¹⁰⁰ This amplifies the need for services to “focus on outcomes that are important to service users” and family members, where “policy is profoundly influenced by service users, families and those most affected by mental distress”(MHAC 2008:10), requiring the development and “strengthening of dedicated service user and family positions in national policy, funding, planning and provision bodies”(ibid:56).

¹⁰¹ Through my involvement with Supporting Families I attended an evening course on stress management employing Cognitive Behavioural Therapy (CBT) – something of a universally applied approach to helping people affect their sense of well-being, agency and empowerment – their state of being a part and being apart.

some change in our environment or social situation¹⁰². We were asked to develop self-monitoring routines, adjusting and responding to internal and external stimuli¹⁰³. CBT involved mediating our part in an intersubjective dialogue between being and experiencing, each informing and affecting the other. This form of recovery involved a reconstitution of self in relation to other, of borders and domains, of agency and responsibility – a kind of reunification, re-embodiment, re-conceptualisation, repositioning and reconfiguration of being – something akin to self-actuation, meditation, or prayer.

And yet the bounds of family included the bounds of the house, and the *value* and *risks* that people assessed from external forces affected their being-as-family (Laing 1967). Carsten & Hugh-Jones point out, kinship

“is not just about sleeping together but also about living together, eating together and dying together, not just about bed but also about house, hearth and tomb, the last sometimes a monumental hypostasis of the house itself” (1996:19, citing Bloch 1971; Wilson 1988:122ff; Hodder 1990).

Carers sometimes struggled with dilemmas of property, family, illness and mortality, ownership and responsibility. James’s sense of kinship and fairness was disturbed by concerns around mental illness that further related to their living in a society in which he felt his son was vulnerable to fraud, violence, and dishonesty¹⁰⁴. At the time I spoke with him he was struggling to write his will – he contemplated giving an external party power of attorney over his son’s inheritance:

¹⁰² We might observe aspects of this in the philosophy, to “be the change you want to see in the world” – the implication for family members being that by responding to our own internal voices with ‘effective’ and ‘worthwhile’ behaviour, we would affect our own state of well-being that might influence others within our social interactions.

¹⁰³ At the “CBT for Stress” course we ‘rated’ our stress levels were given timetables, homework and exercises, and learned to schedule such things as mindful breathing exercises into our day – ways of dealing with life in a complex, stimuli-rich modern world environment.

¹⁰⁴ James’s son had been victim to such violations on various occasions – whether they related to his experience of mental illness was uncertain. As observed elsewhere in this essay, family members worked hard in this recovering moment to separate troubling feelings (with often with physical manifestations) from their loved one’s – thus, the recovery project, for some, involved a form of re-embodiment, and demarcating self.

He could, in a state of unwellness, be taken advantage of by people... Because that is the nature of the world – the vulnerable are preyed upon. So he is left with the situation where there always has to be some check on when he is making any choice on any serious inheritance or something of that nature. [...] And that creates a burden on me, because if I don't leave him with an inheritance then what will he have? [...] If I put that into my will I've sent him a message: "You'll never be well. You'll never be able to manage your affairs. I am your father and this is how I see you. I'm not going to trust you".

Again, the concerns around mental illness related to a sense of unfairness, and an immoral society where the way in which we relate is affected by social anxieties around the value and scarcity of resources, our vulnerability to exploitation, the need to stay alert, policing borders against the improper transgression of boundaries. James wanted his son to seek help, to engage with the institution and treatment, to become familiar with their workings, to understand threats to his wellbeing - thus, protecting his rights might improve his condition. Social anxieties around the perceived value of 'things', 'contributions' and property affect our sense of what matters, and what is at stake in our relationship with others¹⁰⁵. Where many with experience of mental illness in New Zealand reported stigma and discrimination within the home and family (Peterson *et al.*, 2004, 2008), and the workforce (2007), what at first glance seemed discriminative and stigmatising responds to a sense of powerful external forces and anxieties within the wider social system¹⁰⁶.

And where Peterson *et al.*, posit the notion that "Respect Costs Nothing" (2004), there was a sense by family members that respect developed through ongoing exchanges, and involved real work attending to and recalibrating shared values. Yet respect, and responsibility were given and taken, through burden and obligation, contribution and signs of appreciation, exchanges that fostered recovery –

¹⁰⁵ Debbie Peterson, in *I Haven't Told them, They Haven't Asked: The employment experience of People with Experience of Mental Illness*, (2007) explores questions around employer's anxieties around hiring people with experience of mental ill-health, the sense being that the capitalist emphasis on quantifiable 'profit-motivated' values skews our ability to serve community fairly, in part affecting this need for welfare for marginalised people.

¹⁰⁶ Some discussed treating loved one's 'differently' to avoid stress, and being "more tolerant because of the illness" – sometimes referred to as "walking on eggshells" where 'privileging' certain behaviour might be akin, in effect, to discrimination.

“when people are an integral part of safe, strong families, have equal access to education, employment, housing, transport, and goods and services, and are free to participate in the commercial, cultural, political, spiritual and recreational life of their communities”(MHAC 2008:28).

Yet this can be difficult, in a competitive capitalist society, where services remain under-funded and external institutions and corporations fail to support such processes out of concerns for profit margins or budget constraints. As Vanessa observed, respect broke down where voices were negated at the interface between individuals, families and the institution, effectively marginalising groups. Walmisley observed of the regional Health Agreements; “their accountants have created a contracting environment that so narrowly defines the task that is to be done that the gaps between the numerous providers are getting bigger”(1990:71). Like others involved in recovery, Walmisley argues that the client “needs to be placed at the heart of the spending decisions instead of at the rear end. At the moment we are fixated on buying structures”(ibid 71; c.f. Gawith & Abrams 2004:146). Nearly two decades on, service providing informants still reported difficulties in meeting needs in this competitive funding system.

Those aspects of power structures that restrict access to services in response to constraints on funding, staff and space, come at a cost to consumers, families, mental health workers, and the wider community. From a relationship perspective, the social system as a whole suffers. Where funding isn't forthcoming, and wages are low, it is difficult to implement service user-centred treatment (Walmisley 1990). In this recovering moment, “failure to give and receive, like failure to make return gifts, means loss of dignity”(Mauss1980:40), where it is only through tending this ethic of *competitive giving* “that people can create, can satisfy their interests mutually without recourse to arms”(ibid:80).

Embodying Responsibility and Power

Hence, the notion in this Pakeha system that transactions are conducted between unitary individuals becomes problematic when we start to consider matters of responsibility and power. I suggest that our sense of empowerment and responsibility

forms intersubjectively – flowing between individuals and within groups where each understands and is aligned with the other’s needs and expectations. It can’t be ‘pinned’ to individual subjects. Lapsley *et al.* (2002) explained that for recovering New Zealanders,

“there is an ebb and flow around the theme of personal responsibility [where...] at the onset of illness life became chaotic, responsibilities were not fulfilled[...] 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 see that the time was ripe for new responsibilities, as sometimes the next step seemed a matter of chance” (2002:60).

Concepts of recovery remain ill-defined (Lefley 1997, Hatfield 1997), as do our expectations around a person’s recovery journey as it relates to our being-as-family, and to the wider social institution. As Logan’s experience (discussed in Part One) demonstrated, his illness followed a series of troubled, problematic, disempowering interactions with, and ejections from powerful institutions – and recovery involved a stepped progression of successful interactions with social institutions – family, doctors, income support, and the university and employers (Lapsley *et al.*, 2002). He explained his difficulty at home,

I suppose with my family, times when I’m depressed and I might stay in bed most of the day, maybe they think it’s due to laziness. But a lot of times it is just a coping mechanism. You don’t feel capable of dealing with what’s going on in your life. [...] You enter a kind of survival mode, doing what you need to do, and so the expectations that other people have of you – you know that they are there... other’s expectations of you are important to you, because you don’t want to let them down, but at the same time you don’t quite feel capable of handling too much pressure, which causes more depression. You just don’t feel capable of meeting those expectations.

Logan’s experiences of home, family life, poverty, society, institutions and illness all related and intersected – each affecting the other as he was marginalised and fell

through the ‘cracks’. Serial eviction from social institutions absolved them of responsibility for and conscience about his living condition. Families – isolated to varying degrees, may not have the means, or knowledge, to adequately account for, or change their condition that directly, or indirectly relates to social institutions. Logan, like others in New Zealand studies, and some at family support meetings, explained a sense of intra-familial isolation that related to difficulties with extra-familial institutions (Barnett & Lapsley 2006b:26-28).

Participants worked hard to recognise the signs of wellness and illness in themselves, others, and their being-as-family. For some, simply sharing time without stress could be seen as a step forward – recovering a sense of harmony in the home was important for their state of mind. They communicated variant levels of cognitive needs, but also *of feelings*. Family members worked on managing stress and levels of conflict in the home – establish and adjusting their expectations about acceptable behaviour and living conditions. Anita explained of her adult son living at home:

I mean, there was a time where I'd be pressuring him to be up during the day, and I think initially when he started to be up all night and sleep during the day, I believe that was some sort of opt out. If he lived life like that then there was no sort of pressure. You know, there wasn't anybody around saying to him, interacting with him and saying, "you can't do this. You can't be up all night." ... I'd get up and find him in the morning and say to him, "Go to your bed down stairs." And he'd get up and go down there. It makes me wonder why he'd... it's almost as if he wanted to be with us. You know, he didn't want to go downstairs.

Peter's use of family space, and later, his making a family meal were seen as recovering moments – carers looked to partake and promote such exchanges¹⁰⁷. When illness occurred, people became sensitive to the use of space and place – the movement of bodies in the home can be seen as responding and affecting their being-as-family. They came to *feel* their sense of values, needs, responsibilities and

¹⁰⁷ As mentioned earlier in Part One, carers spoke of having to relearn the value of ‘things’ when family members were recovering – meals were for *eating* but also involved exchange, washing dishes together *got things done*, but perhaps more importantly, facilitated communion, shared time and space.

obligations – families worked to articulate, define and demarcate these in relation to objects, public and private space. As Carsten & Hugh-Jones observe,

“Moving in ordered space, the body ‘reads’ the house which serves as a mnemonic for the embodied person. Through habit and inhabiting, each person builds up a practical mastery of the fundamental schemes of their culture.”(1996:2).

Families are fundamentally aware of the uses of space and objects that seem to speak of their loved one’s condition – in Anita’s case she recovers a voice, a message, in her son’s use of ‘family’ space for his private acts – she takes comfort from his sense of comfort in doing so, yet also finds it inappropriate.

Family members often struggle with attributing responsibility and ‘appropriate’ behaviour, pondering the difference between symptoms, illness response, learned behaviour, side effects of medication and so on – again, these are in part ‘defined’ by the psychiatric institution. Education, and discussion about such matters were seen as helpful, and again, CBT was deployed in defining the bounds of ‘self’ and ‘other’, responsibility and agency. From her own experience of depression, and her work with families Vanessa observed,

I don’t think you can really help someone recover, other than just be there and support them and love them. Families have to leave it to the treatment team and keep your own life going.

For families, recovery following an acute phase of illness often involved addressing power displacements within the home, and between families and the social institution – each developing a sense and appreciation for their intersubjective stake in the other’s experience. Carers spoke of managing ongoing demands and concerns around another’s vulnerability – they sought balance in the home, especially where they felt their needs had been impinged upon. Support workers discussed the need to promptly recover order, normalcy, and expectations and again, CBT was deployed as a way of ‘ordering’ behaviour and embodying responsibility.

Recovery involved successful exchanges at the interface of family and institution – this involved family/whānau’ ideals being taken on board in clinical situations and the uptake of professionalized practices in the home¹⁰⁸. Thus, the recovering moment involves reconsidering how we embody and perform self, agency, power and responsibility, sociality, work, and being-as-family.

Recovery in the home involved the redefinition and demarcation of boundaries. Goals, behaviour, values and matters of cultural significance were outlined in a physical manner. For householders, the bounds of ‘acceptable behaviour’ were marked by the delineation of the house, and the body – they worked hard to make concrete and physical what might otherwise be challenged as fluid and debateable – to remain within ‘these walls’ involved adhering to certain values. Someone ‘hitting rock bottom’, in the eyes of family members, involved a crisis in their *being-as-family* at which point physical boundaries came into play.

Yet for those with a sense of disempowerment and a loss of voice, the body sometimes became a site of conflict and expression, the last vestige of our *being* marginalised. An experience of self-in-conflict might play out in threats or acts of suicide or self-harm – the bounds of one’s personal power might be inscribed in the line between life and death (Barnett and Lapsley 2006b). These situations presented real dilemmas for families and individuals with no easy solutions. Those with power took up responsibilities that challenged ideals around self-determination in extraordinary circumstances. The embodiment and recovery of our being-as-family depends, to varying degrees, on the responsiveness of the wider social institution – its open or closed borders and boundaries, and a sense of connection. Developing satisfactory, ethical and respectful exchanges at the interface of the family and the institution might be seen, then, as the primary task in affecting recovery for our being-as-family – as Jasmine and William’s story demonstrates.

¹⁰⁸ Cowan (2008) outlines ways in which family members and carers can employ structured clinical knowledge and practice in their caring role. In mental health recovery, as I have shown elsewhere, there is a great ‘blurring’ of domains and definitions, and those who remain resistant to these transformations (i.e. those whose structures remain closed, inflexible, and impermeable) risk stasis and decay (Jackson 2002:29, Laing 1967:71-78). Both families and institutions work with this challenge of bounded persons, groups and domains such as hospitals and homes, yet in the recovering moment there is a call for transparency and connectivity, for greater, more flexible flow of bodies and information between domains, and voices between bodies, and between internal experience and others.

6. Being Apart - Jasmine and William's Story

“Society takes upon itself the right to inflict appalling punishments on the individual, but it also has the supreme vice of shallowness, and fails to realise what it has done. When the man's punishment is over, it leaves him to himself: that is to say it abandons him at the very moment when its highest duty towards him begins” (Oscar Wilde 1986:916-917).

“What has often been carried out in the name of community care and deinstitutionalisation has often been disastrous. [...] The rhetoric of community care for ex-patients is becoming a cruel euphemism for community neglect” (Brunton 2004:88, citing Mr Basset, the minister of health 1984-87).

In this essay I don't propose an ideal family living situation, but rather discuss some aspects of family life that were mediated in response to mental illness, recovery, and service provision, exploring some of the changes becoming apparent in this recovering moment¹⁰⁹. Rather than suggesting there is an *ideal* service for all, ideal services must be flexible, open and responsive in meeting the particular needs of, and empowering, families and service users (MHAC 2008, MHC 2003; Lumb 2007; Goldsack *et al.* 2005).

Informants sometimes felt that the rigid, inflexible, impersonal nature of our institutions resulted in a lag in responsiveness and attendance to their immediate human and family needs, and these sometimes went begging. Some carers with whom I spoke observed difficulties getting adequate care and accommodation for their loved one, suggesting service providers were short of space, time, staff and finance, and could be eager to move patients through the system (MHC 2000). Consumer and family needs sometimes seemed at odds with inflexible, non-responsive 'blanket'

¹⁰⁹ As Lapsley *et al.*, observe in their discussion of New Zealander's recovery journeys, “*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” (2002:74). Family members and carers also felt it necessary to be close, or apart at different times. Thus, their being-as-family responded to a sense of external and internal threat, or benefits (Laing 1967) and the walls of the house represented something of a concrete definition between family and the social system.

policies and procedures, especially around matters pertaining to security, privacy and safety – institutional practices and policies were very often incongruous with family values. Jasmine’s story highlights some of the needs and strengths of our being-as-family that weren’t being acknowledged by the institution.

Jasmine insisted that her adult son live away from home so that he would develop, and “get a life of his own”. William is in his twenties and resides in a secure ward. Some years back he was diagnosed with schizophrenia, placed in care, given medication, and after some time, against Jasmine’s wishes and advice, released into supported community accommodation. She felt her knowledge of his needs, history, personality and illness were overlooked and undervalued – a common story from parents at some of the meetings I attended. Without supervision, William stopped his medication, became very unwell and after a serious incident was charged, convicted and placed in a secure forensic ward¹¹⁰. In this position he became “immobilised”, as Jasmine put it, refusing medication, not speaking, nor actively taking part in treatment.

Brunton (2004) employs a historical perspective to draw out the complex network of influences and motivations that go into mental health policy and provision of treatments in New Zealand. He observes that progressive policies follow, react to or build upon often-problematic predecessors:

“The lengthy shadow of the institution, no less than its substance, stretches far beyond the institutional walls into today’s post-institutional era. The shadow covers all the policies, plans, practices, and procedures devised to mitigate or counter the institutionalisation of patients and staff”(2004:89).

Brunton observes, “Mental health policy... serves multifaceted social purposes of control, care and cure” (2004:76) – citing Helen Clark who stated that asylums “cut off patients from their families, friends, culture and community activity”(2004:81).

¹¹⁰ Jasmine and her son faced the consequences while the wider institution took no responsibility for their lapse in effective care. Mary O’Hagan shares family and service user stories of forensic wards in New Zealand, where families “talk of their sense of helplessness, of their desire to do their best for their relative, of feeling blamed or dismissed by professionals, and of their enormous struggle to get information and support from the services”. Participants found most helpful “people working in the services who treated them with respect and gave them hope...”(2000b:6).

O'Hagan highlights the “the paradox of sanctuary and confinement within institutional structures”(2000b)¹¹¹. Institutionalisation continues, though its form shifts in response to social expectations and needs around the positioning, conception and flow of bodies and information – in this recovering moment, these relate to an ideal of responsive organic processes, human rights, and public concerns around safety and security. Yet often, the institution disrupts rather than supports its constituents' needs – especially in the forensic unit, as Jasmine observed – where there is uncertainty about what purpose the institution serves and how.

For Jasmine, gaining access to her son and attending to their being-as-family became very difficult – there were locked rooms and wards, short visiting times made by appointment only, and tight restrictions placed on exchanges¹¹². The system was rigid in its security yet flexible, and somewhat two-faced in its self-definition, maintaining a functional dichotomy in their position of power over individuals (*and* by association, families) who were treated both as *sick* and *criminal* (Brunton 2004:80). Jasmine explained,

They used to tell me they were a rehabilitation, or a 'pre-rehabilitation' unit and I just used to say, "No you're not, you're a prison." But then the rest of the time when I used to try to tell them they were a rehabilitation unit they'd tell me that they were actually part of the prison service.

At the time when relationships most need repairing families were divided and members isolated from one another. For William and Jasmine, ‘Treatment’ of the individual involved detention, discipline, surveillance and punishment that effectively extended to their being-as-family. Medication was forced under the Mental health

¹¹¹ Goldsack *et al.*'s study of Home Based Treatment in New Zealand found that patients on the whole found hospital stays problematic; “At best, hospital was seen as a place to go when unwell, but one that is not especially conducive to recovery. Being around other very unwell people was seen as difficult. Also, there seemed to be nothing to do and no one to talk to about issues, and treatments seemed to be entirely medical. Lack of choice, lack of input, compulsory confinement and treatment were also seen as undesirable features of the hospital stay. At worst, inpatient stays were seen as ‘scary’ or, to quote one, ‘just the worst experience ever’.”(2005:22).

¹¹² Jasmine spoke of family members travelling long distances by bus only to be turned away if they were late. Where someone failed to record her appointment she was refused entry – after she argued, she explained that it was a Maori man who “saw sense” and bent the rules to allow her entry.

Compulsory Treatment and Assessment Act (1992)¹¹³. Subdued, tranquilized and passive within these protective, yet silencing walls, William expressed a sense of vulnerability to rape. Safety for the community seems to involve the inverse for patients, where risks to the public are displaced entirely onto the individual and their family and whānau. These humanitarian concerns arise time and again with regard to the New Zealand penal system¹¹⁴.

Jasmine received a letter stating that William – immobilised, numb, silent – would receive Electroconvulsive Therapy (ECT):

I said, 'No, you're not.' I wrote a three-page letter as to why they weren't going to give him shock treatment. [...] It's kind of interesting isn't it, mental health... you get a mental health situation like William where you're mentally ill and then do something and then you kind of become less than a person, a person with no rights, you're actually owned by the state – they can put drugs in you, they can give you shock treatment... you are a thing, a body. You are incredibly vulnerable. I have seen my role in terms of actually advocating for William... I certainly didn't know that if he was in that situation he would be agreeable to shock treatment¹¹⁵.

Brunton observes the move toward treating patients as independent individuals who could be absorbed or “lost in themness”(2004:84). Family members felt they had a stake in the treatment of their loved ones, and practices that assume universally shared ‘ethical’ and ‘humane’ values fail to account for particular personal and familial histories or culture. Despite the possibility of ECT being conducted in an effective, ‘painless’ and ‘humane’ manner, Jasmine’s physical and emotional response was that

¹¹³ Under the Mental Health Act (Ministry of Health 2000b) medication may be administered compulsorily within hospitals, and under community treatment orders (see Gibbs & Mullen 2006).

¹¹⁴ The Salvation Army have an extensive range of information, and articles, many regarding an ineffective, flawed, and self-defeating New Zealand penal system. <http://salvationarmy.org.nz/research-media/media-centre/daily-news-links/crime-punishment/>. They also present research on a range of social and political issues, including penal policy and practice: <http://www.salvationarmy.org.nz/research-media/social-research/social-policy-and-parliamentary-unit/>.

¹¹⁵ As Vanessa explained (and many of my participants observed), when people’s condition became acute, family often had to speak on their behalf – to be their voice. Trish Lumb observes, “If family/whānau have difficulty gaining access to services or they experience a lack of involvement or a feeling of being shut out of their child or youth’s treatment, this can also increase disempowerment. Feeling disempowered can create the feeling that family/whānau has no say in their young person’s treatment and that services have control of their young person’s life”(2007:22).

it was intolerable, with potentially catastrophic ramifications. Her visceral reaction related to her family's refugee history that was negated by the institution¹¹⁶. Like others in this study, Jasmine *felt* pain and joy on behalf of her ancestors, siblings, and children. Her uncle had received ECT as a form of discipline and retribution, and her mother also had experiences. These connotations and memories were ingrained deep within her being, embodied through shared stories, histories and experiences. She *felt* and *spoke* on behalf of her son who in his vulnerable position embodied their being-as-family.

Current recovery rhetoric attests the need to foster dignity in all transactions and exchanges, yet the restricted movements curtailed Jasmine's motherly role. Where the state and services took a paternal role toward both patient and family, ironically, this affected Jasmine and William's sense of family solidarity and reconnection through joint struggle. The forensic 'services' shut down exchanges and undermined the family structure. Like other parents, "Getting through" to her son involved mediating frustrating and difficult aspects of the system. Efforts to remain calm, articulate and polite were often thwarted. Signs of distress, desperation and anguish unmasked often begged, and best ensured, attention – people's outbursts spoke of and to the sense of a non-responsive, impersonal, inhumane system. As Jackson observes,

“any social system tends toward stasis, entropy, and death, unless its field of bound energy – symbolised by inflexible rules, inherited roles and fixed boundaries, as well as psychophysical constraints on body movement, speech, and emotions – is periodically reinvigorated by the 'wild' energies and fecund powers that are associated with extrasocial space and deep subjectivity. This two-way movement across the boundaries that normally enclose both the individual body and the body politic involves throwing open the social system to forces that, while necessary to its re-creation, are potentially destructive of its integrity” (Jackson 2002:29).

Yet in William and Jasmine's case, risks to the perceived integrity of the institution were displaced onto their being-as-family – their taken for granted physical and ritual

¹¹⁶ Jasmine saw her *refugee* history as a defining cultural identity – she, like Maori and Pacific Island people, sometimes felt the need on meeting others to make this 'cultural identity' known.

values and needs were forsaken. Where institutional practices adhere, in structure and function, to policy, they do so at the risk of disqualifying and devaluing the immediacy of human family needs. Words are very often incapable and inadequate in conveying the feelings and knowledge people need to share, and my informants felt systemic structures and processes occluded their being-as-family. Where bodies stand defiant, errant, immobile and silent, the institution might threaten violence, revert to the ‘wild energies’ of ECT, and penetrate boundaries by injecting medication. The mentality differs in our being-as-family – where words failed, Jasmine reverted to cake:

When William was unwell, and we made a cake, we’d always take a piece down, and if I got a good nurse she’d let us take it in, because of this idea that this is... what’s fundamental to whānau relationships, family relationships, is that you eat together, you know. That’s communication... these are fundamental things, in any culture. You’d know as an anthropologist, you go in there and food is what congeals people together.

“It’s communion?” I offered. Jasmine continued,

Absolutely. And when this boy is so unwell that he can’t speak, a piece of cake becomes the point of connection and the communication. But because it’s a lockup ward... I used to have to say to them, “Look, I haven’t got a problem. I don’t want to compromise your security... do a security check on me, for God’s sake, do some kind of evaluating thing – don’t just have a blanket [policy]...”

The cake presented William with something of the hearth and home, a part of their being-as-family. In this recovering moment we must pay serious attention to the transgression of boundaries – the cake penetrated the physical bounds of home and hospital, between the individual and familial bodies, and from the family system into the institution. I offer this story as a matter of ‘common sense’ regarding what is of central importance in human relations, yet so distant from the institutional, structural and functional mentality. Where medical science might measure and document the nutritional value of a piece of cake, the humanities, and families, offer something

more. In this recovering moment, Cake, when allowed, permeates and congeals our being-as-family.

7. Being Medicated

In mind of the movements, transgression and appropriation of bodies, the permeation of borders and boundaries, the mediation of the intersubjective field of relationships at the interface of individuals, families and institutions, I wish briefly to discuss medication. Standing with a group of people waiting for our ride to a service-user-led conference I got talking with Sue – a woman interested in nutritional approaches to living and feeling well, as well as countering symptoms of illness, and side effects of psychiatric medication¹¹⁷.

Sue commented, “You look well.”

“Thanks, I feel okay.”

“I mean, you look well – you know, sometimes the medication can make your skin bad and give you rings around your eyes, and make you kind of jittery, or tired. You look healthy.”

“Oh, I’m not on medication,” I answered.

“Wow. That’s great that you can get along without medicine. You seem to be doing okay.”

“I am doing okay.” I paused. What could I say? What were the implications of her questions and observations? What could I assume, really, about her situation or my own? I often felt I was exploring the gulf between madness and sanity in this *archipelago of the mind* – I wasn’t sure how or where to draw the line, for others or myself.

“What illness do you have?” she asked.

I thought a moment, answered slowly, still uncertain, “I don’t have an illness.”

“Oh,” she paused. There was quiet, then, “Why didn’t you just say you *weren’t* ill?”

“I’m not sure. I didn’t know what to say. I didn’t know how to say it.”

Sue proceeded in telling me about the physical and motivational difficulties she and many others she knew had with psychiatric medication. She spoke about some

¹¹⁷ At the “Practical Tools for Wellness” event we had a nutritional expert speak about diet and nutrition, handing out a timetable, or daily routine recommending foods, and eating patterns that might help with symptoms, side effects of medication, and general wellbeing.

nutritional supplements, her diet, vitamins and ways of dealing with symptoms and side effects through diet. What surprised me was that ongoing medication was so often a ‘given’ – a ‘taken for granted’ aspect of treatment¹¹⁸. Yet to me, at these ‘social’ events, the appearance of corporate pharmaceutical sponsorship and advertising unsettled me – so much of my recovery journey focussed on that which passed between people – medication had taken a backseat in my mind. Yet while socially influenced, mental ill-health was still seen as very much an internal, marginalised, private experience – in part because social ‘causes’ cannot be *seen*, and thus fail to be observed or acknowledged by the natural sciences.

During the course of my year I heard a range of discussions on such matters – stakeholders expressed varied and sometimes contradictory opinions – yet under our medical model medication remains virtually a ‘given’ aspect of treatment for those experiencing serious mental ill health and distress. Where Good suggests that “exclusive attention to neurobiology and psychiatric medications... hides the enormous importance of understanding basic social and cultural processes associated with mental illness”(1997:231), my participants observed that the use of medication *spoke of* our varied social needs, values and expectations as they are experienced at the interface between individuals, family/whānau, and social institutions. Discussions around medication can *emphasise* our social and cultural values, needs and processes.

Some of the family members and service users with whom I spoke felt they had been misled or misinformed about the necessity, availability, suitability, efficacy, side effects, short and long-term impacts of certain medications. Participants talked about their relationships with medication that varied over time and within different contexts and situations, mediated in complex ways in various domains, both personal and

¹¹⁸ In recent years New Zealand became one of a few countries to allow direct to consumer advertising of prescription pharmaceuticals. As I moved about various events, the pharmaceutical stands always seemed out of place to me. I think perhaps with all that socializing going on, and discussions around relationships, behaviour, healthy practices, social conditions, conduct, routines and ritual, exercise, family, respect, empowerment and so on – medication took a backseat in my mind. All the thinking I had done around social aspects of mental illness and mental health, placing a pill inside the body to affect perception and mood, to affect chemistry, thinking and emotion seemed almost absurd. I wondered about these medications – what was at stake and for whom, in their ritualised global consumption?

social¹¹⁹. Debates around potential benefits and costs of taking or refusing medication differ greatly depending on our personal and social position, values, experience and needs¹²⁰. Lyn's daughter was diagnosed several years back with psychosis, and has since accumulated several other labels for her experiences. Lyn talked about treatment;

I have some sympathy for the medical people, because they are understaffed and it's such a huge problem, and they haven't got the time, I think, to spend with families. And they write out a prescription, and...

She felt the medical model, and medication, served important functions within New Zealand – not just for patients, but so that carers can get the relief and help they need. She explained of her daughter's anti-psychotic medication, "It doesn't cure them, but it calms them down enough to start taking control of themselves" – and it provided her, as carer, an opportunity to recoup. Thus, the use of medication had a very social dimension. Yet she felt that patients aren't told enough, or they don't feel able to ask about the drugs, and she worried because her daughter's weight had doubled¹²¹:

I've done research and I know the risks, and yet [my daughter] had never been told. The risks are high. The side effects of Clozapine involve weight gain – which causes as many deaths as suicide does for those not taking it. I feel really strongly about this but I don't have the confidence to say 'stop taking them', Because you need a lot of support and where in New Zealand is someone going to get that support? Someone sees a psychiatrist once every three months for ten minutes – where are you going to get that support?

¹¹⁹ These factors involved the severity of illness-symptoms and side effects, longevity of the treatment, dosage, types of medication, perceptions of efficacy, risks, benefits, stigma around taking medication, the nature of their illness experience, family, work and social needs, lifestyle and access to social support. People also talked about dependency, addiction, and experiences without medication. Family members and 'service users' sometimes related to medication politically and socially, in mind of moral and ethical issues. They engaged with 'scientific' discussions, media representations, and human rights issues. Concerns relating to sex and kinship arose, and the possibility of sexual dysfunction diminishing the likelihood of progeny.

¹²⁰ In New Zealand, Medsafe, a division of the Ministry of Health, is the regulatory body "responsible for ensuring that, as far as possible, the medicines available in New Zealand can be expected to have greater benefits than risks if used appropriately"(Medsafe 2008) – yet the terms of assessment of 'risk' and 'benefit' are somewhat subjective dichotomous descriptors, relatively difficult to qualify or quantify, being further complicated when we ask, "benefits and costs for who?"

¹²¹ John Cosgriff, a New Zealand GP, is putting together a document to identify the issues and develop a new service to support people who are experiencing metabolic syndrome associated with atypical antipsychotic prescribing.

To many family members, medication for serious mental distress, often relating to diagnosis of schizophrenia, psychosis and bi-polar disorder, is very often seen as a necessary aspect of treatment. Yet they acknowledged and empathised with their loved one's reluctance to take them. One father expressed his concern that where weight gain and sexual dysfunction occurred, his son might have difficulty starting a family. One mother hypothesised about her daughter:

They [the doctors] assume that being mentally ill she doesn't need to be healthy or mobile or physically able, or to have children¹²². Perhaps they see mental health as more important than physical – but we need both.

Jasmine explained of her bright son,

he's on quite heavy medication, and he says that medication sits heavy on his head – takes away what he calls his “abstract thinking”.

Yet she felt it kept him safe from harm, despite various burdens. Helen explained that her daughter's dosage had to be adjusted to balance benefits and side effects – the medication calmed her, but diminished her motivation – yet she felt her daughter was “coming back” as she got better. Yet Helen, articulate, well spoken, and acquainted with Pakeha systems and institutions described the extensive difficulties getting the best, most effective medication and treatment for her daughter:

When we asked for other medication: “No, you can't have other medication, this is the best one, the only one you should consider”.

Finally [...my daughter] got to the fifth and last one, and that's the right one, the one that works, and it's the most expensive. And it's the one that works for the most people... So they don't have some sheer common sense – what's

¹²² Some with whom I spoke held the perception that sexual difficulties associated with anti-psychotic medication might be considered negligible risks when applying stigmatised reasoning that people with serious mental illness don't have relationships, start families or work. Peterson *et al.*, (2004) found that New Zealand parents with experience of mental illness reported being treated as incompetent, or lacking parenting skills, or the skills and capacity to take on work – social stigma that was sometimes reflected internally, often involving assumptions that such groups didn't have “jobs, families, relationships” where those free from illness did (2008:20).

reasonable to tell a family, what's helpful for a family to know. You've got to keep fighting for information.

In the current funding scheme, those not in a state or position to question, with limited access to information and understandings of wider contexts and implications, least vocal and familiar with advocacy and systems, least mobile, with limited access to services and alternatives, who seem inarticulate, subdued, marginalised – those perceived as having less at stake – less to gain or to lose by externally applied assumptions of circumstance – might have limited treatment options.

Psychiatric Survivors

For some, gathering in a community, finding a voice, sharing hopes and objectives, feeling empowered, having a choice, and challenging political, professional and commercial/corporate assumptions around our state and needs as human beings was more important to their recovering wellbeing than eradicating symptoms of so-called illness.

Attending the 2008 Psychiatric Survivor's conference in Auckland I gathered with others involved in paraethnographic work and watched footage of an American conference from the International Center for the Study of Psychiatry and Psychology (2006). Some questioned the privileged voice and power of pharmaceutical companies, seeking some way of giving service users, family members and doctors a more balanced, informed understanding of how medications work, their benefits, costs risks and uncertainties. They discussed ploys and politics around legislation, regulation, development, funding, testing, marketing and promotion¹²³, production and prescription (Dukes 2006, Perlin 2006)¹²⁴. Kruszewski (2006) questioned the of validity and terms of reference of 'evidence based science' in tests conducted by the

¹²³ In recent years, New Zealand became one of a few countries to allow direct to consumer advertising of prescription pharmaceuticals. Over the course of my research I came across various advertisements directed at both consumers and families. Some events I attended were, in part, dependent on pharmaceutical sponsorship.

¹²⁴ The study into "the relationships between DSM panel members and the pharmaceutical industry demonstrates that there are strong financial ties between the industry and those who are responsible for developing and modifying the diagnostic criteria for mental illness. The connections are especially strong in those diagnostic areas where drugs are the first line of treatment for mental disorders" – they found that 56% of panel members involved in formulating diagnostic categories in the DSM-IV had financial interests in related pharmaceutical companies (Cosgrove *et al.*, 2006:1).

companies themselves, where side effects and withdrawal symptoms might very often be indiscernible from illness symptoms. They questioned the value systems by which side effects were measured and assessed as ‘worthwhile’, and how these ‘values’ cannot be universally applied in all treatment cases. Breggin (2006) alluded to a sense that these addictive medications affected insight, changed perceptions and potentially affected a loss of identity, personality, and overwrote our ‘human being’. Others discussed ways in which developing nation states deployed medication, and employed incarceration, that had wide ranging social consequences.

Thus, we see that medications played a privileged role in mediating the relationship between individuals, families, the institution and state. They were administered in mind of social support, local policy, and the individual needs of family and whānau – yet we cannot assume a globally produced product is appropriate in every local situation. Medication played an active role in facilitating dignity, relief and empowerment, yet these were equally dependent on people having power to make choices. ‘Users’ and their families looked beyond the ‘intended’ affects of treatments to far reaching social, physical, political and cultural implications – some explaining that in this recovering moment “New Zealand society is structured in a way that fails to recognise that not everybody has or wants stable moods and perceptions”(LMLM 2003:12). Thus, in this recovering moment, we shift away from polemic arguments to consider a diverse multitude of relevant factors.

Human Interventions?

Where Read *et al.*, suggest that “human misery is largely inflicted by other people and that the solutions are based on human – rather than chemical or electrical – interventions”(2004:5), I would suggest that medication and other treatments *are* human ways of mediating intersubjective experience and exchanges between individual bodies, families and institutions – yet the corporate involvement in this exchange must be challenged, and other voices empowered (Deegan 1997).

The meanings and experiences around medication are social, and ‘human’. Where medical and pharmaceutical models exist alongside more complex and particular discourse relating to personal, physical, economic, familial, social, political, commercial and global interests and issues, those with voice hold much power in our

particular lifeworld¹²⁵. ‘Scientific’ findings and professional endorsements do not necessarily speak of or for the particular needs of recipients of this ‘proven wisdom’.

The very act of regularly taking medication, responding to treatment, or taking up a cause and placard in protest involves focussed, routine and ritualised practice. The taking of a pill into the body may be symbolic – to the consumer, family members and clinicians it represents a willingness to engage with the system on a physical level – to take into one’s being some of this Western medicine may be seen to acknowledge that voice and wisdom. Demonstrating a willingness to engage in a social exchange is a form of recovery in itself. Our social institution might do better to acknowledge the sacrifices involved, validate and support people’s decisions, especially where those on the ground challenge the application of universal measures in particular lifeworlds.

¹²⁵ Associates have suggested that regardless of commercial intentions around medication use, their regulation is dependent on political and professional regimes particular to different nations, where the uptake by individuals relates further to, and affects, cultural values and social/institutional/familial structures. We cannot assume, even within New Zealand, that those affected have access to adequate information, alternatives, and power in decision making in this area.

8. The Gift

And so, to finish this part of the journey, I return to the idea of ‘the gift’ within this *archipelago of the mind*. I wish to emphasise the way in which my expert local participants come to partake, engage and share in the intersubjective experience of their and other’s recovering moment through an ethical act of exchange. Nearing William’s birthday, Jasmine and her daughters bought him some nice locally made clothing:

They said I couldn’t gift William these clothes. I said, “Look, I’m quite happy – I respect security, of course I want security... blah, blah. I’ll give you the clothes, you put them through security, even if it takes a week, but you hold on to them and then give them back to me and you create a situation where I can gift them to William. Because when someone’s [hurt] you, you have to repair relationships, you have to mend them gifting. This cost me money. I want to gift them to him. I want to look at the excitement in his face. And I also want some culpability, some sense of responsibility. When someone gives you a gift, you know, nothing’s free in this world. It’s with responsibility, you know. I want him to look after these clothes because they’ve cost us a lot of money, blah, blah, blah...” Anyway, this was not going to be possible. I had to have meeting after meeting, and I just said, “then he doesn’t get the clothes, unless I can give him the clothes. I’m not going to have this impersonal system that takes the clothes off into the ether.”

Eventually Jasmine was able to give the clothes to William. In recognising the gift, the institution recognised their being-as-family. As Mauss observes, “it is groups, and not individuals, which carry on exchange, make contacts, and are bound by obligations”(1980:3). This *archipelago of the mind* forms through our mediating the ‘layers of engagement’ between individuals, families and institutions – suggesting an holistic interplay between minds, bodies, objects, place, space, social structures and the environment. Attending to the needs of their being-as-family involved negotiations with William’s captor and the permeation of cell walls and bodies. We who cross the bounds of ‘acceptable behaviour’ might develop an appreciation of embodied ‘layers of being’ between self and others through being engaged once more

in dignified exchanges. Like cake taken into his body, the clothes returned William's body physically into the fabric of family. These carefully selected adornments are symbols, but more than that they are animate objects, aspects of being that speak to William and the family's senses. The purely articulate, eloquent and aesthetic voice of the senses was important for Jasmine and her family – seeing William dressed well, with dignity, was significant to all – including staff and other patients.

If, as Carsten & Hugh-Jones observe, “the house is an extension of the person; like an extra skin, carapace or second layer of clothes, it serves as much to reveal and display as it does to hide and protect” (1996:2) – where families are separated, clothes and other objects take on vital importance in developing a sense of belonging and obligation. Such inter-layers and inter-objects suggest and affect responsibilities that form not within individuals, but intersubjectively as they are given and taken in ongoing relationships between them. After their departure from the hospital, something of their being-as-family remained in the warmth, smell, look and feel of the gift that became an immediate, encapsulating, protective, fragrant ‘family’ layer placed between William's body and the walls and intrusions of the system.

Eventually William was moved from the forensic to a recovery-focussed ward. A lot changed:

At the moment I'm still going through transition because visiting time is any day between [decent hours], and it's funny... I went there today at 1:30, and there's still some residue in the way that I've been, and he has been regimented into the 'Sunday, 1:30' visit... there's still some regimentation to his expectation for a visit on Sunday afternoon.

The institutional delineation of family time, space, and bodies, exchanges and movements challenges people's dignity¹²⁶. This division within families and the marginalisation of bodies is further affected by limited family finance, geographical location, mobility, work times and conditions, and ability to negotiate with, navigate,

¹²⁶ Jasmine explained not being able to visit her son on Christmas day because of hospital policy, “because, [they said] how if they opened it up that William would be the only person to get a visitor on Christmas day – and it's not a good enough reason... but it's incredibly *confined* thought, isn't it?”

advocate and be heard within this heavily Pakeha-based system. These skills and conditions that are acquired and practiced experientially relate, to varying extents, to race, class, social position and culture. Jasmine explained a discussion she had with the doctor at the clinic:

The burden for me was actually the mental health system. I said to them [at the clinic], “In mental health I meet a lot of exhausted families. And it’s the system that exhausts them, not the actual person.” In the same way that that ward was exhausting me, and actually wearing me out. I was actually fighting the system. It should never have been a fight. I didn’t start that fight. I just started making assumptions.

Families make assumptions that their needs must somehow be met. Beyond the skein of colonialism, the policing, appropriation and silencing of errant voices and bodies, might we not project and envisage mental health and wellbeing as ‘symptoms’ arising out of moral, ethically conducted acts of exchange between groups? As Mauss suggests;

“the persons represented in [these] contracts are moral persons – clans, tribes, and families.... What they exchange is not exclusively goods and wealth, real and personal property, and things of economic value. They exchange courtesies... entertainment... women...children, dances and feasts”(1980:3)¹²⁷.

Gifts as ‘inter-objects’ can serve to insulate and buffer us from negative forces, and as conductors to positive engagement. The benevolent exchange of bodies between the family and other institutions is inevitable in one form or another. It is through such objects, and the promise of ongoing exchanges, that we may exercise some agency, and develop our sense of being, and safety, and a voice in absence of our community. William now has a room, a desk, ‘home’ objects and layers given him by family, with and through which he engages. If we consider Carsten & and Hugh-Jones notion that

¹²⁷ I don’t wish to suggest any lack or deficit of benevolence on the part of any person or group, but rather cast another ‘anthropological’ perspective to help envision something *other*, or some *other* way of seeing.

the “house [or *ward*], body and mind are in continuous interaction, the physical structure, furnishing, social conventions and mental images of the house at once enabling, moulding, informing and constraining the activities and ideas which unfold within its bounds”(1996:2), then sociality and wellbeing arise through and in response to objects, environment, place and space. ‘Proper’ conduct is established tentatively in a similar “anthropological” manner. Wars, violence, transgression, injustice, threats, theft, incarceration – all serve to destabilise our sense of belonging and well-being. Jasmine suggested,

If you put me in that environment you’d have me mad in a week. I’d be needing drugs. But if you put me in a different environment... people are sensitive to their environment... and I see William as someone who responds or doesn’t respond to the expectations of the environment.

It is in attending to such local, particular lifeworlds, and the strengths and needs so often overlooked by institutional structures built upon and born out of outdated, overseas, externally construed ideology and policy (Brunton 2004) that the recovering moment manifests. In this recovering moment, we shift our sites from ideals to engage with matters of needs in their immediacy (Like Minds Like Mine 2003). Through gifts, silences were broken, relationships mended, ripples spread outward to multifarious affect – William began to engage with his support team and treatment. They worked on creative endeavours; employing strengths based approaches, recovering his voice, recovering his sense of being-as-family. I sat with Jasmine at the dining table – the hearth in their family home – something of William was in the room with us:

This kept William alive actually – doing stuff. I wont’ play you his tune. You’d actually quite like his tune... he gave me this mother’s day song... rap song, what does he do? Open mic, that he sung. It’s all about his experiences in mental health actually – it’s very ‘Eminem’, but you know. It’s just a spontaneous moment, but it’s almost like an apology in some ways. It almost brings tears to your eyes. But that’s the way that he helps deal with himself... Well... he has been quite heavily institutionalised, and I don’t know to this day... I haven’t actually said, “Well, how did you survive it?” And I don’t

think I could ask him that question, because I could only think that he might think he survived it because he deserved the punishment... because he was doing time... which comes through quite strongly in the Mother's day song... listen to it, actually... oh, no, you'd probably get quite bored listening to it... I'd have to swear you to secrecy.

I switched my recorder off. We listened. I was really impressed, and moved. “He can rap – he’s got rhythm – he can really sing,” I told Jasmine, “and those lyrics – he’s really good.” William sings of his time *moving between* ‘cells’ – of the Huffer vest his mother gave him, worn proudly, close to his heart. He mentions the individual items of clothing, gifts – daily reminders of his worth, his family, their love – his sense of obligation unburdened and reciprocated in song – it fills the room, it affects me deeply, I hear it as I write, I feel I have no choice but to break my vow of secrecy...

Conclusion

My *archipelago of the mind* is inclusive, and formed in response to my recovering a diverse range of voices in a variety of settings. Much of my discussion refers to common human needs as opposed to what are traditionally portrayed as ‘mental-health’ matters. Mind pushes beyond the skin, and the moment, and is formed as a collective of those people, things, places, memories and stories with whom we engage, both directly and indirectly, each of us partaking in the whole.

Throughout this essay I discuss the gift as motif and metaphor – an important aspect of the recovering moment – a voice that affects a sense of likeness of being.

Attending to the ritual, ethical and moral concerns and practices around the act of giving, receiving and repaying – speaking, listening and responding – is of primary significance in affecting personal and social wellbeing. Phenomenological approaches in anthropology, the recovery paradigm, and holistic indigenous approaches to health and wellbeing ask important questions: What is at stake in the day-to-day lives of people on the ground? Are institutions supportive of people’s rituals and ‘taken for granted’ needs? Are the local, social, and familial needs of individuals being met? Should the safety of ‘the community’ not include those ‘incarcerated’ and their families? What are the consequences of applying or imposing twentieth century, British or American systems, drugs and diagnosis to local Maori, Pakeha, Pacific Island, Asian or other New Zealand lives and families? Can we assume uniformity in how minds, bodies, families and cultural groups respond to treatment, diagnosis, and exchanges in various, changing local and global situations?

Anthropology, and phenomenology, offer approaches to recovering voices that observe how individual experiences speak of the wider social system, where as Mauss suggests, “It is only by considering them as wholes that we have been able to see their essence, their operation and their living aspect, and to catch the fleeting moment when the society and its members take emotional stock of themselves and their situation as regards others”(1980:77). Our *archipelago of the mind* spans the division between private and public realms, between personal and social experience, between the individual and their social system, between ‘mental health’ and our ‘being human’. It is through active, mindful engagement that we form a sense of our society at large –

developing communal responsibility involves paying careful attention to our conduct and exchanges in research and treatment relationships, in trade, and between individuals, families and wider social institutions.

We partaking in the recovering moment mindfully practice a 'social art'. Where words, and perhaps a sense of obligation and responsibility seem to have failed us, gifts and gifting were a way of 'getting through' to others – of drawing others to engage and partake in our intersubjective field. Attending these ethical, ritual exchanges generates a sense of common wealth and health by establishing a shared sense of obligation, hope, perspective and connection. The exchange of gifts established 'interest' in both senses proposed by Mauss, where *interest* in the object validates the giver and translates into a sense of obligation to repay with *interest*, to honour with dignity all those involved – raising one's stake in the social exchange, and the wellbeing of the community (Mauss 1980:73-75).

Where our sense of wellbeing forms from successive recovering moments involving mutually beneficial exchanges, profit motive is significant, yet secondary to the sustainability of the human bond. In 'confining', 'defining', 'extracting' and 'accumulating' in a capitalist, colonial and scientific sense, corporations and institutions have exploited *the other*, and sold their resources back to them. This *recovering moment* is characterised by the grassroots movements of individuals, families and communities, reappropriating their ability and expertise in healing, recovering voices and reclaiming their lives.

The bounds of this *archipelago of the mind* undulate far beyond an individual experience of 'brain-disorder' or 'mental illness', necessarily incorporating all needs and strengths of our human being. Yet for those with an interest in maintaining their power and voice (such as institutions and corporations), the *archipelago of the mind* is contained and confined within the individual 'consumer', and where 'manageable', their being-as-family. Although Extreme human distress can be observed as a response to troubling and problematic social conditions, we negate these in our tendency to pathologise and diagnose (Kleinman & Kleinman 1996). The institution continues to treat individuals before dealing with the social conditions in and from which such experiences arise. As Kleinman and Kleinman observe,

“We are far along in this process of inauthenticating social worlds, or making illegitimate the defeats and victories, the desperation and aspiration of individuals and groups that could perhaps be more humanly rendered not as representations of some other reality (one that we experts possess special power over), but rather as evocation of close experience that stands for itself”(1996:187).

The recovering subject has been portrayed, in many ways, as an *ideal* neoliberal citizen – an active agent partaking in their family and community’s wellbeing. Yet in being liberated from positions of ‘dependency’, various among these citizens now take up paraethnographic roles – seeing their personal condition as being mediated at the interface of the individual, family, and wider social institution – an ever emerging *archipelago of the mind* that involves and implicates global and corporate bodies. Where initially individuals were called to ‘recover’, this responsibility has spread further to include family members and carers, as well as service providers and professionals, and the mental health system as a whole. If, as I propose, wellbeing is recovered when we partake in moral, ethical and fair exchanges – then it follows that our entire system of trade and governance is implicated, and *obliged* to partake – to respond to rather than dictate constituent’s needs

Though challenging (especially for marginalised groups), navigating and mediating such relationships stood carers and those with experience of mental ill-health in good stead in all domains of social interaction and exchange. We *recovering voices* spoke of gaining resilience and strength through facing adversity. We developed core values and skills geared toward understanding and satisfying various, complex needs in our relationships. We developed an awareness of, and sensitivity to people’s emotional condition and needs. We formed strong, collaborative relationships and support systems, developing a sense of the need for, and an appreciation of community forming out of crisis and common objectives. We practiced a *living* morality and ethic involving tentative, careful interaction with the mental health system, family, and the wider community. We developed ways of permeating social boundaries and affecting connection through ethical, moral and exemplary acts as opposed to the use of force, restraint or coercion (O’Hagan 2006). We practiced a form of active anthropology,

carrying these ‘lived’ ethics and skills into our jobs and other domains of exchange – ethics and skills seen as universally applicable yet often ‘lacking’ out there ‘in the *real world*’.

Where responsibility to ‘recover’ is placed with individuals, families, and mental health service providers – groups who give so much without recompense – there remains a sense of disruption and distress. Burdens that might better be carried by the wider social institution are displaced almost entirely onto the least powerful groups. There is a sense that aspects of governance, policy, discourse and service provision that seek to maintain degrees of authority, efficacy, security and economic viability fail to meet, and sometimes undermine, community needs. There is a sense that powerful corporate bodies conducting transactions and exchanges that seek to reinforce *their* stake in the narratives of *our* lives, whilst exploiting and silencing marginalised people, promulgate divisions within this *archipelago of the mind*, perpetuating a legacy of distress on a grand scale. Where people are ripped off, marginalised, subdued and disempowered, where voices are not heard, needs not met; where physical wealth, capital and power is accumulated and territories are staked out, exchanges remain stifled, and stifling. Our communal wellbeing cannot be ‘accumulated’ but involves an aesthetic endeavour through which we “keep what we’ve got by giving it away”.

The recovery paradigm, with its holistic vision, attends to ethical matters of civility and exchange relevant to our entire social system, both local and global. Taken to its full extent, this ‘recovering moment’ challenges us to

“find, measure and assess the various determinants, aesthetic, moral, religious and economic, and the material and demographic factors, whose sum is the basis of society and constitutes the common life, and whose conscious direction is the supreme art” (Mauss1980:8).

Appendix

Recovering Voices

Research by Rowan McCormick

INFORMATION SHEET

I am a student at Massey University conducting research for my MA thesis in Social Anthropology.

The primary purpose of my project is to find out how relationships might affect and be affected by the experience of mental illness. I want to gain an understanding of some of the perspectives and experiences of people whose lives are in some way affected by mental illness. This could include people with personal experience of mental illness, family and whānau, and carers.

Project Procedures

Participants will take part in two one-on-one interviews, each lasting up to 1-½ hours between the months of June and August, 2008. During the initial interview I would like to discuss a range of issues relating to social aspects of mental health. The follow up interview will be used to discuss any issues that might stand out or require elaborating from my first round of interviews.

Interviews will be conducted at a location convenient to participants – either at your home, an interview room at Massey University in Albany, or at some other preferred convenient place. Transport costs to local participants will be reimbursed.

Interviews will be recorded, and I will be transcribing them personally. All measures will be taken to ensure that your identity remains confidential throughout the research process, including the use of pseudonyms, and adjustment to any identifying personal or family details in both the interview transcriptions and in my written thesis.

Participants should be informed that people reading my thesis who know of someone involved (such as a family member or friend) may recognize that person in the writing. A process of consultation will take place to best ensure participants are well informed, and take part in a manner that they are happy with.

A copy of the typed interview transcript will be available to participants on request, as well as the opportunity to amend or withdraw their statements in part or entirely before the end of October 2008. A summary of findings will be available to the participant, who will have the opportunity to request changes to this.

All recordings, transcriptions and information about participants will be held securely on private premises. At the conclusion of my research these will be locked in a storage facility at Massey University for ten years, after which time they will be destroyed.

Participants' Rights

You are under no obligation to accept this invitation. If you decide to participate, you have the right to:

- decline to answer any particular question;
- withdraw from the study (before August 2008);
- ask any questions about the study at any time during participation;
- provide information on the understanding that your name will not be used unless you give permission to the researcher;

- be given access to a summary of the project findings when it is concluded;
- ask for the recording device to be turned off at any time during the interview.

Participant Support Processes

Although the risks of this research process have been assessed and are considered to be minimal, you may wish to seek help or advice regarding any issues discussed in the interview.

You are welcome to have a support person or persons, or family member/s present at the interview. You may wish to have a support person contactable by telephone.

It is suggested that you consider how taking part in such research might affect or concern other people close to you, such as family members or colleagues, and I encourage you to discuss any issues with such people, and with myself.

You may also wish to contact Supporting Families, a non-government organisation working with families where a member has experience of mental illness. Supporting Families has a comprehensive library and a range of resources, as well as trained fieldworkers and peer support workers who would be best able to discuss any related issues or concerns that arise.

Contact: Supporting Families
 Ph Auckland: (09) 378 9134
 Ph North Shore: (09) 440 9812
 Web: www.sfauckland.org.nz
 Email: admin@sfauckland.org.nz
 Address: Fellowship House
 423 Great North Road
 PO Box 78-122, Grey Lynn
 Auckland

Project Contacts

Please feel free to contact me or my supervisors with any questions or concerns you may have. We can be reached through the contact details listed below.

Researcher: Rowan McCormick
 Supervisor: Graeme MacRae
 Supervisor: Barbara Staniforth

Committee Approval Statement

This project has been reviewed and approved by the Massey University Human Ethics Committee: Northern, Application 08/011. If you have any concerns about the conduct of this research, please contact Dr Denise Wilson, Chair, Massey University Human Ethics Committee: Northern, telephone 09 414 0800 x9070, email humanethicsnorth@massey.ac.nz.

My Year Recovering Voices

Summer 2007-2008

- Making enquiries into mental health.
- Attend 'Laugh Yoga'
- Partake in Men's Group for well-being and life change.
- Mailing list for Raeburn House, Takapuna.

February 2008

- Signed up to Mental Health Foundation library and emailing list. Mount Eden.
- Supporting Families Membership: gained access to resources, library, mailing list. Grey Lynn.

March – May

- Applications for ethics approval with Massey University Human Ethics Committee (MUHEC) – approved on third attempt.
- Recruit and commence interviews.
- Attend Supporting Families fortnightly support groups.
- 3 & 4th April – Mental Health and Social Work Block Course. Massey University, Albany.

June

- 14th – Seminar: John Raeburn: Spirituality in the 21s Century. Takapuna.
- 25th – Family Participation Forum: First Aid for Families and Carers summit. Mount Albert.
- 28th – Practical Tools for Wellness: The Experience of Hearing Voices. Point Chevalier.

July

- 8th – MOSAIC: steering group to establish services for children of parents with mental illness and addiction issues.
- 9th – Law and Mental Health for Families and Whānau. Auckland District Health Board. Point Chevalier.
- 24th – Anxiety, The Silent Disability. Phobic Trust of New Zealand Inc. 5th International Conference. Takapuna.

August

- 21-22nd – Mental Health And Social Work block course. Massey University, Albany.

September

- 2 – 5th – TheMHS 18th annual conference; “Be the change you want”. Auckland.
- 6-7th – Supporting Families in Mental Illness Summit. Wellington.

- 14th – World Hearing Voices Day.
- 17th – “Talk with a Buddhist monk”. Discussion about mental health. Chiang Mai, Thailand.

October

- 5-11th – Mental Health Week, NZ.
- 7th – Stigma and Discrimination Discussion. Like Minds and Supporting Families Avondale.
- 9th – Supporting Families support group – Merle Lambert from “The Health and Disability Advocacy Service” discusses family and patient rights.
- 10th – Designing Recovery – Service Users tell their stories (conference). AMHS (Connect), Equip Rodney. Orewa.
- 25th – Psychiatric Survivor’s Education Day. Point Chevalier.

November

- Finish Interviews.
- 17th – Supporting Families Annual General Meeting.
Speaker: Dr. Aaron O’connel – “Early Intervention in Psychosis”. Ponsonby.
- 20th – Stress Management for Family and Whānau; Some Cognitive Behavioural Therapy strategies. Supporting Families and Equip. Mairangi Bay.
- 23rd – Solace Candle Ceremony for Family and Whānau who have lost a loved one to suicide. Grey Lynn.

December 2008

- 4th – “Supporting Families - Peer Support For Families” training day. Glenfield.
- Writing Thesis.

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