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We're all a little mental here:  
Creating positive change through mental health advocacy in  
New Zealand

A thesis presented in partial fulfilment of the requirements for the  
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Samuel Gareth Brown

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## **Abstract**

The following paper explores mental health in New Zealand, and argues for further positive change to occur in this area. This argument is derived from the interviews I undertook with mental health advocates, who seek positive change for consumers through their day-to-day work. My own experiences as a mental health consumer also inform this paper, and position me as both a researcher and advocate. Data analysis takes the form of hermeneutic phenomenology, as this method privileges the advocates narratives, which are typically minimised by mental health specialists. Theoretically, these narratives are analysed through the lens of Foucauldian social constructionism, in order to show how the current dominant biomedical discourse has come into being, and also how this discourse can be challenged, as it represents one of the largest barriers to positive change for mental health in New Zealand.

## **Acknowledgements**

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## Chapter One: Researching mental health in New Zealand

### Introduction

My life to date has been punctuated by periods of mental distress, and a raft of associated outcomes. At times these outcomes have necessitated the assistance of various specialists<sup>1</sup>, as I sought answers as to why I seemed to suffer disproportionately in comparison to many others around me. Initially, the majority of answers I received came from biomedical specialists<sup>2</sup>, who tend to be the first port of call when people have mental health<sup>3</sup> concerns. These well intentioned people diagnosed me with various diseases, and prescribed drugs<sup>4</sup> to fix my apparently broken brain. Without any reason to question otherwise, I spent several years believing what these specialists had told me, and it wasn't until more recent times that I began to investigate if their knowledge was as 'truthful' as they claimed. These investigations introduced me to the works of Foucault, whose concepts dominate the theoretical analysis applied throughout this paper. In simple terms, within Foucault's works I found that the widespread acceptance of knowledge produced by biomedical specialists as 'truthful', infuses this knowledge with power which reconstructs both dominant discourses and subjects.

This finding subsequently evolved into a major aim of this work, which is to investigate how the dominant discourse of biomedicine that underpins mainstream mental health practices has come into being, and the practices and consumer outcomes it is now intertwined with. Furthermore, as I found that such outcomes are typically negative for many mental health consumers<sup>5</sup>, I also aim to situate alternative discourses which are counter to the dominant discourse of biomedicine, as it is through such

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<sup>1</sup> People who have undertaken advanced training to work with people who have mental health concerns. Specialists may be psychiatrists, psychologists, counsellors, or mental health nurses, although other roles may fall under this categorisation.

<sup>2</sup> 'Biomedical specialists' believe mental health concerns are biologically determined physical diseases.

<sup>3</sup> I use 'mental health' as a blanket term covering mental health care, treatment, aetiology, systems et cetera. A detailed discussion of this term can be found in Chapter One.

<sup>4</sup> I use the terms 'drug/s' and 'psychopharmacuetical/s' interchangeably in reference to medications prescribed for perceived mental illnesses.

<sup>5</sup> A mental health consumer is person who is obtaining, or has obtained, specialist assistance for a mental health issue.

alternatives that the potential for enacting positive change<sup>6</sup> lies. In order to meet these aims, I draw upon my own experiences, those of professional mental health advocates, who are both my participants and peers<sup>7</sup>, and also a raft of scholarly literature. In doing so I hope to provide a credible account of the multitude of factors and stakeholders intertwined within mental health in New Zealand. I will now provide a brief overview of the chapters which make up this paper, and some of the major issues discussed within each.

As with all proficient anthropological investigations I begin Chapter One by providing some contextual background. In this case such contextualisation situates where mental health resides internationally, and then domestically within New Zealand. I then turn to the methodologies I used throughout this thesis, which I see as an interpretive study of lived experience or hermeneutic phenomenology. Finally, I investigate the main theoretical device employed within this work, that of Foucauldian social constructionism.

Within Chapter Two, I review literature relevant to mental health in New Zealand. More specifically, I discuss changes which have seen the dominant biomedical discourse sway between environmental and biological aetiological influences of mental health, and also public and community care. Following these discussions, I look at various social science orientated papers in order to situate my work, and also to provide some alternate discourses from which positive change may be enacted.

Chapter Three provides further context in relation to mental health in New Zealand, and specifically reflects the main issues my peers raised during the course of our work together. This contextualisation shows (amongst other issues) some of the outcomes of biomedicine dominating mental health, and also some legal issues which arise as a

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<sup>6</sup> Positive change in relation to mental health care involves consumers gaining the best possible information and choices available, so they have every opportunity to live fulfilling lives.

<sup>7</sup> I consider the participants in this research to be peers, and shall refer to them as so henceforth, as we share common mental health experiences, and seek positive change in relation to mental health through our various roles. As such, I consider myself an advocate through both the academic work I produce, and the dissemination of knowledge around mental health with people I interact with.



result. I also discuss some alternatives to biomedicine, which again exemplify sources of non-compliant resistance to the dominant discourse.

As I am the lens through which this paper's data is interpreted, I begin Chapter Four with a personal narrative in order to situate my perspectives and conclusions in relation to mental health in New Zealand. Following this narrative, I begin the presentation and analysis of transcripts which continues throughout the following two chapters. Within Chapter Four though, I discuss what makes my peers and me a group, as we are a minority in terms of mental health consumers, with specific qualities that have allowed us all to question the dominant biomedical discourse in our own ways, and work as advocates for positive change.

Chapter Five looks at some experiences my peers have had as inpatients within mental health facilities, both public and private. Such discussions accentuate the negative outcomes many consumers experience due to perpetuation of the dominant biomedical discourse. I then give an overview of some alternative ways to maintain wellbeing, as the promotion and utilisation of such alternatives provide means by which positive change may be enacted.

Chapter Six covers some of the major barriers to positive change in relation to mental health in New Zealand as discussed by my peers and me. The primary issue many were concerned with was the Mental Health Act (1992), as it negatively discriminates against consumers, and subjects many to espoused therapeutic measures, which breach domestic and international covenants. Finally, I conclude this chapter with some further suggestions my peers made in terms of enacting positive change in relation to mental health in New Zealand.

## Broad Global Context

It is certainly a sad time for humankind, with unprecedented numbers of people receiving diagnoses for various forms of mental illness. The following examples highlight this seemingly exponential diagnostic growth, and some responses to this concerning health issue. In 2004 The Global Burden of Disease (GBD) study situated,

neuropsychiatric conditions including depression, psychoses and alcohol use disorders, as the leading causes of disability worldwide, representing a third of all years of healthy life lost to disability among adults (GBD, 2004, as cited in Read, Adiibokah, Nyame, 2009, p. 1).

Consequently, in 2008 The Global Movement for Mental Health was launched with three main objectives: the scaling up of mental health services, protection of human rights, and promotion of research in low and middle-income countries (Minas, Wright, & Kakuma, 2014, p.1). Anthropologists also took note of these growing health concerns, and in 2013 The International Union of Anthropological and Ethnological Sciences held a symposium titled: “Evolving Humanity, Emerging Worlds” (IUAES, 2013). A part of the symposium focused on global mental health (GMH) issues, especially in lower socio-economic countries, where such issues are perceived as widespread (IUAES, 2013, p.204). In terms of a principal contributing factor to the prevalence of mental illness, The World Health Organisation (2013) stated,

In many societies, mental disorders related to marginalization and impoverishment, domestic violence and abuse, and overwork and stress are of growing concern, especially for women's health (p.7).

Such an assertion, particularly when viewed alongside the focus of the Evolving Humanity, Emerging World’s 2013 symposium, highlights the positive correlational ties between mental illness and economic inequality. Several studies verify this link, suggesting that improving income/wealth equality can increase the overall average health of a society (Wright, 2013, Foulds, Wells & Mulder, 2014, and Wilkinson & Pickett, 2011). Despite these indicators, a limited amount of culturally relative

ethnographic work has been undertaken by anthropologists looking at GMH issues in lower socio-economic environments (Kleinman, 2009, p.603). The need for such undertakings is to provide information which may be used in attempts to reduce human rights breaches (against those considered mentally ill) prevalent in such areas. And also to utilise a culturally relative perspective in order to effectively investigate alternate explanations as to the aetiology of mental illness (Read, Adiibokah, and Nyame, 2009, p.11). Cultural relativism is an important 'tool' used within my thesis, as the dominant biomedical discourse, which is derived from psychiatry, ignores alternate models of health. As such, in the following chapter I discuss two models of health which encompass a far wider range of aetiological influences in terms of mental health, and therefore provide a wider range of potential treatment modalities. In relation to domestic context, I now turn to the main broad scale issues underpinning mental health in New Zealand.

### **Local context: A snapshot of broad scale mental health issues in New Zealand**

Within New Zealand, the dissolution of the welfare state and economic restructuring involving the implementation of neoliberal ideologies has added to increasing levels of poverty and inequality (Waldegrave et al. 1995, Jamieson 1998). According to the most recent data taken from the 2013 Credit Suisse Global Wealth Databook, 44,000 people hold more wealth than three million other New Zealanders (Suisse, 2013). Further to this, in a 2014 study researching the "association between material living standards and psychological distress", Foulds, Wells and Mulder (2014, p.1) found that "the prevalence of high distress increased steeply with decreasing living standards". Therefore as "46.6% of the population of New Zealand are predicted to meet criteria for a disorder at some time in their lives" (Ministry of Health, 2006, P.5), it seems plausible to suggest that a large number of people endure sub-standard material living standards which negatively impacts their mental health.

Whilst economic inequality influences the numbers of people who are diagnosed as having some form of mental illness, the distribution of such illnesses is also unequal. Several studies have found a higher prevalence of mental illnesses amongst woman,

Maori, and Pacific Islanders within New Zealand (Ministry of Health, 2006, Ministry of Health, 2014). Similar disparities were also discovered within a study undertaken in New Zealand by Fergusson et al. (2005), who found that “those who are not exclusively heterosexual are an at-risk population for mental health problems” (p.979).

Overall, these unequal distributions show that the people in New Zealand most likely to receive a mental illness diagnosis come from lower socio-economic backgrounds and minority groups. Given this finding, it seems that many mental illnesses are more symptomatic of oppression and marginalisation rather than biological diseases in and of themselves. The methods I employed in accessing and collecting data which further reinforces these conclusions is now discussed, followed by relevant ethical issues relating to this project.

## **Methodology**

### **Introduction**

Throughout this section I discuss the mixed methods I employed to ethically access, collect, analyse, and present data. As I prefer qualitative measures, quantitative data is only used to show the gravity of mental health concerns both globally and locally. Whilst such data serves this purpose well, it is limited by its inability to convey the experience of living in New Zealand amongst the multitude of factors that contribute to so many of us struggling with mental health concerns. As such, qualitative approaches dominate my research methods, including data sourced through both semi-structured interviews, and also my own experiences. Consequently, as I may be considered an ‘insider’ within this research, I discuss the ethical issues involved with such a positionality, and the utilisation of personal experiences as data sources alongside reflexivity. To begin with though, I provide some background on the technique of snowballing which I employed to recruit participants.

## Recruiting participants

With this project still in its infancy, my supervisors and I agreed that if I wanted to find out about mental health issues in New Zealand an important source of data would be those who work as advocates<sup>8</sup>. This is because these people have intricate knowledge of mental health issues, derived from both lived experience and also their roles as advocates. In initiating my research, I was initially unsure of the scope of these roles and what exactly they entailed, as various agencies provide advocacy services within the mental health sector both publically and privately. With internet research proving rather fruitless, I decided to call a peer support worker<sup>9</sup> I had met the year prior for some guidance. In our conversation he explained that most mental health advocates operate at either a systemic or individual level, but made it clear that not all would adhere to such a strict dichotomy. He also recommended a mental health advocate to contact, as he believed she would be interested in talking to me about my project. With some trepidation, I plucked up the courage to contact her, and to my relief our conversation went really well. Despite feeling that I was out of my depth discussing mental health issues, I found that my perspectives were shared within our conversation, particularly after discussing our personal experiences. As our discussion came to a close, she suggested some other advocates I could contact, and also some literature to look into. Needless to say I was rapt with such a positive start to my research and it was from this point that the snowball sampling began.

Snowball sampling is a simple data accessing method which involves accessing informants “through contact information that is provided by other informants” (Noy, 2008, p.329-330). I chose to employ this method of sampling as it is known to provide easy access to a broad range of participants (Noy, 2008, p.330).

Retrospectively, this proved to be the case, especially because my initial contact was

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<sup>8</sup> I have purposefully avoided defining advocates within this paper as their roles were not central to the discussions we had. As such, I allow their narratives to provide an understanding of what they do through how they see mental health issues we covered in our work together.

<sup>9</sup> The main undertakings peers support workers engage in are “advocacy, connecting to resources, experiential sharing, building community, relationship building, group facilitation, skill building/mentoring/goal setting, and socialization/self-esteem building” (Jacobson et al., 2012, p.1).

so well respected her referrals put me in touch with other experts<sup>10</sup> who became invaluable in my research.

### **Data collection methods**

In terms of data collection methods, the primary approach I chose involved single semi-structured<sup>11</sup> interviews, which were scheduled in advance my peers' choice of location and time. I employed this method as I realised that the interviews may involve discussions of personal issues pertaining to mental health, and as such I did not envisage more formal methods (such as structured interviews) would allow me to build rapport with people. The necessitation of rapport building was but one aspect of the interviewing process I researched prior to undertaking fieldwork as I wanted to be professional and ethical in my approach. As such, I read various works like DiCicco-Bloom & Crabtree's (2006) article on undertaking qualitative research interviews, and Leech's (2002) work on semi-structured interviews. Rather than feel more confident and prepared by reading these works, it seemed the more research and planning I did the more nervous I became. Despite my nervousness, the day came when I had to meet with my first peer to conduct my first interview. As with many experiences I have had it was nothing like I had anticipated it would be, and better in every way. I found that because of my personal experiences of mental distress I was easily able to relate to the advocate I spoke to, and thanks to the research I had done I was adequately versed in both the specialist language and main issues pertaining to mental health. With each interview I undertook my confidence blossomed, and I felt I was able to really connect with my peers due to our similar experiences and perspectives as mental health consumers.

Finally, in order to undertake this research both ethically and respectfully, I undertook a small amount of collaboration with my peers. This entailed offering them the opportunity to have the final say on what would be included in the data

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<sup>10</sup> 'Experts' in this context refers to those with lived experience of mental health concerns who work in the mental health field.

<sup>11</sup> "In semi-structured interviewing, a guide is used, with questions and topics that must be covered. The interviewer has some discretion about the order in which questions are asked, but the questions are standardized, and probes may be provided to ensure that the researcher covers the correct material" (Harrell & Bradley, 2009, p.27).

chapters, and provide input on any changes they felt were necessary. To this end, I provided each of them with individualised draft copies of the data chapters for their input, so that no one could view anyone else's interview transcriptions until each had approved the content. In presentation of these transcriptions, I have used pseudonyms in place of my peer's real names to ensure anonymity and confidentiality were maintained.

### **Data Analysis: Hermeneutic Phenomenology**

I consider my peers to be experts in their own lives, and as advocates they hold unique positions through which to view issues pertaining to mental health. As such, I have chosen the method of hermeneutic phenomenology to interpret the knowledge provided during our work together, as it privileges lived experience. In simple terms, hermeneutic phenomenology focuses on interpreting peoples' subjective experiences, and then attempting to unveil the world as they experience it (Finlay, 2012, p.11). In methodological terms, the steps I took to achieve this within my research are as follows: Initially, interviews were audiotaped and then transcribed which gave me a 'feel' for the data. I then extracted various themes which highlighted experiences and perspectives common amongst my peers. Finally, these themes became the categories under which I coded the transcriptions, and also the basis for the data chapters. My interpretations of the transcriptions are informed by Foucauldian social constructionism, which integrates well with hermeneutic phenomenology as,

To reach an understanding in a dialogue is not merely a matter of putting oneself forward and successfully asserting one's own point of view, but being transformed into a communion in which we do not remain what we were.  
(Gadamer, 1998, pg. 375)

I found these transformations both liberating and taxing at times. Particularly as alongside Foucault's works, I used my own experiences to provide a source of data, as well as a basis for postionality.

## My personal experiences as data sources

As a mental health consumer, and also a student researcher (amongst various other intertwined fluid subject positions<sup>12</sup>), my positioning in relation to this research not only brings into question the dichotomies of insider/outsider and objectivity/subjectivity, but also a range of ethical, personal, and moral issues I feel necessitates further analysis and contextualisation. Consequently, this section provides both context and reasoning around why I chose to utilise autoethnographic styled<sup>13</sup> research methods, including the benefits and risks these approaches present.

In contextual terms, 'traditional' anthropologists undertaking ethnographic research were encouraged to keep ethnography and autobiography separate as Malinowski had done (Behar, 1996, p.19). In fact, from the early 1900s through to the 1950s, a particularly unreflexive style of ethnography, founded upon logical positivism was the norm within anthropology (Foley, 2002, p.473). Despite this, several 'traditional' anthropologists recognised that their own subjective experience and positionality strongly influenced their ethnographic research, which led to what is known as the 'reflexive turn'. Consequently, reflexivity involved the researcher being constantly aware of their own influence upon research, which was inevitably intersubjective. In more definitive terms, Foley (2002) describes reflexivity as a process whereby,

through a constant mirroring of the self, one eventually becomes reflexive about the situated, socially constructed nature of the self, and by extension, the other. In this formulation, the self is a multiple, constructed self that is always becoming and never quite fixed, and the ethnographic productions of such a self and the cultural other are always historically and culturally contingent (p.473).

In contemporary times, several anthropologists have taken the use of reflexivity a step further by turning the anthropological gaze on themselves and producing

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<sup>12</sup> Such subject positions are in a constant flux in relation to the discourses I interact with.

<sup>13</sup> By 'autoethnographic styled' I am referring to the widespread use of reflexivity throughout this work, and also the personal narrative found in Chapter Four.



autoethnographic works. Alongside the reflexive turn, the representational crisis had a hand in this newfound approach, as by exploring the process of producing ethnographic works, their political, philosophical, and poetic implications also came under examination (Tedlock, 1991, p.79). Autoethnography itself is usually closer to art than traditional science, as instead of trying to portray 'facts', the author attempts to convey meanings and emotions attached to the experiences they have lived (Ellis, 2004, p.116).

Although not strictly autoethnographic, my work draws upon methods utilised by autoethnographers, as part of the 'data' I provide is derived from my own personal experiences which also situates my positionality. Subsequently, in combination with the reflexivity seen in my hermeneutic analysis, the dichotomy of insider/outsider becomes blurred within this work. Tedlock (1991) highlights the disparity of this dichotomy in reference to the work of Dalby (1983, as referred to in Tedlock, 1991, p.70), who during fieldwork in Japan, claimed to have embraced her role as a Geisha in both body and spirit. Despite her adoption of this role and integrating effectively as an 'insider' within the Japanese culture, Dalby did not entirely abandon her role as an anthropologist, publishing a memoir of her experience, *Geisha* (1983) (as cited in Tedlock, 1991, p.70). It is such positioning which may be "considered the 'natural' environment of the anthropologist, the in-between, the margin, the penumbra" (Stringer, 2002, p.79). It is this space in which I found myself throughout the course of this project. As such, various ethical issues arose as I attempted to research mental health whilst struggling at times to maintain my own.

## **Ethical issues in utilising personal experiences: Too close for comfort, or just close enough?**

As production of autoethnography frequently appeals to the marginalized, recounting stories associated with such marginalised positions often creates a difficult situation for authors who must relive potentially painful memories (Grant, 2010, p.112, Smith, 1999, p.268). I have experienced such potentialities within various aspects of my research, as I also struggled in dealing with various subject matters which have personal meaning to me. Despite the risks of becoming mentally distressed, I decided it was necessary to include aspects of myself in this paper in order to clarify my positionality in relation to the conclusions that I draw. Also as a form of academic advocacy in which my work shows, that alongside being a mental health consumer, I am also a proficient anthropologist, and a living example of someone who has sought wellbeing outside of the dominance of the biomedical discourse. My positionality as a consumer also allowed me to empathise with my peers during our work together, and understand issues they faced as people pushed to the margins of society.

In terms of the interviews I undertook, there were several occasions where I struggled to maintain my composure and not let my emotions overtake my ability to attend to the process at hand. Put simply, there were many times where I felt like crying, and instead had to bite my lip, take a deep breath and continue. Thankfully these occurrences were infrequent, and the ease with which my peers could discuss personal issues, combined with the humour we shared meant that for the most part I felt comfortable and safe talking with them, and I hope that they felt the same. Safety is critical to ensuring that research is undertaken in a respectful and ethical manner, especially when sensitive information is being shared. As I mentioned earlier, utilising the semi-structured format allowed me to ensure that my peers had adequate space to drive the direction of our interviews, leaving me more time to undertake what I see as my primary function in these processes; listening. Formally, in terms of undertaking ethical research, each peer was given an information sheet

prior to being interviewed, and initially upon our meeting was provided the opportunity to discuss any concerns they may have before signing a consent form.

Overall, despite the challenges of this research I have found several ways of maintaining mental health wellbeing which seem to work for me. These challenges also showed me that maintaining mental wellbeing is an ongoing process necessitating various strategies to be effective. One of these strategies I have found rather cathartic involves the writing process, which allows me to express myself without undue fear of judgement. One pitfall though is that like all linguistic expressions writing is metaphorical in the sense that it always represents something else. This issue becomes compounded when attempting to describe human experience, as its interpretation is often subject to change alongside the inevitable change people experience as fluid beings (this is a complication, not necessarily a negative). As Ellis (2004, p.116) puts it, "the truth is we can never fully capture experience". Subsequently, the following sub-section investigates the issues that language has for this project and the broader field of mental health.

### **Language: The metaphor of mental illness**

"Words are but symbols for the relations of things to one another and to us; nowhere do they touch upon the absolute truth" (Nietzsche, 1996, p.83).

This is not to say Nietzsche (1996) believed that some absolute truth exists, more so that language restricts the ability to "reach beyond the wall of relations" (p.83).

Despite the relational boundaries of language, much of the knowledge conveyed around mental illness is presented as being both objective and truthful. Thomas Szasz (1994, p.34) spent his career trying to ensure that the public be made aware of the pseudo-science he believed psychiatry perpetuated due to its ignorance of this relational boundary. Szasz (1994) encompasses his own position on this issue in a far superior manner than I could hope to by stating,

When people now hear the term "mental illness," virtually everyone acts as if he were unaware of the distinction between literal and metaphoric uses of the word "illness." That is why people believe that finding brain lesions in

some mental patients (for example, schizophrenics) would prove, or has already proven, that mental illnesses exist and are "like other illnesses." This is an error. If mental illnesses are diseases of the central nervous system (for example, paresis), then they are diseases of the brain, not the mind; and if they are the names of (mis)behaviors (for example, using illegal drugs), then they are not diseases. A screwdriver may be a drink or an implement. No amount of research on orange juice and vodka can establish that it is a hitherto unrecognized form of a carpenter's tool (p.35).

I touch upon why such misrepresentations can become accepted as 'truthful knowledge' later in this chapter in relation to Foucauldian social constructionism. Yet in the interim, in the interests of clarity, I believe it is necessary to delineate between the term mental illness as used by specialists, and an explanation of my preferred term, that of mental health.

As the product of several generations of medical speculation and socialisation, mental illness has become indoctrinated within mainstream psychiatry as a term which represents "diagnosable disorders of the brain" (Szasz, 2006, p.24). In contemporary times this biologically deterministic thesis is derived primarily from research undertaken within the United States of America, with its promotion a popular strategy in attempts to reduce stigma through public education (Corrigan & Watson, 2004, p.477). Corrigan & Watson (2004 p.477) believe that although this approach has reduced blame centred on the 'mentally ill', it has had the unwelcome effect of exacerbating other components of stigmatisation. As such, mental illness is commonly associated with various negative connotations, particularly as it is regularly described in psychiatric terms as the opposite of mental health (Keyes, 2005, p.539).

As an alternative to the term mental illness, I utilise the term mental health as inclusive of all people, and all current aetiological explanations for behavioural variations. Although I do not believe that mental illnesses are biological diseases, I do believe mental health has a biological component. I am not suggesting that someone else who believes they have a biologically derived mental illness is wrong, but they

have a different perspective on human behaviour than I do. I also see mental health as a spectrum rather than the polarised position which the term mental illness implies.

At one end of this spectrum resides mental distress, which necessitates prompt intervention as specified by the person experiencing the distress. Admittedly, there may be occasions when the person is not capable of deciding whether they require intervention or not and specialists may need to intervene for the person's wellbeing<sup>14</sup>. Family members, whanau, and/or friends would ideally be consulted prior to any action being taken. At the other of the spectrum lies mental wellbeing, a fluctuating state in which the person in question considers themselves overall to be flourishing, and where they are capable of choosing whether they would require assistance if assessed by a specialist. They are also able, if they chose, to provide assistance to others who are experiencing mental distress. Another aspect of mental health which makes it distinct from mental illness is that it incorporates all aetiological influences not just biology, including: (but not limited to) physicality, emotionality, context, spirituality, and essentially whatever people believe they require to maintain wellbeing without harming others. Current psychiatrically derived explications of mental illness have come about over time through social constructionism as espoused by Foucault (1965). It is to this process I now turn, in order to provide some background as to how mental health has come to be dominated by biomedicine.

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<sup>14</sup> This then becomes an issue of a person's capacity to provide consent to treatment which I discuss further in Chapter Two in relation to the work of Gordon & O'Brien (2013).

## **Foucauldian social constructionism**

### **Introduction**

I have chosen to utilise a social constructionist theoretical framework as I am interested in exploring the social interactions which shape current understandings of mental illness, and contribute to the myriad of negative outcomes many consumers endure. The social construction of mental illness was investigated by Foucault (1965) in his book *Madness and Civilisation*, with the theoretical devices he introduced within the text, such as discourse, power-knowledge, and truth, examined in his later works. It is impossible within the scope of this thesis to discuss such complex works and concepts without oversimplification, and therefore doing them some injustice. Nevertheless, simplified versions of Foucault's main concepts fulfils the aims of this section, which are to show how current understandings of mental illness have come about, and in doing so, situate potential avenues towards enacting positive change. As such, I begin this section with a brief account of some of Foucault's concepts in order to make sense of the historical outline which follows. I then provide an account of the main discourses underpinning modernist psychiatry that have aided in the construction of the biomedical discourse. It is resistance to these discourses through creation and promotion of alternative discourses where an area for positive change exists.

### **Foucauldian concepts**

Whilst history is commonly perceived as a linear progression of events, Foucault (1965, p.371) saw history as a series of disruptions in which societies organise what constitutes knowledge. The methodology Foucault (1965) used to investigate these ruptures is termed a genealogy, and can be seen in his work *Madness and Civilisation*. In simple terms, this work outlines the move in Europe from control of the mentally ill in a more hegemonic top-down sense incorporating physical incarceration, to a more covert form in which patients' agency was controlled. Foucault (1965) showed that at any particular time a set of formational rules exist which dictate what can be stated as truthful knowledge. Foucault (1969) calls these

the rules of discursive formation, and describes the pursuit of identifying them as the 'archaeology of knowledge' (p.155). These concepts were applied in tracing the formation of the biomedical discourse, which Foucault (1965) situates as derived from the discourse of madness. The concept of discourse itself "refers both the production of knowledge through language and representation, and the way language is institutionalised, shaping social practices and setting new practices into play" (Bratich, Packer, & McCarthy, 2003, p.9).

It is important to note that discourse in this sense is not merely a linguistic term but also incorporates both practice and imagery into its definition. As a simplified example of the practice of discourse re/construction, I will give a brief account of an experience I have had of this process. I once had a consultation with a medical doctor as I was not feeling terribly emotionally stable. After a brief discussion of my symptoms I was diagnosed with clinical depression, and subsequently prescribed an antidepressant. Although I proposed that my emotional state was likely due to negative social experiences, and that perhaps positive social influences could improve my negative state, the doctor suggested that my experiences had altered my brain chemistry requiring me to take medication for any hope of 'recovery'. Whether aware of it or not, the doctor was aiding in the reproduction of the biomedical discourse, as his expression of knowledge led to a change in my actions, and also my self-image. Because discourse formation is an intersubjective practice, I also helped to reproduce the biomedical discourse by believing what my doctor had told me was 'truthful' knowledge, and telling others that I felt a lot better for taking my medication as it worked well for alleviating my depressive state.

In doing so I adopted a specific subject position in relation to the biomedical discourse; that of a mentally ill person. Adopting such a position limited my agency<sup>15</sup> as I accepted that I would require drugs for my 'illness'. Consequently, in this seemingly innocuous interaction my subjectivity was altered from a position of aversion to the biomedical discourse to one of acceptance and compliance.

Therefore, knowledge which is constructed and reproduced by dominant discourses

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<sup>15</sup> In my interpretation, agency for Foucault exists in subject's abilities to question discourses, and in doing so create their own subjectivity and reality.

obtains power through its widespread acceptance as 'truth', and the vast range of social practices it influences.

For Foucault power and knowledge are inextricably bound, as any exercise of power constitutes an exercise of knowledge. Further to this, “knowledge linked to power, not only assumes the authority of ‘the truth’ but has power to make itself true” (Foucault, 1977, as cited in Hall, 1997, p. 49). Truth for Foucault (1977) within a given society entails the types of discourse which it accepts and makes function as true; the mechanisms and instances which enable one to distinguish true and false statements, the means by which each is sanctioned; the techniques and procedures accorded value in the acquisition of truth; the status of those who are charged with saying what counts as true (cited in Hall, 1997, p.49). Therefore, the dominant biomedical discourse gains strength over alternate discourses from the creation of specialised 'truthful' medical knowledge, and thus power to influence the actions of its recipients. (Hall, 1997, p.48). Power as conceptualised by Foucault, is not exercised in hegemonic sense as suggested in Marxist terms. Instead Foucault (1971) stresses,

We must cease once and for all to describe the effects of power in negative terms: it excludes, it represses, it censors, it abstracts, it ‘masks’, it ‘conceals’. In fact power produces reality [...] (p.194).

Consequently, as power relationships are strictly relational, “where there is power, there is resistance” (Foucault, 1990, p.95). This is not to say that resistance is always oppositional, simply that power and knowledge inherent in dominant discourses are constantly reconstructed relationally, which is how change occurs for both subjects and the discourses they are subjected to. Such power relationships took place in the construction of the discourse of madness which Foucault (1965, p.2) situates within three critical phases; the renaissance, the classical age, and the modern age of positivism.



## A genealogy of madness

Throughout the renaissance period, madness was engaged and associated with reason (normality). As such, these categorisations were a positive enterprise with those who exhibited behaviours deemed as 'mad' portrayed as possessing a certain wisdom, and a knowledge of the boundaries of the social world (Foucault, 1965, p.5). In Foucault's (1965) terms; "Madness circulates, was part of common decor and language, a daily experience that one seeks to exalt rather than master" (p.6). It was during the 'Age of Reason', around the mid-seventeenth century that Foucault (1965, p.44) suggests madness began to be conceived of as the product of unreason, and an individual failing. This conception was driven by the moral consensus throughout Europe that reason (normality) could be achieved in a society through the suppression and exclusion of unreason (abnormality) (Foucault, 1965, p.44). As such, it was believed that the confinement of those who represented unreason would meet this need to construct 'normal' societies. Such confinement took place initially to address economic and social problems across Europe, as "it was feared the people would overrun the country" (Foucault, 1965, p. 50). These people were the unemployed, whose idleness through moral consensus was seen as a sin representative of unreason (Foucault, 1965, p. p.56).

Because of this moral consensus, the space invented by society to house such sinners (poor, idle) also became filled with 'madmen' (Foucault, 1965, p.57). These 'madmen' were separated from mainstream society, and a great confinement ensued which also placed a range of other socially deviant groups in institutions all over Europe. Those confined were also subject to great cruelties and put on display for the public to view. The purpose of public display of these madmen was to reinforce the consensus that unreason could be controlled and confined. Foucault (1977) calls such public observation the 'public gaze' (p.120). The 'public gaze' refers both to the idea that through such a gaze it is not just the object of knowledge that is constructed but also the observer. In relation to mental illness, this means by designating some people as 'mentally ill', the 'healthy' have a means of reflecting upon, and subsequently creating their own subjectivity. Put simply, without mental illness there is no mental health.

The repression of unreason came at a cost, and in the following period, which Foucault (1965, p.70) calls the modern age of positivism, a new need for labour, as well as a fear of the repressed returning, led to an emptying of the houses of confinement. This evacuation took place in the early nineteenth century, segregating criminals into prisons, and the mad into asylums, with reformers suggesting these changes took place on humanitarian grounds (Foucault, 1965, p.71). The most well-known of these reformers was Philippe Pinel, a French psychiatrist who is portrayed as “having freed the insane from their chains” (Veith, 1957, p.388). Conversely, Foucault (1965, p.259) believed that these reforms were more about streamlining the control of unreason, and the beginning of madness becoming medicalised. This medicalisation<sup>16</sup> saw madness become theorised as a biologically derived illness under the creation of the positivist inspired paradigm of psychiatry which constructed dominant discourses that continue to present day (Foucault, 1965, p.275-276).

### **Dominant discourses underlying modernist inspired psychiatry**

In line with Foucault’s main theoretical concepts that I have discussed, a number of discourses have aided in constructing modernist thought within psychiatry, such as: subjectivity as individualism, hard science/biological language as truth bearing, and the discourse of objectivity (Gergen, 2001, p.803). In terms of the subject as an individual, this discourse stems from early studies into mental illness which saw the human mind as the preeminent object of research (Gergen, 2001, p.804). It was espoused that knowledge of such minds was most effectively discovered through the observations of individual scientific investigators. Typically within the modernist tradition metaphysical dualism is the distinction that is drawn between the inner world of the mind and the material, external world (Gergen, 2001, p.804). Regarding the discourse of language as truth bearing, Gergen (2001) suggests that “if the individual mind acquires knowledge of the world and if language is the means of conveying the content of the mind to others, then language becomes the bearer of

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<sup>16</sup> “Medicalisation describes a process by which nonmedical problems become defined and treated as medical problems, usually in terms of illnesses or disorders” (Conrad, 1992, p.109).

truth” (p.805). As such, the influence language has upon people is minimized in psychiatric discourse, because it is assumed to be an unproblematic medium for transmission of observed categories and reasoned theories (Lewis 2000 p.74). All of these espoused discourses have aided in constructing the dominant biomedical discourse and are potential areas for resistance through continued critique of their truth claims.

## **Conclusion**

Thus far I have situated the need for positive change within mental health in New Zealand, which also substantiates the need for my research to be undertaken. Such a need is further reinforced throughout this work by my personal experiences, those of my peers, and a raft of literary sources. I also outlined the methodologies I used in accessing and collecting data, and the ethical issues faced as someone who may be considered an ‘insider’ researching potentially difficult human experiences. The issues which arise from the fallibility of language highlighted the concerns of utilising a psychiatric definition of mental illness in categorising certain human behaviours. In contrast to psychiatry’s biologically deterministic diagnostic categorisations, I proposed a holistic way of viewing mental health as a spectrum poled by mental distress and mental wellbeing which is inclusive of biological perspectives and all people. In the theory section which followed I discussed Foucault’s genealogical investigation into the medicalisation of madness, which he proposed came about through social construction of the dominant discourse of biomedicine. In order to situate how this process operates, I then showed how dominant discourses and subjects are constructed and situated a potential area such discourses might be contested and positive change enacted. Specifically I drew attention to the dominant discourse of biomedicine which, as the following chapter shows, asserts truth through the interplay of power and knowledge, and in doing so ignores the perspectives of those deemed mentally ill, and the alternate discourses their voices may represent. Whilst Foucault’s concepts situate a space in which the dominant discourse of biomedicine may be challenged and potentially altered, such an undertaking would necessitate that the discourse be replaced with another which may be equally controlling and excluding. As the following chapter shows, whilst the

biomedical discourse has negative influences, so too have previous environmental discourses in relation to mental health.

## **Chapter Two: From asylums to community care**

### **Introduction**

The following literature review outlines the changes which have occurred within mental health in New Zealand, from the initial beginnings inside asylums, to contemporary times involving community alternatives. Such changes highlight both the dominance of the biomedical discourse in its various guises, and also alternate avenues where positive change may be sought. In initiating these discussions I provide a historical overview of New Zealand's asylums, with specific detail centred upon the Otago region, with content reflecting the geographical beginnings of these institutions, and also the narrow range of literature available. Interestingly, despite the discursive dominance of biomedicine with medical specialists at the helm of such institutions, environmental<sup>17</sup> influences on human behaviour were a significant consideration seemingly ignored in contemporary times. Such considerations were made alongside moral assumptions which were reflected by the practices within New Zealand's only private mental institution, Ashburn hall.

Despite some benefits for patients within both private and public institutions, in line with international trends towards community care, deinstitutionalisation became a priority for governments throughout the 1970s and 1980s. Overall, deinstitutionalisation was a major failure, as a lack of adequate services and specialists meant that many patients were abandoned. It was around this period too that the international consumers' movement began to gain momentum. I discuss this movement here in order to show previous efforts made towards positive change as such efforts situate ways change may now be sought.

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<sup>17</sup> Environmental influences are derived from (but not limited to) social, cultural, economic, and spiritual sources.

## **New Zealand's Asylums**

Whether through optimism or simply a lack of knowledge, professionals, and facilities, throughout the 1850s in New Zealand those classified as mentally insane were placed in jail alongside drunks, vagrants, and convicts for treatment (Bloomfield, 2001, p.22). Due to overcrowding, and at the request of Otago's provisional surgeon, Dr Edward Hume, a temporary lunatic asylum was opened in 1863 (Bloomfield, 2001, p.22). As the asylum was only meant to be temporary, a newer, more suitable institution was created at Seacliff in 1889 (Caldwell, 2001, p.35). Since the government required such institutions be run by medical professionals, Dr Frederic Truby King, was the asylum's first superintendent (Caldwell, 2001, p.35). Seacliff itself was a 900 acre farm, and lent itself well to King's theories which situated mental illnesses as initially environmentally determined and then physically manifested (Caldwell, 2001, p.35). King believed that the wellbeing of the mind was wholly determined by the wellbeing of the body, and he set about 'environmental engineering' to ensure his patients were physically nourished (Caldwell, 2001, p.35). Interestingly, it was this theory that led King to found Plunket New Zealand, as he suggested: "that there is no way of dealing with insanity except by commencing with the baby...Bring up a child healthy and normal, make him vigorous, give him a good body, and the probability is that he will never enter an asylum" (Caldwell, 2001, p.36).

Those who were institutionalised included vagrants, alcoholics, epileptics, and many others considered socially undesirable (Caldwell, 2001, p.36). Custodial segregation during the institutionalism era was not only socially accepted but promoted (Caldwell, 2001, p.36). Yet public opinion was divided over how individuals should be treated once committed, with one side believing society does its duty to the mentally ill by providing a better environment than they are accustomed to, and the other side "filled with indignation at the apathy and positive treatment given towards sufferers" (Caldwell, 2001, p.37). Favouring the opinions of the later section of society, many asylums suffered from overcrowding, an issue which owed to the lack of minimum space requirements, which was not altered until 1891 when a law was passed requiring 600 cubic feet per person (Caldwell, 2001, p.38). Other environmental factors in these early years also contributed to the unpleasant living

conditions, such as a lack of clean air, water, bedding, and adequate sewerage/drainage (Caldwell, 2001, p.39). Positive change regarding these issues were fervently advocated for by King at Seacliff, and at the turn of the century his emphasis shifted to focus on classification of patients, an increase in patients liberty, and 'agitation' for early and voluntary admission which did not exist at the time (Caldwell, 2001, p.45).

Classification ensured appropriate separation of mental patients according to types of illness and severity. The criteria for entrance into a lunatic asylum was laid out in the 1882 Lunatics Act which stipulated that a suspected lunatic had to be examined by two Justices of the Peace, or a Resident Magistrate, assisted by two doctors (Reed, 2001, p.50). The 1882 Lunatics Act also recognised criminal lunatics as a group, owing particularly to the perception at the time that mental illness was often synonymous with violence (Adams, 2001, p.66). Intriguingly, Captain Arthur Hume who was the inspector-general of prisons wrote in an 1895 report that "keeping persons of weak mind shut up in prisons, with no work, no idea when they might be liberated, and only criminals to associate with and talk to, is about the surest way of making lunatics of them in the shortest time" (Adams, 2001, p.67). The government took Hulmes report seriously, and in 1906 Larnarch's castle became New Zealand's first asylum for the criminally insane (Adams, 2001, p.67). Overall, the incarceration of those considered mentally ill in state run institutions reveals more about what constituted socially acceptable behaviour in New Zealand than it does about mental illness (Holloway, 2001, p.164). As the following section shows, these revelations were not restricted to incarceration within public institutions.

## **Class segregation: NZ's only private asylum**

Ashburn Hall, New Zealand's first and only private asylum was opened in 1882 by Mr James Humes and Dr Edward William Alexander (Somerville, 2001, p.83). Dr Alexander was a strong supporter of the need to provide an institution where class segregation could be achieved. In 1864 Alexander stated; "To mix indiscriminately, men or women holding good positions, with the insane poor, would be revolting to the feelings of the friends, and detrimental to the recovery of the former class" (Somerville, 2001, p.87). Similarly, as reflected within the data chapters, many mental health services in contemporary times are only accessible by those with the financial means to afford them.

In terms of entrance requirements for Ashburn Hall, as with the public asylums, family of those incarcerated played a large part in their initial diagnosis, and then instigated legal processes to formalise their decision that their relative was no longer of sound mind (Somerville, 2001, p.91). Overall, "married people were under-represented compared to the general population, but Ashburn Hall saw far fewer single men and more single women" (Somerville, 2001, p.95). Exercise and the need to work were also strongly encouraged at Ashburn Hall, with a majority of the outdoor work undertaken by men whilst women usually stayed inside to cook and clean (Somerville, 2001, p.96). Such opportunities came under the treatment regime known as moral therapy popularised in the late nineteenth century (Somerville, 2001, p.101). The idea of moral therapy being, that by giving patients a daily experience of morally appropriate behaviour they would gain enough self-discipline to overcome their illness (Somerville, 2001, p.101).

## **Deinstitutionalisation**

After the Second World War ended, New Zealanders began to acknowledge the existence of heterogeneous expressions of human behaviour, with mental illness gaining more public attention as many veterans suffered psychological issues (Kavanagh, 2001, p.169). Throughout the 1950s and on into the 1960s vast sums of public monies were directed into the modernisation of mental institutions, with

these new community styled facilities labelled 'mental hospitals', rather than insane asylums (Kavanagh, 2001, p.169). As a definitive sign of these changing times, Seacliff stopped taking admissions in 1964, and finally shut its Victorian styled doors in 1972 (Kavanagh, 2001, p.169). Policy also reflected the changing face of mental illness with the 1961 Mental Health Amendment Act making it easier to both admit and release patients, whilst also establishing day wards in general hospitals which was effectively the first major step towards caring for the mentally ill outside of large scale institutions (Kavanagh, 2001, p.172). New methods of reintegrating patients into mainstream society were developed during the 1960's, yet many still 'relapsed' due to their espoused severe institutionalisation. Regardless of such institutionalisation, the 1970's saw a continued push towards community care beginning with The Department of Health decentralising control over mental hospitals to local hospital boards (Kavanagh, 2001, p.175). 1972 saw a survey undertaken by the Otago University Psychology Department which suggested that a majority of Otago residents were keen to see increased community based care (Kavanagh, 2001, p.175). Combined with poor publicity for the local Otago mental hospital, dubbed "Cherry Farm", the fate of New Zealand's large mental institutions were all but sealed, and so began the era of deinstitutionalisation and community care which the 1980's are now notorious for (Kavanagh, 2001, p.177).

The closing of these large scale institutions occurred at a pace far in excess of community based resources, and ignored the needs of many patients involved. As Brunton (1985) suggests in relation to professional and social thinking; "there has been a tendency for institutional and community aspects of care of the mentally ill and the mentally handicapped to be seen as mutually exclusive care alternatives, or the positive and negative end points on some continuum of care" (p.44). Brunton (1985, p.45) goes on to propose that such thinking can be attributed to cyclical attempts at care for the mentally ill dating back to the seventeenth century, which was hailed as the first great era of community care. This position is reiterated by Alderidge (1979) who suggests: "There are very few, if any, ideas on the public and institutional care of the mentally disordered which have not been around at least once before" (p.321). Such perceived 'cycles' reinforce Foucault's assertion that for



one discourse to dominate other alternate discourse, and the power/knowledge which they consist of, must be subjugated. This assertion is critical to remember when advocating for changes in the biomedical discourse in New Zealand, as the new discourse to take its place will have to be as inclusive of all people. This is why utilising a discourse which incorporates my understanding of the term mental health, and the holistic health models I discussed is all important in seeking positive change.

### **The Mad Movement**

Throughout the 1970s and 1980s a foundational movement for consumer action took hold which is known as the antipsychiatry movement, driven by psychiatrists such as Ronald Laing, Thomas Szasz, Jacques Lacan, and Franco Basaglia. In basic terms, the antipsychiatry movement challenged the biomedical model of mental disorder and also the concept of mental illnesses itself (Dain, 1989, p.8). Although anti-psychiatry proponents produced a substantial amount of literature critiquing psychiatry, less emphasis was placed on representing the needs of consumers.

Subsequently, during the 1970's, in the atmosphere of the American civil rights movement these survivors then began what is known as the consumer's movement (O'Hagan, 1993, p.27). A phenomenal woman who played a major role in the beginnings of this movement in New Zealand, and continues to work tirelessly as a mental health advocate, is Mary O'Hagan (2014). O'Hagan (2014, p.134-135) was instrumental in the movement's humble beginnings whose involvement stems from her own experiences as a consumer, and more specifically her participation in a Mental Health Foundation conference which prompted her to start a survivor advocacy and support group. In O'Hagan's (2014) own words:

At the conference I discovered the door to a new world that had been closed off to mad people by centuries of discrimination. It was an empty world with very few travellers in it-a world where we mad people could organise and stand up for ourselves, where we met as equals with professionals and other sane people. And I was determined to open its borders (p.135).

After initially contemplating a collaborative effort with a pre-existing group led by a mental health professional, O'Hagan (2014) decided to form her own, as she believed that the "structural inequality in their (professional) relationship with mad people destroyed their ability to share power" (p.141). And so in 1987 the first meeting of 'Psychiatric Survivors' took place, where like-minded people came to discuss personal experiences of psychiatric mistreatment and plot a course for change (O'Hagan, 2014, p.161). O'Hagan (2014, p 151, 161) draws a comparison between the beginnings of the survivor movement and the resistance seen in other minority groups at that time such as Maori and Feminists. She suggests that like those in the mad movement, Maori sought self-determination and partnership with the dominant group (O'Hagan, 2014, p.151). Similarly, feminists desired the acquisition of power and knowledge production, which for mentally ill people lay firmly in the hands of sane men in suits who have the 'right' knowledge (O'Hagan, 2014, p.161).

Desiring to research the efforts of consumer-run projects abroad, O'Hagan (2014, p.189) applied for and was awarded the Winston Churchill travelling fellowship in 1989. She visited the USA, Britain, and the Netherlands, and spoke to many survivors who had endured similar experiences of mistreatment to those in New Zealand (O'Hagan, 2014, p.191). Interestingly, despite feeling powerless and devalued as inpatients within psychiatric hospitals, many survivors O'Hagan (2014, p.191) spoke with did not believe that community based services would fare much better. These people were also a part of the international mad movement, and utilised critical analysis in understanding and communicating their experiences. O'Hagan (2014) found that these analyses focused on what she describes as the "tripartite drivers of the traditional mental health system- the medical model, the use of biological sledgehammers such as drugs and electric shock therapy, and forced treatment" (p.192). This perspective was the basis for critique made by many within the mad movement, and continues to be of central concern to many consumers, myself included. Yet O'Hagan (2014, p.196) believed that such critiques were limited by their lack of foresight about what would realistically replace a medically dominated mental health system.

Whilst interviewing a psychiatric survivor in Utrecht, O'Hagan (2014, p.197) found her answer. The man suggested that for there to be positive change in the area of mental health there would need to be a culture of madness in which people felt it was alright to be mad, and that such ways of being may actually have some positive attributions/connotations rather than be seen as conditions to 'get well' from as the medical model proposes (O'Hagan, 2014, p.196). Basically this proposal means empowering people to be proud of who they are regardless of how non-mad people may perceive and/or treat them. As O'Hagan (2014) suggests; "it feels far more creative and effective to generate a culture of madness than to tinker with or destroy the culture of sanity and its guardian-psychiatry" (p.199). Counter to this idea of creating a culture of madness, O'Hagan (2014, p.199) met many survivors who defined themselves in psychiatric terms even if they were opposed to psychiatry. Overall, the research trip showed O'Hagan (2014) that a majority of survivor-run services mimicked many of the negative qualities associated with the biomedical model in their authoritarian hierarchies and continued to oppress clients, prompting her to ask "How do survivors ensure they provide a true alternative and don't end up like their oppressors?" (p.207). Her answer was to be aware that such hierarchical adoptions may occur, and therefore to consciously make efforts to avoid such occurrences (O'Hagan, 2014, p.207).

A year passed since the completion of O'Hagan's (2014) research trip, and she was asked to organise a series of meetings geared towards establishing "an international network of consumers and survivors at an international mental health conference" (p.207). The meetings themselves were marred by divisions and disputes between the various nations represented, with O'Hagan (2014, p.208) spending much of the week playing mediator. Nearing the end of the week, prompted by support from the large Mexican contingent, O'Hagan (2014, p.208) put her name forward and was elected as the first chair of the World Network of Users and Survivors of Psychiatry. Within this role O'Hagan (2014, p.209-211) was invited to several international conferences and meetings where she promoted the mad movement, and alternative knowledge and services to the biomedicine dominating most countries. Utilising these international experiences, O'Hagan (2014, p.219) became a New Zealand

mental health commissioner in 2000. O'Hagan had previously done work for the Commission in the form of recovery content for the publication known as the Blueprint. The Blueprint was the first official document which acknowledged that a recovery approach needed to be utilised within New Zealand's mental health services. Recovery in this context meaning "living well in the presence or absence of our mental distress" (O'Hagan, 2014, p.219). One of the problems with utilising recovery as a term to encompass this subjective account of mental distress is that recovery also has a medical meaning in which "a cure or reduction of symptoms [occurs] as a result of treatment by experts" (O'Hagan, 2014, p.219). Yet despite this semantical issue, the blueprint was able to secure greater funding for community based mental health services (O'Hagan, 2014, p.219).

Despite modest improvements being gained for consumers, the Mental Health Commission eventually reverted to pandering to the needs of those representing the biomedical model (O'Hagan, 2014, p.249-250). In summarising her experiences attempting to affect positive change within the area of mental health O'Hagan (2014) states:

After I stabilised I went looking for other mad people who, like me, no longer believed in the world according to psychiatry. We organised and challenged mental health professionals to change and gradually, many of them did. The discourse of the mad movement trickled into the discourse of the mental health system and drop by drop its logic and language began to change. But it didn't change nearly enough (p.218).

Such an assertion shows just how change resistant dominant discourses can be, and the need to create alternate discourses such as the works that follow.

## **Social science orientated research**

### **Introduction**

The scholarly works discussed within this section show some previous efforts made towards researching mental health, and subsequently situate the contributions my research makes in this area. Each of these works are forms of academic advocacy, as they represent alternate discourses to the dominant biomedical discourse. Yet where my work is unique in this sense is that it makes the desire to create alternate discourses an explicit need, rather than an unknown or unacknowledged consequence of its construction. Further to this, my utilisation of Foucauldian theory in terms of power relations shows how the dominant biomedical discourse is continually reconstructed, and some of the consequences of this process for the stakeholders involved. Such consequences accentuate the need for positive change now, rather than advocating for further research, or interdisciplinary discussions, as many of these works propose.

### **Mental Health research**

Social anthropologist Anne Appleton (2000) undertook qualitative research in which she interviewed consumers regarding the contributions their narratives can make to how illnesses are understood. Within these interviews Appleton (2000, p.43) found her participants felt dehumanised as their narratives were often dismissed by mental health professionals (Appleton, 2000, p.26). In order to improve how consumers narratives are perceived, Appleton (2000, p.39) proposes the implementation of two main elements she suggests are necessary to enact this change. Imagination is the first of these elements, which Appleton (2000, p, 41) suggests can be utilised to “realise empathy”. This need to empathise with those considered mentally ill is crucial, as through this medium ‘others’ may be able to recognise the second of Appleton’s (2000, p.41) elements; existential commonality derived from a reformulation of truth. When seen from this perspective truth around mental illness can be re/constructed by ‘everyday’ citizens (Appleton, 2000, p.41). As I showed within Chapter One, truth is reconstructed by ‘everyday’ citizens through power

relations which maintain dominant discourses. As the dominant discourse involving those categorised as mentally ill is biomedical, it is the truth claims of this discourse which need to be challenged.

Continuing her mental health research, Appleton (2004) created a dissertation more in line with my work which “counters the perceived inadequacies of a solely biomedical approach to psychopathology” (p.ii). Her research was undertaken in Sarawak, Malaysia, where she sought to assess the role culture played in the experience and construction of both psychopathology and psychological wellbeing (Appleton, 2004, p.ii). Appleton (2004, p.263) suggests that rather than a single aspect of culture influencing mental health, there were various cultural, environmental, and biological elements at play. Such a finding reflects the argument I have put forward of the need to abandon the term mental illness in favour of mental health, and to utilise all known aetiological influences and treatment modalities for the best outcomes for consumers.

Reflecting the opening two chapters of this work, Appleton (2004, p.266) questioned whether within ‘developed nations’ “we have lost sight of the connections to each other and our broader context which have a balancing potential”, and if such a loss may “make us more susceptible to psychological illness”. Although, as Appleton (2004, p.266) suggests, answering such a question may be an impossibility, it is likely that the neoliberal mentality she alludes to is a major contributing factor to escalating numbers of people receiving mental illness diagnoses. Overall, Appleton (2004, p.263) argues for culture to be taken into account when assessing psychopathology through the use of ethnographic research. Particularly within ‘developing’ countries as people diagnosed with mental illness within such countries have better chances of a favourable outcomes than in ‘developed’ countries such as New Zealand (Appleton, 2004, p.1).

Investigating some of the personal connections Appleton (2004) spoke of, McCormick (2009) sought to find out “how relationships affect and are affected by the experience of mental illness?” (p.9). In an effort to answer this question, McCormick (2009, p.12) spoke with various people who considered themselves as

recovering from various forms of mental illness. For these people, McCormick (2009, p.151) found that 'wellbeing' came from participation in moral, ethical, and fair exchanges, and suggests that if such exchanges were the basis for social systems such as government, then governance too would be obliged to partake. Common human needs underpinned these 'fair exchanges', and as such bridged the divides between the traditional dichotomies of abnormal/normal, mentally healthy and mentally ill which are prevalent within Western societies. Whilst I agree with McCormick that 'fair exchanges' would likely bridge the divides he mentions, a multitude of barriers exist in the form of dominant discourses that would need to be altered for such changes to take place. As reflected by many of my peer's perspectives, the discourse of risk associated with those categorised as mentally ill is one such discourse requiring change.

This discourse was represented amongst various negative associations Nairn (2003) found in his investigation of media representations of people diagnosed as mentally ill. Nairn (2003) showed that media depictions of mental illness were dominated by representations associated with "dangerousness, criminal violence, unpredictability, and social incompetence" (p.i). Sadly, the same pattern was seen in a documentary designed to reduce stigmatisation (Nairn, 2003, p.i). Overall, Nairn (2003, p.i) argues that such negative representations of mental illness occur because similarly to most 'laypersons', media personnel perceive and represent "mental illnesses as forms of madness". In this context madness refers to connotations of socially unacceptable/undesirable behaviours and beliefs echoing moral issues Foucault (1965) raised, and reasons I covered earlier for segregating those believed to be mentally insane. As such, Nairn (2003, p.ii) believed that in order to enact effective destigmatisation programmes, a new way of depicting mental illness must be found, which both values and empowers personal experience alongside universal humanity. This assertion reflects both the reconceptualization of mental health I provided in Chapter One, and also many of my peers 'perspectives in relation to lessening stigmatisation for those categorised as mentally ill. Whilst such a reconceptualization may lead to positive change, the provision of community care also needs to be questioned.

Driven by personal experiences as a staff nurse at a psychiatric hospital, Warren (1996, p.1) decided to explore the actual work of looking after dependent mentally ill people, and specifically who undertakes this work. Warren (1996) found that much of this work was being undertaken by woman within kinship relations, rather than the assumed 'community', which she suggests is a "fictitious social construction" (p.3). Further to this, many of the woman tasked with undertaking such work were in situations where they would likely need care themselves as they reached later life (Warren, 1996, p.74). As such, Warren (1996, p.74), believes caregiving should be a choice not an imposition for women, as it often creates a situation where one group is cared for at the expense of the other. For these reasons, Warren (1996, p.2) argues, "it is even more important that, in New Zealand, we carry out our own research, rather than develop programmes and implement policies based on overseas data" (p.2). Such a statement reinforces the need for research such as mine to be undertaken, and also assertions many of my peers make regarding the need for the Mental Health Act (1992) to be changed.

## **Conclusion**

Mental health in New Zealand has seen numerous broad scale changes throughout its short history, but has always remained dominated by the biomedical discourse, swinging between state and community care, and environmental and biological aetiological explanations for mentally illness. Socio-economic status also had a large bearing on who became categorised as mentally ill, which as I showed in Chapter One, continues today but is rarely acknowledged. Following global trends of deinstitutionalisation, New Zealand eventually closed all of its state run mental institutions as a cost cutting measure, and instead moved towards community based care. During this period the consumer movement blossomed, and set about enacting broad scale cultural change. Although some progress was made in altering the dominant biomedical discourse and improving outcomes for consumers, the movement lost momentum as it sought greater choice of services for consumers, and neglected to develop a more systemic analysis of the disadvantages people categorised as mentally ill face.



The social science orientated works I discussed offered several suggestions for effecting positive change in relation to mental health, with the need for these changes derived from negative consumer outcomes, as in my work. In discursive terms, all of these works provide alternatives to the dominant biomedical discourse, and as such represent forms of resistance necessary to enable positive change in relation to mental health. Yet they fail to identify the need to challenge the dominant biomedical discourse, and subsequently cement the need for my research to be undertaken. I now turn to further critiques and alternatives involving the biomedical discourse, which directly reflect our<sup>18</sup> understandings and experiences of mental health issues detailed within the data chapters.

### **Chapter Three: Contextualising major barriers to positive change**

#### **Introduction**

Throughout my fieldwork various factors were discussed relating to the dominance of the biomedical discourse, and outcomes for mental health consumers in New Zealand. Consequently, the following chapter is devoted to contextualising these factors, and in doing so highlights the complexities involved in mental health, the multitude of stakeholders who hold varying interests in this area, and also some avenues which may facilitate positive change. To begin with, I discuss the biomedical model and its core tenets around the aetiology and treatment of mental illness. I then outline some ways which biomedicine can be utilised alongside more holistic options. Following on from these options, I discuss two models of health I believe would benefit consumers and service providers alike, as both reflect my peers experiences and perspectives. This discussion then leads into an overview of what commonly occurs when someone decides to seek help for a mental health concern. This typically involves a visit to a general practitioner (GP), followed by either referral to a specialist, and/or prescription of some type of psychopharmaceutical, which reconstructs the biomedical discourse and excludes alternative treatment options.

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<sup>18</sup> The term 'our' is utilised here to denote the views of both my peers and myself.

As an alternative to this, I provide a discussion suggested one of my peers mentioned known as the Tidal Model of Health (Barker & Buchanan-Barker, 2010).

In cases where a person is forced into treatment, they come under what is known as the Mental Health Compulsory Assessment and Treatment Act (1992) (henceforth referred to as the Act). As will be seen in the data chapters to follow, many of my peers have had personal experiences with the Act (1992), and as such questioned its efficacy in terms of the breaches of human rights and negative discrimination it supports. Subsequently, I provide a brief overview of mental health law in New Zealand in comparison with the relevant international covenants. To further contextualise the discussions following this chapter, I next highlight the practice of seclusion utilised in public mental health services. This discussion accentuates just how difficult change can be in the area of mental health, even in the face of seemingly irrefutable evidence that a practice such as seclusion breaches various covenants, and is only semantically differentiated from the torture known as solitary confinement. Discussion of this semantic difference opens the final section of this chapter, in which I show how seclusion is justified through the manipulation of language in concert with the dominant biomedical model, underpinned by risk management measures. Such measures also underpin the Act (1992) and Community Treatment Orders which see certain patients living in the community forced to meet regularly with practitioners, and also to consume any medications prescribed to them. On the whole, whilst many issues of concern regarding mental health in New Zealand dominate this chapter, various avenues for positive change are also seen which provide hope for the future. The real challenge lies in having such avenues implemented.

## **Aetiology, Heritability, and Drugs: What is currently known?**

### **Biomedicine: We're all the same but different...**

Whilst some service providers adopt a mixture of approaches to mental health care, a majority base their treatment measures upon the biomedical model of mental illness founded by psychiatry (Dowell, 2004, p.370-371). Consequently, the biomedical approach currently dominates mental health within New Zealand despite poor outcomes for consumers, which are reflected in our experiences and the literature to follow. So in terms of aetiology, what does the biomedical model actually purport the cause of mental illnesses to be, and what does it suggest are the most appropriate treatment measures? According to Deacon (2013), the biomedical model posits that “mental disorders are brain diseases caused by neurotransmitter dysregulation, genetic anomalies, and defects in brain structure and function” (p.847). Despite claims that mental illnesses are physical in origin, no scientists have identified a biological cause or reliable genetic marker of any kind for any mental illness (Deacon, 2013, p.847). As the following statement from psychiatrist George Engel (1977) shows, such perspectives are nothing new

The dominant model of disease today is biomedical, with molecular biology its basic scientific discipline. It assumes diseases to be fully accounted for by deviations from the norm of measurable biological (somatic) variables. It leaves no room within its framework for the social, psychological, and behavioural dimensions of illness. The biomedical model not only requires that disease be dealt with as an entity independent of social behaviour, it also demands that behavioural aberrations be explained on the basis of disordered somatic (biochemical or neurophysiological) processes (p.130).

The search for the causes of such ‘behavioural aberrations’ as Engels (1977, p.130) termed them, continues in contemporary times, as researchers within the biomedical paradigm seek cures to these espoused illnesses, hoping to find an equivalent to penicillin utilised in treating bacterial infections (Moncrief, 2008, p.24).

Whilst such a cure currently eludes researchers, in the interim various drugs are espoused as sufficient treatments for a wide range of mental illnesses.

### **I don't like the drugs but the drugs like me**

Alongside the failings produced by biomedical practitioners in their search for genetic aetiological determinants, the drugs its proponents produce and prescribe are “generally no more safe or effective than those discovered by accident a half-century ago” (Deacon, 2013, p.847). The most commonly prescribed of these are anti-depressants, about which a broad-scale meta-analysis undertaken by Kirsch et al. (2008) claimed, “the overall effect of new-generation anti-depressant medications is below recommended criteria for clinical significance” (p.260). Not surprisingly then, various studies detail the negative perceptions many consumers have regarding psychopharmaceuticals (Burstow & Weitz, 1988; Everett, 2000; Modrow, 2003; Read, Mosher, & Bentall, 2004; Whitaker, 2002; Hagen, Nixon, & Peters, 2010). Such perceptions were echoed by findings of a recent study undertaken in New Zealand in which over half of the participants reported experiencing adverse effects, most frequently sexual difficulties (62%) and feeling emotionally numb (60%) (Read, Cartwright, & Gibson, 2014, p.67). Overall then, it seems that the way the biomedical approach to the aetiology and treatment of mental illness is applied is inherently flawed. Yet aspects of biomedicine do have a place in assisting people to maintain mental wellbeing, which the following example highlights.

Dr Janelle Sinclair (2014), is a neurochemist and natural health practitioner in New Zealand, providing advice to her clients around the biochemical causes of mental unwellness. Unlike the majority of biomedical proponents, Sinclair (2014, p.1) acknowledges that “mental unwellness can have biochemical (physical), emotional and spiritual causes (or contributing factors)”, and she centres her practice on the biological aspects which are her area of expertise. These aspects include; “hormonal deficiencies, nutrient deficiencies, adverse reactions to food, and toxic overload” (Sinclair, 2014, p.1). Subsequently, after blood testing, the discovery of any underlying contributing factors to a person's mental unwellness can be treated

specifically and effectively (Sinclair, 2014, p.1). Therefore this perspective serves as a source of resistance to the dominant biomedical discourse, as it advocates treatment without the need for psychopharmaceuticals.

### **Models of health: Alternatives to biological determinism**

It is my belief, in line with Foucault (1965) that altering the biomedical discourse through construction and circulation of alternate discourses is an effective way in which positive change can be achieved. As such, two models of health which can be considered alternate discourses are Te Whare Tapa Wha (Durie, 1985), and the social model of disability (Mulvany, 2000). I have chosen Durie's (1985) model due to its simplicity and universality, as it can be applied to any person in relation to their health needs. Te Whare Tapa Wha is an excellent basis for outlining some of the major health requirements people have within its four dimensions. These dimensions are explained here:

A spiritual dimension (taha wairua) recognized the importance of culture to identity as well as the significance of long-standing connections between people, ancestors, and the natural environment. A cognitive and emotional dimension (taha hinengaro) was based on Maori ways of thinking, feeling, and behaving and drew heavily on marae encounters. Taha tinana (physical wellbeing) encompassed the more familiar aspects of bodily health, while social wellbeing was reflected in taha whanau (family aspect) (Durie, 2011, p.29-30)

All four dimensions, acting in unison, were seen by Durie (2011, p.30) as foundations for health and relevant to the full range of health services. Mental health services, for example, should not be so narrowly focused on physical causes so as to ignore spiritual dimensions or social relationships.

Further to this, as I have previously stated, a person's socio-economic status can have a significant bearing upon their mental health. Investigating such contextual concerns is the primary goal of the social model of disability which "demands an identification and analysis of the social, political and economic conditions that

restrict the life opportunities of those suffering from an impairment” (Mulvany, 2000, p.584). Mulvany (2000, p.584) shows that this model focuses upon disabled people’s rights, and also social action and change which may come from these people developing a collective identity. I will investigate these rights further in relation to specific legislation in terms of forced treatment and seclusion practices later in this chapter. In the interim though, I discuss primary health care in New Zealand, which is utilised by the majority of people with mental health concerns.

### **Primary mental health care: Let’s see what the doctor has to say**

As a result of deinstitutionalisation, primary health care<sup>19</sup> practitioners have taken a leading role in the provision of assessment and treatment of people considered to have some form of mental illness. For consumers wanting assistance that have not been forced into treatment under the Act (1992), their General Practitioner (GP) is the most likely first point of contact (Hughes et al. 2006, p.2). As with other primary health care providers, a majority of GP’s approach mental health care “according to principles and philosophies derived from the specialist discipline of psychiatry” (Dowell, 2004, p.370-371). Unfortunately, this means that many GP’s utilise a narrow deterministic approach to the aetiology of mental illness, and promote the effectiveness of chemical cures. As I mentioned earlier, I have been witness to such biologically deterministic attitudes, and was told that such an approach reduced the negative discrimination that consumers are frequently subjected to. Schnittker (2008, p. 1371) suggests that reasoning for such attitudes stems from the idea that tolerance comes from obviating personal responsibility by attributing mental illness to biological derivatives, and in-turn provides the potential for treatment and wellness. Rather than lessen discrimination, Schnittker’s (2008) research found that,

Genetic models may have unexpected negative consequences for implicit self-concept and explicit attitudes of people with serious mental illness. An

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<sup>19</sup> “Primary Health care relates to the professional health care provided in the community, usually from a general practitioner (GP), practice nurse, pharmacist or other health professional working within a general practice” <http://www.health.govt.nz/our-work/primary-health-care>

exclusive focus on genetic models may therefore be problematic for clinical practice and anti-stigma initiatives (p.1370).

Regardless of the reasoning for using biologically deterministic methods, the outcomes for consumers that I summarised in the opening chapter suggest that such methods are not generally successful in assisting in their experiences of discrimination or their mental health concerns. Such failings are evidenced in the work of Ellis & Collings (1997, p.435), who found that a quarter of all those who commit suicide consult with GP's in the week before death, and 40% in the month before, with 50% of GPs failing to recognise cases of severe depression. Although the discussion thus far may seem rather damning of GP's, I must clarify that these findings are generalisations, and that not all GP's operate with such reductionist and deterministic frames of reference. Within the discussions my peers and I had, there are several examples of GP's operating in a far more holistic manner despite their biomedical training limiting exposure to such alternatives.

One such framework which one of my peers brought to my attention is known as the Tidal Model, which "focuses on helping people who have experienced some metaphorical 'breakdown' recover their lives as fully as possible, by reclaiming the personal story of their distress and difficulty" (Barker & Buchanan-Barker, 2010, p.171). In developing the model, Barker & Buchanan-Barker (2010, p.171) drew upon the work of Japanese psychotherapist Morita, who believed that his role was not to try and alter a person through therapy, but more so to assist them to learn from, and give meaning to their life experiences. By drawing on such meaning, Morita et al. (1998, as cited in Barker & Buchanan-Barker 2010, p.171) believed people would then be better placed to respond to any future life challenges they may face. As such, the model accepts the fluidity of the human experience and is holistic so that it can be utilised in working with any person. Overall, despite the deficiencies in GP service provision, the opportunity for consumers to choose to engage their services is still generally preferable to being forced into treatment under the Act (1992).

## Forced assessment and treatment

The Act (1992), alongside other issues covered in this chapter, are far too complex to give adequate analysis to here. However, I will endeavour to outline the main features of the Act (1992) which I see as relevant to the experiences and opinions of my peers, and the aims of my research. In most cases, people receiving treatment for mental health concerns are deemed voluntary patients. Voluntary patients are those who agree to undergo treatment, and have the right to suspend it at any time. In situations where a person's treatment is considered necessary, despite their lack of consent, the Act (1992) may be enacted. Dawson and Gledhill (2013, p.17), produced a comprehensive review of the Act (1992) which they propose serves three main functions: Firstly, it establishes a civil commitment process by which people categorised as mentally disordered can be forced to undergo assessment and treatment; secondly, it regulates the treatment of forensic patients placed in compulsory treatment through a criminal court order; and lastly, to govern the prison to hospital transfer process of those deemed mentally disordered.

The criteria for being committed under the Act (1992) are particularly vague, and as such are open to misinterpretation and misapplication by the psychiatrists who deploy them. Interestingly, these criteria differ significantly from those utilised to establish whether someone is mentally ill. Whilst the criteria for mental illness come from psychiatry's central document, the Diagnostic and Statistical Manual of Mental Disorders, fifth edition (DSM-5), the Act (1992) has its own set of legal criteria to establish whether someone is 'mentally disordered'. The main distinction between mental illness and disorder is that in order for someone to be considered disordered their state of mind must be abnormal. Therefore it is possible to have a psychiatric diagnosis of mental illness without being mentally disordered.

As such, the Act (1992) defines mental disorder as:

- an abnormal state of mind shown by delusions or disorders of mood, perception, volition or cognition; and
- this abnormal state of mind means that either:



- there is a serious danger to your health and safety, or the health and safety of another person; or
- your ability to care for yourself is seriously reduced.

Whether a person fits these criteria is based on the symptoms they are displaying, rather than the clinical diagnosis they may have previously received. It is basically a risk assessment measure which may be undertaken by a GP or a duly authorised officer<sup>20</sup>. Anyone over the age of 18 (not identified as mentally disordered themselves) can ask for these assessments to be undertaken. This is a process the person under assessment cannot legally refuse or police may be called to detain the person in question until the assessment is completed. An issue of contention within this process is that mental disorder is a legal definition which is frequently utilised by psychiatrists in the assessment process. This may be problematic as it is unlikely that psychiatrists are applying the correct legal meaning of mental disorder aside from their own clinical diagnostic criteria for mental illness (Dawson, as cited in Dawson & Gledhill, 2013, p.41). Yet as Dawson (as cited in Dawson & Gledhill, 2013, p.41) proposes, the Act (1992) itself supports a psychiatric approach to assessment due to the key roles in the process which parliament deliberately conferred upon psychiatrists, particularly that of certifying that someone is mentally disordered and requiring compulsory treatment. Psychiatrists also take on the role of ‘responsible clinician<sup>21</sup>’, and are tasked with directing compulsory treatment for a patient, and conducting periodic reviews of the patient’s condition whether they are an inpatient/detainee, or under a Community Treatment Order (CompTO) (Dawson, as cited in Dawson & Gledhill, 2013, p.41). Such roles provide psychiatrists with power over their patients’ lives in numerous ways and further reinforce the dominance of the biomedical discourse in the area of mental illness.

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<sup>20</sup> Duly authorised officers (DOA’s) are health professionals designated and authorised by Directors of Area Mental Health Services (DAMHS) under section 93 of the Act (1992) to perform certain functions and use certain powers under the Act (1992). For a full explanation of these powers and DOA’s roles see <http://www.health.govt.nz/system/files/documents/publications/guidelines-for-duly-authorized-officers.pdf>

<sup>21</sup> "the clinician in charge of the treatment of the patient"  
<http://www.health.govt.nz/publication/competencies-role-and-function-responsible-clinicians-under-mental-health-act-1992>

Prior to being assessed by a psychiatrist, potentially mentally disordered people commonly come into contact with the police. Police frequently feel uneasy attending callouts involving people with potential mental health concerns, as they are not adequately trained or resourced to do so, despite their involvement continuing to rise since the shift to community care (Police News, 2012, p.230). For detainees, the experience is unlikely to be pleasant either, particularly as “people with mental illness are more likely to be subjected to taser discharge than those whose involvement with police is a result of criminal activity” (O’Brien et al. 2011, p.3). Once in police custody the unpleasantness is likely to continue as Wellington Section Sergeant Wade Jennings explains,

We stick them in a horrible little room, and for someone who is depressed it’s not the best place to be. This, in turn, is a real risk to us as we are then responsible for them. (Police News, 2012, p.230)

In an effort to help both police and consumers a Mental Health Intervention Team has recently been set up, and a new training regime launched at Police College (Leask, 2014). Details of these initiatives and their efficacy are not yet available, yet I think it is commendable that the police are taking steps to improve the services they provide, and uphold their duty of care. It would be good to see similar initiatives taken towards caring for the mental health of the officers themselves, as according to Kid (2012), two new officers per day had been undertaking trauma counselling for the five years prior to her article’s publication.

### **Mental health Law and Human Rights**

Once it is established that a person is mentally disordered they become labelled a patient, and cannot refuse treatment until it is determined that they are no longer mentally disordered (that is a risk to themselves or others) (Dawson, as cited in Dawson & Gledhill, 2013, p.42). Whilst receiving compulsory treatment, the Act (1992) outlines a range of patient rights it is meant to provide. Each of these rights interacts with human rights laws both domestic and international in origin. International human rights treaties relevant to the Act (1992) include, “The Covenant on Civil and Political Rights 1966 (ICCPR), the International Covenant on Economic, Social and Cultural

Rights 1966 (ICESCR), and the Convention on the Rights of Persons with Disabilities 2006 (CRPD)” (Gledhill, as cited in Dawson & Gledhill, 2013, p.285). Yet because New Zealand operates under a dualistic legal system that distinguishes between national and international law, domestic courts are prevented from drawing upon, and/or enforcing international laws (Gledhill, as cited in Dawson & Gledhill, 2013, p.286). This means that although several practices currently in use under the Act (1992) may breach international law, they are not able to be challenged through the domestic legal system. Domestically, relevant legislation/documents include “The Treaty of Waitangi 1840, the New Zealand Bill of Rights 1990, and the Human Rights Act 1993” (Thompson, & Thompson, 1997, p.23-24). These statutes, including the Act (1992) are constructed with the intention of meeting New Zealand’s international obligations “as far as possible” (Gledhill, as cited in Dawson & Gledhill, 2013, p.286). As such, decisions whether or not to use certain ‘therapeutic measures’ are framed as ethical issues rather than legal issues pertaining to a patient’s rights (Procter et al. 2004, p.119).

## **Seclusion**

One such therapeutic measure is the clinical practice of seclusion, which is a form of restraint “where a consumer is placed alone in a room or area, at any time and for any duration, from which they cannot freely exit” (Ministry of Health, 2008). I highlight this specific practice as it was an area of particular concern for my peers, and also because it provides an example of how change may be effected in the area of mental health.

According to the duty of care<sup>22</sup>, the following are situations where seclusion may be utilised (Ministry of Health, 2010, p.5):

- (a) the control of harmful behaviour occurring during the course of a psychiatric illness that cannot be adequately controlled with psychological techniques and/or medication

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<sup>22</sup> A duty of care means to use due care towards others in order to protect them from any unnecessary risk of harm.

(b) disturbance of behaviour as a result of marked agitation, thought disorder, hyperactivity or grossly impaired judgement

(c) to reduce the disruptive effects of external stimuli in a person who is highly aroused due to their illness

(d) to prevent harmful or destructive behaviour, using specific indicators of impending disturbance which may be identified by either the individual or the staff, and which should wherever possible be part of an agreed management plan.

Such a practice can be incredibly frightening and detrimental for patients already struggling to maintain any semblance of wellbeing (Meehan, Vermeer, & Windsor, 2000, p.375). And despite New Zealand Health and Disability Services Standards (Ministry of Health, 2008, p.6) stating that seclusion should not be used for punitive reasons, many of my peers suggested that punishment is exactly what it feels like to experience this practice. Further to this, the Act (1992) is supposed to protect an individual's right to company whilst a patient, yet as section 71 shows, this is a qualified right as:

(1) Every patient is entitled to the company of others, except as provided in subsection (2) of this section.

(2) A patient may be placed in seclusion in accordance with the following provisions:

(a) Seclusion shall be used only where, and for as long as, it is necessary for the care or treatment of the patient, or the protection of other patients.

(b) A patient shall be placed in seclusion only in a room or other area that is designated for the purposes by or with the approval of the Director of Area Mental Health Services.

(c) Except as provided in paragraph (d) of this subsection, seclusion shall be used only with the authority of the responsible clinician.

(d) In an emergency, a nurse or other health professional having immediate responsibility for a patient may place the patient in seclusion, but shall forthwith bring the case to the attention of the responsible clinician.

(e) The duration and circumstances of each episode of seclusion shall be recorded in the register kept in accordance with section 129(1) (b) of this Act.

In terms of domestic law, the ability for people to be forced into treatment and secluded under the Act (1992) is in conflict with numerous sections of The New Zealand Bill of Rights Act (1990, known henceforth as the Bill of rights Act), such as; section 9 the right not to be subjected to torture or cruel treatment; section 10 the right not to be subjected to medical or scientific experimentation; section 11 the right to refuse medical treatment; section 19 the right to freedom from discrimination, and at section 22 a right to liberty, including the right not to be arbitrarily detained. Despite such conflicts, section 4 states that the Bill of Rights Act (1990) cannot be used to invalidate any other provision on the basis of inconsistency with the Bill of Rights Act, and consequently cannot be utilised to invalidate the Act (1992). However, the Bill of Rights Act (1990) does include two safeguards to help protect human rights. The first of these safeguards empowers the Courts to prefer possible interpretations of enactments that are consistent with the Bill of Rights Act over interpretations that are not consistent (section 6). The second safeguard requires the Attorney-General to notify the House of Representatives if any provision in a Bill appears to be inconsistent with the Bill of Rights Act (1990, section 7). Yet despite these provisions, people are subject to the Act (1992) and the practice of seclusion on a daily basis.

Under international law, New Zealand is party to the United Nations Convention on the Rights of Persons with Disabilities, which as with The Bill of Rights (1990) has several articles which come into conflict with the Act (1992) in relation to seclusion practices. These include: article 5 which promotes equality and non-discrimination, article 12 which preserves the right to equal recognition before the law, article 14 which protects the rights of liberty and security, article 15 which covers freedom from torture or cruel, inhuman, or degrading treatment or punishment, and article 19 which protects the rights of living independently and being included in the community

(Convention on the Rights of Persons with Disabilities, 2014). Yet as I mentioned earlier, due to New Zealand's dualistic legal system, adherence to such international covenants can only be enforced by international bodies such as the United Nations.

The issue of seclusion has not gone unnoticed by the Ministry of Health (2012) in New Zealand, which is the division of government tasked with overseeing publically funded mental health initiatives. As part of The Mental Health and Addiction Service Development Plan 2012–2017, 'Rising to the Challenge', The Ministry of Health (2012) wants to "support the inpatient workforce to reduce and eliminate the use of seclusion and restraint, based on national and international best-practice examples". Despite this stated goal, The Ministry of Health (2012) has delegated responsibility for implementing the reduction and elimination of seclusion to the 21 District Health Boards throughout New Zealand, and has no legislation in place to ensure that such changes will be effected. According to the Convention on the Rights of Persons with Disabilities (2014b, p.4) the initiatives taken thus far to reduce and ultimately eliminate seclusion are insufficient and,

The Committee recommends that immediate steps be taken to eliminate the use of seclusion and restraints in medical facilities. [Also] the Committee recommends that the State party take all the immediate necessary legislative, administrative and judicial measures to ensure that no one is detained against their will in any medical facility on the basis of actual or perceived disability. The Committee also recommends that the State party ensures that all mental health services are provided with the free and informed consent of the person concerned in accordance with the Convention. The Committee further recommends that the Mental Health (Compulsory Assessment and Treatment) Act 1992 comply with the Convention. (Convention on the Rights of Persons with Disabilities, 2014b, p.4)

Despite these strong recommendations, the current National-led government has as yet no policies in place to review the Act (1992), or put an end to seclusion practices in public medical facilities (Policy, 2014). This situation is summarised well by Gordon and O'Brien (2013) who state,

So, just like 100 years ago, many people with experience of mental illness find themselves taken charge of, and managed, by a State that is not fulfilling its concomitant moral, ethical and political duties to ensuring the most humane treatment of people with mental illness (p.62).

Further to this, risk assessment has been a major contributing factor to the treatment several of my peers have experienced, which when combined with subtle manipulations of language is utilised to justify espoused 'therapeutic measures' such as seclusion.

## **Language**

As I discussed in the opening chapter, language plays a key role in constructing mental health experiences, and in this instance, how seclusion is practised and promoted. Seclusion is defined as a practice "where a consumer is placed alone in a room or area, at any time and for any duration, from which they cannot freely exit" (Ministry of Health, 2008, p.28). This definition seems innocuous enough, and yet it is only semantically different from the punishment utilised within prisons known as solitary confinement. Solitary confinement typically involves, "the reduction or complete elimination of intersubjective contact between the prisoner and others for a significant amount of time" (Gallagher, 2014, p.1). Interestingly, as the practice of solitary confinement is well known to be a form of torture, its utilisation by corrections in the United States of America has become known as "administrative segregation" (Bulman, 2012, p.58).

Overall, seclusion provides a fitting example of Foucauldian social constructionism, in its impact on how people find themselves treated under the Act (1992), and also in how narratives which counter dominant discourses provide a space for resistance which may lead to positive change. The literal term seclusion is promoted in a specific way which fits with the narrative of those who undertake its practice. Seclusion is promoted as a therapeutic measure, and its outcomes are tied to the intentions of the practitioner rather than the rights and opinions of the patient. As I mentioned earlier, in legal terms seclusion cannot be utilised as a punitive measure, yet in practice this interpreted is made by the practitioner, not the patient. Meehan

et al. (1999) suggest that the “benefits of seclusion arise from the belief that the disturbed patient can feel safe from 'persecutors' and other external stimuli in the isolation of the seclusion room” (p.370). Yet, in their investigation of the experiences of those who had been secluded, Martinez et al. (1999, p.19) found that “76.5% of people felt punished, 63.8% felt fearful, 64.4% felt worthless, and 54.3% of people felt a loss of control”. As such, in discursive terms, because seclusion is promoted by specialists who operate under the dominant biomedical model as a therapeutic measure, it remains unchanged as these specialists hold power over what is considered ‘factual’ ‘truthful’ knowledge. Yet, as the many examples I have given of alternate discourses show, challenges to the dominant biomedical discourse of seclusion are plentiful, and have been around for some time with psychiatrists such as Soloff (1979, as cited in Meehan et al. 1999, p.1) condemning seclusion as an “embarrassing reality for psychiatry”, over thirty years ago. As I mentioned earlier, such alternate discourses have led to the reduction and elimination of seclusion being included in the The Mental Health and Addiction Service Development Plan 2012–2017, ‘Rising to the Challenge’ (Ministry of Health, 2012), and more recently, The Convention on the Rights of Persons with Disabilities (2014b, p.4) recommendations to eliminate seclusion immediately. As with many practices undertaken under the Act (1992), “restraint should be perceived in the wider context of risk management” (Ministry of Health, 2008, p.5).

### **Risk management: Power imbalances in practice**

*Can we know the risks we face, now or in the future? No, we cannot: but yes we must act as if we do* (Douglas & Wildavsky, 1982, p.11).

The move to deinstitutionalise public mental health care outlined in the previous chapter, meant that community care initiatives were required to shoulder the majority of consumers’ needs, whilst public institutions geared themselves towards servicing the needs of those considered to be mentally disordered with the introduction of the Act (1992). Consequently, the Act (1992) and its practitioners focus on the risk posed by those deemed mentally disordered, and the need to protect the



public from such people. This need is fuelled by negative portrayals of the mentally ill through the media as I discussed in relation to Nairn's (2003, p.i) thesis, which continue to reconstruct the discourse of violence attached to those labelled mentally ill. Again, as dominant discourses take on the credibility of truth alternate discourses are prevented from circulation. As a result, risk management and assessment practices under the Act (1992) are accepted as representing 'truthful knowledge', making it unlikely many people would question their legitimacy.

In contrast to forced inpatient treatment, as Large et al. (2014, p.2) report, if a person is considered 'low-risk' they may not receive any form of treatment. Although no causative relationship can be established, it is the period directly after release from an in-patient psychiatric facility that a person is most likely to commit suicide, with psychiatric diagnosis itself the strongest predictor of suicidality (Ellis & Collings, 1997, p.435). In an effort to bridge these seemingly polar modalities of care, the Act (1992) allows for involuntary outpatient treatment, under what are termed Community Treatment Orders (CTO's) (Gibbs, Dawson, & Mullen, 2006, p.3). CTO's were originally introduced to deal with a group of patients who frequently failed to comply with voluntary community treatment, and usually receive forced treatment as a result (McIvor, 1998, p.224). Gibbs et al. (2006) suggest such service users usually have "a substantial history of previous hospitalization and non-compliance with medication, and for whom the risk of harm to self or others is a significant factor" (p.1089). In highlighting how controversial CTO's are, Gibbs et al. (2006) cite a range of authors (Allen and Smith, 2001; Pinfold and Bindman, 2001; Moncrieff, 2003) who believe such measures are unethical as they "may permit the involuntary treatment of those who retain their capacity to consent" (p.1090). Further to this, such treatment is derived from the biological model with a core requirement of maintaining a CTO being the acceptance of medicine as it is prescribed (Gibbs et al. 2005, p.357).

As such, the viability of community care becomes questionable, particularly in light of the Mental Health Commission's (2007, p.23) assertion that community based care requires that a person has family, friends, work, and good mental health services in order to establish and maintain wellbeing. Stigmatisation fuelled by misinformation derived from the biomedical model mean that in many cases the aforementioned

requirements are all but impossible to obtain. In light of the negative outcomes of CTO's and other aspects of the Act (1992) I have discussed, I now turn to an alternative system which treats all citizens as equal rather than part of a mentally disordered group.

### **An alternative to forced assessment and treatment**

As I have previously mentioned, many of my peers expressed concern at the practices of forced assessment and treatment undertaken under the Act (1992). At first, when I heard of their desire to abolish the Act (1992) I was in agreement, but as with O'Hagan (1993, p.16) I was unsure of how any alternative could adequately take its place. I shared this uncertainty in a draft of chapter six which I shared with my peers, and was subsequently directed by Paula towards the work of Gordon & O'Brien (2013) who advocate for the abolition of forced treatment (treatment without consent). Gordon & O'Brien (2013, p.61) suggest that rather than a patient's status being based on risk, treatment without consent should be based on a patient's capacity to provide informed consent. This proposed capacity based alternative is known as the 'fusion model', as it creates a single piece of legislation based on a standard for capacity for treatment without consent of both mental and physical illnesses (Gordon & O'Brien, 2013, p.61). Despite the benefits of such an approach, it is unlikely to be introduced anytime in the near future as the current government has not given any indication that a review of the Act (1992) will take place, and so the breaching of international treaty obligations continues (Gordon & O'Brien, 2013, p.65).

### **Conclusion**

The dominance of the biomedical discourse is a recurring issue throughout this work, as it represents a major barrier to positive change in relation to mental health in New Zealand. Despite decades of critique, its practitioners still suggest that mental illnesses are biologically determined physical diseases, with drug therapy the best form of treatment. Such a perspective ignores all other influences on the human experience, and in doing so individualises mental health issues as a personal failing. Biomedicine is not without its merits though, and physical influences upon mental health are a

critical area to consider in terms of aetiology and treatment. In line with my definition of mental health and the models of health I presented, I believe that such considerations need to take into account all known aetiological influences, and in particular the patient's own perspective of such influences. These considerations are typically ignored for many who suffer mental health concerns, as their first point of contact is usually with a GP who will likely interpret their concerns as biologically determined and prescribe them drugs. As I showed in discussing the Tidal model, this certainly does not have to be the case, and as will be seen in the data chapters to follow, GP's do occasionally incorporate alternative treatment modalities with biomedicine.

Unfortunately though, for those considered mentally disordered, the narrow frame of reference biomedicine provides is likely to be applied in both assessment and treatment under the Act (1992). The Act (1992) itself is in breach of a range of domestic and international covenants, and consequently many of its practitioners rob people of their human rights on a daily basis. One specific way this occurs is through the espoused therapeutic measure known as seclusion, which is only semantically different to the torture method of solitary confinement. Despite the United Nations recommending this risk averse practice stop within New Zealand, thus far little progress has been made to this end. Although an alternative capacity based model exists that could replace the Act (1992), and end discriminatory practices based on risk, such changes are unlikely unless the truth claims which underpin the dominant discourse of biomedicine are challenged and a new discourse can take its place. Fortunately such resistance is occurring, and is being undertaken in part by the amazing advocates I was fortunate to work with, whose experiences and opinions shine throughout the following data chapters.

## **Chapter Four: We know what's going on and here's why**

The foundation from which this body of work derives both its direction and credibility is the information shared with me throughout my fieldwork, without which this project would not have been possible. Consequently, the following three chapters are dedicated to examining these narratives through the lens of hermeneutic phenomenology, guided by Foucauldian social constructionism. As I detailed in the previous chapter, the biomedical model currently posits that mental illnesses are inheritable biological illnesses, which is both highly misleading and scientifically unfounded. Despite this, the biomedical model has come to dominate how mental illness is perceived and treated. Although biology plays a role in how people experience the world, I will again show that many other factors also influence the human condition. In order to situate this perspective, and because I am the lens of interpretation within this research, I begin this chapter with a condensed version of my personal history, focusing on factors I believe strongly influenced my own mental health. This personal narrative also situates my positionality in relation to the analyses I apply, and my vested interest in achieving the overall aims of this work. Further to this, my story also serves as a basis for comparison with those following it. Despite our differing roles, such comparisons establish us as part of a distinct group of mental health consumers. I make this distinction, as broadly speaking consumers are segregated through variations in the level of self-insight and agency each is able to express; qualities I found in abundance among my peers. Unfortunately, the biomedical discourse (and others it is intertwined with) minimises these qualities amongst consumers, which stifles the emergence of a cohesive social movement that could affect positive change.

Overall, the ensuing narratives emphasise the disruption to life mental distress can bring, and also the resilience, intelligence, and self-insight we each possess. For many of us, these aspects of subjectivity stem from our experiences of being unwell, and as such bring into question the biomedical discourse which situates mental illnesses as entirely negative occurrences. I therefore discuss the positives of mental illness some of us have experienced, which challenges the positive-negative dichotomy in relation to mental health. I conclude this chapter with an exploration

of the practice of risk management many of us have experienced, and the negative discrimination and segregation it fuels.

### **There's no I in mental, the story of Samuel Brown thus far...**

Despite our differing subject positions, I found myself treated as an equal within the interviews I undertook, which I believe was due to the similar experiences we shared, and also our common desire to improve the lives of others. My own story of joining this illustrious group began the day I was born over 35 years ago in Kew Hospital, Invercargill. Little did I know it at the time, but the formative years ahead of me would be, as a psychologist I saw once put it, all stick and no carrot. I was raised on our family farm in Southland, an area of land my ancestors had worked for five generations prior to mine, and despite its ownership changing hands, still where I consider home. In many ways I had an idyllic upbringing in Southland, and from the outside looking in, we were the perfect family. My sister and I were afforded many privileges others could only dream of, such as ponies we both rode competitively which I absolutely loved. I rode an Arabian pony named Silver Mist (Misty), which alongside hunting with my golden Labrador Max, provided the happiest experiences of my childhood.

Although for me there is no black and white in regards to the value of experiences in my life, I certainly endured many which over-shadowed those blissful days spent with my dog and my pony. A lot of the time on our farm I viewed myself more as an employee than a member of a family, with unjust discipline making a fear of failure my central concern. Such fear and associated self-doubt transposed itself onto my life off the farm, and by the time I entered high school I was a prime candidate for bullying which my peers happily obliged with. Looking for some way to escape, I turned to (illicit) drug use at the age of fourteen, and it was around that time that I believe something inside of me broke. I lost a lot of desire to do things which I had previously enjoyed, and I stopped putting any effort into my school work. In true neo-liberal fashion, I alone was deemed responsible for my situation, and rather than maintaining the high grades I was accustomed to, I dropped out of high school to go dairy farming. After several years bouncing around various dairy farming jobs,

and even a stint as a deep sea fisherman, I became despondent with my life and sought help from my family. Since they knew all too well that I enjoyed drugs, my chemical inclinations were assumed to be the cause of my despondency, and after a short visit to an outpatient alcohol and drug clinic it was determined that I was a drug addict and alcoholic. In retrospect, I could never have imagined how much those labels would influence my life and relationships from that point forward. They have meant that I have little to do with a lot of my family these days, with many believing I am somehow damaged, or just plain bad.

Returning to the story at hand, after receiving my first mental illness diagnoses, it was recommended that I attend a five week programme at the Queen Mary rehabilitation facility in Hanmer Springs, to which I duly complied. I have nothing but fond memories of my time at Queen Mary as the staff were excellent, and for the first time in my life I was amongst people like me: others who had led some truly disturbing lives, and were subsequently trying to get through each day the best way they knew how. Similarly to the people I worked with on this project, the people I interacted with at Queen Mary had vastly different backgrounds to mine, yet we all shared the common bond that suffering and segregation afforded us. Overall, the experience of rehab showed me that I did have something to offer this world, and that I wasn't alone in my struggles. I took these learnings and rather than continue the path I had been on, I began studying within the humanities at the Southern Institute of Technology. Although it took me a few years to complete a qualification, I garnered further self-esteem from interacting with positive motivated people, and learnt a lot about the social sciences. Despite it being recommended that upon graduating I continue on to University, I didn't feel ready and so went back to milking cows. Finally though, after several years, and an equal number of jobs came and went, I decided it was time to try and apply my mind rather than labour away my days with the cows.

With the initial intention of becoming a clinical psychologist, I enrolled for the first year of a bachelor's degree in Business Psychology at Massey University, which I undertook extramurally. It was a real struggle returning to study, particularly with having to teach myself all the intricacies of academic writing. Yet I overcame these

hurdles, and successfully completed my first year with good grades and an eye to the future. Wanting to continue with my studies and become an internal student, I planned to move in order to be near my University. Unfortunately my partner of eight years didn't share my desire to move, and for various reasons we decided to go our separate ways. As I would learn in the years to follow, it was her that had kept me from spiralling into darkness, and without her I would really struggle to maintain my mental health. So in 2010 I moved to Palmerston North in order to attend University in person and immerse myself in student life.

As I was moving from Southland with no drivers licence, I decided the easiest thing to do in terms of living arrangements was to live in one of Massey's halls which house primarily graduate and foreign students. I moved into a house with three young American guys and a semester I will never forget ensued. Fairly rapidly my work ethic of the previous year dissipated as I indulged in partying with my flatmates and our neighbours on a near daily basis. I also found myself in a new relationship with a young German woman to whom I devoted a lot of the time I probably should have spent studying. To cut a long story short, it all ended in tears and I had to withdraw from a paper to make it through the semester. Heartbroken and quite despondent, I went to stay with my mother between semesters, and revisited one of my favourite psychologists in Christchurch whom I had seen the previous summer. She helped get me to an emotional state where I could envisage myself successfully returning to University and completing the year. As such, the final semester went pretty well and after its completion I ventured back to Southland to work on a Dairy Farm for the summer.

Following the summer break, ready to study again, I began the final year of my degree. The first semester started well but due to another ill-fated relationship I ended up back at my mother's trying to piece together what was left of my sense of self. This time though, I think the cumulative effects of the life I had lived caught up with me as I found myself obsessed with ending my life. Every morning I would wake up to the haunting rumination of how I would kill myself that day. I decided a rifle would be the best method, and for around a week I tormented myself creating grizzly plans until my mother persuaded me to see her doctor. The doctor told me

that I was clinically depressed and would require anti-depressants in order to have any hope of living a functional life. Having at least some basic knowledge of human behaviour and the dual influences of nature and nurture which frame the quintessential debate around behavioural causation, I questioned the doctor's assertions enquiring; "If I got this way through experience, shouldn't the way out also be through experience?" To this he replied that 'they' (Doctors) now knew that depression is a biologically derived illness which could only be cured through drug therapy. Although dubious of his assertions, I saw little alternative but to take the medication he prescribed. Whilst the drugs didn't provide a total improvement, they did numb my feelings so I was less suicidal and desperately depressed.

So with my newly medicated body I headed back to University to attempt to finish my degree. My closest friends belittled me for what they saw as 'selling out' because they knew (as I did) that much of the effects anti-depressants produce can be put down to the placebo effect, and ironically that depression is strongly environmentally influenced. Isolation in my suffering, of which I was all too familiar, again descended upon me as I battled towards graduation. I made it to the night before my final exam before I was again hit (literally) with another of life's challenges. I was attacked at a friend's place where we were enjoying a few drinks, and I ended up losing three teeth, breaking my jaw, and received several wounds requiring 76 stitches in my face and head. Chewing was out of the question for the following six weeks, which made starting a new dairying job for the summer difficult at best. After another eventful summer in which I went through a couple of jobs and crashed a quad bike drunk on New Year's day, I decided to head back to University and try my hand at my new favourite subject Social Anthropology. The use of reflexivity I'm indulging in whilst writing this piece is what first attracted me to the subject, as I was no longer required to strive for objectivity as psychology required, and my experiences were seen as a strength rather than shortcomings I needed to work on.

As with previous years, the first semester started off well and I was doing fine with my studies. Nothing really went that astray leading up to the middle of the year, but I felt huge pressure with the mounting workload I saw unfolding ahead of me, and



also terribly inadequate in my new role as a graduate student in a subject I was all but illiterate in. These pressures were enough to confine me to bed for much of the mid-year break after which I ended up moving back to my mother's yet again, and shamefully headed back to her doctor for stronger drugs. I had given up on my year at university and began the unenviable task of withdrawing from papers and informing my lecturers and supervisor that I was unwell. Thanks solely to my current primary supervisor I was encouraged to participate in one theory paper, which in hindsight is a major reason why I am fortunate enough to be in a position to write this piece of literature. Upon completion of the paper I took on a fixed term job with a fencing contractor for summer and again got back into my usual dubious methods of entertainment. After I completed my contract fencing, I started University part time to finish off the previous years' work, and began a job milking cows in central Canterbury. I enjoyed my work and had great employers who supported my ambitions. Overall things went fairly well in both work and study until I had another relationship come to an abrupt end. Shortly after this a friend and I took my newly acquired car on a drive to Christchurch for a night out, and this is about where things started to take a turn for the worse.

We were sharing a bottle of whiskey whilst on this misadventure, and drove around town until the early hours of the morning when I lost control of the car into a power pole. I tried to drive away but as we were near the police station it was only seconds before we were surrounded by patrol cars. Seeing as I was the driver I was instantly arrested and taken to the station for processing. A really nice officer processed me, and I ended up receiving a court date to defend charges of drunk in charge and reckless driving. I took the mistakes I made very badly as I had been down this path numerous times before. Once I sobered up from trying to drown my sorrows I experienced what I can only describe as a panic attack in which I experienced an overwhelming and relentless feeling that my life had again lost its value. The feeling lingered with me into the following day and in an effort to put a final end to the rollercoaster ride that had been my life I took my pocket knife and carved a cross deep into the tattoo of a heart I had on my right wrist. Not satisfied with the depth I had achieved I got a razor blade and cut my left wrist until it was streaming blood.

Fortunately for me my employer wanted to make sure I was okay after the accident and came to my house looking for me. As the door was open he came in and I can only guess as there was a trail of blood leading to the bathroom, he found me. Seeing I wasn't in a good way he wrapped my wrists and called an ambulance. In hospital I got stitched up, and after convincing a psychiatrist I wasn't going to do any further harm to myself I was released.

The experience took a heavy toll on my self-worth, and it was all I could do just to go through the motions of my job with my studies suffering as a result. As my contract was coming to an end on the farm, I decided to move to Dunedin for the remainder of the University year. Despite eventually finding a good environment to live in, I was quite isolated in Dunedin and rapidly slipped back into spending more time in bed than not. The suicidal thoughts returned along with the ruminative self-hatred. Not wanting to give in to these thoughts, I started attending peer support meetings once a week so I could air my concerns, and have someone to walk alongside me in my journey to wellbeing. Despite the service being excellent, I was struggling to make much progress and decided to again visit a medical doctor to go back on the anti-depressants I had stopped after my car accident. The pills helped for a short time and between them, peer support, and a private psychologist I was able to make it through the remainder of my year at University, after which I again headed to my mother's for the summer break.

Still struggling with low self-worth and negative ruminative thinking, I started seeing a psychologist in Christchurch who specialised in trauma therapy which was the area I believed I needed help with. Despite a range of specialists previously discouraging me from investigating the aetiology of my suffering in relation to my early developmental years, she encouraged me to look at this period of my life in terms of how I was treated and the outcomes I experienced. Through these efforts I found a book by Elan Golomb (1992) titled, *Trapped In The Mirror, adult children of narcissists in their struggle for self*, which details the experiences of others like me. This new found information brought me some relief but also tremendous sorrow and I sunk into a depressive state despite the strong medication I was taking. I spent several days in bed, exhausted and demoralised by what I saw as the hateful world I

had been born into. After some venting through writing and constructive conversations with my psychologist I came to feel a lot better and started looking at what I could do with myself in 2014.

Initially I had wanted to focus on personal development by continuing to work with my psychologist in Christchurch. To this end I got a fantastic part-time job just north of Ashburton where I had friends close by and my mother a couple of hours away. Unfortunately things didn't go to plan, as on my first day of work I had a grand mal seizure, which put an end to my job as I was required to provide a doctor's certificate saying it wouldn't happen again; an impossibility, sadly. So with two weeks until the start of the first semester at Massey University, I enrolled again in the Masters programme in Social Anthropology, and moved back to Palmerston North to set about creating this dissertation. In terms of mental health, this is the first time in a long time that I have maintained wellbeing without medications or specialists. Instead I returned to one of my early loves, martial arts. This time in the form of Muay Thai, which requires me to be in the best possible health in every way. The social support and comradery I have found at my gym, and in the broader Muay Thai community, has undoubtedly made my life a lot more stable and taught me to persevere through adversity regardless of its enormity. As has the support of my two supervisors who have continued to be instrumental in my continued wellbeing. Last but certainly not least I have to acknowledge the unwavering support of my dear Mother. For all the hell she has gone through having me as her son she has never given up on me, and has always done whatever she can to ensure I have every opportunity possible to live a fulfilling life. For me these supports highlight the reliance I believe we all have on others as social animals in a world fraught with chaos. If only we valued each other a bit more imagine the possibilities...

## What makes 'us' a group?

Despite my fieldwork being restricted to a single interview with each of my peers, I was privy to some amazing stories during these sessions for which I am eternally grateful. The openness of my peers is a testament to, as Paula put it, "their ability to recognise what's happening within themselves and to be able to express it". I found such qualities in abundance while working with these advocates, and through the sharing of our ideas and experiences I was able to gain a better picture of what other factors contribute to making us a group. These conversations also accentuate the multi-faceted aetiology of mental illness, which situates mental illness as a redundant term due its reductive implications and associated negative connotations.

The first of these conversations I want to discuss took place with a lovely woman by the name of Paula. I knew little of Paula prior to our meeting, and was immediately struck by her fluidity of speech, and enormous knowledge regarding mental health, which can be seen throughout our conversation<sup>23</sup>:

The medical world seems to think there's some kind of biological genetic or you know physical marker for want of a better word that attributes a diagnosis of mental illness to a person, I don't believe that because they don't have proof

*Mmm*

If they can't prove it why would I believe it? But I have an Uncle that had a diag...ummm....he was never diagnosed with bi-polar disorder

*Yip*

And then, and I was the one that they always said was most like my uncle

*Right yeah yeah (Laughter)*

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<sup>23</sup> Within the indented transcribed segments my words are italicised.

Yeah yeah, and so if you go back further through the family, there's hospitalisations and ummm...suicides floating around, so well I don't believe that, I don't believe that that's proof of any kind of biological indicator

*Yeah*

I do think that ummm certain issues can flow through families

*But that's likely due to environmental influences aye?*

Yip

*That's just the same as alcoholism or anything behavioural. To say that your parents were like that doesn't say anything. I mean that's where you learn to do the drinking or...so yeah!*

Yeah, for sure

*But yeah, like you say, it is completely swayed to the biological side aye?*

Yeah yeah, but I think it's kind of its one of those things. I became officially unwell when I was 29 I think, and ummm

*How old are you now sorry?*

I'm 42, I'm 42 this year

*You don't look any older...I didn't think you were any older than me*

(Laughter)... well and ummm

*So 29?*

Yeah, I was diagnosed then

*What kind of path led you to get the diagnosis?*

Well there were a lot of factors going on in my life, like my Nana was dying, I had a stalker (laughter), work wasn't going well, I was having difficulties with

my best friend, and I was having trouble with my other friend putting alcohol issues onto me

*Yip*

And being really demanding and I think there are other things going on. So all this was going on and I wasn't coping

*What did you sort of have around you? You know, support wise? Not a lot going on?*

Nah....because at the time I was working as a lawyer and ummm

*So quite high stress, yeah?*

Yip, and so you don't admit weakness in that profession

*Yip*

So I was trying to deal with all the stuff that was going on and then I started having psychotic symptoms like believing things that I was...now I look back and think, "why was I believing that? Well I understand why I was believing that, but it's not, you know...cameras in the walls, people following me, people watching me, but you know that was melded in with all these other things that were going on, so it was kind of true but it was all stretched out of reality

*Yeah, do you kind of feel like that was a part of you telling you you need a break?*

Well looking back, hell yeah!

Paula's story of becoming unwell highlights the strong influence environmental factors can have on a person's mental health. Further to this, Paula was kind enough to share her knowledge of a study undertaken in the United States of America known as the ACE study (adverse childhood experiences). The ACE study, which had over 17,000 participants, assessed associations between childhood maltreatment

and later-life health and well-being (Centres for disease control and prevention, 2014). Within the study's findings:

A 4- to 12-fold increase in the risk for alcoholism, drug abuse, depression, and suicide attempt was observed among respondents reporting four or more categories of adverse childhood experiences, relative to those reporting that they had experienced none (Felitti et al., 1998, as cited in Chapman et al. 2007, p.363).

In line with these findings, various developmental aetiological influences were expressed by several of my peers, as was the issue of heritability, with many discussing mental health concerns that other family members experienced. Both of these topics were raised by another lovely woman I spoke with, Tina:

So my Dad's from a royalty line of ummm arikis, arikis means royals

*Mmm hmmm*

So my Dad came from that background so our...back when my Dad migrated here he came over with my Great aunty, my Dad's aunty

*Yip*

And she had at that time what they called Makenava, so there's no real name for mental health, all that means is that your head's mental

*Mmm hmm*

Crazy in the Cook Islands, but they didn't know that back then, that she had an illness. They thought that she was a, aww how do you say it in English? Like she had a curse, and she was evil

*I get what you mean*

Yeah, because they come from a long line of royalty so they carry a title name

*Mmm*

A chief name and that's a shame to our family. So from what I know she was heartbroken because she fell in love with a commoner

*Yip*

A commoner who worked the taro patch, and the patch workers were a no go for her, and the parents didn't like it so they made her leave to separate them

*Mmm hmmm*

But then she was heartbroken like she didn't communicate with people, and her mood slowly deteriorated

Tina's story again accentuates the environmental influences currently ignored by the biomedical model of mental illness, and also the isolation and stigmatisation common to many consumers. In a similar vein to Tina, another woman I spoke with, Roxy, also had family members with experiences of mental illness. I initiated our conversation by asking Roxy if she wouldn't mind sharing some personal background, to which she responded:

I guess I've got this family connection to mental illness which I think has pulled me back into it. One of the things I remember from when I was young was that my mother had a brother who got put into Cherry farm as a teenager when he'd broken my Grandfather's arm, and the family decided they couldn't cope. So I have this sort of memory of going for a picnic at Karitane and my uncle was really tall and I remember the trousers he was wearing were really short

*Yeap*

It's quite sad and it was only later when I was talking to people who had been psych [psychiatric] patients during those days that I realised that they couldn't even have their own clothes

*Oh right*



They just had this sort of pile of communal clothes that people would get washed together and would come out communally

*Far out, really?*

Yeah. I've got a couple of childhood memories, and the other one was of my aunty who'd become, I guess psychotic, after she'd had my cousin...after the birth. And my mother had gone and picked her up from the ward, which was just the maternity ward and then had this crash outside on the one way system in Dunedin So yeah, quite funny childhood memories...

These memories, which Roxy kindly shared, reflect experiences with family members which in some ways shaped her subjectivity, and as such are not necessarily indicative of her belief in the genetic heritability of mental illness. Similarly, I also have family members who hold formal diagnoses, yet I believe that my experiences of mental distress are derived from traumatic social experiences rather than a genetic predisposition. Another well-spoken advocate I talked with called Patrick, also endured several traumatic experiences he mentioned as relevant to his mental health experiences:

I think probably, if I really want to sort of define it, I mean there's things that you could say happened earlier but I think if I defined a mental health episode, it was probably through my teens, like leaving home, getting kicked out of home

*Whereabouts were you?*

I was born in South Hampton in the UK

*Yip*

And I did have a difficult childhood in terms of bullying with my brother. I think that is probably the biggest part of the stress I endured

*Yeah*

Yeah and it was physical, and it was quite enduring and heavy

*Yeah*

You know? I mean he would hold me under water or put things across my neck and like just pretty extreme behaviour. And more, probably, it wasn't the behaviour it was my parents not responding to it

*Yeah*

And the few times they did there was a lot of physical punishment in the family and so he would get physically punished which would drive it more

*Yip, I know what you mean*

And I had some of that as well, physical abuse sort of, you know hitting and stuff

*Yip*

You know what I mean? So although I think we were a close family in one way the parenting was just a bit skewed, yeah?

*Mmm*

And I tended to be a linchpin in the family to sort of try and connect people. My brother had a slight disability actually, and I was almost like a parent figure to him. So I think that you're the first person I've actually conveyed that to, yeah?

*I really appreciate it*

And it's only because I'm thinking you know I'm very aware of my mental health.

It seems that for many of us such awareness is garnered through reflexivity after having endured some form of adversity, and is a key part of why we are able to communicate so openly and freely. Self-awareness, and also an amazing level of resilience, were qualities I found we all shared, and were most certainly present in

another lovely woman I spoke to, Kelly. Kelly has extensive consumer experience having:

Used mental health services for forty two years, from the age of nineteen. I had my first psychosis at the age of nineteen, and that was in fairly barbaric days

*Yeah*

So I was admitted to Oakley hospital as a nineteen year old and I've had a series of psychoses

*Oh right*

Overall, I've done 7 years in institutions

*Wow*

Not all in one go

*Yeah*

And I have been in some of the worst institutions in New Zealand, I was in Lake Alice from 1977-79. That's just after the Lake Alice scandal, so I've experienced an immense amount of trauma, and shocking practice. Later when I moved, when I eventually lived, I had two children. During that period of having children really young I was probably the most grounded and happy in my life

*Mmm*

There's a part of my story that I need to let you know and that is when I was young, when I was 20, I had a baby and at that stage I had a diagnosis of schizophrenia

*Mmm hmm*

So, I actually got my notes back so I know exactly what the doctors said. That child was removed from me because it was believed that I could never

parent. So I've come through a really rough rough history of NZ mental health practice

*Yeah*

Now, how did I get into advocating? Well, I've got two children, and we were living in Cromwell

*Oh yeah*

And I was doing music at school

*Ok*

And my husband at the time was on a sickness benefit 'cos he had a heart condition, and we were kind of living on the benefit, up in Cromwell. My children at the time were about ten and I realised I was the only one with the capacity to get us off the benefit

*Mmm hmm*

I had started at Otago University after I got back from Auckland, after I was sick

*Yip*

But the years in the '70's were quite difficult for me, and a few acid trips didn't help my predisposition

*Yeah it wouldn't*

I'm being quite frank here

*Yeah it's all good*

So to jump to the time I had my children...we were living in Cromwell and making ends meet was really difficult

*Mmm hmm*

So I thought well I'll just have to do it, you know, for my children

*Mmm hmm*

And I went to Otago University where I did a Bachelor of Education, and I tried finishing my music degree

*It must've been pretty tough was it?*

It was tough on my kids but they came down the next year

*Mmm hmm*

Now because of my experiences I have a really low tolerance of discrimination.

I would suggest that considering the adversity that we have all faced as consumers, and our shared desire to assist others facing similar issues, intolerance of discrimination is another commonality we share. So too is our resilience in the face of at times horrific circumstances, which is again highlighted in the following discussion between Joanne and me. After some discussion of my project and sharing a laugh over the 'fun' I was having transcribing all the interviews I had done, I suggested a starting point for our discussion might involve sharing some personal information about her life. In her initial response I found that Joanne was also a fellow Southlander, and she proceeded to give a brief overview of her mental health experiences:

Well as I was telling you I was born in Winton and spent my first 16 years in Southland and then I went to University at Otago and that's when I started having major mental health problems

*Mmm hmm*

And from about the age of 18 to about 27 I was pretty upset by things. I was in hospital about five...in fact I've lost count of how many admissions I've had. So my life was incredibly disrupted and everything just sort of petered out by the time I was 30

*Yip*

Ummm and since then I've been working in the mental health sector

*Mmm hmm*

Well or outside it, yeah

*Yeah! (Laughter)*

Well that was it and I was lucky cos I had friends and family who were quite supportive. If I hadn't had that and a questioning mind I think I would've been fucked.

The disruption of life Joanne spoke of is something common to all consumers, and as I discuss in the following chapter can be compounded when a person is forced into psychiatric facilities. Although I have never had such an experience, I can imagine it would be terrifying, and sadly has been for many of the people I interviewed, which we discuss within Chapter Five. Despite enduring such lengthy disruptions, Joanne was able to establish a distinguished career 'within' the mental health sector, which speaks to another commonality amongst us, our ability to find positives in our experiences.

### **It's not all doom and gloom: Positives of mental distress**

If there is a meaning in life at all, then there must be a meaning in suffering. Suffering is an ineradicable part of life, even as fate and death. Without suffering and death human life cannot be complete. The way in which a man accepts his fate and all the suffering it entails, the way in which he takes up his cross, gives him ample opportunity—even under the most difficult circumstances—to add a deeper meaning to his life. It may remain brave, dignified and unselfish. Or in the bitter fight for self-preservation he may forget his human dignity and become no more than an animal. Here lies the chance for a man either to make use of or to forgo the opportunities of attaining the moral values that a difficult situation may afford him. And this decides whether he is worthy of his sufferings or not (Frankl, 1985, p. 33).

The negative connotations attached to mental illness are widely documented (Rose et al., 2007, p.2, Hinshaw, 2004, p.714), and are a common way of perceiving such experiences. These perceptions fuel stigmatisation and negative discrimination consumers' face, essentially devaluing important aspects of people's lives. Reframing these experiences as a part of the mental health we all need to maintain, rather than as mental illness which only a distinct 'faulty' section of our society experience, would contribute to positive change. Throughout my own experiences of mental distress I have suffered an inordinate amount, yet from this suffering I have gained self-insight and empathy I do not believe would be possible otherwise. Several of my peers expressed similar perspectives regarding the positive aspects of their mental health experiences. For me, their courage in expressing these stories is inspirational, as is their ability again to show resilience, and self-insight despite the difficulties they face. I say 'face' rather than 'faced', as many of us still experience mental health challenges, yet as Patrick discusses they do not have to be perceived as entirely negative. In Patrick's words:

I get periods of unwellness and it's invigorating, powerful, insightful, and also terrifying. You know it's all of that rolled into one for me

*Mmm*

But I've come to live with it because I can't stop it

*Mmm*

But generally they just tie all of the negative connotations to these experiences aye?

*Yeah rather than its life in all its complexities*

All I know is that's the way I tick, it's not a negative it's just the way I am. I've had long periods of not sleeping but I've done it all my life

As with Patrick, I too have come to accept that the parts of me which can cause me to suffer episodes of mental distress are just that; parts of me. As Patrick so succinctly put it; "it's not a negative it's just the way I am". As such, I believe if more

people were made aware that it is alright to not be at your best all the time, there would be less fear of mental health issues and more open communication. This point is supported by Paula:

Well I think with psychotic symptoms, because they're so far removed from everyday reality, we're never taught that they're anything but scary

*Yeah*

When they happen you don't know what's going on

*Mmm*

You don't know how to deal with it; you get no support to deal with it so it gets worse.

*Mmm*

So if you're if you're physically unwell and incapable as a result, or if your older and becoming incapable, the same rules should apply, there shouldn't be some special mental health standard

*No*

You know, because that's just discrimination

*Yeah absolutely*

You know, and that's why we call it mental distress rather than mental illness

*Mmm*

Because distress is something anyone can understand

*Yeah*

And if you put mental in front they really understand the realm you're talking about

*Mmm*



But it's to say what we were saying, this is normal human experience

*Yeah*

You know? And try and normalise that idea in the general populous.

Public education around mental health is certainly an area which is dramatically lacking. Yet specialists who hold the power to provide knowledge to the public also risk both their own positions being challenged, and their practices both past and present being questioned if people were to be made aware of current understandings of mental health aetiology. Joanne suggests that current misrepresentations of mental health issues as inherently negative and abnormal are largely derived from:

Risk management; it's got a lot worse than when I was going through the system

*Yeah*

I don't know how they live with it, it's ridiculous

*Well it's [mental illness diagnoses] not something to put on your resume for a lot of things aye*

*Yeah*

*Yeah, its bullshit! It's lived experience! I've learned a hell of a lot more from my own experiences than from what I have at University*

Yeah! And I mean nobody ever said to me "Joanne you'll be learning a lot through this", nobody

*No*

They just said "aww well you're missing out on your degree, and you're missing out on relationships, and you're not doing the usual things that other young people do. It's all bad, and your prognosis is really bad, and you'll be

on drugs for the rest of your life, and you won't be able to have a career like you thought you would"

*Mmm*

And no acknowledgement that actually ok these experiences do take away from you, there's no doubt about it, they do take away, but they also give to you

*Mmm*

But they didn't see that at all, those highly trained people

The positive aspects of experiencing mental distress are rarely acknowledged or discussed. Yet much the same as the dichotomies I discussed in Chapter One, experiences of mental distress cannot so easily be categorised as wholly negative, nor an inherent risk. Risk management, and the negative discrimination it can create, is something I have experienced in attempting to gain employment, sadly as did Paula. And although we could laugh about the experience she had, it was most likely very distressing at the time:

I remember going for a job at an employment agency

*Yip*

So I got an interview, that's all good. I go in there, talk to the guy and the question on the form

*Oh no (Laughter)*

You know the question

*Yeah (Laughter) I can see where this is going*

The "can you think of a situation which may affect your ability to do this job?" kind of question

*Mmm*

And I'm like "I have a mental health diagnosis but it's not going to affect me in my job" because I like to be up front

*Yeah*

You know? It's generally my preference

*Fair enough too*

To be up front, and he was like "oh yeah no no", and shut the interview down,

*Yeah*

So he got me out the door, said he'd ring in the next couple of days and about three days pass so I ring up and leave a message...no reply

*Whoa!*

A couple more days pass...ring them up, leave a message....no reply. An employment agent!?

*Ohh that's awful*

(Laughter) So I was just like, I think I've just experienced really quite bad discrimination

*Yeah, that's just what's ticking through my mind and then there's no way that you can show that that's discrimination. Its black and white but you know they'll just say something else about you wasn't suitable*

Yeah like "I was gonna get back to you, I was writing you a letter" dah dah dah whatever

*That's risk aversion showing through and that's how a lot of the employment service practices work aye. You know, if you've got any of these things, they're like a black flag. You're bugged in a lot of cases*

Yeah and that's the thing... "be a productive member of society". Well you give me drugs so I can't really wake up before 10am in the morning so I need a job that starts around 10.30, 11 o'clock, and what jobs are they?

*Mmm*

Ok, I'll find a job that starts at 11 o'clock in the morning go to the interview, and because of the form that they've given me I disclose I've got an illness

*Mmm*

But they don't want me, so how can I be a productive member of society?

As Paula's story shows, risk management practices can be negatively discriminatory for those with diagnoses, particularly if they decide not to hide who they are. As I discuss in Chapter Five, such practices also contribute to how many who experience mental distress are treated when they come in to contact with service providers.

## **Conclusion**

Thus far I have detailed some of my peer's personal backgrounds in order to provide a picture of the common factors which make us a group, and also the various influences which have contributed to each of us being diagnosed as mentally ill. Such a variety of influences contradict the biomedical model's deterministic categorisation of mentally ill people as suffering from physical diseases which are inherently negative. Despite the prevalence of negative connotations attached to mental illness, I also showed a range of positive outcomes many of us have experienced, which in itself serves to normalise what are otherwise considered abnormal experiences. For some of my peers, their experiences of distress have been compounded by their treatment with the various specialists they have encountered. For this reason I begin the following chapter by looking at our experiences of treatment as mental health consumers, to again argue for need for positive change within this area.

## Chapter Five: Fighting for wellbeing

### Introduction

With ever-increasing numbers of people seeking assistance from mental health services, it is useful to understand what such occurrences may entail. To this end, I discuss a range of encounters we have had with mainstream specialists<sup>24</sup>, followed by some experiences my peers shared of being inpatients within mental illness facilities<sup>25</sup>. As drugs seem to be a popular way to treat people within these facilities, and with most of us currently or previously having been prescribed psychopharmaceuticals, I then focus on experiences of their consumption. Alternate methods of maintaining wellbeing rounds out this chapter; highlighting the need for open communication between all mental health stakeholders, as many of these methods are underutilised due to the dominance of the biomedical model and its practitioner's penchant for drug therapy.

### Experiences with 'specialists'

[...] the control and regulation of biomedical technology (science) must ultimately rest with non-scientists and 'non-experts.' [. . .] The issues are not so much of knowledge as they are of power [. . .] I am convinced of the immediate importance of finding ways of stimulating widespread public involvement. (Restak, 1977, p.168).

During certain times of mental distress we have engaged (whether voluntarily or otherwise) with mental health services tasked with assisting us to obtain wellbeing. A mixture of results ensued, with the majority unfortunately not particularly positive. On the bright side though, many of us managed to find specialists who were/are hugely influential in assisting us to acquire wellbeing, and to give meaning to our experiences. What follows then are some of these positive experiences drawn from discussions with my peers, but beginning with one of my own. The purpose of

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<sup>24</sup> By mainstream specialists I am referring to mental illness service providers those experiencing mental distress will typically come into contact with such as: GP's, pharmacists, psychiatrists, and psychologists.

<sup>25</sup> By mental illness facilities I am referring to both public and private institutions tasked with treating those categorised as mentally ill.

discussing these positive narratives is threefold. Firstly, to again accentuate the resilience we have shown by persevering in our search for adequate assistance. Secondly, to highlight which particular aspects of these specialists' practices set them apart from their less effective peers. And finally, they serve as a reminder that this thesis is not a witch hunt, as I am in no way anti any paradigms outside of anthropology. I merely wish to suggest that more open interdisciplinary communication take place around mental health so that everyone can benefit.

### **Awesome specialists: If only they were all like this...**

Fortunately I have been privileged to work with some fantastic specialists. In particular, one lovely woman's psychological service dramatically improved my sense of wellbeing at a time when all colour seemed to have been drained from my world. Rather than go into specific detail around the work that we did, I will simply discuss what I believe made the difference for me in working with this woman. In our initial meeting I made it clear that alongside whatever psychological methods she wished to employ in assisting me, I wanted scholarly evidence supporting their efficacy. I also requested that my opinions be valued, as although it may seem axiomatic that they would be in working with a psychologist, some of my previous experiences said otherwise. These requests were immediately met, and I found myself supported by both her warm empathetic demeanour, and also the raft of references she provided me on appropriate literature. Although we only worked together for a short period of time, she helped me to understand the possibilities for further positive change which lay before me, and also the valuable accomplishments I had achieved. As such, our work together was central to my maintaining wellbeing from that point forward, without the need for psychopharmaceuticals or more specialists. I am not alone in having such a positive experience, as others I spoke to also had tales of specialists who had done wonderful work with them. The following conversation details one such experience Kelly shared with me:

I've got a good doctor in Christchurch, but anyone else was just kind of useless and just wouldn't do much. But I got a young English doctor who was training, and he was so deeply aggrieved at my experiences and we used to

talk about esoteric things, like *Man's Search for Meaning*, have you read that book?

*Yeah*

Yeah

*Pretty cool*

Yeah pretty cool isn't it; it's one of my favourites

*It's beautiful*

Yeah it is beautiful. So we were having these discussions for about an hour and we'd agree to disagree on some things but he helped me get back to who I was.

The book Kelly mentions was authored by Victor Frankl (1985), and details his experiences during the Second World War in which he lost his family, and endured years of suffering within the Nazi concentration camps. Although an oversimplification of his thesis, Frankl (1985) believed meaning in life came from finding and treasuring reciprocal love. It would seem then that Kelly's doctor's ability to discuss ideas outside of the biomedical model made all the difference for her. Similarly, Paula also found a doctor who supported her outside of the limitations of the biomedical model:

When I got accepted to do this law masterate, I said to my GP "not too bad for a crazy person aye?"

*Yeah (Laughter)*

And he just looked at me and he said "you're the one saying that"

*Yeah*

And I just thought you are a cool GP!

*Yeah*

You know (Laughter)

*Yeah exactly*

He's been my GP for years, and he's always saying that "you are capable, you just need to look after yourself, like know your limitations"

*Yeah*

And work within them, and just get out there and do it

*And obviously in some ways you can push yourself a hell of a lot further than a lot of people would be able to*

Yeah, you know and it's just about knowing more, it's just self-awareness, and how can you be self-aware if someone is saying to you, you're a hopeless case and you're gonna be on these noxious drugs for life?

As with Kelly's experience, Paula found support from a GP who was respectful and treated her as a person of value rather than a broken biological entity requiring fixing. Paula also detailed positive experiences she had with two psychiatrists who also operated outside of the norms for their paradigm. Our chat about the first of these psychiatrists began with Paula saying:

The psychiatrist I've got now, he's very much "oh you wana get off the anti-psychotics, I'll support you in that, we'll give it a try and see what happens, and then we'll deal with the consequences. But you're gonna do it carefully, and you know you can contact me anytime"

*Yeah*

"If anything goes wrong, if you're worried...what supports have you got around you? Who knows about this?" (Psychiatrists questions). He just really covered all the bases, and he is very aware of nutrition and how it interacts with medication and

*Yip*



Wellness in general so I think he's...despite the fact that he's a psychiatrist, I think he's ummm [contemplation]...you know, I hate to say it, but person-centred

*Yip*

You know? Rather than just imposing a model on someone

The experience Paula describes speaks of interacting with a psychiatrist whom to my mind is operating in a holistic manner, "despite the fact that he's a psychiatrist" as Paula says. The ability to operate in this manner in combination with treating consumers as 'regular people', seem to be critical factors conducive to maintaining wellbeing. These themes again surface with the second psychiatrist Paula describes:

One of my psychiatrists, he was a lovely guy, honestly, lovely guy and he had this theory, well it wasn't really a theory, a belief

*Mmm*

About sensitivity

*Mmm*

And like the distinction between being very sensitive and tipping over into unwellness

*Yip*

And so we'd do this exercise where something would happen, and he'd be like "is that a situation of high sensitivity or is that unwellness?", and it was a really good way of saying, "ok maybe I pick up on stuff more than other people might"

*Mmm*

And so I react but it's not because I'm picking up on stuff

*Mmm*

You know? And it was really affirming to think of it that way

*Yeah*

Rather than everything's part of the diagnosis and worth worrying about, you know?

*Yeah absolutely*

It's like, "no that's how you see the world"

*Mmm*

And just respect that about yourself

*For sure*

Throughout these experiences with specialists, it seems they were able to attend to our needs by showing empathy for our distress as fellow human beings. Handling mental distress as a biological illness best treated with drugs devalues both the experience and the person. In my experiences of mental distress I have found that self-stigmatisation from feeling like I am diseased, and that my experience is abnormal has been the most damaging. As an example, recently I had glandular fever and bronchitis, which meant that I was not able to study or exercise. After a week of bed rest with little improvement my emotional state declined and I felt quite despondent. Rather than continue to decline as I have many times previously, I recalled part of a discussion I had with Joanne where she said, "Well I mean why get outa bed, it's quite reasonable to stay in bed if you think everything's fucked". The normalising message I found in this simple statement meant that rather than feeling as though I was slipping into an extended depressed state, I rationalised that I was simply having a perfectly reasonable human experience. Thanks Joanne.

## Not all specialists are constructed equal

In contrast to the positive experiences just discussed, the following section details some of my peers' opinions on less adequate specialists and fields of practice. Roxy spoke of the ahistorical way she was treated, whereby her previous experiences were ignored:

I think perhaps this is what I've noticed from the mental health system. Because I had a challenging childhood and my father was quite abusive and ummm you know it was ummm so...but because I've been given a bi-polar diagnosis they're really uninterested, you know, the current trend

*That's it*

Is really uninterested

*Yeah it's an interesting one aye*

And I think that there have been times in the past where there was that kind of Freudian developed Jungian whatever

*Yeah*

Psychoanalysis which would just go on and on forever

*Mmm*

And now there like you know 6 weeks of CBT [cognitive behavioural therapy] and if that doesn't work...

Albeit brief, this discussion highlights various critical issues which influence mental health service provision. The need for services to be quantifiably cost effective is one such influence, which means that specialist's focus can sometimes be more on quantities of consumers seen over quality of services provided. Considering the disability rates associated with mental illness I detailed in the first chapter, it can be assumed that these services are not healing many people. Also, since outcome measures are typically specialist driven, consumer self-reports of service efficacy are

rare. These are issues I return to in Chapter Five as they represent barriers to positive change which need to be addressed.

An associated issue is raised by Roxy's statement "because I have a bi-polar label they're really uninterested". I find this statement intriguing as I have experienced similar ahistorisation with labels I have received. For instance, when I was diagnosed with major depressive disorder, the focus of the specialist I saw was specifically on my depressed state, with little attention paid to how I got there. Personally, I have found investigating why I may not be feeling very well gives meaning to my experience, and can help me to move through periods of distress through its normalising influence. I have also found that an over-accentuation on the espoused mental illness ignores the fluidity people have, and the ebbs and flows most experience as part of the human experience. All of these issues can be exacerbated by specialists' modes of operation, as Joanne and I discussed:

You know I've been through the system myself, and I've been in meetings with psychiatrists, they're just useless

*Yeah*

Just fucking useless a lot of them

*Don't care, no idea?*

Well even if they do care, I mean some of them do care. Some of them are good people.

*Mmm*

But they've just got this narrow little beam on a person

*Yeah*

And because they hold the most power in the system

*Mmm*

And because their services gobble up most of the resources, people get this little narrow beam chucked at them

*Yeah*

and there's very little help for them to just kind of ummm you know to clean up the kind of mess that... the train smash of a fractured self-belief, and you know, loss of umm, loss of ahhh, your social roles basically

*Yeah, that's it*

Yeah, it's stupid

The narrow beam Joanne speaks of alludes to the biomedical model which underpins psychiatric practice. Joanne also suggests that the narrow beam psychiatry places on people results from both the paradigm's place of power and access to funding.

Further critiques of psychiatry surfaced as our conversation continued:

And what I've noticed about the whole mental health sector is that, you know, there's a lot of events and meetings and training where people go and you get all sorts of people there and you never see psychiatrists there at anything that's sort of generic mental health

*Yeah*

They just talk to each other, and they read their journals and so they've got this very narrow field of knowledge

*Yeah*

That they're operating it in

*It's archaic isn't it?*

It's bizarre, yeah

*What I see in a lot of what I do, a lot of these paradigms are merging now and melting together*

Yeah

*And we all take from each other as anthropology always has*

Yeah

*But more so now, like there's transcultural psychiatry*

Yeah

*Which is a complete blend of anthropology and psychiatry*

Yeah, and there are fringes of psychiatry, there's transcultural, social... but those people aren't. They're not in the power-house of psychiatry. They're not running the show

*No, not at all*

See there's not the money there too, that's what it boils down to

*Yeah the dollars and the biomedical model*

Joanne again highlights the parochial practices which sometimes occur within mainstream psychiatry<sup>26</sup>. Despite these practices, and psychiatry's shaky scientific base, it still maintains its place as the central authority on mental illness. The ramifications of such a positioning are something I discuss in the next chapter, whereas now I want to discuss some of the experiences my peers shared regarding their inpatient mental illness 'treatment'.

### **'Inpatient' experiences**

As with many other nations where mental health is dominated by the biomedical model, New Zealand has a history riddled with cases of abuse. Roxy described the abuses her Uncle and Aunty experienced in their time within state funded facilities. Unfortunately, as I outlined in Chapter Two, their treatment was the norm for many

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<sup>26</sup> Mainstream psychiatry is biomedically deterministic in terms of mental illness aetiology and treatment, as a pose to other fields, such as transcultural psychiatry, and social psychiatry which is more interdisciplinary based.

who found themselves institutionalised, with the legacy of mistreatment they endured continuing to this day. The following discussion reflects Roxy's contemplations of her relatives' experiences:

That's I guess one of the things with my uncle, who's died now

*Mmm*

Is ummm well, yeah, just the huge abuse of his rights. Like he got experimental insulin coma therapy done to him

*Yeah?*

He just had a very abnormal life, and was, you know, hugely institutionalised. He'd spent most of his life in institutions, and my aunty as well actually, she...I think back then they just used to diagnose everyone as schizophrenic

*Sounds about right.*

And so my aunty was on anti-psychotics for years and quite over-medicated whilst raising her children, and then 30 years later like "oh no, you've been on the wrong drugs for all these years" LOL "you should've been on these, which are much milder in their side-effects"

*Mmm*

So I guess that... it's quite recent in our history isn't it?

Many ex-patients who suffered mistreatment in public mental health facilities around the same time as Kelly's relatives are still seeking a formal apology from the government (Kavanagh-Hall, 2013). Part of this wrongdoing involved experimental drug therapies, which have seen explosive growth in contemporary times (Rose, 2003, p.47). Seclusion practices, which I detailed in Chapter Three, are another product of the age of the asylum. Kelly describes her experiences of forced treatment:

I had that work place that was so awful but then I had this real persecution from that guy

*Yeah*

And it spun me out and I had a big psychosis

*Mmm hmm*

I was picked up by the police, I was carted to ummm...(inaudible) Several people came in and out, put me in handcuffs, and umm a psychiatrist, wearing all-black like she was going to a fucking funeral

*Yeah (Laughter)*

And two pairs of (inaudible)

*Mmm hmm*

And I was in seclusion for five days given my background

*Yeah*

Hello? Put me in seclusion for five days? That's gonna work [sarcasm]

*Yeah*

So have you seen a copy of Like Minds End Seclusion Now?

*Yeah I have*

Yeah that's neat, nice work *End Seclusion*. Have you seen the movie?

*Yeah it seems...I can't register them with a lot of my own experiences*

*Yeah*

*Because a lot of this is quite new to me, they're aspects of mental health as well...the hard edge of it is just something else*

Ahhh man I know the hard edge, if anyone knows the hard edge, I know what it's like. I know what it's like to be left in a cell naked with a bucket to shit in. I know what it's like to be punched over. I know what it's like to be thrown in



the day room, thrown down by five guys and down-trowed and injected in the bum. So I mean I've experienced the worst parts of mental health

*Just rights (human rights) out the window!*

Yeah so you've got a pretty tough cookie here to interview (Laughter)

*Sounds like it aye. Yeah I'm lucky I've just managed to keep out of the public system*

Ahhh (claps) Keep it going!

I find the most telling part of this discussion is Kelly's ability to laugh as she calls herself a tough cookie for having endured such terrible treatment, telling in terms of the resilience she exhibited in being able to create a successful life for herself despite the abuse she suffered. As I discussed in the previous chapters, such treatment is commonly justified out of risk aversion towards violence associated with those categorised as mentally disordered and/or mentally ill. I can accept that there is a need to keep people who work with mentally distressed people safe, but the methods employed in New Zealand are barbaric and outdated. Another of my peers, Patrick, unfortunately experienced similarly traumatic incidents, and although he sought help of his own accord, in our discussion he explained:

And like so, I've tried to go in voluntarily and its worse, yeah

*Yeah*

Unbelievable, when I've gone voluntarily its worse. The choices in front of me are worse, so I went to one of the community teams and asked for CBT

*Yeap*

Cos that was, you know, a recommended treatment

*Yeah*

And I was thinking, "who knows what I need?" I've just got these voices in my head always saying one thing or the other, keeping me awake all night. I just

need to have some psychological interventions. And I went with my partner and had the assessment, had the psychiatrist over from the local community team, and he basically said “I can only give you CBT, I can only do a referral for CBT, if you take medication”

*How does that work? I mean that's a difficult one to understand at all. What's the end goal there?*

And it's the same with taking rescue remedy off me, they know its...that's not about truth and wisdom...he knows that CBT's right, he knows CBT is better than no CBT

*Yeah*

Yeah CBT with medication might be better in his view, but he knows that CBT is better than no CBT, but he preferred to send me away

Mmm

Unless I would have his alternative, I mean that's just power and control!

Patrick's experiences here highlight the power imbalances many find when dealing with psychiatrists who seemingly disregard their client's opinions, and in Patrick's case, attempt to force drug use as a treatment necessity. Perlin (1991, p.111) suggests that such imbalances are inherent in these relationships, as psychiatrists in this context act on behalf of the state in a legal capacity. Unfortunately Patrick's experience was not a singular occurrence, as our further dialogue shows:

Yeah and I didn't take medication so that night when I went back I had some advocates that were trying to force me out of the ward, and I didn't show them that I was unwell, and so the advocates said, “well you've got no right to hold him”. And they said they're only holding me to assess me. Like even when there's no evidence

*Sounds a bit strange, “holding to assess?”*

And they took me to another ward as well...and without telling me. They said the staff isn't that happy with you being on the ward, like I wasn't even entitled, so ummm in the end they sectioned me...again and I had no belongings or anything. I got taken there by the police, and I had some rescue remedy on my and they searched me and they asked me what it was and I said... and they let me keep it but then I went to...they showed me the room and six nurses came into the room and they crowded round and I was in the corner and they said right we want your rescue remedy..ok? And I said well that it's what I use when I'm unwell, and it's just rescue remedy, look here's the label. And they said, "No we've got no interest. We want to put it away. If you want to have any medication you can go through the psychiatrist tomorrow"

I find it difficult to imagine what it must have been like for Patrick to have gone through this experience. To feel intimidated and controlled when at your most vulnerable must be simply awful. Both of the incidences Patrick describes involved medical professionals attempting to force him to conform to what they considered the most appropriate form of treatment. Sadly his voice seems to have been ignored, and despite a lack of evidence for him meeting the criteria for detainment, he was not allowed to leave. This pattern of undesirable treatment continued in the following episode we discussed:

So I ended up being sectioned where the police came, and a doctor came to the house to support the people I was with, and umm couldn't. All they were able to do was medicate me, the doctor, not the group of friends who were with me

*Yip*

And then that doctor called the ambulance. The police arrived and I refused to leave. I was in a dressing gown cos I'd been sleeping and the police ended up dragging me out. That was just the spiral downwards, do you know what I mean? So I went into seclusion, being shoved on the floor, put in a strait jacket. Yeah, so I had a couple of weeks in the hospital where I was

completely like, crushed. And as an experience it's probably the precursor to me challenging everything I see in mental health, you know?

*Yip*

And I've had a couple of other episodes, not as extreme as that. But it was that extreme seclusion, a lack of respect and, you know, forced injections, being jumped by nurses, put on a stretcher between rooms, which for me was like death, you know? I was psychotic, but I had an experience of dying. I've had those ever since whenever I'm coming into contact with mental health services

*Yip*

And it stops me getting treated by the services I need most

Patrick's experiences here show a resilient person in times of need being treated very poorly with long lasting consequences. It seems perfectly reasonable Patrick would be averse to seeking treatment after what he has experienced, and sadly the services have not changed in any ways that may alleviate his concerns. In our user pays, neoliberal society, it may seem reasonable to assume that improved access to private services would secure some form of alternate treatment for 'mental illnesses' other than just psychopharmaceuticals. Yet as the following discussion with Paula shows, this is not always the case:

I was lucky and unlucky...Because we were fine with finances, and stuff like that, I was put into the private system, so I was never put in hospital

*Yip*

So lovely psychiatrists, lovely fellas, ummm I'm onto my third in what is it thirteen years I think, so I've done pretty well

*That's really good, I've got...I've been through about 15 (Laughter)*

(Laughter) and then, my current one is I think the best

*Mmm*

But anyway, the first one could not have been more supportive; he had all the time and resources in the world

*Mmm*

But he chucked me on anti-depressants, olanzapine, of all the nasty drugs to chuck a person on, and lithium plus something else. And the side effects of them were just really nasty. Like I had to give up work and I couldn't function, I couldn't think, like I was constantly cloudy. I couldn't even read a magazine

*Mmm*

You know...so for someone who is used to having a brain that works pretty fast

*Yeah*

It was quite shocking

*I bet*

Yeah, so even though he had all the time, the resources, there was money to support me

*Yeah*

Still I just got pills

*Yeah, yeah*

You know? And so yeah so I think fundamental shifts are needed.

I could not agree more with Paula, as I also believe fundamental shifts are needed in relation to psychopharmaceuticals and psychiatric practice. Many of us have experienced consuming these drugs with a range of outcomes. The following section is dedicated to sharing and analysing some of these experiences to provide some insight in what it is actually like trying to maintain wellbeing with chemicals.

## Drugs....

Psychopharmaceuticals are by far the most popular treatment option for mental illnesses, which despite a lack of empirical evidence regarding their efficacy, are continuing to be consumed by an ever increasing number of people. Through our attempts to maintain wellbeing, many of us have consumed psychopharmaceuticals with varying outcomes. As such, there are no right and wrong answers when it comes to making the choice to either take these drugs, and for many they are not seen as choices at all as there are no other options. General practitioners, and/or psychiatrists are usually the first people seen when someone is experiencing mental distress. They are also the people who make diagnoses and write the majority of prescriptions for drugs. My discussion with Paula shows that people generally accept what doctors say, and see them as purveyors of truth:

Because when I was in my late teens I was really physically unwell with a gastro disease

*Yip*

And doctors saved my life

*Yip*

So that was my frame

*Mmm*

Doctors are licenced, so a doctor says "take these pills, there are a few side-effects but you'll be fine"

Yet as time went by Paula found out first-hand that this is not always the case:

Then I moved back to Wellington and got another doctor, and he's like, "ohhh, you shouldn't have been on those pills, you should be on these pills"

*Yeah*

And I'm like, "ok"

*Yeah*

(Laughter) So I take these pills and then I started trying to find out more and what I ended up doing is taking different pills. So I added in lithium plus advanced side-effect drugs at that point and they even gave me an epilepsy drug because it was supposed to help with cognitive function while you take these other pills. I'm just looking back thinking, "why did I do that?" Add another chemical to the mix

The changing and combining of medications is something common to many of us who have sought their espoused benefits. Trial and error, which equates to broad scale experimentation, is the preferred method in establishing which medication is going to be most efficacious for each person. I have experienced such experimentation myself, and found it challenging trialling various drugs whilst trying to meet my obligations for University, and my life in general. The first drug I took to treat my mental illness was an anti-depressant called fluoxetine, more commonly known as Prozac. The doctor who prescribed me the drug explained that I had a chemical imbalance which this drug would hopefully correct. Yet as I outlined in Chapter Three, the chemical imbalance hypothesis is a myth. Paula expressed a similar understanding in the following conversation:

The medical world seems to think there's some kind of biological genetic or you know, physical marker for want of a better word that attributes a diagnosis to mental illness to a person. I don't believe that because they don't have proof

*Mmm*

If they can't prove it, why would I believe it?

I remember going, you know the Mao clinic, have you heard of the Mao clinic? You'd respect them right? Last time I went to their website they were still saying that bi-polar disorder was the result of a chemical imbalance in the brain

*Mmm*

So it's like "oh what you're right, so where's your proof?"

*Yeah*

Come on show me, I'll believe you if you can prove it to me

*Yeah*

But you can't. But if those kind of respected authorities are saying it as you say

*Mmm*

Then the general public are going to accept it.

What Paula describes here is a great example of Foucauldian social constructionism in practice. Put simply, agreeing with those who hold the power to express knowledge which is considered truthful (in this case the Mao clinic), reconstructs knowledge so it continues to be considered 'truthful'. Even, as it is in this case, if the knowledge is unable to be supported, it will still circulate as truth as it goes unquestioned. In my experience some of the specialists who perpetuate this misinformation will defend it vehemently, which became the basis for further discussion Paula and I had which I initiated in saying:

*They really minimise the effects that a lot of these drugs have aye. I've had these experiences, you know, by saying these are my side-effects. They're having a huge impact on my life, and there just like, "well, plenty of people take them without any problems". As if I'm making it up*

*Mmm*

*I didn't realise how strong a lot of these drugs were until I'd tried them myself too aye, they're not something to be played with or toyed with and they're hard to get off, you know*

*Yip*



*They are mind-altering substances aye*

Yeah definitely

*Serious stuff*

It's taken two years and I'm coming off the last anti-psychotic I was on

*Mmm*

And on the third-to-last reduction it was so bad I was just going home...I was coming to work, going home lying in bed just not even doing anything

*Mmm*

Just silence, no movement, I just needed absolutely no stimulation, to just get through, you know? And I know people who have it a lot worse than me

*Yeah*

And you read stories about people who just cannot get off them.

This was something I actually did when researching the side-effects of the last anti-depressant I was prescribed, and what I found was rather disheartening as many stories I read made me fear that I would be on this medication (Effexor XR) for life. I also looked up videos on YouTube<sup>27</sup> to see others experiences of the drug as I was having some fairly dramatic side-effects which were making my life quite difficult. Eventually, after becoming mentally distressed whilst on Effexor XR I stopped 'cold-turkey' and have not taken any since. The main withdrawal symptoms lasted a couple of weeks, and I experienced flu-like symptoms, along with what are known as 'brain-zaps' or 'brain-shivers'<sup>28</sup>, which were quite scary.

I'm reminded here of an argument I had with a GP only a couple of weeks prior to stopping this drug, in which I tried to convince him that such drugs are highly addictive, by drawing a comparison between heroin and Effexor consumption.

Basically, I argued that although heroin initially gets you high, that is not why addicts

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<sup>27</sup> See [https://www.youtube.com/results?search\\_query=effexor](https://www.youtube.com/results?search_query=effexor) for several examples.

<sup>28</sup> For a detailed discussion of 'brain-shivers' see Cortes & Radhakrishnan (2013).

take it. They continue consuming heroin to avoid the withdrawals, rather than to get high. The same can be argued of taking Effexor, as a multitude of people I viewed on YouTube said they continued to consume it simply to avoid withdrawal. Despite my knowledge of these drugs, as I said to Roxy, "I won't say I won't be eating pills again, just whatever it takes at the time aye". Our talk then diverted into Roxy's experiences and opinions of drugs:

*So were the meds never that great for you?*

Yeah I haven't had a significant difference from any of them. I mean sometimes, you know, the psychiatrist or someone suggest aww maybe it's made the depression a bit shorter or

*Mmm*

I don't really feel it has

*You don't feel, I mean rather than just that, you don't feel altered on them though?*

Ummm well there's things like, kind of, maybe feeling sedated or yeah, and I yeah

*Yeah a lot of them haven't done a hell of lot for the depression, but yeah, I've been altered in all kinds of other different ways aye*

Right, well I've definitely had some of the weight gain

*Yeah*

Yeah, and the different things like that

*Yeah*

Less sleep and I kind of felt a bit more numb on them. I didn't really have the same range of emotions on them. John Reid's (et al. 2014) done that study, umm it was his last piece of work I think before he left New Zealand, and it

was talking about the side effects of anti-depressants. Well not the side effects, the effects

*Yeah (Laughter), they are the effects yeah*

Yeah, people felt their range of emotions narrowed, and it impacted on their intimate relationships quite a lot, and close family and stuff.

Joanne elaborated upon the issues which surround these drugs in the following exert:

I mean psychiatric drugs are just... I don't know if you've ever read Joanna Moncrieff?

*Yes*

Well you know her whole idea that actually the drugs don't treat the problem

*No, it's like an anti-depressant*

*Yeah*

*Or anti-psychotic, they're a drug that has a drug effect like any other drug*

Yeah like alcohol. That's not to say they don't have any place in the world; we've just got to be honest about them

*Yeah exactly*

And cos I got spun this line, "ohh well you need lithium like a diabetic needs insulin". Well that's a load of crap

*Yeah*

An absolute load of crap

*Mmm*

They don't even know how lithium works

*Yeah*

All it does is it overwhelms/calms what's going on and, you know, some people find it helpful that's fine, some people don't and

*It's where we get the info from though aye*

Yeah

*First port of call's the GP*

Yeah

*You know, you're gonna trust what they say and you know*

Yeah

*You believe all this*

Well you do tend to believe them

*And what are you gonna believe outside of that*

Mmm

*A doctor or me that's read this literature?*

Yeah well not everyone's gonna dig into the literature to find it

No

And that's why I'm really interested in giving people really easy to read, digestible information

*Mmm*

That's based on sound research...

As Joanne suggests, providing information which is counter to the dominant biomedical discourse is essential in ensuring consumers are able to make informed choices around how they might maintain their wellbeing. This perspective is also shared by Patrick:

They're killing people through dishing out medication, yeah

*Mmm a lot of it based on bad science*

Yeah

*With no clue what any long-term effects are. All the side-effects are downplayed*

Yeah, so I'm a firm believer in anybody having the right to use them. I sort of believe that anybody should have the knowledge of what's available

*I agree*

Yeah, and change the medication if that's what they want, but not just a panacea to sort of all mental health services

These conversations with my peers all suggest an over-utilisation and reliance on chemical treatments by specialists. Yet as I mentioned in my own narrative, drugs are sometimes the best option, and therefore need to be available as a choice for consumers alongside a range of alternative options. The need for such choice is apparent in the following discussion between Tina and me:

You know they say that medication doesn't work, but I think they have helped me

Yip

I think that without the meds, I think I'd be fucked

Yeah I get you

They help me function and do what I need to get done

Overall, our experiences and knowledge of psychopharmaceuticals highlight both their limited efficacy, and question their evidence base. Upon being prescribed a psychopharmaceutical, many experience the trial and error stage as Paula, Roxy, and I did. Unfortunately, even if a drug is found that does have some usefulness the next concern many face is attempting to stop taking it. Such difficulties speak to the

addictive qualities these drugs possess, and the minimisation of withdrawals by many specialists. Whilst drug therapy is utilised by an overwhelming majority of consumers, a range of alternatives exist which can be applied in combination with, or separate to psychopharmaceuticals, in attempting to maintain wellbeing.

### **Maintaining wellbeing**

A multitude of methods exist for maintaining wellbeing, yet access to these methods is not always open to all who wish to utilise them, with funding and the dominance of biomedicine the main barriers. Access was an issue Roxy brought up:

It's actually quite hard to access psychology with a diagnosis like mine, especially as there are only two secondary mental health teams locally

*Mmm*

And they share a part time psychologist

*In the stats I think there's only like 400 New Zealand wide*

Right and a lot of them would be private

*Yeah, the majority of them are private*

Even if access is not a problem, as in my experiences, being able to work with psychologists is little guarantee of a positive outcome. I have seen numerous psychologists who charged substantial rates for the privilege of their expertise. Unfortunately the majority of these highly paid specialists provided little in the way of alleviation for the mental distress I was experiencing, and I often found myself trialling psychopharmaceuticals out of necessity. As Tina and I discussed earlier, the necessity of medication for maintenance is a reality for many who experience mental distress, and is an issue I brought up in my conversation with Kelly:

*So you've still kind of got a maintenance plan going?*

Well I'm pretty highly medicated at the moment. I don't like that at all but...

*Nah, neither do I*

Yeah but for right now

*Yeah its necessity aye*

I've got a good psychiatrist

*That's cool!*

Yeah, and I've got a very good Advance Directive<sup>29</sup>, this is going back to that seclusion experience which taught me...so that cost me a bit of my life

Maintenance of wellbeing is frequently multi-faceted, as often various influences combine for a person to become unwell. Kelly's choice to utilise psychopharmaceuticals highlights their efficacy in certain circumstances, and the variation which exists between consumers. In contrast with Kelly, within the following discussion Patrick explains how he maintains wellbeing without psychopharmaceuticals:

To answer your question, how do I manage without medication?

*Mmm*

And I do, I've attempted treatment along the way but the way I manage is through my activity really. So my recovery at any point is actually putting huge amounts of energy into my work

*Mmm*

Work to actually change or address or you know, point out this is an unjust world that we live in

*Yeah*

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<sup>29</sup> "Advance directives convey consumers' wishes about accepting or refusing future treatment if they become incompetent. They are designed to communicate a competent consumer's perspective regarding the preferred treatment, should the consumer later become incompetent". (Wareham et.al, p.349)

That's probably how I've used activism as a sense of recovery and I'm in...I'm in that process a little bit at the moment, over the last couple of weeks, you know. There's been a lot going on

*Yeah*

Yeah with what I'm involved in it means I don't sleep as well, I tend to talk a bit fast yeah, and I recognise that yeah? But I know that, I know the ceiling

*Mmm hmm*

I've been really lucky I've been living with a partner who's really understanding

*Yeah*

But we're almost intrinsically linked in our recovery, yeah? I would say she's also a consumer in many ways but she does it in a very different way, she'll be on meds or...

*Yeah*

Her recovery is more sort of based on family, yeah?

*Mmm*

Mine is as well but that's how she keeps...just treading lightly and moving along yeah?

*Mmm*

Patrick mentions here that his work is a large part of his recovery. As his work is inherently altruistic<sup>30</sup> it seems that he is benefiting from being able to contribute to the wellbeing of others. Patrick also mentions the support he receives from his partner and family in his recovery which speaks to the need for social support in

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<sup>30</sup> See Schwartz et al. (2003) for a discussion of the mental health benefits of altruism.



maintaining wellbeing. Such support is something Roxy and I also discussed in relation to her workplace:

It's an amazing environment and you can, you know, be very honest about how you're feeling

*Yeah*

And, you know, if you're having a shit day you don't have to hide it

*That must be nice*

Yeah, it's lovely

A work environment which fosters open communication is an important element in maintaining wellbeing, particularly as many experiences of mental distress are extremely isolating, and are often exacerbated by a lack of support (Kawachi & Berkman, 2001, p.458). As the following dialogue with Roxy shows, such support does not necessarily have to be overtly specialist in terms of mental health maintenance:

*What sort of things do you do yourself? What do you find works for you?*

Ummm, well that's kind of what irritates me, that I haven't found a wonderful cure

*Mmm*

I try and do the exercise thing, and I also meditate

*Yip*

But then, like at the moment, I just go once a week to my group. I don't actually meditate everyday

*That's an interesting point; I think about that a lot too ummm. I find it very difficult myself to do all of the things that I think I should be, positively, by myself all the time. You know it's...*

Yeah

*It's challenging alright, aye*

Well I guess the irony is if you're feeling ok you have the energy to do the wellness stuff

*You just don't question it aye, that's just living isn't it? That's not maintaining or....*

The irony Roxy speaks of, whereby undertaking tasks towards wellness are easier during times of elevated mood, illuminates an issue I imagine most people face. The issue is the need to undertake tasks for our future benefit despite a lack of instant gratification. For consumers in particular, delaying such gratification may often seem counter-intuitive when any gratification at all is hard to come by. Particularly when social supports are lacking, and there are ongoing obligations to meet which mean people cannot simply take a break. These may be some reasons as to why drug treatments are utilised by so many experiencing mental distress. A lack of access to effective alternative services is certainly another of these reasons, alongside again the overwhelming dominance of the biomedical model.

## **Conclusion**

The discussions within this chapter showed that for specialists to provide useful services they need to be able to empathise with people they work with, and also integrate and apply knowledge outside of the biomedical model. My peers provided several examples of the outcomes they experienced with specialists who failed to use either of these suggestions, and they suffered as a result. Specialists' ignorance of context, and other aetiological influences upon mental health were also prevalent in these discussions, and provide areas in which specialists may be able to improve their service provision. Overall, these failings are an outcome of the dominance of the biomedical discourse, whose proponents' claims upon truthful knowledge, which many consumers accept, exclude alternative discourses from being circulated. Methods of maintaining wellbeing we discussed provide an example of an alternate discourse, and shows that drug therapy is only but one option available to people

experiencing mental distress. Within the following chapter, we discuss a range of alternate discourses, alongside further barriers to positive change.

## **Chapter Six: The path to happiness is not to avoid unhappiness**

In line with the main aims of this work, within this chapter I explore the various barriers to positive change in relation to mental health, alongside options for remediation. To this end, the issues discussed are intertwined with potential solutions we believe best fit with our understandings of mental health. In terms of issues requiring resolution, several advocates I spoke with pointed to the Act (1992) as the largest barrier to positive change. Particularly as it reinforces the discourse of violence which suggests that people who experience mental illness are a risk to the general public. Such discourses see many consumers segregated from mainstream society, and subject to negative discrimination in various areas of life. From trying to find employment to being forced into treatment, for many of us our basic human rights are ignored on a daily basis. In terms of human rights breaches, I discuss the practice of inhumane practice of seclusion some of my peers experienced, in order to reinforce the need for immediate change. Following this discussion, I present a range of ideas for positive change my peers raised, which are again derived from personal experience with specialists and the Act (1992). To conclude this chapter I discuss some alternate assessment measures which place consumer's voices first in evaluating their treatment experiences, rather than making covert assessments without their input.

### **The Mental Health Act: segregating since '92**

The Act (1992) entitles a range of mental illness specialists and also police to intervene in people's lives based on risk assessment measures. As a result, specialists utilising the Act (1992) can detain those considered mentally disordered for undisclosed periods of time, and subject them to various treatments without their consent. The Act (1992) also serves as a basis for segregation within New Zealand society by designating some people mentally disordered dependent upon the behaviours they exhibit (or are reported to have exhibited). For these reasons, and

various others, many of my peers expressed dismay at the public mental health system and its key policy, the Act (1992). Such dismay was expressed by Joanne who in no uncertain terms stated:

The mental health system is totally fucked, you know...

*Yeah, it seems like it to me. When I had these illnesses, which I found quite isolating, I came to realise how many other people had similar experiences to me. It's not like a major conspiracy going on, there's all this information out there*

Yeah, yeah

*And we're being fed a load of bullshit. I thought it would just need to be made publically known and just change like this (snaps fingers). That's what my naïve idea of this project was you know.*

Yeah well I wish that was the case but I think that systems are like cockroaches, they're very resilient to any sort of pressure to change, and you know we have a lot of dollars going into...\$1.25 billion going into mental health services

*Yeah*

And we treat people terribly and they treat us terribly a lot of the time, not all the time but a lot of people get treated very badly

*Mmm*

And they get terrible outcomes

*Yeah*

So what the fuck! I mean why would the taxpayer be happy with that kind of thing?

*Yeah, it's kind of out of sight out of mind*

Yeah it is, it is, and if I had the energy, you know, I'd be marching on the street about it but I've got too much else on my plate (Laughter)

*Yeah Lol*

I just don't have the time

The resilience of these systems Joanne mentions is reinforced by the difficulties I outlined within Chapter Three regarding attempts the consumer movement made to bring about broad scale cultural change. Rather than attempt such widespread systemic change, many of my peers advocate altering specific parts of the mental health system. Paula was one such peer, whose perspectives on the mental health system are outlined in the following conversational extracts:

So I think the fundamental problem is the Mental Health Act. I think that article 5 of the Convention of the Rights of Persons with Disabilities is the anti-discrimination provision, and if we adhered to that we wouldn't even have a Mental Health Act

*Yeah*

If we're gonna have some argument about people's capacity to make decisions, well then it should be anyone's capacity.

*Yeah*

So if you're if you're physically unwell and incapable as a result... if you're older and becoming incapable as a result the same rules should apply for everyone, there shouldn't be some special mental health standard

*No*

You know? Cos that's just discrimination!

*Yeah absolutely*

I mean we've got a system that is based on this compulsory treatment act [Mental Health Act, 1992]. And I think that that is one of the most discriminatory things we've got going

*Mmm absolutely*

Because that is the foundation that says to the whole of New Zealand, "these people can be locked up cos they could be a danger to themselves or others"

*Yeah*

You know? And that's the message

*Yeah, yeah*

You know? We can seclude people because the legislation says we can because these people...they're dangerous? Am I dangerous?

As Paula points out, if the New Zealand government adhered to the Convention of the Rights of People With Disabilities (2014), the Act (1992) would not exist. This is because the Act (1992) itself is fundamentally discriminatory, as it subjects certain people to different standards of evaluation and treatment than the rest of society. This perspective is echoed the following conversation between Joanne and me:

You know I think there has been a problem with mental health being located in the health system, and I think if there was any better location it would be in the social services aye?

*Yeah*

And one of the really terrible things that we have is compulsory treatment, and well what I mean is we have a special law for 'crazy' people

*Yeah*

The Mental Health Act (1992), and that's blatantly discriminatory

*Mmm*

Blatantly! It's discriminatory because there's a lower threshold. I mean, you know, people in the health system who refuse physical health treatment are allowed to do that

*Yeah*

That's their right

*Yeah*

As soon as you're in the mental health system and you get a diagnosis, you are at risk of having that right taken away from you

*Yeah*

It's a travesty, and the other sort of criteria was the risk of harm to others

*Yeah*

And this is the only piece of legislation I know of that can take your rights away from you before you've committed a crime

*Yeah*

On the prediction that you might, and I just think that's really totally discriminatory

*Mmm*

And the other thing that happens in a system that has compulsory treatment: it just skews the whole system of power; it just corrupts the whole business.

Joanne's assertion that the Act (1992) is discriminatory and breaches patients' rights is evidenced in Chapter Three. In terms of fighting negative discrimination many consumers currently experience, Roxy suggested that:

A big thing around discrimination is defining a group as 'other' or 'those people', then that's why you'll treat them differently

*Yeah*

So I guess our message is that it's part of human experience, and perhaps slightly more extreme, but it's still the human experience

*Yeah, and I guess in amongst that is the idea that we need to be able to have more open conversations. These things don't always have to come about if we've got kind of a bit of a stronger idea of mental health going on the entire time aye.*

Yeah, exactly

Paula shared similar opinions on achieving positive change through fighting for equality from within the mental health system:

If we had a mental health system that was like what we were talking about before, where people were, if they're having an experience and it was outside the range of normal behaviours, people would prepare for that. People would be told that in life things could happen to you and if they do, you need to go here and talk to these kind of people

*Yeah*

'Cos they will support you, not "this is a really freakn weird situation, we need to panic and make it worse"

*Yeah exactly aye (Laughter)*

And so if we had a system like that and we didn't have this nasty beast that makes people other...

*Yeah you kind of wonder what peoples' idea of mentally ill people is. Like some of the people I've talked to want a general sense of what I'm up to and ask "so are you actually working with those mentally ill people?"*

Mmm

*Like (Laughter) that must be freaky or something*

*(Laughter)*



*Like “ohhh I don’t know if you’d wanna do that let alone”...And in actuality I have several diagnoses, so you’re talking to one of those people*

(Laughter) one of ‘those people’

*Yeah, exactly aye*

Then there are people who want to rail, fight, and you know, jump up and down

*Yeah, that’s never worked though*

Exactly

*I mean this has already been done, there was that whole anti-psychiatry movement, well and that was railing hard but for nothing. Because that’s what happens aye, one side against the other. You’ll always have a struggle for right and wrong...whatever*

Particularly with this group of people. Because if we’re jumping up and down all the system’s gonna do is say “you’re unwell we can discount you”

*That’s right aye (Laughter)*

You know (Laughter). And so it’s self-fulfilling

*Yeah it is*

So you have to...I think for this one, I really strongly suspect that the only way we’re going to achieve change is to work within the system

*Yeah I’d agree*

Just by proving that we are capable, reasonable human beings

Paula’s normalising message continued further in the following conversation:

That’s why we call it mental distress

*Mmm*

Because it's...distress is something anyone can understand

*Yeah*

And if you put mental in front they really understand the realm you're talking about

*Mmm*

But it's what we were saying; this is a normal human experience

*Yeah*

You know? And try and normalise that in the general populous. Because as soon as you start saying to people "do you know that you can get locked up in the hospitals when you've done nothing wrong?"

*Yeah*

They go, "what"?

*Yeah (Laughter)*

(Laughter) "How's that work? Why does that happen? What are you talking about?" And if you start talking about it from, like I can't say from my own experience, but I can say that could happen to me

*Mmm*

You know? I don't think that's right, and you start engaging those conversations and people go, "aww but you're so 'normal' and that could happen to you and then they say start questioning it a little bit. And if we could have more of that, just that normalising influence

Both Paula and Joanne's perspectives speak of the 'othering'<sup>31</sup> many consumers' experience which fuels discrimination, and justifies their treatment under the Act (1992). As Joanne proposes, we have every right to be treated as equal citizens, and

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<sup>31</sup> I use the term 'othering' here to denote the categorisation of consumers as both different and subordinate to non-consumers.

the Act (1992) should ideally be abolished to this end. In a continuation of our conversation, Paula speaks about the power imbalances between biomedical specialists and consumers:

I think a lot of it comes back to the Act (1992) and the fact that we've got and built on it is this system of power, you know, with the psychiatrists and the director general of mental health, and the chief psychiatrists at all the hospitals and all these people. And they've all got this power and they don't seem to be able to recognise that they shouldn't, you know? What right do they have to have power over other people?

*Yeah*

And it comes back to what you were saying "I'm a professional, I've been doing this for so long, I know better." Do you really?

*Mmm*

"What makes you think you know better?" Can I question that?

*Yeah, and it's not entirely imposed by them either aye, it's kind of yielded from the other side as well. Like what you were saying, you know like, if that's your belief that this person does have this power, and does have this knowledge, then you know, you'll give in to that*

*Yeah*

*So it's always contracted, reified, reconstructed, and on and on, and why wouldn't you listen to your doctor?*

Because they're the professionals, they're there to help (sarcasm)

*Yeah*

(Laughter) We're in the helping profession (sarcasm)

*Mmm*

Yeah and “we do no harm”, and yet look at the physical health rates. Look at mortality rates. There’s a piece of work being done by a woman with the WISE group<sup>32</sup> doing research around mental health and people with diagnoses. Her numbers are showing that people with diagnoses have significantly reduced levels of physical health than the general population; higher rates of smoking, you know all the mortality figures that float around. Generally diagnosed people die around 20 years before others

*Yeah*

And I think that’s people on anti-psychotics...you might have to check that, but yeah I mean “do no harm”

Joanne also talked about the divisions between mental health consumers that Paula alluded to. I believe such divisions come about as many consumers believe the truth claims of biomedical practitioners, whilst others question the information they are provided. The following discussions confirm that consumers are not a cohesive group working towards positive change:

*It’s a difficult one too, when you think about it, like because it... There is a group there of consumers, mentally ill... However you want to define them but it’s not like, you know, the black rights movement or women’s rights movement or where people actually understand that they’re oppressed and marginalised*

Ohhh! Half of them don’t get it

*No, they don’t question even the meds they’re given*

No, not at all

*To me it’s similar to alcoholism in that it’s self-fulfilling*

Yeah

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<sup>32</sup> “The Wise Group is a family of charitable organisations and is one of the largest providers in the New Zealand mental health and addiction sector” (<http://www.wisegroup.co.nz/>).

*It gives you a crutch and a justification to carry on doing whatever*

Yeah

*Your social circle around you reinforces it and so on and so on*

Yeah and there's a lot of people that are working in this area who have mental experience

*Mmm*

Who are working in the 'system' are totally captured by it

*Yeah, that's right*

Just, you know, we have debates about seclusion with some of them

*Mmm*

Some of them think seclusion is alright

*Yeah*

Ohh well (Laughter), shit

Within the following conversation, Tina and I also discussed the heterogeneity apparent within consumers' perspectives:

For some people too they're just so used to it that they live it.

*Yeah*

Because it's easy

*Yeah, and they don't question it*

No

*They just say, "I've got this diagnosis. I am this. I do this because this is what the doctor told me"*

Yeah

*And that traps a lot of people aye*

Yeah that's why I always say you've got to own it to overcome it. So yes, you'll always have certain challenges but educate yourself and fight

*For sure.*

The variance amongst consumers mental health understandings, both Tina and Joanne speak of, are exacerbated by misinformation spread by biologically deterministic specialists. As I have previously stated, this misinformation is not forced upon consumers, instead they take part in its social construction by accepting that what they are told is factual truthful knowledge, and partaking in the accompanying acts, such as consuming drugs for their espoused illnesses. Further to this, as I discussed in chapter one, the majority of consumers come from lower socio-economic backgrounds, and are less likely to have access to treatment alternatives outside of mainstream biomedicine. Also, as Joanne suggested, many of these consumers are unlikely to investigate the literature around mental illness and draw their own conclusions, as generally their context is not conducive to critical thinking or self-insight required to resist dominant discourses. I begin the following section with some examples of this resistance, which came up in my conversation with Patrick in relation to ending the practice of seclusion, and the silencing of the consumer voice.

### **Seclusion: daily breaches of human rights must be ending soon aye?**

Just over the last two weeks yeah, I've seen a lot of synchronicity of things that happened

*Mmm*

Hey it might just be me reading into things but lots of things have happened

*Mmm*

There's been a little mini explosion, yeah?

*How so?*

Like the New Zealand nurse's organisation has done a huge spread on mental health patients and it's got this picture, (which is the most graphic picture I've ever seen) of a nurse that's got bruises and blood shot eyes. It's so awful to look at, and it's about mental health patients attacks on nurses

*Really?*

Yes, and it doesn't mention seclusion, it doesn't mention anything about why nurses face any violence

*Yeah*

So in terms of where it's going [the movement to end seclusion] I think it's going to get a lot worse

*Yeah*

It's almost like because we have got reduction of seclusion going on

*Mmm*

I mean not everywhere but...

*It's all different at rates because it's all left to these separate entities aye?*

*[District Health Boards]*

That's right, yeah. But hey, all we need is a change of paradigm and we're going to be making real progress

In terms of the picture Patrick mentions, we again see negative discrimination aimed at consumers due to the discourse of violence. As Patrick suggests though, whether this discrimination is a consequence of efforts to end seclusion or not remains to be seen. What can be said though, is that many of the stakeholders involved in the practice of seclusion are change resistant, and risk aversion is likely a major component of such resistance. Paula showed some scepticism around the potential success of the movement to end seclusion:

*Yeah so there are guidelines for that (seclusion) to change by 2017?*

No, umm, the disability action plan is just an action plan

*Oh ok*

So the Act (1992), I think its section 74/72, bit hazy on that, legislates that you can seclude people

*Mmm*

There's a government document called *Rising to the Challenge*

*Yip*

You can get it on the Ministry of Health website

*Mmm hmmm*

And that says that there should be a reduction and elimination of seclusion in New Zealand. There's the Rising to the Challenge 100 action points I think it's called, and one of them is reduction and elimination of seclusion, and the responsibility for that falls with the DHBs

*Yeah*

So the DHB's have to put in place the plan

*It's so splintered though*

And the DHB's...bless them, I imagine are quite risk adverse

*Yeah*

So then they struggle, and you've got a national body seeking to reduce a practice, reduce and eliminate a practice, why haven't you got a national body driving it?

*Yeah*

You know? If they were really serious, if you mean it to happen, put a timetable in place, put practices in place



*That's it, it seems similar for a lot of the legislation and documents they've put out. They're just to shut people up or keep people happy aye, just tokenism aye... Like, "yeah yeah we'll do this," and then maybe somebody will moan by 2017 when nothing's happened*

Yeah, and umm, I saw this thing on the radio NZ website that was John Crawshaw was the director of mental health. I think his title is

*Yip*

And he's talking about seclusion and basically saying "we're not guna rush it"

*Oh yeah, really?*

(Laughter) "Isn't that your job to put in place what the government says they want to happen?"

*It just seems so immoral to me, they're just so disconnected from their fellow man because as another day passes, who else is getting screwed by them. And they just think that that's fine?*

Oh yeah, and also on that website there's an annual report, and it shows those seclusion figures

*Mmm*

And people I've talked to say they will not be accurate, they will be higher

*Yeah*

But I don't have any proof of that

*Mmm*

But even then the numbers are hundreds of people per year, how is that ok?

*Yeah, it's not at all aye (Cynical laughter)*

Yeah, I don't get it...

The admission that seclusion needs to be reduced and eliminated by 2017 shows that the government has concluded the practice is not working, and also signifies that to some extent consumers' voices are being listened to. Unfortunately, as both Patrick and Paula mention, and as I detailed in chapter three, there are no guarantees these goals will actually be met. Despite seemingly insurmountable obstacles to positive change, my peers are still optimistic that various avenues still exist which can be effective in assisting consumers.

### **What else can be done to sort this mess?**

During our interviews I asked several of my peers how they saw positive change could be effected in the area of mental health (or variations on this question). The following conversations convey their expert perspectives around this topic. The first of which was with Kelly, and was centred on the way many medical doctors operate within mental health:

*The one I tried to question treated me like an idiot, like "what are your qualifications?" and "what would you know?"*

Ohhhh! Yeah, no tsss (scolding sound) to that

*Yeah*

You know, what you know is what they don't know

*Exactly*

You have experiential qualifications

*Yeah*

And those experiential qualifications say you are the expert and their real job, a job of any clinician is to be... Are you aware of the model called the Tidal Model, it comes from England

*No?*

Professor Barker, there's a whole kind of show that goes with him ok. I like him and his wife very much, and if you look at the model it's really great

*Mmm hmm*

What he says is that the clinician is just an apprentice, and he's an apprentice to you, to your story

*Power to that, sounds good for a start*

Isn't that great

*Yeah*

They haven't got this great supreme clinical model, and all that fucking stuff about "our" objective opinion of what is happening here, and we go, "how come you get an objective opinion? You come with all your baggage and bullshit"

*Yeah exactly*

So how can you maintain "oh I've got complete objectivity"

*Yeah*

It's not a space that you can occupy

*No its not, its bullshit*

Yeah, so I mean it's interesting, you better explore that.

The idea that people are experts in their own lives holds great appeal to me; particularly as it is a central tenet of the type of social anthropology I attempt to practice. Unfortunately though, whilst the Tidal Model (Barker & Buchanan-Barker, 2010) Kelly speaks of may sound fantastic in theory, much of the knowledge consumers have, and subsequently their agency, is limited by their context and also by dominant discourses. As the following conversation between Paula and me shows, changing specialists' ways of working, and the discourses they reproduce is a

very complicated business indeed, particularly as it would involve altering deep seated power dynamics:

*You know, there is kind of that dollar value floating above people and some people are...we just don't feel are worth it*

Honestly

*A bit of neoliberalism, a bit of all kinds of things going on there (Laughter), it's not good though aye?*

No it's not good, but ummm the CRPD (Convention of the Rights of People with Disabilities, 2014) thing, the convention is saying that people...I think it's called the social model of disability, so it's not that people are disabled

*Yeah*

It's that there are disabling features in society, floating all around these people

*Yeah for sure*

And so I think the Mental Health Act is very much saying these people are disabled

*Yeah exactly*

Whereas if we had legislation which said the circumstances around these people are disabling to them then that would be such a huge shift, I think it would necessarily follow that things would be better

*Yeah, I agree, but I think you're challenging people's whole outlook on life and themselves in amongst that aye? And it's too much for people to swallow. A lot of people that have the power to do something are the GP's, and all the rest of the professionals in amongst it. You know?*

Mmm

*They're quite happy just doing what they've been taught to do; just regurgitate more information*

Well yeah, as you say, it would be a huge challenge for some of these people to accept that everything they've been doing for the last, however many years, is wrong

*Yeah and what they've been struggling for in their own lives and what they do themselves, that's a lot to try and...*

Yeah, but isn't this great because we're expressing an understanding towards their position

*Mmm*

Are they gonna say the same of our position? (Laughter)

*(Laughter) Yeah, that's it*

(Laughter) You know? Like I don't necessarily think that's happening

*No, I don't think so*

This discussion again highlights the need for open conversations to take place between all stakeholders in the area of mental health. The current divisions between specialists and consumers are of detriment to all involved, as each has an important role to play in ensuring that those who experience periods of mental distress are given the best opportunity to live a fulfilling life, and form meaningful connections with others. This sentiment was echoed by Tina in reference to Pacific Islander's mental health needs:

I don't think that we have a fair say

*No*

And like, I'll give you a perfect example why I say that. With the three DHB's (District Health Boards) merging

*Yeah*

They had this guardianship committee representing consumers and they had every ethnic group except Pacific Islanders. How does that work?

*Well it's not going to work*

Yeah exactly

The limitations of the cross-cultural applicability of the biomedical discourse also came into question in my discussion with Tina:

Another reason I don't think it's changed is because although they say they want to help Pacific Island people, they don't want to have to pay to translate information into their languages

Mmm hmm

Well it's that same as if you're writing a book or compiling resources; it all costs money. But not everyone reads English

Mmm hmm

You know? A lot of people that have come over to New Zealand can't understand English. And aside from the language barrier, there's no word for Bi-Polar for Cook Islanders

Mmm

It's Makenava, everything is Makenava. Schizophrenia, depression, any mental illness; one word means all of that

To this end, in congruence with the perspective that consumers need to be treated on an equal basis with the rest of society, Patrick suggested:

*Like Minds Like Mine*<sup>33</sup> would say know me before you judge me. But they're still saying it's a mental illness which...I think we need to get rid of that yeah

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<sup>33</sup> "Like Minds, Like Mine is a national, publicly funded programme aimed at reducing the stigma and discrimination associated with mental illness." (<http://www.likeminds.org.nz/>)

Patrick brings up an important point here, which is that many groups who are advocating for positive change are also unintentionally reinforcing the divisions perpetuated by the Act (1992), consequently contributing to discrimination and alienation. Another perspective on affecting positive change for consumers arose in the following conversation I had with Kelly:

So what else can I help you with?

*Ok, well where do you see things going from here? I think I was quite naïve looking at this coming in and you know...so much of this, it's not a conspiracy is it? I mean it's all out there*

Yeah yeah I know

*But when I came into this I thought somebody will get on Campbell Live and set things straight, you know what I mean?*

Well we're hoping somebody does! You've got me on a flow Sam because I have just done a piece of work which at the end of it says that people wanted the government to offer an apology and acknowledgement. Feeling that this would at least help some of the abuse they'd had

*Mmm*

But that's the gist of it right now the Human Rights Commission put out something, they've got a good lawyer, and they've been working on this. So basically the document says the government must apologise and end seclusion

*Mmm hmm*

Those are the things that I stand for. I also think people should be assessed on the basis of competency

*Mmm*

Not on a danger to one's self or others, especially when...no one's gonna be that greatly happy in that situation are they? So I think we're on the beginning of a wave

*Mmm*

And the work I've just done for the Human Rights Commission I started because I was on the forum. I could speak about the harm, historically, and I could personalise the harm

*Mmm*

And now I'm a part of the group that is seeking a formal apology. Most people wanted an active apology so that their practices would never happen again, and accountabilities were being practised to make sure that people would never be treated this poorly again, and we know they are still treated poorly, so watch this space, anything that comes out from the human rights commission

*Yeah I will*

A formal public apology for the abuses many consumers suffered within public mental institutions would set a strong precedent for consumer led movements. A precedent which may lead to further investigations and alterations involving the treatment of consumers. Particularly around the practices of seclusion and electroconvulsive shock therapy, which are still regularly applied without peoples consent. In the following discussion I had with Joanne also spoke of the need for admission of wrongdoings perpetrated in mental health care:

The thing that we think needs to really happen, are, there needs to be a public admission of wrongdoing

*Mmm*

From the professional groups and from government

*Yeah, I do too*



Just to say, “we did wrong”

*Yeah*

“And we’re not going to do wrong in the future, and we’re going to do everything we can to change things so this wrong can’t happen again”

*Exactly*

And until you get a statement like that coming from the people who run the system and the people who run the state or government I don’t think we’re going to get any change

*No*

Because there’s no acknowledgement, I mean these people are running around in the system, thinking they’re doing ok

*Yeah that’s it, and they’re highly defensive*

Well you’d have to think like that or you couldn’t justify staying here

*It’s the basis for people’s entire worldview too isn’t it?*

*Yeah*

*So like you’re a medical professional and that’s how you see things and here’s the ‘facts’ blah blah bullshit bullshit...*

Pretty much (Laughter)

The potential for change, whereby wrongdoing is admitted, is something Patrick and I spoke of in the next conversational exert, in relation to seclusion:

The agenda that I have personally ends seclusion, and that’s what I’m focusing on, because I know we’re a thorn in the system because they can’t end it now. So it’s a big paradox, what the UN says should be happening, what the DHB’s say we should be doing, the nurses know what we can do. It puts the whole thing in disarray

*Mmm*

Just by putting a flag up, saying, “end seclusion now”. It’s like saying, “get rid of nuclear weapons,” yeah? We know they’re not going to, but the context is in strategy, yeah? It reverberates through the system it makes them very tense, and it gets them starting to ask questions

*Mmm it sets that question for other areas as well doesn’t it?*

Yeah, so if you’re guna end seclusion you need to end restraint, by forcing somebody down or putting them in shackles. They don’t do that in NZ, they do it in Australia. Or by putting injections in you, or by threatening seclusion or putting them under the Mental Health Act. Like, so you know, you could go out further, you could say, “well it’s also about the relationship between the consumer and the community mental health nurse who visits everyone.” But they’ve got every right to say, “I don’t want that injection,” or “I don’t want to go to counselling,” you know?

*Mmm*

It starts to change the whole power structure

### **Assessment measures and information sources: Opening dialogues...**

After the shift to Dunedin that I detailed in my personal narrative, I was having a rather tough time maintaining my wellbeing so I decided to visit a peer support service<sup>34</sup>. After having an initial contracting session with a peer support worker, they suggested we write up some notes together to ensure the outcomes of our work were consumer derived. Up until this experience I had taken for granted outcome measures, and when working with specialists I had never enquired as to how or if I was being assessed. Such measures came up in my conversation with Roxy, and as I

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<sup>34</sup> Peer support is social-emotional support, frequently coupled with instrumental support that is mutually offered or provided by persons having a mental health condition, to others sharing a similar mental health condition, to bring about a desired social or personal change (Solomon, 2004, p.393).

have since found, are of great importance to ensuring consumers have a voice in their treatment:

Speaking of consumer academics, Sarah Gordon, she did a whole consumer self-assessed outcome measure for her PhD

*Yip*

I think it's available but it's not widely used, and mainstream mental health services are still using this outcome measure called HoNOS (Health of the Nation Outcome Scales) where the person doesn't even know they're being assessed. I'll just go away after I've seen you and say "aww yes, it looks like he's had a shower". Tick that box

*That's bizarre, so it's for my outcomes and you're assessing it?*

Yeah yeah

*That's weird, that's quite unethical, and I wouldn't be allowed to do stuff like that (Laughter)*

It happens all the time

From my perspective as a social anthropology student, I would think that the best (and most ethical) way to find out what someone's experience of treatment was like would be to ask them. Outcome assessments undertaken by specialists simply add to the power imbalances frequently occurring in these relationships. This is an area picked up upon by Joanne, who is working towards finishing an electronic application which enables self-assessment, amongst numerous other practical functions.

*What's the online tool?*

Well, basically it's a tool that ahhh...see we did some market research, as they call it, and the key message we got from the service users is: "I'm isolated. It's hard for me to get going in life. I really actually lack self-belief and hope"

*Mmm*

And the frontline workers, which is the most surprising thing, said, “well the training didn’t help me”

*Yeah*

“I just use my life experience when I’m confronted with the difficulties people come up with”

*Yeah*

And you know if someone was hearing voices, well they would have to google stuff to see if they can find anything

*Mmm hmmm*

The service doesn’t give me any resources to help me assist that person in their recovery

*Mmm hmmm*

I found it just extraordinary, and the managers said, “well we don’t really know what’s going on, when the support workers go and visit people. We don’t know what’s going on in the interaction and we don’t know how effective our workers are, and we don’t know what progress the people using the service are making.” The funders said, “well we don’t know what’s going on with services.” So then their accountability reports to us are meaningless, they don’t really tell us much

*No*

So we’re really trying to construct a solution that can help to solve all those problems, and so what we’re constructing is an online platform. An interactive tool that the users have control of which would be introduced to them by the support workers. ‘Cos we want the service user to buy it because otherwise we haven’t got an income stream

*Yeap*

And so it would be organised 'round their life challenges. So what we're gonna do in the next phase is go out and say, "what are the things that bug you in your life?"

*Mmm hmmm*

And do some focus groups and surveys to get a much more refined understanding of what the things that really get to you are, and create some activities that people can work on to reflect on that. You know, to reflect on their problem. Like one might be; we're doing a prototype..."do I disclose if I get a job?"

*Yeah*

It's a really big issue for people

*Yeah it is*

So then the first activity is around what are the pros and cons of self-disclosure. How do I do it? When do I do it and who to? So it's structuring your thoughts about self-disclosure, then the goal of intention about it

*Mmm hmmm*

So you might decide, "yes so I'm going to self-disclose to my employer, after I've been offered the job"

*Yeah*

And then on the other parts of the website you get access to short articles and stories from other people. So we have a one-minute video of someone saying their experience of self-disclosure, or a kind of a two page paper on things to consider about self-disclosure

*Yip*

And then the worker will also have access to that resource centre, so they can you know. So say someone's hearing voices there are plenty of really

good strategies people can use to manage voices, and the fucking psychiatrists won't tell you that

*No*

There's been a lot of work done by Hearing Voices Networks, about the strategies you can use to manage them. So there would be to have resources up there that give support workers as well as people who use the service, really clear guidance on ways you can. You know, get better sleep or ways you can deal with employment services. You know, a whole bunch of things. We're trying to make it really comprehensive

*Sounds good*

And then the user can send what they've done to a trusted third party. So that might be the support worker, but then they've got to be in control of who they share that information with

*Yip*

Now the benefit for the managers is that they get all this anonymous usage data so if they think, "oh my god 80% of people worked on the hearing voices challenge, we need to be much more responsive to that", or they might see that 50% of people who worked on a challenge have reached their goal

*Yeah*

Of what they were going to do or something like that... So there's a whole lot of usage data that could be quite powerful, that could give managers a really good steer on how to respond better to people

*It makes a lot of sense, I know what it's like, it is difficult the way things are, just trying to find resources, find info.*

Yeah, you know there's a load of resources out there and if you could pull them all together into one place in a kind of simple, easy to digest format, you know, all kind of narrated and written in the same style

*Yeah for sure, having that sort of peer-driven information I think is quite critical.*

Implementation of the digital application Joanne is currently working on represents practical change from within the mental health system, rather than attempting to completely overhaul it. Joanne decided to undertake this type of work as in her own words:

I guess I've been doing this for a long time and I realised some years ago that doing this big advocacy stuff, and you know, trying to change whole systems, had been a dismal failure

*Yeah*

And that if I wanted to stay doing this work I'd have to take another approach

*Mmm*

So really what I'm doing, I've got a much humbler objective now, and that's to change from ground up. So through these workshops that we do, we might give some people a different frame of reference than we've been given

*Yeah*

And within the online wellbeing tool as well, we're planting info in there that's based on lived experience for people to absorb, and interactive exercises based in lived experience. So it's much more by stealth now.

## **Conclusion**

The main problem my peers identified as influencing poor outcomes for consumers is the Mental Health Act (1992), which is inherently discriminatory, and breaches patients' rights. Such a finding is reinforced by the discussions of the Act (1992) I presented in Chapter Three, which included an alternative to current assessment measures in the form of a capacity based model. My peers also identified various means by which positive change may be enacted in relation to mental health. A redefinition of mental illness, and the valuing of consumers perspectives, are two

proposals which I strongly support, and have attempted to achieve within this work. As an example of oppositional resistance to the biomedical discourse, the current efforts to end seclusion highlight how change may be sought by consumers, and also the resilience of the biomedical discourse. Another important avenue for change involves the government and mental health practitioners making formal admissions of wrongdoings. If these actions were to take place, it would signal that consumers' voices are being heard, and represent a major challenge to the truth claims of the biomedical discourse.

### **Final Conclusion**

In listening to the stories and perspectives of my peers, I was reminded that a key component of mental wellbeing is meaningful human interaction, which involves the sharing of our truths about who we are and how we see the world. It is quite rare that I get the opportunity to express myself in this way, and as such I found this process both affirming and cathartic. Many of my peers said they also found this process empowering, particularly as it offered a point of reflection, and also as their voices underpinned the arguments throughout this work. I began this work with a desire to find how I could enact broad scale positive change in relation to mental health in New Zealand. Now through this process, and particularly the knowledge my peers shared, my aspirations have changed.

My initial desire for change stemmed from an experience with a GP who told me that my depressed state at that time was due to a chemical imbalance, and would require long-term drug treatment. After this interaction, I realised that he was but one of a large number of biomedical practitioners spreading this misinformation, and I was certain that if enough people knew this, then change would be forthcoming. During the course of this research I was able to find why such change is not so easily enacted, as dominant discourses are change resistant because people who interact with them are often compliant with their truth claims, and so their dominance continues.

I am not suggesting that people should give up on attempting to change these discourses for the better, simply that rather than to try and change entire paradigms



which support the biomedical discourse, the best path towards positive change involves providing consumers with information around mental health so that they can have every opportunity to live fulfilling lives. Such change can be sought through creation of scholarly works such as this, and also through the ongoing efforts of mental health advocates.

For me this assertion affirms just what an amazing group of people my peers are, as they manage to challenge the truth claims of the biomedical discourse and seek positive change for consumers, whilst working to maintain their own wellbeing. Personally, I have been on a long journey seeking happiness, and an end to the seemingly endless struggles I face. Yet my peers showed me that although struggling for what we believe in is often difficult, the opportunity to express ourselves, whilst seeking to improve the lives of others, is what happiness is all about.

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