A Right to a Risk Filled Life:

Understanding and Analysis of the Risk Discourse for Consumers in Mental Health.

A thesis completed in partial fulfillment of the requirements for the degree of

Masters of Arts
In
Social Policy

At Massey University, Auckland, New Zealand.

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2008

Abstract

This thesis documents the perspective and discourse of risk for eleven people who identify as someone with lived experiences of mental illness and mental health service use. The thesis followed a participatory methodology and involved consumers in both formulating and conducting the research. Following qualitative research methods some key findings included that there was a correlation between increased exposures to risk during increased acute unwellness; increased exposure to risk because of service use; that the people interviewed wished to have some control and self-responsibility in managing risks, that life was fill of risk and that this was quite usual; and importantly, that risk was experienced as a stigmatizing phenomena for the participants. The stigma of risk was such that participants had to develop significant coping strategies to manage others perceptions and deal with the experience of having normal behaviours and emotions considered by others as abnormal and risky. The thesis makes recommendations for consumers, services and mental health service staff and for policy makers. Many of the recommendations consider how understandings of risk and approaches to risk management could alter to increase consumer safety and wellbeing. The thesis additionally includes an analysis of the participatory process that was followed with recommendations made encouraging an increased frequency and strengthened quality of consumer participation in research.

Acknowledgements

This thesis has been an undertaking most overwhelming. Without the support, care and guidance of a good many people it would likely have remained incomplete. The value of this support is considerably more than what can be captured on this acknowledgements page; however, I will do my best to portray my heartfelt appreciation to all involved.

This thesis was only able to achieve its ambitions because of the willingness and the bravery of the people who chose to participate in the research. These people demonstrated first-hand the reality of resiliency and recovery, and the strength and hope that people with lived experience of mental illness can hold. I have been energised and charged because of your participation and will always hold dear your perspectives and discourses. Thank-you.

The CAP members, Cavell, Clarie, Carolyn, Clare and Shona have all played a vital part in proving and providing further evidence to the value of consumer participation in research. By agreeing to participate in the open and honest way that you have, you have influenced the findings of this research, the advantages to participatory processes and my understandings and appreciations of consumer participation in research. Your friendship and camaraderie will remain highly valued.

In Mike O'Brien and Christa Fouche, I have had the good fortune of two superbly talented, experienced and considerate supervisors. Your confidence (and simultaneously patience) in my ability to finish this thesis has been hugely appreciated, and the time and thoughtfulness you gave to guidance has been immeasurable. I look forward to future collaborations and work together.

There are innumerable reasons to be grateful to my family and friends. Whilst completing a thesis at times feels like a solo endeavour they have suffered the frustrations and shared the joys all along. Mum and Rob your constant encouragement and procrastinating coffees have been really valuable. Keep at it Mum - your inspirational example has been the reason for my own academic achievements to date. I look forward to reading your next acknowledgements page! To my father, brothers, sisters and friends whom have all had to listen to me use my thesis as an excuse to turn down good times (or have had to listen to me complain about how I should be doing my thesis instead!!) - I look forward to spending more guilt-free downtime. Pam and Ross – thanks for the sunroom, card-table and space to do my work in - now there is no excuse to not go fishing.

To my wonderfully supportive and patient partner Jo, who has shown more understanding and perseverance than I am sure she signed up for when I floated the idea of completing this. Given when I started my Masters, Paris was our little baby and she is now at school and one of three, I am aware of just how long you have been beside me, picking me up when I was flat, boosting me forward when I was excited and keeping the kids entertained and happy whilst I was preoccupied with this.

Paris, Caleb and Isabelle, Daddy is really looking forward to playing more on the weekends. I am sorry for the wildly flailing arms and high pitched shriek that greeted you every-time you jumped on my computer and hammered at the keys whilst I was away from my desk. May you have a wonderfully spirited and risk-filled life. To my brother Jason, whose risk filled life led to a premature end – you taught me to make the most of mine.

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"For social constructionists, it is not a matter of doing more research to obtain a clearer view of exactly to which risks people are exposed. Instead, the primary focus is on examining how concepts of risk are part of world views." (Lupton, 1999:29)

Chapter 1: Introduction

This thesis will document a perspective of risk from the perspective of people who use mental health services. The desire to complete this thesis occurs as a result of the experiences that I have had working in the field of mental health. The desire to achieve the ambitions of this thesis – to document a risk discourse for consumers[1] and to model a method of consumer participation in research - is borne out of my experience working within the mental health sector and witnessing first hand the courageous struggle of people to have some control over aspects of their lives – control at times denied to them on the premise of risk management by the mental health services providing their 'care'. I have worked on a number of service developments with responsibilities for constructing services to deliver highly personalised supports, assisting people with a mental illness to live within a home of their choice, pursuing ambitions of their own. This work has occurred throughout three District Health Boards within the greater metropolitan Auckland region. The ethical basis of this work has demanded that services become closely aligned to the self-expressed needs of people receiving services and that the person becomes a central decision maker of choices that affect them. This work has resulted in challenging aspects of an often risk averse system that does not allow this to easily occur. It has also required assisting consumers to further challenge these aspects. The following brief vignette is an excellent example of both this challenge and of the resiliency and strength that, as evidenced later in this thesis, keeps consumers safe.

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[1] In keeping with current terminology the term 'consumer' has been coined throughout this document to describe a person with lived experience of mental illness. Other terms used interchangeably in literature in New Zealand at present include 'service user' and 'tangata whaiora'.

1.1   A Brief Vignette

Carol[2] is a woman who lived in her own home. She is a fantastic artist and would teach two days per week at an art centre for people who experience mental ill health. Carol had been receiving mental health services from a Community Mental Health Centre and (occasionally) an acute mental health unit for approximately five years. At a time in her life when there was a substantial amount of pressure and stressors, including difficulties in some of her social relationships Carol began defaulting on her medication, becoming distressed and feeling unable to turn to key support people. Carol became acutely unwell and eventually responded to command hallucinations instructing her to jump off a high bridge.

Carol was in an Auckland hospital for about nine months having her legs and hips repaired. It was an extremely difficult time for her and her family. She was finally transferred from the general hospital to her local acute mental health unit. During this admission key clinicians and mental health professionals insisted that the risks Carol posed were so great that she required twenty-four hour care and supervision. The only way of accessing this within the contracted models of service provision was to live in congregate group homes with other mental health consumers, where the provider of service also operated the 'home'. Carol was adamant that she did not wish for this and insisted that taking away her right to live independently would "simply destroy" her. The risk averse position of her clinicians insisting on this course of action showed little apparent concern for the risk of *'destroying'* someone. Carol was feeling well, was very insightful to her needs and to the situations and stimuli that led to the recent events in her life. Importantly, she was aware of the necessary steps she needed to take to maintain her wellness and prevent the same situation from occurring.

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[2] Not her real name

With a great deal of courage and some strong advocacy, Carol was eventually able to convince her mental health clinicians that with good support and good intentional and personalised safeguards, that she would be able to return to community living within her own flat. A condition of mental health services agreeing with this was that Carol was placed on an intra-muscular injection (IMI) to ensure compliance with her anti-psychotic medication. Carol agreed to this because the only alternative allowed to her was to reside in a residential rehabilitation facility – an arrangement that was wholly unsuitable to her.

In a short period of time Carol began to have a tremor in her hand as a resultant side effect from her IMI medication. This was particularly distressing for Carol as it affected her ability to complete her art – an activity she found highly therapeutic and relaxing. Carol continually approached the mental health clinical service who provided her psychiatric care (and determined the medication regime) requesting a change to oral anti-psychotics due to the side effects of the IMI. She was constantly told "no" as her risks were too high when she was unwell and that she needed her medication to remain well. During a discussion with the clinician I tried to point out that Carol was showing a great degree of awareness and insight, that she was determined not to go back to where she was, and that she had considerably strengthened her formal and informal support networks. When told how risky she was when she was unwell I attempted to have the clinician agree that Carol should be allowed some responsibility for managing those same risks – particularly given she wanted that responsibility. I was advised that "its fine to say that but that is not what it says when it hits the papers." Exasperation, but it put a voice to the risk aversion that is present in some mental health services and service workers.

The response to Carol's pleas remained "no – too risky" for over three months of requests, bureaucratic processes, strong advocacy and even stronger perseverance from Carol. She was subsequently denied access to a therapeutic milieu that had great meaning to her – her art. The irony of course in the risk averse approach taken by the mental health service taking sole responsibility for her care, was that due to their inability to allow her to live with risk in her life, they were greatly increasing the likelihood of a high risk event occurring. This likelihood was increased by denying her access to events and activities in her life that gave it greater meaning and by denying her some control over her life. Such narrow and service-centric approaches to risk will often only serve to heighten the actuality of a high-risk event occurring. Ironically, and also indicated in this research process, Carol's risk management plans paid little heed of the vulnerability of harm from services that Carol experienced.

Eventually, with amazing perseverance and resiliency, Carol's medication regime was changed to an oral medication; she regained her ability to complete her art holding a successful exhibition, co-presented at an overseas conference, and while having had a further inpatient admission has not had any occurrence of a 'risky' or hazardous situation. Importantly, Carol expresses a high degree of satisfaction with how things are in her life and with her journey of recovery. Carol is more than happy to have this story shared in this vignette and has spoken eloquently and with a great deal of awareness at public forums on what it meant to have risk defined for her, and what the opportunity of 'taking a risk' has achieved for her.

1.2   Risk and Welfare

Risk is a common feature within welfare, social policy and social service delivery (Kemshall, 2002). The growth in knowledge and understanding of the social science of risk is continually developing and the impact of this discourse has been far reaching. The application of risk to constructing not just social policy but also social relationships has been heightened by the increasingly individualized, uncertain societies we are living in (Nettleton and Burrows, 1998). It has assumed a central place in recent social policy literature. As a policy concept the definition and management of risk is replacing the redress of social inequalities and the meeting of 'need' as the primary function of the welfare state (Dean, 2000). Risk serves a number of functions including determining how and to whom resources should be rationed, how services should prioritize and respond to service users and also how services are held accountable (Phillips, 2004).

Welfare states and social service provision have emerged through the pressures of post-modernism with a new sense of moral responsibility. A shift in responsibility has occurred whereby reliance on state sponsored welfare has reduced and there has been an increase in individual, family and community responsibility (Lister, 2001). Even a cursory glance at policies from New Zealand policy makers over the past decade will reveal numerous references to 'community capacity building' and 'individual and family responsibility' (a good example is the Social Development Approach, Ministry of Social Policy, 2001). This shift presupposes a movement from rights to responsibilities and from passivity to activity. Giddens and Beck in particular, draw on the idea of an emergence of socially responsible and active citizens, confidently acting in their best interests within a political economy that has encouraged active risk takers, individualization, private

consumption and community enhancement (Kemshall, 2002). This emphasis is not too dissimilar to the proponents of neo-liberalism.

In essence, Kemshall (2002) maintains that the current direction of social policy has ensured that responsibility for the purchase and provision of welfare, or conversely the management of risks, is now that of the active citizen. Interestingly, there has been little emphasis on how, as an active citizen within participatory democracies, resistance to this new responsibility has occurred. The implication of this direction of this new social policy is a reduction of the traditional functions of the welfare state. The emergence of a recent social democracy – the Third Way - emphasizes the role of governments in providing the stimulation and the environment required to enable citizens to realize their potential, provide for their own requirements, and manage their own risks (Lister, 2001). Criticism of this (from the left of the political spectrum) state that citizens are being 'cast adrift' and left on their own to face the increasing complexity of risks within modern societies without the assurance of a strong welfare state (Kemshall, 2002). Giddens maintains that a strong welfare system is essential to "guarantee opportunities for individual self-realization" (Kemshall, 2002:116), and that the Third Way calls for welfare reform that increases responsibilities of citizens including the positive engagement of risk (Kemshall, 2002). This is reflected in the heralded rhetoric of 'opportunity instead of dependence' (Taylor-Gooby, et al, 1999) and 'no rights without responsibilities' (Kemshall, 2002).

Kemshall (2002) contends that Giddens holds the thought that an active exploration of risk is required in order to secure economic and social progress and that passive experiences of risk (and the attempted protection of citizens from different risks) has punctuated previous approaches to welfare. This notion is aptly summarized by Kemshall (2002:37-38) when she states that "a social

policy (the 'Third Way') which actively promotes risk taking and a positive attitude to risks has gained currency, and is advocated as the most effective response to the dilemma of the risk society". The extent to which this has occurred is the subject of ongoing debate by perspectives on both sides of the political spectrum.

The challenges for Governments to promote positive engagement with risk are two fold. First, by creating an environment where innovation and risk taking is positively rewarded, they need to provide the resources required for citizens to assume responsibility. It is not simply enough to pronounce a new requirement of individual responsibilities but the state must provide the stimulation for citizens to become so. Second, it must enable citizens to remain protected from the risks of capitalist and global markets. This is certainly a view advocated by Giddens (2003) when considering the rise and globalization of the risk society. Others agree indicating that the state must be able to provide minimal protection and cannot simply take a risk regulator approach (Taylor-Gooby et al, 1999). Risk regulation only will result in a challenge from those been regulated to the governing institutions. This argument is extended by Dean (2000) who outlines that the enforcement of responsibilities upon people will not necessarily reduce the risks they are exposed to. Conversely, he contends, insisting that rights are conditional upon responsibilities may in fact increase the risk of resistance and mistrust in the state and its institutions (Dean, 2000). This has particular implications when considered against the governmentality theorist views of risk as a governing and regulating tool – if there is mistrust and resistance then the ability to regulate social behaviours in an intended manner is reduced.

1.3 Risk and Mental Health Services

Within the mental health sector risk has had a pervasive and in my view predominately negative influence on service delivery because of the phenomenon of risk aversion. A significant feature of risk is risk aversion and avoidance. This occurs where individual professionals, managers and the systems they work for become so sensitive to the attribution of blame and fault that they respond with (often heavily regulated and subjective) interventions intended to minimize, manage or eliminate risk. I believe that this approach however, is more often an impediment on people's abilities to take control, make decisions about or have some responsibility for their lives. This can present as a significant barrier to people's recovery and as an obstruction to their right to live a life of their choosing.

Literature on how best to manage risks within mental health is prolific (Muir-Cochrane and Wand, 2005; Ramon, 2005). Tools, methods, interventions, evidence-based practice and risk assessment and management standards have all been exhaustively published (Evans, et al, 2006; Ministry of Health, 1998). There is a heightened interest in the notion of risk within the sociology of health and illness (Ward, Bissell and Noyce, 2000).

Systemic failures have often been held up as the reason for tragedies considered avoidable while individual blame and liability also exists (Alaszewski and Manthorpe, 1998). Within the field of mental health most of the public enquires to situations of significant public harm or hazard have attributed "systemic failures" wherein individual accountability is also identified. The impact has often been to further entrench positions of risk aversion (Ramon, 2005). I would argue that this

may heighten future situations of potential hazard. Heighten because, as previously mentioned, risk aversion does not necessarily keep people safe – it likely does the opposite.

This thesis is an attempt to understand what risk means to people who use mental health services and how it forms part of their world views. The thesis intends to give voice to a view and experience of risk that has been resoundingly silent. For all of the increased emphasis and documentation on risk in mental health services there has been very little describing the view of risk from people using those services. In beginning to document the discourse of risk for consumers, the thesis will also attempt to help people understand the impact that professional and systemic risk-reducing approaches have had on their lives.

1.4   Participatory Research

The research processes informing this thesis followed a methodology of participatory research. I have a strong belief in the principle of consumer participation in all aspects of service delivery that impact on them. This belief has required that the process of generating knowledge – consumer knowledge – requires active consumer participation and partnership also. To do this I formulated a Consumer Advisory Panel (CAP) who have, over a number of iterations, been involved in this research process from the outset.

The field of mental health research has a chequered history in which people with a mental illness have been the unsuspecting victims of morally and ethically corrupt practices (Frese, 2002). As late as the 1990s research practices have been documented where intentional substantial harm

occurred to unwitting participants (Frese, 2002). Fortunately, there is a growing emphasis on more inclusive and more participatory approaches to research (Beresford, 2002).

People with a mental illness have experienced social exclusion, marginalisation, the loss of dignity, freedom, control, and to degrees, civil and human rights (Healy, 1996). Other groups in society, such as women, indigenous and minority ethnicities, and people with disabilities have also experienced this same phenomenon. In this respect, many of the themes that present as requiring ethical redress for mental health consumers are present for other marginalized groups also. The common experiences of research for these identified groups' parallels their experiences within society; that is that they have not been collaborative partners at any stage of the research process. They have not always experienced control, ownership, or participation in research. Indeed, the disabled peoples movement (on which many of the principles of the mental health consumer participation movement is modeled) is said to have been influenced by the critical social research of the feminist, Black and educationalists writers who have all rejected traditional research imperatives of objectivity, neutrality, distance and an empirical definitive (Beresford, 2002). A consistent argument that is made amongst these groups concerns the dilemma of who owns the knowledge from research and what benefit is the research for those being researched (Beresford, 2002; 2000; Cram, 2001; Kirkman, 2001). Champ (2002:23) while describing this process (the subjugation of knowledge) as the colonization of the experience of consumers by researchers states:

"Sometime research amplifies the concern of consumers by giving statistical weight or an edited focus to our concerns...however; many forms of research often in effect sanitise the message from consumers' experiences by interpreting or failing to reflect the subtleties of our meanings through the language we use or by failing to capture the power of our

stories. This restating of the lived experience of consumers by researchers often recontextualises our experience."

The issues identified by Champ in relation to research recontextualising meaning have been commonly reported by other marginalized groups also (Kirkman, 2001).

1.5   Thesis Structure

The thesis begins with a review of the literature of risk. The focus of the review is particularly on risk as an organizing concept for society and for mental health services. The literature review also explores the opportunity of risk and how risk is relevant to mental health consumers. Chapter three discusses the background and approaches to consumer participation in research; its beginnings, implications, practices and ethics, before chapter four outlines the participatory methodology and processes that informed this thesis. With the involvement of the CAP, data collection methods were determined and undertaken. The find transcriptions of the conducted interviews were thematically analyzed and presented as findings in chapters five and six. Following this chapter seven discusses the implications of the consumer risk discourse for consumers and their family / whanau members, for services and service staff and for policy and policy makers. In addition to documenting the consumer perspective of risk this thesis also analyzes and discusses the approaches, benefits and challenges of consumer participation in research – this is reflected in chapter eight. The thesis concludes in chapter nine with a reiteration of the key findings and learning that emerged from this research.

Chapter 2: The Literature on Risk

This chapter will review the literature on risk by examining the sociocultural theories of risk, the context of risk in social policy, the impact of risk on services and also risk as it relates to consumers of mental health services. Social policy literature on risk has become prolific in recent times (Denny, 2005; Kemshall, 2002). With the burgeoning interest in risk as the new organizing paradigm for the social services, different views and positions are being continually researched and published (Denny, 2005; Titterton, 2005; Furedi, 2002; Taylor-Gooby, 2002; Edwards and Glover, 2001; Lupton 1999). This has occurred to an extent that has some commentators maintaining that literature on risk has already become so diverse in interpretation that it is difficult to identify the common themes in the mass of work (Taylor-Gooby, 2002). There is agreement however, that where the post-war welfare state was concerned with the amelioration of class it is now more concerned with the distribution of both local and global risks (Dean, 2000). It is evident in the literature that the concern extends clearly beyond the distribution of risks to being significantly focused upon the assessment and management of risks. The risk paradigm has had an invasive and far reaching impact on the construction of recent sociological theory and the development of welfare states, social policy and human service delivery (Kemshall, 2002; Lupton, 1999). The following literature review will highlight the impacts risk has had, particularly in relation to policy and practice within the field of mental health.

The word risk was in common usage and existed prior to being adopted within social policy and human service domains. While holding a scepter of negativity and aversion, risk was considered economically value neutral merely concerned with the probabilities of gain and loss (Kemshall,

2002; Fox, 1999). In recent times there has been a significant increase of the State's responsibility for social risk management. While recognizing that a need has existed for the management of economic and market risks, that need has now extended to the management of social risks (Taylor-Gooby, 2000). Along with other postmodern occurrences this has led to a predominately negative view of risks. This view has significantly contributed to defensive and oppressive practices within social services.

2.1   Sociocultural Theory of Risk

Although some commentators (Taylor-Gooby, 2000) maintain there are difficulties identifying common themes within the literature on risk, a number of different perspectives dominate. These include a techno-scientific perspective, dominated by the application of the scientific predictability of risk (Dean 1999) and sociocultural perspectives (Lupton, 1999). In her substantive work on risk theory, Lupton (1999a) maintains that risk has been the subject of significant theoretical debate and attention in the field of recent socio-cultural theory. These debates have created a wide range of interpretations and understandings of the nature, influence, actuality and theory of risk. This thesis has the clear intent of adding to this debate by presenting a view and experience of risk that has mostly escaped literature – that is an understanding of risk from the perspective of people who use mental health services.

This thesis will analyze the sociocultural theory of risk by using the framework provided by Lupton (1999; 1999a). In her early work on risk Lupton identified that the major perspectives of risk, from a sociological paradigm, existed within three broad categories. These categories are

cultural/symbolic, risk society and governmentality (Lupton 1999a) and whilst there is some acknowledged differences between writers within each of these categories their primary concerns are considered similar enough for inclusion within these distinctions. Lupton presents an argument that suggests although there are similarities and overlaps between these different approaches, there have been few attempts at understanding the relationships between them or at utilizing a perspective from a different theoretical viewpoint in order to gather a greater understanding of risk (Lupton 1999a). Giddens or Beck, key theorists in the risk society perspective have done little, for example, to connect aspects of their theory with the work of the cultural/symbolic writers, Mary Douglas, or the governmentality theorists following Foucault. This review will now explore in greater detail each of the three categories of the sociocultural theory of risk identified by Lupton (1999).

Cultural/symbolic

Lupton (1999) identifies, in the risk theories framework, the term cultural/symbolic theorists. Others (Denny, 2005; Kemshall, 2002) identify this body of work simply as the cultural perspectives of risk. In using Lupton's framework this thesis will also use the term cultural/symbolic. The key concept of the cultural/symbolic approach to risk concerns the notion that an analysis of risk can not occur without understanding the community which interprets it (Denny, 2005). Given this, theorist of cultural/symbolic notions of risk, discount the application of risk in an individualist manner. Mary Douglas, whose works are considered seminal in the development of cultural/symbolic risk perspectives (Denny, 2005; Lupton 1999a) contends that perceptions of risk will vary between cultures, societies and individuals within them (Douglas, 1992). The implication is that risk is socially constructed by the norms, values and tolerances of individual societies. Even within

societies, different groups will view and respond differently to risks. The understanding of risk to cultural/symbolic theorists then, depends less on the nature of hazard and more on the existing political, social and cultural context within which it is experienced.

The cultural/symbolic appreciation of risk provides an important consideration for the application of a risk framework. That is, that the context in which it is perceived and understood (the discourse of particular risks) has a bearing on the responses to it. Individuals, families, other social groups, and wider polities in society will all respond in different ways to similar risks due to the varying contexts in which they are understood and emotionally responded to (Taylor-Gooby, 2002).

The construction of risk in the first instance is also subject to this same variation in perception. The identification or labeling of a particular event, phenomenon or object, as being of risk is socially constructed and therefore subject to interpretation (Wollacot, 1998). Douglas highlights this when indicating that many traditional cultures did not have concepts of risk and that the risk discourse emerged from modern societies (Titterton, 2005). In this view the cultural/symbolic theorists have some commonality with the risk society theorists who believe that whilst hazards and dangers were present for traditional cultures it was the advent of industrial modernity that led to the creation of risk perceptions and subsequently to attempts to regulate and manage risk (Beck and Willms, 2004).

Where traditional notions of need, justice and equality can more easily be rooted in evidence and demarcated by outcome measurements, risk has a heightened sense of subjectivity and is subsequently more difficult to reach consensual understanding and measurement (Muir-Cochrane and Wand, 2005). Thus for Douglas (1992), risk is not a neutral, measurable concept but rather a

reflection on the moral, political, and ideological foundations of a community or society. Risk then within this perspective, is less concerned with the scientific application of risk-managing systems and more concerned with the need to highlight societal understandings of what constitutes risk and importantly, how it is constituted (Denney, 2005).

A criticism of this perspective occurs (perhaps unsurprisingly) from positivistic individualist perspectives of risk, when the accusation is made that a broader societal approach to analysis of risk does not account for the ontology of risk for individuals (Denny, 2005). In this regard ontology means the ability for individuals to develop belief systems about their own world (Denny, 2005). The implication is that the reality of risk and the lived experience of it may be overlooked or lost within the broad societal perspective. The cultural symbolic theorists, of whom most of the latter theorist base their work (Kemshall, 2002), response to this has been to emphasize that the construction of risk exists due to the exercising of social relationships and the governance of risk. Douglas in particular, argues that notions of risk are inevitably phrased though cultural assumptions and are thus shared conventions rather than individualist judgments or perspectives (Lupton 1999a).

Cultural/symbolic views of risk account for notions of the 'other' (Lupton 1999a). If risk is socially constructed there are significant implications for those not considered an included part of society – those considered the 'other'. There is a duality of risk issues for groups or individuals considered as 'other'. Firstly, they are not a part of the formulation of risk perspectives. The social epistemology of risk does not include or consider their perspectives or experiences. Secondly they are often identified and labeled as being of risk to others (Warner and Gabe, 2004). This

consideration is particularly important for this thesis given people with mental health experiences have been, and to extents, still are considered 'others'.

The Risk Society

If the cultural/symbolic view of risk could be considered a constructivist view then the risk society view holds a realist position. The founding theorist of the 'risk society' Ulrich Beck (1992), asserts that its' formulation occurred as a result of the emergence of postmodernism, where concerns became focused on risks generated by industrialization and modernization rather than those occurring naturally or imposed externally. Risk is thus viewed by Beck (and other risk theorists such as influential British sociologist Giddens, 1998), as an inevitable and inescapable consequence of our postmodern societies (Beck and Willms, 2004). A distinction between the risk perspectives of the risk society and the cultural/symbolic theorists is the consideration of post-modern risks. Beck in the risk society (1992), and Giddens (2004) in the globalization of risk, both attribute advanced modernization as posing new, greater risks. Cultural/symbolic writers agree to an extent however regard that the fundamental change is actually in how the cultural perceptions of risk have altered (Denney, 2005).

One of the central preoccupations of social policy and the political economy in the new risk society is the distribution of risk as opposed to the earlier focus on the distribution of wealth and resources (Kemshall, 2002). A pertinent point concerning this is the disproportionate level of risk that is inequitably distributed and the role that different sectors of the state and society play in the distribution of risk. A claim of Beck's (1999) is that the new hazards arising in the 'risk society' have fallen unequally on the marginalized and disadvantaged. This has immediate application to

the experiences of people with mental illness as they have historically been (and continue to be) a marginalized and disadvantaged population (Hinshaw, 2007).

Beck's seminal view on the 'risk society' concerns the effects of late (or post) modernity. He views the development of risk as occurring concurrently with reflexivity. Reflexivity is viewed as the process by which risks are (often anxiously) understood and responded to (Lupton, 1999). Beck's argument concerning reflexivity relates primarily to the re-negotiation and challenging (through advancing knowledge) of previously held certainties (Denney, 2005). The notion of a previous certainty becoming an unknown is characterized as anxiety inducing and risky in itself (Lupton, 1999).

Risk in social sciences has a traditional basis in cognitive psychology and decision theory of the individual (Kemshall, 2002). Contemporary social policy analysis concerns itself with the shared risks of the group and of society also (Kemshall, 2002). Following the thinking of Beck and Giddens, Kemshall contends that due to the development of post-modern thought, risk has progressed from a scientific probability to a social uncertainty (Kemshall, 2002). This probability discourse of risk was epitomized by modernist scientific application to risks. The implication is that the formulation of the knowledge of risk fell into the hands of a select few 'experts'. A feature of the response to this single contextual view of probable (and calculable) risk was a strong emphasis on the development of policy primarily concerned with risk regulation regimes and methods of prescribing risk management systems (Kemshall, 2002).

A blossoming feature of post-modernism was an application of varied discourses and subjective realities. A subsequent heightened sense of distrust in the accuracy of expert knowledge

developed. Indeed, the very essence of new discourses (including social theories of risk) has usurped modernist assumptions of the predictability of risks (and subsequent ability to negate them) and has created a notion of "risk as a future uncertainty" (Kemshall, 2002:15). The argument has been extended to include the idea that the uncertainty has created apprehension, unease and anxiety in society (Gibbins, 1998; Edwards and Glover, 2001). This anxiety creates a sense of fear of anything that could be a risk (Furedi, 2002). Beck has claimed that there will be a likely emergence of "a social epoch in which the solidarity from anxiety becomes a political force for directing the future course of development within industrial modernity" (Wilkinson, 2001:103).

A further important view, from a policy perspective, is that within recent modern welfare societies the highest values were placed on promoting equality and addressing structural causes of inequality. With the previously outlined emergence of the risk society there is a newly focused value on the promotion of safety from risks (Denney, 2005). However, there is little evidence on addressing the structural causes, or inequalities of, exposure to risks.

Governmentality

While Foucault did not theorize risk as others outlined in this literature review did, his ideas on governmentality – more specifically on the approach to social regulation and control – have direct application to concepts of risk and the experience of mental health consumers. The governmentality theorist who base their work on Foucault's discursive construction of reality, are concerned with risk in the most relativist position of those reviewed to date. That is, they are defined by a concern of risk as it relates to the states' governing and regulating of moral and civil behaviour (Lupton, 1999). From this perspective risk is understood as a strategy for controlling

populations and individuals behaviours in societies. As a result governmentality theorists are concerned with both the political economy and the regulatory agents of the state (Dean, 1999). It is argued that mental health care is primarily concerned with regulating and managing risk – particularly that posed by mental health consumers to the larger public (Brown, 2006). The service level tools of risk assessment and management are thus seen in this context as being employed as a means of contemporary governance over people with mental illness (Muir-Cochrane and Wand, 2005). It suggests that current approaches to risk in mental health are utilized as a means of controlling the actions and behaviours of others to meet the purposes of the governmental policy.

In attempting to govern through risk there presents a need for significant knowledge generation. Information about diverse risks are gathered, mitigation strategies and polices are developed, calculated and implemented. Particular social groups become identified and targeted as being 'at' or 'of' risk and subsequently have targeted provision of services or policies. Recent public health promotions using media surrounding issues such as alcohol consumption, smoking, driving whilst tired, (being drunk in charge of a stove even) are all examples of the governmentality of risk. A Foucauldian perspective indicates that for all of this scientific application to risk it remains however, a "moral technology" (Lupton, 1999:87). A similar school of thought has viewed risk assessments as a "moral diagnosis" (Warner and Gabe, 2004:391). This is additionally concerning for mental health consumers given the level of public stigma and moral persecution that has existed for this population throughout histories and different societies. Within mental health risk has replaced past conceptions of dangerousness (Lupton 1999). Subsequently all people with mental health are subjected to surveillance (risk management) regardless of whether there is any individual presentation of risk for that individual – it is enough now to be governed simply because of demographic membership to a population.

Governmentality theorists of risk do not place an emphasis on the social construction of risk. Because it exists due to the agency of the state, as a means of ordering the social world, there is little focus on the response of citizens to its application. Lupton (1999) argues that a criticism of Foucauldian scholars concerns the lack of attention to how people subjected to strategies of governmentality negotiate, resist or take them up, although Foucault himself iterated on resistance to power within social and civil relations (Stevenson and Cutcliffe, 2006).

Within recent political contexts of neo-liberalism there is an increased focus within governmentality scholars on the increased responsibility that is befalling citizens to secure (and insure) themselves against risks (Lupton, 1999). The individualization of recent social policies has led to the government promotion of self-responsibility for managing risks and securing safety (Kemshall, 2002).

2.2   Accountability, Blame and Defensive Practice

A substantial degree of the literature and research in mental health is increasingly concerning risk (Heyman, 2004). Within this increasing risk literature are the notions of the precautionary principles of risk; risk prevention and subsequent blame. These themes exist regardless of the previously outlined theoretical perspectives of risk. A strong response to the uncertainty of risk outlined earlier has (somewhat ironically) become an even stronger attempt to regulate, manage and prevent it. This, and the attribution of blame and fault, creates a mostly negative and averse approach to health and social services delivery (Titterton, 2005). As risks are identified as existing

due to human agency then there is potential of blame for both the existence of risk in the first instance and then for a lack of avoidance.

The potential for exposure to blame has had a significant impact on the delivery of social service provision and on welfare agencies. Social services, and indeed those working within, are fundamentally influenced by an aversion to risk, as a result of the attribution of blame. Organizations, occupations, and systems become focused on minimizing exposure to blame and develop defensive practices as a result. Risk management thus becomes an essential part of all charters and missions yet due to the previously highlighted inability to scientifically predict risk the management of it remains somewhat elusive. Dingwall reinforces this notion stating;

> "risk management is an impersonal metric which conceals a range of social and moral judgments. This revelation challenges trust in governments, expertise and science. The rationalities of scientists, technocrats and citizens collide. However, the responsibility for risks becomes increasingly elusive. The interdependence of productive forces characteristic of modern societies dissolves personal responsibility into that of a diffuse system," (Dingwall, 2000:140).

Kemshall (2002) however, makes a salient point about the movement (not wholly) of social policy from being solely concerned with the reduction and alleviation of risks, to the promotion of active responses to local and global risks. The concept of internal and global risks arises primarily from what Giddens (1998) describes as the 'major revolutions' of modern societies. Giddens (1998) continues expressing these 'revolutions' as the interrelated dilemmas of the risk society. They are globalization, individualization, the demise of left-right politics, challenges to political agency, the demise of democracy and finally ecological issues or environmental concerns (Kemshall, 2002).

The common theme within these presented dilemmas is the element of risk adherent to them and the manner in which those risks are perceived and approached. However, a consideration that is lacking in Giddens outlined revolutions of the risk society is the rapid advance of technology and the effects this has had on labour markets, employment relations and interactions between previously disparate or marginalized groups in the community.

Welfare systems are not only subject to pressure simply from the exertion of policy makers or academics, they are subject to pressure from the newly emerging 'active citizens' also. A characterization of our modern societies is the emergence of reflexivity. A key component of reflexivity is that people are becoming more self aware and more aware of their social contexts (Taylor-Gooby, 2000). Challenges to the assumptions of specialist knowledge have occurred and an increasingly broader (and more democratic) formulation of knowledge and understanding of society has developed (Taylor-Gooby, 2000). This is paralleled in other post-modernist thought that highlights concepts of difference, subjective realities and a redress of rationalist assumptions about knowledge and universal truths (Croft and Beresford, 1998). A subsequent implication for welfare states and policy are that it becomes increasingly difficult to implement universalistic strategies or approaches to welfare because people are becoming increasingly aware of risks and are concurrently becoming doubtful of any one approach that assumes a position of authority of knowledge (Taylor-Gooby, et al, 1999). This doubt and questioning gives rise to the features of accountability, blame and defensive policies and practices.

As indicated earlier, social service delivery is increasingly exemplified by a preoccupation with the assessment and management of risk (Morley, 2003). Three identified contributing factors for this include the requirement to ration and maximize the use of resources, an increasing accountability

for services and social service workers, and the requirement to balance freedom and choice with risk management (Kemshall, 2002). Risk assessment and management have subsequently been veewed by some as an instrument to identify those groups that require more resources (rationalization), as a means of improving service delivery (accountability) and a means of distinguishing personal responsibility (freedom and choice) (Morley, 2003). This is in contrast to the previously expressed view that believes they are utilized more as moral judgments to regulate and control populations considered dangerous or risky. Kemshall's (2002) view of freedom and choice above, within a risk paradigm, has relevance when considered within the welfare states role of protecting those most vulnerable. The relevance it holds is that it is the first of the identified factors that is forsaken due to the acute pressures of blame and defensibility. Kemshall (2002:89) asserts that

> "This system not only holds families to account for their harmful behaviors; it holds workers
>
> and managers to account for their decision-making. Central to such decisions are issues
>
> of blame, defensibility and rationing. The social work of the personal social services is no
>
> longer about the collectivist provision to those sections of society deemed to be 'in need'; it
>
> is a residual service for those both at risk and posing a risk."

Within this environment how can there be an emphasis on the freedom of (albeit at risk) individuals to determine a course of outcome for themselves? The initial implications are when considered from a 'risk society' or 'governmentality' perspectives are that there cannot be.

An additional irony of an emphasis on risk management and minimization exists when the consequences occur of systems or organizations becoming the sole responsibility for the risk. When the responsibility for risk management, minimization or containment belongs wholly to an

entity other than the person directly concerned, a likely outcome is an increase in risk. This is reflected nicely in the summation below from Lash and Wynne (1992:4) when they state:

"The primary risk even for the most technically intensive activities (indeed perhaps most especially for them), is therefore that of social dependency upon institutions and actors who may well be – and arguably are increasingly – alien, obscure and inaccessible to most people affected by the risk in question."

The immediate implication of this suggests that strong attempts to regulate, control and minimize risks (mainly due to features of blame and accountability) may increase the likelihood of a high risk event occurring. We can cast back to the vignette at the beginning of this thesis to view a practical example of this occurring. When services could not allow Carol to take some responsibility for some of her risks, they heightened the degree of dissatisfaction and unhappiness in her life and they denied her access to something that would likely enhance her safety.

The development of risk management tools and techniques occurs prior to the individual(s) risks being encountered and understood. A formulaic approach to service delivery, whereby the service is designed and decided upon, is beginning to be recognized as a less than suitable means of designing services. Conglomerating marginalized populations in group homes, on the basis of disability and service design, can be understood as a continuation of institutionalization. Policy makers are prescribing individualization and person-centered services as a more suitable means of designing and delivering services (for examples see the Mental Health Commissions Blueprint, 1998). This has not yet applied to the management of risk however. Risk assessments are implemented as a standardized means of understanding and planning how to deal with presenting and potential risks (Morley, 2003). An implication is that the personalized perception or nuance of

risks are forsaken and therefore not attended to particularly well. Again, an outcome of risk aversion has led to the paradox of a heightened state of risk creation or mismanagement.

2.3   *The Opportunity of Risk*

An additional understanding of risk to those presented in this chapter so far concerns the opportunity of risk and positive risk-taking. Positive risk-taking has its roots in notions of empowerment, service user involvement and participation, normalization and anti-oppressive practice (Kemshall 2002). It can be linked to personal development and self-determination and viewed as a positive liberating experience (Alaszewski and Alaszewski, 2002). As a concept that has been driven by those who have experienced stigmatization, oppressive and restrictive practices (often due to previously highlighted risk aversion), it has a strong foundation in rights-based thought. It is seen then, as having an important function in ensuring that decisions made to reduce or manage risk are made in an explicit and clear manner (Kemshall, 2002). Interestingly, it also has roots to economic development. The successful risk-taking business-person is applauded in western communities – when considered against the previously highlighted neo-liberal framework, this is encouraged as good self-responsibility. Beyond this however, positive risk-taking could also have an important function in assisting decision making in practice and policy that will assist people to receive the benefits from 'taking a risk' with a successful outcome. Remembering of course that it was originally a value-neutral term – as concerned with gain as it was with loss.

Giddens (2003) maintains that active risk-taking is a core element of a dynamic economy and an innovative society. Evidence from Kemshall (2002) and others (Alaszewski and Alaszewski, 2002;

Alaszewski and Manthopre, 1998) would suggest that the active risk-taking approach advocated by Giddens has yet to be adopted by either front-line staff in social services or those in positions to influence service delivery. This suggests that negative approaches to risk have been the predominate influence on social services and service users (via risk aversion, management and containment). Risk-taking and positive approaches to risk have yet to have a similar influence. Risk taking economically is encouraged and rewarded; socially it is controlled and punished – particularly if the individual is a member of a population considered dangerous or 'other'

As previously stated, an implication of the new risk discourse is the positive side of risk – opportunity and innovation. These concepts appear to sit in contradiction to the earlier evidenced response to the new uncertainties of risk namely blame, responsibility, aversion and strict attempts to assess and minimize consequences. Beck (Beck and Willms, 2004) actually extends this thought to imply that risk is the inescapable consequence of opportunity. More specifically, that any episode of risk provides opportunity and all opportunities involve risk.

The use of a broader conceptualization of risk (one that accounts for opportunity and positive outcomes) could have a direct impact on the provision of frontline service. It would substantially shift the process from the identification of specific hazards or harmful events to the process of decision-making (Alaszewski, 1998). This decision-making would account then, for balancing positive and negative outcomes with certainties and uncertainties. A risk management policy document released from the Ministry of Health (1998), advises that at times risk taking is necessary to achieve positive gain and that a strategy of total risk avoidance could lead to excessively restrictive practice with potential harmful consequences.

A positive and balanced approach to risk taking would fit within the current philosophical and value base of Recovery that informs mental health services. Recovery is described by the Mental Health Commission (1998:1) as "living well in the presence or absence of mental illness." Therefore Recovery can be viewed as regaining life rather than simply surviving illness. Recovery has largely grown from the consumer movement and emphasizes the rights and abilities of people to live well with a mental illness. It is concerned with the expression of hope, wellbeing, dignity and rights. Consequently services that pursue or base interventions on the Recovery approach would be more likely to support consumer self-determination. These services would also more likely have the ability to work with the person to understand and determine the risks that may be present and collectively safeguard against them.

2.4   Risk and Consumers of Mental Health Services

Consumers of mental health services are directly impacted upon by risk. The previously highlighted view of governmentality, described by Foucault, holds the view that the sceptre of risk is used as a governance strategy of regulatory power by which individuals and groups of people are monitored and managed (Lupton, 1999). Through ongoing analysis and (social) scientific expertise, social groups or populations are understood to be "of risk" or "at risk". Responses, systems and knowledge about how best to manage these risks are then formulated. Consumers of mental health services (whether warranted or otherwise) are viewed, and often stigmatised, within both of these categories and to date have, for the most part, been excluded from contributing to the knowledge of them.

A key strategic concern for mental health policy has been the effective management of risk heightened by the sense of media and public concern about the risks posed to public safety by people with mental illness (Muir-Cochrane and Wand, 2005). A document released in New Zealand from the Mental Health Commission (1998a) indicates and exposes the recent historical perspective of policy and risk in mental health. The documents' use of language is telling when it indicates a priority is for the "effective assessment and management of those people who pose a risk to themselves, and to others, and those with specific high vulnerabilities such as severe self-neglect" (Mental Health Commission, 1998a:7). This statement captures the highly emotive and de-personalised nature of risk in that it identifies the *person* as requiring managing and not the risk or any of its likely many contributing factors.

Interventions and mechanisms to intervene are developed and applied prior to the individual's needs or risks even being identified. Historically these risk management interventions have involved the incarceration and containment of people in large, geographically and socially isolated institutions. These asylums presumed a number of roles including the asylum and treatment (moral and medical) of people, the containment of the 'untreatable' and surveillance of those posing public threat. An immediate consequence of this institutional policy, aggressively pursued by policy makers in New Zealand from the 1860s through till the early 1990s, has been the exclusionary social position of people with mental illness. The irony of this, is that fear and stigmatisation (a contributing factor to the heralding of asylums) grew as consequence of increased ignorance because of the extent of social exclusion (Grant, 2001). Social exclusion and stigmatisation, whilst lessened since the deinstitutionalisation of asylums, still exists (Pilgrim, 2005). Arguments are made that there has been little focus on addressing social inclusion from new 'community care' services that focus on bio-medical management, a lessened concern for

social inclusion (Pilgrim, 2005), and a rationalisation of health care budgets and resources (Hinshaw, 2007).

The historical misfortune for mental health service users was that they were not entitled, either though policy, legislation or social attitudes, to the benefits of full participatory citizenship, and as such were excluded both in policy and service provision from any form of desired welfare. The Mental Health Commission (2002:12) confirms this stating:

> "the claim to citizenship rights for people with mental illness has only happened recently. As the citizenship rights of people with mental illness have become more widely acknowledged, it is inevitable that over time the mental health sector will have to provide a full range of opportunities for service user participation."

Acceptance of this view implies that services now need to meet not only professionally defined needs but also recognize inherent civil, social and political rights (Hazelton and Clinton, 2002). Clearly citizenship rights are not simply being applied to ones rights to receive services but importantly their rights to help in determining those same services.

There is a paucity of information concerning consumer understandings of risk, consumer experiences of risk regulatory practices or consumers' construction of their own risk discourse. A New Zealand project to develop a standardised training package and template for sound risk assessment and management admirably also undertook to document a consumer perspective of what helps to create safety (Evans, et al, 2006). This document (Cannon, 2006) reports that consumers identified that certain service environments create risk for consumers, in particular acute hospitals and the seclusion rooms within them. It also indicated that consumers identify

strongly the importance of developing strong relationships with others to help create situations of safety.

A significant barrier to consumer recovery occurs due to social exclusion. The legacies of policies of institutionalization and custodial care, stigmatisation, and collective undiagnosed anxiety within society have all been contributing factors to the extent of social exclusion that we presently encounter. Current policy initiatives have been somewhat influenced by communitarianism. One strand of communitarian thought concerns developing more socially and politically inclusive forms of community (Phillips, 2004). Policies informed by this theoretical perspective are focused at promoting opportunities that enhance active participation in communities for all presently excluded members. These policies are implicit within the first national mental health strategy (Ministry of Health, 1997), the still highly relevant Mental Health Commissions Blueprint (Mental Health Commission, 1998) and latter mental health policies and strategic plans (Ministry of Health, 2006; 2005). In order for the ambitions of social inclusion to be achieved for people with a mental illness, a somewhat fundamental requirement would be a reflexive engagement with risk on a significant scale. What is required is a conscious grappling with the tensions that have led to a habitual, problematic response – one of containment and control. All of the different theoretical positions of risk outlined in this literature review; cultural, risk society and governmentality, offer a valuable perspective to assist achieving this.

Whilst literature on consumers' discourse of risk is scarce, so too are published views on how best to assist consumers to engage in positive risk taking. Where these do exist they tend to be disregarded by the predominant medical and bureaucratic discourse of mental illness (Bates and Silberman, 2008). This thesis is taking a constructionist approach to risk by developing and

documenting a consumer perspective of risk. A constructivist view would argue that mental health consumers contribute to the understanding of risk both through their interpretation and their relationship with risk managing systems (and these extend well beyond the mental health system). The intent here is to add to an understanding of risk by presenting a perspective that has been marginalized.

Chapter 3: Consumer Participation in Research

As mentioned in the introduction to this thesis, the methodology that this research followed is based on a participatory approach to research. This chapter will outline the increasing phenomenon of consumer participation in research and offer a review of the literature that supports different approaches. It will do this by examining the principles of consumer participation in research and the conditions which have seen it promoted as an increasingly conducted approach to research. It will also analyze the ways in which it is constructed by reviewing different models of participation. There will be an emphasis on the approach that most appropriately influenced the participatory approach to this research.

3.1   Onset and the Implications

Consumer participation has become a common feature of recent social service development (Beresford, 2000). Participation occurs to different extents and via different means. Over the past decade, to varying degrees, a shift in focus has occurred within mental health service delivery. This shift is away from a paternalist "profession knows best" approach. Personal narratives and individualized experiences of people with a mental illness have been validated as a result of both changes in political ideology (policies of deinstitutionalization and community care for example) and a growing sense of self-identification among consumers. Within consumer movements and with supporters an opposition grew to the previously steadfastly held belief in the pre-eminence of psychiatric thought and treatment. Moreover, evidence was beginning to emerge of some of the harm and negative influence that this thought and treatment conferred (Frese, 2002). This growing

awareness and 'owned knowledge' is paralleled in post-modernist thought that highlights difference, subjective world views and a rejection of the epistemology of previously held universal truths (Croft and Beresford, 1998).

In addressing and dismantling the metanarrative that held that persons experiencing mental illness lacked the ability to control their lives and required 'professional service delivery' (in its myriad of forms), service users began to describe and own, their own knowledge and discourse. This knowledge has become the basis for the increasing participation of consumers in service design and service delivery. Interestingly, the documentation of consumer 'owned' knowledge often escapes the domain of recognized academic literature within the field (Epstein, 2002). This knowledge, referred to by Beresford (2000:493) as 'hidden users knowledge', comes in the form of user wisdom, advice and learning and while he states that it is becoming ever more available in different forums it is still essentially devalued by dominant professional discourses, as lacking in professional integrity and authority.

The implications of the emergence of consumer participation for consumers, healthcare professionals, policy makers and researchers have been far reaching (Mental Health Commission, 2002). Services cannot (contractually) design or deliver services without transparent and clear processes that indicate consumers are involved in the planning, implementation and evaluation at every level of the mental health service (Ministry of Health, 2001). The primary implication is that services have a new sense of moral obligation (not to mention a legal and contractual framework) to ensure that the person being served is central to the purpose of interventions. That same implication exists for social research practices, although some commentators maintain that advances in consumer participation in research are slower and more labored than those same

advances within service delivery (Champ, 2002). Interestingly, parallel discussions are occurring between the similarities of the pressures that shaped and gave rise to consumer participation in social policy and service delivery and those that are shaping social research (Beresford, 2002). Those pressures can be described as reactions to exclusionary practices (and policies), marginalisation, stigmatisation and oppression.

3.2   The Increasing Ethics of Consumer Participation in Research

Ethics in research are initially concerned with ensuring that research is conducted in a manner that protects and enhances the participants (O'Brien, 2001). While this is a marked improvement on the previously evidenced approach to research within mental health, even this notion is being usurped as a result of challenges to traditional research approaches. That is, due to the regaining of some political power (and research can be viewed as a political activity) health consumers are demanding, thorough advocacy groups, political lobbying, informal networks and holding positions of authority within organizations, that research actively seeks to promote the interests and well-being of participants. Research increasingly needs to be accountable to those being researched as being of value to the participants either directly (via increased health or well-being) or indirectly by adding value to the knowledge base and understanding of intervention methods (Truman and Raine, 2001). That is, research processes and outcomes need to be relevant to the lives of consumers (White, 2002). Importantly they also have to be accessible to consumers. Research results are not always disseminated to the people from whom they have arisen (Champ, 2002). There is an occurrence of findings being published in journals not easily accessible to consumers

and written in language that is equally inaccessible. Ethical research would absolutely ensure that the findings are shared and given back to those who contributed to them.

A further challenge to ethical research practice occurs when the definition or understanding of 'ethical' is questioned. The interpretation of what constitutes morally right and ethical research is a matter of agreement among members of a group – unsurprisingly different groups will interpret this in different ways (Babbie, 2004). If this is applied to the previously outlined view of the consumer participation movement having demanded a role in defining knowledge and intervention methods, then surely an important party in the definition of ethical research is the consumer/research participant. The participation of consumers in research processes (including involvement in ethics committees) immediately offers an opportunity to include an 'insider' interpretation of ethical research.

An interesting view prevails, reinforced by the research efforts in Aotearoa New Zealand of Lapsley, Waimarie Nikora and Black (2002), that the consumer movement and more specifically the collectively voiced 'stories' of consumers, has addressed the historical imbalance of consumers and services and moreover recast the 'heroic' role to the consumer rather than the professional. The heroic role is recognition of consumers' resilience, strength and ability to overcome significantly challenging situations. This is a thought that resonates strongly with me. The suggestion is that research that is true to this spirit strikes as having a strong ethical starting point.

This chapter earlier touched on some of the (unintended) positive outcomes of earlier unethical research practices. They were described as relating to improvements in the consent process and more specifically to consent being competent, voluntary, informed and comprehending. This is not

a particularly unique position within social research and is certainly made more complex in the domain of research in mental health. The predominant psychiatric discourse within mental health concerned the disability of illness and the associated deficit approach. Therein, the basis of 'incompetence' and 'incapacity' did not hold the necessity of newly formed ethical practices emphasizing informed and knowing consent. Traditionally consumers have been;

> "stigmatized, regarded as unreliable sources, and denied a voice in the literature of mental health. Linking mental illness (madness or lunacy) with unreason, excess, incapacity and unreliability are historically entrenched attitudes in Western societies. These attitudes sit alongside the growth of power and expertise in the medical and helping professions which have led to the denial of a voice for clients/consumers in treatments for both physical illness and mental illness" (Lapsley et al, 2002:4).

While the above reads a lack of voice for consumers in respect of treatment, the notion of lack of voice for consumers in research could easily be transposed. While there is a sense of the need for the situation described above by Lapsley et al (2002) to be redressed (particularly within a research context) the implication outlined by others (Griffiths, et al, 2004; Epstein, 2002) suggests that this is yet to fully occur.

Coinciding with the consumer participation movement is a strong adoption of the Recovery approach to mental illness service delivery, whereby the experience of mental illness becomes highly personalized and focused not on the disabling consequences of mental illness but on the hope of recovery (Carpenter, 2002). Indeed the Recovery approach currently represents a paradigm shift within mental health service delivery (Lapsley et al, 2002) and has a strong ethic of person-centeredness and consumer involvement. Moreover, commentators maintain that Recovery principles are more compatible with Māori mental health models also as a result of the

holistic and balanced view it holds of all the factors of an individual's life and environment (Kingi, 2002; Lapsley et al, 2002). The principles and ethics of Recovery must also then be considered in research interventions with consumers. While Recovery principles are becoming entrenched in mental health service delivery rhetoric, they have yet to receive the same amount of attention in literature concerning mental health research.

3.3   Models of Participation

While consumer involvement in conventional research agendas is in its infancy, evidence suggests that it is fast becoming a widespread and significant development (Beresford 2002). A number of different models have emerged and no single approach has yet to dominate literature. An important consideration requiring attention is the role that academic researchers have in supporting the disability movement and more specifically the consumer participation movement. This chapter has suggested that more ethical and inclusive approaches to research in mental health have occurred as a result of the increased power of participatory efforts and movements. However, these movements have a long history of staunch advocacy from the academic field – more so within the social sciences than the medical sciences. An important role that academic supporters of consumerism have had is in publishing positions and views that induced change by challenging traditional methods of intervening and theorizing. It also challenged consumers themselves to be more politically and civilly active.

The first model of research participation reinforced by the consumer participation movement that will be explored reflects concerns about the purpose of research. This approach is considered

emancipatory research. The central purpose to this type of research is to support empowerment in service users and to influence broader social change (Beresford, 2002). The three key priorities for emancipatory research concern reciprocity, gain and empowerment. If we cast back to Whites (2002) claim that research needs to be relevant to its participants then emancipatory research will be fitting in that regard. Within this approach however, consumer involvement is not viewed as an absolute necessity but rather as a principle of good research (Beresford, 2002). So while its ambitions (reciprocity, gain and empowerment) are relevant to the participation movement the focus of this model is emancipatory and not necessarily participatory.

Where a focus of emancipatory research emphasizes the equalisation of research relationships, the focus of user controlled research concerns consumer ownership of all aspects of the research including where it originates from, who makes research and evaluation decisions, who undertakes, disseminates, and actions follow up from the research (Beresford, 2002; 2000). Beresford (2002) explains that user controlled research is primarily concerned not with user participation as subjects (or participants) but rather as active and predominant partners along the whole continuum of the research process. There is a parallel continuum of the degree to which control is achieved from user-absence to user-controlled research. White (2002:443) while discussing a model of user participation in research presents a challenge to user controlled research when he maintains: "although it is important to seek input from consumers as collaborators in the research process, one should recognize that there is a tension between maintaining research rigor and relevance." While the concept of research relevance is maintained by the principles of consumer participation (Peterson, 1999), White's (2002) concern about maintaining rigor can be addressed by developing the research capability of consumer collaborators.

The final research model within the participation movement to be explored has variously been described as user research (Beresford, 2002) or academic consumer research (Griffiths et al, 2004). To date the discussions in this thesis about consumer involvement in research concerns the role of non-academic consumers. Griffths et al. (2004:192) hold that researchers have been 'artificially dichotomized' as either 'professional researchers' (individuals with research and/or health qualifications and experience in the field of health research) or 'consumer researchers' (defined as people with little or no formal training and experience in doing research). This presents as immediately flawed when the possible potentials and impacts of the consumer researcher are considered. There has been little evidence in the literature on the benefits of consumers as researchers (Griffiths et al, 2004) although interest in this research approach is growing and the phenomenon is increasingly occurring (Beresford, 2002; Champ, 2002). However, not all of the interest is viewing consumer researchers in a positive manner. Indeed, Beresford, an extremely active social researcher, champion of methods that incorporate fully inclusive research practices and self described 'long term user of mental health services', while promoting the benefits of user research suggests that there are still accusations of a lack of objectivity and independence (Beresford, 2002). An immediate advantage of consumer research is apparent in its ready application to well entrenched research practices. Consumer participation as outlined in this thesis has not been universally welcomed by researchers and evidence suggests that some of the same stigma facing consumer participation in service delivery also confront consumer participation in research (Griffiths et al, 2004; Champ, 2002). That is, less than equitable relationships, tokenism and no real authority or power.

Research conducted by consumers with solid research backgrounds has immediate presence in that the consumer has previous research training and experience. Additionally, they are a full

partner in the research process, they have access to funding mechanisms and dissemination methods, they are in positions to influence research policy and funding, and perhaps most importantly, they are in a position to increase participation from other consumers as participants or co-researchers. The 'insider' consumer researcher can negate the challenges facing 'outsider' researchers.

The approach taken to this research is both participatory and emancipatory. The ambitions of the research are certainly for it to have empowering outcomes for both participants and other consumers. Additionally, the research involves consumer participation in many aspects of its processes. The next chapter, looking at the methodology of the research, explains in greater detail the level (and limitations) of participation that occurred in the research.

3.4   Other Considerations

Within the domain of health service delivery there is an increasing emphasis placed on evidence-based practice and policy, both locally and nationally (Lunt and Davidson, 2002), although it has been a concept that has existed for some time (Nutley, et al. 2003). Commentators are beginning to question not simply which evidence is stronger, but also question the epistemological status of the evidence (Thornicroft and Rose, 2005). This has direct application to consumer participation in research, because the source of evidence will have greater integrity if it has had significant contribution from those whom the evidence concerns (Beresford, 2006).

A further benefit of consumer activism and participation in research not touched on in this chapter occurs via the collaborations of researchers and consumers creating a substantially stronger polity for the lobbying of scarce research funds and grants (Champ, 2002). In the ever-increasing competitive domain of funded research, this edge could prove significant for research entities.

Well-designed social policies and services, intending to improve the social, economic and civil well-being of consumers, will benefit from solid evidence based on the experiences of consumers. This chapter has argued that consumer involvement in research is a particularly effective approach to increasing the likelihood of eliciting the true and lived experiences of consumers. Thus increased consumer input into research practices and methods, and consumer participation at all levels in social research, should be seen as essential to effective evidence-based practice. It is for this reason and the additional benefits addressed in this chapter that this research will follow a participatory methodology.

Chapter 4: Methodology

The previous chapter outlined the process, benefits and differing approaches to consumer participation in research. The arguments presented indicated that consumer participation in research can have a positive impact on research processes and outcomes and on the consumers involved in the research. This chapter will explain the methodology that was followed to achieve the ambitions of this research. These ambitions include documenting a consumer discourse of risk and implementing an approach to consumer participation in research. To explain the methodology the chapter will briefly explore social constructivism, describe the creation and contribution of the Consumer Advisory Panel (CAP), describe the data collection methods used, the participant recruitment processes and the data analysis utilized in the research. Conducting research that concerns participants that are vulnerable or marginalized requires careful ethical consideration and responsiveness. This chapter will therefore also discuss the ethics of the research and the approaches taken to protecting participants.

4.1   Social Constructivism

As previously stated this research intends to understand and document a consumer perspective of risk. To achieve this I did not have a perspective that needed to be tested or a hypothesis to be proved or disproved. I have always been hopeful that risk is understood in a way different to how it is assessed and managed within services. There has been very little documented that begins to capture what risk means to people who use mental health services. Promisingly, a UK consumer group determined a priority for research on positive risk management and how this may promote

more holistic approaches to consumer wellbeing (Chilvers, et al. 2005). The result of this intended priority is still to be seen.

The research intent is best achieved via a qualitative research approach. This is primarily because the research wishes to generate insights and an increased knowledge of the consumer perspective and understanding of risk. This is known as inductive reasoning – beginning with an observation and interest and through the application of data collection methods moving eventually to the creation of a formal theory (Tolich and Davidson, 2003). Qualitative approaches to research are commonly defined by open-ended data gathering approaches, a greater reliance on words and images than on statistical data and representations (Hill, 2006), and a concern for phenomena as it occurs and exists (Cutcliffe, 2005).

Qualitative research is then a suitable approach to developing greater understandings of complex social, 'lived' and experienced phenomena. It is a suitable approach when knowledge is sought concerning complex, personal and inter-personal processes and understandings (Ridgeway, 2001). It is not intended to be positivist in an attempt to prove (or disprove) an absolute. Rather it should be reflexive and continually raise and auger many more questions and topics and questions of inquiry. Within qualitative traditions there are a number of different paradigms and perspectives. The labels and identifiers of these different perspectives are as varied as the writers who apply them.

The perspective that informs this study is commonly referred to as social constructivism. For researchers within the field of risk and mental health, interested in following a constructivist approach the emphasis of the research agenda would be on exploring personal perspectives and

understandings risk. In applying this thought to constructivism, Lupton (1999:29) indicates that "it is not a matter of doing more research to obtain a clearer view of exactly to which risks people are exposed. Instead, the primary focus is on examining how concepts of risk are part of world views." This rather fantastically represents the ambitions of the research project.

A central tenant of constructivism is that reality and science are socially constructed and understood. That is, people 'construct' their social worlds and research seeks to interpret and present that construction (Holliday, 2002). Social constructivism in this sense then has commonalities with the earlier outlined cultural symbolic theorists of risk (Kemshall, 2002). An emphasis on constructivist research concerns the subjectivity and interaction between the researcher and the participant. The researcher is very much a part of the research setting and is not a distinct entity attempting not to influence that setting. In actual fact some strategies of inquiry intentionally try to influence the research setting. Examples of these include action research and grounded theory (Holliday, 2002).

4.2   *Consumer Advisory Panel (CAP)*

In order to follow a participatory methodology for this research I created an advisory panel made up of three consumers. The group was called the Consumer Advisory Panel (CAP) and they remained involved from the beginning and throughout the research process. Analysis of the CAP involvement and impact on the research (and researcher) will in occur in Chapter Seven of this thesis; however their function and involvement in the research is important and requires a methodological explanation.

An approval process was followed via the Massey University Ethics Committee (MUHEC) prior to proceeding with recruitment to the CAP. This process included writing a letter to the MUHEC describing the ambitions of the participatory approach to the research and requesting advice and support to proceed with the creation of CAP in order to make the decisions that would then bring the full ethics application to bear. The MUHEC approved the approach to recruiting people to CAP and the attended approach to design the research methods and processes. The CAP members all self-identified as someone with lived experience of mental illness. The CAP had a clearly determined Terms of Reference (Appendix A) and the members were required to sign consent for involvement and additionally sign a confidentiality form (Appendix B).

While participation was achieved throughout much of the research it did not follow a participatory action research methodology. This approach requires a much stronger process of consumer control over the research including decision making about the issue the research process will address for a particular community. In this sense participatory action research more closely aligns to the model of user-controlled research outlined in Chapter three of this thesis. The construction of this research occurred prior to the formulation of CAP including the topic – understandings of risk - and the social constructivist approach that was to inform it. Furthermore, the writing up of the research report (this thesis) has remained my responsibility and it remains a thesis written for academic purposes (irrespective of how honest the CAP will keep me in giving back to the consumer community). In this respect the ambitions of participatory action research are not wholly applicable to this study.

The original three members of the CAP were recruited following a very good response to the recruitment flyers that were distributed among consumer networks and on a community health website (www.webhealth.co.nz). Attached as Appendix C is a copy of the CAP recruitment flyer. Significant interest was generated in being involved in the research process with over fifteen people indicating a desire to be involved in the CAP. This included two people living in the South Island. Recruitment to the CAP occurred on a 'first in' basis. People were desired participants in CAP because of their identification as person with lived experience of mental illness not because of criteria based on research experience, employment, consumer community standing or other such criteria. Recruitment simply involved someone indicating an interest in response to the flyer. Following further discussion about the research ambitions and processes, and the opportunity for the prospective member to have any questions answered, the CAP member would sign a consent form. As soon as three people had been recruited to the CAP, interested individuals were advised that the CAP had been recruited and were asked if they wished to be informed of the research findings. Two individuals took up this request. The reasons for three people being recruited to CAP were to ensure that consumers had the support of each other on the panel and to account for any absences at meetings by some CAP members whilst still allowing consumer representation.

An unforeseen yet positive outcome of distributing the flyers was a request from the Auckland Consumer Advisor Network for me to meet with them to present and discuss consumer participation in research. In particular the request was to speak about the approaches, benefits and ways of securing participatory research. I undertook this and it was pleasing to see both the interest generated in participation in research, and the further interest generated in the research topic also.

One person who identified as wanting to be involved in the research was unable to commit to the CAP prior to it convening and beginning. This was due to a change in living circumstances prior to the first CAP meeting. Two members of the CAP left prior to the completion of the research for various personal reasons and were replaced. The impacts of CAP members changing will be discussed in chapter seven of this thesis.

The model of consumer participation in research that was utilized for this study reflected both user-participation and emancipatory research – a model that attempted to emphasize the equalization of research relationships. The CAP had a significant role in influencing and completing many of the research requirements, including determining the methods of enquiry, the process for recruitment of participants, participation in data collection and analysis, and in connecting these to implications. A member of the CAP even provided access to the venue for one of the focus groups. The venue had been collectively identified by the CAP as needing to be a place that was welcoming and known to consumers. The CAP members contributed to the research methods in a number of ways. An important assertion first however, concerns the importance of consumers involved in research being given the opportunity to really understand the subjects upon which they were advising and discussing. If this does not occur then the very real risk can occur whereby their involvement is tokenistic and less likely to have a positive impact. It was important that the CAP had a good understanding of the thesis topic and the critical understandings that I wished to develop by undertaking the research. It was also important that they were aware of the desire for the research process to be of some direct benefit for the participants who participated in the study.

The first way the CAP contributed to the research was to help decide upon the methods of inquiry for the research. The CAP members were given an information sheet describing, in lay terms, both

the topic of the thesis and the various approaches and means of constructing social research (see Appendix D for the research options discussion document). Additionally they were given time with me to discuss in a group setting the implications, approaches and possibilities for conducting the research. The resulting decision was to follow a mixed-method of inquiry utilizing both focus group research and individual key informant interviews. The reasons for this decision will be discussed later in this chapter. The CAP members additionally assisted with hosting one of the focus groups, gathering data, analyzing themes and contributing to discussions about the implications of the research.

CAP members were involved early in the research in making decisions that informed research processes and ethical considerations. This chapter will now explore those ethical considerations and processes, and will then explore the data collection and analysis approaches including an explanation of why the CAP and I determined that they would inform the research.

4.3   Ethics Approval

As discussed the MUHEC were approached and gave approval for the formulation of the CAP. Once this occurred the CAP were involved in research decisions that were required to bring the MUHEC ethics application to bear. MUHEC considered the ethics application and advised that the research was required to go before the Health and Disability Ethics Committee (HDEC), administered by the Ministry of Health. The HDEC gave ethics consent for the research with feedback from the Committee indicating that the participatory methodology was to be applauded (attached as Appendix E is a copy of the HDEC ethics consent). A number of changes to the

information sheet and recruitment flyers were updated and sent to the Ethics Committee. These changes were on the basis of changed phone numbers or employment circumstances of the primary researcher or the names of the CAP members.

Ethical concerns for doing research with people with mental health experiences are considerable (Asmundson, et al, 2002). Important considerations for this research included the need for informed consent that accounted for capacity to consent also. Potential participants were able to self-identify to be involved in the research. Having the CAP involved additionally meant the participants could have questions answered by other consumers who were involved with the research and able to inform of the research processes. Active consent and confidentiality processes were followed with all participants being made aware they could withdraw their participation at any time.

The CAP and I agreed that should somebody's level of wellness indicate that they may not be able to understand the research information, their rights or the consent process, that we would discuss with them the possibility of participation at a later time when this was more clearly able to be understood. Given the nature of the topic and the likelihood of participants discussing potentially traumatizing experiences it was important that their welfare was considered. All participants were advised that this may occur and were requested on the consent form to supply the contact details of someone they wished contacted should participation cause any distress. All participants indicated a contact person although contact was not required for anyone. The focus group participants were additionally advised of the need to keep others information and personal stories confidential. A confidentiality agreement was included in the focus group consents. A means of securing participants welfare in the focus groups was via the involvement of the CAP members in

the groups. It was felt that the presence of the CAP members meant that they could respond to and support anyone that was feeling distressed and needing a break without that disrupting the group.

4.4   Recruitment of Research Participants

Increasingly people involved in social science research are referred to as participants. This thesis will continue this trend however I want to emphasis that the term participants in this sense, refers to the research participants and not the CAP participants. The process of recruiting participants proved to take some time and required some active involvement of the researcher and CAP members. The research process intended for people to self-identify to be involved as a participant. It was important to the CAP members and I that people were able to identify themselves and come forward to be involved without pressure or coercion of any sort. There is a commonly spoken view within the mental health sector that consumers are over-researched, over-evaluated and continually asked to recount their stories and experiences. With this in mind it was agreed between CAP and I that recruitment flyers would be placed in positions of prominence and distributed among consumers via consumer channels and networks, and people would be afforded the opportunity to self-identify for involvement.

Recruitment flyers (see attached copy as Appendix F) were placed in a number of community based services where consumers were often present. This included a consumer run service. The recruitment flyer was also placed on the same website as the CAP recruitment flyer (www.webhealth.co.nz). For ease of coordination and response to potential participants I decided

to advertise my contact details for potential participants to first register interest. Following poor responses to the flyers, I decided to use a forum, where I was co-facilitating a consumer consultation process, to introduce the research aims and intent and leave flyers and information sheets for people to take away with them. Between this and snowball sampling (also via the CAP members) there was an increase in the number of participants wishing to be involved in the research.

A common discussion had with potential participants was a reiteration of the intent of the thesis and the value of the views and experiences that they brought to the subject. Participants frequently expressed that they did not know much about risk and what it was. Equally, there was an expression of surprise at what they did know following the interviews. All participants were given a copy of the research's information sheet (copy attached as Appendix G) and were explained their rights during the process of consent. For the individual interviews a consent form (attached as Appendix H) was explained and signed and, as agreed by CAP, the participants were required to indicate the name of a contact person they wished to have contacted should involvement in the research cause them significant distress. Likewise for the focus groups consent was explained and individuals were asked to sign a consent form that included a confidentiality agreement (attached as Appendix I).

A number of participants indicated an initial interest for involvement in the focus groups and would later withdraw their intent to participate due to changes in their level of wellness or their ability to commit to the meeting. One focus group was missing two participants who intended to be present and the other was missing one. This occurrence is not unexpected when conducting research with populations that have additional vulnerabilities. The importance from an ethical perspective on

research in mental health is that all potential participants are able to provide informed consent, are not coerced to participate, and can withdraw their consent at any point (Asmundson, et al. 2002).

4.5   Methods of Inquiry

The CAP contributed both to the decision about the methods of inquiry and the conducting of the research. The CAP was collectively clear in its assertion that following an approach including both focus groups and individual interviews was the best way to complete the data collection. The CAP felt that focus groups were a particularly empowering approach and that these would allow participants to best interact, support and connect with each other. This certainly fits with the emancipatory aims of the research. Additionally, they held a strong view that individual key informant interviews should also be offered. It was verbalized that these two options should be presented to potential participants thus giving them the opportunity to determine how they wished to be involved. Following an approach to data collection that utilises a number of complementary methods such as this can be an effective means of research (Babbie, 2004); however, the assertion from the CAP was less driven by methodological considerations and more by the perspective of giving potential participants choices and control in the research processes. Fortunately this resonated with me and concurrently promoted data collection techniques that were a good fit with the aim of the research.

It was agreed between the CAP members and I that the focus group interviews should occur first thereby creating an opportunity to shape the questioning and inquiry of the individual interviews. Additionally, this would also provide the possibility of follow up individual interviews with any of the

focus group participants who provided particularly valuable perspectives that should be explored in greater detail.

Focus Group Research

Focus groups are essentially a facilitated, intensive discussion about a topic or issue, between a group of people selected due to particular characteristics (Waldegrave, 2003; Bloor, et al. 2001). Focus group research as a data collection method for this research has a number of advantages. Firstly focus groups are appropriate for studies that are centrally concerned with norms and meanings (Bloor, et al, 2001). They provide a powerful means for gaining an insight into the opinions, beliefs and values of certain populations (Waldegrave, 2003). Focus groups, whilst needing to establish group rules and processes around confidentiality, are also beneficial to test consensus and differences in opinions about particular topics (Smith and Pitts, 2007).

The CAP identified a desire for participants to be able to relate to each other, support each other and discuss the issues of risk collectively. Participant unification and support can certainly occur thorough the use of focus groups. However, it is important to ensure that the focus group process does not become unsafe for participants due to conflict in views or positions. This can be managed by experienced facilitation, a semi-structured interview schedule and consideration of the participants recruited. The CAP assisted in the process of managing vulnerability by being present during the first focus group held.

An identified issue with focus groups concerns the attendance of members (Bloor, et al, 2001). This was certainly an experience of this research. The optimum size of a focus group is commonly

indicated as between six and eight participants although Bloor et al. (2001) indicate that focus groups can have as little as three members in them – particularly when the topic of discussion is particularly sensitive. The first focus group held for this research had five participants and further two CAP members who participated in the discussion bringing the number to seven (the CAP member's participation is discussed later in chapter eight of this thesis). One potential participant did not show up. The second focus group had four confirmed participants with two not showing up, leading to a focus group with two participants. CAP members were also not able to attend the second group although the participants were offered the option of contacting CAP members to discuss the research and any issues arising if required. They did not take this up. I made a decision to honor the contribution of the two participants and the efforts they undertook to attend, so preceded with the focus group discussion. Whilst not ideal, some of the same advantages to focus groups outlined earlier occurred even with only two participants. The total number of focus group participants was nine over two groups.

The focus groups followed a semi-structured interview (attached as Appendix J) that was contributed to by the CAP members, although the process of focus group research determines that group discussion and interaction leads the discussion in a direction of importance and priority for participants. It was important, as the facilitator, to ensure that the discussions remain relevant to the intent of the research. The findings captured in the next chapter confirm this to be the case.

Key Informant Interviews

A further form of enquiry followed for this research was individual interviews, also referred to as key informant interviews. The recruitment process indicated that people could opt for either attendance

at a focus group or participation in an individual interview. Three people chose to participate in an individual interview, one of whom chose to attend a focus group also following their participation in the individual interview. One participant wished to have a support person present and this was accommodated. The interviews occurred in-between the two focus groups. The intent of the research design was to follow up the focus groups with individual interviews so that specific enquiry about preliminary findings could occur giving the opportunity to create a deeper understanding of some of the concepts and findings that initially emerged from the data. This occurred to a degree; however, recruitment to the second focus group was delayed and resulted in the individual interviews occurring in-between the focus groups.

In keeping with the intent for the individual interviews to follow up some of the findings of the focus groups, a semi-structured interview schedule was also developed between CAP and I. However in conducting the interview, additional questions are asked as they related to the themes that emerged from the first focus group. A copy of this interview scheduled is attached as Appendix K. The individual interviews occurred in a setting determined by the participant. Two were in the participants own home and one in their place of work. Participants in the individual interviews were aware of the CAP's role in the research and were able to contact CAP members if and as required about the research. However CAP members were not requested to be present for the interviews by the participants and were not able to participate due to other demands on their time.

4.6   Making Sense of the Risk Discourse: Thematic Content Analysis

This section accounts for the process taken to understanding and presenting the outcomes of both the focus groups and the individual interviews that were conducted during the course of this study. It begins with a description of the analysis process including a discussion on latent content analysis and then discusses how the findings have been categorized under common themes that emerged from the participants' discussions; it then introduces these themes.

When conducting qualitative research the researcher is faced with the challenge of understanding a broad range of complex data (Berg, 2004). The data as it is understood in its social reality (Holliday, 2002) is, because of its varied sources and contexts, particularly involved and multifarious. In order to reconstruct the data into a form that allows interpretation and understanding the researcher must begin to process and analyze the information which was first presented in the interviewing process. Arguably, with the process of semi-structured interviewing and participant involvement in focus groups, the social reality is being interpreted from the very beginning of the research process (Wilkinson, 2006).

Methods of analysis for qualitative research are varied. The method used for this research was thematic content analysis. This occurs where the researcher is grounded in the data in order to sift, categorize (and re-categorize), select and determine common themes and code the data to those themes (Holliday, 2002). It is particularly interpretive. That is, the researcher has to understand the content of the data, understand the context of the data and determine which aspects are commonly occurring and which aspects provide valuable insight into the perspectives of the research participants. This analysis approach is also particularly suited to focus group

research collection methods as it additionally lends itself to the analysis of interactions (Wilkinson, 2006). As indicated earlier this research has an inductive agenda – the desire being to create an understanding of risk from the perspectives of people who use mental health services. In doing this there is no hypothesis that requires testing – no predetermined themes that the data will be either categorized to or left out of. The creation of themes occurred through developing a close understanding of the entire content of the data. Some themes merged, some did not emerge as themes at all but rather as interesting (and still valuable) adjuncts, and yet other themes were clear to both the CAP members and I during the interviews and were made clearer and stronger during the data analysis.

Thematic content analysis can occur in two predominant ways, namely, manifest content analysis and latent content analysis (Berg, 2004). Manifest content analysis concerns what was said, the surface structure of content with little interpretation by the researcher who is intentionally objective. Latent content, the process followed for this analysis, concerns more, that which was implied. The meaning and context of the dialogue is examined by looking at the deeper structure of conversation and the interaction between researcher and participants. Latent content analysis allows for, and encourages, the researcher to interpret and richly describe social phenomena (Berg, 2004). Latent content analysis is consistent with constructivist research processes and critical theory which argues that the researcher, their interpretations and perspectives, due to research being an interpretive endeavor, cannot be separated from the data (Hill, 2006).

An example of latent content analysis occurred when examining a conversation with an individual who was using a metaphor of crossing the street whilst describing that risk is, in fact, a part of life and a requirement if you needed to get to where you want to go. The following conversation, if

taken at face value – at its surface structure, suggests that the discussion is about the danger of roads and the need to find safe ways across them.

> *Interviewer:* *So you were saying about the good and the bad and about positive things that can happen. Can you give me an example about a positive thing that can happen, a positive outcome from taking a risk?*
>
> *Participant:* *Crossing the road on your own. You know, say it's a busy road like Wyllie Road or Manukau shopping centre. Now there's a dangerous road to cross over on your own. You gotta use the lights there. You must do.*
>
> *Interviewer:* *But you gotta cross it if you are going to get to where you want to go?*
>
> *Participant:* *Of course but I would sooner use the lights than go down the mall.*
>
> *Interviewer:* *So in some ways are you saying that sometimes life is about taking calculated risks in order to get to places?*
>
> *Participant:* *Yep but I wouldn't like to cross that road when it is so dangerous. All the roads are bad now. I remember when I was a kid you could cross the road where you liked, you could play games on the road but you can't do that anymore.*

However using latent content analysis the conversation fits with, and adds value to, a number of themes that emerged from the data. These include categorized themes of the self-management of risks and taking a risk/life's a risk. Whilst it was the participants metaphor, my interpretation and application of the metaphor is that risk is an everyday occurrence and a part of life. When asked further about positive risk taking the same participant sang the lyrics to Bob Dylan's "Blowing in the Wind". The interpretation, in the context of the discussion, being that a person required a lot of experience to begin to understand (as the participant put it) the *"yin and the yan in life you know, the ups and the downs."*

Other qualitative research traditions, such as post-positivism, call for a greater degree of objectivity and processes to limit bias from the researcher (Hill, 2006) to ensure that the perspective being

presented is that of participants rather than the researcher. One of the means of accomplishing this is to use multiple judges of data with one person overseeing all judgments so as to reduce persuasion and group think. Whilst the constructivist and interpretive approach to this study does not require this, there was an opportunity available to complete this to a degree. The participation of the CAP allowed an opportunity to 'test' my understandings of the context of the data and also the categorization of data into the various themes. They provided a valuable perspective to the data which was analyzed. This occurred in a number of ways. The first was through immediate dialogue following the completion of the focus groups. The CAP members and I met immediately following the focus groups and discussed things that were raised during the interviews both in relation to the process and the richness of the various discourses. The second way of participating was to provide the CAP members with a copy of the thematically collated themes from the interviews and seek their feedback. Included within these discussions were considerations about the connectedness of the different themes and decision making about categories and sub-categories. Participating in the interviews positioned the CAP members well for consideration and comment on this. Additionally the CAP was presented with the draft findings and members contributed to discussions concerning the implications of the findings.

The themes that emerged through the course of the data analysis have been categorized and presented in six headings. Included in the development of these categories are some rich perspectives shared that were unique in their verbalization. In order to give these perspectives considerations they are discussed under the heading "additional views of interest".

The categories are listed in table 4.6.1 overleaf. Each category will be presented and discussed in turn in chapters five and six. This discussion includes the somewhat tricky activity of establishing

the correlations and connections between different categories. Following this, chapter seven will discuss the implications of these findings including a comment on observations about a premise that did not emerge in the discourse as such, but was observed and witnessed by myself and the CAP members. This was the trait of resiliency.

Table 4.6.1   Categorized Data Sets

1. **Risk and Unwellness**

2. **Risk of Harm Due to Service Responses**

      a. Unintentional Harm

      b. Intended Harm

3. **Managing Risk, Creating Safety**

      a. Self-Management of Risk

      b. Safety and Relationships

4. **Taking a Risk / Life's a Risk**

5. **Additional Views of Interest**

      a. Choice and Control

      b. Participation

      c. Supporting other consumers

6. **The Stigma of Risk**

      a. An Introduction to the Stigma of Risk

      b. Rendering the Normal / Abnormal

      c. Managing Others Perceptions

Chapter 5: The (In)Dignity of Risk

As previously indicated, the next two chapters, discussing the findings of the research, are constructed under the headings reflecting the themes that emerged from the data. Each theme will discuss the data that contributed to it and will concurrently include an analysis of that data. A comprehensive discussion on the implications of all the findings will be presented in Chapter Seven. The findings and analysis of the research presented here are discussed collectively. The information is not differentiated into that gained during either focus groups or individual key informant interviews. Whilst this may risk the oversight of analyzing the interaction aspect of the focus groups it is being completed this way because the individual interviews and the direction of those questions were in fact influenced by the content of the discussions held in the first focus group and because the focus of the thesis is on the understandings of risk not on the group processes.

I ask the reader to consider the title of this chapter whilst reading the findings that emerged from the participants as it lends weight to the implications that I have drawn from the findings. That is the reader should be thinking about the implications and impact that the findings are likely to have on people with mental health experiences and how these findings are both dignifying and also denote an experience of indignity.

5.1   *Risk and Unwellness*

"To me risk is when you get unwell."

The discourse of risk for the participants is reflected under each of the six categorized themes. I would urge the reader to continually bear in mind the complex correlations between the perspectives presented here as there are, at times, realizations that appear conflicted. This is certainly in keeping with the complex construction of risk as presented in the literature review.

Within the mental health field there is a positive move in both discourses and literature on mental wellness as opposed to previous, medically dominated, discourse on mental illness. The notion of wellness is connected to Recovery theories touched on earlier in this thesis. An interesting and often present perspective of participants was that when asked simply to describe what risk means to them it was apparent that in the first instance risk was considered connected to a person's level of mental wellness. The two concepts were often seen in a connected way. That is, risk was initially understood and discussed in the context of being unwell with a subsequent experience of having an increased exposure to risk.

Concurrently when discussing the notion of mental unwellness and risk, participants focused on the things that had occurred that were hazardous to themselves or others. These things included suicide attempts or suicidal ideation, neglect of dependents, isolation and on occasion assault. Unwellness, in and of itself, was viewed as a risk, not simply the behaviours, circumstances or

vulnerabilities that occurred as a result of being unwell. This was reflected in a participants' view that when she is unwell risk is the furtherest thing from her mind.

Risk in the first sense appeared very much about identifying as a person with mental illness and subsequently being of risk, or at risk to others, as a result of becoming unwell. The identification of risk existing because of unwellness (as an often expressed first response) may be due to a number of reasons. One reason being the conditions under which people were participating in the research. Because they had lived experience of mental illness and were aware that the perspective being sought was because of this, the direct correlation when asked to describe what risk means for them, is the experience of mental unwellness. Mostly, this theme emerged at the beginnings of the interviews and appeared less often once the participants started recounting personal experiences of risk or considerations of positive risk. Interestingly, people started by professing to not knowing that much about risk and then, when reflexively engaging with the interviewer or each other, they would talk for some time about a broad range of related risk concepts. A number of participants commented at the completion of the interviews that they knew more about risk than they initially thought.

Interestingly, when talking about risk as a fundamental part of everyday life, or about positive risk-taking, participants saw this not as relating to mental health and unwellness but rather to a common experience connecting everyone – an expression of humanity.

The participants' dialogue on risk and unwellness reveals a disconcerting paradox. As mentioned it indicated that participants saw a correlation between increased unwellness and increased risk of a harmful event (to themselves or others). At the same time people recognized a decreased

awareness about risks while they were unwell – the irony being that the more people were exposed to risk or risky events the less aware of them they were. This is reflected in the conversation below:

> Participant: To me risk is when you get unwell – I go quite high umm – I'm capable of doing anything and putting myself in danger, plus the people that are supporting me. Yeah that's what risk means to me.
>
> Interviewer: Yep – so when you become unwell you're in danger?
>
> Participant: Yep. If I'm becoming really unwell I am – yep. You know I can put myself in danger in the community. I have done and then actually put my children at risk as well – I didn't know it but I realized it after it has happened cause you sort of don't remember, you see only bits and pieces of what you have done which can be quite embarrassing as well.

The implications are significant when considered against other findings that materialized concerning the things that keep people safe. The things that were identified as keeping people safe included the creation of strong, supportive relationships and the requirement to personally self-manage risks, both of which can be compromised if the person is unwell to the point of lacking awareness of their exposure to risks.

So for some of the participants the correlation between unwellness and risk was about awareness or more specifically, a lack of awareness, about risks and vulnerabilities. Others viewed it as about losing a sense of control. Losing a sense of control occurred both from the sense of personal control over their wellness and safety, and additionally about the loss of control because of the forced interventions of health professionals. When recounting an experience of being placed in a respite facility during a period of unwellness a participant indicated;

> "I've been placed in respite and I've just taken off from respite and gone and sat on railway tracks and stuff like that. So for me it is losing that control."

Again it is important to emphasize that participants discussed unwellness as having two impacts on risk. First, that it increased the risks that they felt exposed to and second, that it increased the likelihood of disconnections with those things that secured their safety, namely strong relationships and self-management. As indicated earlier personalized narratives of strong relationships and self-management emerged from the participants as two of the critical factors that contributed to people's sense of safety. It was identified that both of these factors were compromised during periods of unwellness.

5.2   Risk of Harm Due to Service Responses

The immediately proceeding section indicated that the participants commonly felt that deteriorating mental health had an impact on the risks that people felt exposed to. A strong theme of how this occurred was in the sense of harm that occurs due to how services and service staff responded to them and their circumstances. This theme emerged in two predominant ways. The first concerned the vulnerabilities that participants were unintentionally exposed to as a result of interventions intended as 'risk reducing'. The second was in the identification of risk existing due to what was believed to be intentional, abusive responses from services.

Unintended Harm

The experience of hospitalization in inpatient units and the other institutional care arrangements such as Kingseat, Porirua Hospital and Tokanui, almost exclusively led to narratives of trauma for

the participants. Participants indicated that the experiences of admission invariably occurred at times of acute distress and unwellness. Often the process of being admitted to an inpatient unit or institution exacerbated these feeling of distress and anxiety – ironically resulting in behaviours that contributed to others' perceptions of the risks they posed. The experience of one participant as captured in the conversation below is a fine illustration of this point:

> *Interviewer:* *So I want to go back to when we talked about your admissions. You said that you were scared and paranoid, was there anything that lessened that for you?*
>
> *Participant:* *Not for a while. Basically the cops took me there. My wife was there and they told her to go home and ahh the staff at (the acute unit) threw me into (the secure ward) – no family, no one telling me what was going on. And so when you're in there, everyone else is freaking out too you know and umm I was just like wow these bizarre people were coming and talking to me and saying freaky shit and I was just like..."fuck this" so I got up in this little corner and sat there with my back against the wall and took a while to calm down you know. And there's a stigma that goes with it, "hell I'm mental" you know. Don't know if that is relevant to what we are talking about.*
>
> *Interviewer:* *I think it is hugely relevant because I believe most people end up in that situation because of how services, police and other people perceive them as being either at risk to themselves or being of risk to other people and often the reaction to that doesn't do anything to eliminate it – it only heightens it in some ways.*
>
> *Participant:* *That experience definitely escalated it.*

During both this experience and a further one the participant indicated that his wife had been forced to leave against both of their wishes. He spoke poignantly of the need to be near his wife when he felt most scared and paranoid (she was a source of safety) yet remembers being forcibly separated from her.

Within this conversation is a sense of concern and fear as a result of being confined with other people who may also be experiencing heightened states of unwellness, agitation and anxiety. The

implication is that, particularly at times of acute unwellness and distress, people experience increased risks to themselves due to acute service provision models that congregate people commonly experiencing acute unwellness.

> " Yeah, cause when I was in there I had someone pick up a chair and try to hit me with it and so I grabbed him and knocked his hand in the process and so he whacked it over my head and that's the sort of people you were put amongst and you don't know who you're going to be put amongst."

Ironically, as much as congregation of people acutely unwell and distressed was a topic under this theme, so to was the experience of seclusion. Seclusion is used within almost all acute units in New Zealand (Mental Health Commission, 2004). It is often a small room with little more than a mattress in it. One participant described it as "a padded cell with a cardboard box for a toilet". The walls are often soft so that a person is unable to harm themselves against them. A commonly cited reason for use is to manage people safely to prevent them from harming themselves or others and is viewed as one of the most restrictive practices used in modern psychiatry (Mental Health Commission, 2004). Other consumers have commented that the use of seclusion is viewed as a breach of human rights whilst the use of restraint is viewed as assault (Cannon, 2006).

The experience of the participants of this research indicated that the consequences of being in seclusion lasted a lot longer than the time spent within it. During a conversation about seclusion a participant indicated how the experience reaffirmed nothing more than he "must be completely insane." There was agreement that the use of seclusion often escalated angry, harmful behavior, with one participant of a focus group indicating that they felt challenging behaviour was more often displayed after a "stay" in seclusion. This elicited a strong chorus of agreement from the other participants. This was further reinforced during three separate key-informant interviews as captured in the following conversations:

Participant: And then the next thing these two big dudes came out grabbed me under each arm, dragged me to the secure room and threw me onto the floor, the rest of them then jumped on top of me and pulled my rings off. Then they locked me in that room for the next day.

Interviewer: So they kept you in isolation?

Participant: Yeah what do they call it the hot box or cool box or something. I wasn't scared then I was just pissed off you know.

And:

Interviewer: So the response to them thinking you were risky was to put you in place you didn't want to be?

Participant: Yep.

Interviewer: And your reaction to that was...?

Participant: Very violent.

And rather sadly:

"But being around people and with people is the safest place I can be right now and not being left alone."

Additionally, people felt also that seclusion, or the threat of seclusion, was at times used in a punitive way by staff. This will be addressed in the next section of this chapter. It is encouraging to note that it was felt that this occurs less often now than in the past. There was a view expressed by at least three participants that the current use of seclusion was more judicious and a significant improvement on the use of it during the days of the large mental health institutions (asylums). The experiences these participants recounted within the institutions reflected a sense of trauma because of how they were treated. Whilst it is not the ambitions of this research to contextualize the different risk-management approaches of services over time, understanding the impact of these different approaches on consumers is important for two reasons. First, the understanding of risk for consumers appears to be significantly shaped by how services and service staff respond to them.

Second, some approaches to risk management over time have created significant stigma for participants. (An exciting emergence from the data has been titled the 'Stigma of Risk' and will be addressed in the next chapter; however, it requires a mention in relation to the unintentional harm experienced by people from services). Service responses that isolated people, or removed any personal authority or control (such as being *"locked up"* in seclusion) appeared to encourage negative self-beliefs, lack of confidence, and reinforced feelings of anger, frustration and fear. It is obvious that these thoughts and feelings do very little to keep people safe and reduce risk in their lives. Ironically, they were identified by participants as contributing to the occurrence of higher risk events. Sadly, there was also a stigma attached to that high risk event which participants felt then existed without understanding or consideration of the circumstances (created by service responses) that were present at the time. I have included these discussions here under the heading 'Unintended Harm' from service responses as the participants did not seem to believe that these occurred due to purposeful intent from services but rather happened as a result of a lack of deep, knowing and trusting relationships between staff and service users.

A further risk that emerged for participants they felt existed as a direct consequence of having mental health experiences, was the risk of harm from psychopharmacology. Medications, their side-effects, and contraindications were universally seen as being both helpful and potentially harmful.

> *Participant 1:*   *Side effects from the pills. The medication we take is a risk – we are taking a risk just taking this medication until you find one that works. For example it took over sixteen years to find a medication that worked for me.*

> *Participant 2:*   *Faith is a big thing of risk taking and that is what I find. The doctor might prescribe a medication to me and he says 'look we'll try it out' but it is actually faith that this medication is going to do the job.*

> *Participant 1:*   *It takes months for medication to start working and side effects.*

There was a sense that the risk factors for medications were often downplayed by people prescribing them so as to encourage compliance. If we cast our minds back to the vignette at the beginning of this thesis that described the experiences of Carol, hers was a vivid example of the side-effects of a medication, prescribed under compulsion, having a marked and mostly negative impact on someone's wellbeing and safety. There was very strong insistence from participants on the rights of people taking medication to have access to all information about the ingredients, side effects and physiological impacts of that medication.

"But also you have the right to ask your doctor or your chemist to ask for all the information about what the medication is made out of, the side effects and how long is it going to take to adjust it....You've got the right to ask your doctor"

People indicated that an often changing diagnosis and medication regime left a sense of vulnerability and concern over the physical impact of medication they had been taking that was suddenly changed and no longer required. Some people indicated experiences of taking many different types of medication over extended periods of time (ten years, sixteen years in some instances), in order for developments in psychopharmacology to present an opportunity for medication that they felt finally worked. When discussing changing patterns of treatment one participant exclaimed:

"It's like take this, take that, take this and you're a guinea pig until they see what works."

People found that where a medication assisted their wellness and reduced symptoms they were prepared to put up with either the side-effects or potential risks that the medication may also pose. However, the notion of faith was again connected to this. People felt that they had to trust that

medications taken today were not going to end up having physical implications revealed at some point in the future.

> *"Even the physical risk aye. You know like what it's doing to your body and things. Like I know that it is working for me but it's fairly new. They don't really know what twenty years down the track whether there are any long term side effects."*

A final comment on the issue of medication concerns an experience someone recalled where they were wrongly administered medication. Others indicated that they knew of similar occasions whereby medication errors occurred. There was a perceived need for people to make sure that they knew their treatment approaches so they could ensure that medication protocols followed by services were actually correct and adhered to. The fallibility of service systems and staff indicate (particularly in discussions concerning pharmacology) that receiving services in itself is viewed as risky.

Intended Harm

Whilst participants did not refer to intentional harm and abuse there were, within their dialogues, references to practices that can be considered and understood as abusive. I have categorized these separately to the unintended harm experiences in order to clearly distinguish a difference; however these interpretations of what constitutes intentional and unintentional harm from services are mine.

The common experiences that were described concern actions or behaviors of staff that reflected a lack of concern for the emotional, mental or physical wellbeing of the participant. This would range from people describing being the recipients of threats and promises of consequences to actual

physical force. Whilst a lot of these experiences occurred within the institutional era of asylum care, some occurred very recently. Participants commonly described threats that they believe were intended to modify their behaviour. These invariably were veiled, in that people would be advised if they do not comply they would be admitted into inpatient units, forced to live in residential care, placed back on medication they did not like and other such threats. One participant recalls the threat that should he "use" the hospital again he would be forced into residential care. His read on the situation:

> *"Well risk means a lot of things but I just came back to my wife and I was down but now I'm fighting to get on top of my life again. Yet they said if I use the hospital again for any reason they're going to bloody rip me away from home and I won't have any contact with my wife."*

Others recalled similar situations where they were not allowed any freedom of decision making over even the minutia of detail in their lives.

> *"I forget the women's name but she put up a big front when I had to move there and she was just like "nah" and I wasn't allowed to do this and I can't do this and I can't do that. All I had was just a small room and I had to stay in that room 24 hours. I wasn't gonna do that – that wasn't me. So I decided righty-o I'm gonna change this plan, I'm gonna hop out the window each night and go for walks, go and see the neighbour, searching out the blackbirds and searching out the odd possum on top of his roof*

Previous discussions about the use of seclusion are also relevant to this section as a number of participants referred to being "locked up" not as a genuine, required measure to keep them safe but rather as a punitive form of punishment. Being held in seclusion for twenty-three hour stretches after being told *"you will get what you deserve."* This is consistent with other findings that indicate seclusion has been used as punishment (Mental Health Commission, 2004).

One conversation from a participant indicated a range of uncaring attitudes that they encountered and the subsequent impact it had on his sense of self-worth. The attitudes of staff, as expressed to

this person, contributed significantly to presenting risk and, importantly for this thesis, his understanding of risk. Because, as indicated in the following dialogue, the attitudes of staff imply that risks are not only "managed" by services but also contributed to by services. Additionally the suggestion is that the attitudes of staff also influence the perspectives of risk of consumers.

> *"Yep. A lot of that is because again how I've been treated by the mental health system in the past. I can remember being at (an institution) at one time and we were asked to write about how we were feeling and I had been in seclusion for a couple of days because I had climbed up on top of the roof ready to jump umm so I wrote all this stuff about how I wanted to do away with myself and the lovely nurse came along and read it and then threw it in the rubbish tin. So I figured from there on in that obviously it was just all me – nobody was really interested so I had to put that to one side. Then I had an interesting conversation just recently with my Psychiatrist and the crisis team put me in respite and told me when he came to visit that he thought I was just being trouble and you know he was going to have no joy and that I was too much of a hassle. And so I hate the crisis teams now. Yeah so I've had all this stuff where people say I'm not worth worrying about or I'm too much trouble to deal with. The last psychologist I had dropped me because I didn't do CBT the way CBT was supposed to be done whatever that is - so I'm not even good enough for therapy. All that has added to – well if I get unwell I might as well just kill myself because I'm too much trouble – I'm trouble for the crisis team, I can't do therapy because I don't play by the rules, if I put it down on paper because I want someone to read it and because I want help that doesn't work because it gets thrown in the rubbish. So I might as well just do myself in. So there is always that – when I'm starting to feel unwell – that risk that I will do that because I'm not worthy of being treated. So that was my past. When I start to feel unwell I try to shut myself down so that won't happen – though of course that doesn't work either it just adds one more hurdle to the recovery. "*

The concept of intentional harm did not occur through direct conversation with participants but rather by implication. Although in one conversation a participant indicated intentional abuse occurred when he worryingly recalled how staff would use other patients (sic) in the hospital to administer 'punishment'.

> *"But even the nurses, if you ran away, the staff that were working in places like that would get other patients to actually do you over and that was the risk of being in there. And I saw that happen. I'm glad that it doesn't happen today. I don't know whether it still happens in places like Lake Alice, or maximum security places, whether it does happen but that was the way they treated people."*

So in concluding this section it is apparent that as much as services will intervene because of perceptions of risk, participants see that how they intervene can place them in risky or vulnerable situations. In particular, this occurs around medication management, varying diagnosis, inconsistent treatment plans, being placed in acute units (often with police involvement), being forced to do things against their will and experiencing some mental health staff as distant, aloof, uncaring or simply abusive.

5.3   Managing Risk, Creating Safety

This section of the thesis captures those themes that emerged through the data that relate to what works in keeping people safe. While the interview schedule did not specifically ask for people to disclose their personal risk management strategies and approaches, there was considerable conversation throughout the interviews that related to the things that keep people safe. The discussions concerned the participants' beliefs of the primary role that consumers need to play themselves to keep safe and manage risks, and also of the crucial importance of strong, trusting relationships with others in order to create safety.

Self-management of Risks

"You just got to basically take every day as it comes you know."

The title of this section essentially captures this aspect of the risk discourse. That is, participants viewed risk, be it an event, episode or perspective of others, as a phenomena that needs to be managed by them in the first instance. This was not expressed as defiant opposition to risk

managing systems or staff but rather as a spoken awareness that consumers themselves need to be aware of what risks are for them, how best to limit and manage those risks, how to identify them and then seek the support of others in managing them. There was an acknowledgement that this is not an easy thing to complete due to the stigmatizing barriers indicated earlier in this chapter and elaborated in the next:

> *"Yeah so it's picking your moments to take that chance and let yourself out there and that's bloody hard to do when you are running around with a mental health issue. Knowing who you can trust to take it for what it is and not interpret it as something different."*

There was also an appreciation that the experiences of mental illness itself can compromise the ability of individuals to manage their own risks. This view was reinforced by a participant who indicated that when she was unwell she has no awareness of what risks she is exposed to let alone having the ability to safely minimize and manage them.

The view remained and was supported however, that consumers need to be afforded the opportunity at every instance to, at the very least, be involved and have some control over risk management and minimization as it concerns them. There was strongly expressed emotion concerning the degree to which professional staff have risk management responsibilities yet their relationship is experienced by the person whose risks are being managed as distant, aloof and not particularly caring.

Participants described a range of activities that they do to manage risky situations and keep themselves safe. These ranged commonly from practical activities such as *"eating and sleeping"*, *"affirmations, meditations and listening to good music"* to other intentional activities such as (for one participant) the removal from the home of any implements which could be used to self-harm.

The predominant activity that participants felt that they had some ability to manage in order to deal with risk was in the establishment and maintenance of strong relationships. There was a universal expression of the role that good, stable and consistent relationships had in keeping people well and in minimizing risk factors and consequences. Conversely, a lack of good relationships implied heightened states of risk and vulnerability.

Safety and Relationships

The discourse of risk for the participants somewhat naturally lent itself to discussions on the things that limit risk. Of those that have been mentioned to date, by some margin the most universally agreed, was the role that health professionals and loved ones played in supporting the management of risk.

Participants indicated that friends and families were an important source of safety. When recalling his first admission to an inpatient unit, a participant indicated that he was unsure that he needed to go; however, as his wife was with him and also supporting the admission, he felt a sense that it obviously needed to occur.

> *Participant:* "In hindsight yeah but I don't know that it was a secure unit I needed. I look back and can see that the stuff I was doing was bizarre but....I don't know. They were required. I can't see my wife helping put me there if it wasn't really needed you know.
>
> *Interviewer:* Yes. So again a real source of your safety in some ways is the relationship you have with other people – your wife, friends and other people who look out for you.

Somewhat sadly for this participant in the midst of the admission that he was describing above he recalls being forcibly restrained whilst his wife was made to leave the inpatient unit. He recalls being scared and unsure and without explanation or understanding having the one person he recognized and who he knew cared for him removed. He touchingly continued stating:

> "And being in [the acute unit] you know I look back and think man – I'm fortunate enough to have a family and people that care about me. A lot of people in there have nobody – you know."

Another participant indicated a lack of involvement of family from mental health services. There was some agreement that family were often kept in the dark in relation to the person's care. One particular participant felt that this created a situation whereby his family did not appreciate or understand what occurred for him at times. This was viewed as critical by another participant who took the discussion further in articulating that his partner was often viewed as the 'safety net' by crisis services who he believed relied on his wife to secure his safety, whereas others without good family supports may have received a quicker response and more interventions. It was felt that good practice from mental health professionals included sustaining family/whanau supports and helping build them where they have been pressured because of the social stressors resulting from mental health. An interesting paradox was apparent in that as much as families and loved ones were identified as critical in minimizing risk; at times those relationships were particularly strained and considered 'at risk' of being damaged because of unwellness and risky behaviours when unwell.

There was sustained discussion that almost unanimously determined that the quality of the relationship between professional mental health staff and service users was a significant contributor to managing risks. Participants almost universally felt that relationships that kept

people safe, those built on trust and mutuality, take significant time to develop. Unfortunately, the predominant experience was that this time was seldom afforded due to what people described as rapid turnover, high caseloads and lack of concern from individual staff among others. The following conversation held during a focus group captures the essence of these concepts.

> *Participant One:*   *Like when I was first transferred over to [a clinical team], I had one person for six months, another person for six months, I had one person for three months then another for three months until I got one person and I'm happy cause I've had him for four years now. So you need to get on with the one person for a long, long period before you can trust and feel safe with that person.*

> *Interviewer:*   *So there's a really interesting aspect of risk if part of being safe or of you managing and being in control of risk is having a deep relationship with people who support you and they keep changing all the time that makes it really hard doesn't it?*

> *(Chorus of agreements)*

> *Participant Two:*   *And also sharing really personal stuff with someone that you don't know and don't necessarily have a connection with and it just goes on and on. A new person comes round and you gotta share the same, often horrible, kinda traumatic stuff, and for the most part you're sharing with someone who doesn't understand the value of reciprocity and actually I'm not going to give you my whole life but I can kinda understand cause.... You know its like you're doing all this work to connect and you're just talking to someone who is really not interested in making themselves as vulnerable as they expect you to be.*

> *Participant Three:*   *Professional boundaries.*

> *Participant Four:*   *I was just going to say that.*

> *Participant Three:*   *You're not allowed to get close.*

And further:

> *Participant One:*   *Yeah sort of but people come and go you know, a lot of social workers, same as doctors. One week this guy was my Dr. then another week it was a different Dr. and they all try something different - its like "far out" its just crazy you know.*

Participant Two:　　　*They should stay at least eighteen months before they get transferred to someone else rather than changing every six months so that that person gets used to that person and so on. It takes a long time to trust someone to open up.*

Participants identified the constant turnover of staff as contributing to their exposure to risk and vulnerabilities. The reasons for such included the increased likelihood of mistakes being made, the lack of trust of new staff members, lack of consistency in treatment approaches and a loss of oral histories.

The concept of mutuality in relationship referred to earlier was again raised with another participant indicating how difficult it is to develop rapport and a relationship with someone when that person is *"not giving anything back to you."* There was a sense that this type of inequity in relationship resulted in difficulties in mental health support staff really getting to know the person and subsequently really getting to know the things that might reduce hazards and manage risks. I cannot help but adapt a term coined in the recent high profile television campaigns - "know me before you manage my risks for me".

Where mutuality in relationship did commonly occur it was in fact, with other people with mental health experiences. The common experience of mental illness and mental health service utilization created conditions for deep understanding and relationship. This was reflected in participants in the focus groups who would comment on the value of discussing the topic of risk with others who had similar experiences and perspectives. One participant indicated that the learning from others with mental health experiences was a significant aspect of her own wellness.

"I think it is a positive risk when people with experience of mental health get together and have a few chats because we are enlightening each other on our experiences. They are

the same but they are different. You know they all got a similarity of experiences but it all comes to one thing you know – an understanding of each person. Every time I meet someone I am learning a positive thing about people with mental health experiences."

In summation, it was apparent that the quality of the relationship was dependent upon certain factors regardless of whether the person was family and friends, professional staff or other people with lived mental health experiences. These factors included genuine care and concern, the ability to listen, to authentically understand, continuity and the investment of time. Participants believed that they had a large part to play in establishing and maintaining these relationships. Subsequently this discussion has connected safety and relationships with the earlier discussed self-management of risks.

5.4   Taking a Risk, Life's a Risk

The literature review of this thesis touched on the notion of risk being concerned with gain as well as loss; on the likelihood of an outcome or consequence being either positive and promising or negative and hazardous. To this end, during the interview participants were intentionally prompted questions to illicit conversation about understandings of positive risk. The result was an affirming notion that risk is an inescapable phenomenon that is experienced as a part of life and part of being an included member of the community. Interestingly, when asked about risk the response was very much attached to the identification of someone with mental health problems who used mental health services however, when asked about positive risk it was more frequently discussed whilst identifying as a person with the same citizenship rights as other community members. Furthermore, an aspect of the positive side of risk was related to the concept of recovery, to regaining wellness and reconnecting to communities as indicated in the following conversations.

Participant One:	*And another really good thing with the positive risk side is that we really help with the stigma in the community because we take the chance and get out there. When we stay at home all alone that's really impacting on us and hurting us, when we take these risks a get out, and its really hard I appreciate that, then other people out in the community that know think well if they're doing it.*
Participant Two:	*I did it. I didn't like going out.*
Participant One:	*I know but I bet you feel good about it now though?*
Participant Two:	*I do I get out there and I smile at people and people approach me and talk to me – it's really neat. Yeah.*
Participant Three:	*But risk shouldn't just be about mental illness.*
Interviewer:	*Yeah? Can you tell me more because that is a really critical point. Is it part of being...*
Participant Four:	*Human – life is risky*

An important aspect of Recovery is the notion of living well in the presence or absence of mental illness. The conversation above and the extract below indicate that people felt very much that there were events or episodes in their life that led to better circumstances and importantly that these events required taking a risk in the hope of positive outcomes. These perspectives were common.

Participant One:	*A major risk is when.....quite a few years ago, I think its about five, maybe four, four years ago. I was staying in a residential home.*
Interviewer:	*So this was a service delivered by mental health providers?*
Participant One:	*Yeah and when I was offered to go out by myself a lot of people were saying no I wouldn't be able to make it. To this very day I say to myself well done – I made it, I made it. Here I am still in a completely different place and here I am still out on my own. In spite of the odds and how I'm feeling it's just great.*

An interesting aspect of this participants' experience was that there were "a lot" of people telling him that he would not be capable of living on his own in his own home. In taking the chance (and

the risk) he was able to prove, in spite of skepticism from care-givers and support people, that he was capable. A strong principle of the Recovery approach to service delivery is the notion of hope and the critical role that people can have in holding it for, and engendering it in, those with mental health experiences. Hope was not particularly present from those who doubted this participant's abilities and strengths.

Earlier this thesis touched on the consequences of social exclusion and institutionalization. The reconnection with community and creation of a sense of belonging was seen as a positive result of risk-taking. This was often expressed as taking a lot of effort from participants and appeared as a deeply personal experience. The risk presented as having a positive outcome (and subsequently being an example of positive risk-taking); however, there was acute awareness that there was also potential for a negative impact or outcome.

> "And for me the positive side of risk is also fear as well. Fear of the unexpected. It was like the others were saying so once you put yourself out there, yes you going to face anxiety at least we grow from that; that is how we grow as individuals. And everytime we have a positive experience within that it helps rebuild our self esteem whereas a lot of the other stuff that has happened in our lives has demolished that. And I think that it is really, really important that we keep putting ourselves out there because that is how we get good experiences.

Other participants felt that being a part of community required risk-taking in order to be a member of that community. This was expressed as more than simply being 'out there' but rather as being an active member in the management of others' risks. This is wonderfully illustrated in the two examples below:

> *Participant One:*   *For example I saw some kids walking towards the road, young ones, babies and I said "where's the mothers'. The mothers were up the end of the driveway, on the end of a bottle laughing away, drinking away and didn't know what their little ones were doing. And what were they doing? Chasing a ball, quite a light one and it was being blown by the wind, quite a powerful wind, a strong*

> *one. And I thought am I gonna go and jump my fence – no. I walked to my gate going towards to pick up the ball, and I yelled to the kids "stop there, don't go any further". And that's when the mother saw what was going on and came dashing down. And just at that time this other school girl came rushing past and picked it up and beat me to it – but good on her. A least I did my part by stopping those two little girls that have got no road sense at all. And that goes back to my example of being out by myself...*

Interviewer: *And being a contributing part of your community.*

Participant One: *Yeah. Absolutely. And I could say it any better than keep going – keep doing the good work.*

And additionally:

> *"The other day I was walking up the street and I noticed this lady that had very little sense of English...anyway she was trying to get her car out onto the road from a park and she just couldn't. She was going to cause an accident because the way she was parking the car she was nosing the front end onto the pavement and the back end was out in the middle. I rolled up and showed her my license. Oh oh, me driving the car – haven't done for a long time and she said 'you drive here's the keys, you park the car". I thought "flippin heck" why not. I took that risk and I took control and pretended I was a truck driver using both mirrors. I took that risk and I helped her out"*

The idea that risk-taking was about life and learning was also present. A number of participants indicated that taking a chance and making mistakes was an aspect of positive risk – particularly if there was the opportunity to learn from the mistakes. The idea was expressed that the there was opportunity for learning and for personal growth when taking risks and making mistakes. One participant felt that this opportunity was not afforded to people who used mental health services. This was strongly supported by others in the focus group.

Participant One: *I've made some errors of judgment that aren't so much errors of judgment as they are opportunities to learn. You know because too often we might make an error but it gives us a chance to learn rather than a reason for another pill.*

Participant Two: *And no ones perfect, everybody makes mistakes all the time*

The final word about risk as a part of life and an aspect that is apparent for all citizens is best left to the participant who declared:

> "It's like taking a car home. We don't even know if we are going to get home tonight alive - it's a risk. Going down the street is a risk. The next breath is a risk, I'm not saying I hope it'll happen cause I don't want that but someone could have a heart attack today."

5.5   Additional Views of Interest

As indicated earlier there were a range of other considerations. These considerations did not present with enough frequency to warrant their inclusion as a theme, however they provide some valuable insight and awareness to the consumer discourse of risk. This final section of the findings in this chapter captures these discussions and the correlations between these and the previously presented themes.

Choice and Control

The first discussion concerned the subject of choice and control. This was referred to on occasions throughout the discussion on risk and unwellness and risk of harm due to service responses; however, the content of the dialogue differed enough to warrant separate consideration here. The key message of choice and control was that participants identified that they had it prior to becoming a mental health service user and lost it once receiving services. It was agreed by participants of one focus group that if there was one aspect of their lives that presented with some risk that needed to be safeguarded, all of a sudden all aspects of their lives became under scrutiny and control. Often this was felt to occur to such an extent that people lost the right to decision making over even the minutia of detail in their lives.

"So you don't even get to live your own life. Your ability to make choices about the simplest things is taken away from you."

People indicated that resistance to this loss of control had often resulted in being labeled non-compliant – an experience that was seen to be very stigmatizing. Ironically, participants would indicate that a consequence of this would be that they would experience an even greater loss of control.

Choice and control seemed also to extend to who people had to work with. It was felt by one participant that having to share personal stories and vulnerabilities with a staff member that they had little choice over was particularly risky.

"And I think also that people who live independently in the community people get to decide who they share their story with. Whereas if you're in service you don't really get to decide that. You don't really get to decide that this person doesn't feel quite right to share your story with so it becomes where its something that you have to do whether you like it or not and their aren't any other options for that. And I think [of] the risk of that and the fear of how they are going to use that information."

An encouraging aspect of risk, choice and control was that it appeared as people regained their wellness – or experienced Recovery - they felt that they had more choice and control. It was not clear whether regaining some control contributed to the process of Recovery however. It is encouraging as choice, control and empowerment were viewed as being vital to maintaining wellness. This is consistent with Recovery focused literature (Lapsley, et al, 2002).

Participation

Participants indicated throughout a number of the interviews and during a focus group that they were not always involved in determining solutions to their problems or that they were a part of the

formation of their own risk management strategies. A number of people indicated that they had not even seen or read their own risk management plans.

> *Interviewer:*   *Have you ever had a risk assessment done on you from services?*
>
> *Participant:*   *I'm not sure mate – maybe when I was unwell they did but I am not sure about that. Possibly – I think so yeah.*

Given the evidence that emerged where participants identified the need to self manage risks, it is apparent that consumer participation in risk management planning would be crucial. There was an indication that information sharing went entirely one way. This was reflected in the conversation outlined earlier where a participant indicated vulnerability about sharing personal information and having to trust how it would be recorded and used. This notion of participation in the identification and management of risks is particularly important as participation is one of the key standards to be achieved in the National Mental Health Sector Standards (Ministry of Health, 2001).

Supporting Other Consumers

Within the mental health sector there is a rapidly growing phenomenon of consumers in specialized support roles (Doughty and Tse, 2005). These roles, commonly known as Peer Support Specialists, involve people with lived experiences who have experienced Recovery, working with others. This lived experience allows Peer Support Specialists to offer a unique understanding and relationship with other consumers on the basis of mutuality, shared experience and the role modeling of hope and Recovery. Whilst, the formalization of these roles is encouraging and called for by the consumer movement, consumers supporting and caring for each other has occurred informally for a long time. Peer groups and friendships are common due to shared experiences

and contact. During one discussion a participant indicated that his first admission to an acute unit

was particularly distressing because *"man it was like nothing you've ever seen."* However, he

recounts that after a while other people in the unit became friendly and they developed an informal

support group to help each other deal with the experiences of acute inpatient care, the distress of

symptoms and ways that they can increase their wellness (and by implication, safety).

A further participant strongly indicated the sense of purpose that he experienced from helping other

people when they were in crisis and displaying particularly risky behaviour. The following extract

indicates how being purposeful and supporting other people heightened his own sense of wellbeing

– an experience I am sure many health professionals can relate with.

> *Participant:*   *I've found that a certain person when I was staying at a certain place this person was so much at risk. When I say this person – I'm not naming names – but this person was getting so wound up and so upset that even some of the certain people were not willing to go into the persons room to settle the person down. And this person was winding them up so much that just couldn't think, they were hitting the walls and they were... I could hear them just so much so upset and I was about within one hundred feet away if not more and I could hear them quite clearly. And I went up and I said look I can calm this person down. And I went there - went down to their level and said I understand, take some deep breaths and saw them calm down. And that to me was the biggest impact of my life – being able to help that person out. From the panicky situation, from the risking that she could have done more harm to herself.*

> *Interviewer:*   *So when you said it had a big impact on you is this because you supported someone else while they were...*

> *Participant:*   *Yes a very bad state of mind. It could have turned things a lot worse. The police could have been involved and the crisis team could have been around.*

> *Interviewer:*   *How did it make you feel? How did you feel being involved in a situation that was quite risky?*

> *Participant:*   *It made me feel – hey – if I can do this I can do other things.*

Chapter 6: The Stigma of Risk

Stigma has been seminally described by Goffman (1963) as a discrediting attribute given to people outside of social norms and expectations. People with mental health have certainly been, both historically and currently, recipients of stigma and negative stereotypes (Hinshaw, 2007; Grant, 2001). The impact of stigma on people with mental illness has a dramatic and mostly negative effect (Angell, et al. 2005). Stigma is a concept that has existed in mental health and human service policy, and in literature, for some time (Hinshaw, 2007). Invariably the literature talks about the stigma of having a mental illness and does not specifically address the stigmatizing nature of risk and risk perceptions.

In recent times within the mental health sector in New Zealand there has been a significant emphasis placed on combating the impact of the stigma associated with mental illness. Destigmatisation campaigns have been implemented with a considerable number of high profile initiatives having success, such as the 'Like Mind, Like Mine' and the 'Depression Awareness Initiative'. These campaigns have the intent of normalizing the experience of mental illness and focusing on the strengths and abilities of people with lived experience.

A significant finding of this research concerns the (mostly harmful) consequences on people of the stigma of risk. However, this concept has very little consciousness in the discourse of mental health policy or service delivery. The use of it in this thesis and the reason for addressing it as a chapter in its own right is purposeful for two reasons. It was a particularly strong and emotive theme that emerged from the participants. When discussing the experiences attached to the

stigmatizing of risk the participants disclosed very emotionally charged perspectives – the impacts of the stigma of risk shared during this research were (and are still) particularly challenging. The second reason for coining the phrase is that it offers a valuable means of understanding the impact of risk on the lives of people with lived experiences. Additionally, it begins to develop a way of understanding how services, service staff, families and other community members can begin to address the consequences of this phenomenon. These consequences will be discussed later in this chapter whilst the implications will be discussed in following chapter.

The findings of this section have been structured under three headings. The first is an introduction to the discussions on what the stigma of risk is and the impact that it has had on participants. The second concerns a notion phrased rendering the normal, abnormal. The conversations with participants revealed that the occasion of a high risk event in a person's history appears to then influence the perception that other people hold over subsequent events or happenings even when they are quite benign and normalized. The final section is titled managing others' perceptions. Here the discussion will center on what participants described as having to manage how others perceived their risks and wellness. This section will show how participants feel that having had events in their past that were risky, many of the subsequent events that were not risky were perceived as being so.

6.1   An Introduction to the Stigma of Risk

> *"Once you've had an event that was risky, be it verbalizing suicide, harming yourself or harming others, that actually sticks with you and that becomes a stigma."*

Participants were forthcoming about the fact that high risk events had occurred for them that placed either themselves or others at potential harm. These experiences included suicide attempts, or suicidal ideation, assault, verbal abuse and on occasion self-neglect. Participants felt that a substantial consequence of this was not simply the potential harm to themselves or others that occurred at that time, but the ongoing judgments they were subjected to because of that event. It was described that these judgments would occur without consideration of the context that was present before and during the event. Participants felt that the high risk event stayed with them forever. What was remembered and known was only ever the perception of the event from the person who documented it – the participants were not aware of their perspectives on the risky event ever being documented. This consideration of context and perspective was very important to people. There was a strong sense that the event itself is what is remembered and very little about the factors or circumstances that contributed to it. The things that were occurring for them (the contributing variables) are not understood by others, simply the risk event itself. An example presented when an individual disclosed that almost fifteen years ago they assaulted a staff member whilst being admitted to an inpatient unit. There were a number of contextual factors that contributed to the assault including heavy drug use, a range of social stressors, variable compliance with anti-psychotic medication and acute mental unwellness. It was the only time that the person has assaulted someone although they have experienced a number of subsequent admissions. The person indicated they have since seen their file and their current risk assessment indicates 'risk of assault when unwell.' Again, the event of risk is episodic, the stigma of it remains – surmised poignantly in the declaration of a participant: *"They don't look at what you are now and how you are now."*

Participants felt like they were being constantly judged for any risk event that occurred in the past. There was a sense of injustice about it with a number of people indicating that offenders have opportunities to have their records quashed, or to 'do time' and then get on with life yet this was not an opportunity that was afforded to them.

> "Yeah if someone goes to jail for assault or something like that but then they get out and have ten years free without having a criminal record they can have that quashed but we can't have our records squashed and that is wrong."

The following conversation during a focus group further reinforces the notions of both ongoing judgments on the basis of previous risk events and on a sense of injustice because of this.

Participant 1:   I must admit that I went to court with someone who was trying to get off a treatment order and I was there next to her and I wasn't involved in the case itself I was just there to support this person and the lawyer went through to three years previously that said that this person was at risk because she was violent. And they continued the order and I was just like what!!! (agreement) They went back years and years and it was just surreal. This person wasn't able to move forward you know because it was on her file and because it was convenient for the workers for her to remain on an order.

Participant 2:   Yet people get out of jail and it's a get out of jail free card. You get a chance to get on with you're life you know.

Participant 3:   Yep you paid you dues.

Participant 2:   You know significant, minor or major and it's always dragged up with mental health.

Participant 1:   I was astounded.

Interviewer: So is some of what I am hearing is that risk is a stigma in and of itself?

Participant 4:   You got it on the head mate!

There were a number of apparent consequences to this. Frustration and anger were obvious responses including a declaration that as soon as an individual attempts to challenge this then they are dismissed as becoming unwell (and subsequently increasingly risky):

> *"Yep and if you stand up and start actually getting proactive and assertive about it you are seen as getting unwell."*

It also tends to lead to significant questioning and self-doubt:

> *"Other people are allowed to move on why can't I? What's wrong with me that I can't without history following me?"*

Other consequences that were expressed included a very real frustration and lack of control over aspects of their lives. It is important to note that this was felt not only with formalized mental health services but was also felt to be the case with other government agencies and departments and, as we will learn later, with families and loved ones. One person in particular had a concern about how mental illness and risk was assessed and viewed by the Child Youth and Family Services. Having her children removed and placed in care had been very difficult. However, what seems to make it more difficult is a sense of not being listened to and being stigmatized as being 'of risk' regardless of what positive changes she has made since having her children placed in care.

As indicated earlier two related concepts emerged from the discourse of the participants that occur because of this stigmatizing nature of risk. The next to be discussed concerns the concept of normal situations and behaviours being viewed, through others perspectives of risk, as abnormal.

6.2   Rendering the Normal, Abnormal

In the previous section a highlighted statement indicated that a participant, in attempts to assert some personal authority over an aspect of their life, was subsequently viewed by a health professional as becoming unwell. There were a range of other discussions that indicated an experience for people of having routine and usual aspects of their lives becoming viewed through a lens of mental illness and risk. Most often this was referred to in relation to the person's perceived level of wellness. This was expressed as occurring from both professionalized mental health service staff and also from participants' family, friends and other loved ones.

The experience of this was most definitively identified as existing for people because of their mental health experiences and backgrounds. When asked if my assertiveness could be misinterpreted in the same way the response was an emphatic: *"no way because you haven't got a history."*

Participants reported that it was not just behaviours that were suddenly brought into question and made abnormal but thoughts and feelings also. This seemed to be the case whether the feelings were of happiness and joy or of sadness and frustration. One participant indicated that since experiencing mental health problems she is no longer allowed, by anyone around her, to have a bad day. An experience she identifies as common to many people is now not allowed for her:

> *"You know it's all those simple things – it's not rocket science – it's feeling like you have to work twice as hard if you have a history of mental illness to appear normal. And you have to justify even though everyone has bad days, and there's times where I'm having a bad day but I have to say "I'm having a bad day, I'm not getting unwell everybody, I'm just having a bad day."*

There was a suggested sense that this rendering of normal behaviours and emotions into abnormal concern was actually a means of health professionals exerting some sense of control over service users. This is reflected in the comment below.

> "Because once you have been mentally ill and so on and people who know about it – if something doesn't suit them with what you say, it doesn't lie right with them they'll be like "oh it's your mental illness" you know and a lot of the times its not."

Interestingly the participant believed that this was often the case when staff members were trying to convince him to follow their course of action and not his. It is likely that the frequency of this would increase with the perceived level of risk the staff member was trying to avoid.

I remember an acquaintance who lived with bi-polar disorder and who often behaved in ways that put her at risk when she was experiencing significant mania. We were at a public gathering to celebrate the launch of an exciting service initiative. She was understandably happy and excited (as both myself and others were) at the recognition of the efforts of many people and loudly pronounced "this is the best ever – I am so happy" to which the looks and silence of staff around her prompted the reserved and somewhat ashamedly stated "but not too happy – not like that kinda happy". This fear that a normal response is being viewed as an abnormal expression of unwellness (whether the case or not) appeared to also be the experience of the participants. It correlates to a further subject that emerged through the data concerning the stigma of risk which I have termed 'managing others' perceptions'.

6.3   Managing Others' Perceptions

> "And risk is how an individual perceives it really."

> "Definitely. You always have to manage how other people perceive you."

One finding of the stigma of risk concerned the perceived lack of control that people had over things in their life because of risk perceptions that others held. A range of consequences emerged that will be addressed throughout the remainder of this chapter. Firstly, participants felt the very real need to try and control how they (and their risks) were perceived by others, secondly they needed to be primarily responsible for risk management as they could then maintain some control over what happened to them, and thirdly they needed to develop deep and strong relationships with people so that they could access support in dealing with risks that did not involve losing control to others.

The notion of control was an important factor in the analysis of managing the perceptions of others. The primary reason for this was that most participants had experienced significant loss of control or say over what happened to them during experiences of unwellness and risk. One of the suggested reasons why this occurred, and why the perceptions of others needed to be managed, was because of fundamental differences in understandings about what was occurring. That is, participants commonly indicated that their view of risk and what was risky was very different to what others' perceptions were. The ability to develop a common understanding depended greatly on the strength of the relationship and the level of trust the participant felt that they had in the other person.

One participant felt strongly that the risk reducing practices of staff were invariably about reducing the risk of blame and accountability to them should something adverse occur. This was supported by others in a focus group who reiterated that at times police, mental health professionals and others were invariably concerned with risk of exposure to *"getting in the crap"* rather than genuinely concerning themselves with the person's wellness and safety. A further illustration of the potential

difference in perceptions (and the vulnerabilities that people felt as a result) occurs in the following conversation:

Participant One: *And I think because if you under a system and notes have to be written– because how we feel is so subjective – your risk can actually go up because someone has decided that they are going to write notes through their own knowledge and because it is so subjective, so you can be trying to explain something that is just pretty average normal day stuff and it can be interpreted in a completely different way that increases your risk if they see it as more of an issue than it actually is.*

Participant Two: *And it can impact on being released from wherever you are and things like that.*

Participant Three: *That's right you end up playing a game. You go and see your psychologist and you know if you say this, in my case, "I'm feeling a bit depressed and I'm worried about what I might do" all of a sudden "He's a danger to himself lets up his meds, put him in respite, lets put him on watch." So instead of getting help you go along and it's like "How are you going?" and you respond "oh great."*

Participant Two: *That's really a deficit for us on our behalf because we feel we have to lie to keep ourselves safe but really we have to be honest to keep ourselves safe - but who you choose to be honest with is very important.*

Invariably it was past experiences of the trauma of being a mental health service-user that led to people identifying the need to be cautious about to whom and how they communicated issues or concerns. A desire not to lose control over their circumstances and situations seemed to be at the heart of this discourse. There are two further interesting aspects of the above discussion. The first is the notion that someone is vulnerable not because of an actual risk being present rather because someone else believes a risk might be present. This, in and of itself, is a significant contribution to the risk discourse of consumers – the suggestion being that risk is additionally understood as being about the perceptions and views of others. The second, which will be further elaborated upon in the implications highlighted in chapter seven, concerns the scenario where the

participant does not seek assistance, although required, through fear of the response from the health care worker. Given that participants clearly identified that self-management and strong relationships are what minimize risk and keep people safe, it is particularly concerning that this aspect of the stigma or risk creates situations where neither of these things can occur.

An additional example of this aspect of the stigma of risk follows in the perspective offered below:

> "The more you feel like you've got your own risky behaviour the less control you know you're going to have so it ends up quite a fear thing involved where its like - OK I need to be honest but being honest can land me somewhere where I don't want to be or where something will be written on my file that is going to be used against me and so as my personal risk goes my fear of losing control and of having decisions made without me become more and more apparent. And so you just like well what do I do? Do I shut up about it and just try and manage or do I actually take the risk and try to step out and just keep my fingers crossed and hope that the other person is actually going to hear me without engaging the clinical team, sectioning me, taking control and I think ummm that's really big! For me the risk is sharing my story yet again with someone who has power over me and can make decisions that I have to follow and that's a really big thing. People out in the community – they get to live their lives and have an understanding of risk without people necessarily making decisions for them."

This participant is indicating a strong sense that, due to the tarnished view others hold because of her past behaviours or situations, she will again lose control and some decision making authority over things that deeply matter to her when she next presents with risky behaviours. Again, there was a sense of inherent vulnerability because of this and a barrier to accessing the things that could contribute to her safety.

It was not simply mental health professionals whose perspectives require managing; participants felt that this was the case with their family members also. There was, for a few participants, an acute awareness of the distress that their loved ones had suffered during times when they were unwell. One participant poignantly recalled how his suicidal behaviour had a distressing impact on

his wife. Subsequently he now feels significantly compelled to protect her from any further distress and so is acutely aware of how she perceives his mental state to be – and significantly he manages this perception. Primarily he manages it but not allowing her to know when things are not going so well for him. Given the findings indicting the importance of relationships in contributing to people's wellness and safety this is a phenomena that is particularly concerning.

The stigma of risk that is experienced by people as indicated in this chapter has a negative effect on people's safety, wellness and exposure to more risks. Given the identified importance of having strong relationships to keep people safe, it is apparent that the stigma of risk presented here places significant barriers to this occurring. These barriers occur both within the personal and professional relationships that people have. As damaging as the stigma of mental illness appears to self-identity (Angell, et al. 2005), the stigma of risk appears to keeping people safe.

Chapter 7: Implications of the Consumer Risk Discourse

The previous two chapters, presenting the analysis of the research findings, clearly indicated that the consumer discourse of risk included phenomena that is both dignifying and dignity stripping. The notion of being stigmatized as risky clearly resulted in a loss of dignity for participants. The concept of self-managing risks and of supporting others to also self manage risks presents a dignifying perspective of risk.

This chapter, using the findings and analysis outlined previously, will discuss the implications of the themes that emerged. Evident within the findings are implications for three groups; consumers (and family/whanau and loved ones), services and service staff, and policy and policy makers. This chapter will address the implications for each group in turn. For clarity this will be made explicit under each of the headings; consumers, services and staff, policy and policy makers. Some of the findings have implications for each of the three groups. Where this is apparent reference will be made to it at the time rather than repeating the discussion in each section. The implications of the different themes that emerged from the data will be addressed simultaneously within each of sections. The implications for the stigma of risk are important to all of these groups and will subsequently be discussed under its own heading.

The implications of this research are grounded in the data and the data source. That is, the purpose of this constructivist research is not to present a generalist view or a meta-narrative that claims to be indicative of the perspective of all consumers (in this instance). However, for the group of participants who discussed this subject matter there are some immediate implications that

relate directly to each of the findings. On the basis of those findings, using constructivist research, we can begin to document a perspective which holds validity in making recommendations at personal consumer levels, service delivery levels and indeed strategic policy levels. Prior to discussing these recommendations a comment is required on a suggestion of the trait of resiliency that appeared present for the participants of this research.

7.1   A Comment on Resiliency

The concept of resiliency was not discussed during the interviews; however, it became apparent during discussions between the CAP members and I following the interviews. We collectively reflected on the apparent resiliency of participants who, although faced with the often traumatic experiences they shared, continued to manage their lives and achievements in the presence of these significant, additional hardships. I believe that this characteristic of resiliency and the importance that it has to risk literature and consumer perspectives cannot be overstated as it presents as a further critical factor in determining what assists in managing risks and creating safety for people. Resiliency is a common concept in psychology literature. A succinct descriptor suitable for this discussion is offered by Bonanno (2004:20) when he defines resiliency as pertaining to:

> "the ability of adults in otherwise normal circumstances who are exposed to an isolated and potentially highly disruptive event, such as the death of a close relation or a violent or life-threatening situation, to maintain relatively stable, healthy levels of psychological and physical functioning."

It was apparent during interviews with people that the participants identified a significant range of stressors and challenges. These existed not necessarily because of their mental health experiences or symptoms but rather as a result of service responses and community responses to them. Furthermore, having experience of mental health issues was also identified as increasing exposure to risk and harm including the experience of being 'of risk' to either self or loved ones. An extrapolation could be that people with mental illnesses become a population with additional and unique risk exposures than other citizens within the risk society. This is certainly a view reinforced by the findings of this research and by Taylor-Gooby, (2001; 2000) who argues that hazards of risk, within modern welfare states, fall inequitably upon those most marginalized by health, poverty, discrimination and other such concerns.

However even with the experience of increased exposure to risk and its consequences, the participants approached for this study communicated incredible strength of character in dealing with this increased exposure to risk. Many of the identified factors that increase exposure to risk (deliberate harm from services for example, the loss of control as another) could easily increase responses and behaviours that, in themselves, place others at harm. Due to what I interpret as traits of strength and resiliency, participants mostly dealt with these frustrations in ways that did not either resort to violence, or increase hazards. A recollection of the experiences of Carol indicated at the beginning of this thesis and partially responsible for my interest in this subject, is a very good example of incredible resiliency and robustness in the face of adversity. Similarly, there were a considerable number of stories shared that indicated particularly traumatizing experiences for the participants that they were able to overcome. This supports Ridgeway's (2001) argument that recovery from mental illness is in fact an example of resiliency.

I believe that there is a very real concern that mental health services and service staff can overlook or underestimate the importance of resiliency in people. This is the view also of Bananno (2004) who suggests that theorists working in the area of loss and trauma often under-estimate or misunderstand resiliency, viewing it as rarely existing and when so, primarily within healthy individuals. If mental health services staff overlook people's resiliencies, an opportunity is likely to be missed to reinforce safety and manage risk by strengthening the very thing that has assisted in keeping people safe to date. The implications for service staff are that they should recognize and enhance consumers' strengths. They should continually affirm the coping strategies of people they work with and help them identify and enhance further ones. An active engagement with risk, by allowing positive risk taking and learning, would likely also result in building peoples resiliencies further, through encouraging self awareness and recovery and allowing people to assume some responsibility for their own wellbeing and safety.

7.2   *Implications for Consumers*

An immediate conclusion drawn from the findings comes from the theme of risk and unwellness. This concerns the consideration that to increase safety a critical strategy is to secure and maintain peoples level of mental wellness. Participants identified that exposure to risk is increased at times when they are increasingly unwell. This risk was in the form of increased reliance upon services and service supports, decreased ability to self manage risks and additionally deterioration in behaviours resulting in an increased likelihood of high risk hazardous events occurring. Recent times in mental health service delivery have seen a trend in consumers becoming increasingly included and involved in their own care and wellness planning. Recovery informed services are

beginning to apply principles of participation and empowerment in service settings. This has led to a greater emphasis on consumer self-directed recovery. There has been a global increase in the process of completing Wellness Recovery Action Plans (commonly referred to as WRAP), whereby consumers are responsible for identifying and implementing their own wellness strategies (Copeland, 2008). These encouraging developments have occurred in New Zealand also. The themes that transpired from the participants call for further developments in consumer self-directed service delivery. They do so because efforts that support achieving and maintaining mental wellness address many of the concerns that arose. In particular addressing the abilities (and necessities) to self-manage risk, deal with the stigmatizing nature of risk and keeping people from the harm or traumas of service delivery and treatments.

On an individual, case-by-case basis consumers need to actively advocate for an ongoing role in the creation and formulation of their own risk management processes. Whilst not denying the responsibility of services to manage risks for people whose ability to do so may be limited or compromised, there appears apparent benefit in closely involving consumers in that process. It is alarming that almost all of the participants had disclosed stories that highlighted episodes of risk to self or others (implying that most would have documented risk assessments and risk management plans), yet only a couple had actually witnessed their risk management plans let alone actively contributed to them. This can be addressed through a range of means including the creation of policy, and incorporating participation in risk management as standard practice. However, due to the identified theme of risk management as needing to start with consumers I would emphasize that this can occur on an individualized basis with consumers advocating for participation in risk management processes. There is some sense that this could occur while people are experiencing good mental health and wellness whereby they simply indicate, in the form of something akin to an

advance directive, how they wish for their safety to be secured during times of acute unwellness and decreased capacity to understand risks.

When considering risk and safety it was apparent for participants that the strength of personal relationships was a significant contributor to creating conditions that reduced hazards. An implication is that this requires an emphasis on working hard to maintain good, supportive relationships with family/whanau and friends (informal supports). Recognition is required on the impact on loved ones when witnessing or being subjected to a high-risk, hazardous event. Participants indicated that these phenomena often placed strain on relationships rather than encouraging stronger ones. There is a requirement for consumers informal support networks to be educated and aware of risk exposure and mitigation strategies. Participants indicated that this often occurred sometime after a particular crisis event or episode and subsequently required work to "mend" strained relationships. The proposition is that engagement of informal supports should routinely occur as a preventative means prior to the experience of heighten risk.

There are a range of rights, Acts and agencies that are intended to help protect health service consumers from poor care. This is the case for consumers of mental health services also with a range of specific Acts and commissions in situ (Health and Disability Commission, Mental Health Sector Standards, court appointed District Inspectors among others). Some of the practices that participants were exposed to were significant enough in their intentional mistreatment to cause concern. Whilst it was unclear whether people were unaware of their rights or were aware but simply unable to exert them, a clear recommendation is that consumers become more assertive in ensuring that these are adhered to. Additional to perceived, intentionally abusive practices, is the notion of duress and coercion that participants were subjected to. Strengthening consumers'

abilities to identify and challenge these practices will go some way to redressing this discourse of risk identified by the participants.

An observation of the interview methods for this research concerned the collegial and supportive relationships that were present for the participants of the focus groups. The CAP members favoured the focus groups as it was viewed as a means of people connecting and supporting each others' perspectives and experiences. This process of support and encouragement was mirrored in the findings where people recounted the strengths, understandings and encouragement that they received from other consumers. An implication is that consumers should continue to seek out and pursue opportunities to support, and get support from, other consumers. This can occur formally or informally. If the discourses of risk presented here are common for others, there is likely some benefit in consumers connecting with each other to develop strategies for addressing some of the findings. For example support groups to understand and deal with the stigma of risk.

A final implication and recommendation for the people who use mental health services is to ensure that there remains a focus on positive risk-taking. The findings indicated that when discussing positive risks participants clearly identified that this was concerned with recovery. That is, in order to have opportunities to pursue and experience wellbeing, people needed to take chances, try things, be prepared to learn from mistakes and as a participant indicated *"put yourself out there and give it a crack."* For the participants positive risk-taking was connected to hope, growth and was seen as the practice of citizenship. The implication is that on a personal level there is the necessity to believe in each person's own ability for recovery and wellness. Therefore, if consumers engage with positive risk-taking and learning from this there is an increased likelihood of recovery and regaining wellness.

7.3   Implications for Services and Service Staff

The implications for services and the staff within them are particularly significant as it is apparent that the consumer discourse of risk is considerably influenced by the interactions between service staff and consumers. This is not particularly surprising given that participants' involvement in the study was on the basis of their lived mental health experiences and their experiences of services delivery; however, its significance lies in the fact that the influence that service delivery has on the risk discourse was predominately negative. This does not suggest that services or staff do not have any positive impact; however, it does imply that there needs to be significant work from services and service staff to understand and improve the impact that their approach to risk has on consumers.

Whilst the following implications will not be addressed in a prioritized order, I wish to highlight the first one as being of primary importance as it seems to relate to many of the findings. That is the importance of developing deep and personalized relationships between staff and consumers. Earlier in this thesis, when discussing accountability and blame, the literature suggested that risk management for services has become an increasingly depersonalized process with significant value judgments made. The findings from consumers indicated that where relationships with service staff were strained this contributed significantly to feelings of increased exposure to risk and increased vulnerabilities. Quite simply, relationships that are of good quality between consumers and their clinical and support staff will increase safety and ensure significantly more robust risk management processes.

There were a range of identified factors in developing quality in relationships between participants and staff, not the least of which was time and consistency. The mental health sector in New

Zealand has had significant issues with recruitment and retention of staff (Hatcher, et al., 2005). There is likely a range of contributing factors for this. I suspect one strong factor is due to the strong effect of the attribution of blame and fault within the context of our risk society. Regardless, an impact of poor recruitment and retention is that both time spent, and consistency of relationships are not common experiences for either staff or consumers. Instead the experience is one of pressure, little time to spend with people, constant turnover and the necessity for consumers to have to 'start over' with a new staff member. A common complaint I have heard expressed within the consumer sector is of the need to continually 're-tell' personal life-stories. Many of the participants identified that a good clinician or support worker who had faith, belief and who valued them was often the catalyst for increasing their wellbeing and for keeping them safe. They also identified that it was really difficult to accept also that these same people would then depart and they would need to repeat the whole process. Services need to look at the allocation of work and the systems they work within to create conditions favorable to developing and sustaining good staff who are able to maintain quality in relationships with people. The importance of developing a Recovery focused workforce is particularly significant as participants were clear that when they have had relationships with staff on the basis of Recovery principles, these have been crucial in supporting people to be safe and to increase their wellbeing.

Risk management plans and assessments need to be completed 'with' people not to them, at them or for them. Participants identified that risk management needs to involve an aspect of self-responsibility. Risk management practices and documentation needs to reflect this desire for responsibility, involvement and participation. The earlier findings in the literature on the creation of risk avoidance and aversion are likely to offer a significant barrier to this. Therefore, services need to critically engage with risk management processes and pressures within their respective services.

A conscious attempt at identifying behaviours, policies or processes that exist due to intentions of risk management will begin to allow services to engage in risk discussions with consumers in a way that supports their participation and subsequently, as indicated in the findings of this research, increases the likelihood of their safety. If risk management is intended as a process to identify potential hazards and minimize both the possibility and impact of their occurrence, then it seems absurd that the person whom the plan concerns is not involved in the development and review of it.

It is imaginable that the practice and documentation of risk management varies from service to service, although national guidelines have been developed (Evans, et al 2006). I would like to see services begin to identify in the risk management plans what the positive impacts may be for people if they are to engage in a positive way with risks. While care-plans, relapse prevention plans, Wellness Recovery Action Plans (and the myriad of many other plans people are recipients of) may well begin to address strengths and opportunities there is a need to ensure that risk management considers positive aspects of risk and risk-taking. Reflexive engagement from services with consumers' experiences of risk may begin to go some way towards addressing the stigma of risk as indicated previously.

A further and final implication for services and service staff is the need to better engage family / whanau and significant others. Given the theme of good relationships creating safety it seems an important risk management strategy for services to focus on supporting people to develop good, strong, relationships with family and significant others. Participants indicated that the experience of acute unwellness or risky events occurring often placed significant strain on their social relationships. There would likely be some benefit in services focusing on supporting people to address the strain on these relationships following a period of unwellness. Engaging and

educating informal supports, responding to the needs of family / whanau members and supporting stronger consumer relationships would all be effective strategies for assisting people to secure their safety.

7.4   Implications for Policy and Policy Makers

Consumer participation and involvement in many aspects of the mental health sector has occurred as evidenced earlier in this thesis. With a collective consumer 'voice' being present in many parts of the mental health sector a concerted attempt needs to be focused on increasing the dialogue and the capturing of the 'voice' of the consumer risk discourse. This is in keeping with a commentary by Mental Health Commissioner (at the time) Mary O'Hagan (2006) who indicaed tha there needs to be more attention given to the risks consumers associate with harmful environments, violence and coercion and the damaging effects of treatment.

Further research and development of the consumer risk discourse will expand the sectors understanding of this infrequently discussed or documented narrative. There are a number of benefits to this. Firstly, it could lead to changes in how services and service staff perceive and respond to risk. Secondly, it could begin to empower greater consumer ownership of their risk discourse. An interesting observation in recruiting participants for this study was that many felt that they did not know much about risk and that they would not be able to offer a perspective. I believe that this is partially because risk concepts and responsibilities have been considered the domain of services, bureaucrats and policy makers and not consumers. Increasing consumer involvement in understanding and capturing risk discourse could lead to shared strategies between consumers for

managing and responding to risks – particularly those that relate to harm from services. A further benefit to increasing understanding of consumer perspectives of risk will be in addressing the current stigmatizing nature of risk – this will be elaborated in the next section.

Policy initiatives have had a considerable impact on mental health service delivery. The policies of de-institutionalization enacted over the past two decades are a good example of the impact that policy can have on service delivery and on the experiences of consumers. Policy focused on increasing consumer involvement in defining, assessing and managing risk can likewise have a positive impact on service delivery and consumers experiences as it will begin to address some of the experiences shared that emerged from this research.

Finally, policy can begin to enable services to contend with the current pressures that give rise to risk aversion. By making consumer involvement and responsibility a best practice principle then an increased approach to shared responsibility can begin to occur. The findings of this research indicate that as people take greater control and begin to experience choice in the delivery of their services, the risks that they either contribute to, or are exposed to, decrease. Policy that directs this to occur more frequently will begin to create an environment where risk aversion is minimized.

A feature of the risk society outlined earlier in this thesis is the expectation that state agencies will reasonably protect citizens by the responsible regulation, management and control of risks. With this expectation comes a heightened awareness of liability should this not occur. This liability (accountability and blame) significantly contributes to environmental concern for risks. This concern has had a pervasive influence in mental health. The attribution of blame is a common feature of mental health services with public inquiries occurring at incidents of failure of care. A

tension of the recommendations of this research is that risk embracing services may soon retreat should an event occur which leads to significant harm for either a consumer or a community member. Policy that supports a change in approach to risk that accounts for the consumer perspectives as indicated in this thesis needs to be robust enough to withstand the pressures of the risk society that has created the current environment.

Given other areas of state provision of services, such as child protection, general health, justice, and social security are also influenced by risk, there may be some benefit in cross-sector understandings of the risk discourse for the respective "users" of these services.

7.5   Implications of the Stigma of Risk

A significant and unexpected finding of this research was that the participants are acutely aware of, and impacted by, what has been titled 'the stigma of risk'. Stigma for people with mental illnesses has been acknowledged as existing throughout history (Hinshaw, 2007). There is a view among researchers and advocates that stigma impacts most seriously and most negatively upon people with mental illnesses (Corrigan and Kleinlein, 2005). The consequences of this impact are significant and include (among others) fear, discrimination, loss of rightful life opportunities, social exclusion, ridicule, criminalization of behaviour and other such injustices (Corrigan and Kleinlein, 2005). Within mental health in New Zealand there have been concerted campaigns at a policy and service delivery level to destigmatise mental illness. Encouragingly, recent research shows that despite evidence that stigma does exist, the majority of New Zealanders are sympathetic and understanding towards people with mental illness (Gendall, 2006).

Stigmas are commonly held as occurring due to stereotyping by media and naive members of the public (Angell, et al. 2005; Hinshaw, 2007). However research conducted in New Zealand by Peterson (2004) indicated that consumers mostly identified stigma as existing due to attitudes of staff, family / whanau members and others known to the individual. This is supported by Angell et al (2005) when they indicate that professionals can hold attitudes that are pejorative and paternalistic, expressed in the use of coercion and duress. These findings have direct application to the implications of the stigma of risk. That is, participants were clear in their consideration that the stigmatizing nature of risk was primarily sourced from service staff and family / whanau members. A significant source of this stigma arises from how it is captured within service records and notes. The findings indicated that it was felt by participants that little heed was paid to the context of risky events. In the documenting of episodes or perspectives of risk, service staff can unintentionally add to the creation of risk by stigmatizing the individual. It is important that the documentation of risk accounts for environmental and contextual considerations so that people happening upon the information do not begin to make judgments or develop perspectives that are unjust.

There was a strong sense that people were unable to 'overcome' a historical risk event. It was felt by some participants that any episode of risk was never allowed to be forgotten regardless of how much time had passed since the event. This has greater implications when considered against the findings that staff change and new professional relationships are continually developed. The ways in which risk events are documented or communicated can form and have impacts on consumers' new relationships with other mental health support staff. People's histories of risk become, with

distance from the event, little more than a descriptor of what occurred. The implication is that knowledge that is passed on to other staff is incomplete and skewed.

The findings which indicated that risk management was seldom discussed with the participants yet practiced by staff, contributes to the stigma of risk. It does so through the implications that risk is a phenomenon and perspective that is the domain of professional staff and not something that the person involved should have an active role in determining. The lack of engagement with the participants in identifying risks and mitigation strategies led to beliefs that this was something that they did not have any say over. It appears that when services take sole responsibility for risks and protections, and they do so without communicating this clearly with consumers, they send a message to consumers that risk is a shameful thing that they should not have any involvement with. If the practice of very little professional engagement with consumers over their risks and risk plans is more commonly experienced, then this needs to be addressed promptly.

The findings of the stigma of risk are equally important for consumers. Primarily because much of the impact of the stigma of risk concerns experiences that expose people further to the likelihood of harm. One of the findings of the research concerned the need to manage others perceptions of risk. This is concerning for a number of reasons. Firstly, there is additional pressure on people to ensure that their behaviours, thoughts or feelings are not being misinterpreted by others. Participants did not express concern about managing others perceptions when they were unwell, rather they were concerned that they would be perceived by others as being unwell or risky when they were not feeling so. Managing others perceptions (and perhaps worrying when you are not) must place an additional burden on individuals who are striving to overcome other challenges. The other concern of this, of course, is that in managing others' perceptions a strain is potentially

placed on relationships that should be supportive – relationships that should help manage risk. Consumers need to be able to have discussions with service staff, family / whanau members and other loved ones about this very phenomenon. Should an increased awareness of this occurrence occur, on a personal basis, between consumers and their support networks then strategies can be developed to address this issue.

Self-stigma is a concept that applies to the experiences of the stigma of risk. The internalization of shame, a decrease in self-esteem and self-efficacy has been identified as a consequence of stigma (Corrigan and Calabrese, 2005). This is likely to be the case for the stigma of risk also. If communication and contact with people primarily concerns risk identification and management then there is a high chance that this is what the person identifies with and internalizes. Consumers need to take an active role in engaging with services in a positive way with risk and ensure that plans and approaches to risk management are openly discussed. Consumer activists, academics and politically active groups can start to bring attention and light to the stigma of risk. Further work to develop greater understanding of it can be led and promoted by these same groups in much the same way as they have leant weight to consumer participation in research as outlined earlier in this thesis.

Lastly, as with the earlier implications concerning resiliency consumers need to continue to be resilient in the face of adversity. The participants indicated significant frustrations and concern about the impacts of the stigma of risk – having normal behaviours, thoughts and feelings questioned and subsequently having to manage how other people view those. It is important to find productive means of dealing with these frustrations and rely again on strengths to ensure that these frustrations do not end up contributing further to the creation of risk.

Chapter 8: To CAP it off – Analysis of Consumer Participation in Research

As indicated earlier, the research processes followed in the completion of this research demonstrated a participatory methodology. It also hoped to be emancipatory in terms of being purposeful to the participants. These processes were discussed in chapter four. This chapter is dedicated to an analysis of the participatory methodology, the lessons learned and the changes in approach that I would take in further participatory research. It does this by looking at the advantages and the challenges that participation offered to this particular research and researcher. Bearing in mind that the research process that was followed was not wholly user-controlled, an important part of the analysis is on my role, as the person with primary responsibility for the research, in keeping the participation as influential as possible.

8.1   Advantages

There were a range of advantages that occurred due to the involvement of the CAP in this research. These advantages were to the research processes, the research outcomes and to the researcher and the CAP members also. This section will address the advantages to each of these aspects of this study.

The CAP was formulated following a surge of interest at the distribution of the flyers indicated in the methodology chapter of this thesis. This interest proved to me that there is significant interest and readiness within the consumer community to be involved in research processes. As evidenced earlier in this thesis, participation in research is occurring at a slower rate than participation in service delivery and policy development. However, the overwhelming response to

the invitation for participation in the CAP is suggestive that the slowness is not necessarily due to a lack of consumer readiness or intent. There was no financial incentive for involvement in the research. CAP members (three out of five of whom were previously known to me) reasons for involvement varied for the most part; however, a common factor was the suggestion that people wanted to become involved in something that was new. There was also an indication from CAP that research, particularly research that was ethically influenced by consumers, was a means of contributing to the development of the mental health sector and to other service users. I recall a conversation where I had indicated a process that I would have to follow to ensure that the research would "give back" to participants. A CAP member commented "don't worry; we will make sure that you absolutely do that." This suggests that contributing to research as a means to contribute to positive consumer experiences is an important consideration. In appealing to consumers to participate in future research processes, a potential attraction to emphasize is the likely positive impact the research may have on improving outcomes for service users or their experiences of service delivery.

The CAP ended up participating in more than just the research process. One CAP member assisted me to put together an abstract for a conference presentation on consumer participation in research and evaluation processes. We successfully secured funding to support the CAP members flight, accommodation and conference costs and we co-presented a well-received workshop titled "Increasing Research Relevancy and Impact" at the 2005 Standards Plus "Rising to the Challenge" conference in Wellington. This experience was particularly valuable for us both and further reinforced the value of participatory processes.

Recruitment of research participants proved to be difficult. There are a number of hypotheses for this, including a view that people did not believe that they had something to offer (an interesting observation of where the power in risk definitions and discourses is presently located). A further possibility is that a consequence of wanting people to participate free from duress meant that initial methods of participant recruitment primarily relied upon self-identification. This altered as the recruitment rate was slow. It altered to consumers identifying to others the possibility of participating. A number of the focus group research participants (including one who was unable to attend on the day) were recruited via their connection to a CAP member. The advantage of participation in this regard is the immediate presence and access to the research target population. This highlights the advantage of the 'insider' researcher who has relationship and common understanding established, versus the 'outsider' researcher who may have to work significantly harder to develop those relationships.

A further advantage occurred in access to a venue for one of the focus groups. A CAP member who has been present from the beginning of the research is a respected member of consumer run service where she was able to secure a room to host the focus group. It was felt by the CAP that the interviews needed to be offered in a setting that was comfortable and known to the participants. The consumer run service was fitting in that regard. Again an unforeseen benefit to participation is in increased access to potential research resources.

It was at this focus group that a participant became visibly upset when recounting a particularly difficult story for him. He left the meeting tearful and upset whilst apologizing. There were two CAP members and myself present in the interview. A CAP member immediately got up and followed the participant out of the interview and as a researcher I was able to continue the

interview seamlessly comfortable in the knowledge that the participant had someone to talk to and process his distress. They both returned to the interview with the participant presenting composed and able to contribute to the conversation again. Following the interview I discussed the occurrence with the CAP member who indicated that they simply had a cigarette and a discussion about the circumstance that caused the upset, and with that the participant calmed and felt able to return. Had I been alone in the conducting of the focus group I would have faced the decision of either halting the interview and checking on the welfare of the participant or continuing the interview and having the distraction of ongoing concern for the participant. CAP's involvement in this instance assisted in limiting the risk in being involved in a research process that required the discussion and disclosure of sometimes distressing personal experiences. Additionally, I suspect, although did not test this view, that the presence of the CAP members and the fact that the research was participatory had a reassuring value for the participants.

On a personal note it was fantastic to have other people involved and excited over a subject that excites me. Sharing my passion for the subject and generating interest and support had a very motivational influence. CAP embers were not necessarily intended to be involved in the research as participants. However, during the first focus group the two CAP members who were present happily and engagingly contributed personal accounts that contributed both to the stimulation of discussion and also to the findings. At the conclusion I discussed the options of their involvement and they both indicated a significant desire for their views to be included in the analysis and that they simply could not help but participate. This reflects, I believe, the level of excitement that had been created for them and the level of trust established between myself and the CAP members.

Following the focus group the CAP and I had the ability to sit down and reflect on and discuss both the content and the views that were expressed and also the process of the group. This proved a valuable research process. The thoughts that we discussed were captured and, after the completion and transcription of the interviews, proved helpful in reflecting on the findings and the themes.

A final advantage for me in this research was the camaraderie, friendship and reaffirming presence that the CAP members had on me. It is always helpful to receive constructive advice and support when undertaking research. Involvement of the CAP provided this for me in an unprovoked way. For the CAP members themselves advantages included involvement in a new activity (for most), the opportunity to learn research processes, involvement in an activity that gives some enjoyment and purpose and the ability to meet with and connect to other people they otherwise would not have.

The advantages of consumer involvement in this research then, reflects those indicated by Davis (2005) when the argument is made that the involvement of consumers in research results in more relevant, reliable and likely to be utilized research. Whilst the previously documented advantages to this research may not be applicable to other participatory research processes, many of them, if conducted in a genuinely participatory way, will be present when similar methodologies are followed.

8.2   *Challenges*

In identifying these challenges, it is clear that they are on the basis of my experiences of this research process. They do not reflect at all upon the value that I believe the CAP members have had in this process or the gratitude and humility that I have for their participation and their individual and collective wisdom.

This thesis has been a significant undertaking at a time where career demands, family excitements (three children under five at one point during the thesis!) and other of life's happenings continue to monopolize time. Research in itself can be a time consuming endeavor. To complete it in a way that includes and involves others becomes an even more time consuming endeavor. In order for the CAP to have genuine input into the processes of research it was important that they had a good understanding about the research ambitions and aims, research processes generally and methods of analysis. Without spending time ensuring that this understanding is present, the risk is that the participation in research becomes tokenistic and less purposeful and in this instance is itself a risk. The means of increasing understandings for this research process were to develop discussion documents, distribute these to the CAP and then discuss them further in collective meetings to ensure that understandings were comprehensive and common.

Consumer contribution to research decisions is admirable. However, if there is no understanding about what the decisions involve then problems will develop and participation will be tokenistic. For example, making decisions about the inquiry methods requires an understanding of the many different options available and which methods might best suit the research subject. This has required ongoing dialogue and the need for information to be made available (and accessible) to

the CAP members. This led to a greater understanding and increased ability for contribution to decision making to occur. In discussing it with the CAP members it also led to feelings from the CAP members that their participation was considered valid, genuine and meaningful.

Keeping the CAP connected to the research was difficult at times when there was little progress. The research and thesis was completed (very) part-time and progress was often slow. Whilst it was always immediate for me this was not the case for CAP who were only consulted with during times of progress. A consequence was that we would have to reconnect and 'catch up' with where things were at in terms of the research. This can be overcome of course; however, it requires significant more effort on behalf of the researcher than if one was to complete research as an individualist pursuit.

Over the period of this research life events occurred for various members of the CAP that meant that their participation was limited. At the onset of the CAP involvement a CAP member who was recruited became unwell and was in an inpatient unit for some time prior to their ability to be involved. When she left the inpatient unit she also decided to leave Auckland to pursue an opportunity presented to her so subsequently opted out of the CAP. A further member of CAP who was living in a supported residential rehabilitation service decided to withdraw participation in CAP to concentrate on pursuing her goal of moving out of the service and organizing her wedding. Whilst these events were reasons for the CAP and I to celebrate, it did have a disruptive (though not insurmountable) effect in that other CAP members would need to be replaced and given the opportunity to 'catch up' to the research process and progress. While this disruption is possible regardless of the research methodologies or timeframes, there is a chance that it will be lessened in research that has shorter timeframes.

Again in order for participation not to be tokenistic it is important that consumer participation has a genuine influence over the process. Whilst there was never a decision or process that led to a particular challenge for us there was the need to ensure that a process was in place to address any issues that arose. I believe that the issue never arose as a result of a good level of trust between the CAP members and I. Certainly, following discussions about their involvement in the focus group two CAP members indicated that they felt able to be involved given a belief that I would have comfortably advised them should this have not been the case. Developing a genuine level of trust in the relationships between the CAP members and the researcher is once again an important task to achieve that is also time-consuming. Significant efforts were made at the start of the research process to have safeguards in place to ensure that we were able to trouble-shoot any situations of difficulty. This investment in relationship is an important consideration and in fact parallels the findings of the research indicating the importance of strong relationships in maintaining safety for people.

8.3   Risky Business – Involvement in Research

There are a range of other parallels between the findings of this research and the participation of consumers in the research process. Whilst this was not an intentional conclusion it does offer an interesting way to reconsider both the research findings and the research process. Firstly, risk and unwellness; an intended CAP member was limited in their ability to participate due to becoming unwell and subsequently involuntarily admitted into an acute inpatient unit. This forced intervention (for a significant time) contributed to the CAP member choosing to pursue a considerable change in life circumstances and led to their not being involved in the CAP prior to written consent.

Another CAP member who participated for a short time decided to leave to concentrate on other things in her life indicating that it was important that she stayed focused on maintaining her wellness. This aptly reflects both the risk and unwellness findings and the notion that risk management begins with self.

Significant time was invested in creating a clear terms of reference for CAP and working on documenting the safeguards in the relationships between CAP and myself. This was intentional given the subject matter of the thesis; however, unintentionally reflects the findings concerning the importance of relationships in creating conditions of safety. The CAP and I were clear that participation in the research should not have created any conditions of additional stress on CAP – particularly during involvement in the data collection. Developing strong and supportive relationships between the CAP and I was an important factor in keeping them safe should participation cause any distress.

The CAP had to risk that their involvement was going to be honored, that their participation was going to be genuine and purposeful and not simply leaving them frustrated at tokenism. I imagine this risk taking was made easier due to the relationship that was developed during the research and the assurance of following the processes of the two research ethics committees (Massey University Human Ethics Committee, HDEC Northern Region X Ethics Committee). Certainly the findings concerning participation were reflected in the research methodology. The findings indicated that participation and involvement were vital considerations in the management of risk. Participation in both defining personal risk and developing the strategies to manage it was considered important. Earlier this chapter discussed the advantages of participation in research.

The final parallel between the findings and the methodology concerns supporting other consumers. One of the reasons the CAP were keen on focus groups as a research method was that they expressed a preference for people to be able to connect to the topic with the support and common experiences of others also. This was certainly a part of the focus groups where participants were able to identify common experiences and views and were also able to support each other in the process. It was a finding of the research and additionally was part of the process of CAP. Having three consumers on the CAP meant that there was usually at least two consumers and myself present at any one meeting throughout. Having more than one consumer involved provided the opportunity for CAP members to support each other also and created a sense that the participation was not simply one person with no real authority or influence. On larger research projects with more intensive time and resource requirements, multiple consumer membership for this reason alone would be an important deliberation.

Chapter 9: Conclusion

This thesis began with a review of the literature of risk understanding it as a construct that influences social relations, health and human service policy, health service delivery and the recipients of health services. The literature of risk was then grounded in the delivery of services to mental health consumers. Following this was a descriptor of the approaches to consumer participation in research and an outline of the participatory approach used for this research. The findings of the research were categorized and presented under the broad headings of the (In)dignity of Risk and the Stigma of Risk. These findings indicated that the consumer discourse of risk is a highly emotive, experiential and powerful discourse that has implications on consumers and their families / whanau, services and service staff and on social policy. These implications indicate the need for further engagement and consideration of risk from all aspects of the mental health sector and a review of the critical aspects of risk concept that impact on the lives of people with mental health experiences.

Lastly this thesis concluded with a personal reflection on the participatory methodology that was followed. This methodology brought about both significant benefit and challenges. However, the previously outlined benefits of participation notably outweighed the challenges, subsequently indicating it to be a valuable research exercise. Furthermore, it was experienced with a heightened sense of ethical responsibility. That is, a participatory approach to research felt ethically and morally appropriate.

Within the sociocultural theory of risk there is a perspective surmised by Lupton (1999a) as concerning the personal 'self' and its understanding of risk. This thesis identified that whilst people with mental health experiences have predominately been viewed as being 'of risk' their understanding of risk was significantly different. Their view, shaped and influenced both by the experience of mental illness and considerably by how their loved ones, families / whanau and service staff related to them, concerned much more, the personal consequences of risk. These consequences primarily related to exposure to additional hazards due to mental health service use, exposure to additional risk when unwell, a loss of control and choice, and shouldering the burden of the stigma of risk.

This thesis, in taking a constructivist approach, supported the previously outlined view of the cultural / symbolic theorists views of risk. In constructing the risk discourse of mental health consumers this thesis has affirmed that risk is socially determined, constructed and understood. For the participants of this research it was constructed in a way that both extenuated their dignity and additionally also clearly highlighted a loss of dignity.

In attempting to document consumers' discourse of risk it was my intent to contribute to the mental health sector's understanding of risk. The participants that participated in this study indeed contributed and altered my understanding of risk. This is quite a special process to have experienced. A quote from Lupton at the beginning of this thesis indicated that social constructivists are concerned with how risk forms part of people's world views. In completing this study my world view has been altered and informed by consumers in a positive and enduring way. It appears that an unforeseen benefit of social constructivism is that the researcher undertaking

this approach comes away from the research, with their own construction of the social world influenced and affected.

It is fitting for a thesis that documents someone else's discourse that the final word is left to them. It is a statement that normalizes risk, challenging the stigma of risk that presently only concerns potential threat and harm from consumers. The title of this thesis, so as not to presume an outcome, originally involved a question: A right to a risk filled life? The conversation below during a focus group indicates that for consumers there is no question.

Interviewer: *I am going to have to start drawing this to a close because I suspect that we could keep talking for a long time which is great because it says to me that it is an important topic and there is some really valuable knowledge which we are generating. I quick question for everyone I suppose is that I have called the topic of my thesis a right to a risk filled life and we spoke about the rights earlier, then there is a question mark. Should we be taking the question mark away and be replacing it with an explanation mark?*

Participant 1:   *Absolutely because it is not a question it is actually a statement.*

(Agreement)

Participant 2:   *An expectation!!*

(more agreement)

Participant 2:   *Yeah - a human expectation.*

References:

Alaszewski, A. and Alaszewski, H. (2002) Towards the creative management of risk: perceptions, practices and policies. *British journal of learning disabilities.* 30, pp56-62

Alaszewski, A. (1998) Health and welfare: managing risk in late modern society. In A. Alaszewski, L. Harrison, and J. Manthorpe (eds.) *Risk, health and welfare.* Buckingham, Open University Press. pp127-154.

Alaszewski, A. and Manthorpe, J. (1998) Welfare agencies and risk: the missing link? *Health and social care in the community.* 6 (1), pp4-15.

Angell, B., Cooke, A. and Kovac, K. (2005) First person accounts of stigma. In P. Corrigan (ed.) *On the stigma of mental illness: Practical strategies for research and social change.* Washington, American Psychological Association. pp69-98.

Asmundson, G., Norton, J. and Stein, M. (2002) *Clinical research in mental health: A practical guide.* California, Sage Publications Ltd.

Babbie, E. (2004) *The practice of social research* (10th ed). Belmont, Wadsworth.

Bates, P. and Silberman, W. (2008) *Modeling risk management in inclusive settings.* http://www.ndt.org.uk/ETS/ETmain.htm accessed on 01/05/08.

Beck, U. and Willms, J. (2004) *Conversations with Ulrich Beck.* Cambridge, Polity Press.

Beck, U. (1999) *World risk society.* Cambridge, Polity Press.

Beck, U. (1992) *Risk society: Towards a new modernity.* London, Sage

Beresford, P. (2006) A service-user perspective on evidence. In M. Slade and S. Priebe (eds.)

Choosing methods in mental health research: Mental health research from theory to practice. East Sussex, Routledge.

Beresford, P. (2002) User involvement in research and evaluation: Liberation or regulation. *Social policy and society.* 1 (2), pp95-105.

Beresford, P. (2000) Service users' knowledges and social work theory: conflict or collaboration? *British journal of social work.* 30, pp489-503.

Berg, B. (2004) *Qualitative research methods for social sciences.* Boston, Pearson Education.

Bloor M., Frankland, J., Thomas, M. and Robson, K. (2001) *Focus groups in social research.* London, Sage Publications Ltd.

Bonanno, G. (2004) Loss, trauma and human resilience. Have we underestimated the human capacity to thrive after extremely aversive events. *American psychologist.* 59 (1), pp20-28.

Brown, P. (2006) Risk versus need in revising the 1983 *Mental Health Act:* Conflicting claims, muddled policy. *Health, risk & society.* 8 (4), pp343 -358.

Cannon, T. (2006) *Creating safety within mental health environments.* Auckland, Mental Health Programmes Ltd.

Carpenter, J. (2002) Mental health recovery paradigm: Implications for social work. *Health and social work.* 27 (2), pp86–95.

Champ, S. (2002) Questionnaires from the heart: National agendas and private hopes. *Nursing researcher.* 9 (4), pp20-29.

Chilvers, C., Spiers, S. and Barnes, S. (2005) NHS research and development in mental health. In

D. Sallah and M. Clark (eds.) *Research and development in mental health.* Edinburgh, Elsevier Churchill Livingston. pp179-203.

Copeland, M.E (2008) WRAP. Http://mentalhealthrecovery.com/aboutus/php (accessed on 14/07/08).

Corrigan, P. and Calabrese, J. (2005) Strategies for assessing and diminishing self-stigma. In P. Corrigan (ed.) *On the stigma of mental illness: Practical strategies for research and social change.* Washington, American Psychological Association. pp239-256.

Corrigan, P. and Kleinlein, P. (2005) The impact of mental illness stigma. In P. Corrigan (ed.) *On the stigma of mental illness: Practical strategies for research and social change.* Washington, American Psychological Association. pp11-44.

Cram, F. (2001) Rangahau Māori: Tona tika, tono pono – the validity and integrity of Māori research. In M. Tolich (ed.) *Research ethics in Aotearoa New Zealand.* Auckland, Pearson Education. pp35-52.

Croft, S. and Beresford, P. (1998) Postmodernity and the future of welfare: whose critiques, whose social policy. In J. Carter (ed.) *Postmodernity and the fragmentation of welfare.* London, Routledge. pp103-117.

Cutcliffe, J. (2005) Qualitative methods in psychiatric and mental health research. In D. Sallah and M. Clark (eds.) *Research and development in mental health.* London, Elsevier Churchill Livingston. pp57-76.

Davis, A. (2005) Service user involvement in mental health research and development. In *Research and development in mental health.* D. Sallah and M. Clark (eds.) London, Elsevier Churchill Livingston. pp145-160.

Dean, H. (2000) Managing risk by controlling behaviour: Social security administration and the erosion of welfare citizenship. In P. Taylor-Gooby (ed.) *Risk, trust and welfare.* Houndmills, Macmillan Press. pp51-70.

Dean, M. (1999) Risk, calculable and incalculable. In D. Lupton (ed.) *Risk and sociocultural theory: New directions and perspectives.* Cambridge, Cambridge University Press. pp131-159.

Denney, D. (2005) *Risk and society.* London, Sage Publications Ltd.

Dingwall, R. (2000) Risk society: The cult of theory and the millennium? In N. Manning and I. Shaw (eds.), *New risks, new welfare signposts for social policy.* Oxford, Blackwell Publishers. pp137-153.

Doughty, C. and Tse, S. (2005) *The effectiveness of service user-run or service user-led mental health services for people with mental illness: A systematic literature review.* Wellington, Mental Health Commission.

Douglas, M. (1992) *Risk and blame: Essays in cultural theory.* London, Routledge.

Edwards, R. and Glover, J. (2001) (eds.) *Risk and citizenship: Key issues in welfare.* London, Routledge.

Epstein, M. (2002) Where has all our knowledge gone? – Consumer participation and the generation of knowledge. Sydney, *TheMHS Conference Book of Abstracts Sydney 2002.*

Evans, C., Humberstone, V., Maniapoto, W., McKenna, B., Simpson, S., van Altvorst, S. and Wack, R. (2006) *Risk assessment and management of risk to others: Guidelines and development of training toolkit.* Auckland, Mental Health Programmes Ltd.

Fox, N. (1999) Postmodern reflections on 'risk', 'hazards', and life choices. In D. Lupton (ed.) *Risk and sociocultural theory: New directions and perspectives.* Cambridge, Cambridge

University Press. pp12-33.

Frese, F.J. (2002) Ethics in neurobiological research: one consumer/provider's perspective. In P. Backlar and D. Cutler (eds.) *Ethics in community mental health care.* New York, Kluwar Academic. pp187-205.

Furedi, F. (2002) *Culture of fear risk taking and the morality of low expectation.* London, Continuum.

Gendall, P. (2006) *New Zealanders' attitudes to mental illness.* Stigma in Global Context Mental Health Study. Palmerston North, Department of Marketing, Massey University.

Gibbins, J. (1998) Postmodernism, poststructuralism and social policy. In J. Carter (ed.) *Postmodernity and the fragmentation of welfare.* London, Routledge. pp31-48.

Giddens, A. (2003) *Runaway world: how globalization is reshaping our lives.* New York, Routledge.

Giddens, A. (1998) Risk society: the context of British politics. In J. Franklin (ed) *The politics of risk society.* Cambridge, Polity Press. pp 23-34.

Goffman, E. (1963) *Stigma: Notes on the management of spoiled identity.* New Jersey, Prentice-Hall.

Grant, S. (2001) A separate world? The social position of the mentally ill, 1945 – 1955. In B. Brookes and J. Thompson (eds.) *'Unfortunate folk': Essays on mental health treatment 1863 – 1992.* Dunedin, University of Otago Press. pp235-255.

Griffiths, K., Jorm, A. and Christensen, H. (2004) Academic consumer researchers: A bridge between consumers and researchers. *Australian and New Zealand journal of psychiatry.* 38, pp191–196.

Hatcher, S., Mouly, V.S., Rasquithna, D., Miles, W., Burdett, J., Hamer, H. and Robinson, G. (2005) *Improving recruitment to the mental health workforce in New Zealand.* Auckland, Health Research Council of New Zealand.

Hazelton, M. and Clinton, M. (2002) Mental health consumers or citizens with problems? In S. Henderson and A. Peterson (eds.) *Consuming health: The commodification of health care.* London, Routledge. pp88-101

Healy, B. (1996) In doing you learn: Some reflections on practice research on an advocacy project. In J. Fook (ed.) *The reflective researcher.* St. Leonards, Allen and Unwin. pp70-82.

Heyman, B. (2004) Risk and mental health. *Health, risk & society.* 6 (4), pp297-301.

Hill, C. (2006) Qualitative research. In J. Norcross, L. Beutler, and R. Levant (eds.) *Evidence-based practices in mental health debate and dialogue on the fundamental questions.* Washington, American Psychological Association. pp 74-81.

Hinshaw, S. (2007) *The mark of shame: Stigma of mental illness and an agenda for change.* New York, Open University Press.

Holliday, A. (2002) *Qualitative research.* London, Sage Publications Ltd.

Kemshall, H. (2002) *Risk, social policy and welfare.* Buckingham, Open University Press.

Kingi, T. (2002) *'Hua Oranga' best health outcomes for Māori.* Unpublished doctoral dissertation, Wellington, Massey University.

Kirkman, A. (2001) Ethics and the politics of research: Where gender and sexuality still matter. In M. Tolich (ed.) *Research ethics in Aotearoa New Zealand.* Auckland, Pearson Education. pp53-63.

Lapsley, H., Waimarie Nikora, L. and Black, R. (2002) *Kia mauri tau! Narratives of recovery from disabling mental health problems.* Wellington, Mental Health Commission.

Lash, S. and Wynne, B. (1992) 'Introduction'. In *Risk society towards a new modernity.* U. Beck. London, Sage.

Lister, R. (2001) 'Work for those who can, security for those who cannot' a third way in social security reform or fractured social citizenship? In R. Edwards and J. Glover (eds.) *Risk and citizenship key issues in welfare.* London, Routledge. pp96-110.

Lunt, N. and Davidson, C. (2002) Increasing social science research capacity: Some supply-side considerations. *Social policy journal of New Zealand.* 18, pp1–17.

Lupton, D. (1999) *Risk.* London, Routledge.

Lupton, D. (1999a) Introduction: Risk and sociocultural theory. In D. Lupton (ed.) *Risk and sociocultural theory: New directions and perspectives.* Cambridge, Cambridge University Press. pp12-33.

Mental Health Commission (2004) *Seclusion in New Zealand mental health services.* Wellington, Mental Health Commission.

Mental Health Commission (2002) *Service user participation in mental health services: A discussion document.* Wellington, Mental Health Commission.

Mental Health Commission (1998) *Blueprint for mental health services in New Zealand: How things need to be.* Wellington, Mental Health Commission.

Mental Health Commission (1998a) *Critical mental health services improvement report number*

one: Report on the present state of clinical risk management in mental health services documentation provided by crown health enterprises. Wellington, Mental Health Commission.

Ministry of Health (2007) *Like minds, like mine national plan 2007-2013: Program to control stigma and discrimination associated with mental illness.* Wellington, Ministry of Health.

Ministry of Health (2006) *Te Kokiri: The mental health and addiction action plan 20065 – 2015.* Wellington, Ministry of Health.

Ministry of Health (2005) *Te Tahuhu: Improving mental health 2005 – 2015: the second New Zealand mental health and addiction plan.* Wellington, Ministry of Health.

Ministry of Health (2001) NZS 8143:2001 *National Mental Health Sector Standards.* Wellington Ministry of Health.

Ministry of Health (1998) *Guidelines for clinical risk assessment and management in mental health services.* Wellington, Ministry of Health.

Ministry of Health (1997) *Moving forward: The national mental health plan for more and better services.* Wellington, Ministry of Health

Ministry of Social Policy (2001) *The social development approach,* Wellington, Ministry of Social Policy.

Morley, C. (2003) The dominance of risk assessment in child protection: is it risky? *Social work Review.* 15 (1), (2), pp33-36.

Muir-Cochrane, E. and Wand, T. (2005) *Contemporary issues in risk assessment and management in mental health.* Greenacres, Australian & New Zealand College of Mental Health Nurses Inc.

Nettleton, S. and Burrows, R. (1998) Individualization processes and social policy: Insecurity, reflexivity and risk in the restructuring of contemporary British health and housing policy. In J. Carter (ed.) *Postmodernity and the fragmentation of welfare*. London, Routledge. pp153-167.

Nutley, S., Davies, H. and Walter, I. (2003) Evidenced-based policy and practice: Cross-sector lessons from the United Kingdom. *Social policy journal of New Zealand*. 20, pp29–48.

O'Brien, M. (2001) Doing ethical research legally: Research ethics and the law. In M. Tolich (ed) *Research ethics in Aotearoa New Zealand*. Auckland, Pearson Education New Zealand. pp25-34.

O'Hagan, M. (2006) *The acute crisis – towards a recovery plan for acute mental health services in New Zealand*. Wellington, Mental Health Commission.

Pilgrim, D. (2005) *Key concepts in mental health,* London, Sage Publications Ltd.

Peterson, D. (2004) *Quality, discrimination and participation in mental health research.* Unpublished doctoral dissertation, University of Victoria, Wellington.

Peterson, D. (1999) *Ethical research with mental health consumers.* Wellington, Mental Health Commission.

Phillips, R. (2004) Risk, social work and the third way: the opportunities of knowledge and the hazards of ignorance. *Social work review.* 16 (1), pp32-36.

Phillips, R. (2006) Consumer participation in mental health research. *Social policy journal of New Zealand.* 27, pp171-182.

Ramon, S. (2005) Approaches to risk in mental health: A multidisciplinary discourse. In J. Tew

(ed). *Social perspectives in mental health: Developing models to understand and work with mental distress.* London, Jessica Kingsley Publishers.

Ridgeway, P. (2001) Restorying psychiatric disability: Learning from first person recovery narratives. *Psychiatric rehabilitation journal.* 24 (4), pp335-343.

Smith, A. and Pitts, M. (2007) Researching the margins: An introduction. In M. Pitts and A. Smith (eds.) *Researching the margins: Strategies for ethical and rigorous research with marginalised communities.* Houndmills, Palgrave MacMillan. pp 3-41.

Stevenson, C. and Cutcliffe, J. (2006) Problematizing special observation in psychiatry: Foucault, archeology, genealogy, discourse and power/knowledge. *Journal of psychiatric and mental health nursing.* 13, pp713-721.

Taylor-Gooby, P. (2002) Varieties of risk. *Health, risk and society.* 4 (2), pp109-111.

Taylor-Gooby, P. (2001). The politics of welfare in Europe. In P. Taylor-Gooby (ed.) *Welfare states under pressure.* London, Sage Publications. pp1-28.

Taylor-Gooby, P. (2000) Risk and welfare. In P. Taylor-Gooby (ed), *Risk, trust and welfare.* Houndmills, Macmillan Press. pp1-18.

Taylor-Gooby, P., Dean, H., Munro, M. and Parker, G. (1999) Risk and the welfare state. *British journal of sociology.* 50 (2), pp177-194.

Thornicroft, G. and Rose, D (2005) Health services research: Is there anything to learn from mental health. *Journal of health services research and policy.* 10 (1), pp1–2.

Titterton, M. (2005) *Risk and risk taking in health and social welfare.* London, Jessica Kingsley Publishers.

Tolich, M. and Davidson, C. (2003) The fascinating world of social research. In C. Davidson and M. Tolich (eds.) *Social science research in New Zealand. Many paths to understanding.* (2nd Edition). Auckland, Pearson Education. pp7-22.

Truman, C. and Raine, P. (2001) Involving users in evaluation: The social relations of user participation in health research. *Critical public health.* 11 (3), pp215-229.

Waldegrave, C. (2003) Focus groups. In C. Davidson and M. Tolich (eds.) *Social science research in New Zealand. Many paths to understanding.* (2nd Edition). Auckland, Pearson Education. pp251-262.

Ward, P. Bissell, P. and Noyce, P. (2000) Insights into the uncertain world of the consumer: Reflections on the risks of non-perscription medicines. In P. Taylor-Gooby (ed.) *Risk, trust and welfare.* Houndmills, Macmillan Press. pp131-148.

Warner, J. and Gabe, J. (2004) Risk and liminality in mental health social work. *Health, risk & society,* 6 (4), pp387-399.

White, G. (2002) Consumer participation in disability research: the golden rule as a guide for ethical practice. *Rehabilitation psychology.* 47 (4), pp438-446.

Wilkinson, S. (2006) Analysing interaction in focus groups. In P. Drew, G. Raymond and D. Weinberg (eds.) *Talk and interaction in social research methods.* London, Sage Publications Ltd. pp50-63.

Wilkinson, I. (2001) Anxiety in a risk society. London, Routledge.

Wollacott, M. (1998) Risky business, safety. In J. Franklin (ed.) *The politics of risk society.* Cambridge, Polity Press. pp 47-49.

Appendices:

Appendix A: CAP Terms of Reference

1.0 Introduction and Purpose
The purpose of this term of reference is to act as a guide for the work of a consumer advisory panel for the Masters Thesis research being conducted by Ross Phillips (Researcher), at Massey University. The thesis, titled *"A Right to a Risk filled Life? Understanding and Analysis of the Risk Discourse for Consumers in Mental Health"*, will demonstrate a model of consumer participation in research. It is intended to be emancipatory research and will display a degree of consumer controlled research. A panel of selected people, who will be self-identified consumers of mental health services, will contribute to research decisions, methods and processes. This panel will be called the Consumer Advisory Panel (CAP) and will assist the Researcher in decision making about research methods, processes, and implementation.

2.0 Selection
Decisions about membership of the panel will be made by the Researcher based on the following criterion;
- Self-identification. People have to self-identify to be members of the CAP and will be consensual and willing participants.
- Posters requesting registration of interest will be placed in prominent positions within Community Mental Health Centers, Non-Government Organisations and other mental health service providers within the Auckland region.
- Eligibility for the CAP will require that a prospective member is receiving formalized mental health supports[3] and recognizes themselves as person with experience of mental illness.
- Once three members of the panel have consented to involvement, recruitment will cease.
- As the researcher works for Counties Manukau District Health Board, CAP members can not be selected if they receive services from this DHB or any providers the DHB contracts with.

3.0 Terms and Frequency
The CAP will exist until the outlined purpose has been met. Panel members can withdraw their involvement at any time. Decisions about replacement will be made by remaining members of the Panel and the Researcher. It is envisaged that time commitments will be approximately ten meetings of one to one and a half hours duration over a period of eighteen months. CAP members will not be paid for their participation but will have the costs of participation covered.

4.0 Consent and Confidentiality
To reasonably secure the dignity and rights to privacy of information the members of the CAP will need to sign both a consent form (see appendix i) for their participation in the research process and a confidentiality agreement (see appendix ii). The consent form indicates the voluntary and informed manner with which the CAP members agree to participate in the research. The confidentiality agreement indicates that the CAP members will treat any and all personal

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[3] Defined as services from a mental health provider contracted by either a District Health Board or the Ministry of Health.

information, disclosed by possible research participants as private and confidential, as per the Health and Disability Code of Rights.

All research participants will be asked to nominate a contact person that they would like to have contacted should a support person be required to attend. In such a case the reasonable disclosure of information to increase that person's safety is deemed appropriate.

5.0 Decision Making

Decision making over research issues will occur by attempted consensus. If consensus or majority rule is not obtainable then the Researcher will be responsible for final decisions. The Researcher has final decision making over the content and writing of the thesis.

6.0 Ownership of information

The data that results from the research will be used to inform the submitted thesis by the Researcher in order to meet the requirements of Master of Arts (Social Policy). Any transcribed data will be kept locked within the Researchers premises and destroyed twelve months following completion of the thesis. Opportunities for the shared publication or presentation of research findings between the Researcher and the CAP members will be explored and encouraged. Members of the CAP can chose whether they wish to be personally identified in the written thesis.

Appendix B: CAP Consent Form and Confidentiality Agreement

Consumer Advisory Panel Consent Form and Confidentiality Agreement

Ross Phillips,
Massey University, School of Social and Cultural Studies
█████████

Consent

This consent form indicates my willingness to participate as a member of a consumer advisory panel for the research (short) titled "A right to a risk filled life?" being undertaken by Ross Phillips, a Massey University Student of the School of Social and Cultural Studies.

I understand that my participation is entirely voluntary and that I can withdraw my involvement at any stage of my choosing. I appreciate that the final research decisions and choices are to be made by Ross Phillips as the principal researcher.

I am aware of the Terms of Reference for the Consumer Advisory Panel and the implications this has for me.

Signed: _____   Date: _____

Confidentiality Agreement

As a member of the CAP for the research (short) titled "A right to a risk filled life?" being conducted by Ross Phillips, student of Massey University School of Social and Cultural Studies, I am aware that I may be exposed to personal information about people involved as research participants.

I am aware that I need to treat any and all personal information I receive about others as strictly confidential and private. I will adhere to the Health and Disability Code of Rights as they pertain to the protection of personal information.

I will act in good faith with all information that I receive that concerns the research purposes. Should someone disclose information that raises any concern about the safety and wellbeing of that person or others, then with their knowledge (and if possible permission), I will inform both Ross Phillips (principal researcher) and/or the person they have previously nominated as wishing to be contacted should this be required.

Signed: _____   Date: _____

Appendix C: CAP Recruitment Flyer

> Interested in being on a Consumer Advisory Panel for Research within Mental Health?

Hi, My name is Ross Phillips. I'm from the Waikato but currently live in Auckland, while working at Counties-Manukau District Health Board, as a Project Manager for a Community Living Service.

As a part of my Masters in Social Policy at Massey University I am currently doing a thesis on consumer experience and understanding of risk. I want to get a good understanding of what risk means to people who use mental health services.

I also want to demonstrate consumer participation in research. To do this I want to have a Panel of (up to) three people with experience of mental health acting in an advisory role, assisting in research decision-making. All you need is a natural curiosity and an enthusiasm to be involved in something exciting. Being on the Panel will not require you to share personal information.

The Consumer Advisory Panel has initial approval from the Massey University Human Ethics Committee. The role will be voluntary although there will be compensation for costs incurred by Panel members. Time requirements would be approximately 10 meetings for 1 ½ hours spread out over about 18 months. Once up to three people have given consent to be involved I will stop recruitment.

I would love to have a talk with you if you are interested in knowing more. Simply give me a call on the number below.

Cheers, Ross

Ross Phillips 262 9574 or 021 784 408	Ross Phillips 262 9574 or 021 784 408	Ross Phillips 262 9574 or 021 784 408	Ross Phillips 262 9574 or 021 784 408	Ross Phillips 262 9574 or 021 784 408

Appendix D: CAP Research Method Options Discussion Document

CAP RESEARCH METHOD OPTIONS

The aim of the thesis – to understand, analyze and write up a consumer view of risk – means that there are a number of approaches that could be used to achieve the aim. All research methods (ways of doing research) have strengths and weaknesses. I will briefly describe some of the more likely methods that may be used to do the job.

Quantitative Research

This is statistical based research and depends on large numbers of people producing large *quantities* of data that can then be statistically analyzed. Survey questionnaires, seeking to get a whole lot of information about a broad range of aspects on the subject, are often used in this form of research. It means that you can do a lot of comparing about relationships between different aspects of the subject.

This is good for measuring things over a group of people too large to talk to or observe directly – for example if you believe New Zealander's are opposed to whaling in the South Pacific you could not ask all New Zealanders, nor could you interview five people and assume that they represent New Zealand's view of whaling in the South Pacific. You could however do a survey questionnaire to a large representative sample of New Zealander's and then state that you have an accurate view on the subject.

If we were making a statement that said 'consumers views of risk is X' we would then test that by asking a representative number of consumers what their view of risk is so we could confirm our statement. This is called **deductive reasoning** (starting with a view and breaking it down) and would suit *Quantitative research*. Instead we are asking 'what are consumers views of risk?' This is called **inductive reasoning** (starting with a clean slate and building up a view) which is better suited to *Qualitative Research*

Qualitative Research

In order to get a personal and in-depth understanding of a topic the better approach to use is called qualitative research. This can give a very full understanding of the topic based on the experience of a few people. This approach is good if you do not have a firm view that you want to test (hypothesis). Qualitative research is well suited to exploring questions which relate to the meaning of human experience. This fits with the aim of this research.

There are two ways (methods) of doing qualitative research that would suit this research topic. **In-depth interviews** – the most common way to do qualitative research. Views people as the experts on their own experience so believes that they are best able to report that. Allows good flexibility to get information and gives the opportunity to clarify understandings. Useful when the issue that is being explored can't be observed i.e. understanding a personal view of risk.

Focus groups – have many of the same benefits as in-depth interviews plus the group nature of the discussion means that additional information can be gather because of more interaction. Using

focus groups can also take the pressure of any one person to feel like they have to answer every question. However, focus groups can lead to peer-pressure to agree to a dominant view or stay silent about a particular issue. Equally, people can be embarrassed or feel reluctant to share personal information in a group setting. Using focus groups you can get more peoples views (greater variety) but you have less time to go into greater detail and depth about the views (less in-depth).

Mixing methods
Any research can use a mixture of methods and can even mix quantitative and qualitative styles of research. The researcher has to be clear about what methods are going to be best for getting the information they need.

You can even have stages to research where you use one method of getting information and then depending on what you get – use a more suitable method to explore the aspects of the information that you got.

Discussion and decision
We need to discuss the above ways of doing research and make decisions about the ways that we want to proceed. To do this we all need to be clear about the critical things that the research is going to address;

So,
1. Are we clear about the research aims?

2. Are we clear about the different methods we can use to research the subject?

3. What (if any) methods have an increased chance of being of benefit to the people participating in the research?

4. What methods are going to inform this research?

Once we have answered question four we are (excitedly) going to explore how we recruit people to participate in this research and how we are going to make sure that they are kept safe during their involvement.

Fantastic!!
Ross

Appendix E: Health and Disability Ethics Committee Approval

Health
and
Disability
Ethics
Committees

31 March 2005.

Mr Ross Phillips

Dear Ross,

NTX/06/03/026   **A right to a risk-filled life? Understandings and analysis of the risk discourse for consumers within mental health.**

Principal Investigator: Mr Ross Phillips, Massey University, School of Social & Cultural Studies.
Supervisor: A/P Mike O'Brien, A/P Christa Fouche.

Thank you for your amendments, received today.

The above study has been given ethical approval by Northern X Ethics Committee for the Northern Region. A list of members of this Committee is attached.

Approved Documents:
- Participant Information Sheet/Consent Form V#2, 18/03/06
- Focus Group Consent Form, V#2, 18/03/06

Certification
The Committee is satisfied that this study is not being conducted principally for the benefit of the manufacturer or distributor and may be considered for coverage under ACC.

Accreditation
This Committee involved in the approval of this study is approved by the Health Research Council and is constituted and operates in accordance with the Operational Standard for Ethics Committees, March 2002.

Progress Reports
The study is approved until 31 March 2007 (to cover writing up and reporting to the Ethics Committee). A progress report is required for this study by that date.

..../2

A form should come off our database requesting this information two months prior to the review date but if a form is not received, it is still your responsibility to provide a progress report and this may be obtained from the website below. Please note that failure to complete and return this form may result in the withdrawal of ethical approval.

Please advise the Committee when the study is completed and under the ethical approval process, a final report is also required at the conclusion of the study.

Requirements for SAE Reporting
Please advise the Committee as soon as possible on the SAE form to be found on the website below, if there are any serious adverse events that may relate to this study.

Amendments:
All amendments to the study must be advised to the Committee prior to their implementation, except in the case where immediate implementation is required for reasons of safety. In such cases the Committee must be notified as soon as possible of the change.

Please quote the above ethics committee reference number in all correspondence.

It should be noted that Ethics Committee approval does not imply any resource commitment or administrative facilitation by any healthcare provider, within whose facility the research is to be carried out. Where applicable, authority for this must be obtained separately from the appropriate manager within the organisation.

Yours sincerely,

Pat Chainey
Administrator, Northern X Committee

Cc: Massey University

Appendix F: Participant Recruitment Flyer

A Right to a Risk Filled Life? Do you want to have your say?

A lot of work has been done to say what 'risk' is and how services should assess and manage it. Let's find out what it really means from the people who have personal experience of mental health!!

Hi, my name is Ross Phillips. As a part of my Masters in Social Policy at Massey University I am currently doing research on consumer experience and understanding of risk. I want to get a good understanding of what risk means to people who use mental health services.

If you would like to contribute to this understanding then there are two ways you can be involved. I am conducting a focus group interview with between seven and ten people who will be sharing their views together. I will also be doing about five or six interviews with individuals on a one-on-one basis where we will be having an in-depth discussion about the subject. It should take about an hour to an hour-and-a-half for each of the different interviews. You are welcome to indicate interest in the focus group or the individual interviews.

This research has had significant consumer input to its design via a Consumer Advisory Panel. Involvement in the research is entirely voluntary and will require consent.

I would love to have a talk with you if you are interested in knowing more. Simply give me a call on the number below.

Cheers,
Ross
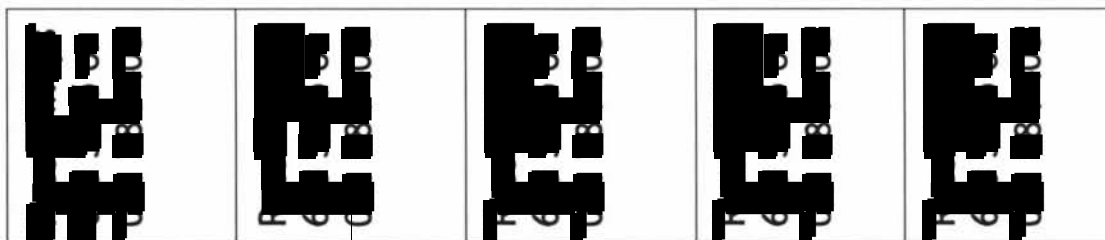
Appendix G: Participant Information Sheet

PARTICIPANT INFORMATION SHEET

A Right to a Risk Filled Life? Understandings of the Idea of Risk for Consumers within Mental Health.

Ross Phillips: ███████████████████████

Research Introduction

Would you like to be involved in a research project intending to understand consumer views of risk? This sheet provides further information about the research being conducted by Ross Phillips. I am a student of Massey University at Albany. I also currently work as a Consultant in Mental Health for Inclusion Solutions.

The research is a part of my Masters of Arts (Social Policy) and is being supervised by Associate Professor Mike O'Brien and Associate Professor Christa Fouche at Massey University. The research intends to gather, analyze and write up a consumer perspective of 'risk'. It is hoped that this will lead to a greater understanding of the nature of risk and what it means for people who use mental health services. This research has received ethical approval from the Northern X Ethics Committee at the Ministry of Health.

Participants

Flyers have been placed in mental health services and consumer networks asking for people to self-identify to be involved in the research. To be involved you need to be using mental health services and identify as a person with experience of mental illness. If your level of wellness indicates that you are unable to give informed consent then, in discussion between us, you will be considered unable to participate in the research.

The research will be conducted in two focus groups of between seven and ten people each. Five or six individual interviews will also occur in order to explore in more detail, the themes that arise from the focus groups. The focus groups and the interviews should each take between an hour and an hour-and-a-half.

If you are involved in the research you will have your travel costs covered by receiving a $10 petrol voucher for each interview you are involved in. Refreshments will also be provided during the focus groups and the interviews.

You will be asked to provide the contact details of a friend, family member or other support person whom you would like contacted should involvement in the research lead to any distress, frustration or impact on your wellbeing.

Project Procedures

The information that is gathered during the interviews will be analyzed and written up as a thesis. You will not be identified in the thesis and all participants will be given pseudonyms (different names). The interviews will be taped and later typed. The person who types the tapes will be bound by a confidentiality agreement. The tapes will be destroyed at the completion of the thesis. The written transcriptions and all other data will be securely held at Massey University. At the completion of the thesis this information will be securely held by the Head of Department at the School of Social and Cultural Studies, Massey University, where it will be destroyed following a period of ten years.

Participants in the focus groups will be asked to sign a consent form that includes a confidentiality agreement indicating that personal information they hear from other participants will be kept confidential. You can indicate on your consent form if you wish to receive a summary of the research findings. You will also be offered the opportunity for a verbal feedback session and if enough interest is indicated I will verbally tell you about the outcomes of the research (when it is finished).

Participant's Rights

You are under no obligation to accept this invitation. If you decide to be involved, you have the right to: decline to answer any particular question; withdraw from the study until the collection of data is complete; ask any questions about the study at any time during your involvement; provide information on the understanding that your name will not be used unless you give permission to me; be given access to a summary of the project findings when it is finished; to request a verbal feedback of findings; ask for the audio tape to be turned off at any time during the individual interview.

Support Processes

This research has included consumer participation. Three consumers have been recruited to act as a Consumer Advisory Panel and have assisted me to make research decisions. The members of the Consumer Advisory Panel will be available as support for you to talk with if you want this. Any of the three Consumer Advisor Panel members will be present during the focus groups as supports if required. Their names are Cavell Morrow, Claire Evergreen and Shona Clarke. They are all committed to a confidentiality agreement regarding any personal information they may hear in the course of their help with the research.

You will also be asked to supply the contact details of a support person you wish to have contacted if required. During the interviews local crisis team contact numbers and a phone will be available in order to contact any required support people or services.

Project Contacts

You are more than welcome to contact me or my supervisors at any stage of the research process.
Mike O'Brien: 4140800 ext 9161
Christa Fouche: 4140800 ext 9082
                Massey University, Albany, Private Bag 102904, NSMC, Auckland
                m.a.obrien@massey.ac.nz
                c.b.fouche@massey.ac.nz

If you have any queries or concerns regarding your rights as a participant in this study, you may wish to contact a Health and Disability Advocate, telephone no. █████████

In the unlikely event of a physical injury as a result of your participation in this study, you may be covered by ACC under the Injury Prevention, Rehabilitation and Compensation Act. If you have any questions about ACC, contact your nearest ACC office or consult the website www.acc.co.nz/claimscare/making-a-claim/medicalmisadventure.

Appendix H: Individual Interview Participant Consent Form

PARTICIPANT CONSENT FORM

A Right to a Risk Filled Life? Understanding and Analysis of the Risk Discourse for Consumers within Mental Health

This consent form will be held for a period of ten (10) years

I have read the Information Sheet and had the details of the above research explained to me. My questions have been answered to my satisfaction and I understand that I am able to ask further questions at any time during the study.

I agree/do not agree to the interview being taped.

I wish/do not wish to have my taped interview returned to me.

I agree to participate in this study under the conditions set out in the information sheet.

If I start to feel unsafe and want someone to be contacted – the person I would like contacted is:

Name:_____
Contact number:_____

Signature: .... Date: ....
Full Name - printed ....

Please indicate by ticking the box and supplying a mailing address if you would like to receive a summary of the findings of the Research ☐

Address:_____
_____

Appendix I: Focus Group Consent Form and Confidentiality Agreement

FOCUS GROUP CONSENT FORM

A Right to a Risk Filled Life? Understanding and Analysis of the Risk Discourse for Consumers within Mental Health

This consent form will be held for a period of ten (10) years

I have read the Information Sheet and had the details of the above research explained to me. My questions have been answered to my satisfaction and I understand that I am able to ask further questions at any time during the study.

I understand that the focus group will be taped.

I agree not to disclose anyone's personal information that is discussed in the Focus Group.

I agree to participate in this study under the conditions set out in the information sheet.

If I start to feel unsafe and want someone to be contacted – the person I would like contacted is:
Name:_____
Contact number:_____

Signature: Date:
Full Name - printed

Please indicate by ticking the box and supplying a mailing address if you would like to receive a summary of the findings of the Research ☐

Address:_____
_____

Appendix J: Focus Group Semi Structured Interview Schedule

"A right to a risk filled life?"
Focus group semi-structured interview questions:

Ross Phillips,
School of Social and Cultural Studies,
Massey University, Albany
█████████

1. What does risk mean to you personally?

2. What are the things that have influenced this meaning?

3. How does your meaning of risk affect your view of yourself and your life?
   i. Can you give examples?

4. Do you think that your view of risk is the same as the people (staff) who support you? If different how?

5. Do you think that your view of risk is understood by the people (staff) who support you? If not why?

6. Do you think that you have control over the amount of risk you are allowed in your life (positive or negative)?
   i. Can you give examples that indicate how you do/don't?
   ii. What are the outcomes of this (lack of control, or presence of control)

Appendix K: Individual Interview Semi Structured Interview Schedule

"A right to a risk filled life?"
Individual interview semi-structured interview questions:

Ross Phillips,
School of Social and Cultural Studies,
Massey University, Albany
███████

This interview schedule will be partially determined by the outcomes of the findings of the focus group. Themes that arise from the focus group discussions will inform the direction of the individual interview questions. The interview will also focus on getting data related to the individuals' view of risk by following questions concerning the individuals' understandings.

1. Tell me what does risk mean to you personally?

2. What are the things that have influenced this meaning?

3. What does positive risk taking mean to you?

4. Do you take positive risks? If not why not?

5. Do you feel you have control over the amount of risk in your life?
    a. Can you give examples how you do/don't