# A Right to a Risk Filled Life:
# Understanding and Analysis of the Risk Discourse for Consumers in Mental Health.

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**Ross Phillips**

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## 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

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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.

# Contents

"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.