The place of community in a community organisation: Negotiating relationships in the third sector

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ABSTRACT

Community-based and non-government organisations are the subject of increasing academic debate. Although they are now understood to be an integral part of our social and political system as the third sector, separate from the government and market sectors, how these organisations will realise their critical potential and overcome practical and theoretical challenges is largely unexplored.

This thesis draws on qualitative research conducted with workers at a hepatitis C community-based organisation – the Oliver Smith Council. The thesis provides an actor-orientated account of the complexities and challenges of working in the third sector as it stands between civil society and the state. It examines two interrelated concepts that are important for the positioning of the organisation: understandings of 'community' in the organisation, and experiences of spatiality of the organisation.

At the Oliver Smith Council the work and space of the organisation had become increasingly contested. Changes in size, location and internal policy had resulted in tensions and debates within the organisation with regard to how the Council would endeavour to continue to work with community, and what objectives, functions and roles are fundamental to the Council being a 'community-based' organisation in the third sector. Workers had a sense of shifting spaces of their organisation; many were concerned that the organisation was losing its grounding in civil society and the third sector and becoming too closely aligned with the state. In particular, workers were concerned that there was no longer a place for community within the walls of the organisation. These concerns manifested themselves in workers' concerns about how the Council worked with its community groups, and the types of organisational space it occupied.

Through exploring the praxis of the Oliver Smith Council in this thesis, I examine how and why working in the third sector is complex and, at times, difficult. I argue that the tensions and concerns experienced by Council workers relate to the organisation's, and the third sector's, positioning between civil society and the state. In addition to enhancing our understanding of the third sector and its complexities, this thesis is also aimed at assisting workers at the Oliver Smith Council to make sense of the debates and tensions within their organisation.

LIST OF FIGURES

DECLARATION

This thesis contains no material which has been accepted for the award of any other degree or diploma in any university or other tertiary institution and, to the best of my knowledge and belief, contains no material previously published or written by another person, except where due reference has been made in the text.

Gemma Carey
March 2007

I give consent to this copy of my thesis, when deposited in the University Library, being made available for loan and photocopying, subject to the provisions of the Copyright Act 1968.

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For a Thesis that contains publications

ACKNOWLEDGEMENTS

In the first week of my fieldwork I found myself at a 'homeless expo'. This strange concept was only made stranger to me by a number of unexpected faces. As I sat diligently at the ' hep C table' scrawling notes in my brand-spanking new fieldwork book, people with facial tattoos milling around me, a familiar looking woman walked past me. As she caught my eye she burst into an animated greeting: 'Gemma! What are you doing here? Oh! That's right, you're hep C! I'm social integration, Nathan's here too, he's homelessness". That's right; no less than three Adelaide University anthropologists had descended on this small gathering of around forty local homeless people. It dawned on me that day that there was something absurd about what I was doing. As I progressed further into my fieldwork, and then in turn into my thesis writing, I realised that, while there are certainly absurd moments in qualitative research, there *is* meaning in the absurdity. I would like to acknowledge and thank all the people that helped me find that meaning.

My first, and biggest, thank you must go to Annette Braunack-Mayer, my principal supervisor. Without Annette's guidance, assistance, negotiating skills, compassion, friendship and ability to work through any situation, I wouldn't have stood a chance. My second thank you belongs to Jim Taylor, who picked this project up part way through but blessed us with his insight and enthusiasm, despite joining us late in the game.

I would like to thank, and to acknowledge the input from, all those who took part in the research reference group, for whom I have heart-felt gratitude. Our discussions were always lively and enlightening, if not always smooth! In particular, I am extremely grateful for the guidance, assistance and commitment to this project of two very special women in the reference group (you know who you are). You're an inspiration to everyone around you! I would also like to thank all workers at the Council for taking part in the research.

There's not a doubt in my mind that this journey would have been twice as difficult without the support and advice of my peers. Having such a breadth (and, yes) depth of views and perspectives always provided me with food for thought and a fresh outlook. So, thank you to James Smith and Adam Elshaug, who put up with my constant company and whining.

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My last thank you is reserved for those closest to me. For my family and Laurence Szucs for your tolerance, and for catching me every time I fell. Thanks for the times that you spoke up about my exhaustion and over-exertion and, equally as important, thanks for the times that you didn't. Cris Carey and Roger Murphy also provided critical feedback and careful reading when it was needed most, and I would like to acknowledge your efforts and abilities I so envy.

> Understanding what is happening with and through organizations such as NGOs and adapting to the changing conditions within which they operate present challenges to anthropological researchers. Community-based organisations may be close to traditional sites of anthropological concerns, but the networks and alliances they increasingly have come to form open up new sites for ethnographic research (Fisher 1997: 459).

Introduction

This thesis comes at a time of serious academic questioning and debate concerning the role of community-based, or non-government, organisations. Conceptually and theoretically we are aware that these organisations have a fundamental social and political role to fill. Community-based and non-government organisations have become known as the third sector, separate from the government and market sectors. Such organisations have developed out of civil society and offer the potential to provide a voice for, and services to, those marginalised from the government and market sectors. Although the third sector is now understood to be an integral part of our social and political system, just how these organisations will realise their potential and overcome practical and theoretical obstacles remains unclear.

The research for this thesis took place at a hepatitis C-related community organisation which, for the purposes of this work, shall be called the Oliver Smith Council for Hepatitis C. The research consisted of a mixture of ethnographic techniques and qualitative interviewing. At the time I began my research the Oliver Smith Council was in a state of flux; changes in size, location and internal policy had resulted in tensions and debates within the organisation with regard to how the Council would endeavour to continue to work with community, and what objectives, functions and roles are fundamental to the Council being a 'community-based' organisation in the third sector. Such debates are not unique to this particular organisation; rather they represent significant practical and theoretical concerns for community-based, non-government organisations generally. Despite this, few detailed studies of what is occurring in specific organisations have been undertaken. Through exploring the praxis of the Oliver Smith Council, in this thesis I examine how and why working in the third sector is complex and, at times, difficult. I argue that the tensions and concerns experienced by Council workers relate to the organisation's, and the third sector's, positioning between civil society and the state. In order to articulate this argument, in this thesis I take an actor-orientated approach to explore how this positioning shapes, and is shaped by:

1. Understandings of 'community' in the organisation.
2. Spatiality in the organisation.

These two themes are interrelated; workers' understandings of community are 'played out' spatially in the organisation.

Through an exploration of these themes it is evident that workers at the Council were concerned that their organisation was becoming too closely aligned with the state, and losing its networks in civil society and its grounding in the third sector. In the praxis of the Council these sentiments manifested as tensions over whom the Council should work *with*, and who should be working *in* the organisation. From the perspective of workers, these tensions related to an overarching concern that there was no longer a place for community within the organisation. As stated earlier, the challenges faced by the Oliver Smith Council are common to many third sector organisations. In this thesis I contend that there is a space for the third sector between civil society and the state. However, this positioning has important ideological and spatial consequences for organisations working in the third sector.

Scope of the Thesis

Before embarking on reading this thesis, I want the reader to be clear about what the focus of this research *is* and *is not*. This thesis is concerned with the sentiments, experiences and perspectives of workers at a community organisation. The emphasis is on an actor-orientated discussion of how these workers understand the shifting spaces of their organisation as they negotiate their relationships with community groups and the state. These perspectives at times diverge significantly; for some people at the Council, discovering this diversity of perspective has caused surprise and frustration. However, the diversity of opinion and the strong emotional reactions of individuals to this diversity demonstrate that the issues explored in this thesis are contentious, difficult and, most importantly, pertinent to community-based organisations. Often workers' perspectives are conflicting and, at times, contradictory. In such cases I have attempted to capture all aspects of these debates and to show the complexity of the challenges facing the Oliver Smith Council in full.

As with any qualitative or ethnographic piece of research, and consistent with a multi-disciplinary approach to public health, a range of theoretical perspectives or lenses can be used to articulate and explain findings. I have drawn on multiple theoretical perspectives to analyse my findings through the concepts of power and space.

The importance of space in this thesis is twofold – there is a macro and a micro view. At a micro level, both space and spatial metaphors are used by my participants as an explanatory vehicle for describing the tensions, challenges, and changes they experience within the organisation; for the workers at the Council, space – and particularly how it has changed over time – represents a central organising theme for their experiences. Multiple 'lived' spaces exist within the organisation and, the reader will note, at times these spaces overlap and even contradict one another – as Halford and Leonard (2006: 11) phrase it "organisations are complex formations of different spatial and temporal relations". It is for these reasons that I have drawn on Edward Soja's and Henri Lefebvre's lived space, which emphasises actor-orientated experiences of space.

On a macro level, whilst largely unexplored in the literature, the organisation of space is pivotal to the notion of a third sector. Space is political and strategic and both the formation of, and debate about, the third sector is concerned with the ability of third sector organisations to transform the spatial organisation of society and concomitant power relations.

This brings me to the second analytical purview of this thesis: power. The spaces of third sector organisations are characterised by complex intersections of power, primarily due to their positioning between civil society and the state apparatus. In this thesis I have drawn on the work of Michel Foucault so that I may approach power as relational rather than as a possession invested in specific individuals or groups. The experiences of Council workers are indicative of their need to negotiate complex power relations between the state and civil society. It is worth noting that the material in this thesis could have been approached with a more 'pure' Foucauldian analysis of power, resistance and space (see, for example, Cresswell 2000, Crang 2000, Sharp, Routledge, Philo & Paddison 2000, Keith & Pile 1997). However, I have chosen to incorporate multiple theories of Foucault in order to increase the utility of this research for those who took part in it. While resistance offers an insightful theoretical tool, it is limited in its practical application; that is, it does not necessarily tell us how to 'act out' against forms of power. Although I attempt to make a theoretical contribution to our understanding of the third sector, as the reader will see this research is also founded in a strong sense of reciprocity. Concurrent with this I have used Foucault's work on power and resistance to elucidate, explain and reveal, while utilising his notion of 'Counter-discourse' as a means to suggest how to 'act'.

There are obviously other approaches that could have been taken to the material in this thesis. For example, I could have focused on elements of workplace identity or gender. Our identities are continuously negotiated and formed in the course of our day-to-day lives (Pile & Thrift 1995; Crossley 1994); work shapes our identity but we also create different 'selves' in our workplace. Furthermore, relational power effects the formation of these workplace identities (Halford & Leonard 2001). Similarly, gender is integral to organisational structures and in its own way impacts on workplace identities (Halford & Leonard 2006a; Pringle 1988; Massey 1994). However, such perspectives are not incorporated in this thesis, due to the normal constraints of academic writing: we must make strategic choices about which theoretical lens we wish to apply and no one framework will encapsulate all elements.

Finally, I wish to make it clear at the outset that this thesis does not attempt to canvas a specific discipline; rather it is a multi-disciplinary piece of work which encompasses theory and perspectives from a range of disciplines. Although the scope of the research and the research methodology is strongly informed by my background in public health and anthropology, the thesis itself also draws upon elements of philosophy, sociology and social geography.

Outline of the Thesis

Part One: Background & Methodology

Chapter One provides the relevant background for the thesis. In this chapter I outline the development and impact of the Australian hepatitis C epidemic. I give an overview of the community-based response to blood-borne viruses as it relates to the Australian experience. In particular I emphasise that the community-based response, and the formation and development of community-based organisations, has followed a pattern. Such groups form out of civil society in reaction to perceived inadequate attention to a health issue and gradually, over time, their objectives and activities become increasingly entwined with that of the state. Of particular importance to this thesis is the realisation that this shift occurs in parallel with increased state funding and ties. In this section I provide a discussion of the socio-political placing of community organisations before, lastly, giving a brief description of the development and current structure of the Oliver Smith Council where the research took place.

Chapter Two articulates the methodological principles and approach which informs this work. Primarily this research was informed by ethnographic and qualitative methodologies, with an emphasis on reflexivity at all stages during the research process. This chapter also explains the methodological pathway of this project. During the course of the research my project underwent substantial changes in focus and conduct. In this chapter I reflexively examine how these changes came about and the reasoning behind key research decisions. I also consider the ethical implications of my unorthodox research pathway, both in regard to this thesis and also for ethnographic and qualitative research more generally. The most significant change that took place during the research was the formation of reciprocal researcher-participant relationships. These reciprocal relationships have underpinned my choice of topic to address, the types of interpretations I have made and, perhaps most significantly, the kinds of research outcomes on which I have focused. Through consideration of the implications of these changes, in this chapter I make clear my orientation to the theoretical analysis and interpretations to come. Lastly, in this chapter I explain how the difficulties which I confronted while conducting the research related to, and are expounded by, the major themes of this thesis. Particularly, I explain how my experiences as a researcher relate to the organisation's sense of vulnerability between civil society and the state.

Part Two: Thinking About Community

Chapter Three concentrates on the first of two interrelated themes analysed in this thesis: community, and how workers at the Council understand it. Although the themes of space and community are interrelated, for the purpose of clarity I firstly explore understandings of community. In this chapter I discuss how community is conceptualised, both in scholarly literature and by workers at the Council. In this analysis of how community is understood and conceptualised by workers, I also explore who is considered to constitute the hepatitis C community. In this chapter it is evident that there is considerable debate at the Council regarding how the organisation works with community.

In Chapter Four I draw on the theoretical assertions made in Chapter Three in order to elucidate the perspectives and experiences of workers as they relate to the community at the Oliver Smith Council. In doing so, I provide an actor-oriented discussion of the tensions within the organisation concerning what skills are required to work at the Council, and with whom the Council should be working.

Part Three: The Spatiality of the Third Sector

In Chapter Five I discuss recent academic debates concerning the relationship of the third sector to the state and civil society. In doing so I provide a theoretical discussion on the third sector and its position between civil society and the state. In this chapter I argue that space is important to third sector debates for two reasons. Firstly, these debates are spatial arguments; they are concerned with how community-based organisations and non-government organisations operate in a space between civil society and the state. Secondly, I contend that an incorporation of spatial theory enables an actor-oriented discussion of what is occurring in specific organisations – an account that, until now, has been sorely lacking in academic discussions of the third sector.

In Chapter Six I draw on the theoretical arguments outlined in Chapter Five to explore how the positioning of the third sector is experienced spatially within the Oliver Smith Council. This chapter provides a discussion of how workers perceive and experience, in spatial terms, the changes taking place in their organisation. On a theoretical level, this chapter demonstrates that the third sector's positioning between civil society and the state has important spatial consequences as well as the ideological ones discussed in Part Two.

Part Four: Conclusion

In my concluding chapter, Chapter Seven, I demonstrate how my argument – that the complexities associated with working in the third sector are attributable to its position between civil society and the state – was developed throughout the thesis. In conclusion, I offer a discussion of two further considerations. How we might begin to better conceptualise the role of third sector organisations with civil society and the state, and how the space of the third sector may be enhanced through the praxis of third sector organisations. I conclude that, while relations between civil society and the state may make the third sector a challenging place to work, through an appreciation of the socio-political landscape in which they operate such organisations can begin the process of repositioning themselves.

Part One

Background & Methodology

Becoming immersed in a study requires passion: passion for people, passion for communication, and passion for understanding people. This is the contribution of qualitative research… In the qualitative arena the individual is not inserted into the study, the individual is the backbone of the study. (Janesick 2003: 71).

Background & Methodology

Introduction

In Part One I provide an overview of community organisations and of how the research which forms the basis of this thesis was conducted. Part One of this thesis is divided into two chapters: Chapter One provides the relevant background regarding hepatitis C and the formation of community organisations, while Chapter Two describes my research journey.

Chapter One provides an overview of the extent of the hepatitis C epidemic in Australia, and the subsequent government and community response that has ensued. In this chapter I also discuss the role and function of community organisations. Of particular relevance to the theoretical purview of this thesis, and the analysis of my findings to come, is a discussion of the socio-political placing of community organisations. Such organisations have come to occupy a space between civil society and the state; how organisations will operate in this space is a topic of considerable academic debate. I outline these issues in Chapter One, before discussing them in greater detail in Part Three of the thesis.

In Chapter Two I discuss my research pathway. As well as commenting on my methodology and methods, in this chapter I trace the steps of my research pathway and outline substantial changes in research methodology and conduct. This thesis is strongly informed by the methodological principal of reflexivity. Consequently this chapter is formed as a reflexive narrative. I also provide a reflexive discussion of the ethical considerations which my research pathway poses, both for this research project and also for ethnographic research more generally. I conclude Part One by explaining how my research experiences are contextualised by my research findings and analysis. The difficulties in negotiating my research pathway and methodology relate to how, as a researcher, I was positioned with regard to 'community' at the Council, and the organisation's sense of vulnerability between civil society and the state. Through considering my research journey through the theoretical lens I have applied to my findings, I have been able to appreciate the complexities and difficulties I encountered in negotiating a research pathway at the Oliver Smith Council.

Chapter One

The growth of hepatitis C and the community response in Australia

CHAPTER INTRODUCTION

Hepatitis C represents a significant, and serious, public health burden for Australia. An integral part of the Australian response to this virus has been the formation of a community response and the subsequent establishment of community-based organisations, known as Hepatitis C Councils. Hepatitis C Councils have received little, if any, consideration or close examination by researchers from any discipline. However, such organisations are currently negotiating major practical and theoretical challenges in conducting and conceptualising their objectives and roles. In this chapter I provide an overview of the history of hepatitis C in Australia, and the community response which has ensued. I also discuss the socio-political positioning of community organisations, as it relates to this thesis. In doing so I argue that the community-based response, and the formation and development of community-based organisations, has followed a pattern. Such groups form out of civil society in reaction to perceived inadequate attention to a health issue and gradually, over time, their objectives and activities become increasingly entwined with that of the state. Community-based organisations (CBOs) and non-government organisations (NGOs), such as the Oliver Smith Council, are therefore positioned between civil society and the state. Furthermore, I argue that this positioning creates tensions and complexities for such organisations.

PLACING COMMUNITY ORGANISATIONS

The formation of community groups around a health issue has been an increasing phenomenon since the 1960s (Allsop, Jones & Baggott 2004).[1] In this section I discuss the position that community organisations have come to occupy in our socio-political landscape since they developed in the 1960s.

In the majority of cases, health-related community groups develop out of civil society as charities and volunteer organisations. In Australia, government funding of community organisations first began with the Whitlam government during the 1970s (Baum 2002). Predominately, health-related community organisations are established in response to dissatisfaction with government efforts and funding contributions towards an area of concern to a collection of individuals. Community-based organisations support collective agency and increase the ability of their constituents to effect political change and health care provision (Allsop et al 2004; Barton-Villagrana, Bedney & Miller 2002). This results from their close relationship with civil society. In addition to developing out of civil society, many authors (Lehman 2006; Sending & Neumann 2006; Altman 1994) envisage CBOs and NGOs as vital to invigorating a healthy and robust civil society. However, through growth over time, these organisations attract government funding and become community-based organisations funded by the state.

The terms 'civil society' and 'the state' are fundamental concepts in NGO and CBO literature. I will provide a brief discussion of each here, before discussing the literature in detail in Part Four. Civil society has been described as a problematic term because it is often invoked in a variety of different capacities (Sanders, Labonte, Baum & Chopra 2004; Brown 1997). Most commonly it is understood to refer to a wide range of public spaces and interactions which occur outside, or beyond, 'the state' (Brown 1997; Mauter 1996; Johnston 1994; Hegel 1991). For the purposes of this thesis, civil society is used to refer to "social relationships and organisations outside either state (government) functions, or market-based relations" (Sanders et al 2004: 757).[2] With regard to 'the state', in this thesis I recognise that

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[1] The development of such groups, in response to social movements such as women's health, was well documented throughout the 1960s and 1970s (Allsop et al 2004).

[2] Until the nineteenth century civil society was regarded as a synonym for political society. However Hegel reframed the concept stating that it is a social formation intermediate between the family and the state (Hegel 1991).

the modern bureaucratic state comprises many multi-faceted institutions, institutional locations, services and so on. Consequently, the focus is placed upon the relations between the state and state-influenced community organisations. It is worth noting at this juncture that civil society and the state are at times articulated as homogenous entities (Mercer 2002). In this thesis I recognise that the state and civil society are characterised by diverse and complex networks, interactions and ideas. I do, however, frame the state and civil society as concrete realities, despite their diversity.

The third sector

The last two decades have seen the development and expansion of NGOs and CBOs (Fisher 1997). During this time CBOs and NGOs have become known as the third sector, separate from the government and market sectors. The development of this 'third sector' has captured the imagination of planners, policy makers, activists and researchers in the struggle to increase the provision of services to marginalised people, and to reformulate current structures of governance (Fisher 1997): "NGOs of all types have increased dramatically in number and scope in recent years, becoming a component in the fabric of democratic institutions" (Lehman 2006: 2). It is increasingly recognised that marginalised and vulnerable sections of the population require representation and many authors (see Lehman 2006; Bryant 2002; Mercer 2002; Fisher 1997) comment that the third sector is often envisaged as a means to achieve this. They are considered effective because they are everything that governments are not: they have no large bureaucracy, they are flexible and open to innovation, they are faster in implementing and responding to changes and, most importantly, they are able to identify 'grassroots needs' and work with marginalised sections of the population (Fisher 1997; Altman 1994). Furthermore, they have a close relationship with civil society - third sector organisations such as CBOs and NGOs develop *out* of civil society, and maintain strong ties to their community groups *in* civil society.

Notwithstanding this close relationship with civil society, the growth and development of community organisations have tended to be accompanied by increased government funding and attention. It has been argued that funding of community organisations by government represents both a de-centering of health service delivery, and an increased appreciation of community participation in health affairs (Allsop 2004). This de-centering shifts the point of service delivery away from the state, towards civil society.[3] Yet, Shaver (unpublished work cited in Altman 1994) argues that community organisations, over time, become co-opted by government to become part of a 'para-state', whereby their autonomy becomes severely limited. Similarly, Wolch (1989) describes this process as becoming part of the 'shadow state'. Other authors (see Sending & Neumann 2006; Bryant 2002; Fisher 1997) have used the lens of governmentality to analyse these relationships. Under such analysis, NGOs and CBOs have both been hailed as the answer to transforming current mechanisms of governing, and condemned as perpetuating governmentality, or the governing will and reach of the state.

Many accounts envisage these organisations as a vehicle for challenging and transforming the power relationships between the state and civil society (Fisher 1997; Fisher 1993). They offer the potential to represent, or rally, civil society in such a way that it may engage meaningfully and challenge or critique the state (Mercer 2002):

> NGOs have the capacity to efficiently transfer training and skills that assist individuals and communities to compete in markets, to provide welfare services to those who are marginalised by the market, and to contribute to democratization and the growth of a robust civil society.
>
> Fisher 1993: 444; See also Mercer 2002

Alternatively, Fisher (1993: 445) and Mercer (2002) argue that much of the rhetoric concerning NGOs is idealised, as "relatively few detailed studies of what is happening in particular places or within specific organisations" exist. They suggest that the capabilities of the third sector have been over-emphasised in their ability to assist where governments have, to date, been unable to do so (Fisher 1997; Altman 1994).

Despite these debates, it is well acknowledged that the third sector has a contribution to make, both in terms of representing marginalised groups and in a broader socio-political sense by offering an alternative to government and market sectors (Lehman 2006; Bryant 2002; Mercer 2002; Fisher 1997; Altman 1994; Bratton 1989). However, this positioning of third sector organisations between civil society and the state presents significant challenges to NGOs and CBOs. Perhaps the most portentous of these challenges is the question of how such organisations will negotiate a relationship with both civil society and the state, without

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[3] Allen (1997) argues that community organisations and grassroots movements have been embraced by 'free market' or neo-conservative thinkers as a way to increasingly rollback the welfare state.

compromising their core objectives and values. In this thesis I explore the work of the Oliver Smith Council and the experiences of its workers, and elucidate how these relate to the organisation's positioning between civil society and the state. In doing so I expand upon the debates and issues raised here in Parts Two and Three.

THE FUNCTIONS OF NGOS & CBOS

Active community organisations are usually comparatively small with a nucleus of permanent members and leaders. The majority of community organisations perform dual roles: they satisfy specific individual social needs, whilst forming the basis from which to address broader social issues such as inequity and injustice. Despite the relatively small number of core members, CBOs and NGOs are often able to mobilise larger groups of people and therefore substantially increase their constituency (Jones, Baggott & Allsop 2004). Often, they provide face-to-face support to a smaller group of people. Barnes and Shadlow (1997) suggest that one of the key roles of such organisations is to aid individuals in reclaiming the right to define oneself and one's problems. Thus, members of community organisations may be attempting to reclaim the right to define themselves and their problems in their own terms:

> Participation within such movements can demonstrate that those formerly viewed as passive and dependent … can be actors capable not only of controlling their own lives, but also of contributing to shaping the nature of welfare services and of achieving broader social objectives. Participation itself can contribute to a surer sense of identity.
>
> Barnes & Shardlow 1997: 293

Arguably, the need to fulfil both micro and macro social needs can be a source of difficulty and tension for such organisations. Indeed Jones et al (2004) found that many such organisations face difficulties in choosing priorities, due to competing pressures on resources.

Many health-orientated community organisations engage in community development and empowerment. Community development and community empowerment are two related terms, which are frequently used interchangeably: "community development empowers individuals and groups" (Lumsden, Bunning & Eichmann 1996: 52). Both involve community participation and working in collaboration with community groups to determine and achieve objectives (Baum 2002). An integral component of both community empowerment and development is the involvement of these groups in setting priorities, making decisions and planning strategies (Lumsden et al 1996). However, the terms do differ in that community development places a greater emphasis on self-reliance and sustainability. The goal of community development is to create strategies and programs, which community groups then manage and sustain (Lumsden et al 1996). Through this community development, communities can become 'empowered'. This is achieved by assisting groups to mobilise resources, think critically, and access opportunities and networks. This development can operate at an individual, organisational or community level (Baum 2002). Community organisations' role in development and empowerment is critical, as:

> Community empowerment results in a community in which individuals and organisations work together to meet their respective needs. They provide support for each other, deal with conflicts constructively and establish control over the quality of life of the community.
>
> Baum 2002: 354

Community organisations, especially those which are larger and more established, are becoming increasingly involved in health policy (Jones et al 2004). Through the community participation initiatives discussed previously, they are well positioned to give a voice to the perspectives and concerns of those they represent. They offer a means through which their community groups in civil society can critique and influence government policy. From a government and health policy perspective, they are ideally positioned "to contribute to health service planning by providing a unique perspective on their own health-related needs and identifying health needs that are difficult to measure" (Green, Parkinson, Bonevski & Considine 2004: 142).

This relationship, however, is not a straightforward process; these roles are often contradictory and consequently do not always sit easily in one space. For community organisations, their new roles with government have raised questions about how to manage their 'community-base' while attempting to enhance their effectiveness. This is because much of the strength of community-based organisations lies in the term 'community', and their self-definition as 'community-based'. These terms refer to ascriptive and voluntary association, which can often become compromised by a close relationship with the state. Regarding the concept of community-based, Altman states "there are echoes of the sense of family, of sisterhood/fraternity, which is more powerful than the more limited concept of 'voluntary association'" (Altman 1994: 9). The concept of a community-based organisation requires that the organisation represents the community in question, and has substantial community participation. Altman captures perhaps the most significant challenge for CBOs and NGOs: "Certainly any idea of 'community-based' must involve some sense that the organisation represents the community in question, and how this is done is one of the major theoretical problems facing … community-based organisations" (Altman 1994: 7).

THE EPIDEMIOLOGY OF HEPATITIS C

In this section I discuss the formation of infectious disease related CBOs, in particular Hepatitis C and HIV/AIDS Councils. The etiology of hepatitis C has shaped all responses to its spread, both goverernment and non-government. Consequently, it is important to appreciate the epidemiology of the disease before discussing the evolution of hepatitis C-related community organisations.

It is evident from the epidemiology of the disease that hepatitis C represents an important public health issue for Australia, and a significant burden of disease. Viral hepatitis infections were first identified during the 1960s, shortly after virological markers were identified and the diseases became known as hepatitis A and hepatitis B (Farrell 1999). Through the development of reliable testing (using serological assays) for hepatitis A and B, it became clear during the 1970s that a third type of hepatitis existed which induced chronic, fluctuating illness (Purcell 1997; Farrell 1999). This condition was labeled non-A, non-B hepatitis and was understood to be a symptomatic liver disease which caused hepatic inflammation, fatigue, jaundice and nausea (Alter 1999). Non-A, non-B hepatitis was most commonly diagnosed in people who were post blood transfusion. Hepatitis A is transmitted along the faecal/oral route, whilst hepatitis B is transmitted through blood-to-blood contact and body fluids. Hepatitis C transmission, however, occurs only through blood-to-blood contact. Initially, the majority of diagnoses came about incidentally through the testing and elimination of hepatitis A and B. In 1989 this third strain of hepatitis was identified and became known as hepatitis C (Loveday & Wallace 2001; Alter 1999; Kidd, Cheng & Wilson

1999). Soon after the isolation of the virus antibody tests were developed which are now used to identify exposure to the hepatitis C virus.

Based on Australian studies, once exposure to the virus has occurred, approximately 25% of people will undergo viral resolution; the virus is cleared from their system, and progression to chronic infection does not occur. The other 75% of people will develop chronic hepatitis C. Both acute and chronic hepatitis C result in symptoms such as fatigue and depression. An individual may, however, be asymptomatic for a period as long as a decade after initially contracting the virus (Farrell & Cossart 1999). Indeed, many people who have contracted hepatitis C will not experience acute symptoms. If the disease becomes chronic, it can result in liver cirrhosis, liver cancer and, in some cases, death. The clinically acceptable model for cirrhosis prevalence, based on longitudinal studies, has found a cirrhosis prevalence of 10-20% after a ten-year period of infection (Dore, Law, MacDonald and Kaldor 2003).[4] Some studies, however, have reported cirrhosis prevalence as high as thirty percent (Ramalho 2003). Progression to cirrhosis is related to age at infection, gender, hepatic iron content, obesity, duration of infection and excessive alcohol intake (Ramalho 2003; Dore et al 2003; Dore, Prichard-Jones, Fisher & Law 1999). Those who do develop cirrhosis are at a higher risk of liver failure; 19% of hepatitis C cirrhosis cases result in death (Dore et al 1999).

Gauging the extent of hepatitis C infection in Australia is difficult. It is believed that notifications underestimate prevalence due to the asymptomatic nature of acute infection and the long latency period of the disease; many people in the Australian population may have been exposed to, or infected by, hepatitis C but remain unaware. At the time of writing it is estimated that 39,000 people are affected by hepatitis C, but unaware (AHC 2006). Hepatitis C prevalence and incidence estimates primarily rely on testing in specific populations which have been identified as at high-risk of the virus (Amin et al 2004).

In 1990 hepatitis C became a notifiable disease in Australia and, within two years, became Australia's leading notifiable disease (Croft, Dore & Locarnini 2001). From 1994 to 2000 there were approximately 20 000 new cases per year with cumulative notifications totaling over 160 000 for the period of 1990-2000 (Dore et al 2003). However Amin, Gidding, Gilbert, Backhouse, Kaldor, Dore & Burgess (2003) suggest that the cumulative notification

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[4] Studies into hepatitis C related cirrhosis prevalence found differing results. Currently, 10-20% is the accepted prevalence.

rate was severely under-estimated during this period, due to limited testing. Estimates based on retrospective testing of pathology samples suggest that approximately 433 000 Australians had been exposed to the virus by 1998, as demonstrated by the presence of anti-bodies (Amin et al 2003). Although the overall burden of disease is unknown, at the time of writing it is estimated that hepatitis C prevalence is 1-1.5% of the Australian population, and an incidence rate of 50 per 100 000 per year (Croft 2001; Dore et al 2003; Annual Surveillance Report 2005). At the time of writing, it is estimated that approximately 264 000 people in Australia experience liver disease of varying degrees as a result of hepatitis C (AHC 2006).

The highest rates of hepatitis C notifications have occurred amongst young adults (20-29 years) with an incidence rate of six per 100 000 people (AHC 2006). Australians over the age of forty have an incidence rate of four per 100 000 (AHC 2006). Females currently have a higher rate of notifications than males in the 15-19 year age group. Since 2000 the number of newly reported diagnoses has been declining in all age groups for both males and females (AHC 2006).

In Australia, transmission of the virus is most strongly associated with injecting-drug use, especially once the virtual elimination of blood transfusion acquired hepatitis C since testing began in 1990 (Dore et al 2003). Whilst studies based on notification data suggest that up to 90% of new infections are a result of injecting-drug use, only 55-60% of those currently infected report injecting-drug use as a primary risk factor (Annual Surveillance Report 2005; Dore et al 2003; MacDonald, Wodak, Dolan, Van Beek, Cunningham & Kaldor 2000; Croft, Hopper, Bowden, Breschkin, Milner & Locarnini 1993). Risk factors associated with the acquisition of hepatitis C transmission amongst these populations include age, duration of injecting, history of incarceration, and frequency of shared injecting equipment (Annual Surveillance Report 2005; Dore et al 2003; MacDonald et al 2000, Croft et al 1993). Other modes of transmission include tattooing, piercing, sharing of personal items and blood transfusions prior to 1990 (Alter 1999; Ramalho 2003; Inquiry into Hepatitis C 1998).

Government response to the epidemic

During the late 1980s and early 1990s, Australia was still recovering from the initial and rapid spread of HIV/AIDS (Hulse 1997). The discovery of another potentially fatal blood-borne virus triggered public alarm and early media reports referred to hepatitis C as the 'new killer disease', however, the early 1990s was characterised by an apathetic response from government (Lowe & Cotton 1999; Loveday & Wallace 1999; Hulse 1997; Larriera Aug 1993; (Dewsbury Sept 1990). Hulse (1997) comments that this was a result of perceptions concerning the disease. Unlike HIV, hepatitis C was not perceived to constitute a risk to the broader community; this resulted in decreased political pressure to show initiative in responding to the spreading disease. As public alarm grew, media reports accused the government of a complacent and perfunctory attitude towards an increasing problem (Larriera Aug 1993; Larriera Dec 1993). Those living with the virus had to contend with little government support and a lack of information (Lowe & Cotton 1999; Loveday & Wallace 1999; Krug 1995). Health officials believed that the existing strategies put in place during the 1980s to control the spread of HIV/AIDS would protect the public from the spread of hepatitis C.[5] In 1997 Hulse commented, even at this stage in the epidemic, that "no national strategy to deal with hepatitis C [had] been forthcoming" (Hulse 1997: 175). A national strategy is essential for the allocation of funding and resources and to provide a directed response to the epidemic. It was not until 1999 that the Australian Government launched its first national strategy for hepatitis C.

In 2006 hepatitis C remains one of Australia's leading notifiable diseases and the federal government has since launched its second national strategy (Hopwood & Southgate 2003; Gifford, O'Brien, Bammer, Banwell & Stoove 2003; The National Hepatitis C Strategy 2005-2008). As discussed above, hepatitis C is now most strongly associated with injecting-drug use. Consequently it is common in marginalised populations such as people with a history of incarceration and homelessness (Puplick 2001; Croft et al 2001). This strong association with injecting drug use has resulted in it being a highly stigmatised disease. Many people affected by hepatitis C express feelings of isolation and feel as though they are judged, excluded or mistreated by broader society and medical institutions as a result of their condition.

The stigma attached to the disease shapes both the government and community response to its spread in Australia (Croft 1997; Loveday, Deakin & Neophyton 1999; Puplick

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[5] In addition, whilst interferon had been established as a treatment for the virus during the 1980s, the government was disinclined to subsidise treatment costs as late as 1993 (Larrieta Nov 1993).

2001; Temple-Smith, Gifford & Stoove 2004; Waller 2004). There is still a very low level of awareness of hepatitis C in the general community. This has been linked to stigma and the illegal nature of the behaviour most commonly leading to hepatitis C infection (Loveday & Wallace 2001). Certain aetiological characteristics of the disease are also problematic to prevention, support and education:

> The current hepatitis C epidemic is unlike many other epidemics where the consequences are fairly immediately obvious. With hepatitis C there is a considerable lag period between the epidemic of infection and the epidemic of consequence.
>
> Inquiry into Hepatitis C in New South Wales 1998: 19.

An individual may be infected with the virus for as long as a decade before experiencing symptoms. Whom the virus infects, and how, acts not only as a substantial barrier to prevention, but also as a barrier to increasing awareness, education, support and acceptance within the general community. Due to the constrained government reaction to hepatitis C, the community response and establishment of community-based organisations has been an integral part of the Australian response.

COLLECTIVE ACTION & INFECTIOUS DISEASE

The Australian community response to hepatitis C cannot be fully appreciated without an understanding of the HIV/AIDS community-led response which occurred during the 1980s. The HIV/AIDS experience set a precedent for the formation of community-based infectious disease Councils. In addition to HIV/AIDS setting an initial precedent for this type of community involvement in Australia, hepatitis C has a longstanding association with HIV/AIDS at social, funding and organisational levels (Hulse 1997; Loveday & Wallace 2001). In this section I briefly discuss the relationship between the two epidemics, and compare the hepatitis C community response with that of the HIV/AIDS epidemic.

The relationship between HIV/AIDS & hepatitis C

The community response to HIV/AIDS created a framework which has guided and informed the hepatitis C response. The HIV/AIDS epidemic demonstrated the need and effectiveness of community participation and community-led action in reducing the impact of infectious disease, both in terms of prevention and support. The close affiliation of the HIV/AIDS and hepatitis C epidemics has stemmed largely from their close temporal proximity; hepatitis C became established as a serious public health concern relatively soon after the discovery and spread of HIV/AIDS. There are also shared characteristics which have encouraged comparisons between the epidemics: both are blood-borne viruses that spread through behaviour considered to be 'high-risk', and both affect marginalised sections of the population (Loveday et al 2001). This association has shaped hepatitis C strategies, policies, and funding throughout its history. Many in the hepatitis C sector contend that although HIV/AIDS has created a framework for community-based responses, it has also resulted in hepatitis C becoming inferior to HIV/AIDS in terms of political attention and funding.

This close association of the two epidemics has had both positive and negative effects on the hepatitis C sector. At times it has been beneficial due to the high-profile nature of HIV/AIDS. However, hepatitis C has also been subordinate to HIV/AIDS in terms of political attention and funding, despite its higher prevalence (Loveday & Wallace 2001). Structurally the hepatitis C response has persistently been attached to HIV/AIDS. This association is grounded in political sentiment, rather than etiological association. At a federal level, and for many states, hepatitis C is grouped under 'HIV/AIDS and related diseases'. One of the many examples of this is the peak Australian representative body for the hepatitis C medical research – the "Australasian Society for HIV Medicine".

Although the HIV/AIDS response acted as an important forerunner for hepatitis C in the early 1990s – whereby peer education, community agencies and advocacy were established as effective measures to combat the effects of infectious disease – for the most part HIV/AIDS affected a cohesive community group who were well positioned to assert collective action (Hulse 1997). The gay community in Australia was instrumental in raising awareness, and in education and prevention measures, along with providing support to those who were directly affected (Altman 1994). Those affected by hepatitis C are not well positioned to replicate this level of collective agency. The virus affects disparate and often marginalised sections of the population, who often share nothing in common aside from a diagnosis. Whilst the disease is common in those currently identifying as injecting drug users, many people affected by hepatitis C may have contracted the virus decades earlier and no longer identify with this lifestyle (Krug 1995). In comparison to HIV/AIDS, this has made a community-led response more difficult to organise.

HIV/AIDS & HEPATITIS C COMMUNITY ACTION

As stated earlier, in Australia the HIV/AIDS and hepatitis C epidemics are closely affiliated. It is therefore worth noting that, both nationally and internationally, community responses to HIV/AIDS have followed a pattern. Due to the highly politicised nature of the virus and its new and rapid growth, State and Federal governments were often hampered in their ability to provide support and education (Altman 1994; Brown 1997). This lack of response or guidance spurred community groups into action, to supplement the government response and "provide what we would otherwise expect to be services delivered by the state" (Brown 1997: 89). An early feature of community-based AIDS groups was a desire to provide 'hands-on' assistance to those affected by the virus. The dissatisfaction with state responses, coupled with the 'need to do something', resulted in groups of affected people coming together to form volunteer organisations (Brown 1997). As these organisations grew, they began to draw funding from government, whilst remaining primarily staffed by people affected by HIV/AIDS. As they expanded further, their connections with state apparatus become increasingly complex, and the staff came to include those not directly affected by the condition (Brown 1997).

The Australian community-based response to the hepatitis C epidemic has followed a similar pattern. As discussed previously, as with the beginning of the HIV/AIDS epidemic, the start of the hepatitis C epidemic was characterised by the absence of a national response. This resulted in increasing isolation for the people who had been affected by the condition. The provision of contradictory and inaccurate medical information further compounded this sense of isolation and confusion, both in the general public and amongst diagnosing clinicians (Loveday & Wallace 2001). In the face of government inactivity and widespread confusion concerning the aetiology of the disease, small groups of hepatitis C affected people began to come together to assert collective action. As a result, Hepatitis C Councils began to emerge around Australia in the early 1990s (Loveday & Wallace 2001). Establishment of these Councils occurred first in the eastern states of Australia, and resulted in each capital city having a form of Hepatitis C Council by the conclusion of 1995. It is worth noting that some Councils around Australia are not designated as specific Hepatitis C Councils; several Councils are general hepatitis Councils, and others are combined with HIV/AIDS. During 1996 a National Hepatitis Council was established to provide a peak representative body called the Australian Hepatitis C Council (Loveday & Wallace 2001).

Today, many of these Councils retain the features so dominant at their conception, such as the presence and influence of those directly affected by the virus and the utilisation of volunteers (Loveday & Wallace 2001). The workforce of many of these Councils has also grown from a small group of directly-affected individuals and interested health professionals to include a more diverse range of people. Similarly, the growth of Hepatitis C Councils has seen the preservation of many of the original roles, in conjunction with the acquisition of new responsibilities. Increasingly, their core business has become intertwined with the objectives of State and Federal Government. Currently, Hepatitis C Councils in Australia are a conglomeration of many of the features of a self-help group, a pressure group to advocate for increased funding and research, a service provider and an expert group intervening in public debate.

Research into Councils

Hepatitis C and HIV/AIDS Councils have received surprisingly little attention from researchers of all disciplines. In fact, no social research has been conducted into the establishment, functioning or role of Hepatitis C Councils, the one exception being Loveday and Wallace's (2001) chapter in *'Hepatitis C: An Australian Perspective'*, which offers a brief discussion on the formation and core functions of Australian Hepatitis C Councils.

Internationally, HIV/AIDS Councils have also received little attention from researchers. Throughout the eighties and early nineties Dennis Altman provided social commentary on the Australian HIV/AIDS epidemic. In 1994 he published *'Power and Community: Organisational and Cultural Responses to AIDS'*. In this text Altman provides an overview of the Australian community response to HIV/AIDS, and contrasts it with other countries, both developed and developing. Altman's book, however, is not based on research carried out within HIV/AIDS Councils, although it does provide a retrospective commentary on the community response to HIV/AIDS. Michael Brown's (1997) *'RePlacing Citizenship: AIDS Activism and Radical Democracy'* constitutes the only qualitative research conducted within an HIV/AIDS Council in a developed nation. His book is based on ethnographic research conducted in Vancouver. Brown is a cultural geographer concerned with the changing nature of citizenship. Although his work does not have an explicit public health focus, many parallels can be found both between his explorations of the changing nature of HIV/AIDS Councils and the hepatitis C experience, and the Australian and Vancouver experience of HIV/AIDS more generally.

Whilst Altman's and Brown's texts are informative, and provide a point of comparison for the research found in this thesis, a study of HIV/AIDS Councils is by no means inclusive of the hepatitis C experience. Considering the importance of Hepatitis C Councils in Australia's response to the hepatitis C epidemic, investigation of, and research into Hepatitis C Councils is not only informative, but also necessary in assisting them to fulfil their mandate.

THE OLIVER SMITH COUNCIL FOR HEPATITIS C

In this section I provide a historical overview of the Oliver Smith Council for Hepatitis C with which the research for this thesis was conducted. This overview is constructed from my fieldnotes and documents supplied by the Oliver Smith Council, such as community newsletters and Annual General Meeting reports. It is difficult to gain information on the Council's history as there is no formal documentation. I also had difficulty gaining a consensus from people who work, or have previously worked, at the Council. Consequently, I have concentrated on a broad overview of the development of the organisation.

The Oliver Smith Council for Hepatitis C began when a hepatitis C-positive clinician advertised a public meeting for those affected by the condition. This meeting took place in 1993, and uncovered a group of individuals who were seeking information and support regarding hepatitis C. This group, in conjunction with several supportive clinicians and healthcare workers, developed into what is now known as the Oliver Smith Council. From its inception two distinct roles were established and these remain fundamental to the Council's operations today – effecting political change and providing, and advocating for, accurate information and support to those affected by hepatitis C. Development of written resources containing accurate information was, and remains to this day, a priority of the organisation. In the early stages, people's living rooms were used to develop resources for sending to individuals requiring information.

In late 1994 the Oliver Smith Council became incorporated. As an incorporated organisation, the Council's role was to provide information and support for, and advocate on behalf of, those affected by hepatitis C. It began a phone counseling service, held information meetings, produced a community newsletter, and formally established a governing committee. As the demands on the Council, and its workload, grew, it moved to its first official office. Here it shared the premises with a project for homeless children, funded by a local charity. This move, in conjunction with the appointment of its first paid employees, occurred in 1996. Funding was received by the State Health Department through money allotted for HIV/AIDS.[6]

This funding grant from the government enabled the Council to "develop and stabilise its infrastructure and build upon the foundations laid by volunteers" (Oliver Smith Council for Hepatitis C Newsletter July 1996: 1). This new office provided a further degree of professionalism for the Oliver Smith Council; it now contained an interview room to allow individuals affected by hepatitis C to seek information and advice in private. One of the first Council newsletters proudly boasted of its new premises that it offered a place "where volunteers can come to lend a hand with the newsletter, a mail out, or with anything that may

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[6] Funding mechanisms have not changed much since Commonwealth monies became available with the beginning of the National Hepatitis C Strategy.

require an extra hand now and again" (Oliver Smith Council for Hepatitis C Newsletter July 1996: 1).

As the Council continued to expand, it soon outgrew its first office and, around 1997, the organisation was given a room at the rear of one of the state's drug and alcohol service's premises. In 2001 the Oliver Smith Council finally received a building of its own. This, in conjunction with the erection of signage, raised the visibility of the Council as a community organisation (Annual Report of the Oliver Smith Council for Hepatitis C 2000-2001). During this time the Council was funded to provide information and education on hepatitis C to the public. It also provided support groups, referral and advocacy for those affected by hepatitis C. The telephone line still represented the Council's main contact with those affected by hepatitis C.[7]

The current structure of the Oliver Smith Council

Due to its substantial growth, during 2004 the Council moved once more to a larger office where it is still located now, three years later. In 2003 a Management Committee was established and, as of 2006, the Oliver Smith Council is run by a Board of Governance, who determine the overall scope and direction of Council activities, in collaboration with a manager who overseas day-to-day running. This Board is composed of a selection of elected individuals derived from the community, health-care institutions and partner organisations. The Council is now comprised of a considerable body of both paid employees and volunteers. In terms of funded roles, the Council has resource and information sections, a Support Line, an education team, and administrative support. Although the organisation has grown substantially since its inception, it remains relatively small with approximately thirteen employed workers filling seven full-time equivalent positions, and roughly the same-sized pool of volunteers. The structure of the organisation can be seen in Figure 1, with staff arranged into three core sections. Figure 2 shows the physical layout of the Council and arrangement of offices spaces.

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[7] The Council receives recurrent funding from the State's Department of Health via HIV, Hepatitis C Policy and Programs, which is part of the Communicable Diseases Control Branch. The Council also receives project money and one-off grants from the Commonwealth Department of Health and Ageing under Hepatitis C Prevention & Education funding. The Council also applies for funding from local sources for small amounts.

Administration, the Manager and the Support Line can be found upstairs, whilst the education team and resource section are located underground, in the downstairs section of the building.

The education team contains three core members and two part-time employees and is the most rapidly expanding section of the organisation. The workload is roughly divided between rural and metropolitan education programs. Historically, education efforts carried out by the Oliver Smith Council have been predominately one-off education sessions. In late 2005 funding was granted to employ an Education Coordinator. Although community development and health promotion approaches have always been part of the Council's work, the appointment of an education coordinator has shifted the team's focus towards more sustainable interventions. The expansion of funding given to the Council for community education efforts indicates the increasing importance of hepatitis C on state and federal agendas. While volunteers originally carried out education work, the current education team rarely uses them, with the exception of 'positive speakers'. The Positive Speakers program allows individuals directly affected by hepatitis C to discuss their experiences in an attempt to influence attitudes and behavior, particularly health professionals and people affected by hepatitis C. Staff and volunteers may undertake additional, paid Positive Speaker work; this work is evidence of the fluidity of roles in a small, community-based organisation.

The presence of volunteers has been a fundamental component of the organisation since its inception. They demonstrate the organisation's 'community roots'. The relationship between the Council and its volunteers is aimed at being reciprocal – in return for time, skills, experience and energy, volunteers receive training, work experience and the chance to develop new skills (Loveday & Wallace 2001). Whilst empowering and developing individual volunteers was seen as a priority in the past, recently the organisation has begun to focus on running larger community development and empowerment projects with community groups situated outside the Council. Similarly, the number of volunteers affected by hepatitis C working at the Council has begun to decline. Primarily this change has occurred because the Council has required volunteers who have skills in running organisations. For the Council, this raises questions about their self-definition as community-based. Volunteer involvement is considered pivotal to the operation of the Council and is one of its defining characteristics as a community-based organisation. Furthermore, an important facet of the hepatitis C epidemic (first found in relation to HIV/AIDS) is that those living with hepatitis C should have a voice.[8] Hepatitis C-related community organisations, often in collaboration with volunteers, give this voice form, and foster experience-based expertise.

Currently, the Council has reached what can be described as a critical juncture in its growth and development. The focus of the organisation has begun to shift. Originally the Council was established to provide support to those affected by the virus, and recently it has begun to work in areas more closely aligned with government objectives and needs, such as hepatitis C prevention work. The types of changes and discussions taking place within the Oliver Smith Council are not unique to the organisation. They represent common challenges for many NGOs and CBOs. Brown (1997) describes the process as 'bureaucratization', and argues that it is a fundamental challenge for community-based organisations. The socio-political landscape that gives rise to the bureaucratisation of community organisations will be discussed in Part Four.

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[8] Similarly, individuals directly affected by hepatitis C poses certain expertise in relation to medical and government authorities, with regard to the social and experiential aspects of the virus (Brown 1997; Altman 1994).

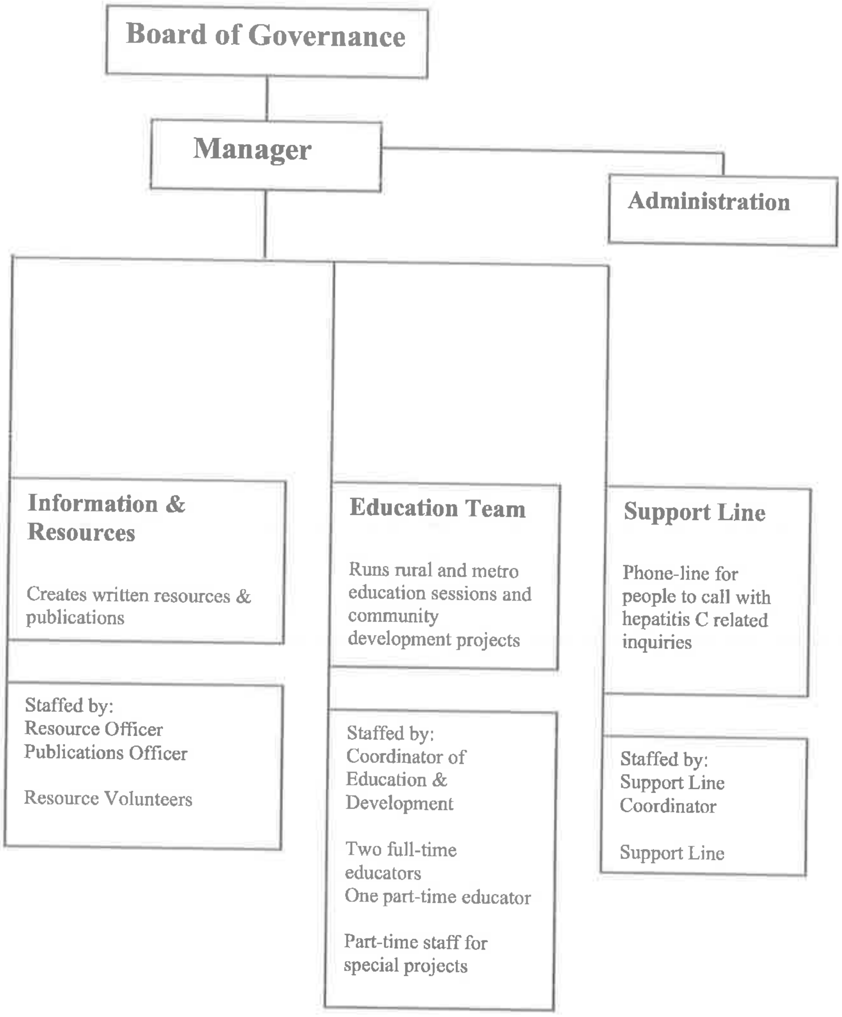

Figure 1. Organisational Structure of the Oliver Smith Council for Hepatitis C

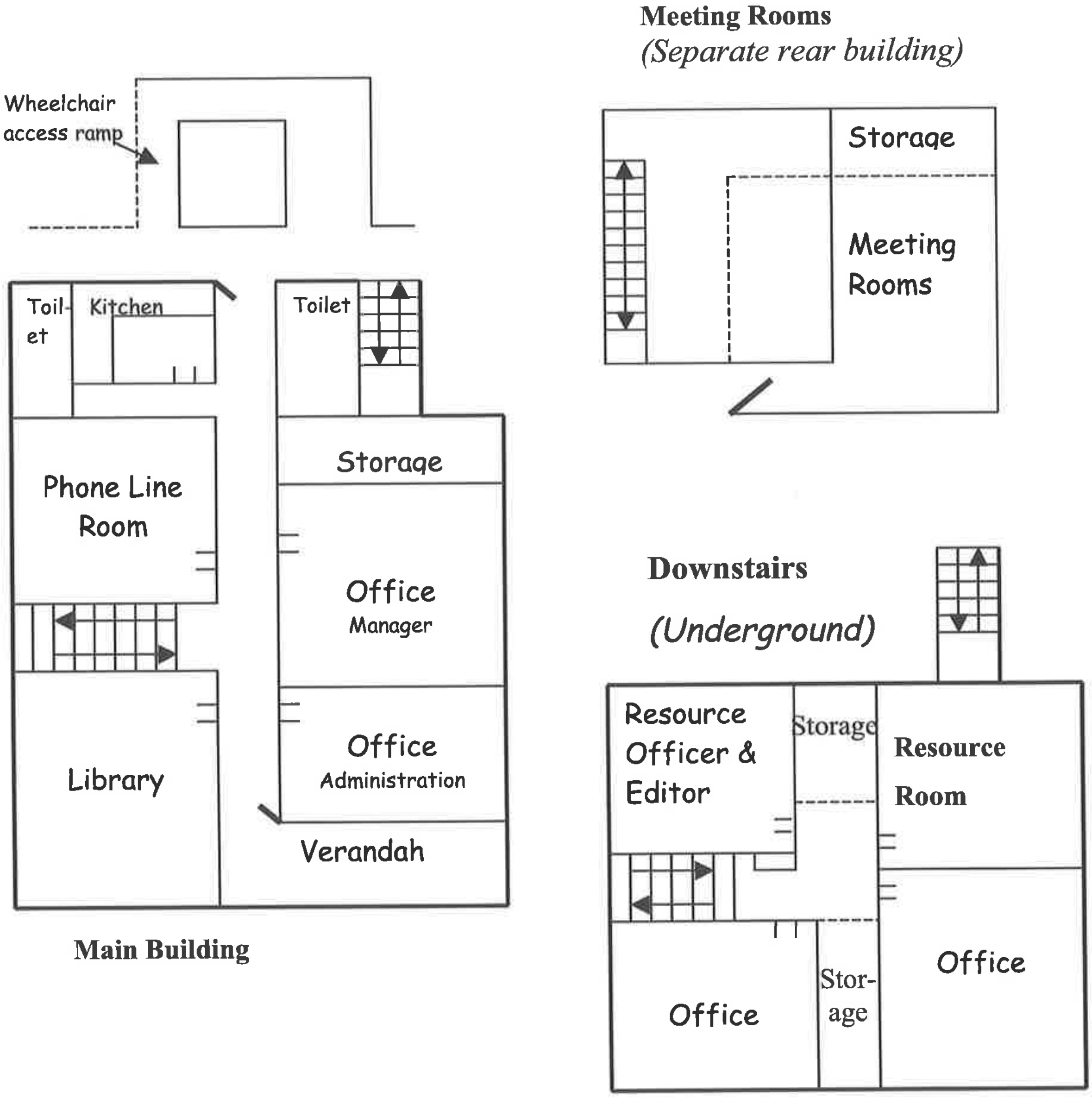

Figure 2. Physical Structure of the Oliver Smith Council.

CONCLUSION

Hepatitis C constitutes a serious public health concern and a significant burden of disease for the Australian population. It is commonly associated with marginalised sections of the population such as people who have spent time in custodial settings, or have been involved in injecting-drug use. The association of hepatitis C with marginalised groups has resulted in the disease being heavily stigmatised. This stigma has shaped both the community and government response to the epidemic. The initial government response was minimal, primarily due to a disinclination to expend the resources and funding required to control the epidemic. Hepatitis C Councils around Australia were formed in reaction to this inadequate government response. Over time these organisations have grown from a small group of directly-affected individuals into functioning NGOs, funded by the state. Whilst these organisations offer a critical potential for developing a community response, as demonstrated by HIV/AIDS, they face major practical and theoretical challenges.

Chapter Two

The challenges of ethnography 'at home': Methodological considerations

> Observational research involves an inexhaustible variety of settings and an endless range of situational exigencies for which ready-made recipes do not exist. The conduct of the researcher, and the outcomes of the research, are vulnerable to unique developments in the field and to dramatic predicaments that can be solved only situationally. (Punch 1986: 27).

CHAPTER INTRODUCTION

At the beginning of my fieldwork a colleague explained to me that 'Doing ethnographic fieldwork is like starting a new job: everyone knows what they're meant to be doing except you. Only you're doing the first day of the new job over and over again!'. This statement reflects my experience of conducting fieldwork in an organisation. With participants neatly tucked away in offices working, one cannot wander freely between people, chatting and participating. Indeed, conducting ethnographic fieldwork 'at home' in an organisational setting presents unique challenges. Although you may not need to learn a new language or travel a great distance to 'the field', there are still subtle differences in the use and acceptability of words, and you are still entering a foreign social world. To further complicate matters, the people within the organisation are not isolated from your work or life within the university. The lines between the research you conduct in the field and your professional life back at the university can become (confusingly) blurred.

My initial intentions as a graduate student, when undertaking this project, were to conduct twelve months of ethnographic fieldwork exploring the occurrence and experiences of hepatitis C-related discrimination. It was arranged with the Oliver Smith Council that a large part of this fieldwork would be spent there. Through my time at the Council I became increasingly interested in the challenges, tensions and debates occurring within the organisation. Consequently, during the course of conducting fieldwork, both my topic and methodology changed. For many ethnographers, and for qualitative researchers more generally, such a shift in research focus is an accepted (and sometimes standard) part of conducting social research: "good ethnographers do not know what they are looking for until they have found it" (Fine 1993: 274; Cheek 2003).[9] However, as my experience demonstrates, such conceptual changes can be difficult for the participants in the research. In my research, changes in research focus led to confusion, complication, challenges and tensions; and, as the reader will discover in this chapter, this in turn created a rather unorthodox research journey with substantial changes in methodology and conduct. Rather than an extended phase of ethnographic research, at the point of completion my project comprised four months of ethnographic research accompanied by nine semi-structured, qualitative interviews. In this chapter I explain how these changes came about and the reasoning behind key decisions which have resulted in what may appear to be a rather ad hoc research path.

This thesis aims to provide an actor-orientated account of the complexities and challenges facing a community organisation. While in the later chapters of this thesis the actors whose experiences are explicated and explored are the workers at the Oliver Smith Council, in this chapter I am the actor and the experiences I explore are my own. I have chosen to construct my methodology as a narrative because I believe that it best contextualises the research decisions that were made during the project. It is worth noting, however, that in telling *my* story I occlude the stories of others. There are at least three stories which could be told of how this project was conducted: mine, the University's and that of the workers at the Oliver Smith Council. Arguably, each of these stories differ markedly. Although I have listened to, and am mindful of, the stories of others, the following narrative is told from my perspective. While my own narrative is influenced by the perspectives of others, at the end of this chapter I provide a discussion of the ethical implications of this research which draws more explicitly upon what I have learnt from other people's stories of this research project.

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[9] Punch (1986: 17) comments that due to the fluid nature of qualitative research, and particularly ethnography, there is a "greater element of risk and uncertainty associated with this style of research compared with other methods".

Before discussing the occurrences and negotiations which took place in finding a research pathway, I will briefly discuss two methodological principles that underpin this research: ethnography and reflexivity.

Ethnography

> The methods of ethnography have become highly refined and diverse, and the reasons for doing ethnography have multiplied. No longer linked to the values that had guided and focused the work of earlier ethnographers, the new ethnography ranges over a vastly expanded subject matter, limited only by the varieties of experience in modern life.
>
> Vidich & Lyman 2003: 95

Ethnography is an inductive research technique which involves the study of groups of people as they conduct their day-to-day lives (Emerson, Fretz & Shaw 1995). The principal aim of ethnographic researchers is to emphasise and build upon the perspectives of the people in the research setting who are participants in the research (LeCompte & Schensul 1999). Ethnography involves "an ongoing attempt to place specific encounters, events, and understandings into a fuller, more meaningful context" (Tedlock 2003: 165). LeCompte and Schensul (1999: 6) argue that ethnographic research should be centered on two goals: "understanding sociocultural problems in communities or institutions [and] using the research to solve problems or help bring about positive change in institutions or communities".

Ethnography, like most qualitative research, is necessarily fluid and flexible (O'Reily 2005). Ethnographic research is often considered to use any or all available research methods that will assist in making sense of the world around us (O'Reily 2005):[10]

> Qualitative research involves the studied use and collection of a variety of empirical materials – case study; personal experience; introspection; life story; interview; artifacts; cultural texts and productions; observational, historical, interactional, and visual texts – that describe routine and problematic moments and meanings in individuals' lives. Accordingly, qualitative researchers deploy a wide range of interconnected interpretive practices, hoping always to get a better understanding of the subject matter at hand.
>
> Denzin & Lincoln 2003b: 9

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[10] Janesick (2003: 46) draws a parallel between qualitative research design and choreography; "the essence of good qualitative research design turns on the use of a set of procedures that are simultaneously open-ended and rigorous and that do justice to the complexity of the social setting under study. A good choreographer captures the complexity of the dance story by using rigorous and tested procedures and in fact refuses to be limited to one approach of choreography."

Although ethnography is considered to be a principally qualitative technique, ethnographers have been known to use quantitative methods such as surveys and statistical analysis (Denzin & Lincoln 2003b). However, observing and participating in daily life for extended periods of time (or conducting participant-observation) is considered the staple of ethnographic research (O'Reily 2005; Tedlock 2003; LeCompte & Schensul 1999; Emerson et al 1995).[11] While conducting participant-observation the researcher makes notes and recordings. The researcher also documents what is encountered and observed. Qualitative and ethnographic researchers must undertake inductive analysis – this means identifying categories, themes and patterns which emerge from the data (rather than imposing such themes upon it) (Janesick 2003). Through this systematic documentation of social life, the ethnographer attempts to create a rich description of everyday life.

The above account of ethnographic research is perhaps the glossy brochure description of 'doing ethnography'. In reality, it is a technique which is no more precise or impartial in its attempt to uncover or capture 'truth' than any other research method of investigation. Gary Fine captures the dilemmas of ethnographic research effectively in his piece 'Ten Lies of Ethnography'. Fine divides ethnographic 'lies' into three categories: classic virtues, technical skills and the ethnographic self. Arguably, Fine's ten lies are in the main concerned with the same central lie: the glossing over, or gentle misrepresentation, of the ethnographic craft in all its claims and stages, so that ethnographers are able to get on with the noble art of 'doing ethnography'. Our ethnographic attempts at 'truth' are in fact partial, imperfect and not to mention at times inextricably bound with our own desires, should they be to portray ourselves in a particular light, or to advance our academic standing. Fine (1993: 276) explains that:

> The illusion of verisimilitude is crucial for the grounding of qualitative research. We embrace its rich precision. The belief that this is 'real life', not fiction or guesswork, provides a methodological charter for participant observation. This depiction of reality gives ethnography an advantage over survey research, experimentation, and other techniques, but it is a belief that is at best only approximately true.

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[11] Participant observation was founded as a method for the study of small, homogenous societies (Tedlock 2003). Historically, this method allowed ethnographers to be both engaged participants and objective observers: "this strangely empathic yet impassive methodology was widely believed to produce documentary data that somehow reflected the natives' own points of view… The oxymoron *participant observation* implies simultaneous emotional involvement and objective detachment" (Tedlock 2003: 180)

Fine (1993: 267) quotes Everett Hughes in saying that there is an "underside" associated with all work: "each job has techniques of doing things – standard operating procedures – of which it would be impolitic for those outside of the guild to know… Illusions are essential to maintain an occupational reputation". Qualitative research is no exception; there is an 'underside', as in other trades. Acknowledgement of this fact does not, however, undermine the craft but rather is just that – an acknowledgment that there is no one technique used to examine human interaction which is not imperfect or above reproach. Of particular relevance to this research is Benjamin's (1999: 49) comment that "research is an imperfect endeavor, embedded in power relations and necessitating difficult ethical decisions". When negotiating a research pathway it is these elements of research design, power and ethical considerations which the researcher must carefully balance.

Reflexivity

"The production of good things may not be pretty" (Fine 1993: 267).

Reflexivity is "perceived as a way of ensuring rigor… the goal of being reflexive… has to do with improving the quality and validity of the research and recognising the limitations of the knowledge that is produced" (Guillemin & Gillam 2004: 275). Reflexive engagement is an important component of ethnographic research, and of qualitative research projects more generally. It is often offered as the answer to acknowledging the limitations of research in a way which does not undermine its findings, applicability or usefulness. In ethnographic research, reflexivity is vital in the constructing of an insightful ethnographic account, since ethnographers must convey not only the context of the research but also their place in it (O'Reily 2005; Guillemin & Gillam 2004; Fine, Weis, Weesen & Wong 2003; Mason 1996; Emerson et al 1995). By engaging with the reflexive turn, we acknowledge that we are not merely the conductors of the research, but part of the research process. In my research I kept notes and memos on my thoughts, impressions, reactions and reasoning.

Through reflection on these and recognising that I am part of the world I study, I hope to make this study informative and useful for others.[12]

Hammersley and Atkins (1995) believe that research design must be a flexible and reflexive process, one which must operate throughout all stages of the project (see also Mason 1996). Guillemin and Gillam (2004: 274) similarly state that "reflexivity in research is not a single or universal entity but a process – an active, ongoing process that saturates every stage of research". In this chapter I therefore aim to illuminate, and make transparent, my research process. As well as explaining my methodology, I will also use this reflexive discussion to elucidate how I came to write about community at the Oliver Smith Council. In doing so I aim to locate myself in the thesis which I have written and acknowledge that my observations are filtered through my own understandings and interpretations (O'Reily 2005). O'Reily (2005: 66) explains this well when she states that conducting qualitative research is not a simple matter of discovering truth: "what we find will depend on how and where we look, and on who ultimately we think the research is for". When we come to write our findings "chapters do not appear by themselves. We decide on them. Subheadings are not natural phenomena. They are imposed on the data" (O'Reily 2005: 218).

What can be found and read in this thesis is based on *my* perspectives, understandings and interpretations of what I observed and was told.[13] The aspects of the Council that I have chosen to write about have been chosen because they stood out for me as important issues for the participants in the research, issues which those at the Council may find beneficial, useful or even enlightening. Having said this, this may not be true for all who took part in the research. Richardson (2003: 108) explained it nicely when she said "A continuing puzzle for me is how to do sociological research and how to write it so that the people who teach me about their lives are honored and empowered, even if they and I see their worlds differently". I hope that at the completion of a difficult research journey – for both my participants and me –this is something I have come close to achieving.

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[12] Denzin and Lincoln (2003: 9) describe qualitative research as an interpretive *bricoleur* process, whereby the research is shaped "by his or her personal history, biography, gender, social class, race, and ethnicity, and by those people in the setting. The political *bricoleur* knows that science is power, for all research findings have political implications".

[13] Janesick (2003: 69) contends that validity in qualitative research "has to do with descriptions and explanation and whether or not the explanation fits the descriptions. In other words, is the explanation credible?… Qualitative researchers do not claim that there is only one way of interpreting an event. There is no one 'correct' interpretation".

The problem of biographical positioning

Much has been written about the biographical positioning of researchers in ethnographic research and texts. How much can, or should, one include about oneself in a text whilst avoiding the problems of narcissism or partiality (Richardson 1992)? A common criticism of ethnographic texts is the detached account, the findings minus the observer: "There has long been a tendency to view the self of the social science observer as a potential contaminant, something to be separated out, neutralized, minimized, standardized, and controlled" (Fine et al 2003: 169). Fine et al (2003: 169) also lament that to leave ourselves out of our ethnographic texts leaves our informants with the sole "burden of representations as we hide behind the cloak of alleged neutrality". In contrast, many authors are also quick to remind us that including too much of 'ourselves' in our text can silence the research subjects. Ronaldo (1989), for example, warns against the tendency of reflexive accounts to be 'self-absorbed' pieces which obscure the voices of participants.

Richardson (2003) believes that, to avoid the postmodern problem of how much we should include about ourselves in our research accounts, one should evaluate one's reflexive accounts on the grounds of whether or not one is writing in order to valorise oneself. Similarly, Fine et al (2003) suggest that the insertion of biographic information can serve as a technique to establish the author's authority, rather than acknowledge the impact of the researcher on the research findings and presentation. Whilst reflexivity may be an attempt to overcome the subjective nature of research, reflexive accounts can in themselves be biased, partial or produced from the viewpoint of a researcher who may be consciously, or unconsciously, attempting to present their research in the best possible light (Punch 1989). As Fine (1993: 283) states:

> Recent experimental attempts to move oneself into the center of one's ethnography can no more escape the dilemmas of exposing one's candor than can attempts to pretend that one wasn't there at all. New techniques of ethnographic description demand the same bracketing of candor as does the claim of the absent ethnographer.

Fine (1993: 283) articulates this conundrum well when he states "one cannot escape the reality that the presentation of one's own role is invariably an exercise in tact. There always is a reader looking over a writer's shoulder".[14]

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[14] Many authors (see, for example, Alder, Adler & Johnson 1992; Punch 1986) advocate the review of one's research setting as an audience for one's writing (Ellis 2005).

In my own attempt to grapple with the postmodern problem of self-awareness and self-acknowledgement in the research process, I have constructed my methodology as a personal narrative as it unfolded from my perspective. Whilst I am not always as overtly or explicitly present in the pages of this thesis which lie after this methodology chapter, by establishing my reactions to my fieldsite, ethical considerations and the processes of conducting research in this methodological account, I hope to firmly establish my orientation to the research findings.

FINDING A PATHWAY

If both my participants and I are to be honest about my time at the Oliver Smith Council, we must admit that at different times we each perceived the other to be a threat to the work we were undertaking. Fine (1993) and Punch (1986) both note that many ethnographers like to create the illusion that affairs have been managed sweetly and well, free from hostility and animosity. Similarly, I cannot deny that I find it difficult to reflect on and discuss the more contentious moments of my fieldwork experience. In my first attempt at writing my methodology I glossed over many of the tensions and bad feelings that developed between some of my participants and myself. However, as Fine (1993) (and my principal supervisor) rightly note, these tensions and animosities are not only relevant to the research, but fundamental in shaping its pathway and outcomes. Similarly, Punch (1986: 15) comments that:

> A full history of the research process is an essential element in reporting a project because of the light it can shed on the nature of the data. Increasingly… people are beginning to appreciate that a truncated, flippant, or anodyne account of the project's development is not sufficient, and that a serious and deep analysis of the research role, and the research project, must form a prominent part of an observational study.

Punch (1986: 15) contends that we must "come clean" about our relationships with our field settings and participants. Thus, despite the risk of further animosity or damage, the tensions of my fieldsite and fieldwork experience need to be explored in full.

This process is made easier by one realisation. For many graduate students, conducting research can be a lone journey towards discovery and understanding. At the conclusion of my research, and on reflection of the research process, it is evident that this was not the case here. In the end my participants and I peeled back the layers of their social world together to ask ourselves and each other: “What is the place of community in a community organisation?”.

First encounters

I begin this discussion of ‘finding a pathway’ with a narrative constructed from my fieldnotes:

The Oliver Smith Council is located in an old turn-of-the-century terrace building just outside city limits. The space which the Council occupies is most fittingly described as liminal. It is neither quite in the city nor in the suburbs. The buildings flanking the Council are an eclectic mixture of commercial buildings, houses, and a ‘half-way house’ of dubious reputation. Despite this hostel-like accommodation, the suburb is one of the wealthier in the city. Lastly, although the building is near the city’s botanic gardens, the location fails to be picturesque due to a busy main road running along the edge of the city. During my time at the Council, many of its staff and volunteers commented that they felt that it was an odd location for the organisation; they felt that it should have been central and located within the city limits, or embedded in low socio-economic suburbs. Difficulty in finding a building and financial limitations resulted in the Council occupying this space between the peripheries of the city and the wealthy suburbs. However, the liminality of the Council’s location is poetic: it is not what it once was, and it is yet to reach fruition in its new direction. At the time this research was conducted, the organisation was in a pivotal state of flux.

Despite the miscellaneous collection of buildings that form the Council’s surrounds, the first time I approached the Oliver Smith Council I was struck by what a pleasant, ‘homey’ building the organisation was housed in. It is at the end of a series of several terraces, which in a former incarnation have clearly been houses but have now been renovated to be used as office space. An illustration of the Council can be found in Figure 3.

Fig. 3. Oliver Smith Council For Hepatitis C.
Drawing Courtesy of N.E. Carey.

However, when I walked up the stairs to the front door this perception altered; as I went to twist the handle I discovered it was locked. To my left, I then noticed a doorbell. One could argue that a locked door and a doorbell made the building more house-like; however for me it undid the initial welcoming feeling that the building portrayed. In the instance in which I felt the stubbornness of the locked door, the Council became incongruent with my previous experiences of community services and organisations: never before had I encountered a locked door in such places.

What I first took to be so welcoming, compared to the grand sandstone buildings or the callous nineteen-seventies constructions of the university from which I had come, quickly took on a different dimension. If my first sense of the Council was welcoming, my second was the feeling that I was an outsider. I may have come to a community organisation but I could not enter freely, I needed permission. Behind the heavy wooden door existed a foreign social world, and the doorbell in front of me hinted that this was a world which had solid boundaries where permission to enter needed to be sought continually. I do not presume that the emotions that the building and the locked door invoked in me are common to everyone who approaches the Oliver Smith Council. My first experience of the Council was shaped by where I had come from and what I was coming to do. For me, it appeared welcoming because I had come from the grand surrounds which are typical of Australia's oldest universities. The locked door made me feel like an outsider because I was filled with the trepidations which accompany anthropologists to the field: what will this foreign social world be like and will I be accepted?

Unbeknown to me at the time, what I had observed from the outside was fundamental to all that I would observe and experience within. The appearance of the Council building and the existence of the locked front door were the result of the changing nature of the organisation. They were symbolic of the organisation having reached a watershed in terms of its growth and role. To those within, the building and the locked door had become the physical representations of ideological tensions within the organisation. During the course of my research I discovered that, depending on one's ideological positioning, they could represent either achievement or a sense of loss. I believe that to many people in the organisation they often represented both simultaneously.

It is no coincidence that my first observations proved to be so pivotal to what was taking place within the organisation. The ideological tensions within the Council occurred because boundaries exist between community and community organisations. Such boundaries are necessary to their functioning; there must be people who belong inside the organisation, and people who belong outside. These boundaries are physical and ideological, and where they exist and how they are created are highly contested issues. At the Oliver Smith Council, the ideological tensions of the organisation were being played out at the physical boundaries between the organisation and the broader community which lay beyond its walls.

Finding what to research

The thesis which I have written, based on the research which I conducted at the Oliver Smith Council, explores how the Council's position between civil society and the state influences workers' understandings of community and experiences of spatiality at the organisation. This is what my participants and the data that I collected led me to write about but, as I stated earlier, like many graduate student projects this was not my original area of inquiry. In my initial literature review I noted that hepatitis C-related discrimination poses a significant burden for people living with the virus and that very little social research was being conducted into the area. This topic offered the potential to expand on previous work I had done which examined infectious disease and social exclusion. Exploring the scope and impact of hepatitis C-related discrimination fitted with the objectives of the National Hepatitis C Strategy, and was an area of inquiry supported by those working 'on the ground' at the Oliver Smith Council. Initially I, and the Council staff, envisaged the Oliver Smith Council as a starting place for my research: a platform from which to launch off into the 'hep C sector'. Subsequently, I had arranged with the Oliver Smith Council that I would spend a substantial period 'finding my feet' and making contacts.

As a cross-enrolled student between Public Health and Anthropology the research area which I had chosen enabled an easy split between the disciplines. I was able to explore an area of clear public health relevance, using the ethnographic techniques conventionally associated with anthropology. However, it became evident early on in the research process that my research focus was not well aligned with my interests and that my research methodology was not apposite for the Council. When I first began spending time at the Council trying to explore discrimination, the workers[15] and community members whom I approached were welcoming and eager to talk. However, it seemed that people had very little to say on the topic of discrimination. The following excerpt from my fieldnotes at the time provides a good example of this:

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[15] The Oliver Smith Council is principally comprised of staff and volunteers. I have chosen to use the term worker to encompass both of these roles, as both groups contribute to the functioning of the organisation and are considered part of the Council's workforce.

Fieldnotes. Oliver Smith Council. 7/07/05

Today I went to the Council to attend a meeting. After ringing the doorbell I was greeted by a middle-aged woman, her hooded eyes gave the impression that she was very tired. She seemed to know who I was and ushered me into the library just inside the front door and introduced herself as Heather. She told me to take a seat, and that everyone else was "out back at a meeting", incidentally the meeting I was there to attend. Once I was seated, she stood at the front of the room. The library at the Oliver Smith Council is a grand room, with high ceilings, bay windows at one end and large fireplace at the other. Heather stood in front of the fireplace. The room and her positioning in it made it seem as though she were about to give a formal presentation to a large group of people. These people, however, were invisible to me as I sat at a table on my own, in the middle of the room. I soon discovered that Heather ***was*** *about to give a presentation, of a kind, and without further ado she embarked on a brief, direct and business-like report: "My name is Heather, I've been diagnosed for ten years and I've never experienced any discrimination. My daughter 'outed' me at school but I've never been discriminated against". Slightly taken aback, I asked "well, do you think discrimination is a problem for many people with hepatitis C?" to which Heather replied, "Oh yes, the terrible stories I hear!". With this brisk report delivered, it seemed she felt she had fulfilled her obligations in talking to me, the researcher, and excused herself from the room. Shortly after Heather's exit, and in a slightly bewildered state, I left the library in search of the meeting I needed to attend.*

This passage exemplifies the types of discussion which characterised my first weeks at the Council. Everyone was keenly aware that discrimination was a problem for people living with hepatitis C, that it was pervasive, and damaging to the individual. However, few conversations progressed beyond these statements.

Due to the difficult nature of conducting fieldwork in an office space, I sought out the most approachable and least disruptive interaction. Although I had envisaged the volunteers, rather than the employees, at the Council to be the more distrustful of a researcher, they appeared to have the most available time to talk and seemed enthusiastic to tell their stores. The volunteers are located in two areas as delineated by their roles: the resource room and the Support-line room. The resource room is on the ground floor of the building, underground. It is a small room with no natural lighting. The volunteers I encountered in this section of the building seemed hesitant about my presence, and this was exacerbated by the small confines of the workspace. The Support-line room, however, is the centre of the organisation. It is the place where staff, volunteers and 'the community' intersect. Many of the Council workers also took regular trips outside to the back of the main building to smoke; it was rare to find the small concrete area vacant. Consequently, during my fieldwork I spent the majority of my time either in the Support-line room or in the smoking area. Here, conversation was able to flow most freely, with limited fear of interrupting the functioning of the organisation.

The discussions I had with the staff and volunteers at the Council during my fieldwork, especially early on, frequently revolved around the Council rather than hepatitis C-related discrimination. In my experience, whenever you go to a foreign place, whether it be a new city or an organisation such as the Oliver Smith Council, it is common for people to talk at length about their home territory. In light of this, perhaps it is not surprising that many conversations revolved around explanations of the Council. As people seemed eager to discuss the Organisation and their work, I would ask questions about what the Council does, how it works, who comes there and what its role is. The explanations I received were characterised by discussions of growth and change.

Within the first week of my fieldwork, the Council had its Annual General Meeting. The meeting was held in the evening at a local community centre. When I arrived, I once again experienced the sensation that everyone knew what they were meant to be doing, except me. I recognised several faces, but was hesitant to approach anyone since they seemed to be busy in their official capacities. I noticed a woman sitting in the front row who was on her own. She seemed perfectly serene in the midst of all the chatter and flurry occurring elsewhere in the room. Due to my awareness that I was very much absent of flurry and chatter, her serenity seemed approachable. Gingerly, I took my seat beside her.

Throughout my time at the Council I was constantly shocked and appreciative of people's openness about their personal experiences. As someone who is relatively reclusive when it comes to divulging personal information, I was frequently in awe of the trust and openness which people displayed. This openness was extended not just between each other but also to me – an outsider, a stranger and an intrusive participant observer. My time at the Council was often spent listening to frank stories and recollections, many of which far outreached the realm of my personal experience and understanding. The discussion which took place with the woman in the front row was one of my first tastes of the kind of honesty which seems to accompany those who are involved in community organisations.

The woman in the front row had barely managed to tell me that her name was Gwen before launching into the events which led her to the Oliver Smith Council. Gwen's boyfriend had hepatitis C but, fortunately, she did not. Originally, she had become a member in order to obtain support but her boyfriend had since been cleared of the virus. Like many people who have contact with the Council, it had become integral to her life, and she was loath to part with it, explaining, *"Now I provide support to them"*. Like so many people, when discussing the Council Gwen began to speak of growth and change. She did this through describing the Council in its previous location, or 'the old Council' as it is often referred to: *"it was rundown, but you could walk in and out as you pleased, and it had a meeting area for people to congregate. It was more inviting. The new Council doesn't have this, you have to ring the doorbell... "*. As Gwen said this, the memory of the locked-door, and the impact it had on me, returned to me. As these thoughts formed in my head Gwen continued *"...it's a barrier. Many people with hepatitis C have a lot of trouble accepting their condition... You can't put any barrier in their way, they need all the support they can get"*.

Shortly after the AGM, I asked Sam, a senior staff member at the Council, about the difference between the 'new Council' and the 'old Council'. She stated that the old Council *"was really homely... people liked walking off the street into the home-like environment...it had a kitchen. The new Council is more professional"*. When I asked why this shift had occurred, Sam explained: *"As you get bigger you need to create an environment that's welcoming to a whole range of people... [The new Council is] more professional and up-market"*.

With this my curiosity was piqued; not only was the organisation changing, this change was a contested issue.

Finding a methodological pathway

Anthropologists and ethnographic researchers are frequently the outsiders of the social world they study. Consequently, it takes time to learn the appropriate behaviour, customs and language of the foreign place they have entered. Punch (1986) comments that, for fieldworkers conducting fieldwork 'at home', this is no less the case. Although I realised that the issue of growth and change was contested, it was sometime before I appreciated the extent to which it formed the basis of many tensions within the organisation. After several months at the Council, I began to notice that, although people involved in the Oliver Smith Council had a lot to say about the changes and growth, it was not a topic which was always available for open discussion. Occasionally volunteers and staff began to look over their shoulder, to make sure no one was listening when they told me their thoughts on the matter.

The words of Gwen and Sam suggest a concern as to the place of community in a community organisation. Based on my observations and discussions during my fieldwork gradually I began to realise that the tensions within the organisation were based on a fear that the organisation was *losing* the community. Kate, who is a staff member at the Council, captures this concern in the following passage:

> *"It's a community organisation [but] the doors are locked! It's something I've argued about many times – don't lock the doors! As an affected community member as well as a staff member here, I wouldn't come here if I had to ring bells to come in, I like to walk into a service. It's not the same place it used to be – it's not as personal as it used to be for people, the volunteers are not as empowered, it's not as empowering for them. I feel like community is being left behind, because that's how it is, the further up corporate the ladder [we go] and the more of peak body stuff we get into, the more bureaucratic we become. It's just a way that things happen, so community get left out. Yes we have the information lines where people can ring, and that's a great service, and we have individuals like myself who go out and do [work], but we're really looking more at working with workers, educating workers, doing everything with workers, rather than working with community ourselves. Which I can see the wisdom behind that, but it sort of leaves community floating a little bit because there's no other body here for them to pick up what the [Oliver Smith] Council use to do… I understand that you've got to move on but [sentence trails off]"*

My questioning and probing of the idea that the organisation might be 'losing community' stirred the tensions within the organisation and brought to – or perhaps allowed them to come to – the surface. It began a very turbulent and difficult process for both the Council and me.

Leaving the field

At the start of my research I conducted what could be described as several unproblematic months of fieldwork. There were, of course, the normal questions and explanations: What is anthropology? Why do you have a notebook? Are you really staying here for a whole year? It's the study of people and culture; So I can remember what you've told me and showed me; Yes, that's how long it will take for me to gain an appreciation of your lives here.

Several months into my fieldwork, at Christmas time, I decided to take several weeks leave when the Council was shutting down for a period over Christmas. I explained to my participants that I was going on leave but would be back in the New Year and that I looked forward to spending time with them again when I returned. When I exited the field I felt triumphant; I had negotiated the initial shaky stages of fieldwork and a 'workable' fieldsite awaited my return.

Unfortunately, upon my return I found that I had been mistaken. I am uncertain whether my absence perpetuated the state of anxiety regarding my research that I found at the Council upon my return, or if the types of events and conversations which took place when I re-entered the field would have occurred in time, regardless of my presence or absence. I suspect that the answer to this is both. The problems that occurred between my participants and me would have arisen in time irrespective of my absence; however, in my absence workers who were concerned about my research were able to be vocal about their hesitations and rally support.

The following excerpt from my fieldnotes explains what happened when I returned from leave:

Fieldnotes. Oliver Smith Council 20/01/06

Return to fieldwork after annual leave – I entered by the back door as I felt more at ease approaching the organisation after my prior months of fieldwork. The manager, who appeared genuinely surprised to see me, greeted me at the door. I have not seen the manager for several months as during my time at the Council he has largely been on sick leave. He escorted me inside the building and directed me into his office whereby the following scene took place.

Once inside his office the manager took his seat behind the desk, and motioned at a chair sitting along side the desk. He then picked up a file that had my name on it. The manager begins by telling me that several people, some staff, some volunteers, feel confused about my role at the Council. They thought I was going to be a volunteer, but I am not behaving like other volunteers.

I had previously wondered if this issue might need to be discussed again. Initially I had suggested that I undertake volunteer work so that I could begin to build relationships with my volunteer participants. However, when I began fieldwork several staff members were excited with my 'resource' potential and began to think up special jobs for me. These jobs, however, seemed to be solitary affairs. I explained to the manager that being embedded as a volunteer, and undertaking solitary volunteer tasks would prohibit me from conducting the research that I was there to do.

He nodded and shifted to the next issue: Several volunteers feel that the note-taking is a problem.

In order to overcome these points of confusion the manager then suggested that we needed to repeat the staff and volunteer information sessions which took place when initially setting up the research project.

At this point in the conversation he called Gail, a senior staff member, to join the conversation. Gail reiterated the manager's concerns, adding that these sessions should explain to everyone the benefits of ethnographic research, as most people were not familiar with it and were more used to the idea of interviews.

The conversation ended by the manager suggesting that Sam be present for these sessions and any further negotiation between the Council and me, as she is "very good at guiding people through these processes". To me, this also seems to be a good idea. However, Sam is away for three weeks and I am keenly aware of losing time. The manager walked me to the front door of the building and said that we would talk again when Sam returned.

I've been kicked out of the field!

This excerpt highlights the first of several key miscommunications between the Council and me. Initially, I had agreed to be embedded as a volunteer in the organisation. I made this decision because I thought that partaking in volunteer work would afford me opportunities to 'participant-observe' with the volunteers at the Council. However, when I began volunteering, I was given solitary tasks which inhibited rather than facilitated my research. Consequently, I quickly resigned from my volunteering role and opted for 'helping-out' in more general, yet social, ways. For example I would assist with 'mail-outs' where several people pack, stamp and seal envelopes for distribution. Volunteers never indicated that they did not understand this role change, and seemed nothing but appreciative of the help I did offer. Having said this, I quickly learnt that channels of communication between volunteers and volunteers, and staff and volunteers, (and presumably between volunteers and me) are often far from straightforward. To this day I remain confused by the disparity between what volunteers said to me and their sentiments as relayed by staff.

During my time out of the field I was encouraged by colleagues to reflect on what my removal from the field said about my fieldsite and participants. In my fieldnotes I noted the following concern – *When discussing my concerns and hiatus from the field with more experienced anthropologists they reiterate the same point; my removal from the field speaks volumes about my fieldsite. However, I cannot help but find that Punch's (1986) comments resonate more strongly – that such cynicism is the luxury of those who do not have the pressure of producing a thesis.* Indeed, at the time, I was more concerned with feelings of uselessness induced by the days spent trying to find tasks to occupy myself while waiting for Sam to return and for conversations with the Council to begin again. Later, when reflecting on this stage of the fieldwork, I came to appreciate my colleagues' comments. The uncertainty and nervousness with which I was received, and that I appeared to induce, is certainly indicative of the organisation's feelings of vulnerability.

The second issue of note taking, raised by the fieldnote excerpt above, is perhaps more common for anthropological fieldworkers (O'Reily 2005; Punch 1986). As Gail once phrased it to me, "*That fly on the wall thing*!". At this stage it seemed like a minor hurdle, which could easily be overcome by communicating my role and, more generally, the principles of ethnographic research. Once Sam had returned, this is indeed how we began to solve the problem. Sam organised a meeting with workers where I would be able to explain my project and my methodologies. She encouraged me to include accounts and examples of how ethnographic research had been used, and how it had benefited participants in the past. This meeting took place and taking Sam's advice I explained in detail ethnographic fieldwork, drawing strongly on the work of Bourgois (2002) to illustrate its use and utility in stigmatised, injecting-drug-user communities. I strongly emphasised participants' rights in ethnographic fieldwork, steps that can be taken to assure confidentiality, and attempted to explain my own understanding of consent in research. In particular I tried to emphasise that I understood their consent to be fluid, that some times and topics may be off limits, whilst others may not and that both of these may shift during the research process. A written copy of this presentation can be found in the appendices (see Appendix One).

What followed my explanation could only be described as serious cross-examination. I was shocked and unprepared for this level of tension and interrogation. When I left the field over Christmas I thought that my participants and I had established firm relationships. I could not understand when this level of animosity towards my research activities had occurred – if it had been there before I took leave how could I have been oblivious to it? To further compound my surprise this questioning came not from volunteers, as I had expected after my conversation with the manager, but from two staff members. I was shocked again when a senior volunteer began to defend my actions. Even now, at the conclusion of the research when participant-researcher relationships have been well mended, I am unclear on the exact processes which led to my first expulsion from the field.

Despite the obvious tension in the room, with my supervisor as a mediator we managed to arrive at several compromises that would enable the research to continue. Firstly, that I would no longer have my notebook with me; and secondly, that I would always ask if it were appropriate and convenient for me to observe or participate at various events and times. However, I would soon find out that the presentation I had given only served to exacerbate matters.

Prior to the meeting, I had decided, in discussion with my supervisors, that this presentation offered an opportunity to explain that my research focus had shifted. No longer was I principally concerned with discrimination; although that was a facet of the hepatitis C experience which was still influential, integral and important to the new research, focus had now shifted to the organisation. By the end of the meeting, although its progress had been tense, I felt that between my supervisor, Sam, and myself, we had succeeded in quelling the concerns of workers, at least to the extent that I would be able to return to the field. Indeed, Sam and I organised a strategy for my gradual re-entry. This included a 'formalising' process of my positioning in the organisation, such as being given an office space and pigeonhole, and I was also encouraged to allocate specific times when I would be present in the organisation.

Blurring lines – the field & university life

This process of re-entry to the field was short-lived. Shortly after organising my return to the Council through a variety of sources, including the Council and contacts at the University, I became aware of small scholarship prizes for students working in HIV/AIDS and hepatitis C areas. Application for the scholarship required a short abstract of the research project. In accordance, I wrote a summary which encapsulated the new focus of the project. Until this time I had been operating under the misapprehension that my life in the university was separate to my life in the field. However, I quickly learnt that, when conducting ethnography 'at home', compartmentalising in this way is not possible.

The actions which I took in regard to reformulating my research project – predominately the decision to change the research focus, my explaining it to participants, and my abstract written for the scholarship application – did not seem to me in anyway subversive, dishonest or unethical research decisions. In my understanding it is common for qualitative projects, especially at a graduate student level, to shift in focus after commencement (O'Reily 2005). Furthermore, senior academics from anthropology assured me and my supervisor in Public Health that this was common territory for anthropology and was unproblematic. One only need pick up any 'How To Do Fieldwork' textbook to read about similar scenarios (O'Reily 2005; Fine 1993; Punch 1986). However, retrospectively, it is clear how these decisions damaged relationships and created researcher-participant rifts which proved to be largely irreparable.

Before submitting the summary for the scholarship I sent the abstract to Sam; as part of facilitating my re-entry into the field Sam wanted to distribute a summary of my research to workers at the Council. The next day the manager of the Council approached me, abstract in hand, and explained that my actions were potentially undermining and embarrassing for the organisation. The institutional body offering the scholarships was the head research body in

HIV/AIDS and hepatitis C in the country. It is therefore an organisation to which the Council is well known, and is in contact. The manager felt that had I sent the abstract, when he had not been made explicitly aware of the change in research focus, it could potentially reflect badly on the organisation. He also informed me that, due to the change in focus, the new project would have to be discussed with the Council Board. By shifting the focus of the research onto the Council, the organisation had to conduct its own risk-management procedures. This assertion by the Council Board was fair because although I was able to guarantee confidentiality and discretion with regard to individual's comments, both internally within the Council and at an organisational level I was unable to guarantee anonymity. Ellis (2005), O'Reily (2005) and Punch (1986) rightly note that insiders can identify individuals involved in research. For the Council this represented a major concern with regard to its relationship with the State Government (see also Israel & Hay 2006). Furthermore, I now understand that, for many at the Council, the change in research focus undermined the trust which had been established between myself and the organisation. The manager informed me that I should come and meet the Board the following week, and that my research activities should cease until this new matter had been resolved.

Leaving the field - again

Fieldnotes. Oliver Smith Council Board Meeting. 29/03/06

It's a Tuesday evening and I have just finished a meeting with the Council Board to discuss changes to my research project. The manager's discussion with me about attending this meeting, and my informal discussions with Board members before the meeting commenced left me with the impression that this was not to be a problematic affair. Certainly not something which could stop the research in its tracks.

When I walked into the meeting I was confronted with a large table, surrounded by people. Each one of them had a copy of the summary abstract I had prepared for the ASHM scholarship submission, and a copy of my original (lengthy!) research proposal. I was totally unprepared for this scenario. Whilst I provided the manger of the Council with a copy of my research proposal before commencing research, it had not been given as a formal document of my conduct and intentions whilst researching at the organisation. Rather, my supervisors and I had regarded the documents as an internal, academic exercise. I wonder how classical ethnographers would have fared had, for example, the Trobrian Islanders had a copy of their research proposals?

The Board asked me to explain the two documents and how the research had changed. It was evident that they felt that this was not only a substantial shift in research focus, but an entirely new research project. I explained that from my perception this was not the case, that in actuality I was staying in the same location, talking to the same people, and asking many of the same questions. Vulnerability in regard to funding was raised as a major issue now that the focus had been turned on the organisation itself. I stammered, replying that the thesis could always be kept from the public eye through an embargo...

The following day I received a letter from the Council Board detailing the requirements and steps which needed to be taken before any research activities could continue or be recommenced. This event resulted in my second absence from the field, an absence from which I never returned as an ethnographer. The letter from the Council Board requested the following: the re-formulation of a research proposal, the regaining of consent from all participants, assurance from the University ethics committee that a new ethics proposal was not required, the establishment of a Research Reference Group, and the right of the Board to embargo my thesis or material published about the Council. A copy of this letter can be found in Appendix Two.

This letter marked the start of many negotiations between the University and the Council, the ethics committee and me and, perhaps most importantly, between my supervisors and me. Although the requirements of the Board were time-consuming, they were able to be, and in due course were, completed. However, the letter brought the viability of the project into question. Two issues in particular appeared detrimental: firstly, what would be the damage to my academic career if I could not publish material from my PhD? And secondly, if I had been forced to halt ethnographic fieldwork twice, would it be a continuing problem? My supervisors and I debated various options: Could the project be moved to another Council? Perhaps another organisation in the sector? Maybe interstate? None of these options lent themselves to a straightforward or timely completion. With regard to pushing the project ahead in its current form at the Oliver Smith Council, the stakes, as it were, appeared too high.

As a final option my supervisors presented me with the suggestion of changing my PhD candidature to a Masters degree and complete the project with literary, rather than empirical, research. At the time this suggestion caused me great distress: it changed not only my immediate project but shattered all my professional plans for the coming years. In particular I was concerned with whether I would find funding to undertake another PhD at a later date. With time and careful consideration I concluded that, despite the personal costs, changing to a Masters degree was the most plausible option for the completion of the project.

However, I was loath to part with the data I had collected; I felt strongly about what I had learnt at the Council and that, for their sake and my own, it should not be lost. I felt that if I could retain the data from my fieldwork and combine it with interviewing data from a range of workers, that I would have enough information on which to write a Masters thesis. Through long and careful negotiation between my supervisors and senior staff at the Council we decided that this was how the project would progress. In accordance with the demands of the Board a new research proposal was written, along with new information sheets, consent forms and letters outlining the change in project. After much deliberation it was decided that multiple information sheets and consent forms were required to obtain permission to retain previously collected data and future interviewing data (these can be found in Appendix Three along with relevant documentation from the University Ethics Committee, the final agreement between the University of Adelaide and the Council Board regarding publication. Appendix Four contains the interview schedule, and letters and consent forms given to Council workers). Lastly, the manager suggested that we establish a Research Reference Group comprised of Council staff and Board members to discuss the development of the research, concerns which may arise, and to review work (see Appendix Five for recruitment form and terms of reference). Upon reflection, I believe that this step was the most important of those taken to save the project and I am grateful to the manager for his thoughtful recommendation. Not only did the Reference Group help to calm the concerns of workers, but it also provided an open forum for discussion of ideas and findings.[16]

The process of negotiating the change in my project took considerable time and effort on behalf of my principal supervisor, the manager of the Council and Sam, the senior Council staff member discussed earlier. Whilst negotiations and discussions were often complicated and time-consuming affairs, it is the dedication and investment of these people that enabled the research to not only continue, but also to be completed.

Reformulating the project

Sam and I organised that I would spend time at the Council to begin to rebuild rapport after my time away. When I returned to the Council to help volunteers and with the job of re-issuing consent forms, information sheets and letters, a situation, which was complex and difficult to explain, was further compounded by a rather unexpected turn. Very few people knew why I had been absent for the last four months. My surprise and frustration is best demonstrated by my fieldnotes at the time:

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[16] Whilst some texts on fieldwork imply that "scholars often have to go out of their way just to get a reaction out of the people they studied", in my experience I have found the opposite to be true (Lofland & Lofland 1984: 158; Ellis 1995).

Fieldnotes 20/06/06

Returning to the Council yesterday and today has been difficult – it appears that no one has been told the real reason for my absence, rather they seem to think I have either ceased the project or been on holiday. Even staff members who I was sure would be 'in the loop' appear to have no comprehension of where I have been. Similarly, many volunteers have been asking where I have been all this year. This has placed me in a very awkward position; I am not sure if I am allowed to tell them what has been going on. I find it perplexing that Board decisions and activities seem to kept secret from the rest of the organisation. Why has no one explained where I have been and why? Have they decided I should explain, or am I prohibited from doing so?

I feel that this places me in an extremely awkward and difficult situation. By saying nothing I undo the rapport and trust that I have built with workers, especially volunteers. It must appear to them as though I rather uncaringly vanished and that my activities have been, to an extent, dishonest. Certainly several volunteers seem uncertain about return and attempting to sidestep their inquiries does not help the situation. Neither the Board or the manager has not told me whether or not I am permitted to discuss the reasons for my absence. Whilst on the one hand I do not want the trust and relationships I have established to be damaged, my relationship with the Board is of equal importance to the continuation of the research and I am conscious not to jeopardize this now we have reach a (delicate) understanding.

While I believe that my alternating, and prolonged, absences from the field damaged my credibility as a researcher and my relationships with my participants, these negatives were ultimately balanced out by extinguishing the possibility that I was a 'threat' to the organisation. When I was in the organisation on a daily basis, asking about how it had changed, I was a daily reminder of the concern that the organisation may be 'losing the community', emphasising feelings of vulnerability. By conducting interviews outside the daily life of the Oliver Smith Council, participants were able to reflect and consider their experiences and opinions concerning the organisation's growth and change. My participants and I were now able to explore the place of community in a community organisation more freely, without fear of interruption or interference in the functioning of the organisation. Furthermore, the change in research methodology subsequently resulted in a change in the research relationship. I no longer felt as though I was the lone researcher in a foreign world. Rather, through both interviews and the Research Reference Group, participants and I began to explore their social world together and help each other to understand the meaning, symbols and language which characterised it.

ETHICAL CONSIDERATIONS

Guillemin and Gillam (2004) suggest that being reflexive in qualitative research involves more than consideration of the epistemological aspects of research, such as why we choose to research particular research questions, and why we approach these questions with particular methods. Being truly reflexive involves consideration of the entire research process. Inclusive in this is asking questions about researcher-participant relations, and questioning who it is that we research for. In this section I offer a discussion of these broader considerations.

Many ethnographers voluntarily feed material back to their participants, either out of courtesy or for validation, and attention has been given to the complexities of this practice (see, for example, Forbat & Henderson 2005, Stake 2003 Janesick 2003, Ellis 1995, Emerson & Pollner 1988, Bloor 1983). Through sharing findings and analysis with my participants, this research touched on many of the complexities experienced by other qualitative researchers. However, this project presented additional intricacies in that participants fundamentally shaped the research project – from methodology to ethical practices as well as intense discussion of results. It is worth noting that those involved in action research may encounter this level of participant involvement – in action research participants and stakeholders are regarded as collaborators rather than subjects (Lofeman, Pelkonen & Pietila 2004).[17] However, action research differs from this project in several significant ways. Firstly, research usually centers on problems identified by stakeholders before the research has begun (Greenwood & Levin 2003; Hart & Bond 1995; Somekh 1995). Secondly, participant and stakeholder involvement and collaboration is organised structurally and is part of the research proposal

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[17] Action research was first developed by Kurt Lewin (1949) as a means to refer to the generation of knowledge about a social system whilst attempting to change it (Hart & Bond 1995). The roots of action research lie in criticisms of positivist approaches to social science, however it also draws upon a variety of methodological and theoretical principles including pragmatism, interpretivism, critical theory and postmodernism (Hammersley 2004). Hammersley (2004: 165) describes the core feature of action research as "an intimate relationship between research and some form of practical or political activity – such that the forces of inquiry arises out of, and its results feed back into, the activity concerned".

and plan, designated before the commencement of the research.[18] Lastly, action research is a cyclical process (Hammersley 2004; Morton-Cooper 2000; Hart & Bond 1995).[19]

The closest approximation to my field experience is that of Alan Benjamin (1999), outlined in '*Contract & Covenant in Curaçao: Reciprocal Relationships in Scholarly Research*'. Benjamin, like myself, was bound by a strict contract to a governing Board throughout the duration of his ethnographic research. Similarly to my own, Benjamin's contract governed not only his conduct while in the field, but also what he wrote about it after he left. There are, however, two significant deviations in our fieldwork stories – on a minor note, Benjamin needed to submit only written text for approval, whereas I must gain approval on verbal presentations. A far more significant deviation in our experiences is that Benjamin negotiated his contract *before* embarking on research, rather than having it arise out of difficulties encountered during the research process. I propose that this is why he was able to continue with ethnographic fieldwork where I was not.

Of his fieldwork experience Benjamin explains:

> My fieldwork experience presents a challenge to anthropological – and by implication, to scholarly – authority. In effect, board members said that having a 'voice' in ethnographic productions about them was not enough; relying on the sensitivity of ethnographers was not enough; and the reciprocal relationship... normally established during the course of participant-observation was not enough for them. They insisted on the right to determine for themselves the acceptability of all material that I publish about them.
>
> Benjamin 1999: 50

These same remarks can be made of my own fieldwork experience: the Council Board and workers felt that these agreements needed to be formalised. This formalising process left me and my research restricted. Fox (1999) comments that she would not have consented to undertaking fieldwork in these conditions. Similarly, it would be dishonest of me to deny that at certain stages during my research I have felt frustrated, exasperated and generally annoyed, not necessarily by the actual demands of my contract, but rather by the 'tethering' nature of it

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[18] Action research presents its own ethical dilemmas concerning consent, the role of the researcher, ownsership of the research and the power relations involved in the research process (Khanlou & Peter 2005; Lofeman, Pelkonen & Pietila 2004; Hammersley 2004).

[19] "Lewin portrayed action research as involving a spiral process in which hypothetical solutions to a problem is formulated and tried out, its level of success monitored, the proposed solution reformulated in light of this, the new strategy implemented and assessed, and so on." (Hammersley 2004: 166).

and what felt at times like an underlying hostility towards my presence, and towards research more generally.

Having said this, upon conclusion of my research my instinctive reaction to Benjamin's statement is as follows: If we anthropologists were being studied, would we not make these same demands? Ethically speaking, is it not the right of the participant to make sure that the research has no adverse effects on them, and are they not in a better position to judge this than an ethics committee? In addition to Benjamin's comments regarding scholarly authority, by requesting multiple rounds of information sheets, consent forms and information sessions far beyond the requirements of the University Ethics Committee, my participants also challenged the belief that formal academic ethics processes are adequate for protecting the interests of research participants. Their actions reflect an underlying sentiment that they, as research participants, were best placed to understand the threats and risks of the research.

Guillemin and Gillam (2004) draw a distinction in ethical matters between 'procedural ethics' and 'ethics in practice'. Procedural ethics refers to the formal ethical processes presided over by ethics committees, such as gaining informed consent. The principles of procedural ethics and the notion of informed consent developed out of biomedicine and the need to protect individuals taking part in medical research. Gradually, these standards have been extended to encompass all research involving humans, including social research (Israel & Hay 2006; Guillemin & Gillam 2004). Ethics in practice refers to the more day-to-day ethical considerations which occur as a matter of course during the research process. These ethical dilemmas occur 'in the field', far from the assistance of the University Ethics Committee and the particulars of informed consent (Guillemin & Gillam 2004).

Many social scientists (Israel & Hay 2006; Broom 2006; Guillemin & Gillam 2004: 272; Fine et al 2003; Goodwin, Pope, Mort & Smith 2003) argue that a greater emphasis needs to be placed upon ethics in practice, as the "potential harms to participants in qualitative social research are often quite subtle and stem from the nature of the interaction between researcher and participant".[20] Guillemin and Gillam (2004: 275) contend that it "is in these interactions that the process of informed consent really occurs… not on the pieces of paper that an ethics

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[20] Broom (2006: 154) contends that "researchers should constantly review the degree to which [participants] are willing to provide information". Indeed Israel and Hay (2006), Broom (2006), Goodwin (et al 2003), and Punch (1986) all note that often consent and ethically complicated scenarios are best dealt with situationally, rather than procedurally.

committee peruses" (see also Goodwin et al 2003). In everyday encounters "lie the possibilities of respecting the autonomy, dignity and privacy of research participants and also the risks of failing to do so" (Guillemin & Gillam 2004: 275; see also Broom 2006, Goodwin et al 2003, Christians 2003, Homan 1991). Thus, there is often a disparity in perspectives between ethics committees and social researchers (Hoeyer, Dahlager & Lynoe 2005; Bosk & De Vries 2004; Guillemin & Gillam 2004; Christians 2003; Hannigan & Allen 2003). While academics have commented on this gulf between the procedural ethics of committees and the ethics in practice of researchers, my research project presents a different challenge in that my *participants* became concerned with procedural ethics and shaped and governed the research process accordingly.

Much like the disparity of perspectives between social scientists and ethics committees, the Oliver Smith Council Board and at least some of the other workers at the organisation had a medical, or procedural, understanding of the consent-giving process in research. This may have occurred due to the pervasiveness of medical discourse. Many of the Board members and workers at the Council had taken part in clinical trials, or at least had substantial negotiations with medical professionals and institutions either through having hepatitis C or being involved in the sector, and at least two individuals were medical practitioners. They therefore already had a working understanding of the researcher-participant consent process. However, this understanding was based on a comparatively rigid, bio-medical model of consent such as that supported by ethics committees, whereby consent is sought for a specific purpose, process and outcome. This is a phenomenon which is not confined to the individuals who sit on the Council Board; what were initially conceived as ethics procedures for bio-medical research have increasingly come to represent the standard for all types of research involving humans (Israel & Hay 2006; Fine et al 2003; Christians 2003; Guillemin & Gillam 2004; Homan 1991; Punch 1986). Whilst, arguably, social research and social science models of consent are still in the process of being created and refined, they are by nature more fluid than their bio-medical counterparts (Israel & Hay 2006; Fine et al 2003; Christians 2003 Guillemin & Gillam 2004; Homan 1991; Punch 1986). As a social researcher entering the field, I understood consent to be negotiated on a day-by-day, conversation-by-conversation basis. In other words, I was concerned with ethics in practice. My participants and the Board, however, were concerned with procedural ethics, and consequently considered consent to be a more 'black and white' affair, whereby consent is given for a specific project and process when an individual signs a consent form; hence the need for multiple rounds of consent. This disparity in our concerns – between procedural ethics and ethics in practice – elucidates some of the difficulties that arose during the course of my research.

For some researchers my project may raise, once again, the debates of the 1960s regarding how overt researchers should be about their research intentions. Many ethnographers contend that researchers should remain vague about their intentions upon entering the field (Punch 1986). After all, we ourselves are often vague about our intentions until well into the research project (Fine et al 2003; Fine 1993; Punch 1986). Similarly, Goffman (1989: 126) suggested that one's story need only 'hold up' if brought to the attention of informants. Although one could argue that being less defined about my research topic might have afforded me greater access to the field or allowed my ethnographic research to continue, ultimately this type of subterfuge is characteristic of more classical ethnographers and is contradictory to the goals and objectives of the more applied, public health orientated research which I aimed to undertake. Such research should not compromise the well-being of participants, even if the alternative means acquiescing to participants' decisions regarding what will, or will not, be damaging.

These ethical considerations are intertwined with questions of research integrity. On the one hand, research subjects have the right to know what they are taking part in, how it will be carried out, and what will be written. However, some researchers question whether involving participants in all levels of research undermines its integrity – it is no longer 'clean', or may be 'skewed' (Fine 1993). In the case of my research, the notion of the detached scholarly account is not only challenged but demolished. Through the difficulties in fieldwork, and the subsequent negotiations and arrangements, my participants and I explored their social world together to create research findings which were meaningful and acceptable to both of us. But, rather than sullying the research, I contend that this has enhanced its integrity; it means that the research, ultimately, must be meaningful to those who took part in it, rather than to academics and scholars largely abstracted from the day-to-day reality of these people's everyday lives. Benjamin questions whether or not this should be a basic right of all individuals who take part in research:

> The people being studied often are perceived as a threat to the integrity of research, but the subtle, hidden threats of researchers and research toward those studied is 'solved' conveniently by the signing of informed consent forms – a procedure limited in scope and replete with its own problems. Researchers too often expect the trust of those they study as their due, yet seem to find it difficult to extend the same trust to those studied.
>
> Benjamin 1999:61.

I support Benjamin's claims, and contend that when trust becomes reciprocal the integrity of the research is enhanced, not undermined.

With regard to the process of negotiating and sharing findings, like Benjamin, I was initially concerned that anthropological and sociological terms and theory would prohibit or present challenges to the acceptance of my work by both the Research Reference Group and the Board. While, at the time of writing, the Board has not reviewed or seen my work, apart from the members who sit on the Reference Group, all chapters except the most theoretical have been reviewed and discussed by the Research Reference Group. When I have discussed with colleagues how my work has been received by the Reference Group I often tell the following anecdote: when reviewing a thesis chapter of mine Gail once turned to Sam and said "*Do you feel* ***continually*** *pulled between civil society and the state?*", to which Sam replied "*Continually… hmm… I would say I* ***often*** *feel pulled between civil society and the state*".

The lesson I have learnt through the Reference Group is that allowing people to engage in all stages of the research process is likely to create a richer, more meaningful account. This is particularly important for this type of public health research, which has a focus on reciprocity and positive change. Through the establishment of the Reference Group my assumptions, perspectives and conclusions have been discussed, debated, enhanced and validated by being workshopped with those whom the research is about. This workshopping process has had significant effects not just upon my work, but also on that of the Council. For example, after circulating the material found in Part Three of this thesis, workers at the organisation changed the spatiality of the Council. These changes included amendments to the internal layout of offices, but also the shifting of the entire resource volunteer section from downstairs to the lower meeting room at the rear of the Council building. This establishment of reciprocal researcher-participant relationships, I believe, can only strengthen the integrity, validity and utility of research and research outcomes. Indeed, these principles underpin applied methodologies such as action research (Morton-Cooper 2000; Hart & Bond 1995;

Somekh 1995). I do however feel impelled to point out that, for this to occur, one must be willing at times to swallow one's scholarly pride!

While I believe that the completion of the project is not just a tribute to all those who became invested in it along the way – and in its own way it can be deemed a success – it is clearly not without its missed opportunities and regrets. Most of these I have already touched on, but one, which is particularly unfortunate, is that in the wake of my project I have undoubtedly left confusion and, perhaps for some, even mistrust. Benjamin (1999) believes that his contract eased the tensions and concerns of the research participants. In the case of my own fieldwork experience, I have found the opposite. The discussions that occurred at a Board level never fully filtered down to workers in the organisation. This issue, more generally, was often raised in interviews; workers, especially volunteers, felt distanced from the Board and Board decisions. I believe that the Board's consent procedures were not successful in relieving this confusion. Even at the time of writing, when I visit the Oliver Smith Council some workers ask what my next project will be and when I will be coming back to talk to them again, despite the multiple presentations and explanations of the past; when I explain that it was all one project and that I am now writing a thesis they still look genuinely surprised to hear this news.

For me, the myriad of methodological and ethical quagmires that this project raises are encapsulated by the following question – who is it that we research for? For academics who believe that we research for the pursuit of knowledge, with an objective scholarly gaze and authority, my project and its methodology may be confronting to the way in which such researchers go about thinking and doing research. Those who are more applied in their orientation and who adhere to the notion that research must first and foremost be meaningful to those who take part in it – not just at a theoretical level but at a intrinsically practical one – will appreciate that my project is a difficult and messy yet determined step in this direction.

UNDERSTANDING THE RESEARCH PATHWAY

In my discussion about finding a research pathway, I mentioned that the foundations of many of the difficulties which my participants and I encountered during the research processes continually eluded me. While at the end of the research journey I still do not understand all the starting points for the tensions of my fieldsite, through the process of analysing my data many of the reasons that such difficulties arose have become clearer. Indeed, my turbulent research journey is reflected in, and at least partially explained by, the major themes of this thesis.

As I discussed in my description of 'first encounters', boundaries exist between community organisations and civil society; some people belong inside, and others belong outside. These boundaries are necessary for the organisation, both in order for it to function and also to define what kind of organisation it is; such boundaries form the parameters of the organisation, both physically and ideologically. In the discussion provided earlier of my first impressions of the Council, I stated that where these boundaries are placed and how they are formed is a point of contestation for community organisations. Upon reflection, I believe that it is the placement, and crossing, of these boundaries that led to difficulties and tensions during the research process.

For many workers at the Council it has been, and continues to be, important that the Council acts as a safe space and protected environment for people affected by hepatitis C. As the reader will discover throughout this thesis, there is often a sense at the Oliver Smith Council that inside the Council walls is a safe space to disclose without fear of discrimination or recrimination. However, outside the Council lies uncertain territory where people affected by hepatitis C might be marginalised and discriminated against. While at the end of this project it is evident that gradually the boundaries of the organisation are beginning to shift, and individuals who are not affected by hepatitis C begin to find comfort, compassion and roles within Council walls, at the time I began my research such boundaries were more solid. As an individual not affected by hepatitis C I was not only an outsider to the social world of the Council, I physically belonged outside of the organisation; by entering the organisation on a long-term basis I was crossing the boundary of who belonged inside the organisation. This dangerous outsider status was compounded by my role as a researcher; if the Council was a safe space for people with hepatitis C to escape the threats of the wider world outside, I represented a danger entering the organisation. I was not affected by hepatitis C, and to compound this I wanted to research, analyse and examine people inside the Council. In anthropological terms, I was 'othering' them inside the organisation, as they had been 'othered' outside in the community (O'Reily 2005; Vidich & Lyman 2003). For some workers within the organisation, I believe that this sense of being 'othered' in a space which was meant to be safe, was an unsettling experience which gave rise to the kinds of difficulties I explained in my discussion on 'Finding a pathway'.

The foundations of the tensions which occurred between the Board and myself, were gradually elucidated to me as I developed the major argument of this thesis. Authors (such as Brown 1997 and Altman 1994) have commented that it is difficult for third sector organisations to maintain relationships with both civil society and the state. Furthermore, authors have conceptualised these organisations as at risk of either being dissolved, or consumed, by the state. These concerns in the literature were mirrored in the praxis of the Council when my research began. Consequently, the reader will notice in the later chapters of this thesis where an actor-orientated account of workers experiences and perspectives is provided, that there is a sense of vulnerability about the organisation and its relationships with civil society and the state. For the Board, I represented a further destabiliser to their space between civil society and the state. Through my research I may have undermined their relationship with state government, had I represented them in an undesirable light.

CONCLUSION

At the end of my research journey I do not profess to know all the reasons for my turbulent research experience, nor have I been privy to much of the reasoning of the participants in this study. However, through gaining a greater appreciation of the challenges and complexities that community organisations face, and through 'looking back' on my research pathway, I feel that I have begun to understand the difficulties of researching the place of community in a community organisation.

In this chapter I have described my research journey and the reasoning behind methodological decisions and changes. Through a reflexive discussion I have considered the practical and ethical implications of what occurred during my research, both for this project and for ethnographic and qualitative research more broadly. Through constructing my methodology as a personal narrative, and reflexively examining how I decided upon my area of research, I have aimed to articulate my orientation to the arguments I make in the following chapters.

Part Two

Thinking About Community

'Community' is one of those words – like 'culture', 'myth', 'ritual', 'symbol' – bandied around in ordinary, everyday speech, apparently readily intelligible to speaker and listener, which, when imported into the discourse of social science, however, causes immense difficulty. (Cohen 1985: 11).

Thinking about community

Introduction

This thesis explores the third sector's positioning with regard to civil society and the state. This is achieved through an exploration of workers' ideas about community and their experiences of the space of the Council, as these concepts of community and spatial experiences are strongly shaped by the third sector's positioning between civil society and the state. Furthermore, these two concepts are interrelated; workers' experiences of the spatiality of the organisation are shaped by their perceptions of community. Workers are concerned that the organisation is shifting away from civil society and becoming too closely aligned with the state, where it may lose the values which distinguish it as a community-based organisation in the third sector. These perceptions and concerns about community are also exhibited spatially within the organisation. They affect how the organisation's spatiality is changing, and how it is experienced by workers. In Part Three of this thesis I demonstrate how these themes are interwoven in the praxis of the Oliver Smith Council. Firstly however, for the purposes of clarity, I will consider the theme of community separately.

In Chapter One I discussed how third sector organisations are placed between civil society and the state. Such organisations develop *out* of civil society, and often retain links with community groups *in* civil society. Over time, these organisations often attract funding from the state, causing their objectives to become more closely aligned with a government agenda. Third sector organisations therefore need to negotiate and maintain an ongoing relationship with both. In the case of the Oliver Smith Council, this positioning and need to work with both civil society and state apparatus has meant that the work and space of the organisation has become highly contested. In this section I explore this contestation with regard to the work of the Council.

In the first chapter of Part Two I provide a background for exploring the complexities of the Council's work by critically analysing the term 'community'. 'Community' is a fundamental term at the Council; the organisation has formed out of community (or civil society), and maintaining community links is vital to the organisation's self-definition as community-based, its positioning in the third sector, and the work that it carries out. In

Chapter Three I offer an analysis of the term 'community' as it is used both in the literature and by workers at the Council. In Chapter Four I provide an actor-orientated discussion of the Council's work. In doing so, I demonstrate how the perceptions of community, as outlined in Chapter Three, relate to the organisation's positioning between civil society and the state with regard to the work of the Council.

Chapter Three

Thinking about community: The positioning of the third sector

> The term community is one of the most complex and imprecise in the vocabulary of social science (Altman 1994: 7).

CHAPTER INTRODUCTION

The self-definition of NGOs and CBOs as 'community-based' is vital to their positioning in the third sector – being 'community-based' distinguishes these organisations from government and market sectors. Thus, as a key descriptor, the term requires investigation. In this chapter I critically examine the term 'community' from the perspectives of both the literature and the workers at the Oliver Smith Council. In sociological literature, the concept of 'community' has been the subject of considerable investigation and critique by philosophers, sociologists and anthropologists since the 1800s. In this chapter I discuss the different ways in which community has been used, developed and interrogated since its first substantial investigation by Tonnies in the late 1880s.

In this chapter I also discuss how 'community', with regard to being a 'community-based organisation', is used and understood by the workers at the Oliver Smith Council. I argue that 'community' is used by workers as a summarising symbol to represent the values of the third sector. I also examine who is conceptualised as being part of the 'community'; workers at the Council at times understand 'community' as being contained within the organisation, while at other junctures depict it as something which exists outside the organisation. In this chapter I argue that these alternating perceptions of who constitutes the community are demonstrative of the organisation's positioning between civil society and the state.

UNDERSTANDING COMMUNITY

Many anthropologists have noted the 'slipperiness' of community (Amit & Rapport 2002; Cohen 2002; 165; Bauman 1996). They have found it "too vague, too variable in its applications and definitions to be of much utility as an analytical tool" (Amit & Rapport 2002; 13; Cohen 2002; Bauman 1996). This stems largely from ambiguity regarding its definition; in the 1950s Hillery (1955) researched over ninety different definitions in use by sociologists. As a result, among many academics it has been considered a redundant term that "serves more to confuse than illuminate" (Phal 1970: 170; Farrar 2002; Bauman 1996). Studies of communities have progressed from the work of Tonnies and Weber at the turn of the twentieth century, in which the concept of community was grounded in inter-relationships, based on face-to-face interactions, towards a more abstract notion, cast adrift from physical place or physical relationships as in Benedict Anderson's *Imagined Communities*.[21] It is arguable that if one seeks a concrete definition of the term, then community will offer little in the way of an analytical tool. However, if community is approached as a linguistic or semantic tool, in the same way as a symbol which invokes certain meanings and emotions, its utility is greatly enhanced.

Substantial exploration of community can be traced back to the work of Tonnies and Weber at the turn of the twentieth century. Prior to Tonnies' *Gemeinschaft und Gesellschaft* (translated as Community & Society) discussions of community focused on a dichotomising of village and urban life (Tonnies 1887; Brint 2001). Tonnies, however, concerned himself with unfurling the common elements between the two (Brint 2001). Tonnies stressed the "foundational aspects of inter-relationships" (Gold 2005: 3). He presented community as organic, beyond human control, ever-growing and ever-present: community "possesses *by nature* a will and a life force all of its own" (Tonnies 1887: 187). Tonnies' imagery is drawn from the natural world; his 'community' has vegetative qualities (Gold 2005). In *Gemeinschaft und Gesellschaft,* Tonnies creates juxtaposition between community (Gemeinschaft) and civil society (Gesellschaft). In Gemeinschaft he presents an idealised

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[21] Similarly to the concept of space, 'community' has received substantial attention from those exploring nationalism, identity and deterritorialisation (see, for example, Anderson 1983, Appadurai 1995, 2001 & Clifford 1997).

notion of community: a silent connectedness, beyond human control and organic in nature. In contrast, Gesellschaft embodies the qualities of individualistic society.[22] Even in this initial, formative text, one can already sense that community is a term to which many qualities are ascribed; it is notable that these qualities also have a moral dimension (Brint 2001). Tonnies' community is given earthy, organic and positive, almost utopian, descriptors which are emphasised by contrasting the term with the undesirable qualities of Gesellschaft.

Tonnies' Gemeinschaft, which was later embraced by Weber in *Economy and Society* (1978), is distinctly grounded in the physical interactions of human beings. Weber suggests that, as the term is readily applied to a collection of people, it should be "defined by nothing more than this subjective state" (Weber 1978: 40). Whilst sociologists have failed to devise a definition of the term, most attempts emphasise the sense of belonging and inter-relationships as characterised by Tonnies' and Weber's early work (Brint 2001; Brow 1990; Kaufman 1959). Werbner (1996) argues that Tonnies' work restricted the concept of community. However, even after considerable debate, community is still most usually associated with the characteristics Tonnies first assigned the term. Community is often conceptualised as a small group of interconnected people, who share a locale and sense of belonging. As a result, research into community has a tendency to seek homogeneity, both between communities and within (for commentary see Diprose 2003; Secomb 2003; Joseph 2002; Secomb 2000). Many sociologists have sought a definable set of characteristics that indicates a community. Similarly, communities are often constructed as homogenous units. Both of these pursuits have tended to be flawed and unsatisfying as "communities are not... monolithic, undifferentiated entities" (Murphree 1994: 403. See also Diprose 2003 & Secomb 2000).

Community was not liberated from this subjective state of physical interaction until Benedict Anderson's *Imagined Communities* (Anderson 1983). Anderson's 'community' stems from his exploration of nationalism and he offers little by way of a substantial, transferable definition of the term.[23] His term 'imagined communities' stemmed from his

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[22] Tonnies was strongly influenced by Hobbes. Hobbes' social theory strongly influenced his notions of Geimenschaft and Gesellschaft as he perceived such theory to outline a new, competitive society, in contrast to traditional 'communities' (Mautner 2005).

[23] Anderson's work primarily focuses on nationalism and identity and has become prominent due to the debate surrounding globalisation and the blurring of national boundaries (Anderson 1983). His work is frequently cited as a formative piece for such work; see, for example, James Clifford's *Traveling Cultures* (1997) and Ulf Hannerz's *Notes on the Global Ecumene* (1989). Clifford's and Hannerz's work is primarily concerned with the

search for a definitive description of what makes a nation. Anderson's concept of a community as 'imagined' freed the term from previous constraints. In his exploration of national identity Anderson (1983: 6) suggested that all communities are imagined, as even in the smallest nation, members "will never know most of their fellow members". Anderson's work led to explorations of community whereby community was no longer tied to physical inter-relationships, but rather to a collective sense of belonging and identity.[24] Anderson's imagined communities mark a shift from mapping social relations towards understanding (somewhat abstract) sentiments. In liberating community from a base of interaction, its bonds with ethnicity and locality have also been loosened; this is most aptly demonstrated by explorations of virtual communities.[25]

In the search for a transferable definition of the term 'community', it could be argued that we have emptied the term of substantive meaning. We have established that groups which may describe themselves as a community or be described as a community have no set of characteristics applicable to all. To be part of a community one no longer has to be in the same geographical locale as others, share the same ethnic background or, to a lesser extent, culture (Amit 2002). This certainly contextualises Bauman's statement that it lacks utility as an analytical tool. However, despite casting community adrift of physicality, we are still seeking a tangible construct. That is, we are still *looking* for community.

Cohen's (1985) *Symbolic Construction of Community* has been accused of further stripping away substantive meaning. However, he began the exploration of community as a symbolic construction, rather than as a tangible entity. Cohen sets aside structural debates, such as that of Tonnies, and attempts to centre community on a system of values or social norms, which result in a sense of identity and binds its members (Hamilton 1985). Cohen offers an alternate line of inquiry into community to that of Anderson; notably Cohen's community is once again founded in face-to-face interaction. Cohen concentrates on community as a relational idea; it is a means by which to expound similarity and difference between groups (Cohen 1985). Cohen primarily sought to define community as "the meanings people attribute to [it] and their membership in it" (Amit 2002: 4). He focused on identity,

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movement of culture and identity. Anderson's work is also associated with 'imagined spaces', place, locality and nationalism, such as that of Arjun Appadurai (1995; 2001), and Gupta and Ferguson (1992).

[24] Imagined community and identity has enthusiastically been taken-up by those concerned with virtual communities, see, for example, Slater (2001), Rheingold (2000), Stratton (1997) and Poster (1995).

[25] See footnote 31.

belonging and the boundaries of community, which Bauman (1996) suggests resulted in a framework for conveying cultural difference, rather than explaining social practice.

What is common throughout most explorations of community, whether they be theoretically driven or practically based research, is the ascribing of certain values to the term 'community'. In Tonnies' formative work community was given positive, idealised descriptors. Many researchers have commented on the term's linguistic capacity to evoke certain values and emotions; "the word retains connotations of interpersonal warmth, shared interests, and loyalty" (Bauman 1996: 15). Williams (1976) comments that it is never used in a hostile sense; all other descriptions of social organisation can be used with negative connotation, for example state, nation and society.[26] Williams (1976: 66) believes there is an inherent danger in the term as a linguistic tool since it is never used unfavourably, nor given any "opposing or distinguishing term". This lack of distinguishing terms is arguably the result of the term 'community' being used as a symbol. Amit and Rapport (2002: 14) suggests we must "shift away from community as an actualised social form to an emphasis on community as an idea or quality of sociality", as the term requires a "skeptical investigation, rather than providing a ready-made social unit upon which to hang analysis".

Through exploring community as a symbol, rather than a tangible construct, its utility can be regained. Symbols are not necessarily tangible objects. Indeed anything can be a symbol, providing it is the vehicle for cultural meaning (Ortner 1973). Furthermore, symbols are often associated with cultural organisation. If community is primarily used as a symbol for a particular set of values, the inability of researchers to uncover a substantial and transferable definition of the term is certainly contextualised. Many urban ethnographers have been confounded by the repetition of the word community. This is especially so for those involved in advocacy, health and/or government agencies. When continually told of the importance of community, researchers naturally ask "Who is the community? What is this community you speak of?" And, as has been the case for centuries, no definition or characteristics can be decided upon. Farrar (2001; 2002), for example, conducted research in an inner city district of Leeds. He found that the term community was used repetitively with no obvious meaning.

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[26] Similarly, Secomb (2003: 85) states that "if nation is increasingly perceived as a less than honorable institution formed through war, invasion and geo-political territorialisation, and government is widely denounced as the site of political intrigue and the means of subjectification of citizen-voters, community appears to escape this critique and be viewed as an idyllic formation based on bonds of affinity".

Originally (as I also thought when initially conducting fieldwork) Farrar believed community to be an empty signifier, a subject constructed with no content or meaning (1999). He refers to this as the "fantasy of community" (Farrar 1999; 10). However, with time, Farrar grew to realise that the term stood for a set of values in this particular case – intimacy, warmth, and support (see also Olson 2005).

Similarly, Barrett and Parker (2006), in an ethnographic study of a community mental health service, discovered that community was used as a symbol, invoking a variety of meanings. They contend that in their research setting, community acted as a summarising symbol.[27] Summarising symbols are those which draw together a range of values or sentiments in an "emotionally powerful and relatively undifferentiated way" (Ortner 1973: 1339). Ortner uses the example of the American flag, which stands for what she describes as the 'American way' – the flag invokes an amalgamation of sentiments such as democracy, entrepreneurial endeavour, freedom and so on. As a summarising symbol, the flag stands for all of these values simultaneously. It does not encourage differentiation or reflection on individual terms. This, in fact, is the purpose of the summarising symbol: "to compound and synthesise a complex system of ideas" (Ortner 1873: 1340).

Community (italicised to indicate the symbol *community*) is generally associated with positive values such as warmth, inter-relationships and trust. While individual variants exist, as remarked by Williams, their connotations are always positive. The proliferation of *community* (the symbol) is due to these associated values:

> Key lexical terms such as community, nation, culture persist in usage because they evoke a thick assortment of meanings, presumptions and images. This kind of thickness doesn't make for precise definitions but it does ensure that the invocation of 'community' is likely to have far more emotional resonance than a more utilitarian term like group… the resonance of a term like community makes it a useful rhetorical adjunct to a wide variety of public appeals seeking to exploit the terms generally positive connotations of 'interpersonal warmth, shared interests and loyalty'.
>
> Amit & Rapport 2002: 13- 14. Quoting Bauman 1996: 15

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[27] Secomb (2000) and Diprose (2003) advocate for an understanding of community which incorporates diversity, rather than seeks out homogeneity of the past. Whilst Secomb and Diprose's arguments are well founded, they do not have a place in this thesis. In this thesis I focus on how community is understood by workers at the Council. Rightly, or wrongly, these workers adhere to the traditional sentiments of community outlined in this chapter.

UNDERSTANDING 'COMMUNITY' AT THE OLIVER SMITH COUNCIL

> *"[The Oliver Smith Council] is a community-based, community organisation, that reaches from community… it represents community interests… its services are targeted to community, it [is] responsive to community needs"* (Oliver Smith Council worker).
>
> *"community organisation… fuzzy, isn't it"* (Oliver Smith Council worker).

In this section I relate the theoretical assertions, made in the previous section, to the praxis of the Oliver Smith Council. As mentioned, the self-definition of NGOs and CBOs as 'community-based' is vital to their positioning in the third sector. Their community roots distinguish them from market and government organisations. In the case of the Oliver Smith Council, and perhaps in the third sector more generally, the term 'community' acts as a summarising symbol to draw together a collection of values associated with working in the third sector, and being a 'non-government', 'community-based' organisation. That is, as a symbol *community* articulates what it means to be a community-based organisation. In this section I explore what *community* means to the workers at the Council. I also provide a discussion of how workers conceptualise whom the community constitutes. In doing so, I argue that the way in which workers speak of and conceptualise "the community" is indicative of the organisation's positioning between civil society and the state.

The term community is used to invoke a variety of positive meanings, and the Council does not differ here. Similarly to the findings of Barrett and Parker (2006), the term is used as a summarising symbol. At the Council *community* represents an amalgamation of sentiments and terms: these include "supportive", "about-people", 'hands-on' and "welcoming". These sentiments are reflected in the way the Council is described: *"It's welcoming and safe"*, *"It's welcoming, it's friendly"* and *"to me a community organisation is supportive to community"*.

Oliver Smith Council workers perceive being community-based as synonymous with a 'hands-on' approach. Thus one of the sentiments provoked by *community* is 'hands-on':

> *"Here it's all in: there's not that difference between a manager and his staff."*
>
> *"There's a sense of trust that you're doing what you believe in so you're just going to get on and do it."*
>
> *"That grassroots approach, that hands-on approach."*

This list is by no means conclusive; a wide range of positive descriptors are invoked to describe what it is to be a community organisation and part of the third sector, for example: *"[it's about] giving more than your job description ... being enthusiastic... but also being supportive".* As well as being used in conjunction with other terms, other descriptors may also be used in place of the word community, for example "organic", "dynamic" and "grassroots". This substituting of terms further emphasises the shared understanding of *community* the symbol.

As a summarising symbol, *community* therefore invokes a variety of sentiments, which explain what it is to be a community-based organisation. Similarly, *community* enables reflection upon what a community organisation, and more broadly the third sector, is not. In this sense *community* implies "not-government", "not-corporate", and diverse rather than homogenous:

> *"You have to deal with other people's ideas and ways of doing things, I think that's what makes part of the dynamism... I've certainly seen some organisations where they all look the same... but here you get a range of personalities."*

Another worker explained this in terms of the people being 'real':

> *"All the people here, paid or unpaid workers, are actually real people. Not someone that is just here for the paycheck and gone again in eight months when they get a better offer... There's a sort of rawness and naturalness in the people."*

At times the Council is anthropomorphised, as though it is an entity separate from the people who work there. When described in this manner the same sentiments are invoked:

> *"The Council, it's not judgmental; it doesn't tell you what you should or shouldn't be doing, or shouldn't have been doing. It's accepting of diversity."*

Much like Ortner's flag, this allows for a synthesis of these notions, and a shared understanding between the workers of the Council and the third sector more broadly. It draws together all the elements which are desirable in a community organisation, whilst indicating how it is different from the government and market sectors. It does not, however, invite reflection on each individual term but stands for all of these values simultaneously. It is also indicative of how staff and volunteers feel about the organisation as a whole, its environment, and the people who create it. For example, if a community organisation is warm, welcoming and supportive, so too are the people who come together to create it, as demonstrated by the comments of one staff member:

> *"It is... one of the most welcoming workplaces I have ever encountered. Staff members here were very quick to trust me with confidences and other private information, and to treat me as one of the group. I suspect that this is because a community organisation like the Council attracts the sort of people who are empathic, compassionate, caring, etc, and interested in the sort of work that lets them express those feelings."*

Another worker described this as the "Council Spirit":

> *"A worker here that says 'Oh! But that's not in my job description!', that would be the thing that would irk me the most...I don't think that's part of the Council Spirit. Giving more than your job description says that you have to [that's the Council Spirit], being enthusiastic about your work, enjoying it, but also being supportive of people having a hard time with their work... Selfishness is not part of the Council spirit."*

Community, and its ascribed values, is harnessed throughout the organisation, at various levels, and with a variety of purposes. Whilst *community* is synonymous with these positive values within the organisation, it also resonates with broader society. As discussed earlier, the term community is always used with positive connotations; this demonstrates a very broad shared understanding, which enables *community* to be harnessed for purposes both within the organisation, and the organisation's interaction with civil society and government. In this thesis, I predominately focus on the use of *community* by workers to explain how they experience the organisation's positioning between civil society and the state.

Within the organisation *community* is used when describing what the organisation is: *"How you define yourself as a community organisation... it's of the community... should be for the community"*. Some staff and volunteers also refer to a 'sense of community': *"I think that there is that sense of community... I just think that that's a welcoming feel to people,* *particularly around something that's stigmatised".* Its imagery is also called upon when describing how the organisation has changed over time. Indeed, the values that are associated with *community* are important when examining what a community organisation is, and what it does, particularly in terms of its relationship to civil society and state apparatus. The imagery of *community* is drawn upon both in the following chapter, and in Part Four, in order to elucidate workers' experiences and perceptions of the organisation and its work.

Community: in here or out there?

Within the Council considerable discussion, both explicit and implicit in nature, occurs around whom the 'community' constitutes. As discussed previously, hepatitis C is associated with a number of high-risk groups such as injecting-drug users, people who have been incarcerated, and homeless people. Hepatitis C does not affect a cohesive group of people, such as the term 'community' denotes. Rather, it affects a disparate collection of individuals who may have nothing more in common than a diagnosis. Indeed, a hepatitis C community is as slippery a notion as the term community itself. Despite this, the Council's identification of itself as a community organisation creates a need to be able to conceptualise who constitutes the 'hepatitis C community'.[28]

Community, and how it is conceptualised by workers, alternates between being something which is "in here", inside the organisation, and "out there" beyond Council walls. I contend that this relates to the organisation's positioning between civil society and the state. At times Council workers will express that 'the Oliver Smith Council is community', at other junctures community is conceptualised as something which exists outside the Council and with which they work. When workers describe the Council as being synonymous with community and as 'in here' – the organisation is community and represents community – they often articulate this around the presence of the volunteers, as one staff member explained:

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[28] It is also likely that the need to identify 'the hepatitis C community' may also be a result of the virus' close affiliation with HIV/AIDS. As discussed in Chapter Two, due to the close timing of the two epidemics, hepatitis C has always been strongly associated with HIV/AIDS, both in policy and practice. Those involved in the HIV/AIDS sector, however, have been able to more easily define their community, as HIV/AIDS is most commonly associated with the 'the gay community' who represent a cohesive network of individuals. Thus community here is understood as a cohesive group based on interrelationships. The association of the two diseases has begged the question 'If a HIV/AIDS community exists, where or who is the 'hepatitis C community'?'

> *"[Volunteers are] one way of involving affected community in the organisation... [They are the] vital link between the ideal as a community organisation and our practice."*

However, at other times community becomes something which is 'out there', external to the Council. This can be seen in the following explanations of the hepatitis C community expressed by workers:

> *"As far as their view of the community, I think they see them as people 'out there'."*
>
> *"[The Oliver Smith Council] has got a really big role with getting hepatitis C, what hepatitis C is, out into the community. Getting information out into the community not waiting for the community to come here."*
>
> *"[We're] providing support to... people who are out there."*
>
> *"Hep C community, I think of the people outside the Council."*

The differing and alternating explanations of who constitutes the community is representative of the Council's position between civil society and the state, and the difficult nature of balancing these relationships. Altman (1994) suggests that the functions that many NGOs fill do not 'sit easily' together in one space. For example, in Chapter One I discussed how the Oliver Smith Council manages an on-going relationship with the state, at the same time as engaging in empowering marginalised individuals, politicising the un-political and at times confronting government policy. Third sector organisations are therefore providing a voice or mechanism through which the state can be critiqued. Such activities are, however, subversive to a state which would prefer these organisations to extend service provision in line with government objectives.

In light of this, the conundrum that workers' comments present – is community in here or out there? – demonstrates the complexity of the Council's positioning. Previously, community was conceptualised as something which is 'in here' because the organisation was more voluntary based, and consequently more grounded in civil society. However, as the organisation has increasingly become funded by the state, community has become something which is more often conceptualised as 'out there', beyond Council walls. This is because, as Rose and Miller (1992: 181) contend, "government is a *problematizing* activity: it poses the obligations of government in terms of the problems they seek to address". By labeling an infectious disease community, the Council is demonstrating its alternate role; in knowing where the hepatitis C community is, and that they have the means with which to locate and work with such a community, they demonstrate to the state that they have a role in extending services to those the state has difficulty reaching. These issues will be explored in more detail in Part Three.

CONCLUSION

In this chapter I have demonstrated that community is a key term at the Oliver Smith Council. Firstly, because the Council self-defines itself as 'community-based', and secondly because for the staff and volunteers it functions as a summarising symbol which draws together a collection of values associated with being a third sector, community-based organisation. Being "grassroots", 'hands-on' and "welcoming" are important to the organisation's self-definition as 'community-based'. These values, which are associated with the term 'community', explain what the organisation 'is about' and what it does.

The issues raised in this chapter are considered in greater detail at later points in the thesis. In Part Three I consider the conflicting roles of community organisations with regard to theoretical debates concerning the third sector. In the next chapter I begin the process of exploring the tensions over work and roles of the organisation by providing an actor-orientated discussion. In doing so, I argue that workers at the Council are concerned that, due to the positioning of the organisation between civil society and the state, the key values associated with *community* are beginning to shift.

Chapter Four

Concerns about community: Shifting values in the space between civil society and the state

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> One of the current challenges facing the community movement is how to strengthen its effectiveness without thereby compromising a genuine basis in grassroots participation and control. (Altman 1994: 161).

CHAPTER INTRODUCTION

In the previous chapter I demonstrated that the term *community* is used as a summarising symbol at the Oliver Smith Council. As a summarising symbol, *community* draws together a collection of values which describe what it means to be an organisation in the third sector. Furthermore, *community* enables us to understand what distinguishes organisations in the third sector from government and corporate organisations. In this chapter I draw on this notion of *community* to explore how the work of the Council has become increasingly contested. In doing so I elucidate the ideological consequences and tensions of being placed between civil society and the state. Furthermore, I demonstrate that balancing relationships with both is difficult.

This chapter deals with two interrelated issues regarding the work and role of the Council: firstly, what work should the Council do as a third sector organisation? And secondly, what people are required to work at the Council? I begin this chapter by discussing how changes are occurring within the organisation with regard to what people, and what skills, are required to work there. I then discuss how the type of work being carried out by the Council has begun to shift. This shift in work is a topic of considerable debate within the organisation, much of which revolves around perceptions concerning who constitutes the community. By exploring the contested nature of the Council's work, and particularly how it relates to ideas about community, in this chapter I also demonstrate that the tensions within the organisation relate to the difficult positioning of the third sector.

IDENTITY & EXPERTISE

> *"Before it used [to be], it was part of the criteria, that you needed to be hep C positive [to volunteer]... that's [changing], people that aren't hep C positive... are expressing an interest to come on the phone-line"* (Oliver Smith Council Worker).

In this section I explore the debates within the Oliver Smith Council concerning who belongs in community organisations and why. These debates have been sparked by recent changes in the organisation's volunteer policy; whilst previously the Council sought people who were affected by hepatitis C, it now allows non-affected individuals to volunteer. This change has occurred due to the perception that the organisation needs to obtain 'skilled workers', instead of people with lived experience of the virus. The tensions caused by this change of policy relate to perceptions concerning the place of community in a community organisation, and what role such organisations fill.

During my fieldwork at the Council I would often sit in the support-line room at a spare desk. This is the heart of the organisation; it is the one space where staff, volunteers and the community regularly intersect. This made it both an interesting and an informative space to conduct participant-observation. One afternoon in the support-line room I was assisting two volunteers, Frank and Heather, to fill envelopes for a mail-out. Frank and Heather can be considered 'senior' volunteers; they have been with the Council for many years and go about their work with an air of authority which portrays substantial knowledge of the daily functioning of the organisation. On this afternoon Frank, Heather and I were discussing 'brain fog'. Brain fog is memory lapses, which occur as a result of hepatitis C and hepatitis C treatments. We had come to discuss this topic because Heather had spent much of the afternoon calling me Fleur, instead of my real name. Fleur was the name of a previous staff member at the Council and Heather and I joked that only a finite number of names can be used in the organisation which must then be recycled to ease brain fog by preventing workers from having to try and remember new names.

During our discussion of brain fog, a volunteer whom I had not met before came into the support-line room to start his shift. As the volunteer sat down at the desk designated for those attending to the Support-line, the conversation changed from hepatitis C-specific matters to more general topics of interest. The new volunteer introduced himself as Jack. Throughout the next hour I spent in the support-line room Jack slowly revealed his story. Unlike the other volunteers, he has never had hepatitis C. Jack does, however, suffer from a different chronic illness which, like hepatitis C, causes fatigue and depression. He first came to the Council on a placement as a social work student, but stayed at the Council beyond the duration of this placement because he finds the people in the organisation empathetic towards his experiences. While I was unaware of it at the time, and I suspect Jack remains unaware to this day, his presence as the first non-hepatitis C-affected volunteer at the Council was a source of tension, and an indication of changes to come. Indeed, at the time of writing, the Council has taken on more non-affected volunteers.[29]

Shifting notions of expertise

The presence of Jack, and other non-affected volunteers, has signalled a changing notion of expertise within the organisation. Until recently, lived experience of hepatitis C represented a fundamental knowledge base for volunteers who worked on the Support-line and in education and service delivery roles. The notion of lived experience as expertise can be described as a typically third sector belief; it is common for third sector organisations to perceive community connection and personal involvement as important skills for work within non-government, community organisations. This is because, for many third sector organisations, their primary objectives are concerned with moral imperatives rather than economic gains. In the case of the Council, workers explained to me that the shift in volunteering policy occurred because the organisation needed to seek 'skilled workers':

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[29] It is worth noting that the number of affected individuals in contact with the Council has increased. However, there has been a 'formalising' of this association; 'affected community' are found in roles such as positive speakers, rather than informal association with the organisation.

> *"People with mild fibrosis... talking to people with serious cirrhosis, that can be really difficult... [We're] not excluding disclosure but not making it mandatory... [It's about getting people] who have the skills... I think it's about an organisation identifying... the skills it needs and attracting that, sitting alongside people who reflect or represent lived experience. But I think in the early days we went more for lived experience."*
>
> *"Then it takes a lot of energy also to support people who are coming in from the community who may not have those skills to run the organisation."*
>
> *"[It's] spreading your resources further [and getting] more skilled people in... so it's about trying to balance up who you see through the door and who you're trying to reach and work with outside the actual doors of this place."*

The term 'skilled workers' implies individuals who have 'professional' experience gained in the market, and/or government sectors. Thus, at the Council, the notion of expertise has begun to shift from third sector ideas of 'lived experience as expertise', to government and market sector notions of 'professional experience as expertise'. This shift in policy is in accordance with other changes taking place in the organisation; as the Council increasingly gains government funding, it must attract workers who are skilled at managing this funding. Thus, the Council's relationship with the state has meant that it must regulate its core values and principles.

As discussed in Chapter Three, non-government and community-based organisations have, historically, developed out of civil society in an attempt to assist people and issues not adequately addressed or represented by the government and market sectors. It follows that the principal objectives of these organisations are not founded in economics, but rather in notions of social justice. As mentioned in Chapter Three, Oliver Smith Council workers stated that people in the organisation were "real people", who are seeking more than just a pay cheque: *"The pay is lousy, the people who work here do it for the passion, not for money"*. Staff and volunteers must be engaged with the organisation's moral imperative and be 'passionate' about their mandate to assist people affected by hepatitis C. Indeed, due to the blood borne nature of the virus and its connection with injecting-drug use, many of the old volunteers who have been affected by hepatitis C share certain life experiences and perspectives:

> *"I suppose a lot of the issues in this place are associated with injecting drug use.... If you've actually been an injector at some point in your life ...[you've] gone against the main stream. So in some way you rebel...that's part of the reason you tend to get some strong characters come into the place... I would think people [here] have got a sense of social justice... you know our client group... they do deal with oppression in one way or another."*

Indeed, Padilla (1977) suggests that the sources of trust and solidarity within community groups stem from the belief that these people have common problems, social identities, opportunities and perhaps futures. Consequently, some staff and volunteers question the commitment and understanding that new volunteers who are not affected by hepatitis C have of the Council's ethos and objectives:

> *"In the early stages you mostly get people who may not have all the skills, but want to get in there because of their personal experience... when funding increases, people are attracted with skills, but [they're] invested in a different way."*

> *"I think [the Council] will... continue along the track it has been, and volunteers ...I think there will be more people who don't have anything to do with disease itself. I think there will be more people coming in who are just looking for volunteer work and fewer who really have an interest in it because they have hepatitis C and they want to help others get the word out..."*

The changing notion of expertise in the organisation reflects the positioning of the Council in relation to the state; values, such as 'professional expertise', which are derived from government and market sectors, have begun to find their way into the organisation. For some workers, this is a cause for concern:

> *"It's important [to have] people who actually have practical understanding and experience [of hepatitis C], not just things that they've read out of books... if you only have the theory without the practice that's really empty, and I don't think the Council is empty."*

Having people affected by hepatitis C working and volunteering in the organisation is important for retaining the core values of community: *"[When I first started] there was the sense that it was a community-based organisation so people that were directly affected should be really integrated into the organisation and at the forefront of the organisation"*. A shift in values away from third sector notions of 'lived experience' as expertise and towards government and market sector concepts of 'professional expertise' raises broader questions about what kind of organisation the Council will be in the future. Some workers at the Council understand this shift as occurring because, as the organisation grows, they require people with 'the skills' to run it. Having said this, the issue of where these people come from (affected community or not-affected community) and how they gain these skills, remains a point of contention.

Identity politics

> *"[At the Council] there's a sense that the personal* ***is*** *professional and vice versa"* (Oliver Smith Council Worker).

The benefits of gaining workers with lived experience of the virus are related to the use of identity politics. Identity politics in this thesis refers to the practice of imparting knowledge, services and support along the lines of identity. Identity politics is a term most often associated with collective identity and social movements. Post-modern uses of the term often relate to queer theory and gay, lesbian and/or feminist movements (see, for example, Polletta & Jasper 2001; Gamson 1995; Nicholson & Seidman 1995). However, the notion of identity politics can be found in neo-Marxist, New Social Movement and post-modern approaches to social movements, each invoking the term in a different way (Bernstein 2005). Bernstein (2005) contends that, despite the varying invocations, a commonality to all uses of the term is the belief that identity is important to social movements. Bernstein considers this on three levels: firstly, a collective identity is necessary for mobilisation of a social movement; secondly, expressions of collective identity can be used politically; lastly, identity can be the goal of a social movement or activism, for example gaining acceptance of a stigmatised identity (such as hepatitis C). The term can also be found in relation to gay communities and HIV/AIDS prevention. For example, Brown (1997) discusses the 'mixing' of identity politics and service delivery in an HIV/AIDS community organisation, stating that, by imparting knowledge along the lines of identity, organisations can strengthen their ability to work with community groups; "the mixing of identity politics with service delivery does not simply improve accessibility. In many ways it is absolutely crucial to successfully carrying out the service" (Brown 1997: 92).

Indeed, community organisations, especially those who work with marginalised people or in areas which are shrouded in stigma, often impart information and services along the lines of identity; this is aimed at making information less threatening.[30] Although different terminology is used, this same notion underpins 'peer organisations', whereby shared experience and identification with community groups is considered fundamental to service delivery, support and imparting knowledge.

Clearly, the recent change in volunteering policy has also raised issues concerning identity politics and service delivery. Bernstein's (2005) observation, that creating a collective identity is fundamental to advocacy for the acceptance of marginalised or stigmatised groups of people (such as those affected by hepatitis C), is an important consideration for this work. By imparting knowledge and support along the lines of identity, one can begin to form a collective identity within a community group which will in turn form a social movement that is likely to be able to affect political change. As Bernstein (2005: 59) states, "many studies show that to act politically, all social movements need identity for empowerment… [and] to create and mobilize a constituency" (see also Bernstein 1997).

At the Oliver Smith Council identity politics in service delivery is aimed at normalising hepatitis C: *"I can portray a happy face as a person who's had a lot of problems with hep C, I think that helps them*". Several workers explained to me that when they first approached the Council after diagnosis, they found it comforting to see that people who are hepatitis C positive have normal lives, and are able to maintain employed and voluntary positions. Thus, by treating hepatitis C as a normal part of life and showing that hepatitis C positive people can work and function, the Council aims to undo the stigma associated with the condition. Because normalising hepatitis C is fundamental to the organisation's mandate, the decline in the mixing of identity politics and service delivery has caused concern for some staff and volunteers.

Identity politics at the Council is viewed as being more pivotal to some areas of service delivery than others. The education team consists of a mix of hepatitis C positive and negative workers. For other types of work within the organisation, lived experience of hepatitis C and

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[30] Peer organisations, and identity politics and service delivery, are most commonly associated with the community response to HIV/AIDS, and have been effective in HIV/AIDS prevention with gay communities and injecting drug users (Aitken, Kerger & Crofts 2002; Brown 1997; Trautmann 1995; Altman 1994). Identity politics is also found in the disability sector and services (see, for example, Putnam 2005).

the mixing of identity politics is pivotal, for example the 'positive speakers' who often work with educators are considered to provide a 'powerful tool' for education. On a policy level, disclosure is determined by the individual, as Gail explains:

> *"I guess for me (I'm a bit of an idealist), it would be great if staff or Board members concerned felt comfortable to disclose whenever it came up – and some do – as this helps normalise hep C - not something you can't talk about openly. I think it is particularly useful when speaking to others with hep C as it models successfully managing hep C in your life - e.g. on telephone info & support line, support groups, education sessions for people with hep C.*
>
> *I do however recognise that people are up to all different stages around disclosure, and often they are not so worried for themselves, but for their families, particularly children – due to the stigma attached and lack of knowledge and fear from the 'outside world'. I also recognise that the nature of their work here is usually not related directly to hep C – and if they were doing similar tasks in other organisations – why would they disclose? Thus to carry a sense of some responsibility about always disclosing could feel quite a burden."*

Regarding disclosure, identity politics and the education team, Frankie (one of the educators) confided:

> *"I have tried to start the conversation in the education team about, because we're not a peer organisation, we don't identify that way, but start that conversation about why and what is ...what are the factors in educating and disclosing, not disclosing and what the possible benefits are of us being peer educators, and what the possible benefits are about doing that. Perhaps, what's the value of standing back from that and not disclosing or identifying?"*

However, the mixing of identity politics and work can be difficult for those involved in the work. For volunteers, identity politics in their work can create personal distress, and at times the Council has lost volunteers because the work has been confronting:

> *"[It is a] double edge sword for volunteer[s], being here, because the information is quite scary... they may not be ready for bad news... Being exposed to people on treatment can [also] scare them off."*

> *"I get a bit surprised lately because one of our roles here especially on the phone-lines when people ring if they're newly diagnosed or a bit frightened is to try and normalise you know having hep C but every now and again when you come across someone who is quite ill or in advanced stages of liver disease, I tend to get a surprise... I'd forgotten how, because you get so used to normalising it, that some people do progress to getting quite ill and that can be a bit of a shock sometimes."*

Brown (1997) argues that, when providing services to marginalised or stigmatised groups, the use of identity politics is pivotal for successfully engaging individuals. However, this argument relies on the belief that an organisation is providing services to a relatively homogenous community group. In practice, the type of 'identity' required depends on whom the service is targeting. Not all workers perceive this change in volunteer policy as a 'shutting out' of affected community. Other workers believe the change is opening the Council up to people outside of the affected community. This is considered important because everyone in the community needs to know about hepatitis C, not just those who have already come in contact with the virus. In this sense, the identity of non-affected volunteers is considered crucial to service delivery. Julia, who runs the support-line, believes that allowing non-affected volunteers *"will create a ripple effect of correct information*" into the broader community, and that this is best done through incorporating non-affected volunteers on the Support-line: *"it shows that anyone can give information on hepatitis C"*. Frank, a senior volunteer I discussed earlier, reiterated Julia's beliefs:

> *"That took a while for that to change and that got, you know there was lots of discussion before that got changed and there was a few people that opposed it, but I think it was realised that there was a lot more to gain by opening it up to others you know to those affected by hep C and those that aren't as well. I saw benefits in opening it up really and I thought, I didn't really understand why someone would feel threatened by someone who wasn't hep C positive, working at the Council. I just couldn't understand that. So I guess I did see benefits in opening it up. Get the message out to a wider community by them taking it back out themselves to people that aren't hep C positive. So, doing a bit more work to reduce discrimination."*

Whilst these workers therefore believe that identity politics is important for service delivery for non-affected people as well as for those with hepatitis C, there are broader social issues to be considered with regard to the use of identity politics within a community organisation. As discussed earlier, social movements with a strong sense of identity are well positioned to effect political change. Through the mixing of identity politics and service delivery, the Council is able to begin to build a collective hepatitis C identity which in turn may serve to reinforce the work of the Council through political recognition. One must note however that, when dealing with such a heavily stigmatised disease, this is unlikely to be a straightforward process. It has also been suggested (Allsop & Jones 2004; Altman 1994) that an important component of health-related community organisations is their ability to help people redefine themselves in non-medical terms. Creating a collective identity grounded in one's experience with hepatitis C may be undesirable, or even damaging, to some individuals.

Community participation

On a broader level, changing notions of expertise and beliefs concerning identity politics elucidate larger issues within the organisation, such as: how integral is community participation to a community organisation, particularly at an informal level? As I have discussed, seeking professional experience rather than lived experience and becoming 'professionally detached' from service delivery are not third sector concepts. Rather they stem from the government and market sectors. Conversely, community participation – particularly that of the 'affected community' – has in the past been central to the organisation's self-definition as being community-based; it draws on the values of *community* which are fundamental to third sector organisations. Thus, as with shifting boundaries and moving away from the utilisation of identity politics in service delivery, many workers are concerned that the Council's new volunteering policy raises concerns regarding the organisation's ability to align itself with the third sector. Gail, a senior staff member, explained that, although she can be pragmatic about this change, it is not congruent with her beliefs about being part of the third sector:

> *"It's that skill level and that skill base as opposed to, you know, and also it's just as important I guess if people who don't have hep C to know about the issues... but if you get back to that I guess more purist idea of what a community organisation is, and who it's for... I guess my views are even more on that wave."*

> *"[It's related] to how you define yourself as a community organisation... it's of the community... should be for the community and [building their skills]... In the early days the phone-line was peer... personal experience... that's been taken in a different direction."*
>
> *"One of the... key things to my sense of community... is ideally people who are working in these organisations and operating these organisations are actually people who are belong to the community... so people directly affected, that would be my ideal."*
>
> *"A community organisation: ideally community should be in control of that, community should have the input into that. Within practical stuff, the community should be working and be volunteering, everything else. It used to be on the phone-line here that it was affected community, or to be a volunteer here you had to be affected community. There's a big difference between infected and affected... but people had all these different thoughts about that. So anyway, it ended up that they changed that and they opened it up. We have ... the phone-line, which is advertised as a peer organisation where you can ring up and talk to people who are living with hepatitis C about various things. Now when you ring up that's not the case anymore, you could be talking to anyone. I'm not saying that the volunteers that work on the phone-line, that there's anything wrong with those people, they're great. It's around [that] there's probably ten places to volunteer at the Oliver Smith Council, there's 14 000 people living with hepatitis C around [the state]. I think that positive discrimination was a good thing because I think those ten places... are really precious."*

In this section of the chapter I have explored the shifting notions of expertise at the Oliver Smith Council. Primarily this shift has involved a change from perceiving 'lived experience' of hepatitis C as being paramount to volunteering, towards 'professional experience' as being necessary. Similarly, the mixing of identity politics and service delivery is no longer considered a necessity. Some workers in the organisation feel that these changes have broader implications for the organisation's 'community base' or – using the terminology of this thesis – they are concerned with losing the key values of third sector organisations, articulated by the term *community*. At an analytical level these changes suggest a shift of the organisation's values towards that of the government and market sectors, and are further representative of the Council's positioning between sectors.

WORKING WITH WHOM, AND HOW?

"It seems a long way from community sometimes"
(Oliver Smith Council Worker).

As discussed previously in this chapter, the Council's work has become an increasingly contested issue within the organisation. Whilst some workers feel that the organisation should cater specifically to those affected by hepatitis C, others contend that working with other organisations and institutions will have a greater impact on the epidemic. In this section of the chapter I describe these different perspectives and debates regarding whom the Council should work with and how. I then explain how these debates relate to the Council's positioning in the third sector.

When the Council was first established in the early 1990s, the affected community members who came together to create it were concerned with establishing an organisation for the support of people affected by hepatitis C, after diagnosis. In the early days of the Council this often took the form of one-on-one support, either through the support-line, in face-to-face interactions or volunteer positions. Although this kind of support is still offered by the Council, it has begun to decrease in favour of larger projects outside of the organisation, involving a wide range of people, not just affected community:

> *"It's no longer a drop-in environment, we must spend a lot of time and energy getting out to the community."*
>
> *"I think [previously] it was probably more [about] people living with [hepatitis C], or affected by hepatitis C... over the last three years we've been... trying to target and work more with organisations... we've increased our focus and capacity."*
>
> *"These days the Council is for people in [our state] affected by hepatitis C, primarily, so that's people living with hepatitis C and people supporting people.... It's an interesting dilemma that, because the Council was originally set up by people with hepatitis C, generally there was a focus [on people who were] close to diagnosis, but... clearly an organisation like ours... should be [doing other work] and preventing [hepatitis C]... but that's an ongoing challenge for us."*

> *" I think that things were more laid back before... I think it was more like peer work most of the time whereas now there's you know a lot more dealings with other organisations."*

This is explained by people at the Council as "working with workers" instead of "working with community". Not surprisingly, a range of perspectives exist within the organisation as to whether this should be the Council's focus:

> *"Yes we have the information lines where people can ring, and that's a great service, and we have individuals like myself who go out and do [work], but we're really looking more at working with workers... We're really looking more at working with workers, educating workers, doing everything with workers, rather than working with community ourselves. Which I can see the wisdom behind that, but it sort of leaves community floating a little bit because there's no other body here for them to pick up what the Council used to do. What happens to those people if the smaller organisations start shutting out the community as well?"*

> *"There are different schools of thought in the Council. Some people want to concentrate on the most marginalised people in the community, and that's probably a good thing to do, but at the same time in [our state] there are tens of thousands of people with hepatitis C who don't even know they've got it, and even if they do know they've got it, they probably don't think that a hepatitis C Council is anything to do with them. So perhaps we need to work [with these people too]."*

> *"In terms of support, personally I think that's probably the most sort of contentious area because I think what's happened historically is... you can have a number of people who are affected by hepatitis C who get together and are mutually supportive but haven't always seen the necessity for providing support to lots and lots of people who are 'out there', unknown people."*

> *"I'd like to see [the Council]... put something solid back to the people that are living with Hepatitis C rather than prevention and stuff really."*

> *"I suppose we do that to a degree, support, there's a support group here, but I think we could do that better. I think we miss a massive amount of people who are living with the virus."*

Funding agreements with the state government have further perpetuated this shift in focus:

> *"Workers [from other organisations and institutions] are our secondary target group, but we're working more towards them. So there's been a definite shift. Which is about funding as well, it's from a governmental level, it's not one person sitting at the Council saying let's change let's do this, it's the way that things happen. The Council is evolving into something else, a much more political entity, and I'm not saying that that's a bad thing. I just think that perhaps, probably we need another body, or another..."*

Kate, a staff member and former volunteer at the Council, argues that changes in whom the Council works with has had effects on how the Council works:

> *"There's other things too, we're getting uniformity and branding within our presentation, and it's more of a one-size fits all approach. I can't take a PowerPoint presentation for Centrelink workers or psychologists or workers or nurses or uni students, and show it to street kids or aboriginal people... Things need to be appropriate and be aimed at an appropriate audience. You can't possibly have one-size fits all approach, you can't use identical language everyday. You cannot use the same language to talk to professionals as homeless people because you're using words that go over their heads and that is poor communication to say nothing about ignorance, so there's no use talking in academic language to people who are really marginalised because they just don't understand you and they don't want to talk to you then. You have to use appropriate language, it's one of the first rules of communication: to listen and use appropriate language. We're doing this exercise right now where we get everything really professional and this is how we'll do it and this is what we'll say, and that's what we'll say. I'm sitting there thinking this is really crazy."*

Historically the Council has been involved primarily in the support of people after diagnosis; however, due to funding requirements, the Council has begun to work in areas which are more in line with government objectives:

> *"Supporting people who were living with hepatitis C, for a long time I thought that should be our only focus, but I realised that an organisation like ours needs to be contributing... that's also around funding, I think probably that was the bottom line, the state department really wanted us to be thinking about this. I think that's a bit of a trade off, if we're really here to support people with hep C we should be doing this."*

Part of the process of scaling down one-to-one support is the reduction of volunteer duties. The change in volunteering policy to allow people who are not affected by hepatitis C to volunteer has also had an effect in this area. Until the last two to three years, volunteer positions and the support and skill development of volunteers were viewed as part of the Council's community development and empowerment work – *"there's a number of workers here who came in as volunteers and over time you know took on the responsibilities, responded to the environment, responded to the challenges and the support"*. At the time, most workers within the organisation were also part of the 'affected community' and thus empowering, up-skilling and supporting people with the virus occurred in the day-to-day running of the organisation. In the following statement Kate reflects on the impact of volunteer policy changes on the Council's community development and empowerment work:

> *"With the right community development approach [the volunteer positions are] going to be empowering to the hepatitis C infected community... they are so marginalised, you can't marginalise them more...if the Council is about community development those positions should be used to develop members of the affected community... [Not] people who are already empowered... it should be an opportunity for those affected by hepatitis C to be empowered."*

Indeed, as Altman (1994: 161) suggests of AIDS organisations, NGOs "also provide skills and resources to people who otherwise would not have come together, and this in itself is an empowering act".[31] However, at the Council, this type of work began to decline predominately because it was considered to be a drain on staff time and resources, as workers explain in the following statements:

> *"[People coming to the Council were] people who were generally fairly messed up, who were looking for nurturing and a fairly high level of personal support... and that's what people use to give them. There used to be a volunteer coordinator and that person gave pretty personal attention to people who were here, they needed to be involved in something that was supportive for the way they were feeling about themselves. That kind of fairly intensive, immediate support is not really available anymore because the general idea is to be supportive of a whole range of people at a more moderate level."*

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[31] In the 1970s Padella (1977: 229) also argued that local organisations meet a social need for "supportive face-to-face interactions in the midst of the impersonal and dehumanizing events of urban society".

> *"I think we have invested a lot of energy in people but sometimes it's for the organisation, and for the greater good... I've realised that in a number of [instances] there was a lot of energy going around... volunteer stuff. If you look at the bigger picture... we really needed to make some changes in our work that was much more 'out with the priority population'... [Work] more broadly. I see the move as being, ultimately, really positive but there [have been] some causalities along the way...There is so many in the community, do we put our resources into few or do we spread our resources further?"*

> *"[I would] like to see volunteers remain in every level of the organisation. Volunteers used to come in five days a week, they are now limited to three. Some staff perceived them to be time consuming, and drawing upon resources."*

Reducing volunteer positions and one-on-one support raises broader concerns about the place of community within the organisation. As discussed previously, this relates to concerns about the community-based nature of the organisation, and the values and work which should be associated with third sector organisations, Sam explains:

> *"I remember probably five years ago when we were in the other premises, having to decide... the organisation seemed to always be in chaos, and so we [decided to have] one afternoon where we didn't really have our volunteers on board or whatever and that was actually perceived as really outrageous."*

> *"Those people take more support in the workplace, but the rewards are greater."*

The competing ideas within the Council are best articulated by the following comment made by Frankie:

> *"I can see we're going in that direction – working with workers – at the same time I see a need... I see that there are some people who work here who are very invested in maintaining that grassroots approach, the hands-on approach... and seeing that as being very important for maintaining the contacts with people in our communit... Always trying to weigh them up and balance them... [it's about where] our priorities go, sometimes they'll be competing for resources or whatever... You can't force a result from that sort of thing, I think having that conversation is very important, but what you've got to do is acknowledge that...it's just different agendas, and how can we use these tensions so that it works, rather than potentially becoming a problem."*

There are, however, benefits in placing resources and energy into education and community development and empowerment activities outside of Council walls. For example, workers feel that their time is used more productively and that the new direction has enabled them to feel that they are making a broader contribution to hepatitis C awareness. This shift has been precipitated by the practical limitations associated with identifying and working with people affected by hepatitis C; such individuals are dispersed and often do not identify hepatitis C as a 'commonality'.

> *"Even though five years ago we might have had more community representation I don't think it was, that doesn't necessarily equate with the best governance or the best direction."*
>
> *"Just building up the profile. Getting everyone to work in a more effective way... before, education workers were working in a fairly reactive way... someone would say there's a problem occurring in that particular place, they're discriminating against people... so an educator would go out there. A lot of what's been happening [now] is trying to make educating systematic, it's like training the trainer, so you develop capacities in other organisations."*
>
> *"We do so much more, before we would be doing limited information sessions around the place, they were very often reactionary to requests we would get. A lot of our resources were re-printed from other Councils, we didn't produce things ourselves... our lobbying capacity was much less, because when you have less staff you need to be doing more practical things and there was less thought about the future."*
>
> *"At the same time you could argue that the Council is more effective as a community organisation because it is trying to reach out to a whole range of people."*

The competing ideas within the Council about whether it should work with community or with workers are indicative of broader concerns regarding the positioning of the organisation and whether or not it will remain strongly grounded as a community-based organisation in the third sector. Indeed, as Altman (1994) suggests in this chapter's opening quote, one of the biggest challenges facing third sector organisations is enhancing their effectiveness without compromising their grassroots and community participation. 'Working with workers' enhances awareness in the general community and is likely to create a 'flow-on' effect of information through other agencies passing on hepatitis C information to their clients.

However, the process of developing community programs for prevention, support and care simultaneously involves building communities. These communities then serve to build political support for the continuation of the Council's work (Altman 1994). The following statement made by Altman (1994) of the HIV/AIDS epidemic, is a poignant reminder for the hepatitis C sector:

> In Western countries, particularly those most affected by the individualistic ethos of the 1980s with its denial of social obligations other than those of the market-place, the AIDS movement has been important as a reminder of the importance of communal activity and altruism in social life. As a number of South American activists remind us, the strengthening of grassroots and community organisations is central to the creation of a strong 'civil society', which acts as a counter to the bureaucratic rationale of the state and the economic rationalism of the market-place.
>
> Altman 1994:166

CONCLUSION

Part Two has considered the first theme of this thesis: community and how it is understood and conceptualised by workers at the Oliver Smith Council. In Chapter Three I argued that *community* acts as a summarising symbol at the Council to articulate what it means to be a community organisation. While in Chapter Four I drew on the theoretical assertions made in Chapter Three to explore workers' perceptions of how the organisation works with community.

Based on the experiences and perceptions of Council workers I have provided a discussion of the challenges and tensions occurring at the Oliver Smith Council. It is evident that there is considerable debate within the organisation regarding who should work in a community organisation, and what work the organisation should be doing. I have demonstrated that these debates relate to the organisation's positioning between civil society and the state. There is a concern that, due to this positioning, the organisation is losing the values which characterise it as a community-based organisation in the third sector. This was demonstrated through the concept, and use, of *community*. At the Council *community* acts as a summarising symbol to articulate, and draw together, the values which are important for a community organisation. Workers at the Council were concerned that, due to the organisation's positioning and its relationship with the state, it was beginning to lose *community*. This represents a significant challenge for the organisation; while the policies and practices which develop out of *community*, such as community integration and participation, are pivotal to the organisation's position in the third sector and its ability to achieve where governments cannot, by "becoming professional" the Council is able to be more effective. These concerns and tensions regarding *community* will be developed in Part Three of this thesis. In doing so, I will demonstrate that the positioning of the third sector has important spatial consequences, as well as the ideological ones discussed in Part Two.

Part Three

The Spatiality of the Third Sector

Once it becomes accepted that the organisation of space is a social product – that it arises from purposeful social practice – then there is no longer a question of its being a separate structure with rules of construction and transformation which are independent from the wider social framework (Soja 1980: 210).

The Spatiality of the Third Sector

Introduction

As I have discussed previously, this thesis is concerned with the positioning of the third sector, and how this positioning is evident in workers' understandings of community at the Oliver Smith Council – and their experiences of the space of the Council. In Part Two I firstly considered workers' understandings and perspectives of community in isolation from the spatial dimensions of this issue. In doing so, I demonstrated that workers are concerned that the organisation is shifting away from civil society and becoming too closely aligned with the state, where it may lose the values which distinguish it as a community-based organisation in the third sector. These concerns were articulated in workers' discussions of community at the Council and the work that the organisation carries out.

The two central themes of this thesis, community and space, are interrelated concepts. Both workers' understandings of community and their experiences of spatiality are shaped by the organisation's position in relation to civil society and the state. Furthermore, workers' understandings of community, as they are affected by the positioning of the third sector, have spatial dimensions. Thus, the importance of space in this thesis is twofold – there is a macro and a micro view. At a micro level, workers at the Council use spatial explanations and metaphors to the tensions, challenges, and changes they experience within the organisation; for the workers at the Council, space – and particularly how it has changed over time – represents a central organising theme for their experiences. On a macro level, the organisation of space is pivotal to the notion of a third sector. Space is political and strategic and both the formation of, and debate about, the third sector is concerned with the ability of third sector organisations to transform the spatial organisation of society and concomitant power relations. The spatial dimensions of the third sector have received little to no consideration in academic literature. Consequently, the addition of space to third sector theorising is an important contribution to the area.

Part Three of this thesis is divided into two chapters. Firstly, in Chapter Five, I outline recent debates and theorising of the third sector and analyse these debates in terms of their spatial dimensions. Scholarly debate regarding the third sector is largely concerned with the socio-political contribution of NGOs and CBOs. In attempting to understand the contributions and roles of such organisations, academics have begun to consider the power relationships between third sector organisations and the state. I argue that such debates require recognition, and consideration, of the spatial dimensions of these power relations of the third sector. Discussions and debates about the third sector, its positioning and the power relations which characterise it, have remained abstracted from the experiences of individuals and organisations. Recognition of the spatial dimensions of these arguments, and the use of spatial theory, enables an actor-oriented discussion of how the power relations of the third sector are experienced by those within third sector organisations. In Chapter Five I therefore provide a discussion of 'lived space', and how it enables us to appreciate the confluence of mental, symbolic and material elements of experience. Such an account has, until now, been sorely absent.

In Chapter Six I draw on the theoretical arguments outlined in Chapter Five, to build an account of how the positioning of the Council is experienced spatially. In this chapter I also draw on the notion of *community* outlined in Part Two. As discussed in Part Two, workers at the Council were concerned with a shift in the core values associated with being a third sector organisation. For many workers, this has resulted in a sense of shifting spaces within the organisation, away from civil society and towards the state. In providing this actor-orientated discussion, I demonstrate that the power relations of the third sector have important spatial, as well as ideological, consequences.

Chapter Five

Exploring power, space and the third sector

> …governmentality is intrinsically linked to the activities of expertise, whose role is not one of weaving an all-pervasive web of 'social control', but of enacting assorted attempts at the calculated administration of diverse aspects of conduct through countless, often competing, local tactics of education, persuasion, inducement, management, incitement, motivation and encouragement (Rose & Miller 1992: 175).

> At the base, the relationship between governments and non-governmental organisations is a political question that impinges on the legitimacy of various types of institutions to exercise power (Bratton 1989: 570).

CHAPTER INTRODUCTION

In this chapter I discuss recent debates concerning the relationship of third sector organisations to the state and civil society. In doing so, I provide a theoretical discussion of the third sector. To explore and enhance understandings of the socio-political role of the third sector, scholars have begun to develop a more complex analysis of power. Previously, some scholars envisaged third sector organisations as being able to seize power from the state. Recently, others have argued against this transactional analysis of power in favor of exploring the positioning of the third sector through an interpretation of relational power and governmentality. Under this framework the third sector has been theorised as offering either a mechanism through which the current structure of governing can be changed or as a means by which the state is able to extend its governing abilities. In this chapter I argue that the third sector is more complex than either of these previous appraisals.

As I stated in Chapter One, much of the literature regarding the political dimensions of NGOs regards both the 'state' and 'civil society' as homogenous entities. In reality, both comprise networks of ideas, beliefs and interactions, which are broad and even contradictory (Mercer 2002). Civil society and the state are not homogenous entities, nor can they be found in a singular central locale. Indeed, as Patton (1997: xvi) suggests: "the state and civil society are constantly evolving stages for politics". However, for the purpose of gaining an understanding of the broad socio-political role of the third sector, it is conceptually useful to consider both civil society and the state as diverse but concrete realities: "'state' and 'civil society' do not exist in any pure abstract sense, but are bundles of social relations that are always located somewhere" (Brown 1997: 85). [32]

Brown's statement brings me to the second theoretical consideration of this chapter: space. In this chapter I argue that spatial theory offers an important, and overlooked, contribution to the theorising of the third sector. Debates regarding the power relations of the third sector are spatial debates: they are concerned with how NGOs and CBOs operate in a space which is separate from the government and market sectors. With regard to this thesis, the inclusion of spatial theory is important on a number of levels. Firstly, space is an important and overlooked concept when conceptualising the role and positioning of the third sector between civil society and the state. Secondly, the aspects of spatial theory utilised in this thesis allow for an actor-orientated discussion of how this broader socio-political positioning is experienced. With regard to NGO and CBO literature, this is an important dimension to capture since few studies have given attention to what is occurring in specific organisations. Lastly, space was often a central organising theme and explanatory vehicle for the workers at the Council to articulate and elucidate their experiences.

A SPACE FOR THE THIRD SECTOR

> Public health initiatives that wish to engage communities (especially poor ones) will have to be grounded in an understanding of the ways in which power operates (Baum 2002: 355).
>
> Political power is exercised today through a profusion of shifting alliances between diverse authorities, in projects to govern a multitude of facets of economic activity, social activity and individual conduct (Rose & Miller 1992: 174).

In this section I outline recent debates and theorising of the third sector. Recently, such theorising has begun to focus on analysing relational power in the third sector using

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[32] Furthermore, the lens of governmentality which is used in this thesis, is grounded in the belief that in practice these relationships *are* diverse and complex, but this diversity and complexity does not limit the flow of power through and between them.

Foucault's work on governmentality and power. As stated in Chapter One, some activists and theorists have optimistically envisaged the third sector as a means to transform the state, whilst others believe that third sector organisations merely perpetuate the will of the state. In this chapter I outline both sides of these debates, but argue that they do not sufficiently capture the relationships or positioning of the third sector. Previous academic accounts of relational power and the third sector, such as that of Sending and Neumann (2006), have argued that third sector organisations resist and perpetuate the governmentality of the state. In this chapter I argue that in addition to resisting and perpetuating power, the power of the state also acts upon organisations themselves causing them to self-regulate in accordance with government perceptions and objectives.

Analyses of relational power of the third sector have also envisaged such organisations as either situated in civil society (wherein they are able to transform the state), or as becoming a subsidiary of the state. Through closer analysis of these theoretical debates, I contend that the third sector is positioned between civil society and the state. Under Foucault's concept of power, the state and civil society are involved in a reciprocal, mutually constructive relationship due to the governmentality of the state. With regard to this, I argue that the tensions and concerns experienced by Council workers relate to the organisation's, and the third sector's, positioning between civil society and the state.

Locating the third sector

Academic debate regarding the politics and power relations of the third sector tends to conceptualise the sector in one of two ways. Some activists envisage the third sector to be an 'apolitical' space from which organisations can effect political change:

> Most common is the allegiance to the normative ideal that civil society and NGOs are inherently 'good things'; microcosms of the (liberal) democratic process, comprised of the grassroots, both separate and autonomous from the state, while acting as a 'bulwark' against it.
>
> Mercer 2002: 9

Others have viewed such organisations as merely perpetuating the will of the state (see Bryant 2002; Fisher 1997). The idea of the third sector as a means by which to transform the state is largely premised on the belief that these organisations are able to effect political change from the safety of an apolitical space – outside the influences of the market and government sectors (see Altman 1994; Ferguson 1990). However, the space of the third sector is far from apolitical. Many NGOs have arisen from civil society in opposition to state agenda. Consequently, such organisations operate in a nexus between civil society and the state, a space that is complex and frequently fraught.[33] For example, the Oliver Smith Council, like many national third sector organisations, is government funded.[34] Furthermore, the health-orientated nature of the Council means it is also subject to the influences of medical institutions, which in turn have their own complex relationships with the state.

In recognition of the complex political landscape of the third sector, attention has been turned towards analysing the power relations of CBOs and NGOs (see, for example, Sending & Neumann 2006; Bryant 2002; Mercer 2002). Initial conceptualisations of power and the third sector argued that the state had lost power to non-state actors, through NGOs and CBOs representing civil society (Sending & Neumann 2006). However, if politics and power are analysed as being relational, rather than as a possession, it is evident that these dichotomous interpretations are over-simplified. In order to explore the relational aspects of power and the third sector, scholars have turned towards Foucault's concept of governmentality (see, for example, Sending & Neumann 2006; Bryant 2002). [35] Under this concept of governmentality, government is conceptualised as a form of power. This makes governmentality a useful framework for analysis of power relations in the third sector (Foucault 1991; Burchell, Gordon & Miller 1991; Dreyfus & Rabinow 1982).

In Foucault's rendering of power, power is relational and not held in a central political rationale; it cannot be seized from one and given to another (Foucault 1984).[36] Rather it flows through everyday aspects of life:

> Power must be analyzed as something which circulates… And not only do individuals circulate between its threads: they are always in a position of simultaneously undergoing and exercising this power.
>
> Foucault 1980: 98

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[33] Wolch (1990) terms the third sector 'the shadow state' due to its "indirect but important relationship to the state through funding and contracting" (Brown 1997: 19). Brown (1997: 19) suggests that the shadow state complicates the "geography of the state because its organisations mediate between the community of service recipients and state bureaucracies".

[34] Whilst the Council is able to seek funds from alternative sources, currently it is solely funded by the government.

[35] The term governmentality "sought to draw attention to a certain way of thinking and acting embodied in all those attempts to know and govern the wealth, health and happiness of populations" (Rose & Miller 1992:174).

[36] This perception of power is not unique to Foucault. Deleuze also viewed power as embedded in the techniques and practices of daily life (Allen 2003).

This analysis of power takes one beyond conceptualising power as related to the quantity of resources at one's disposal, or invested in an institution or group, to an understanding that power is ubiquitous and pervades throughout daily life (Allen 2003). Foucauldian notions of power also perceive power as embedded in techniques: "what defines a relationship of power is that it is a mode of action that does not act directly and immediately on others. Instead it acts upon their actions" (Foucault 1994: 340). Techniques of power are capable of inducing appropriate forms of conduct amongst people and populations (Allen 2003):

> Government is a domain of strategies, techniques and procedures through which different forces seek to render programs operable, and by means of which a multitude of connections are established between the aspirations of authorities and the activities of individuals and groups.
>
> Rose & Miller 1992: 183

In the governmentality perspective, state power is therefore regulatory in nature. It passes through institutions and acts upon individuals, rewarding conformity to social norms (Foucault 1980; Foucault 1977). Thus governing is not so much a matter of:

> ...government itself, but the welfare of the population, the improvement of its condition, the increase of its wealth, longevity, health, etc. and the means that the government uses to attain these ends are themselves all in some sense immanent to the population; it is the population itself on which the government will act either directly through large-scale campaigns, or indirectly through techniques...without full awareness of the people.
>
> Foucault 1991: 100

Thus, government is able to reach so deeply into the lives of a dispersed population that individuals internalise its effects (Allen 2003). Rose and Miller (1992) and Ballard (1998) argue that these regulatory powers are a means by which governments can 'govern at a distance' and create populations, communities and individuals who are capable of living a regulated autonomy.

Under this conception of power, some authors consider NGOs and CBOs to merely be the 'handmaidens' of governmentality; third sector organisations are viewed as a means by which the state is able to extend its ability to govern at a distance, and regulate hard-to-reach ,marginalised sections of the population (see Bryant 2002). As discussed in Chapter One, Shaver (unpublished work cited in Altman 1994) and Wolch (1989) articulate this in terms of community organisations becoming part of a 'para' or 'shadow' state, whereby their autonomy becomes severely limited and their objectives become aligned with those of the state.

Alternatively, NGOs and CBOs are considered to be able to draw power *from* the state. However, under the Foucauldian conceptualisation of state power, NGOs are not involved in an instant transfer of power from state to non-state; rather they are a means by which to change the functioning of governmentality through the empowerment, development and harnessing of civil society (Sending & Neumann 2006). Indeed, in Foucault's rendering of power, resistance is a condition of operation, and one does not exist without the other:

> No moment of domination, in whatever form, is completely free of relations of resistance, and likewise no moment of resistance, in whatever form, is entirely segregated from other relations of domination: the one is always present in the constitution of the other.
>
> Sharp, Routledge, Philo & Paddison 2000: 20

Creswell (2000: 264) argues, "Resistance, then, is not opposed to power but is a subset of it. Resistance becomes the deployment of power with the motivation of alleviating or transforming the conditions under which one lives". Thus NGOs may act as sites of resistance to state power. Through attempts to advocate, empower and develop those marginalised by market and government initiatives, such organisations attempt to transform the mechanisms of governmentality.

NGOs and CBOS are therefore actively involved in *both* resisting the power of the state through harnessing civil society, *and* extending the government's ability to govern at a distance. Similarly, Sending and Neumann (2006) suggest that the third sector represents a change in governmentality whereby civil society is not a passive object which is acted upon but rather an entity which is both an object and subject of government; the non-government sector enables the mobilisation of civil society whilst simultaneously enhancing the government's ability to carry out regulatory functions. In this thesis I agree with Sending and Neumann's appraisal but contend, based on my research at the Oliver Smith Council, that – as well as resisting and perpetuating governmentality – third sector organisations are also regulated by state power.

Many authors (see, for example, Lehman 2006, Sending & Neumann 2006, Altman 1994) conceptualise NGOs and CBOs as being involved in a reciprocal relationship with civil society, stating that third sector organisations can only form where there is a 'political space' free from government and bureaucracy. However, they are also considered instrumental in creating, harnessing and invigorating a robust civil society to oppose the government and market sectors, and to prevent civil society from being merely 'acted upon' by the state. However, if one returns to Foucault's conceptualisation of this, it is clear that he argues that the existence of civil society is not a given reality, nor an ideological construct, but rather the "correlate of a political technology of government" (Burchell 1991: 141). He states that civil society is a 'transactional reality' of governmentality. Through attempting to regulate and control individuals, communities and populations (much like resistance) there will always be those who outstrip the reach of the state (Burchell 1991). This is similar to the argument of Rose and Miller (1992) who contend that, through the diminishment of the sovereign state, governments became responsible for civil society and thus needed to form new methods of governing which in turn gave rise to governmentality. Thus according to Foucault, Rose and Miller (1992), and Burchell (1991) civil society and a governmentality-based state are transactional realities of one another.

In light of this I contend that, where there is governmentality, there will always be a political space for NGOs. To form this space NGOs and CBOs must work with both civil society and the state. Thus, third sector organisations are situated in complex networks of power whereby they simultaneously resist, perpetuate, and are regulated by, state power. In this complex (and at times difficult) position, third sector organisations represent a "central feature of how power operates in late modern society" (Sending & Neumann 2006: 652).

Relational power & the Oliver Smith Council

> To the extent that the modern state 'rules', it does so on the basis of an elaborate network of relations formed amongst the complex of institutions, organisations and apparatuses that make it up, and between state and non-state institutions. (Rose & Miller 1992:176)

> Problematics of government should… be analysed in terms of their governmental ambitions. Through an analysis of the intricate inter-dependencies between political rationalities and governmental technologies, we can begin to understand the multiple and delicate networks that connect the lives of individuals, groups and organisations to the aspirations of authorities in the advanced liberal democracies of the present. (Rose & Miller 1992: 176)

Theoretical accounts, such as those outlined above, have not incorporated the experiences of specific organisations.[37] In this thesis I explore, using the example of the Oliver Smith Council, how third sector organisations resist, perpetuate and become regulated by, the state. I begin this process in this section by relating the theoretical debates from the previous section to an overview of the Oliver Smith Council's position, before going on in the next chapter to discuss how the positioning explored here is experienced in the day-to-day running of the organisation.

The Oliver Smith Council first arose from civil society as a volunteer organisation, due to dissatisfaction with government inaction and policy. The initial meeting, from which the Oliver Smith Council grew, was called because of frustration on the behalf of organisers at the lack of information and support for people with hepatitis C. As discussed in Chapter One, a selection of individuals who attended this meeting decided that they would begin the process of addressing this gap in government services. Bratton (1989) believes that while NGOs are small, they may be overlooked by the state and concurrently avoid any form of conflict. However, as they grow, they are likely to attract official attention and become increasingly involved with other sectors. This has certainly been the case for the Council, which now has complex ties to government and medical institutions.[38] With regard to the Council's relationship with the state (the focus of this thesis) the organisation has substantial ties to the state, the most tangible of which is funding. The majority of the organisation's funding is through the State and Federal Governments. Thus, the Council is situated between civil society and the state and, due to its reciprocal relationship with civil society (outlined in the previous section), is involved in a complex and ongoing relationship with both.[39]

Bratton (1989: 570), the first commentator to draw attention to the political landscape of NGOs, stated that "because governments resist any reduction of their leadership role… they

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[37] Bryant (2002) is the notable exception to this.

[38] One of its main objectives is to distribute correct medical information concerning hepatitis C, and the Council must therefore rely extensively on the medical sector to provide this information. Knowledge and power are differing sides of the same coin, and the need to be 'up-to-date' with medical research places the Oliver Smith Council in a network of power relations with medical institutions (which in turn have their own complicated relationship with the state) (Allen 2003; Turner 1997; Foucault 1975).

[39] Brown (1997: ix) makes a similar argument regarding community-based AIDS organisations: "the assimilation-vs-autonomy question is not merely grist for idle debate among gay community-based AIDS groups across North America. Rather, shaping their financial relationship to the state is an ongoing political issue for *all* activists who seek to alleviate immediate suffering but also want to work for long-term change in how people are permitted to order their own social world".

are likely to control NGOs by enacting legal and administrative regulations to govern the voluntary sector". Governments can invoke a variety of measures to maintain control over third sector organisations, such as laws, administrative rules and political pressures (Bratton 1989). Indeed, the Communicable Diseases Branch of the State Government must approve all projects and materials for dissemination by the Council. The Council's strict funding and policy agreements and requirements are an articulation of the state's regulatory power; much like the regulatory effects which state power has on individuals, the Council self-regulates in order to maintain its relationship with the state. This is done through adapting projects, appearance and information for distribution to suit government objectives and policy. If the Oliver Smith Council does not self-regulate, it faces the possibility of losing funding. The state offers a seemingly mutually beneficial relationship; through acquiescing to state power the Council is able to run more, and larger, projects due to an increase in funds. Furthermore, this close relationship with the state enables the Council to advocate for civil society at higher political levels.

Brown (1997) suggests that, as community organisations grow, their objectives become increasingly intertwined with that of the government. This is similar to Bratton's argument, stated earlier, that as community organisations grow they attract official attention. Through the lens of governmentality, this change can be considered as the regulation of organisations by government. For community-based organisations there are costs involved in this process – they begin to lose their volunteer base and community networks. Of particular concern to the Council is the fear that they will lose their ability to work with people marginalised from the government and market sectors.

However, the Oliver Smith Council is *not* on a uni-directional course towards the state. As noted previously, the non-government sector provides an important alternative to government because it can achieve in areas where governments cannot. The Council has community involvement, networks and the ability to work with marginalised sections of the population. It is these attributes which make the Council appealing to cooption by the state. By bringing such an organisation under the 'umbrella' of state power, the government is able to extend its ability to govern at a distance. Paradoxically, these attributes also formulate the Council as a site of resistance, and threat, to state power. They enable a mobilising of civil society and provide a voice through which it is able to critique government policy. Bratton

(1989: 570) argues that NGOs are among the only formal organisations who "enjoy a degree of autonomy from government and have a direct presence among mobilised communities at the grassroots level". The ability to maintain community links in the face of governmentality is perhaps the biggest challenge facing the Council and the non-government sector more generally.

It is evident that the third sector is not free from the surveilling and regulatory influences of the state: NGOs are embedded in a network of politics and power relations. Third sector organisations occupy a space between civil society and the state and consequently are subject to the regulatory forces of government as well as extending the reach of governmentality. This is true of the Oliver Smith Council, which simultaneously resists, perpetuates and is regulated by state power. Due to the reciprocal relationship between civil society and the state, the Council is, and will remain, involved in an on-going relationship with *both* civil society and the state.

THE SPATIALITY OF THE THIRD SECTOR

> Space and the political organization of space express social relationships but also react back upon them. (Soja 1980: 207).

As mentioned previously, the majority of discussions concerning governmentality and the third sector (with the exception of Bryant 2000) provide theoretical debate which is not grounded in the experiences of organisations and individuals. In this section I discuss spatial theory and its importance in providing an account of the third sector that is actor-orientated, before exploring the experiences of Council workers in the next chapter.

Recent attempts at conceptualising the politics and power relations of the third sector have remained abstracted from physical interaction and space. However, these debates, and their concomitant analysis, are in fact spatial arguments. They are concerned with how NGOs and CBOs function in a space between the state and civil society. Thus, despite the lack of explicit explorations of space, relevant literature is scattered with spatial references, for example: "The ability of the community sector to respond to [an] epidemic is closely related to the political space available for affected groups to organize" (Altman 1994: 157). It is likely that this has occurred because many explorations of the third sector use the work of Foucault. Arguably, in Foucault's writing, space is present yet often elusive; Lefebvre argued that Foucault makes no explicit attempt to articulate what space it is that he is referring to, "nor how it bridges the gap between the theoretical realm and the practical one" (Sharp et al 2000: 27; Soja 1996; Lefebvre 1991). However, the relational aspects of power are contained and articulated in society and space (see also Philo 2001):

> Different social groups endow space... with amalgams of different meanings, uses and values. Such differences can give rise to various tensions and conflicts within society over the uses of space for individual and social purposes, and over the domination of space by the state.
>
> Sharp et al 2000: 26

Similarly, Lefebvre argues that:

> Socio-political contradictions are realized spatially. The contradictions of space thus make the contradictions of social relations operative. In other words, spatial contradictions 'express' conflicts between socio-political interests and forces; it is only in space that such conflicts come effectively into play.
>
> Lefebvre 1991: 365

Thus particular spaces become sites of "contestation where the social structures and relations of power, domination and resistance are interwoven" (Sharp et al 2000: 26).

The space of NGOs and CBOs, such as the Oliver Smith Council, are where "discourses of power and knowledge are transformed into actual relations of power" (Wright & Rabinow 1982: 14. See also Sharp et al 2000). Similarly, Lefebvre states that "space is not a scientific object removed from ideology and politics; it has always been political and strategic" (Sharp et al 2000: 28; Soja 1980: 207). Thus spaces, such as those of NGOs and CBOs, can become "counter spaces", where alternative discourses and knowledges can be created (Lefebvre 1991: 382).

If the complexities of working in the third sector are to be elucidated, it is necessary, as Sharp et al (2000) suggest, to pursue more grounded inquiries into power relations and explore how specific spaces are created, used and defended. It is evident that complex power relations characterise the nexus between civil society and the state, which the Council occupies. However, how these power-relations are 'played-out' physically within organisations has not been explored. Brown (1997: 86) suggests that third sector "organisations have come to be spaces where relations of state and civil society weave together". In this thesis I have taken a 'spatial turn' to explore how the staff and volunteers at the Council negotiate, and are affected by, the power relations of the third sector.

RECENT DEBATES IN SPATIAL THEORY

Anthropologists have been relatively slow in embracing the spatial turn; "there has been surprisingly little self-consciousness about the issue of space in anthropological theory" (Gupta and Ferguson 1992: 6). In anthropology, space has primarily been theorised in terms of its disciplinary abilities or in relation to deterritorialisation (Foucault 1977; Gupta & Ferguson 1992; Appadurai 1986). With regard to the former, Foucault's work on disciplinary techniques initiated a trend in the social sciences to explore space predominately through its negative implications. Although Lefebvre argues that Foucault's theorising is not grounded in space or the spatial dimensions of social interaction, and that his use of floating spatial metaphors "obscured the political concreteness of social spatiality", space is nonetheless present in Foucault's work (Soja 1996: 146).[40] The spaces Foucault discusses are that of regulation, restraint, surveillance and dominance. Furthermore, his work provoked a proliferation of research into the effects of hospitals, prisons and other institutions on individuals (Stoller 2002; Sharp 2001; Osborne & Nikolas 1999). Foucault (1986) called these sites of rupture and disjuncture 'heterotopias'. However, it has been suggested that this propensity for investigating heterotopias has skewed social science research, limiting investigation into the positive effects of space in creating subjectivities (Conradson 2003; Thrift 2000).[41]

Concerning space and deterritorialisation, commentary on the politics of place has also resulted in a more anthropologically-based discussion of space and culture. This stemmed from anthropology's post-modern preoccupation with globalisation, national identity and diasporatic communities. The debate focused on the mapping of culture onto space and culminated in the delineation of space and place. Space and place came to offer "differing yardsticks by which the geographical world [can be] described and analysed" (Kearns & Joseph 1993: 712). While place was 'anchored' in human experience, space became "a kind of

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[40] Foucault admits that spatial metaphors were an 'obsession' for him (Smith & Katz 2003). Smith and Katz (1993: 73) argue that Foucault's spatial metaphors "encouraged the task of making the 'space in question concrete', but that Foucault failed to grasp the 'full power' of his use of metaphors.

[41] Thrift (2000: 269) argues that whilst Foucault "embraced a positive notion of power, the fact is that his world view is not very positive".

neutral grid on which cultural difference, historical memory and societal organisation [were] inscribed" (Gupta & Ferguson 1986: 7; Kearns & Joseph 1993). It is arguable that this demarcation of space and place resulted in a diminished appreciation of the experiential aspects of space for much of the social sciences; "it is in this way that space functions as a central organizing principle in the social sciences at the same time… it disappears from analytical purview" (Gupta & Ferguson 1989: 7). Kearns and Joseph (1993: 712) argue that this preoccupation with demarcating space and place "involves a geographical fixation amounting to little more than an out-dated search for regional synthesis".

Whilst the space-versus-place debate has dominated anthropological inquiry, social geographers have been primarily concerned with space as either perceived or conceived (Bondi & Fewell 2003; Shields 2001; Soja 1996; 1989; Kearns & Joseph 1993; Lefebvre 1991). Perceived space, otherwise known as first space, consists of the tangible, intelligible space which can be mapped and measured. Perceived space is buildings and roads, the literal objects with which we interact; "the material form of things in space" (Soja 1996: 76). In this theorising of space human sociality is conceptualised as merely an outcome or a product of space (Soja 1996). Consequently, perceived space theorising is commonly criticised for being positivist. Alternatively, conceived or second space poses the question 'What are the possibilities of the perceived space which lies before us?'. It is predominately the concern of artists, architects and town-planners, and exists in the realm of possibility (Soja 1996).

In the last decade spatial theorising has turned towards creating a synthesis between previous spatial dichotomies. Kearns and Joseph advocate a "marriage between …views of space and place" (1993: 716), whilst Shields (2001) and Soja (1996) have supported a breakdown of the perceived/conceived dualism (see also Bondi & Fewell 2003). Contemporary social geographers have begun to favour an alternate theorising of space which considers space to be both "the medium *and* outcome of social relations… [space] guides *and* records individual and collective behaviour" (Kearnes & Joseph 1993: 712. Emphasis added). Consider, for example, that a city is not simply a "collection of people and things in space"; it is both more complex and more abstract than this (Lefebvre 1991: 138). The work of Lefebvre (1991), Soja (1996) and Shields (2001) on 'lived space' is central to this new theorising of space.

This turn in social geography allows not only for a breakdown of the space/place and perceived/conceived dichotomies, but enables an exploration of space that encompasses a broader gamete of human experience than previously found in the social sciences. Lefebvre's and Soja's alternate theorising of 'lived space', or third space, focuses on how social actors *experience* space, rather than what is *in* space. Lived space is closer to anthropological notions of place, in that it too is "anchored in human experience" (Kearns & Joseph 1993: 712). However, it encompasses elements of space and place, and perceived and conceived, but transcends these former concepts. Subsequently, social geographers have begun to use lived space as a means to explore human experience.

Lived Space

The notion of 'lived space', and the spatial turn in Western social theory, stemmed from the work of Henri Lefebvre, a French Marxist 'meta-philosopher' (Soja 1996; Shields; Kearns & Joseph 1993).[42] Lefebvre's work is also grounded in existentialism; his focus on the 'lived' and 'experienced' portrays an existential-phenomenological foundation.[43] Prior to Lefebvre's work, space was conceptualised as being either perceived or conceived.[44] Analysis of these types of space created discourses 'on' space (Shields 2001); it concentrated on what we, as human-beings, are able to inscribe *on* space. Anthropological forays into space and place occupy this paradigm, concentrating on the inscription of culture onto space through the experience of place. Lefebvre's legacy to spatial theory was to provide the initial impetus to shift thinking beyond conceptualising people and objects in space. This 'spatial turn' has resulted in space ceasing to be about 'What we can do with it?', towards asking questions such as 'How do we experience it?'.

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[42] Lebefve dedicated much of his writing to critiquing state power through a Marxist framework. Lefebvre's Marxism underpins much of his theorising on space; production, in the capitalist and consumer sense, is a recurring theme in his work. At times this Marxist-orientated critique is more than a theme, it is the driving force behind his attempts to break down conventional perceptions of space.

[43] Despite denying it for a considerable portion of his lifespan, Lefebvre later in life conceded his work was influenced by that of Sartre. Sartre was the leading advocate of existentialism, basing his early work on Husserl's phenomenology (Smart 1999).

[44] Due to his strong Marxist orientation, Lefebvre viewed these impressions of space as being based in capitalist ontology. They were the sites of, or the imagined sites for, production. Lefebvre understood these types of space to be a commodity; they were "capitalist space" (Lefebvre 1991; 135). At his most optimistic, they were the sites of production of knowledge and power 'used' by the 'capitalist hegemony' (Lefebvre 1991; See also Merrifield 2000).

Lefebvre's lived space was initially conceived as a way of exploring space whereby previous binary oppositions were inconsequential; 'subject/object', 'structure/agency', 'space/place' no longer needed to be 'either/or' categories. Lefebvre achieved this by conceiving of a third: "one always has three. There is always the other" (Lefebvre quoted in Soja 1996; 53). In terms of space, this third option was 'lived space'. By exploring space as it is experienced by social actors, lived space encompasses elements of 'perceived/conceived', 'subject/object', 'structure/agency' and so on, as our daily experiences of social life and space incorporate both elements of these categories;

> Space is simultaneously objective and subjective, material and metaphorical, a medium and an outcome of social life; actively both an immediate milieu and an originating presupposition, empirical and theorizable, instrumental, strategic, essential.
>
> Soja 1996: 45

Many social geographers have used Lefebvre's work to extend beyond theorising real and imagined space, towards an appreciation of lived space (Kearns & Joseph 1993).

Distinct from previous conceptualisations of space, Lefebvre's lived space is social. [45] Our interaction with space operates at different levels. At an individual level we understand ourselves in spatial terms; we are bodies that extend into space, physically and mentally (Shields 2001). On a collective level we experience multiple bodies interacting with space, and thus lived space has social dimensions; "when we evoke 'space', we must immediately indicate what occupies that space and how it does so... space considered in isolation is an empty abstraction" (Lefebvre 1991: 134). Lefebvre states that lived social space is:

> ...constituted neither by a collection of things or an aggregate of (sensory) data, nor by a void packed like a parcel with various contents, and that it is irreducible to a 'form' imposed upon phenomena, upon things, upon physical materiality.
>
> Lefebvre 1991: 137

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[45] Whilst Soja and Lefebvre's lived space is distinctly social, it differs significantly from previous notions of social space. The concept of social space was first described by Durkheim in *De la division du travail social* in the late 1890's, and was expanded upon by French geographers such as Maximlien Sorre and Chombart de Lauwe (Durkheim 1960, cited in Buttimer 1969). These previous humanistic theories of social space focused on the movement of people through various social spaces or landscapes (Buttimer 1969). They concentrated on mapping the distribution of social groups, and later progressed to explore the shaping of environment by people (Buttimer 1969). These theories were constrained in their approach, and have since been supplanted by Soja's work (Kearns & Joseph 1993).

As stated previously, the work of Soja (1996) has also been instrumental to the new spatial turn. It is worth noting that Lefebvre and Soja's lived space is similar to the space of Homi Bhabha. Bhabha's work is primarily concerned with exploring cultural difference. In the *Location of Culture* Bhabha (1994) uses a "thirdspace", much like Lefebvre's lived space, to explore cultural difference which is not bound by hegemonic perspectives of culture. It is worth noting that Soja has also clearly been influenced by Homi Bhabha's work, as demonstrative of the term thirdspace.

Soja (1996) reformulates ideas from Lefebvre's text *The Production of Space* in an attempt to give Lefebvre's work greater utility (Soja calls this reformulation of lived space 'Thirdspace'). Soja believes that lived space 'expands the spatial imagination' so that one can capture the complexities of lived social life as both a medium and an outcome of social relations.[46] For example, the space of the Council is created by those who work there; they choose the building, they determine what it looks like inside through the layout of offices and decorations. Lastly, their interaction shapes the social environment within. Simultaneously the building is the 'face' of the organisation to the community; its internal structural layout effects interaction within, which in turn forms the social environment of the Council. Thus, space is both a medium and an outcome of social relations.[47]

Space & relational power

Previous explorations of the power relations of the third sector have remained abstracted from space. This may be because these accounts draw on the work of Foucault and, as mentioned earlier, while space is present in Foucault's writing, it is also elusive. However, an analysis of relational power is not complete without an understanding of its spatial dimensions; as Sharp et al (2000: 24) phrase it, space and power are inextricably entangled as "relations of power are really, crucially and unavoidably spun out across and through the material spaces of the world". While at times elusive, a "comprehensive and critical

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[46] Soja argues that we should explore lived space as a way of understanding 'being in the world' which is simultaneously social, historical and spatial, without being bound by 'either/or' categories. By exploring lived space, or Thirdspace as he calls it, we are able to bring elements from previously opposed dichotomous thought to allow for the "free play of human agency" (Soja 1996: 63).

[47] Soja states that "space in itself may be primordially given, but the organisation, and meaning of space is a product of social translation, transformation, and experience" (Soja1989: 79-80).

understanding of spatiality was at the center of all [of Foucault's] writing" (Soja 1996: 148).[48] Indeed discussions of governmentality and the relations of power are in essence spatial arguments; Foucault was interested in power, knowledge *and* space, as they relate to the power of the state (see Philo 2001, Smith & Katz 1993). Although Sharp et al (2000) and Philo (1992) comment that space is often elusive in Foucault's writing, the disciplined bodies which Foucault examines are located in specific spaces and times. Foucault stated that "Space is fundamental to any form of communal life; space is fundamental in any exercise of power" (Foucault 1994: 361). Interestingly, while it did not reach intellectual fruition, during the mid-1960s Foucault began to outline a new approach to space which is close to Lefebvre and Soja's lived space or Thirdspace (see 'Of Other Spaces', Foucault 1986).[49]

An exploration of space is essential in providing an account of power which is grounded in experience. Conversely, Soja suggests that an exploration of lived space is not complete without an understanding of how power crosses and intersects it; he argues that lived space is characterised by an "interstitial flowing of power", such as that conceptualised in Foucault's theorising of power and governmentality (Soja 1996: 145. Quoting Baudrillard). Indeed, Soja states that "hidden in the underbrush [of the theorising of lived or third space]… is the body and mind of Michel Foucault" (Soja 1996: 145). This is because power affects how we use, experience and 'live' the space around us – it is a "social relation diffused through all spaces" (Sharp et al 2000: 21).

Through the use of lived space I am able to provide an account of the effects of relational power which is grounded in experience and actor-orientated. With discussions of 'margins' and 'decentrings', Sharp et al (2000: 27) comment that "space-talk" can often become too metaphorical. Lived space, however, provides a way of speaking about space which emphasises material manifestations of power and resistance. With regard to this thesis, an exploration of lived space enables the effects of the power relations of the third sector to be expounded spatiality and experientially, in a way which has not formerly been achieved.

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[48] However, as stated previously in this chapter, Foucault's work focused on the negative effects of space. Philo (2000) and Soja (1989: 16) argue that Foucault's work on power was instrumental in shaping human geography: "The contributions of Foucault to the development of critical human geography must be drawn out archaeologically, for he buried his precursory spatial turn in brilliant wheels of historical insight".

[49] 'Of Other Spaces' consists of re-printed lecture notes published after Foucault's death. As these notes were never reviewed for publication by Foucault himself, many academics do not consider them to be part of his official body of work (Soja 1996).

CONCLUSION

In this chapter I have provided a discussion of recent scholarly theorising of the third sector and the power relations which characterise it. While I agree with Sending and Neumann (2006) in stating that third sector organisations both resist and perpetuate governmentality, I contend that third sector organisations are also regulated by the power of the state. Thus, third sector organisations are positioned in complex power relations, between civil society and the state.

Few detailed studies of what is occurring in specific organisations have been undertaken, and previous theorising of the third sector has remained abstracted from the experiences of organisations and individuals. Through exploring the praxis of the Oliver Smith Council, in this thesis I examine how and why working in the third sector is complex and, at times, difficult. I argue that the tensions and concerns experienced by Council workers relate to the organisation's, and the third sector's, positioning between civil society and the state. To do this, I draw on spatial theory. In this chapter I have outlined recent debates in spatial theory and, more specifically, provided a discussion of Lefebvre's (1991) and Soja's (1996) work on lived space. I have demonstrated how space can be used as a conceptual framework at two levels. Firstly, theoretical debates regarding the third sector are most appropriately framed as spatial debates; they are concerned with how CBOs and NGOs function in a space between civil society and the state. Secondly, utilisation of spatial theory enables an account of the third sector which is grounded in the experience of individuals and organisations. In the next chapter I provide such an account.

Chapter Six explores how the positioning of the third sector is experienced spatially by workers at the Oliver Smith Council. I show how the power relations of the third sector are 'played out' in the space of the Council and, as Sharp (et al 2000) suggests, how the space of the Council is created, used and defended. The discussions of power discussed in Chapter Five form the foundations for the experiences which are articulated in Chapter Six. This is because, as Soja states, an exploration of lived space is not complete without an account of how power intersects it.

Chapter Six

Shifting spaces in the third sector

> What we are concerned with, then, is the history of space, even though space is neither 'subject' nor an 'object' but rather a social reality – that is to say, a set of relations and forms. This history is to be distinguished from an inventory of things *in space*... as also from ideas and discourse about space. (Lefebvre 1991: 166).

CHAPTER INTRODUCTION

Throughout this thesis I have discussed the Oliver Smith Council's positioning between civil society and state apparatus. This positioning creates challenges and tensions within the organisation; tensions, which have spatial as well as ideological dimensions. In this chapter I offer a discussion of how workers experience this positioning spatially, in the daily running of the organisation. This chapter also draws on *community*; it is evident in workers' spatial observations and experiences that the workers at the Council are concerned about a shifting of core values associated with being a community organisation. Indeed, this is creating a sense of shifting spaces within the organisation away from civil society, towards that of the state and market.

In this chapter, I draw on the notions of space and spatial theory outlined in the previous chapter. Space is an important and often overlooked concept when analysing the positioning of the third sector. While diverse and complex networks constitute civil society and the state, they are concrete realities and, as concrete realities, they exist in space. Also, broader debates concerning the interaction, politics and power relations between civil society, state apparatus, and the third sector are spatial debates; they raise questions about how NGOs function in, and negotiate, a space between civil society and the state. At a micro level space is often a central organising theme, and an explanatory vehicle, for the workers at the Council to articulate and elucidate their experiences.

CREATING A SPACE OF CARE

"The idea of support is so varied, it's hard to be everything for everyone" (Oliver Smith Council Worker)

The positioning of the third sector between civil society and state apparatus means that it is characterised by complex power relations, primarily due to a need to maintain networks, relationships and work with both. This challenging positioning of the third sector has consequences for the day-to-day functioning of the Council. It affects policy and decision-making at an organisational level and is also reflected in the experiences of individuals who work at the Oliver Smith Council. In this section I discuss the challenges that are created by this positioning when creating a space of care for people affected by hepatitis C.

The primary concern of the Council is to assist people affected by hepatitis C. It is important to the staff to ensure that the Council remains a place where people affected by hepatitis C may come and receive information and support and are given a chance to discuss their condition openly. It is important to the workers that the Council remains a space where people affected by hepatitis C can be cared for. Whilst care is predominately conceptualised as involving physical assistance or nursing, care can be framed more broadly as the "proactive interest of one person in the well-being of another" (Conradson 2003: 508; 2003a).[50] Care may therefore be…

> present in everyday encounters between individuals who are attentive to each other's situation, who perhaps provide practical assistance or who simply make time to listen to what the other has to say. It is about a movement towards another person in a way that has the potential to facilitate or promote their well-being.
>
> Conradson 2003: 508

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[50] Williams (1998: 193) frames spaces of care as 'therapeutic landscapes' which are "places, settings, situations, locales and milieus that encompass both the physical and psychological environments associated with treatment or healing".

As a geographer, Conradson extends this broader definition of care and gives it spatial dimensions.[51] Concurrently, a 'space of care' is any location designated for interaction involving the 'proactive interest' in the wellbeing of individuals. Through reconceptualising care in these broader terms, the Council can be considered a 'space of care' for people affected by hepatitis C.

This is similar to the language used by workers at the Council who describe the need to ensure that the Council is a 'safe space'. As discussed in Chapter One, the affiliation between hepatitis C, injecting-drug use and other marginalised sections of the population has resulted in pervasive social and systemic discrimination and stigma which adversely affect many people with the virus. Many of the people who come to the Council do so after discriminatory experiences, as Sam explains: *"I think a lot of people, you know, when they are first connected with the Council it's as a result of... fairly negative experiences"*.[52] The need to create a 'safe space' stems from the stigma associated with the disease, and the negative impact this has on individuals: *"[the Council is about] providing a safe space for people, to be able to express their concerns about having this thing that in the outside environment you can't talk about"*.

Social and medical discrimination and stigma often results in people being uncertain about, or even afraid of, disclosing their hepatitis C status (Temple-Smith et al 2004; Hopwood & Southgate 2003; Gifford et al 2003). A safe space is therefore related to people's ability to disclose and discuss hepatitis C without fear; a space of care for people affected by hepatitis C must also be a safe space. Furthermore, a space of care for those affected by hepatitis C must be a "place in which the trauma ... specific to the epidemic [are] not only permissible affectivities" but part of the culture of the organisation (Patton 1997: xv).[53]

Conradson argues: "spaces of care are shared accomplishments and, in reflection of this, may at times be socially fragile" (Conradson 2003: 508; Thompson 1993). Thus, creating a space of care is dependant upon how the space shapes individuals' subjectivities or identities. What is experienced as safe and caring for one person may not be for another.

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[51] Conradson's work is part of a growing body of literature on the geographies of care. A significant portion of this research is concerned with mental health and care landscapes, see Kearns and Joseph (2000), Parr (2000) and Philo (1997).

[52] Similarly, Barnes and Shardlow (1997: 297) suggest that organisations such as the Council provide "'safe environments' in which sometimes fragile identities can be supported, and confidence and skills can be developed".

[53] Patton's comment is made in reference to Brown's ethnography on AIDS community-based organisations. Despite this, her comments resonate strongly with the hepatitis C epidemic.

Experience of a space of care is dependant on individual subjectivity formation within the space and the individual's broader circumstances away from the space of care (Conradson 2003). The processes of care-giving are also relational: the creation and endurance of a space of care depends upon an individual's willingness to be receptive of care and engage with the space in which it is being given (Conradson 2003). Thus, creating a space of care for people affected by hepatitis C is challenging – hepatitis C affects a diversity of people, who may seek very different things in a space of care. The Council must therefore negotiate multiple and diverse needs. This will be demonstrated in the following discussion of workers' experiences of the Council as a space of care.

In Chapter Two Sam, Gwen and Kate explained that the change in the Council's location has resulted in a shift in the Council's spatiality from being experienced as 'homely' to being experienced as 'professional'. For some individuals this change has meant that the Council is no longer a safe space where they are comfortable to talk about hepatitis C and receive 'care'. For others, however, the change in the Council's spatiality has meant they are able to "move towards others…[and] engage" with the Council in a way they were unable to in its previous locations (Conradson 2003: 508). This reflects the difficult and contested nature of creating a space of care for people affected by hepatitis C as the virus affects a very diverse population. In the following comment Sam explains the challenges of forming the space of the new Council building as a space of care:

> *"The last place we were in was like a small house... people really liked the feel of it, walking in off the street ... but to come into this, I see it as much more professional and maybe for some it's a bit alienating whilst for others it would be quite positive... to outweigh some of the negatives of the stigma of hepatitis C... so it's like 'of course this organisation deserves a nice place to work'. But I think... in the growing... some people feel they get distanced from maybe having a sense of input or ownership."*

In the following narratives two Council workers, Ryan and Lily, further elucidate Sam's comments. The differences in Ryan and Lily's experiences demonstrate the diversity of perspectives which exist within the Council, and the challenging nature of constructing a safe space of care for people with hepatitis C.

Ryan

Ryan volunteers at the Council for support and to keep himself abreast of changes that are occurring with hepatitis C treatments. Ryan has had counselling for his hepatitis C in the past, and it was suggested to him by his counsellor that volunteering at the Council may help his depression and self-esteem. Through volunteering Ryan receives support for his hepatitis C and enjoys the social contacts he makes through his involvement with the Council. He first began volunteering in the space of the old Council and feels strongly about the changes that have taken place. Originally, the Council space and the act of volunteering affected him positively; he found it welcoming and inclusive. In the new space of the Council, however, he has begun to feel disconnected.

> *"I've made a lot of friends and acquaintances here. That is the main thing that keeps me going, although that has dropped off a bit in that the social side for the volunteers has dropped off considerably... It [has] not only changed for the volunteers, in my opinion, it's changed for affected people out in the community, past and present. I remember back at the old Council we used to have many visitors. They were always welcome. They're always welcome here but this is a very different sort of office compared to the old place. The old place was very homely, it was a house with a built in kitchen, with a verandah immediately out the back. People who had worked here before, people who had been affected, people who had had liver transplants, I used to get to meet all sorts of people in that little area.*
>
> *[Volunteering] has not been so enjoyable. In both ways, both in the social aspect, because I don't feel that this building is conducive to that kind of thing... you see there's nowhere to sit down outside anymore, forget about going outside. [Being downstairs] is another problem, something I didn't like at first... the house was sort of a little bit more open in that people were very close, but I understand they had to come out of there because it was getting too crowded, but people weren't so far away.*
>
> *I don't think this is a supportive place for affected or infected community anymore. We don't have a drop-in [environment] anymore."*

Lily

Lilly works in Administration at the Council; she was not involved with the Council it its previous location. However, Lily approached the Council for volunteer work when it was located within the state's drug and alcohol services in Smithtown. When Lily first approached the Council in Smithtown she did not experience the Council as a safe place and could not engage with it as a space of care, due to her perceptions of hepatitis C. In contrast to Ryan, however, the new Council's 'professional' appearance has enabled Lily to both give and receive care:

> *"When I was [at the Council] in [Smithtown]... I wasn't there for a long time because it was located at the back of a drug and alcohol clinic...it was this pokey little place, which really when I first saw it I thought – this isn't good. It wasn't. While the people were nice it just didn't seem professional, it didn't have that sense that they could get things done. It was very chaotic, chaotic in some ways, very laid back in others. I had the impression that everyone but me must have been a full-on druggie, had all sorts of life issues. [I thought] are they going to come out and stab me? But that was just paranoia at first diagnosis. I think even here though, because of the stigma, there seems to be a lot more people who access the services here... I don't know if it's a lower socio-economic background, but certainly it's people who are on disability... they're the people who perhaps don't have supports outside, they don't have the resources to do that. I know that the injecting drug users are one of the main targets, because that's where it mostly comes from, but there are a lot of others as well that I think wouldn't come to the Council because they don't want to be associated with that. Again I think that's the stigma. There might be a person who injected a few times in their younger years and don't want to let people know. They assume that by coming here [that] other people might see them with [someone with] long hair and tattoos and think 'oh no, they're gonna think I'm a druggie!'... I hear that all the time – 'I didn't know she took drugs'.*
>
> *I think the change of building and the change of location [has reduced that]... When I came back this time it was into this building, which was a beautiful building – everyone seemed really positive, it was very welcoming... [When] people hear 'hep C' they just think of people lounging around injecting drugs and drinking heaps, generally having a party of a life... but when they walk into an office and there's a reception, a library and resource centre, it all looks good. It's that first impression thing, yes this is a professional organisation, it's not a haphazard bunch of people who got together."*

Ryan and Lily's narratives demonstrate that radically different experiences of the Council exist side-by-side. Ryan's discussion of the spatiality of the Council demonstrates his uneasiness with the 'newness' of the building; that it lacks the lived-in, or homely, feel associated with a building which has been in use for a substantial period of time. Similarly, Ryan's sense of 'ownership', despite being a volunteer, is diminished by the office-like appearance. The lack of informal meeting areas, and the 'office' layout of the new Council means Ryan feels isolated, as demonstrated by his comment that people are far away. In contrast, Lily feels that the spatiality of the Council helps to undo the stigmatised nature of the disease. The appearance of the Smithtown Council exacerbated her concerns at first diagnosis, particularly that people would think she was an injecting drug user. In contrast, the 'professional' appearance of the Council's current spatiality is more congruent with her subjectivity. For Lily the Council's new space makes her feel "positive" and "welcome". Lily now feels she can 'give care' to others because she is now more confident about the organisation and its appearance.

The fragile nature of a space of care

Conradson argues that space has a critical role in creating identity. This is similar to Berger and Luckman's (1967) concept that individuals' subjectivities or identities are created intersubjectively with other people. Conradson extends this, stating that we also create our identity intersubjectively with space. Space and identity are linked (Keith & Pile 1993; Massey 1994; Pile & Thrift 1995). This can be contextualised by the idea that we are different, in different spaces:

> we may observe significant changes in subjectivity—our sense of self, who we are and feel able to be—across different spatial settings. In immediate terms, people may thus speak of 'feeling comfortable', 'somewhat awkward' or 'more able to be themselves' within particular environments. We may notice shifts in both mood and affective state, from feeling (say) confident to somewhat diffident, when moving between settings.
>
> Conradson (2003): 509

Thus space is "more than backdrop" (Halford 2003), the spatiality of the Council affects people's perceptions and experiences of the organisation and, more broadly, their perceptions and experiences of hepatitis C. Ultimately, it determines people's willingness to engage with the Council as a space of care. Thus, the change in the Council's spatiality has resulted in a subsequent change in how the organisation acts as a space of care for people affected by hepatitis C. This is because the spatiality of the Council impinges on people's subjectivities. This can be seen in the comments made by Ryan and Lily. Spaces of care are co-constructed between individuals and space, and between individuals and individuals. The Council as a space of care is therefore, as Conradson suggests, socially fragile. The change in the Council's spatiality has meant that for some it is no longer a space of care, while others now find they are better able to engage with others in a welcoming and supportive way.

Both Ryan and Lily make a broader statement about how the community perceives the Council and its operations based on their experiences. Ryan is concerned that people in the community will feel like him – distanced from the Council as a place of support and care. For Lily, however, the new and office-like appearance shows that the Council is now a place which can 'get things done' and will therefore have broader appeal. Although all workers acknowledge a change in the Council's spatiality and atmosphere, not all are as strikingly affected by it as Ryan and Lily. This can be seen in the following comments from workers:

> *"I think [the old Council] was more of a laid back casual atmosphere really... the atmosphere's changed I think. I don't think it's any less welcoming to people though, I think it's a better thing, it's just that before it was more casual. I think it was a bit more casual before, especially for people coming in off of the street for information and what have you whereas now it's straight into the library, there's no like hanging around in the kitchen and having a chat like we had before."*

> *"The larger community, we've always had a space for when people come in, now it's the library, we used to have a front room in the other place... there was always space where they could have privacy and have a meeting. It's more in terms I guess of the [people] who come in and work here, those community members. Yeah maybe I do feel a little bit... that it's been kind of lost... I think we've all been grappling a little bit because where do you get that space in here."*

Whilst these statements focus on the interior space of the Council, Bondi and Fewell (2003) argue that exterior space is just as important as interior space on the care-giving process; appearances can have different "symbolic values for [individuals], and impact differently" (Bondi & Fewell 2003: 542). Indeed, Sam's comments quoted earlier draw attention to the exterior space of the Council and the feel one gets when "walking in off the street". For the Council, the exterior façade of the building determines how the organisation presents itself to the community.

The effect of exterior space can be seen in the way the Council is approached by different people. The Council building has front and rear access. The staircase and the ornate balcony provide the front entrance with a grand appearance (see figures 2 and 3). The rear entry, however, is less formal, characterised by a network of concrete ramps and metal railings. Workers at the Council use both entrances routinely. However, once a fortnight the Council hosts a support group in one of the rear meeting rooms. Individuals who attend the support group do so through the rear access, rarely if ever approaching the front entrance. Often support group attendees wait in their cars at the rear of the building until the meeting has begun, rather than waiting outside the Council door, or entering the main building. Several support group attendees have never set foot inside the main part of the building. This indicates that the exterior spatiality of the Council is not always congruent with the subjectivities of individuals coming to the Council for support. It also raises questions with regard to workers' concerns that a community organisation should have a 'sense of ownership' by the community. The behavior of the support group attendees suggests that they feel that they do not have this sense of ownership.

Creating a space of care is always difficult due to its co-constructed nature – one space can never have a positive impact on everyone's subjectivity. However, in the case of hepatitis C some clear distinctions can be made. As Council workers explained, many people affected by hepatitis C are marginalised and vulnerable. Arguably, it is unlikely that these people will find a formal office space inviting or comforting. In contrast, people of higher socio-economic backgrounds are more likely to find such spaces comforting. This is particularly so for higher socio-economic people affected by hepatitis C, such as Lily, since they often wish to distance themselves from the stigma associated with a disease that affects marginalised people. Thus, the Council is faced with difficult decisions concerning who the organisation will appeal to as a safe-space of care.

Undeniably, the Oliver Smith Council is in a difficult position. It is important to workers that the Council premises act as a safe-space of care. There is, however, little – if any – uniformity in those affected by the virus; as Ryan's and Lily's comments demonstrate, the

Council cannot be a space of care for all. Arguably, there have always been (and presumably will always be) many people in the State affected by hepatitis C who do not, or cannot, access the organisation. This is due to a range of factors, the most straightforward of which being geographical limitations; one organisation cannot provide face-to-face support for the population of a whole State. However, as I discussed in Chapter One, Jones et al (2004) state that one of the most important functions of community-based organisations is to provide face-to-face contact and support to a (relatively) small number of people. It is in this aspect of the organisation's functioning that its appearance, and ability to act as a space of care, is important.

Spaces of care & relational power

Decisions regarding how the Council will act as a space of care are further complicated by the organisation's position between civil society and the state. As discussed previously, what makes governmentality effective is that it acts upon actions so that, as Allen (2003) states, the government is able to reach so deeply into the lives of a population that they internalise its effects. By this Allen (2003) means that individuals begin to self-regulate in accordance with government objectives. The regulatory effects of governmentality on the individual have been widely analysed and debated. However, in the case of the Council, self-regulation has occurred on an organisational level. The Council has begun to self-regulate and change its appearance because workers perceive that a building resembling a house is not congruent with government perceptions of what an effective, productive organisation should look like.

This process cannot, however, be assumed to be wholly negative for the organisation; working with the state is important to the Council because is enables them to advocate and influence political agendas at a higher level. Some activists may contend that this type of advocacy is a long way from the initial 'grassroots' action of NGOs and CBOs; however, it may also enable organisations to be more politically effective (see, for example, Bryant 2002). With regard to the day-to-day functioning of the organisation there are, however, effects which must be considered. In the case of the Council, they must choose between a 'homely' building which individuals like Ryan felt comfortable in, or a more 'office-like' and 'up-market' appearance which is likely to allow the organisation to work more closely with government. Arguably, there are no easy solutions; while senior staff at the Council may feel that the new spatiality of the organisation appeals to government, the more fragile in the community find it threatening. Thus, the organisation must simultaneously make decisions concerning whom it will act as a space of care for, while negotiating the tensions of the third sector.

In summary, for the Oliver Smith Council the process of receiving care has spatial dimensions; how the organisation looks and feels to an individual determines whether they are able to take part in a 'care giving' interaction. With the move in premises, many workers feel that there has been a shift in the Council's spatiality from a place which is experienced as "homely", to one which is more "professional". Spaces of care are co-constructed and socially fragile. This shift in the Council's spatiality has meant that different people are able to engage with the Council as a space of care; individuals like Ryan no longer feel that they can receive care at the Council, whilst others who previously felt uncomfortable in the environment of the Council are now more easily able to engage with the Council in this manner.

FORMING BOUNDARIES

> *"Here, it's 'all in' ... there's not that difference between manager and his or her staff"* (Oliver Smith Council Worker).
>
> *"That was [one of the past manager's] attitude, that everyone comes along together, this is not about whether you're a paid worker or not a paid worker, and one person has more power. [The manager] actually saw 'community' has power and was really encouraging of any community member coming into the Council"* (Oliver Smith Council Worker).

The Council's positioning in the third sector, and the subsequent power relations operating between the third sector and the state, has led to shifting spaces of inclusion and exclusion within the organisation. This can be seen in my previous discussion concerning the Council as a space of care, and is demonstrated again in this discussion of the forming of physical and mental boundaries between staff and volunteers. The term boundary refers to a sense the workers at the Council have about being disconnected, or distanced, from other workers. This distancing has both physical and mental dimensions.

As mentioned previously, for workers at the Council, space often operates as an important explanatory vehicle. In order to articulate their experiences, workers draw spatial comparisons between the premises the Council formally occupied and where it is currently located. In this section the terms 'old Council' and 'new Council' are used to refer to these different primacies. By drawing comparisons between the two, workers are able to explain their sense of shifting boundaries within the organisation. Soja (1996) argues that we must recognise that sociality, spatiality and history are linked; the weight of historical associations, understandings and interactions impact upon what social actors do, socially and spatially, in the present.[54] It is therefore not surprising that the workers at the Council articulate their experiences in terms of the Council's social and spatial history. In the spatial comparisons drawn between the old and new Council, workers explain that in the old space of the Council they experienced the organisation as 'hands-on' and free of boundaries. However, in the new spatiality of the Council they feel that the layout, or internal spatiality, organises them into separate sections and has no informal meeting areas. In relation to these comments it is important to note that space is both a medium for, *and* an outcome of, human interaction and experience (Soja 1996). As Lefebvre suggests, space "is thus not merely a 'frame' or 'container' for lived experiences, but is rather a tool for thought and action… through which individuals may give expression to themselves" (Lefebvre 1991: 26-33. Quoted in Halford & Leonard 2006b: 5).

The spatial changes experienced by the workers are not arbitrary; the way in which the organisation is developing is reflected in the building they have chosen to accommodate them.[55] Halford and Leonard (2006: 5) state that organisational spaces "are often physical representations of discursive constructions".[56] Indeed, for many workers the buildings which

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[54] The re-insertion of space in sociality, or understanding social interaction as having spatial dimensions, is part of Lefebvre's broader argument that history, sociality and spatiality are linked. This broader argument is concerned with 'being': Heidegger's *Dasein* and Sartre's *etrê-la*. Lefebvre and Soja argue for a re-orientation of ontology to conceptualise 'being in the world' as simultaneously historical, social and spatial (Soja 1996).

[55] It is worth noting that workers, both volunteer and paid, were consulted in the choice of a new building for the Council.

[56] Furthermore, Halford and Leonard (2006:5) argue that "Organisations are also located within particular locales, themselves carrying embedded meanings, opportunities and practices", which are in turn interconnected with other spaces which have implications for the construction of meaning and identity".

the Council has occupied have come to embody the ideological changes they sense in the organisation. Consequently, the old Council building is often conceptualised as being synonymous with a casual, grassroots organisation, whilst the new Council building stands in distinct contrast as tantamount to an organisation which is developing a "corporate" or "government" feel. In other words, an organisation that lacks the key values of the third sector which are encapsulated by the symbol *community*: 'hands-on', "grassroots", "welcoming" and so on.

During my fieldwork, both staff and volunteers often commented that, in the 'early days' of the organisation, workers and work were not divided into sections. When work needed to be done, whoever was around would help – manager, staff member or volunteer: *"[it] was just like whoever was on hand would help"*. This gave the organisation a more informal, grassroots atmosphere. Workers associate the terms "grassroots", 'hands-on' and "all-in" with an absence of boundaries within the organisation and between its workers. As discussed in Chapter One, the Council has recently undergone a substantial period of growth. In its previous location both the organisation and its premises were small in comparison to its current formation. Workers at the Council explain that previously the size of the organisation and its building meant that both space and work were constantly shared: *"If something had to be mailed out it was all hands on, for everyone to pitch in and get it done"*. This small space was conducive to informal discussions, and the 'workshopping' of ideas. The constant interaction which this enabled reduced boundaries between workers, both physically and mentally: *"[when we were smaller] we had more interaction... you may not have been able to tell who was what [kind of worker]"*. More specifically, workers at the Council notice, and comment upon, the boundaries forming between paid staff and unpaid volunteers:

> *"The whole volunteer thing is a bit different to when I was here before as well, initially when volunteers first came in... we were only a small organisation and we all had probably a lot more to do... they were just there in a small organisation and you'd get to see them all and have more interaction with them."*

> *"Generally speaking you tend to have a bit less interaction [with the volunteers]... it feels different... I don't know if that's just a matter of the size of the organisation. I would say that volunteers who were involved initially – we had a lot to do with them and knew them very well, and I would feel like all of us knew them very well."*

Previously there were fewer physical and mental boundaries between the staff and volunteers – they shared work, meals, conversations and ideas. However, volunteer work has become increasingly restricted to specific times and tasks and informal interaction between staff and volunteers has been reduced.

Workers feel that the workspace of the current Council means that they are now divided into sections, which are relatively separate from one another. At the Council's current location, the underground level of the building is arranged into an education section and a resource section, while the upstairs level houses the manager, administration and the support-line. Workers feel that the spatiality of the new Council 'sections them off' and reduces interaction. Decisions, which once involved all workers, are now more likely to be made separately by individual teams or sections within the organisation:

> *"I think the structure is different...[the] volunteers, they come in on certain days and they tend to stick in the phone-line... there's not that movement across all the areas and I think it's about having these more kind of structured areas now than we did at one point"*

Workers explain that the workspace of the old Council was 'more like a house', whilst the new Council *"is just like other offices"* that you find in the corporate and government sector. Furthermore, workers perceive that the spatiality of the new Council perpetuates this sense of shifting and forming boundaries within the Council, which may in turn serve to further diminish the grassroots nature of the organisation. This has lead to a growing concern from workers that the organisation is losing its 'hands-on' nature; that is, the boundaries within the organisation have reduced fluidity between workers and sections, both at an informal and a formal level.

In their spatial comparisons workers are particularly concerned with the absence of informal meeting space in the new Council – for example, workers talk of missing a 'kitchen table' in the new Council building. The kitchen at the old Council provided an opportunity for informal gatherings which broke down boundaries between levels of workers and ensured the integration of volunteers and affected community into the organisation; it ensured that the Council was 'hands-on'. This can be seen in the following statements made by workers:

> *"I know that people would probably like a good space around, for both staff and volunteers... a more informal meeting and joining place. There doesn't seem to be that so much in this new set up... it tends to be within your own sections now, and I think that's a thing of the size of the place... it has to have something to do with kind of where you place your values too doesn't it."*

> *"I suppose I miss not having a kitchen, because [previously] we had a kitchen area where we would sit. At Smithtown we had a large room... and that was sort of like a kitchen as well, but it was sort of a workroom. The communication that happens there quite informally is important."*

> *"I'm aware of people that volunteer, [their] attitudes around their space in this place and the start of attitudes. We [don't have] a good eating place in this place... whereas [at] the last place certainly the kitchen was kind of almost the heart [of the Council]. A lot of things happened around the kitchen table in the last place so it's quite interesting [that] we don't have a kitchen or a kitchen table in this place."*

In these statements workers are indicating that they are concerned that they are losing and, furthermore, that they miss the "grassroots" or "laid back" nature which the Council used to have, where they cooked and shared meals, discussions, and work.

Boundary formation & community roots

> Although the NGO sector has become increasingly professional over the last two decades, principles of altruism and volunteerism remain key defining characteristics (Lehman 2006: 2).

The formation of boundaries within the organisation is of considerable concern to workers because of the perceived relationship between boundary formation and third sector values; the formation of boundaries is perceived to enable a shift in the space of the Council from what workers describe as a "community-based organisation" space, towards a "government" or "corporate" space. Workers at the Council often refer to this process as "becoming professional", the effects of which are most clearly articulated through the utilisation of *community*. In Chapter Three, I demonstrated that the term *community* is used as a summarising symbol at the Oliver Smith Council. As a summarising symbol, *community* draws together a collection of values which describe what it means to be an organisation in the third sector. Through exploring the symbol *community*, we are able to understand what distinguishes organisations in the third sector from government and corporate organisations. Workers at the Oliver Smith Council understand "grassroots", 'hands-on' and having a work environment which is "all in" as integral to being a third sector organisation. Thus, workers are becoming concerned with how boundary formation is affecting the spatiality of the organisation and its core values. Workers are increasingly concerned that the space of the Council has begun to shift from that which is "grassroots" and 'hands-on' towards an atmosphere that is "corporate" or "like government" and more closely resembles the government and market sectors. In this thesis I have attributed these concerns to the positioning of the organisation in the third sector and the power relations which characterise this space.

Workers at the Council are concerned that, by becoming professional, they are shifting away from the core values of *community*. This is of considerable concern to the workers and the organisation, because the organisational policies which grow out of *community*, such as community integration and participation, are pivotal to the organisation's position in the third sector and to their ability to achieve where governments cannot. This can be seen in the following statements from workers:

> *"I feel like community is being left behind, because that's how it is, the further up the corporate ladder [we go] and the more of the peak body stuff we get into, the more bureaucratic we become. It's just a way that things happen, so community get left out. I think that's part and parcel of things getting bigger... I don't think there's a way out of it. I think that there almost needs to be another body set up for community, and the Council as a peak body because that's where we're going – we seem to have moved out of the community organisation into the peak body category. I think it's like we've moved up the ladder to that peak body situation and we're going after the quality management sort of stuff... which is very corporate. And I think the community is being left behind because we're up on this level [now]."*

> *"It's becoming more impersonal. It used to feel like community has power here, nowadays I don't feel that community has power here. There are some community members on the Board but on the whole I don't think community knows who they are and are talking to them. Slightly different thing, you know we used to have BBQs once a month for community, that doesn't happen anymore, we don't have any community functions anymore."*

> *"I do worry a little bit that some of the community, they may not access the Council if it's a bit more like that... it might seem a bit more, I don't think that's it professional but more like a, I don't know what's the word I'm looking for, kind of a strictly structured organisation really where it's not really community friendly maybe, I think some people might see it like that."*

> *"I think it's become more corporate. It used to be really community focused, now we're getting more into quality management systems... I understand that, you've got to move on. It's not the same place it used to be it's not as personal as it use to be for people."*

> *"When I talk about the place being lifted up to another level, it's become more professionally affective, but I don't necessarily think it invites people in."*

> *"A lot [more of the work] will be caught up in more bureaucracy, more accountability. So unless we get a lot more funding, more resources will be tied up in the administration side of it, and less going to education, which sort of defeats the purpose... A lot of energy [is] taken up in trying to keep the place running, trying to get funding, trying to get recognition. I think before it was a lot more 'ok this is what money we've got', let's go do it... I'd say for most of the people here they're more attracted by... the interaction with people and what we're trying to do rather than... supporting the organisation or administrative [work] in a systematic way."*

Gail explains that this is a conundrum faced by many in the third sector:

> *"It's a thing about community organisations when you are first starting off... it's much more grassroots at the beginning and then as you attract funding [it changes], it's kind of this bureaucratization process that goes on. You know as you get more money and you have to become more, not that you're not accountable but you, I guess it's more you have to write everything, document everything, so it tends to take you away from that service delivery."*

In these statements workers are clearly concerned that, through their relationship with the state and the mechanisms of governmentality, the organisation is increasingly resembling government and market organisations both in terms of policies, appearance and objectives. It is important to note at this juncture that there are distinct benefits in 'becoming professional'. As an organisation they are better able to advocate at higher political levels and to negotiate more effectively with government because they are more closely aligned with government perceptions of what a functioning, effective organisation looks like. However, since the

Council is situated between civil society and the state, they must also maintain their community networks.

As boundaries form, and the organisation becomes professional, there has been a decrease in informal collaboration and discussion. This decrease is indicative of a broader concern at the Council and for community-based organisations more generally: how do community-based organisations retain their voluntary association, community representation and community integration while appealing to state apparatus and power for funding and recognition (Altman 1994)? In terms of the theoretical argument of this thesis, this question may be framed as follows: how can the Council maintain the key values of the third sector (articulated by the symbol *community*) while they are increasingly affected by the governmentality of the state through their need to maintain a funding relationship? The forming of boundaries, and the subsequent lack of informal collaboration, means that volunteers are increasingly isolated from the totality of the organisation – they are directed into specific volunteer jobs and roles, rather than being involved in all work and at all levels of the organisation. However, the integration of people affected by hepatitis C, through volunteering roles, into the functioning of the organisation is pivotal to the Council's self-definition as community-based. Furthermore, an environment which is congruent with the informal meeting of community members is important for maintaining crucial community networks. Much like informal collaboration and the absence of boundaries, this type of environment is important in creating the "grassroots" spatiality of a community-based organisation. Whilst the Council maintains community integration at a Board and project level, informal collaboration and integration through volunteering and the informal "drop-ins" by community members are important to retaining *community*.

At a broader level, community integration and representation is crucial to the organisation's, and the third sector's, ability to offer an alternative to government interventions and projects. Thus, losing the values of *community* due to the effects of governmentality is a concern for the Council which extends beyond its walls and day-to-day interaction. Although many of the workers' comments revolve around their own experiences within the organisation, there is an underlying concern about how these changes may impact on the community's perceptions of the organisation:

> *"I think it was a bit more casual before, especially for people coming in off of the street for information and what have you whereas now it's straight into the library, there's no like hanging around in the kitchen and having a chat like we had before."*

In the following statement Sam explains that, to be true to *community,* the organisation must also retain its connections with the state:

> *"[The Council must be] something which is not only sustainable, but something which is responsible to community needs, that is judged by community... judged isn't the right word... the Council needs to be professional to be responsible to our community. I think it's important that we're able to advocate for a diverse community at higher levels. In order to do that we need to be perceived at those higher levels as being professional because if we're perceived as being a tinpot organisation... we're limited to what we can do. We're limited in what we can achieve for the people we're here to service and that's very important... So as an organisation... you've got to get communication happening at that level and it's got to come sort of trickle down."*

Spatial experiences of boundary formation

The formation of boundaries within the organisation has resulted in shifting spaces of exclusion and inclusion; the work and physical location of the volunteers is increasingly organised into specific areas. For some volunteers, this has resulted in feelings of isolation. The following quote from a volunteer expresses his recent sense of disconnection from the organisation:

> *"I'd like to know exactly where these decisions are coming from to make these changes [I see happening]. Do they come from the manager? Do they come from the Board? Who's making the decisions? I don't know! Sometimes when there is a change going on you wonder 'why didn't they ask the people on the ground that thing first?'"*

Similarly, in the following excerpt a staff member expresses her concern that volunteers are beginning to feel undervalued, and that they are "getting less" out of their volunteering due to the shifting spaces within the organisation:

> *"We used to do research, we had a whole lot of input into the Council, however you've got to remember that the Council was a lot smaller then so we probably had a lot more value. The volunteers now don't seem to do that much that seems to be empowering for them."*

It is important to note, however, that the concerns of workers are not indicative of the demise of the Council. Whilst workers are concerned about the impact of shifting boundaries within the organisation, they also believe that the organisation is more developed and productive than it has been in the past:

> *"We do so much more [now], before we would be doing limited information sessions around the place, they were very often reactionary to requests we would get. A lot of our resources were re-printed from other Councils, we didn't produce things ourselves... our lobbying capacity was much less, because when you have less staff you need to be doing more practical things and there was less thought about the future."*

> *"What I have said it may have given the impression that, you know, I might worry about how [the Council is] going in the future... I don't really worry about where it's going I have every faith that... it will just go from strength to strength."*

Indeed, the change in spatiality and boundary formation has also enabled the organisation to work more effectively:

> *"People can concentrate on their work more."*

> *" You get a greater capacity when you get the chance to focus... which is really important when people are able to focus, otherwise people become really eclectic and it just becomes very fractured work."*

> *"It gives us that autonomy to run things how we think they should be running."*

> *"People [find] it very different working here. There wasn't as much communication between staff because we didn't have an area to sit down at a kitchen table and have lunch together and people were separated into their rooms and stuff like that. I think that's progressively improved, people have found ways to communicate even though we don't have a table to sit around. Some people much preferred that open type thing, but I think equally a lot of people prefer having individual areas."*

> *"Certainly the Council has grown, the staff has grown, we've certainly got a lot more resources than we had [previously], so I think we've been successful in growing the organisation over [the] years. In terms of our communities there's probably a lot more awareness of hepatitis C if not the fact that people know about it in depth I think they're at least aware"*

> *"We didn't have the capacity to separate out the manager into much more of a strategic sort of office [before], they were too embedded in the day to day role of the organisation".*

The workers at the Oliver Smith Council are concerned about losing the core values associated with being a community-based organisation because, as one staff member explained, it is important that the Council *"maintain that grassroots approach, that hands-on approach… [we see] that as being very important for maintaining contacts with… community"*. These characteristics, or values, are an important part of the organisation's self-identification as a community-based and third sector organisation. However, as I discussed in Chapter Three, state power is, in the words of one worker, 'seductive' as it offers a mutually beneficial relationship. Although workers may be concerned that they have lost some of their grassroots, they have gained the ability to work more productively and to create further-reaching projects which are likely to be more sustainable.

Through the shift in Council primacies, workers have begun to feel that boundaries, both physical and mental, are forming between themselves and other workers. In particular, boundaries have begun to form between staff and volunteers. This boundary formation has both positive and negative effects for the organisation. For workers, there is a concern that such boundary formation is leading to a loss of *community*. In the theoretical context of this thesis, this is indicative of a larger concern that the organisation may become a subsidiary of the state, or part of the 'para-state'. However, forming of boundaries has also enabled the organisation to become more effective and enhanced its "professional" appearance and, in turn, its ability to work with the state.

CONCLUSION

Part Three of this thesis has analysed the second theme of space and spatiality. Throughout Part Three I have demonstrated that the Council's positioning between civil society and the state leads to challenges and tensions within the organisation. It is evident that workers at the Council are concerned about losing core values associated with being a community organisation. This is creating a sense of shifting spaces within the organisation, away from the third sector and towards that of the state and market.

In Chapter Five I demonstrated that space is an important concept to this thesis and the theorising of the third sector. On a broad level, debates about the third sector are in essence spatial debates – they are concerned with how community-organisations function in a space separate from the state. From a theoretical perspective, spatial theory also enables an actor-orientated account of the power relations which characterise the third sector. In Chapter Six I provided an actor-orientated discussion of the space of the Oliver Smith Council.

Patton (1997: xv) argues that the connections between community organisations and the state are creating a "new kind of community place" and that no matter "how problematic these new spaces are" their existence puts issues such as hepatitis C "on the map", enabling them to be politicised. In Part Four I suggest a way forward for the problems and difficulties which have been discussed in Parts Two and Three. In doing so, I discuss how the formation of Patton's new spaces may be better facilitated.

Part Four

Conclusion

It may be inappropriate to regard the fluidity of the NGO field as a weakness or the impermanence of any given NGO as a failure. Rather, we might look for permanence in the rebellious process from which many NGOs emerge and within which some NGOs remain engaged. NGOs and social movements may come and go, but the space created... may contribute to new activism. (Fisher 1997: 459).

Chapter Seven

Conclusion: Creating new spaces in the third sector and beyond

At the time this research was conducted the Oliver Smith Council was in a state of flux; changes in size, location and internal policy had resulted in tensions and debates within the organisation with regard to how the Council would endeavour to continue to work with community, and what objectives, functions and roles are fundamental to the Council being a 'community-based' organisation in the third sector. As discussed throughout this thesis, these debates are not unique to this particular organisation; rather they represent significant practical and theoretical concerns for community-based, non-government organisations more broadly.

Through exploring the praxis of the Oliver Smith Council, in this thesis I have demonstrated that working in the third sector is complex and, at times, difficult. I have argued that these complexities and difficulties relate to the organisation's, and the third sector's, positioning between civil society and the state. In order to articulate this argument, I took an actor-orientated approach to explore how this positioning shapes, and is shaped by:

1. Understandings of 'community' in the organisation
2. Spatiality in the organisation.

Below I provide a summary of how this argument has been developed throughout the thesis:

In Chapter One I introduced the concept of the third sector and explained how it relates to civil society and the state. I argued that these relationships place the third sector between civil society and the state. Through the narrative account of my research experience, provided in Chapter Two, I demonstrated that workers at the Oliver Smith Council felt vulnerable about the space of their organisation and began the process of exploring how and why the third sector is a difficult place in which to work.

In Part Two I considered the first theme of this thesis: community and how it is understood and conceptualised by workers at the Oliver Smith Council. In Chapter Three I explored how community is understood both in the literature and by workers at the Council. I argued that *community* acts as a summarising symbol at the Council to articulate what it means to be a community organisation. In Chapter Four I drew on the theoretical assertions made in Chapter Three to explore workers' perceptions of how the organisation works with community. In doing so I demonstrated that, within the organisation, considerable debate exists regarding who should work in the Council and what work the Council should be undertaking. I argued that this debate has arisen as a result of the organisation's positioning between civil society and the state.

In Part Three of this thesis I analysed the second theme of this thesis: space. In Chapter Five I considered the space of the third sector on two levels. Firstly, I argued that debates concerning how the third sector relates to, and works with, civil society and the state are spatial debates; they are concerned with how these organisations operate in a space separate to the state. Secondly, I contended that an appreciation of the spatial dimensions of this argument enables an actor-orientated account of the power relations of the third sector. Subsequently, in Chapter Six I drew on Lefebvre's and Soja's notion of lived, or third, space to explore how workers experience the spatiality of the Council. I demonstrated that the positioning of the third sector has profound spatial, as well as ideological, consequences for those working in CBOs and NGOs.

REPOSITIONING

As stated throughout this thesis, while the third sector is broadly understood as 'doing good' by fulfilling an important social and political role, what exactly this role is and how it may be filled has received little attention (Fisher 1997). Similarly, it is evident that working in the third sector is complex and difficult; however, why this is the case has not sufficiently been explored. This thesis has attempted to fill some of the gaps in our knowledge of the third sector by offering an exploration of the Oliver Smith Council as a case study of what is occurring in specific organisations and places. However, this project is also founded in a strong sense of reciprocity and consequently aims to assist Council workers in making sense of the debates and tensions occurring within their organisation.

When I first came to the Council I often received the impression from workers that they were caught in a current they could not escape; that, whether they chose to or not, they were on an unstoppable, unidirectional course out of the third sector towards the paperwork of bureaucracy and the homogeneity of the market. However, as I noted in Chapter Two, workers at the Council have begun the process of repositioning their organisation. At the time of writing workers have reorganised the internal layout of the organisation. Among these changes has been the shifting of the volunteers to the upper level of the organisation. Also, whilst previously under threat of conversion to office space, the library room at the front of the Council has been retained as a space for community. The straight-backed, semi-antique chairs have been replaced with lounge chairs and a coffee table. The walls have become colorful – now decorated with memorabilia from community-related activities.

Through these changes the workers at the Council are not only repositioning their organisation as a space of care but also ensuring a place for community within their organisation. With an enhanced understanding of the debates occurring within the organisation, I hope that this research enables the Council to continue to reposition itself with regard to civil society and the state.

This thesis has explored the positioning of the third sector through an actor-orientated discussion of Oliver Smith Council workers' experiences. While diverse opinions and perspectives exist within the organisation, it is evident that these debates and tensions are caused by concerns about the Council's relationships with their community groups and the government. I have argued that these concerns and tensions have arisen due to the third sector's positioning between civil society and the state. In the next section I provide a discussion of how we might begin to better appreciate the space of the third sector, by conceptualising the Council's 'counter' practices between civil society and the state.

CREATING NEW SPACES

> *"I think there are some core [values] around social justice and accepting diversity... You're working towards the world being different by working in an organisation like this"* (Oliver Smith Council Worker).

The perhaps small changes noted in the previous section demonstrate that the Council is actively engaged in reinterpreting its place between civil society and the state. However, that these changes are relatively small and remain essentially internal, hints at a much larger question: how can we (re)conceptualise the relationship between the Oliver Smith Council and the state in a way which respects the actor-orientated account I have presented in this thesis?

As discussed in Chapter Five, Foucault (1991) and Rose and Miller (1992) argue that civil society is a condition of operation of the state. According to these authors, they are involved in a reciprocal relationship – civil society is a transactional reality of governmentality, and in turn governmentality is a transactional reality of the existence of civil society. As a voice for civil society NGOs and CBOs will continue to be involved in an on-going relationship with *both* civil society and the state. As Bratton (1989) phrases it, NGOs and governments may be uncomfortable bedfellows, but they are destined to cohabit.

In this thesis I have discussed the recent debates regarding the social and political roles and position of the third sector and third sector organisations such as the Oliver Smith Council. It is evident, both from the perspectives of those who work within the organisation and from theoretical commentary, that NGOs and CBOs must continue to work closely with both civil society and the state. While some academics (see Lehman 2006; Mercer 2002; Bryan 2002) believe that it is not yet clear how NGOs and CBOs will fulfil their objectives, it *is* clear that third sector organisations have an important socio-political role in offering discourses, knowledge, services and support, which differ from that of the government and market sectors. I conclude this thesis with a discussion of how we may better conceptualise third sector organisations' work with civil society and the state, using the example of the Oliver Smith Council. To do this, I use the concept of 'counter-discourse' as a framework.

Counter-discourse

"In the end, one must, in the most uncomplicated sense, act"
(Moussa & Scapp 1997: 92).

Whilst the previous chapters of this thesis have used Foucauldian conceptualisations of governmentality to provide a lens which enables a clear articulation and exploration of the experiences of Council workers, I do not use Foucauldian notions of resistance as a framework for the following discussion regarding the forming of new spaces.[57] As I discussed in Chapter Five, resistance is a condition of operation of power; it is "the deployment of power with the motivation of alleviating or transforming the conditions under which one lives" (Creswell 2000: 264). In my earlier discussion of the power relations of the third sector, I used Foucault's concept of resistance to discuss the ability of third sector organisations to critique government and challenge governmentality. While this is useful for theoretical discussion regarding the positioning of the third sector and the concomitant power relations, Foucault's notion of 'counter-discourse' offers a more appropriate framework for pragmatic action in response to governmentality. Counter-discourse is a lesser-known concept of Foucault's and, although it certainly is grounded in ideas of resistance, it offers "not another theory, but rather a practical engagement in political struggles" (Moussa & Scapp 1996: 88; Delueze & Foucault 1977). Arguably, Foucault's concepts of resistance and Counter-discourse are closely related: they are both concerned with how individuals may interrupt the regulatory nature of power. However, the concept of resistance remained somewhat abstract in Foucault's theorizing. It conveys a general notion that people are not always subordinate to power and at times they attempt to change power by resisting its regulatory effects. It does not, however, tell us *how* to act in order to resist power. In contrast, Counter-discourse offers an actor-orientated account of *how* to 'act-out' against power. That is, Counter-discourse outlines ways in which people may resist.

Foucault's work has often been criticised as "radical political analysis with little practical value" which fails to adequately encapsulate a theory of agency (Moussa & Scapp

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[57] Having said this I have made reference to Foucault's concept of resistance earlier in the thesis, and recognise its applicability.

1996: 87; Lyon & Barbalet 1994. See also Lazarus 1991 & Ehrenreich 1992).[58] However, Foucault *was* an activist:

> He never wanted to establish timeless, acontextual truths. Instead, he hoped that his books would have the effect of hand grenades, scattering the accepted theoretical ideas about madness, social order, and sexuality.
>
> Moussa & Scapp 1996:88; See Foucault 1987

Foucault contends that there is no disparity between theory and practice with regard to his work because his 'theories' have emerged through, and are therefore inextricably bound to, the political struggles of marginalised people against forms of power (Foucault 1987; Moussa & Scapp 1996). Moussa and Scapp (1996: 92) also argue that Foucault's *practice* of theory arose from his desire to "provide clearing for political action":

> In the realm of theory, for example, he 'allows' prisoners to speak by disrupting common assumptions about the French penal system with *Discipline and Punish…* Of course, neither Foucault the theorist nor Foucault the activist is literally capable of allowing or disallowing prisoners to speak…Rather… Foucault the theorist provides a political clearing in which others, including himself as an activist, might then speak – might form counter-discourses. Foucault's *practical theorizing* is the act of creating spaces, within a discourse, where a counter-discourse can emerge.
>
> Moussa & Scapp 1996: 92

Even counter-discourse has been accused of being merely another theory, to which Moussa and Scapp (1996: 93) respond: "[counter-discourse is] in metaphoric terms… a voice that arises directly from below; it is, for this reason, not a theory or discourse that bears a merely uncertain relationship to practice".

Counter-discourse is "when the formerly voiceless begin to speak a language of their own making – a counter-discourse – [in doing so] they have begun to resist the power seeking to oppress them" (Moussa & Scapp 1996). Moussa and Scapp (1996) call this 'Foucauldian activism', whereby groups in civil society are able to undermine the oppressive discourses of institutions and the state by ensuring that the discourses they create are as 'counter' as possible. Counter-discourse closely resembles development and public health notions of community empowerment. However, it is more theoretically informed and conscious; it also incorporates a greater appreciation of the role of discourse and theory in community development and empowerment activities.

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[58] Moussa and Scapp (1996) believe that the practical political value of Foucault's work has been overlooked due to reluctance of academics to rely on an intellectual support that is anchored on human social practice.

When considering counter-discourse in relation to this thesis, the act of theorising or outlining the political landscape in which the Oliver Smith Council operates enables us to understand why a counter-discourse is necessary, and how it may be created and facilitated. One can only ensure that a discourse is 'counter' when the broad socio-political picture has been revealed; Moussa and Scapp argue that Foucauldian theorising such as the governmentality framework used in this thesis is a means by which to assist in creating new discursive spaces for stigmatised individuals.[59] Predominately this is because this type of practical theorising enables discourses and power-relations to be revealed and understood so that we may begin to assist in the creation of a counter-discourse:

> In our terms, a counter-discourse is the hoped-for result of *practical theorizing* – an activity with, as we understand it, comparatively modest goals. The practical theorist hopes only to clear a discursive space in which those who were previously silenced might speak up…
>
> Moussa & Scapp 1996: 90

Counter-discourse offers a tool for conceptualising the role of CBOs and NGOs and how they may work in a space between civil society and the state.

Understanding the space of the third sector

Under the framework of so-called 'Foucauldian activism', the role of third sector organisations may be understood as intermediaries for the creation of counter-discourses. They enable counter-discourse to be created through arming marginalised and stigmatised individuals with the skills and knowledge to speak for themselves, while ensuring that their voices will be heard by the state. Allowing counter-discourse to be created by those affected by hepatitis C is paramount to this process: "Just as only those who hold political power can meaningfully discriminate against stigmatised groups, so only those who have been oppressed by a discourse can form a counter-discourse" (Moussa & Scapp 1996: 93).

Counter-discourse is concerned with enabling marginalised people to speak for themselves. It is evident that the role of the Council, with regard to the creation of counter-discourse, is to provide skills and create a political space for individuals affected by hepatitis

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[59] Moussa and Scapp (1996: 103) do not contend that Foucaulidan theorising is the only means by which a counter-discourse can be created. Similarly, Foucault never argued that he had found "*the* way to combat disciplinary power".

C to speak for themselves. This role is being carried out by the organisation through its work with positive speakers – projects which aim to increase individuals' skills and knowledge around hepatitis C – and its encouragement of affected community members to take part in political forums. As mentioned, counter-discourse bears a resemblance to the concepts of community development and empowerment and it is through this work that the Council assists in creating a counter-discourse; they are able to give hepatitis C-affected individuals the skills and ability to speak with regard to their stigmatisation and marginalisation. In this way, community organisations can become 'counter spaces', creating alternative discourses and knowledge (Lefebvre 1991).

Although I have argued in this thesis that the third sector is located between civil society and the state, in this position NGOs and CBOs are subject to the regulatory power of the state. The Council must therefore be conscious of the dangers, as Foucault and Deleuze (1977: 209) phrase it, of "speaking for others". In an interview with Foucault, Deleuze referred to the act of "speaking for others" as an indignity – because we must encourage and create a space for those, who are usually spoken for and about, to begin to speak for themselves (see Deleuze & Foucault 1977: 209; Foucault 1987).[60] Foucault responded by explaining that it is only through this process of enabling others to speak for themselves that a counter-discourse may be created. One must, therefore, be aware of the dangers of "speaking for others", predominately because, as Foucault (1987) argues, speaking for others does not challenge or change hegemonic discourses or the governmentality of the state (Deleuze & Foucault 1977: 209). Consequently, the Council must think carefully about its future decisions and directions – whether they involve seemingly small issues such as appearance and the organisation's physical space, through to the core business of the organisation.

Creating counter-discourse is fundamental to the work of the Council if it is to reduce the stigma associated with hepatitis C and prevent those who are affected from being marginalised. However, there are additional benefits for the organisation associated with this process. As stated previously, while there is a general perception of third sector organisations as "doing good" (Fisher 1997: 442), the exact role of these organisations, or more precisely the ambiguity of their role, is a topic of increasing debate. The lens of counter-discourse helps

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[60] In this well-known interview Deleuze revealed that "In my opinion, you were the first – in your books and in the practical sphere – to teach us something absolutely fundamental: the indignity of speaking for others" (See Foucault & Deleuze in Foucault 1987: 209).

us to further conceptualise the space of the third sector as it relates to civil society and the state. By creating a space for marginalised sections of civil society to speak, third sector organisations also articulate and legitimise their role with the state – those who can now speak for themselves may in turn advocate for the existence and role of CBOs and NGOs. It can also be argued that the creation of counter-discourse is a step towards fulfilling the potential which has often been ascribed to third sector organisations: to challenge the governmentality of the state by creating a space for marginalised people to speak out and critique the state.

Enhancing the space of the third sector

Part Three of this thesis concluded by quoting Patton (1997) who makes the insightful suggestion that, due to the pull of state apparatus, community organisations are becoming 'new spaces', different from their initial conception but still politically active and effective. In this last section I discuss suggestions, made by third sector commentators, as to how the space of the third sector may be enhanced through practice.

If third sector organisations are involved in a reciprocal relationship with civil society, as argued by Sending & Neumann (2006), Lehman (2006), Fisher (1997), Altman (1994) and Bratton (1989), arguably it is civil society to which they must, first and foremost, be held 'accountable'. Furthermore this must be measured in civil society's terms, not in corporate or bureaucratic terms: "An NGO is done a disservice by one end of the political spectrum if all activity is accountable in strictly rational terms" (Lehman 2006: 8). In understanding their broad political and social position, and what they have to offer the state, the Council may begin to determine how it answers to the state in terms of its effectiveness and accounting for its outcomes and achievements. These may be modeled on third sector values which may, for example, incorporate elements of *community* and/or counter-discourse. Lehman's (2006) suggestions may assist in managing the power relations of being placed between civil society and the state in a way that does not compromise the Council's core values and objectives.

Throughout this thesis I have argued that one of the key functions of the third sector is to offer an alternative to the discourses of the market and government sectors. However, Lehman (2006: 8) suggests: "A key problem with NGOs is that they are susceptible to capture by the same system they aim to reform". The third sector aims to offer alternatives to economic-rationalist and neo-liberal discourses. However, increasingly, third sector achievements are assessed in economic-rationalist terms. We have come to measure the achievements of NGOs by the discourses and measures they originated to oppose (Lehman 2006).

Lehman (2006: 8) argues that this has stemmed from the pervasiveness of the government and market sector: "The assimilating logic of economic structures has often been referred to as 'commodity fetishism'– which means the reduction of social values to economic and utilitarian calculations". NGOs and CBOs must strive to 'escape' corporate logic and discourse if they are to remain true to their objectives (Lehman 2006). Lehman (2006: 8) suggests that we need to evaluate and assess the achievements of NGOs and CBOs not in terms of money but in "their effectiveness in fulfiling their social purpose". Indeed, their achievements and productivity are not necessarily quantifiable in government or economic terms; rather their progression and achievement should be gauged by 'third sector' markers, rather than products and discourses of the government and market sectors.

Workers at the Council tell me that Lehman's suggestions, although valid, are difficult to put into practice. How Lehman's suggestions may be developed in the everyday world of NGOs and CBOs warrants further investigation.

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Appendices

Appendix One

Presentation given to Oliver Smith Council workers, February 2006.

Ethnography & participant's rights.

I thought I would start by just going over what exactly ethnographic research is, although you've all had a first hand look at it after my time at the Council. As you've probably noticed it involves me observing, asking questions and to a limited extend participating in the day-to-day activities at the Council. A fundamental part of this is also to document what I learn and experience, hence you've probably been aware that at most times I have had a notebook with me.

Anthropology literally means 'human study' which is exactly what we do – we observe and document human experience, in particular the meaning behind taken for granted day-to-day activities.

Whilst ethnographic research revolves around a particular style that may take some getting used to, it is a very valuable and effective way of conducting research. Everyone here would probably agree that more social research needs to be done into hepatitis C. I believe that ethnographic research is a particular type of social research which (although often appears to be rather ad hoc) results in a much deeper understanding of a social environment or problem. I understand that people are more used to the idea of formal interviews or surveys, but such methods often result in a snap shot of people's lives, rather than an understanding based on observation and participation over a reasonably lengthy period of time.

I think at this point it's important to talk about your rights as participants –

- Not to answer
- Everything is confidential
- Fake name
- Notebooks not seen by anyone
- Withdraw anytime

What have I noticed so far?
In order to give you an idea of the types of things I have been looking at during my time at the Council last year I'll run through some of my observations –

During the two months I spent here I concentrated on gaining an appreciation of the structure of the Council, both internally and the way the Council interacts with other organisations.

It appears to me that the Council is in a state of transition. It has recently moved premises, from what I gather was a rather run down house in ****, to this more up-market office in ****. In its previous location the Council was frequently used as a 'drop-in' place for people affected by hepatitis C, looking for information and support. The new Council can be described as more 'up-market' and is presented more in keeping with an office. I understand that this has been an important move for the Council as presenting the organisation in this way allows for more funding to be attracted, and therefore different types of projects to be undertaken. I've also noticed that perhaps there is a trade off between attracting funding and being accessible to people affected by hepatitis C, particularly very marginalised people who may be put off by the 'professional' appearance of the Council.

During my time here I also noticed that the term 'community' is used in three different ways. Firstly those who are directly involved with the Council are referred to as the hepatitis C community, for example volunteers and those who attend calming the C. The second way community is used is to describe the high-risk groups and those most likely to be affected by the virus, whether or not they have contracted hepatitis. Lastly community is used to encompass the general public.

Based on these observations I would like to re-orientate my project a little to continue to explore the organisations involved in the hepatitis epidemic. Particularly, the way that community organisations, such as the Council, interact with these three community groups. I am still interested in discrimination, particularly how community organisations impact on these types of day-to-day problems. For example does the way Council present itself to community, government or medical facilities affect the impact or occurrence of discrimination?

Going back to what I said previously about community, I would also like to find out more about whether or not people identify as being part of a hepatitis C community, and again how being part of a community may impact or help in coping with hep C.

I would also like to explore how the Council interacts with both government and clients.

Understanding such a complex environment requires more than one off interviews, it requires substantial time spend observing and taking part in Council activities. I would like to emphasise that this is a collaborative approach, not an evaluation by any means!

In this style of research the ethnographer becomes the student, and the participants of the study become the teachers.

To give you all an example of how ethnographic research can be really beneficial I thought I would tell you about the work of Philippe Bougois who is an anthropologist based in the states. Philippe works on HIV/AIDS and Hepatitis C. Recently he did some really interesting ethnographic research into heroin injection clinics in Geneva.

The Swiss approach to heroin addiction has most recently involved providing free pharmaceutical grade heroin. They believe that this stabilises long-term heroin users. However the Swiss health services were baffled when they found that people were either refusing the free heroin in favour of buying it on the street, or joining methadone programs instead.

Philippe went to the injecting clinics and spent a substantial amount of time watching the interactions between clients and staff, and talking to people who used the clinics. I will read out some of his fieldnotes which describes a typical interaction between a client and a nurse who worked in the injecting clinic;

(P. Bourgois 2002)
"The nurse admits four people at a time into the injection room for sessions limited to 10mintues. They sit separately at individual Formica tables with plastic chairs. The nurse who remains standing the whole time walks around the room supervising silently. Each person first picks up from the counter by the entrance a plastic Tupperware-looking food container with their name written on the top with a black magic marker and an oversized sanitary wipe. They each carefully lay the sanitary wipe on the Formica table in front of them. The pharmacist distributes loaded syringes of perfectly clear liquid to each individual.

A man with scars on both cheeks and up and down his arms is having a hard time locating a vein in the crook of his left arm. He keeps slipping in and out of his veins as he pokes into the scar tissue and then pulls back on the plunger to check for blood. The nurse explains to me in a loud voice so that he hears – almost as warning, "Our policy allows patients to make three injection attempts before the nurse takes over and administers the injection".

"The unsuccessful injector ignores her, switching arms to continue poking at least three or four more times to no avail. His needle is now completely bloodied and the pricks in his arm are oozing blood. The nurse walks over to him. He stands up and waves his arm around like a helicopter presumably in order to get the blood flowing, "Please just let me try one more time. I'll use the tie," and he sits back down. She says nothing but walks closer to him and is now standing immediately over him.

"He quickly opens his Tupperware container and pulls out the program's regulation-sized, two and a half foot long strip of quarter inch pale yellow rubber tubing. He tightens this around his arm ... and he finally manages to register a vein from which his needle does not slip. The nurse bends over, presses the release mechanism, and he injects.

She notices that he has a terrible case of impetigo between the fingers of his right hand as he settles in his plastic chair. The nurse tells him, "I want you to get up and go see the doctor now"...(she then starts explaining the treatment options for his condition)."

I think from that passage you can get the sense of why the injecting clinics were not popular. The Swiss government and those working in the health sector thought that heroine addiction was purely chemical, ignoring the social aspects of drug use. Phillip's work was able to catch the subtleties of the interaction, which made injecting clinics undesirable to clients.

Back to the Council.

In terms of benefits, I hope that this research helps the Council as it navigates a very tricky area between government and community. Hopefully this will lead to an understanding of how to engage certain high-risk groups. What would be really beneficial is if this research is able to be taken up by the Council and used to provide even better support.

For me, of course, the benefit is that this research will form the basis of my PhD.

Suggestions on how to open the research process up a little –

- Suggestion box
- Report every couple of months at volunteer meetings
- Book in manager's room for anyone who no longer wants to take part
- Focus groups - If people would like to have focus groups to open up the research process a little more this would be something I would be happy to organise, and would definitely benefit my understanding as well.

Appendix Two

Wednesday, 29 March 2006

Gemma Carey
Department of Anthropology & Department of Public Health
University of Adelaide

Dear ~~Gemma~~ Gemma

RE: "An Ethnographic Study of Hepatitis C"

On behalf of the Board I am writing to thank you for meeting with the Board of the [redacted] to discuss your research proposal. The Board is committed to facilitating research in the area of hepatitis C and endorses your research at the [redacted] with the following conditions:

1. Documentation of the new research proposal supplied to Board and Management
2. Revised draft of the "Staff & Volunteer Information Sheet" with revised research proposal and updated contact details
3. Documentation that the revised research has been approved by an ethics committee at the University of Adelaide
4. Revised consent form for all participants including community members and stakeholders of the [redacted]
5. Establishment of a "research reference group" and clear role of reference group detailed in the terms of reference for this group
6. Documentation of the [redacted]'s right to reply to and/or embargo any research findings.
7. Meeting to be arranged with research supervisors and representatives of the [redacted] to discuss the above.

The Board requires that these matters be addressed as a matter of priority before any further interviews proceed. We hope that these matters can be resolved before the next Board meeting of April 18, 2006.

Yours sincerely,

[redacted]

Manager

Appendix Three

THE UNIVERSITY
OF ADELAIDE
AUSTRALIA

ABN # 61-249-878-937

A/ PROF ANNETTE BRAUNACK-MAYER
DISCIPLINE OF PUBLIC HEALTH
SCHOOL OF POPULATION HEALTH & CLINICAL PRACTICE
FACULTY OF HEALTH SCIENCES

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TELEPHONE +61 8 8303 3569
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annette.braunackmayer@adelaide.edu.au

Wednesday, 31 May 2006

[redacted]

RE: agreement on publication of Gemma Carey's thesis "An ethnographic study of Hepatitis C".

Following Annette's attendance at the May board meeting of the [redacted], we have continued to work on the issues related to publication and embargo of Gemma's thesis.

We would now like formally to propose the following:

> Gemma Carey shall be entitled to present and publish findings from her project "A[redacted] study of Hepatitis C" subject to obtaining the prior written consent of the Manager o[redacted] Council, for which consent shall not be unreasonably withheld.
>
> A copy of any proposed publication, including conference abstracts, which Gemma prepares will be forwarded to the Manager of the [redacted] prior to submitting the publication to a publisher or to a conference. For articles in journals, the time period will be two (2) months prior to submission of the article. For conference abstracts, the time period will be two (2) weeks prior to submission of the abstract.
>
> If Gemma does not receive a comment from the [redacted]ithin that period of time then it is deemed as acceptance and Gemma is entitled to publish the proposed publication. This agreement will lapse two (2) years after examination of the thesis.
>
> It is agreed further that the [redacted]will advise the University of Adelaide within 30 days of receipt of a copy of the thesis if it requires the thesis to be placed under embargo. If such a request is made, the University of Adelaide will ensure that the thesis is kept confidential for a period no longer than 12 months from the examination of Gemma Carey's thesis, unless otherwise agreed.
>
> Yours sincerely

ANNETTE BRAUNACK-MAYER
Associate Professor in Ethics

GEMMA CAREY
Higher Degree by Research Student

cc: Heads of Discipline, Public Health and Anthropology; Postgraduate Coordinators, Public Health and Anthropology; Dean of Graduate Studies.

THE UNIVERSITY
OF ADELAIDE
AUSTRALIA

OFFICE OF THE DEPUTY VICE-CHANCELLOR
(RESEARCH)

SABINE SCHREIBER
SECRETARY
HUMAN RESEARCH ETHICS COMMITTEE

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CRICOS Provider Number 00123M

3 May 2006

Associate Professor A Braunack-Mayer
Public Health

Dear Associate Professor Braunack-Mayer

PROJECT NO: *An ethnographic study of Hepatitis C*
H-102-2005

Thank you for your letter dated 27.4.06 requesting variation to the project *An ethnographic study of women's experiences of hepatitis C related discrimination in Australia.*

I write to advise you that on behalf of the Human Research Ethics Committee, I have approved the following changes to the project:

- The research now focuses on the [redacted] and participants' experiences of their involvement with the Council.
- The revised title for the project is *An ethnographic study of Hepatitis C.*
- A revised information sheet will be used and written consent will be obtained from participants to use data previously collected.

It is noted that Gemma Carey is transferring from a PhD to a Masters degree.

The ethical endorsement for the project applies for the period until 30 September 2006.

Yours sincerely

Associate Professor Garrett Cullity
Convenor
Human Research Ethics Committee

Research Proposal

An Ethnographic Study of Hepatitis C

Gemma Carey B.Health Sc. (Hons)

Discipline of Public Health &
Discipline of Anthropology
University of Adelaide

Project Description & Background

The project will involve research with the H[redacted]e [redacted]as created through collaboration between a group of hepatitis C positive people and supportive friends. The group was initially created to provide support, and advocate on the behalf of, hepatitis C positive people for accurate medical information with regard to the illness. In 1994 this group became known as the [redacted]l and began receiving funding from the South Australian Government

[redacted] is a non-government, community based organisation, and acts as the 'front-line' in hepatitis C prevention, support and education by providing support and information to those whose lives are affected by hepatitis C.

The project will explore how various staff and volunteers became involved with [redacted] and what characteristics of the place and the work keep them involved. It will also seek to explore how they perceive [redacted] role. The project will also examine how participants understand the development of [redacted], since inception, and the ways in which the organisation may change in the future. Primarily, the focus of the project is to explore how individual's experiences shape and inform the organisation and how the organisation in turn shapes their lives and, specifically, their experiences of hepatitis C.

Approach

Ethnographic data has already been collected through participant observation conducted at the Council. The project will draw on and use this information for constructing questions for the interview and in later analysis after interviewing has taken place.

Drawing on this ethnographic data Gemma and her supervisor, Assoc Prof Annette Braunack-Mayer, will approach a selection of staff and volunteers to request an in-depth interview. These interviews will explore themes, which emerged during the initial fieldwork, and seek to explore how these participants describe and understand their own experience within th[redacted]These interviews will explore how the participant came to be involved with the [redacted] how they perceive the organisation and what its role is. Gemma will ask questions about how individuals understand how [redacted] has changed over time, and how it might change in the future.

Interviewees will be invited to consent to interviews after receiving an information sheet and summary of the interview schedule. Interviews will take place [redacted] (although an alternative location can be arranged if required). They will take approximately an hour to an hour and a half. Interviews will be recorded (provided consent to do so is given); this is to provide a record of individuals' stories and experiences. The information provided will be held in the strictest confidence. Gemma will personally transcribe the tapes, and will uphold confidentiality. The name and identity of the individual being interviewed will not be identified in publications. Participants are also welcome to view their transcript if they wish.

Outcomes

From the research a masters thesis will be written and lodged in the University of Adelaide Library. In addition a report will be written for [redacted]

Communication of results

Results will be predominately communicated in the form of a Masters thesis, which will be submitted through the Discipline of Anthropology and Public Health. After examination the thesis will be lodged in the Barr Smith Library of the University of Adelaide. It is envisaged that results will also be communicated in papers in academic journals, and presentations given at conferences and within the respective departments.

DESCRIPTION OF PERSONNEL

Gemma Carey. B. Health Sc. (Hons). (Masters of Medical Science HDR candidate. Disciplines of Anthropology and Public Health, University of Adelaide)

Associate Professor. Annette Braunack-Mayer. Discipline of Public Health, University of Adelaide – Principal Supervisor.

Dr. James Taylor. Discipline of Anthropology, University of Adelaide – Co-Supervisor.

Appendix Four

Interview Schedule

Key Question	Factors Requiring Exploration
Can you tell me/us how you came to be involved with the [redacted]?	• How did you find out about it? • Why did you get involved with [redacted]? • Where was it? • In what capacity did you get involved? (looking for information? staff/volunteer?)
Why are you involved with [redacted]ow?	• What keeps you here? • Who keeps you here?
Has being involved with [redacted] changed your understanding of hepatitis C?	• What was your understanding before? • How does it compare with your understanding now? • Who/why has it changed?
What is your understanding of what the Council is?	• What does it do? • For whom? • Where does it do this? • How does it do this?
Has the Council changed over time?	• How has it changed? • What has not changed? • Does it work differently now? • Where did it use to be? • What did it used to look like? • Who use to be involved? • Who did it use to provide support to?
The Council is often described as a community organization -what is your understanding of community?	• Are there different types of community? i.e. affected/general? • Who is part of it? • Who isn't part of it? • Are staff and volunteers part of it? • Why/why not?
What do you think the Council ought to be doing?	• Who should it be helping? • In what ways? • How does this compare with what it is doing?
How do you think it might change in the future?	• Who might be involved/use the council in the future? • What might they do? • Will it look different to how it does now? • Will it work differently?

THE UNIVERSITY
OF ADELAIDE
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DISCIPLINE OF PUBLIC HEALTH
FACULTY OF HEALTH SCIENCES

LEVEL 9 TOWER BUILDING
10 PULTENEY ST
(MAIL DROP 207)
UNIVERSITY OF ADELAIDE
ADELAIDE SA 5005

Dear [redacted] Workers,

As you are aware, I have spent several months conducting research at the [redacted] This has involved observing, participating, and discussions about hepatitis C [redacted] and your experiences. I would like to thank you all for the time and effort you have taken to talk with me, and for making me feel welcome at [redacted].

Originally I came to [redacted] to discuss women's experiences of discrimination. During the time I spent with you I became more interested in [redacted]. Particularly what brings you all together, and keeps you working together in the organisation. As a result the research I have been conducting has changed. Rather than spending time at [redacted] on a daily basis, I would like to invite a selection of staff and volunteers to take-part in an interview. More information regarding this new part of the research can be found in the Information Sheet, attached.

When I began my research with [redacted] I obtained written consent from you to allow me to use our discussions about hepatitis C in my research. I would still like you use this information as part of my research. I have therefore provided a consent form, which is very similar to the original consent form that you signed, to re-affirm that you are willing to allow me to use this information from my previous time spent at [redacted]. In signing this consent form you will not be agreeing to another interview, but simply re-confirming your consent for the information previously collected. If you chose not to re-affirm your consent, information that you have previously provided me will not be used in any way.

In due course I will approach a number of staff and volunteers and invite them to take part in a recorded interview. If you are requested for an interview, and chose to take part, there will be a separate consent form to sign.

Thank you for participating in my research so far.

Gemma.

Information Sheet

You have been invited to participate in a research study. Before agreeing to participate in the study, it is important that you read and understand the following explanation of the research.

Title
An ethnographic study of Hepatitis C

Aim of the study

Primarily, the focus of the project is to explore how individual's experiences shape and inform [redacted] and how [redacted] in turn shapes their lives and, specifically, their experiences of hepatitis C.

Researcher
The researcher for this study is Gemma Carey, a postgraduate student with the Disciplines of Public Health and Anthropology at University of Adelaide. Assoc. Prof Annette Braunack-Mayer, from the department of Public Health, will also be assisting in the research.

What does the study involve?
A selection of staff and volunteers will be invited to take part in the next stage of the study, which will involve an in-depth interview.

These interviews will explore how individuals describe and understand their experience with [redacted]cil. They will also explore how the participant came to be involved with cil, how they understand the organization and its role. Gemma will ask questions about how individuals understand how [redacted] has changed over time, and how they think it might change in the future.

There are no 'right' answers as the study is concerned with how participants understand the role of community organizations involved the hepatitis C epidemic.

The interviews will take place in the [redacted]. If you would like the interview to take place elsewhere this can be arranged. It will take approximately an hour to an hour and a half.

What are the risks of participating in the study?
There are no physical risks associated with participation in the study. If participants feel uncomfortable answering any of the questions they can chose not to answer them.

What will I get out of the study?
There may be no immediate benefit to you personally. There will be a report which you are welcome to have, which will also be kept in th[redacted] library.

What will happen with the study?
Results communicated in the form of a Masters thesis, which will be lodged in the Barr Smith Library of the University of Adelaide. Results will also be inc[redacted]apers in academic journals, and conferences. Lastly, a report will be written for [redacted]

What happens if I decide not to take part in the study?
There are no consequences if you chose not to participate in the study. Should you choose to take part in the study, but later change your mind, you may withdraw. As mentioned previously, if there is information you have shared with the researcher that you do not want used in the thesis or reports you may request that it be excluded from the study.

Questions & Contact Details.
If you have any questions about the study you can contact the researcher, Gemma Carey. Gemma's details are as follows-
Email: gemma.carey@adelaide.edu.au
Phone: (08) 8303 3588

You may also contact the supervisors of this study-

Dr Annette Braunack-Mayer (Discipline of Public Health)
Email: annette.braunackmayer@adelaide.edu.au
Phone: (08) 8303 4637

If you wish to make a complaint please refer to the attached complaint form.

If you feel that you need to discuss the contents of interviews, or personal issues that may have been touched on during the interview you may contact [redacted] who is the director of the [redacted]

Email: [redacted]
Phone:

If you wish to speak to someone outside of the [redacted] Australia you may co[redacted]

[redacted]

THE UNIVERSITY OF ADELAIDE HUMAN RESEARCH ETHICS COMMITTEE

STAFF & VOLUNTEER CONSENT FORM

1. I, ... *(please print name)*

   consent to information **previously collected** for the study *An Ethnographic Study of hepatitis C,* **to continue to be used.**

2. I acknowledge that I have read the attached Information Sheet entitled:
   Information sheet: An ethnographic study of hepatitis C

   and have had the project, as far as it affects me, fully explained to me by the research worker. My consent is given freely.

3. I have been given the opportunity to have a member of my family or friend present while the project was explained to me.

4. I have been informed that the information I provide will be kept confidential. Tapes will be stored in a locked cupboard within the Discipline of Public Health.

5. I understand that I am free to withdraw from the project at any time and that this will in no way affect my relationship [redacted].

6. I understand that the study may not directly benefit me.

7. I am aware that I should retain a copy of this Consent Form, when completed, and the attached Information Sheet.

....
(signature) *(date)*

WITNESS

I have described to ....

the nature of the research to be carried out. In my opinion she/he understood the explanation.

Status in Project: ....

Name: ....

....
(signature) *(date)*

THE UNIVERSITY
OF ADELAIDE
AUSTRALIA

DISCIPLINE OF PUBLIC HEALTH
FACULTY OF HEALTH SCIENCES

LEVEL 9 TOWER BUILDING
10 PULTENEY ST
(MAIL DROP 207)
UNIVERSITY OF ADELAIDE
ADELAIDE SA 5005

Dear [redacted] worker,

Thank you for considering participating in interviews for the project *An Ethnographic Study of Hepatitis C.* This letter is about what will happen if you agree to be interviewed.

The aim of the interviews is to explore your story about how you came to be involved with [redacted] and about your involvement [redacted] will be asking questions about:

- how you found out about [redacted];
- how you became involved in [redacted];
- what you have done and now do in [redacted]
- your reasons now for work[redacted]olved with [redacted];
- how being involved with [redacted] may have changed your ideas about hepatitis C;
- how you understand the role of the [redacted], including your thoughts about how it has changed over time, and how you think it might change in the future;
- how you think about the 'community' aspect of the [redacted]'s work.

With your consent I would like to tape and transcribe the interviews so I have a record of your stories and experiences. The information you provide will be held in the strictest confidence and I will uphold the highest levels of anonymity. Your name and identity will not be disclosed in any way. If you would like to have an opportunity to view your transcript or have a copy of it, please let me know.

If you agree to take part in the study, by way of an interview, a time will be established which is suitable for you. The interview can take place at [redacted], or if you prefer, an alternate location can be arranged.

I look forward to your participation in the study,

Best wishes
Gemma Carey

THE UNIVERSITY OF ADELAIDE HUMAN RESEARCH ETHICS COMMITTEE

STAFF & VOLUNTEER CONSENT FORM

1. I, ………………………………………………………………………… *(please print name)*

consent to take part in the research project entitled:
An Ethnographic Study of hepatitis C

3. I acknowledge that I have read the attached Information Sheet entitled:

Information sheet

and have had the project, as far as it affects me, fully explained to me by the research worker. My consent is given freely.

3. I understand that the project may not benefit me personally.

4. I have been given the opportunity to have a member of my family or friend present while the project was explained to me.

4. I have been informed that the information I provide will be kept confidential. Tapes will be stored in a locked cupboard within the Discipline of Public Health.

5. I understand that I am free to withdraw from the project at any time and that this will in no way affect my relationship with [redacted]

7. I am aware that I should retain a copy of this Consent Form, when completed, and the attached Information Sheet.

8. I agree/disagree to be audio-taped throughout the interview process .

……………………………………………… ………………………………………

(signature) *(date)*

WITNESS

I have described to ………………………………………………

the nature of the research to be carried out. In my opinion she/he understood the explanation.

Status in Project: ……………………………………………………………………………………

Name: …………………………………………………………………………………………………

………

(signature) *(date)*

Appendix Five

Research Reference Group

A research reference group is being established to work with Gemma Carey (who is a postgraduate student with the departments of Anthropology and Public Health) and Assoc. Prof Annette Braunack-Mayer, from the University of Adelaide, concerning the project '*An ethnographic study of hepatitis C'*.

We are seeking verbal expressions of interest from individuals to join a research reference group. This group will meet once every two months to discuss the progress, outcomes and direction of the research, which is being carr[redacted] Australia.

The purpose of the reference group is to provide feedback concerning the research being undertaken a[redacted]. It will provide an open forum for discussion concerning research and research findings.

- The research reference group shall meet bi-monthly for the remainder of 2006.
- The reference group shall meet inside of working hours, at th[redacted]
- The reference group will have a chair, and minutes will be kept of each meeting.
- Members of the reference group will be responsible for relaying findings of the group to others.

Ideally we would appreciate a representative from each volunteer section (resource and phone-line), staff, management and the Board.

If you are interested please contact Gemma Carey by 22nd of May.

If you cannot locate Gemma in person please leave a note in the pigeonhole in the office or by email- gemma.carey@adelaide.edu.au

The fist meeting will be held in June.

[redacted]

Research Reference Group

For the project: *An Ethnographic Study of Hepatitis C*

Aim:

- Facilitating communication between the research project *An Ethnographic Study of Hepatitis C,* and staff and volunteers of [redacted]
- To provide feedback and comments to the researcher on conduct and findings.

Terms of reference:

- Reference Group is to be chaired by a member of the reference group.
- The Reference Group will meet a minimum of bi-monthly until the submission of the thesis.
- [redacted] will be responsible for disseminating the content of the meetings.
- Gemma Carey will be responsible for keeping a record of the meetings.
- The Reference Group will assist in identifying and addressing emerging issues.
- The Reference Group will provide comments on progress reports and preliminary chapters.