CHAPTER 1

INTRODUCTION
"In 1991, the world learned of a recently discovered ancient language devised at least one thousand years earlier in a mountainous region of the Hunan Province in central China.

It was a totally female language........

'Nushi’ ('women's writing') used characters derived from standard Chinese to represent the syllables of the local dialect. Standard Chinese has no such phonetic base; it uses characters pictographically, to represent meaning only. Chinese linguists believe that the women developed the script because they were forbidden to learn standard writing......for hundreds of years women used the script to record their hidden emotions and to communicate with each other surreptitiously........

[O]ne Nushi author wrote, 'Men leave home to brave life in the outside world. But we women are no less courageous. We can create a language they cannot understand.'

These were the words of a woman who might as well have written, 'We shall not suffer in silence.' Because this female language was an underground code - an act of rebellion in conception, an utterance of rebellion in content" (Robin Morgan 1992: 276-276).
Preamble

Sitting at the computer to begin writing this introduction I, probably like many other writers, am struggling with the questions of: what do I want to say here; what is the purpose of writing this; how do I say what I want in a way that encourages us to connect? I want to hold on to you and say "listen, I have this story to tell. It is important to me that we collaborate now, that we co-create some meaning from the telling of this story, that somehow the empty space between us becomes smaller for a while as we reach out and touch each other".

Sounds quite intimate doesn’t it? A peculiar way - maybe - to think of a thesis. But it is intimate. In writing this, I make myself visible: what it is that I feel passionately about, what I believe in, how I feel, how I live my beliefs, how I am with people and how I interpret my world. To do this requires trust. It requires that somehow we know each other. For some of you who read this, we will have a relationship of trust which is reciprocal, for others we will not.

There is here, a need to write for multiple readers. This highlights a tension in writing. I am one of the readers for whom I write. In writing, I clarify my thoughts and understand and know myself better, I also take a risk as I make myself visible to myself and you. I write for the people who have participated in this research in a multitude of ways; the people who told me their stories as part of interviews and focus groups; and those who co researched with me as part of our collaborative Inquiry Group.

I am also mindful of the readers from the academy who will judge this work, in addition to fellow students who may read the work to help them in writing their experience of researching. The tension then, is in being true to myself, being accessible to others who have made this thesis possible.
through their collaboration and active participation, and at the same time being able to connect with, be understood and validated by those of you in the academy.

I do not wish to develop a secret code, as the Nushi writers did, my desire is to be inclusive rather than to separate. But, like the Nushi writers I do wish to communicate courage and hidden emotions. I want you to hear all the voices of the people involved in this research so that they no longer "suffer in silence". This writing is an "act of rebellion in conception, an utterance of rebellion in content" (Robin Morgan 1992: 276).

It is an act of rebellion in the same way that I believe the practice of Social Ecology to be so.

The discourse of Social Ecology

The discourse of Social Ecology actively integrates the private and public personas, the thinking and feeling which is part of living and learning (Course Review Document 1996). That is, this research is as much about me as anything else. The discourse is also transdisciplinary, it transcends the more traditional disciplinary boundaries that we are accustomed to in universities. As such it enables me to use theory from a variety of contexts which have been useful in making sense of the world. Whilst this research is embedded in critical social science in terms of its methodology and methods, you will find that I have drawn upon specific parts of the disciplines of sociology, psychology, anthropology, feminist theory and practice, as well as education.

With ecological thinking (Tim Hayward 1994) as the thread that holds this diverse discourse together, Social Ecology is interested in relationships: relationship with ourselves, with others, with systems and structures; relationship between different and competing discourses; relationship
between words and actions, theory and practice; relationship between
disciplines and theories; and our relationship with the 'natural' world. It is
interested in these relationships for a purpose: that is, making them 'better'.
'Better' in terms of equity, sustainability and social justice.

The politics of Social Ecology is not dualistic but inclusive, it recognises a
multitude of meanings and realities. In this sense it is informed by
postmodern and poststructural thought. Social ecologists do not seek to
develop grand theories but are concerned with the local and particular, they
live the slogan 'think globally, act locally.' Social ecology is concerned with
liberation, social change and transformation and can be put simply as, "the
study and practice of innovative social change based on the critical
application and integration of ecological, humanistic and community values"
(Stuart Hill 1996). As a social ecologist then, I am concerned with the
global issues of social justice, equality and acceptance. But I act locally,
within the community in which I live, to work with people in understanding
sources of oppression and inequity and to actively transform them.

Within Social Ecology there is a concern with both process and outcome,
with both needing to be liberating and empowering. In no way would a
social ecologist subscribe to the notion that 'the ends justify the means',
rather it is held that the means will shape and influence the ends, and vice
versa. As such, if we seek to understand, to enhance and promote liberty,
freedom and relationship, then how we go about doing this is as important
as the outcomes we achieve.

So I write this as a social ecologist. I attempt to be inclusive, to include the
thoughts and feelings of myself and my collaborators in the telling of these
stories. And I use the words 'I' and 'we' purposefully. I am doing this
writing now. In other chapters we, the Inquiry Group, wrote and thought
together. It is in the spirit of inclusiveness that I write with one voice.
The substantive research issue/s

It is tempting to tell you 'where I am coming from', what I believe and how I know; to explain my ontology and epistemology. These things might enable you to understand why I have done what I have done in the way I have done it. However, in terms of learning, I need to know the what first, then I have something concrete to work with. I am not alone in this 'Way of Knowing', I know through my experience with literally hundreds of other students over the years.

I will start by telling you what it was that I sought to do in this research, what the substantive issue was. During the 1980's, as a lecturer in a School of Health teaching Health Studies and Primary Health Care, I became increasingly interested in the idea of 'community participation'. This idea had been articulated in the Alma Ata (1978) one of the central, international, documents of primary health care (PHC). It sounded like a good idea but, in terms of the New South Wales (NSW) health system I could see little evidence of it actually happening. I was fascinated by ideas such as:

- Who is the community to whom they refer?
- How do you get people to participate?
- Do people want to participate?
- How do you ensure that participation is meaningful and representative?

Whilst still at the 'playing stage' with these ideas, the local, Blue Mountains Team Leader and Nursing Unit Manager of Community Health came to talk to our third year students. In the course of her talk she mentioned that part of her District Community Health strategic plan included doing community participation. Delighted I asked what she meant by this and how were they going to do it. What transpired was the beginning of a long partnership with
community health. I was told that Blue Mountains Community Health Personnel had no idea how to do it. Would I like to work with them in translating the theory into action? I was being given a very valuable gift, one I accepted in 1993, and which I am still unwrapping!

So began the Inquiry Group’s shared quest for working out how to do it and actually doing it, together. We invited people in the local health district to work with us, and a core group of people comprising key community health practitioners and hospital personnel have been meeting, planning and acting since. At the outset we agreed that our collective aim was for public/community participation in community health decision making, service planning and evaluation and that we sought a sense of partnership and democratic decision making. In a way, this is the story of what we did as a group of people concerned with the same issue.

As we proceeded, my concern also crystallised around hearing the voices of the many people connected to and affected by health services, particularly the voices of those we don’t often hear; the consumers and the staff. Hearing to understand their thoughts, feelings and wants in addition to hearing to inform our actions. We chose to hear and listen to the voices of four groups (Service Users; Service Providers; Non Service Users and Providers of Other Services in the local area) of people who we believed were central to the health mosaic. We were concerned that we often hear what the politicians, doctors and managers believe health to be about in terms of policies, legislation and funding decisions. Working within a community development framework, we consciously chose to work this time from the bottom up, and whilst our outcome was to be one of greater community participation, we also chose to have community participation as part of our process of researching.
Establishing ourselves as a working party, or Inquiry Group, (Peter Reason 1988) we were responsible for the cycles of planning, implementing and evaluating strategies to promote, enable and enhance community participation in health planning, service delivery and evaluation. The framework which we used from the outset was one of collaborative and participatory action research (Stephen Kemmis & Robin McTaggart 1988; Shirley Grundy 1986). The questions we sought to answer were:

- What is really happening in community health?
- Is the rhetoric translating into practice and if so how?
- Does the health system support community involvement in health-in practice?
- How empowered do people feel in terms of their health?
- What are health personnel doing to empower and include their consumers and the general public?
- How can we, at a local level, establish systems and procedures to enhance and strengthen community involvement and participation in health?

Given the nature of the questions we were asking we believed it imperative to use an empowering research process - empowering for us as a group and for the participants in the interviewing process. Our primary concern was one of collaboration, of working together, hearing the voices of many. Our aim was to change the system. We believed that by hearing the voices of those at the margins - in terms of power and decision making - the system would, by necessity change. We acknowledged that this would be a slow and evolutionary process of reform and restructuring.

Using a participatory action research methodology, community development, feminist and social ecological frameworks, the Inquiry Group conducted over 100 in-depth interviews and focus groups with health
service workers, consumers, community groups, GP's, community service providers and the public.

Questions of Methodology

All researchers construct their object of inquiry out of the materials their culture provides, and values play a central role in this linguistically, ideologically, and historically embedded project that we call science (Patti Lather 1989:5).

Having recently bought Yvonna Lincoln and Egon Guba's (1985) rather expensive book, I proceeded to skim the pages. I always read the quotes people use as chapter headings, I like this convention and am interested in what has inspired the authors chapters. The quote "As we think, so do we act" (Schwartz and Olgivy 1979: in Yvonna Lincoln and Egon Guba 1985:14) was used for the opening chapter, and I was excited at the 'aha' that followed. If talking about why I have acted in the way I have in terms of this project, sets the frame for the research, it becomes clear that I need to discuss how I think, and how I think others think, in order to make my actions intelligible and transparent.

What is it that informs both my thinking and my actions? Does thinking come before action or are they informed by each other? While I am heavily influenced by the discourse of social constructionism, this can be seen to constrain the individual's capacity for agency and for making a difference. While our identities are undoubtedly constructed by our environment, culture and the dominant discourses of the time, we also have a capacity to take action, independently and collaboratively. Do all of us have the same capacity? Are we all equally endowed with the desire for social justice and social transformation? Are we equally able to work, to act, towards this end?
I believe not. Some people are too busy with mere survival; others are quite happy with the way things are and actively work to maintain the status quo. With the rise of the New Right in American culture, we can also see that some people seek social change of a kind which does not include social justice goals for all people (Susan Faludi 1991). In any society, only some will be working towards radical social change.

My trade is to teach. Originally I qualified in education to teach children in the 8-13 age group. Shortly after my graduation, my partner and I arrived in Australia; I was convinced that I wanted to teach and got placed on the Education Department list - then with a three year waiting list. There followed a series of jobs, for me, in the non government sector, from special educator for children and adults who had a disability to running a service training consultancy organisation, and finally, to academia, teaching and learning with adults. The educational focus of my work has always been paramount, fuelled by the modernist belief that through education comes both social and individual change. I have been strongly influenced by the works of Freire, Brookfield and Rogers.

The words 'liberation', 'empowerment', 'emancipation' still send a shiver down my spine. My practice is based on the premise that my role as an educator is to facilitate people's knowing: to encourage, enable and support peoples learning and actions and that learning can occur when we reflect upon our socially constructed assumptions (David Boud 1985: Robin McTaggart 1988). It is through this process that we begin to work out ways to resist this conditioning, so constructing ourselves and society in new ways.

While in the beginning I could not name the epistemological tradition I was working within, it has become clearer to me that critical theory and critical
social science have informed my practice and my theorising. It is also becoming clearer to me that I live, work and play in the postmodern age. This understanding helps me to unsettle, question and probe my own discourse and to constantly challenge my own standpoint.

I understand critical social science as the method, the way of doing critical theory. Whereas critical theory can be thought of as a school of western Marxism (David Held 1980), I prefer to think of critical theory not so much as Marxism and its variations but rather as a theory which is dialectical in method and has liberation as its content and aim......The essence of liberation as conceived of in critical theory is the recovery of wholeness or the abolition of alienation. That wholeness may be defined as a non-alienated relationship between man (sic) and nature, man (sic) and others, subject and object, or the various aspects of a single persons existence (Sheirry M. Weber 1976: 79).

It is this holism which locates social ecology within the critical theoretical tradition. Social ecologists believe that integration, mutuality, respect and a knowing of our place in and of the world will enable transformation to occur. This thesis seeks to contribute to the overall project of critical theory by working towards "an alternative path for social development" (David Held 1980:14).

This study is a critical inquiry which seeks not only to understand and explain the existing social order, it also includes the imaginal by asking 'how could it be different?' (Stephanie Short et.al. 1993; Evan Willis 1994; Alan Peterson 1994). I believe that critiquing rationalistic, hierarchical and individualistic ideologies which support capitalism, patriarchy, scientism and
all the oppressions that go along with these, is a necessary part of the movement towards a more satisfying future.

Inspired by Nancy Fraser and Linda Nicholson (1990) I argue for, or locate myself within, a postmodern/feminist/critical social science. A postmodern politics embraces a diversity of contemporary struggles and resistances to a complexity of dominations. A postmodern critical social science will resist economic and state systems from the cultural margins rather than engaging with them in conventional political ways. That is not to say that head on battles are not necessary, rather that a plurality of resistances need to be supported. What a postmodern perspective can offer us is the ability to value and honour the local in its own right and specificity. In this research then, I chose to stay in the margins and work at destabilising these systems by inserting the voices of many into the health discourse.

Feminist theory and poststructuralist/postmodernist theoretical positions have had a major influence on the present research project, particularly the debate concerning social constructionism. This has been part of my imaginal journey. If health and illness can begin to be seen as being predominately socially, rather than genetically constructed, then we can begin to contest biomedical dominance of the health agenda. A post strucutralist/postmodernist perspective enables us to see how power and knowledge - in this case medical-scientific discourses - shape our understandings of health and illness, the services we provide, how they are provided and relations within/without these. To further convey the force of these power relations, I have discussed the economic imperative, the 'business of health' and health expenditure in chapter 2.

I see this thesis as both modernist and postmodernist at the one time. This position is at once comfortable and uncomfortable. Let me try and explain. I use the term postmodernism to include post structuralism after Patti Lather
1989, 1991. There is much about postmodernism that is appealing and helps me to make sense of the world. In addition to enabling me to think anew the age old problems of injustice and inequity, I see a conjuncture with social ecology here.

Much of my understanding of the postmodern is knowing that there are many voices, many realities and many experiences. Knowing this can enable us to resist privileging one voice, one way of knowing or experiencing over others. This I feel is one of the things we try and do in social ecology with our 'transdisciplinary approach'. We do not privilege psychology over sociology, education over anthropology - we do not say that there is only one way of making sense of the world, rather there are many. In the spirit of ecological thinking and knowing, we value diversity and difference. Knowing diversity and difference is part of what enables sustainability and survival (Tim Haywood 1994; Luke Martell 1994).

In terms of the thesis, this is one of the tacks I have taken. The research has been about hearing the voices of many people within/without the structure of health, and inserting these voices into the mainstream, insisting that they get heard. At one level, interviewees have been heard by middle management in community health, as these were the people with whom I researched. They took part in listening to people, in hearing and making sense of what was being said and this 'listening to' has changed their practice. At another level, the people who took part in the interviewing process have had the opportunity to hear themselves and others through the Research Report: From Rhetoric to Practice - of which they all have a copy. Finally senior management in the Wentworth Area Health Department have been provided with a copy of the research report and have been asked to respond to the recommendations listed.
I, and the people whose stories are told here, assert that the people who make decisions about the structure and nature of health services should work in collaboration/partnership with those who are going to use the services. This includes most of us at one time or another. To me this seems only fair and just. To include only bureaucrats, doctors and politicians in these sorts of decisions seems patronising and conservative - it serves to maintain the status quo. Furthermore I am arguing that this should happen as the Health Department itself says that community participation in decision making is desirable (Blue Mountains District Health Service 1993; National Health Strategy 1992; Wentworth Area Health 1993). Part of what I wanted to do was to see if this was in any way happening, if the community itself wanted to participate or if this was just another good idea of those who already run the system.

I discovered that, already there is a large degree of community participation at the grass roots level which is undervalued and unacknowledged and that people do want to have a say in the decision making process. I also discovered that there are many, many obstacles and barriers which preclude participation happening and that if the department wishes to pursue this line then these obstacles need to be acknowledged and dismantled.

I am not saying that if we have partnerships, collaboration and participation then the services will be more rational, although they would be more responsive. Initially there may be chaos, more hospitals, a greater emphasis on the medical model - who knows? Although I would hope that this would not be the case, it may be so. I support the idea and practice of community participation because it is equitable and just not because the outcomes may necessarily be better - according to my criteria. Like Eva Cox I have "no recipe for a future magic pudding. The complexity of human society... defies the easy answers" (1995:12). I too am looking for a more sound, fair and democratic process rather than a particular outcome.
We need a just, equitable process of decision making and resource allocation. Part of establishing this process is to include all the stakeholders in the myriad of decision making processes. This corresponds to Luce Irigaray’s notion of a utopia in process (Margaret Whitford 1991). This I believe is achievable. But the outcome? I have no idea. Part of this is me letting go of some of my power and control, acknowledging that it might not end up as I would like it to. This is also one of the major obstacles to enabling such a process to happen - the bureaucrats, politicians, doctors and scientists would need to take a similar position, to work with the process and let go of some of their influence, power and control. This I cannot see happening and this is where I see the Health Department’s hypocrisy at play.

Consultation and participation are discussed but only within the parameters of actually maintaining existing positions of power and privilege. Add into this equation the drug companies, the AMA and those companies responsible for the manufacture and selling of medical technologies and we can see that there are huge vested interests involved in not letting people participate in decision making.

Here is where I feel I enter into the modernist/structuralist debate as opposed to the postmodern one. While I have attempted to do this in a postmodernist way via examining some of the discourses in health, my position in terms of critical social science is undoubtedly grounded in both humanism and Enlightenment ideals. It is here that I experience the most tension and the most difficulty explaining where I am coming from. It would require more theorising around structuralism and modernity, to include analysis of capitalism, economics and globalism. I have talked briefly about technologies in health, about the drug companies about the economic
rationalist agenda, but I have resisted letting this become the main focus for this thesis.

I have worked to keep this study very much at the level of the local and in particular to continue to ask the question posed by Michel Foucault (1972-1977) - how do things work at the local and the every day; what is happening in peoples lives and how do those who have 'subjugated knowledge's', understand the world? I see this as vitally important, as grounding. And I agree that this is not enough; this is only one struggle, one site of resistance. There need to be others struggling in different ways. What follows is an account of a social action project which has made a difference already at the local level - quietly and without fuss. It is only one way of resisting and changing the power relations in society, there are many others.

It could be said that the provision of community health services is part of the state legitimising itself, of keeping us satisfied as after all it is better than nothing. I wonder if community health programs are a 'band aid' for a totally unjust, unfair social system. I think on the one hand they are. But, as they are at the margins of the system they are also, I believe, ideally situated to agitate, to struggle for change. That paradox has been one I have struggled with throughout the journey of this research.

I am reminded of some of Paulo Freire's words: when he talks of change he talks of having one foot in the system and one foot outside of it, a position which he acknowledges is difficult and dangerous, but a position he feels is necessary for change. I experience this position as a never ending compromise. I have to be accepted - if I am to get heard- from both within and without - so I end up rarely saying what I really want to, the sharp, adversarial edges have by necessity been rubbed smooth. We do have a
right to name power when we see it, but what if the naming in effect silences us, means that we do not get heard?

Something which quite intrigued me, as I attempted to theorise coherently and meaningfully, is that no theoretical perspective is absolute or complete. One can always critique a person's writings about their position, there are always gaps, incompleteness, opaquenesses. Part of this is due to the limitations of language - we only have words and words require linear construction. Our knowings, our understandings are often multi faceted, multidimensional and sometimes chaotic. And yet, we are required to explain ourselves in one dimension; there is no room for the multitude of voices, thoughts and feelings that occur in our meaning making in our bodies. We tend to take what a person has theorised/written as that person, as the whole of who they are and what they mean.

Part of this taking is to put them into the appropriate box 'ah, so they are a radical feminist; ah, this ones definitely a postmodernist; yep, this ones neo - marxist' as if anything as simple as this could account for, or adequately describe anyone. Often this box is not one the person would put themselves into. Foucault is known to have said that he did not describe himself as a post structuralist (David Macey 1992). It is also rather lazy. Instead of entering into debate and dialogue with the person, clarifying what they mean/are trying to say we ask instead 'what is your position?' when they answer 'I am a socialist feminist' this closes the debate. We assume that we both know what we are referring to and that we now know as much as we need to about this person's position.

This is one of the reasons I have called chapter 4 "Boxes", recognising that I need to state my position, while at the same time knowing that this stating will be incomplete, open to interpretation and to some extent closing the dialogue between me and the reader.
In terms of community participation, one of the main things I have done is meet the challenge spoken about by Adam Farrar and Jane Inglis (1996) who say that "reestablishing the legitimacy of participation itself" (1996: xvii) is where our efforts need to be directed. The Inquiry Group have been part of this legitimation process by focusing our efforts on the substantive issue of community participation in community health. We have explored, understood and come to know what prevents this from happening, while at the same time clearly identifying strategies and actions to help this become more of a reality.

This thesis explores the questions raised in the introduction in more detail. In some ways it is an uneasy thesis. Living with paradox, feeling the tensions leads to a feeling of unease, of having more questions than answers. Understanding the unsatisfactory present does not lead to a blueprint for change. It does though, enable us to clearly know and name what it is we wish to struggle against and this naming, this knowing enables us to change our practice, to reinvent, rewrite ourselves and in so doing reinvent, rewrite the practices of one of the largest systems in our society - that of health and illness.
CHAPTER 2
DISCOURSES IN HEALTH
"Everything you see or hear or experience is specific to you. You create a universe by perceiving it, so everything you perceive is specific to you" (Douglas Adams 1992:83).

"The culture in which we live hands us a set of intellectual glasses to interpret experience with, and the concept of the primacy of subjects and objects is built right into these glasses. If someone sees things through a somewhat different set of glasses, or God help him [sic], takes his [sic] glasses off, the natural tendency of those who still have their glasses on is to regard his [sic] statements as somewhat weird, if not actually crazy" (Robert Pirsig 1991:120).
Introduction

When looking for a metaphor to help me in structuring part of the story, I settled on that of a play. This section is setting the stage, the backdrops, scenery, props all needed in order for the action to take place; for it to make sense to both the actors and the audience. The actors in this case are myself, my co-researchers and the people who participated by way of interviews and focus groups.

The audience includes these people too, as while we act we also watch, we step in and out of our roles in a meta sense, making personal meaning of what is happening as we go along, maybe pausing to share some insights and to test out new ideas. The audience also includes you, the reader. Through the writing we want to invite you into our world, to see and hear what we saw and heard. For this to happen we need to provide you with the scenery, the backdrop and the props, a rich visual picture needs to be painted so that you have the opportunity to be there with us, to hear our story.

The play itself focuses on a group of people, mainly employed by the NSW Department of Health, struggling to find another way of doing what they do. The central theme is that of participation. The reader follows the actors as they begin to define what they mean by this and how they attempt to live their commitment to participatory decision making, to integrate it into their practice.

But why is this a theme of concern, why take up time, energy and commitment in struggling to define and live this idea? To begin to understand this we need to have the backdrop and the scenery. .............
Backdrop

Discourse theory is not just a simple theoretical or epistemological approach; it implies, by asserting the radical historicity of being and therefore the purely human nature of truth, the commitment to show the world for what it is: an entirely social construction of human beings which is not grounded on any metaphysical 'necessity' external to it - neither God, nor 'essential forms', nor the necessary laws of history (Chantal Laclau and Ernesto Mouffe 1987:106).

My use of the word discourse is informed primarily by the work of Michel Foucault who was heavily influenced by the work of Derrida and Nietzsche (David Macey 1993). Discourses can be seen as systems of thought, or bodies of knowledge, which are constitutive; that is, discourses construct social phenomena, they do not simply describe them (Deborah Lupton 1993:298). Foucault argues that discourses are discontinuous across history, they are not cumulative and progressive, therefore change is not seamless and rational.

Foucault asks the question 'how can truth be told, by what techniques, according to what regularities and conditions is it possible for something to count as the truth - about sickness, life, labour, language?' In Discipline and Punish (1977), for example, Foucault was concerned with revealing different knowledges, what he calls, 'subjugated knowledges'; knowledges which are not usually valued - the knowledge of the criminal, the deviant, the sick. In his work, Foucault values, by listening and recording the knowledge of the local, of the particular (Colin Gordon 1980; Alec McHoul & Wendy Grace 1993; Michel Foucault 1973 &1977):
Let us not .....ask why certain people want to dominate, what they seek, what is their overall strategy. Let us ask instead, how things work at the level of those continuous and uninterrupted processes which subject our bodies, govern our gestures, dictate our behaviours etc. (Michel Foucault in Colin Gordon 1980:97).

In much of his work Foucault traces how particular discourses came to be dominant. Whilst there are many, often competing discourses, some are more dominant than others. A pertinent example in Australia in the 1990's is the discourse of 'economic rationalism'. This discourse is in conflict with another less powerful discourse in our society, that of social relations and human needs (NCOSS 1992).

Thus we have a large number of people unemployed as the work-place becomes streamlined in order that the products we wish to sell are more competitively priced, whilst the amount of public money available to support the unemployed continues to shrink and students in Australia are told to 'get a job'. These things are explainable and necessary in terms of the discourse of economic rationalism. Robin McTaggart draws our attention to the fact that it is the interests of the transnational companies, in particular, which are served under the guise of economic necessity, "moral questions are denied completely (de-moralisation) in a cult of economic inevitability (as if greed had nothing to do with it)" (Robin McTaggart 1992:50) with the effect being that all organisations defer to economic values ahead of any others.

In the health arena, there are two competing discourses operating that I wish to discuss. These are the 'medicalisation of health' and 'primary health care'. Each of these discourses have shaped how we 'do' health, how we define it, what we see as our health needs and the roles we expect the
health professionals to play. They determine what type of health research receives funding, what our spending priorities are in terms of infrastructure, technology, personnel and education. In terms of discourse theory, each discourse constrains and enables thoughts, words and actions to take place and truth becomes a function of this writing, this thinking, this speaking. So, in each discourse there are truths, indeed these truths are constructed by the discourse (Alec McHoul and Wendy Grace 1993).

Our understandings of, and relations with, 'health' are constructed by the dominant discourses in health. In fact health and illness as phenomena are socially constructed by the dominant discourses. Peter Freund and Meredith McGuire (1991) talk of the "complex interrelationships of body, mind and society in producing health and illness" (xi) their premise being that power is "a key social-structural factor in health and in societal responses to health" (xi). Whilst our bodies and our health are not totally socially constructed, genetics do play a role, I will argue that societal influences are the dominant ones.

If we see health as primarily as an idea, constructed by our culture - beliefs, actions, values, language and material objects shared by people - then we need to understand what our ideas of health are. One of the dominant ideas of health is constructed by the medical discourse.

**The medicalisation of health**

The hospital is an anachronistic solution that does not respond to the real needs of the poor and stigmatises the sick in a state of penury (Michel Foucault 1973:44).

The words of Michel Foucault take on an even more sinister meaning in light of the recent Australian study which shows that hospitals may even cause
death and disability. The study by the Federal Department of Health estimates that between 10,000 and 14,000 patients died in hospitals in 1992 as a result of "unintended injury". "A further 25,000 to 30,000 suffered some degree of permanent disability" (Don Greenless & Justine Ferrari 1995:1). The hospital is the centrepiece of the medicalisation of health.

The medical model of health is firmly grounded in the positivist tradition where modern medical practice is seen as both scientific and objective. If we travel back to some of the earliest civilisations, those of Greece, Rome and Egypt we can see that medical knowledge and religious knowledge were intertwined. Theological and cosmic explanations were given to explain any number of illnesses, epidemics and diseases. In this, the priests had control of both the knowledge of the cause and the possible cure for illness and disease. The scientific positivist tradition and modern medicine which was born in the nineteenth century, heralded a move away from this theological/cosmic and superstitious belief about health and illness and focused instead on empirical, scientific approaches to medicine (Michel Foucault 1973: Alan Davies and Janet George 1988).

Within this medical discourse the assertion is that illness and health are biologically determined and not affected by environmental, social or cultural factors. The International Dictionary of Medicine and Biology defined health as "a state of well being of an organism or part of one, characterised by normal function and unattended by disease" (Becker 1986 in Peter Freund and Meredith McGuire 1991:6). Here health is seen as a biophysical condition. The person is written out of the definition and one has to ask: well being in whose terms? Is normal functioning the same for you as it is for me? If we consider paid employment as a normal function of people, are those who are unemployed functioning abnormally and therefore unhealthy?
Is a person who uses a wheelchair and not able to walk, in a perpetual state of ill health?

Furthermore, this definition illustrates well what Foucault was saying when he said: "In order to know the truth of the pathological fact, the doctor must abstract the patient" (Foucault 1973:8). In terms of medical knowledge, labelling a symptom, an abnormal functioning of the organism, as a disease, brings it under the jurisdiction of medical control and care. Childbirth is a good example of this, although we do not call childbirth a disease, it is seen nowadays as a medical problem, or rather the risks associated with childbirth have been so elevated that childbirth is now, almost exclusively, under the control of the medical profession. "The high risk birth unit is booming" (Rochelle Green 1984 in Paula Treichler 1986:5).

Whilst it could be argued that the intention was 'good', there was undoubtedly a gender issue involved in setting up the high risk birth unit. Mothers who used to be assisted solely by midwives, women, are now assisted by doctors, mostly men, who are assisted by midwives, mostly women. It is extremely difficult in Australia to give birth without some sort of medical intervention. Indeed, a medically assisted birth is the only one covered by Medicare and private health funds. Those parents who wish to have a home birth assisted by an independent midwife do so at their own expense.

*The Birth of the Clinic* documents the rise of medical control of health, the medical gaze, medical imperialism and how "the medical gaze circulates within an enclosed space in which it is controlled only by itself" (Michel Foucault 1973:31). Before the rise of this gaze "at the dawn of time, medicine in its entirety consisted of an immediate relationship between sickness and that which alleviated it" (Michel Foucault 1973:55). At this time, most people knew about this. Many women specialised in the
relationship as herbalists, but the knowledge became specialised as it was written about, taught in universities and read by those trained, or in training, to become physicians.

Although Foucault claims to be only documenting how things came to be, his book, *The Birth of the Clinic* is a powerful condemnation of the hospital system. The reader is left in no doubt of the fact that hospitals and clinics were primarily established to train doctors and define and control medical competence. In so doing, medical knowledge, knowledge about health and illness became the province of the medical profession.

The growth in the institutionalisation of health and illness, via hospitals and clinics, also coincided with the move to institutionalise other people who did not function normally in society. This included the mentally ill, the physically and intellectually disabled and the aged. As people were defined in terms of normal functioning, abnormal functioning was seen as a condition which could be cured. People became machines to be fixed by physicians too.

Doctors in training needed to see the sick person, to touch, smell and feel the person. In the hospitals and other institutions, they had a readily accessible showcase of examples from which to learn. What is more, the examples from which they learnt were extremes in terms of disease, most people dealt with the more simple ailments on their own, at home. The growth of hospitals and clinics where people now had to go in order to be diagnosed and treated, served well the purposes of the medical profession but, did they also serve well the interests of the person who was ill?

[C]an one efface the unfortunate impression that the sight of these places which for many are nothing more than 'temples of death', will have on a sick man or woman, removed from
the familiar surroundings of his (sic) home and family? This is loneliness in a crowd (Michel Foucault 1973:17).

In the medical model of health and illness, by abstracting the person and focusing on the illness or disease, the body could been seen as a machine. Illness occurred when the machine stopped functioning properly. Here the physician becomes the mechanic who has control of fixing and repairing the part of the body that is not working as it should. This whole approach is based on a mind/body dualism, where the body is separate to the mind and diseases occur in the body. This is physical reductionism. In this discourse, it is the physician who becomes the keeper, and producer, of knowledge about our bodies, about how they function, and about how to fix them. This one group now hold all the answers about life and death.

Treatment thus now typically involves skilled diagnoses and specific intervention to prevent further degeneration, to balance deficiencies, and eliminate invasive bacteria, or to effect surgical repair, reconstruction or removal and prevention of secondary complications. This in turn gives rise to particular distributions of roles in health care in which primacy is given to diagnosis, specialisation, lengthy training in basic sciences, and medical charisma based on diagnostic acumen and memory. Such roles emphasise activity, technology, a focus on the exotic disease, and the hospital as the locus of 'real' medicine (Alan Davies and Janet George 1988:172).

The biomedical discourse is dominant in the way capitalist societies provide health services. It means an illness focus, a disease system rather than a health system (Ivan Illich 1975) where the money and energy is spent on
fixing problems not preventing them, where technology in curing sick people is seen as necessary and glamorous and attracts the funds.

This biomedical discourse, or the medicalisation of health, determines how decisions are made in terms of funding. If 'real' medicine is done in hospitals and if primacy is given to the people who can diagnose and treat illness and disease, then it follows that money spent by capitalist societies on health and illness will reflect these priorities.

Health is an expensive business in Australia. In 1991, national expenditure on health was $30 billion, 8.6% of gross domestic product and "of this about half is spent on hospital in-patient care" (Ashok Tulpule & Kaye Johnston 1993:41).

Right now, average Australians visit the doctor more often than they go to the movies or attend church, they spend more time in hospitals than in rented holiday accommodation, they outlay more money for pharmaceuticals than they do for alcohol, and they pay more for health care than they do for national defence (Ron Williams 1992:14).

The costs of health care are huge, and it is bureaucratised institutions and the technologies used which account for much of this cost. While the technological revolution is happening in all spheres of life from business, to education, it is the technology in health which needs some discussion as most of the increased funding spent in the health sector is due to the increase in available medical technology (Erica Bates and Susie Linder Peltz 1990).

The technological imperative, "that urges that if we have the technological capacity to do something then we should do it" (Peter Freund and Meredith
McGuire 1991:225), is difficult to talk about. Technology covers such wide and varied ground from drugs, anaesthesia, surgical procedures, devices implanted in the body, machinery and scientific knowledge. It also includes vaccines, contraception and stress management programs.

However this imperative has led to most hospitals having high technology areas such as intensive care and coronary care. This imperative has also led us to expect that life will be extended due to such interventions. That if my heart starts to play up then there is technology that can be used to increase its functioning and thus help me to live longer. This is all part of the medical model, where death is seen as a failure and where nature has to be controlled. But whose life and in what circumstances?

A recently documented story in the Weekend Australian magazine about anticipated further directions in medical technology adds an interesting dimension to the debate. "Surgery in Cyberspace" (Gary Tuabs 1995) paints the picture of surgeons undertaking operations with computers and virtual technology. Computer technology, robotics, fibre optic communications, virtual reality, high tech medical diagnosis and surgery are all combined. Medicine becomes just another aspect of the information age.

In the US, the Government’s Advanced Research Project Agency (ARPA) is investing millions of dollars in this technology, technology which is already being used at Brigham Women’s hospital in Boston. The aim of this technology, it is stated, is to enable surgeons to do a better job with existing operations and to enable them to operate in previously inoperable places. It will all be done via remote control and there will be no need for any physical contact between the surgeon and the person as they boldly go where no man has gone before! As usual, the technology is being used first on women. Tim Cartmill, Chairman of the Royal Australian College of Surgeons commented on this research thus, "it’s a hugely interesting field
which, so far, is at the conceptual level. But most of us think that we'll be seeing things like this working in 10 or 20 years" (Gary Taubs 1995:22).

Whose interests does this serve? Surgeons are not going to get excited about a technology that will diminish their already substantial power base, indeed this technology which is dependent still on surgeons will serve to make them even more remote and powerful. There will be no need to deal in the messiness of human interaction, to look the person in the eye as they go under anaesthetic, to feel the person's body, in fact there will be no need for any human contact between surgeon and patient at all as bodies become virtual reality. People who stand to become obsolete as part of this possibility are the operating suite staff, the nurses, people who have up till now played the vital role of support for both surgeon and patient, the people who specialise in the care of the person - primarily women.

High technology often involves large capital outlay e.g. organ transplants, nuclear magnetic resonance scanning machines, intensive care, "[c]ertain characteristics are common to most modern medical technologies. They are generally expensive, and some technologies are extremely expensive" (Erica Bates and Susie Linder Pelz 1990:122). Do we spend millions of dollars keeping someone on total life support in case they come out of a coma? And if they do come out, how much more technology and cost do we expend to assist them to live a near 'normal' life? Does the answer change when I talk about my son who has been left nearly dead as a result of a car accident? What about the use of technology, which in itself causes pain e.g. chemotherapy? When is a body a person or a person a body and who decides where to draw the line?

There are obviously many examples where technology has saved life, extended life and improved life. But who is really benefiting: scientists and academics, the developers of the technology; manufacturers and
businesses; doctors who use the technologies; politicians and hospital
boards who gain widespread acclaim from purchasing and using new life
saving equipment for their constituents. "Thus it is the powerful and
wealthier people who primarily benefit from the growth in medical
technology" (Erica Bates and Susie Linder Peltz 1990:136).

During the 1980’s it was becoming increasingly evident, if one sought out
the evidence, " that all too often the damage inflicted by a technology
outweighed for many patients the benefits that had been expected, because
no adequate evaluations were being done before the technology became
widely accepted. The prestigious medical literature is full of examples "
(Erica Bates and Susie Linder Peltz 1990:130). We all remember the
consequences of thalidomide and the more recent examples of silicone
breast implants.

In a story in The Bulletin (March 7 1995) we are told of faulty heart valves
which have caused death in 375 patients across the world. In Australia
tests were carried out on 1,169 people who potentially had faulty
valves/pacemakers sold from 1987 and withdrawn in 1994. In March 1982,
it became obvious that there were problems with the valve and in May
1982 they were withdrawn in the United States but Australia was not
informed of the withdrawal. By the time of the recall 86,000 valves had
been implanted.

The ensuing legal challenge rested on the fact that the manufacturer "hid
its knowledge of valve breakages and deaths from authorities in the US and
Australia" (Mark Ragg and Ian McIlwraith 1995:31). A frightening thought
and a sober reminder that in terms of technology, we are dependant on the
companies that produce and market it, in addition to the medical profession
who are responsible for using this technology on people.
A wonderful example of the financial costs involved in technology is provided by biotechnology, which manipulates the very process of life, and has emerged as one of the driving forces in medical technology. "The essence of biotechnology is exploiting genes...It cost $150 million just to identify the gene that causes cystic fibrosis" (Joan Hamilton et.al. 1992:57). It is big business in the USA with more than 50 biotech companies going public since 1991. Drug companies are developing - usually with research funds from the government - new 'super drugs' to treat alzheimer's, aids and multiple sclerosis. "By the year 2000.....$50 billion worth of biotech products should be on sale around the globe " (1992:53). As it costs $150 million to bring a new drug onto the market " [o]nce biotech companies have a product to sell, they tend to charge a big premium: TPA , for example, costs $2,200 per dose, while a full years treatment with EPO can run to $5,000" (1992:57).

It would seem that within the medicalisation of health our priorities are ones of high technological 'fixes' for diseases and illness in the late twentieth century. We have a system established to treat illness, not a system for promoting and maintaining health. This focus serves the interests of the already powerful groups in society, doctors, surgeons, hospital boards, politicians and business.

Unfortunately, there will still be a steady flow of diseases that provide the environment for medicalisation. Despite all the money poured for decades into health research right around the globe, and despite the multitude of technical and service delivery advances in diagnosis and treatment there is still a vast reservoir of diseases that haunt human-kind and guarantee that the medical industry need have no fear of redundancy (Ron Williams 1992:18).
We can see that medicalisation and technology have primacy in health care and are undoubtedly useful in a curative sense, especially in terms of emergency medicine and acute medicine. However, it does have its limitations. We need to seriously ask if the amount of research, funding and kudos attached is appropriate. The rise of life expectancy in the so called developed countries is often attributed to medical progress and technological advances but "improved nutrition and population control, the control of predators, and improvements in dwelling conditions and hygiene have played a much greater role in extending life expectancy than did medical technology" (Peter Freund & Meredith McGuire 1991:20).

**Primary Health Care**

It was in reaction to the increasing medicalisation of health and the associated high technology that the discourse of 'primary health care' began to gain currency. A number of issues were identified which called into question the appropriateness of putting all of our health eggs in one basket. Along with the increase of high technology came the question of access and affordability. As the cost of technology became increasingly prohibitive access became even more of an issue, as people are often ignorant of affordable channels of entry (Anne McMurray 1992:6).

The very technology and specialisation of tasks that made hospitals plausible sites for the centralised practice of medicine have also been major sources of spiralling costs leading to the present US health care crisis......The proliferation of technologies - from the minor (e.g. blood tests) to the massive (e.g. intensive care units) have driven up hospital costs not only because they are expensive to acquire and house but also because they necessitate costly specialised support workers (Peter Freund and Meredith McGuire 1991: 284-285).
Additionally the assumption that high technology and high medicalisation of health did lead to a healthier general population was being questioned. In an article written in 1993, Vincent Navarro reviewed health services in both capitalist and socialist countries. He was challenging the assumption that in capitalist - and by definition - wealthy countries the health of the general population is higher as there is more money spent on peoples health than in socialist countries.

He revealed that there is no correlation between the level of medical expenditure of a particular country and the level of health of the general population, nor does the level of health correlate with the level of medical consumption. "The health of the population is the outcome of a whole set of social, economic, and political interventions, among which medical care plays a minor role" (Vincent Navarro 1993:9). For example, in Kerala, an economically poor Indian state with a strong socialist presence in the government, infant mortality has declined at a higher rate than in other Indian states.

The ideas of poststructuralists, postmodernists and ecologists have also had an impact on the primacy of biomedical truth and knowledge about health and illness. There are in fact multiple truths. Our bodies, and thus our health, are socially, culturally and environmentally determined. by the late 1980’s substantial evidence had been collected which showed that socio-economic status, occupation, race, age gender affect our health, in addition to where and how we live (National Health Strategy 1992).

Health policy and provision in many industrialised countries such as America, Canada, UK and Australia, has been dominated by a treatment orientation. The escalating rise in costs of the technological approach and a number of reports which questioned the effectiveness of this approach
(Lalonde 1974; McKowan 1976) in disease prevention established the climate for the World Health Organisation to champion the "twin concepts of primary health care and an emphasis on community development" (John Ashton 1992:2).

Health ministries have been overwhelmingly preoccupied with curing illness and have not been able to make people aware of their right to good health or of how to obtain it. Many preventable and avoidable health problems continue to oppress people in both developing and developed societies (WHO 1991: 47).

It is against this backdrop and the questions being asked of the dominant medical model of health services that the World Health Organisation held an International Conference on Primary Health Care at Alma Ata, USSR in September 1978. The report of this conference - known as the *Alma Ata* - is one of the founding documents for a new way of 'doing' health around the world. In effect, it challenged the benefits of the prevailing and dominant way of providing health care to people, and proposed that health is actually a social issue requiring social changes not merely technical fixes (John McDonald 1993). It looked at health through a different set of glasses.

The conference worked from the premise that the health of the majority of the worlds' population was at an unacceptable level, caused by the inequitable distribution of health resources between and within countries. A broad strategy for achieving health for all of the world's population by the year 2000 was outlined. This included:

essential care based on practical, scientifically sound and socially acceptable methods and technology made universally
accessible to individuals and families in the community.

that governments have a responsibility for the health of their peoples which can be fulfilled only by adequate and equitably distributed health and social measures.

that the primary health care approach is essential to achieving an acceptable level of health throughout the world in the foreseeable future as an integral part of social development in the spirit of social justice.

activities in the health sector must be coordinated at national, intermediate, community or local levels with those of other social and economic sectors.[and] should be undertaken concurrently with measures such as those for the improvement of nutrition, particularly of children and mothers; increase in production and employment, and a more equitable distribution of personal income; anti-poverty measures; and protection and improvement of the environment.

the importance of full and organised community participation and ultimate self reliance with individuals, families, and communities assuming more responsibility for their own health (WHO 1978:16-17).

As can be seen, a primary health care approach insists that we move away from the medicalisation of health to a more participatory, collaborative and empowering model with a focus on health promotion and disease prevention (Michael Yeo 1993). The underlying values of primary health care are ones of social justice, equity and access in both health status of individuals and
the community. This implies access as well as to a variety of services and information.

Fundamental to a primary health care approach is the encouragement of individuals and communities to collaborate in a critical and creative way to attain health goals which are holistic, equitable and ecologically sustainable. Community action and community participation are seen as major strategies for implementing primary health care (Feuerstein & Lovel 1983, Stuart Hill 1991).

The call for change in the orientation of health services is gathering momentum (Anne McMurray 1991, Van Den Bergh - Braam 1988). This is evidenced in part by the fact that universities providing Nurse Education talk of primary health care in their curriculum documents at both an undergraduate and postgraduate level. Primary health care is part of the curriculum for medical students in Australia at the University of Newcastle and is becoming an area of increased interest for pharmacists. These three groups, Doctors, Nurses and Pharmacists between them, account for the majority of people employed and/or funded by the Health Budget. The focus on primary health care means that a process of change in health provision has begun.

Primary health care, as articulated in the Alma Ata, demands change, a massive shift, both in the type of health services available and in the way health services are planned, organised, controlled and provided (Barbara Mather and Lyn Scruby 1992, Wendy Farrant 1991, John McKnight 1985, WHO 1986). It also calls for social change.

How else can you address issues of equity and access? Poor people get sick more often and die sooner. Kooris die much sooner and have a greater prevalence of preventable diseases. White women have a higher morbidity
rate than white men and are more likely to be diagnosed as being mentally ill. Unemployed people - regardless of class - are more likely to use drugs of dependence and suffer from depression. The unequal distribution of health and illness is not due solely, or even largely, to inherited or genetic factors but due to socio-political factors such as economic status, class, gender, employment status, race and age. Issues such as sexism, ageism and racism have a profound influence on people's health and well-being (National Health Strategy 1992).

In Australia, one of the main strategies for achieving health for all by the year 2000 is that of 'health promotion' and disease prevention. While I have chosen to include this within the discourse of primary health care, these two discourses are sometimes at odds with each other. The Alma Ata's focus is very much on social and economic reform, in decreasing the gap between the 'haves' and the 'have nots' and the assumption that by decreasing this gap there will be a general, overall improvement in a country's health. Whilst a focus on health promotion can also work to this end, there can also be a tendency for this discourse to focus on the individual, with the inherent dangers of victimising those people who are 'unhealthy'.

The Ottawa Charter for Health Promotion (WHO 1986) emerged from the first international conference on health promotion in Ottawa in 1986 and is seen as the founding document of health promotion. It focuses on enabling people to live healthy lives. It integrates freedom and health, individual and community. Enabling is seen as the task of health promotion and it recognises that people may need resources, information and power to enable them to assume responsibility and greater control of their health. In a 1984 background paper to the conference, a WHO working party stated that a socio-ecological approach to health provided the conceptual framework for its discussions and the emphasis was on social, economic
and ecological perspectives on health, not a physical and mental perspective.

A health promotion framework recognises the interconnectedness of environment, lifestyle and biology in determining health. It is a "reform movement advocating a shift of priorities and resources in alignment with a broader way of thinking about health, and advocating new and broader social interventions in order to protect, maintain and promote health" (Michael Yeo 1993:225).

In the *Charter for Action*, which was the result of this conference, there is a balance between an individual and social focus. The charter clearly states that "[t]he fundamental conditions and resources for health are peace, shelter, education, food, income, a stable eco-system, sustainable resources, social justice and equity" (WHO 1986:2). It further reinforces the *Alma Ata*’s call for equity in health and an intersectoral approach to the health of a country’s people.

Five key frameworks are identified: building healthy public policy; creating supportive environments; strengthening community action; developing personal skills; and, reorientation of health services. Only one of these five focuses on the individual. However the focus on getting people to change their behaviour, e.g. to give up smoking, is an attractive path to follow, as it does not require any major structural change and is less costly for governments (Nancy Milio 1986).

Russell Caplan (1993) argues that health promotion has many meanings but is basically a social intervention based on the nature of the data, evidence, on which we make decisions for intervention and the nature of the knowledge that we have about health. "The knowledge base around which we plan our programs for action is thus a crucial dimension in determining
what we do in the name of health promotion/education, how we do it and most importantly how we compete for scarce resources" (Russell Caplan 1993:149). At present there are two competing discourses - that of science and rationality, with a focus on the linear cause and effect of health and illness (medical model) and that of the social constructionists who believe that people’s behaviour and health are the result of complex socio-economic, cultural and ecological systems.

If you believe that society is organised in an essentially fair and just way, then health problems have little to do with the way in which the economy is organised, wealth and opportunity distributed, and political power executed (Russell Caplan 1993:151).

Regarding the Ottawa Charter Caplan says "[i]n the final analysis the Ottawa Charter in the interests of consensus means all things to all people and precisely because of that is unlikely to provide the means for a clear strategy of action in raising the public health" (Russell Caplan 1993:152). He believes that the Charter contains no solid theoretical/philosophical grounding and this is its downfall. Furthermore the radical education model, the political economy model, self empowerment and community development, all of which predate the charter, reflect with greater analytical precision the key ideas contained in the Charter. He is basically saying that what we believe it is to be human determines the policies we develop, the programs we run, and what programs get funded.

I would agree that many of the programs that have been established in the name of primary health care and health promotion still reflect the medicalisation of health. There is still a long way to go, this is hardly surprising:
[With training rooted in the biological and medical sciences, some health personnel have been slow to embrace the concepts and practices of community approaches. In a sense, they were trained to know the answers, not to assist others in searching for them. Even when the term 'community diagnosis' is employed the connotation is still largely that of professionals, rather than the community, making the diagnosis (Feuerstein and Lovel 1983).

If the medicalisation of health discourse has political primacy, then the understandings of a new and competing discourse will be contaminated, and maybe even high-jacked by the dominant discourse. Indeed, if one took the Alma Ata at face value, a lot of people stood to lose influence and control. If health becomes intersectoral and participative, then the keepers of knowledge, and therefore power, in health, will have to share their privileges.

If the major causes of ill health for the majority of people across the globe are injustice, poverty, war and malnutrition (John McDonald 1993; John Ashton 1992), then surely funds and personnel should have different priorities and roles? These problems do not require high tech solutions. What is called for is "political and social reform to remove structural barriers to health" (John McDonald 1993:75). A heart lung bypass will not stop poverty, though it will make the surgeon, the hospital shareholder and the pharmaceutical executive richer!

In Australia, it is not surprising to learn that whilst we have adopted the call for 'Health for All by the Year 2000', the Federal and State governments have not embraced the political and social changes required. Whilst in 1988 the report of the Health Targets and Implementation Committee to Australian Health Ministers - Health for All - acknowledge the inequity in
health status for Australians, inequity caused by socio-economic differences, race and gender, the priorities for action detailed in this report focus on nutrition, control of high blood pressure, cancer prevention, injury prevention and improving the health of older people. The way this is to be done is through education and information giving so that people can change their unhealthy behaviours into healthy ones!

The report does include strategies for intersectoral collaboration but, if we take the case of nutrition, which the report clearly states is an outcome of socio-economic status, there are no strategies to improve the low status of those people who have poor nutrition. "A fundamental defect in the Health for All philosophy is the implicit assumption that equity in health can be attained in the absence of a radical restructuring of society" (Wendy Farrant 1991:429).

Both the Alma Ata and the Ottawa Charter are important as they recognise the fact that health is socially constructed and that the health and well being of a country’s population is a political outcome. There are however difficulties in the implementation of these ideas.

Part of this difficulty is, I believe, that these documents can be seen at the level of 'mission' or 'values' statements, they do not articulate how these values can and should be put into practice. While this was done to enable each country to interpret the documents in their own cultural, political and economic circumstances it does weaken their potential. Neither do they explicitly articulate their philosophical underpinnings and basically subversive nature. As a result they have the danger of becoming 'feel good' statements, a catch all for anything that is not seen as traditional health.

Defining health is extremely complex and difficult, and means many different things to many different people, thus, working out what it is we
are meant to be promoting is complex. It is useful though, to take up Russell Caplans’ point regarding other models which pre-date the Ottawa Charter, and their potential for achieving the goals of the Alma Ata. In particular, I will focus on community development.

Community development

Community means strength that joins our strength to do the work that needs to be done. Arms to hold us when we falter. A circle of healing. A circle of friends. Someplace where we can be free (Starhawk 1989:92).

Community development principles have received strong endorsement from WHO in its Health for All by the Year 2000 strategy (Wendy Farrent 1991). WHO believes that community development is central to shifting the inequalities in health and is therefore central to operationalising primary health care. Certainly the rhetoric of community development and community involvement in health is gathering pace (Michael Yeo 1993).

Whilst in the context of this research, I am concerned with community development in the health arena, it is both useful and interesting to note that community development, on an international level, was originally applied and funded, in the 1950’s, by industrialised countries to assist the development of ‘so called’ underdeveloped countries in terms of agriculture (Peter Oakley 1989; James Christenson and Jerry Robinson 1989).

Community development as a health strategy, a way of doing, or a theory, is contentious to say the least. Part of this contention is based upon the historical uses of community development, especially in light of our colonial and colonising past. Part of it arises from the debate over the very term ‘community’. This is a term frequently used by politicians, bureaucrats,
policy makers, the media. Indeed most of us talk of 'community' in our everyday lives and the use of the term generates emotive energy. It is not a feeling free term.

But what do we mean by it? Is it really the 'Spray on Solution' as critiqued by Mowbray and Bryson (1981). Mention the word community and we all feel that it must be OK as the warm inner glow spreads. Do we mean a geographically bound group of people; people who share an interest or interests; people who work in the same place; people who have the same values and ideals; people of the same gender? Do we mean a group, and when does a group become a community? (Watt 1986).

To talk of community as a human collective remains so ill-defined as to be virtually meaningless unless other perspectives are immediately added to it (David Clarke 1987:54).

David Clarke, whilst recognising the difficulties in defining the term takes a community development perspective when he says,

"[t]he only way to minimise the problem just described is to attempt to begin where people begin. And more often than not this starting point is in the arena of feelings - in the gut rather than in the head. The advantage of this point of entry is that it gives the community the emotive dynamic it deserves and grounds it in the experience of the actors" (David Clarke 1987: 55).

He then defines community as a feeling, where both the individual and the group are of equal value.
This is an attempt at holism rather than the dualism of the individual or the group. It integrates both. Michael Yeo (1993) develops these ideas further, and feels that where we have got it wrong in the past has been where we have seen the issues in terms of 'the individual verses the community debate'. Michael Yeo wonders why often an either/or approach is adopted - not both. Why do we pitch the individual against the community? The freedom of the individual and the health of the community are not always opposing.

Jane Mansbridge (1995) discusses this tension, between individualism and community, and advocates that we proceed "selectively on both fronts" (1995:341). She believes that if we shift the focus to women's experiences light will be shed on "the undervalued components of community and underestimated threats to individual autonomy" (1995:341). Ultimately, she believes that it is possible to both strengthen community ties and respect for the individual.

Michael Yeo goes so far as to suggest that in health promotion we actually should be promoting community. Health promotion should at the same time promote individual freedom and collective responsibility. His emphasis is on responsibility for the solution, not the problem. The task of all of us is to work with this creative tension, this can lead to empowerment.

However there is, with this notion of community, a danger that we try to homogenise; that difference will be seen as a difficulty, something to be resolved not celebrated. Iris Young takes this position when she says

"[t]he ideal of community...privileges unity over difference, immediacy over mediation, sympathy over recognition of the limits of one's understanding of others from their point of view........deconstruction...shows that a desire for unity or
wholeness in discourse generates borders, dichotomies, and exclusions" (Iris Young in Linda Nicholson 1990: 300-301).

Moreover, Iris Young sees the idea of community, which she defines as small decentralised units, as both politically undesirable and impossible to achieve. Indeed, she equates proponents of community as wanting to dismantle cities. Neither Michael Yeo or David Clarke suggest this, although undoubtedly some people would have us all to return to preindustrial bliss.

Iris Young’s alternative, is to start where we are at - some similarities here with a community development approach - and that our "political ideal is the unoppressive city" (1990:317). In this unoppressive city, the basis of human life will be the fact that we relate to each other and each other’s history and yet remain strangers together. There is no attempt to believe that we can truly understand each other in our difference. "In such encountering people are not 'internally' related, as the community theorists would have it, and they do not understand one another from within their own perspective. They are externally related, they experience each other as other, different, from different groups, histories, professions, cultures, which they do not understand" (1990:318).

While Iris Young is dismissive of notions of community for its potential to negate, and even expel difference, African American activist bell hooks does not feel that this is necessarily how community could be. Arguing for a global community of women, a sisterhood, she says; "women do not need to eradicate difference to feel solidarity. We do not need to share common oppression to fight equally to end oppression......We can be sisters united by shared beliefs, united in our appreciation for diversity, united in our struggle to end sexist oppression, united in political solidarity" (1995:140). For bell hooks, while we can acknowledge that we experience oppression differently depending on our context and our individual experiences, the
coming together, acting together, and forming a political community is both desirable and necessary.

For me, the major difficulty with the word 'community' is that we see it as a vision, an end point. We try to build community. Having community feelings becomes a utopian dream, something we strive for but never attain. And, if we do not feel that we are in a circle of friends, if we experience conflict and difference, then we ask why? What is wrong with us, why haven't we got this warm fuzzy glow? If we rephrase community as a verb, something that we do then we can escape this searching for the elusive\(^1\). Here community can come to mean simply a group of people being together. Adrienne Rich sums this up well saying : "[w]e affirm diversity out of which we come, the clashes and pain we experience in trying to work together, the unglamorous ongoing labours of love and necessity" (1995:403). Accepting this means that we accept that there will be difference, that we are strangers to each other, with different histories, different experiences, what is important is that we act together "If not with Others, How?" (Hillel in Adrienne Rich 1995:404).

While I acknowledge the difficulties inherent in the term 'community' it is the term 'development' which really causes me to shudder. In his critique of the Alma Ata, Vincent Navarro eloquently summarises some of my concerns: "capitalist development is redefined as "development", a process perceived to be so intrinsically good that it undoubtedly brings about improvement in health" (Vincent Navarro 1986:223). In fact it is more than capitalist development at work, it is capitalist, patriarchal development.

Additionally Navarro states in relation to primary health care strategies " to consider them as the most important interventions to achieve Health For All

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\(^1\) I am indebted to my friend and colleague, Hilary Armstrong, with whom I talked, thought and played with this concept.
is profoundly incorrect. Most improvements in health have been due to changes in economic, social and political structures rather than in the health sector" (Vincent Navarro 1986:224). His final damming comment on the Alma Ata: "Its recommendations reproduce for the most part, the point of view of the development establishments. These views are part of the problem and not of the solution; they represent the perspective of the dominant classes in today's world" (Vincent Navarro 1986:227).

Robin McTaggart is similarly unimpressed by notions of development, "development practised by the West expresses an ideology which is economistic, patriarchal, individualistic, Judaeo - Christian, ethnocentric and Western democratic.......Moral idealism is subordinated to materialism. The cornerstone of this ideology is a persistent and unexamined confidence in Western economic systems....despite their ecological unsustainability" (Robin McTaggart 1992:50). Again, development is seen as part of capitalist and colonialist development. Robin Morgan also believes that both of these 'developments' are, in fact, part of the growth and consolidation of western patriarchy:

Traditional technical assistance (sometimes forcibly) exported by "developed nations" so far has rarely included specific plans and activities aimed at involving women's participation in the development plans for their countries. On the contrary, Man's neocolonial assumptions have been no different from his previous ones: that all bargains are made between men and over the heads of women (Robin Morgan 1994:203-204).

With these critiques of 'community' and 'development' in mind what is meant by the term community development? A recent textbook definition reinforces the conservative agenda behind this concept. "Community development is the name given to the efforts made by authorities (for
example, governments and churches) to set up programs to address problems arising from the inadequacies of social systems" (Kelly and Sewell 1990:93). So, we encounter another reproduction of the medical model, treat the symptoms and not the cause!

**Empowerment**

At its best, however, community development can be concerned with transforming the situations in which people find themselves. It can be subversive and political, a way of working that aims to change a social system, not individuals within that system. Individual change in behaviours, knowledge and ways of being, may be an outcome of the process but it is not an explicit aim. community development should be concerned with changing inequitable and unjust social arrangements and power structures.

Jane Dixon (1989) has provided an interesting historical overview of community development. In a well argued and critical article, she delineates the ways in which the concept can be seen and worked with - as a process, a method, a program or a movement (Sanders 1958 in James Christenson and Jerry Robinson 1989:13). She is critical of some of the claims that have been made under the banner of community development and favours using the term to refer "to the ongoing process of developing self-reliance, both in terms of personal and social group capacities" (1989:82). Her position is that community development "is useful in the promotion of personal and planned social change and has little to do with fundamental social change.... ongoing class, race or gender struggles to transform the existing economic and power structures" (1989:83).

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1 Jane Dixon's implied separations of the local versus the global, and personal versus fundamental change is problematic, especially for a social ecologist. She does, however, succinctly highlight a number of major critiques of community development. I have used her work here as an entry point to discuss these critiques. While we both are arguing for change in social systems, how we engage with these systems, where we put our energies, who we work with differs.
One of the major principles of community development is that when we work with people we start 'where they are at', with their issues and concerns, with the things that they feel are important. In this way, the group or community with whom we are working truly have ownership of the issue and the plans for action and change. They have a vested interest in ensuring that the process continues and that change occurs and is maintained. Furthermore, this is empowering, for when we take a community development approach we validate people’s concerns and issues and put our time and energy into working 'with' them, not 'on' them. The people with whom we are working are actors within the process of transformation.

Jane Dixon believes that this way of working "involves the emphasis upon a process which accepts and does not challenge the existing power relations (and indeed makes use of them). This tends to deny, in all situations except where there is an already politically active constituency, the potential for fundamental social change" (Jane Dixon 1989:257). Surely empowering people does affect the power relations and creates some sort of space for change to occur?

"Community Development does start where the people are at and remains where the people are at - it is not about the redistribution of power, even within an area, although less powerful members may benefit from the innovation or a new service" (Jane Dixon 1989: 89). So, if a community development program succeeds in establishing a new child care centre which enables more women to go to work and earn money is this not altering the economic power of these women and their ability to make choices?
Overall Jane Dixon feels that community development is a useful way of working with people and achieving micro change, but that many of the claims attributed to community development are exaggerated. The point I feel she misses is that, while we work with the local and particular, we are, in fact inserting ourselves into political structures and transforming these too.

Susan Kenny takes up this discussion asking if community development is merely a "trumpet in a herd of elephants?" (1994:257). In answering this question, in relation to contemporary Australia, she believes that yes, it is only a trumpet, among many other trumpets: "one dynamic of change among many" (1994:258).

However, while community development often has contradictory implications, it continues to survive at a time when humanism and the welfare state are under threat. This survival, she contends,

> can be understood in terms of its ability to strike a balance; on the one hand, putting forward a vision and breaking new ground; and on the other, working pragmatically in the material world, accepting the authenticity of people’s lives....Community development can play its part in imagining and developing strategies and processes for the transformation to a more humane, democratic and open society (Susan Kenny 1994:258).

In focusing on process, rather than specific ends, community development can be open, flexible and daring. It enables us to take risks together and to resist the status quo. Most of the ways in which community development is used, in the health arena, focuses on the process. Community development is not about 'development', it is not outcome driven. Rather it is a way of
working with people on issues and concerns that are relevant to them. The United Nations definition of community development reinforces this focus on process:

the process by which the efforts of the people themselves are united with those of governmental authorities to improve the economic, social, and cultural conditions of communities and to integrate these communities into the life of a nation, and to enable them to contribute fully to national progress (James Christenson and Jerry Robinson 1989:14).

This quote also underscores Jane Dixon’s point about the process not really being one of fundamental social change.

As we can see people work with governmental authorities and agencies. What if the people concerned feel that it is the governmental agencies which collude in the causes of their social problems? Russell Caplan (1993) argues that community development is "the best attempt at constructing a truly radical practice in health education/promotion" (1993:155). But he would agree with Jane Dixon that it lacks a critique of power relations. "It is a piecemeal attempt at solving social and political issues of poverty and multi deprivation through local community activity" (Russell Caplan 1993:156).

Against these rather pessimistic views, this thesis has been undertaken with the assumption that adopting a community development approach in health can be radical. It insists that we move away from the more traditional relationship of the expert provider and the novice consumer. It asks that bureaucrats, doctors, health workers and the community work together on issues of collective importance and urges that people themselves are best placed to identify what it is they wish to work on. The health professional,
in this milieu, brings some technical expertise to issues already identified. Central to community development is the concern with "redressing inequalities in health by facilitating collective responses to community defined health needs and enabling powerless and disadvantaged groups to have an effective voice in policy decisions that effect their lives and health" (Russell Caplan 1993:43. See also Nancy McWaters, Chris Hurwood and David Morton 1989; Watt 1986).

Community development in health is one of the major strategies for implementing primary health care. It is a process not an outcome. Broadly, what this process means is that there is local participation and involvement in the planning, delivery and evaluation of health care services. It can, however, mean many things depending on the political ideology of its advocates - nothing is value free! It does, though, require a fundamental shift in power in the health system particularly in terms of decision making as it demands that the 'community' become equal and active participants in decision making processes. However, these challenges can cause serious moral dilemmas for health personnel, who may become caught between the potentially conflicting agendas of the community and a health agency employer (Jane Dixon 1989).

Whilst community development may not be a new idea, it is certainly a new practice in health, and one with which the health sector is struggling (WHO 1991). This is hardly surprising as it calls for a bottom-up rather than a top down approach and is

a dynamic, unquantifiable and essentially unpredictable element. It is created and moulded by the participants...[it] is concerned with building up pressure from below in order to bring about change in existing institutional arrangements. It does not necessarily begin with any preconceived set of quantifiable
targets or objectives; it is more concerned with developing a genuine dynamic of analysis and involvement and then allowing the process to follow its natural course (Peter Oakley 1989:11).

At the very least, one of the outcomes of working with community development as a process, is that of 'empowerment'. Working with people on their issues, needs, wants and desires is empowering just of itself. By enabling and assisting people to network, to gain knowledge of local systems and decision making processes and by becoming part of some of these processes, people develop their own skills and knowledges.

Like 'community' though, 'empowerment' has become one of those words which make us feel good, but it is a complex term. The ideology and practice of community development operates with the belief that power is something that can be seized, taken. Michel Foucault (1972-77) has given us another way of understanding power. He contends that power permeates all social relations, it occupies multiple sites, it is created and maintained by us all in our everyday interactions and through these interactions power also creates and maintains us. Furthermore, power and resistance operate together, one cannot exist without the other "[p]ower and resistance are inseparable because the very existence of power relations presupposes forms of resistance" (Susan Kenny 1994:117).

This way of seeing power can be useful in community development, as it supports the community development charter to 'begin where the people are at', to work with the local and particular in seeking social change. It also enables us to be aware that in terms of resistance, we need to look at multiple sites and practices.

Empowerment, is premised on the belief that to be fully human we "have to be able to participate in a cultural form of life" (Doyal and Gough 1991:61
in Susan Kenny 1994:118). This participation can only occur if people have access to "resources, knowledge, decision-making, and enriching social relationships" (Susan Kenny 1994:119). Nina Wallerstein (1992) advocates a Freirian model of empowerment, which includes: improved self concept, critical analysis of the world, identification with others, and participation with others in organising for environmental and political change. She defines empowerment as: "a social action process that promotes participation of people or organisations, and communities towards the goals of increased individual and community control, political efficacy, improved quality of community life, and social justice" (1992:198). Empowerment then is seen as a strategy which aims at addressing people’s lack of control over their own destiny and empowerment education becomes the role of health educators. "With this perspective empowerment is not characterised as achieving power to dominate others but rather power to act with others to effect change" (Nina Wallerstein et.al. 1988:180).

Examining dominant discourses in health is both necessary and useful in terms of understanding why things are as they are. It is though, an exercise in deconstruction, and while useful and necessary, does not necessarily lead to action. Foucault showed, in The Birth of the Clinic (1975) that all medical knowledge is socially constructed and that medical knowledge is relative. What we do in terms of health, how the system is constructed, how the money is spent, how the decisions are made, would be different under a different regime of truth. To move back to the metaphor of the play, it is not enough to see the backdrop, the scenery, the props, we need also the actors - something needs to happen, we need to move away from the blank, indifferent space.

Critical social science gives us a framework for doing this. In effect it informs the scripts of the actors. Within this space we can say that it is not
enough to understand the world, the point is to transform it, you and I - today.

To have knowledge is to have power. The powerful are less curious than the powerless. It is because they are sure they know the answers - and they do. But not to the questions that the powerless are asking (Robin Morgan 1994:170).

Working with/in critical social science, which takes a social constructionist view of health, any research we undertake must begin to find out what questions the powerless are asking; what it is that they have to say; what their stories are. For our research practices to be empowering we have to start where the people are at and move forward to better places, wherever these may be.
CHAPTER 3
THE WOMEN’S STORY
"[A]s a woman I am entitled to full recognition of myself as a person, as an achiever in my own field, as a success on my own terms. Our terms are valid. Our success lies in embracing the real achievements of women who have worked, lived, strived in this country to create a world where women and men are equally recognised as human and women are fully acknowledged as contributing to the cause of humanity" (Jocelyn Scutt 1992:8).
What follows is a number of stories - presented here in linear sequence, although in reality there was much concurrence and overlap in the telling, recording and writing of the stories. The story telling and writing took place within a specific context and at a specific point in time. While the broader context has already been discussed, it is important to sketch the local and historical context of the Community Health Centre in which the research took place.

The Australian Context

Although not named as such, Community Health programs and services can be traced to the beginning of this century. In 1907 school health programs began with basic health screening and referral to doctors. The first Baby Health Centre opened in NSW in 1914, with similar services spreading rapidly throughout other states. In 1926, as a result of a Royal Commission of Health report, the maternal welfare movement was established - the precursor of Baby Health Clinics and Early Childhood Centres (Fran Baum, Denise Fry and Ian Lennie 1992).

During the years when Whitlam was Prime Minister of Australia (1972-1975) a universal national health care system, and Community Health program was established (Lois Bryson 1992). This foreshadowed much of what was agreed upon in both the Alma Ata (1976 WHO) and the Ottawa Charter (WHO 1986). Community Health services were to be concerned with "health maintenance and education; illness prevention and rehabilitation; and the delivery of services in the community rather than institutional settings" (Ann Wall 1996:25). These developments in health sprung from the 1973 report to the Whitlam government, A Community Health Program for Australia, whose principle feature was an "emphasis on primary health care delivered by multidisciplinary teams of health practitioners ... in a designated locality" (Sidney Sax 1992:xiv).
Furthermore, and of particular relevance to this study, there was a strong emphasis on community participation:

\[(b)\] involving people in decision making concerning their local health services, they will be given opportunities to influence the acceptability and availability of services. Involvement might be fostered by outreach programs, discussion papers, public meetings and the appointment of community representatives to management and advisory committees (National Hospitals and Health Services Commission 1973 in Judith Dwyer 1989).

These developments in health were seen as part of a radical social reform agenda with an attempt to shift health care from a curative to preventative focus within local communities and to ensure access and equity in service provision. During these years, 1972-1975, 300 Community Health centres were established. By 1994 there were 800 Community Health and Early Childhood centres in NSW employing at least 60,000 or 8.3% of the NSW public health sector staff (NSW Health 1994) at a cost of 7% of the total health budget. It should be borne in mind, however, that these figures are somewhat misleading as George Palmer and Stephanie Short (1989) point out. The actual proportion of funds that go to Community Health Centres and services is difficult to ascertain.

Community Health is a diverse, flexible and complex network of services, almost defying definition. The Australian Community Health Association views Community Health as an approach as well as a service which is concerned with access and equity, the provision of comprehensive services and continuity of care, participation of people and communities and services
which are community and not institutionally based (Australian Community Health Association 1991).

While Community Health services have grown, and survived over the past twenty years, they have been marginalised with no legislative support. They are "marginal to the medical establishment...the hospital establishment...health finance...the public... and it continues to be in the margins, in many cases having lost its sense of changing the health systems priorities to a resigned acceptance that this is what is and what will be" (Fran Baum, Denise Fry, Ian Lennie 1992:11).

An Australian wide review conducted by the Australian Community Health Association (1986) concluded that while Community Health was a marginalised group of services, this marginalisation enabled them to be ideally situated to be a leading player in a national primary health care, health for all, strategy in addition to challenging the dominant medical hegemony of health policy and those supporting the sick care system (Loiuse Sylvan and David Legge 1989). However, it is clear that while we have seen the rise, and in some instances the fall, of certain types of Community Health programs, like Aboriginal Health Centres and Women’s Health Centres, the dismantling of the 'sick care' system has not happened.

Part of why this has not happened is the dominance of the biomedical view of health and the gender structures in health and our society. Community Health services employ nurses and allied health personnel, most of whom are women. Combine this with economic pressure from the integration of the Australian economy into internationally controlled capital, with its attendant ideology of deregulation, managerialism and adulation of the private sector and we begin to understand the changing practice of Community Health with its talk of 'customers', 'corporate plans', business plans' and 'total quality management'.
Community Health is asked to live with the tension of combining the ideals of the Whitlam years, expressed still by many of its workers, with the day to day reality of increased surveillance of its workers, more paper work, higher administrative accountability and less flexibility. While ideally situated to reorient the health system due to its position at the margins Community Health has developed a siege mentality and directs most of its efforts at mere survival.

**The local context**

Funding for Community Health was supplied differently to the States and Territories under the Whitlam Government. This led to different organisational and administrative structures which has had a direct impact on the autonomy and security of Community Health services in each State and Territory. In NSW, Queensland and Tasmania, states were divided into Areas with management responsible to an Area Health Board. Health Boards were established with the joint purpose of state financial control and community representation.

What this has meant for NSW in practice, is that Community Health services are seen as a part of the health service as a whole, they compete directly with hospitals for resources, with "hospital issues absorbing the attention of most area health boards" (Lois Bryson 1992:3). Under this regime Community Health is in danger of being seen as a luxury, to be supported and funded only after the hospitals have been given sufficient resources.

The Wentworth Area Health Service of NSW is broken down into three districts: The Blue Mountains; Hawkesbury and Penrith. In 1991 the population of the area was 270,000 (1991 Census) this has been predicted

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to grow to over 300,000 by 1997 (Wentworth Area Health 1993). There is a mix of people from non English speaking backgrounds, with the dominant grouping the Anglo Celts. Over one fifth of the states' Aboriginal and Torres Straight Island population live in the area. Locally, the main causes of death are heart disease, cancer, accidents, respiratory disease and suicide (Wentworth Area Health 1993).

It is within the district of the Blue Mountains that the current study has taken place. This district comprises:

The Blue Mountains District Anzac Memorial Hospital, a 93 bed acute facility located at Katoomba; the Queen Victoria Memorial hospital, an 82 bed Nursing Home located at Wentworth Falls; the Springwood hospital, a 32 bed acute facility located at Springwood; and three Community Health centres located at Katoomba, Lawson and Springwood (Blue Mountains District Health Service 1993:1).

The district received $4,265,200 in 1992/3 with $2,830,453 being spent on Community Health services. In 1995 the district Community Health services employed 75 staff. There is rhetorical support for many of the historical aims of Community Health. For example, in 1993 health promotion and disease prevention was seen as 'priority A' of this district with goals focusing on establishing a better balance between prevention and curative health services, community participation, shared responsibility for health between providers and the community while at the same time striving for efficiency savings (cuts) of $440,000 in the 1993/4 financial year (Blue Mountains District Health Service 1993:1).

The Community Health centres offer a wide range of services in drug and alcohol counselling and needle exchange, early intervention, palliative care,
respite care, home nursing, school screening, dental clinics, speech therapy, occupational therapy, physiotherapy, and counselling services. Staff are often 'on the road' in peoples homes, local schools, running groups or classes. At the time this study was conducted the community nurses operated under a generalist model. That is, they were required to provide a cradle to grave service; running immunisation clinics, providing parenting education, palliative care services and home nursing, for example, all in a days work.

The Community Health centres in the Blue Mountains district were managed by a team leader who was also the nursing unit manager of the centre. Two of the Community Health centres in the district had been purpose built, the third occupied an old cottage on the fringes of the town. It is with/in this third centre that the current study took place; where the participants for the Staff’s Story and Consumers Story came from and where we met monthly as an Inquiry Group.

Overview

This chapter tells the stories, briefly, of the women who were integral to this research, the women of the action research Inquiry Group. We did not set out to be a group of women, rather this happened. No men joined us. This is not surprising really as so few men are employed in Community Health services in the Blue Mountains in middle management or direct service provision positions. I do though want to make it clear that we were not pursuing a separatist line, our concern has been the health of all people, women, men and children. Indeed, only three members of the group would call themselves feminists - Debbie, Dot, and Lucy.

I have included this chapter for a number of reasons. A group is comprised of many individuals and whilst I hold the view that 'the sum is greater than the parts' it is important not to render invisible the individuals. Each one
has her own voice and not just a group voice. Each of these women brought
different life experiences to this group, different dreams, different
backgrounds, different skills and ways of knowing the world. It is important,
however briefly, that we acknowledge these differences. We were not
homogenous, it was our differences and that enabled us to be challenged
and to reflect on our own practices.

This has been one of the more difficult chapters to write. As women we are
not accustomed to claiming space for ourselves, or believing that our
voices are important, that we have something to say.

Women are reluctant to arrogantly project themselves, to
applaud and promote themselves so to preclude anyone else
from being appreciated for their contributions (Jocelyn Scutt
1992:3).

This chapter is one way of honouring the women of the Inquiry Group, of
thanking them for their time, commitment and support by saying you are
important as an individual, as a person in your own right.

The silences that abound about our lives, and in our lives must
continue to be broken. Women’s lives are replete with ‘odd’
happenings and quirks associated with living in the world.
Despite discrimination and oppression, we have an
immeasurable capacity for laughter, life, achievement and
success. The full complement of the circumstances of
women’s lives are not generally known ..... Living in a
male-defined world, women frequently ignore, or have never
come to see, their achievements, their very real successes,
and the way they have stepped out, into the world, as
political and social beings (Jocelyn Scutt 1992:2).
Introduction

I want to tell you about the people who have been part of this Inquiry Group for the past four years, to tell you about their dreams and goals, where they came from and who they are. For as much as this thesis is my story, it could not have happened without these remarkable, yet ordinary, women. Remarkable in that they have been prepared to take risks; remarkable in that they have supported me and each other for four years during this project and remarkable in that they have acted in ways that were not always approved of by the bureaucracy for which they work. Ordinary in that they are like you and I "in their light and laughter, their acknowledgement of sorrows" (Jocelyn Scutt 1992:4). By calling them remarkable, I do not want to distance them from other women. Rather, like Jocelyn Scutt who says "all women are extraordinary", I also say "all women are remarkable" as they keep on going. But, it is of the few women who have shared the journey of this research with me, of whom I now wish to write.

To write of these women though requires care on my part. So it is with a strong sense of care and responsibility that I begin.

The process
In weaving the tapestry of the group and of these women I want to weave together how I knew them, in addition to giving them the opportunity to tell their own stories. To capture both ways of knowing, I asked these women to respond to some 'reflective questions' taken from Virginia Kaufman Hall’s thesis Women Transforming the Workplace (1995), (see appendix 1 for questions).
These questions were handed out to the group at our meeting in June 1995. People wrote their responses and posted them back to me. For two members of this group this process did not work, so I interviewed them using the questions as a guide. I have only drawn on the answers from questions 1-5, 6 and 12 for this chapter as they focus on the individuals, who they are and how they felt answering these questions. Questions 6-11/13 are specifically related to their relationship with the research group and are woven into Chapter 6.

I have used both mine and their words to enable you to have a context for the group, to know a little of the women involved. After completing a draft of this section each woman was given a copy along with permission to change, add or delete any of the information contained in it. What follows is a collective agreement of who we were at the time.

**Meet the women: The Health Workers or "Handmaidens" and "The Good Little Girl"?**

At this stage of the research project the group comprised nine women, including myself and an undergraduate student from the School of Social Ecology who was working with us as a research assistant. The ages ranged from 20-59. Apart from myself and the student, the women were employed by Wentworth Area Health. What follows is a brief profile of each person.

**Dot**

I had known Dot for two years before we worked together on this project. We had taught together in the Nursing undergraduate programme at the University of Western Sydney-Hawkesbury. When I was seconded to another school at the university Dot, was employed to fill my position. Dot and I were, at the commencement of this project, both postgraduate students in the school of Social Ecology, sharing the same supervisor.
At 59, Dot was the oldest member of our group. She continuously teased us with the fact that she would soon be able to retire from her position. When this project commenced Dot was the Team Leader of one of the health centres in the Blue Mountains. During the time of this project Dot became Director of Community Health in another district but continued her involvement with the group. Dot is married and has two adult children.

Dot began her nursing career in working class England. This experience combined with being part of the establishment of community health in Australia during the Whitlam years, led to her passion for community nursing:

"being a district midwife in England, being a health visitor in England, having the good fortune to join the program here in the early 1970's when there was some really exciting people (women) around who still are my heroes - we have to have heroes-legends to try and live up to-to inspire us. Working in Liverpool in the 1960's in a very poor dockland area first as a midwife then as a health visitor left me with an indestructible dream to work with people."

It is also from here that Dot attributed her understanding of health as a social condition "to be able to associate at a very early stage in my career because of the practical experience I had, in the north of England the association of social conditions and peoples health in a way that books can never teach - by working in a mining town, and in a big city in a very poor area."

Dot had certainly achieved a great deal during her time in community health in Australia. She is a well known Blue Mountains woman and can take credit for helping to set up the generalist community nursing programme in the 1970's, as well as developing a needed and exciting community health service in Lawson. In my experience Dot was never afraid to stand up and
'be counted' for what she believed in. She said that this was because she
was so near retirement that it didn't matter any more. I felt that it was more
to do with her passion for community nursing and her tremendous sense of
service to the people, that gave her the strength to find and use her voice.
However this stand can take its toll as Dot says she "sometimes gets tired of
fighting the system-running out of energy-have to conserve some to look at the butterflies
in my old age!"

Her education which "came late but never too late...... has enabled me to attach
theory to my practical experience- and gain an even deeper insight into what is happening
for people " has been very important. If she had any regrets it was that she
went to university late in life and this lateness hindered her achievements, "I
feel that if I could have achieved a higher standard of education earlier in my life I could
have achieved more"

While their have been "millions" of opportunities for Dot which she has
"grabbed" and "enjoyed them to the fullest" . Most women face a number of
challenges in pursuing a career. For Dot while having a family meant time
out from her career she enjoyed this time too much to see it in any way
other than positive. For her the lateness of her educational opportunities and
the patriarchal nature of society have been her greatest barriers "I still felt
there are strong barriers for women to break through to achieve higher levels of power in
the work force, and really resent the pat on the head attitude I still receive from some of
my male colleagues." Although Dot knew that this patronising attitude was not
of her making she admitted to a "tendency to feel a personal sense of failure when
things do not work out, even when I know that it's really the system."

An honest knowledge of herself was apparent. Dot believed that she was
an ideas person who easily got bored with "the nitty gritty details". Knowing
this she made a "conscious effort to stick in there to the bitter end and complete
things." This self knowledge combined with "communication skills, a huge network
system, varied experience in the field" and a "network of friends and colleagues in the
community health field, and my friends outside of work ... my other interests-music art theatre-reading and ... a very supportive husband" have enabled Dot to thrive and survive during her career.

Joan

Joan was the nursing unit manager/team leader of Springwood community health centre. It was through Joan that I made initial contact with community health, and through that contact in turn that this project was conceived. Joan began her nursing career in Canada working in hospitals in obstetrics and various relief positions such as the IV therapy team and total perinatal nutrition team (TPN).

On coming to Australia Joan worked as a "TPN sister" and joined "Western Metropolitan health region as a community nurse in 1975 - stayed as a community nurse until became nurse unit manager/team leader in 1984." In these 20 years as a community nurse, Joan has remained committed to the original ideals of community health and continues to see the health of people as being determined as much by their sense of alienation and powerlessness as by any biological determinants. She is committed to working with others to achieve a more equitable system of health care.

Joan has always had "a holistic approach to dealing with clients." She has enjoyed her working life as a nurse and believed that in working with people she has had the most to offer and where she got the most pleasure:

"I have given consistent support and advice to some clients when they were ill and feeling depressed such that they kept going and returned to full functioning. As a community nurse I supported a 50 year old woman who was being physically and emotionally abused such that she had no self esteem and became physically ill with heart problems - her husband wanted her to die. She eventually got away from him got her own place, went to university to do 'something for herself'."
A committed team worker Joan believes that she has "been lucky to have some job situations where I had good and supportive colleagues and realised the benefits of everyone working together to get the jobs done... I have always tried to promote teamwork as a way of getting things done with less effort from everyone because they all pulled together." She also focuses on supporting staff "to realise their strengths."

Working with Joan one got the sense that she was a fighter who has had to struggle at maintaining a sense of integrity in her working life. Part of this has been the fact that she was a 'working mother' and a 'woman at work'. "[N]ot having back up support for sick children when both of us worked - no family to back up. Later - having to work in a male oriented environment with economic rationalist policies giving us continual budget cuts and lack of support for workers as people. I gave up any idea of going further in the system and decided I wanted to get out."

Recent changes to her role and the structure of community health has meant that she no longer enjoys her work in the same way as she did. "I'm not a paper pusher and I hate dealing with facts and figures ... I do not enjoy doing reports and hence can find them difficult to produce. I force myself to get statistics and compulsory paperwork done as soon as possible so I can't procrastinate doing it. I don't enjoy the politics of the health system.....This system favours the bean counters and number crunchers and doesn't support those who could provide a better environment for people to reach their full potential." This way of thinking and working is in direct opposition to Joan's more democratic and people centred approach to her life and her work. As a result Joan is disillusioned and frustrated in her role. She dreams of being able to" retire to spend some time doing what I want to do e.g., travelling, taking up the piano again, having time to enjoy nature etc.... I do NOT want to push useless pieces of paper around anymore ! This is not what health care is about !"

During the process of this research project Joan's commitment and tenacity enabled her to make herself more visible and open to scrutiny. It was the community health centre that Joan managed that formed the focus of the research project. Additionally as 'results' came in Joan was asked to
present at seminars/workshops in the Health Department, often being in a position of telling people what they did not want to hear. Her conviction in, and commitment to, empowering processes and community participation gave her the strength to 'say it out loud and clear for all the world to hear'.

In answer to the question" How did you feel writing your responses to these questions" Joan says "I rarely get time to think or write down how I feel about my work or what my aspirations are because I'm so busy writing reports and shuffling papers around. Once I got started I felt good about writing this."

Lesley

Lesley was qualified as a dental therapist and has worked for twenty years in this field predominantly with children" learning something new every day." As she felt "awkward" and "intimidated" in answering these questions I received the barest amount of information to work with. While I have found Lesley's participation in the group to be both consistent and useful (for example she always reads all the paperwork and comments on it) I believe that she feels she contributes little.

Lesley is married, has a young son and teenage daughter. Seeing herself strongly as a clinician, Lesley described her strengths as "compassion, empathy, strong clinical skills, good knowledge of clinical techniques. Developed over the years as I became a mother. Am able to reassure a very distressed and terrified child who may need weeks of work and by the end of the treatment they have enjoyed their visit." I would add that Lesley has a strong sense of social justice and service to the community. She is able to see the possible ramifications of decisions and had great attention to detail.

Lesley frequently gave up her personal time to be involved in this project, often participating in events, such as interviewing the community, where she felt both awkward and shy. Perhaps these qualities and actions come from "Trying to please too many people too often. Being vague too often due to having
too much on my mind. Not assertive enough. Sometimes it’s easier to just admit to being in the wrong."

Training and educational opportunities were important to Lesley. Emigrating from New Zealand and being unable to work when coming to Australia meant that she was looking forward to being able to "to attend and survive the Forensic Dentistry Course later this year".

Lucy

At twenty Lucy was the youngest member of the group. Her presence was also transitory. She was working with us for ten months as a research assistant and student. Lucy had no background in health and did not know any of the women in the group, except me. She had been a student in the undergraduate course in Social Ecology, a course in which I taught. She became involved at my invitation, an invitation ratified by the group.

Lucy was passionate about "working with people and relationships, groups and conflict" a passion informed by her experiences where she had "learnt the importance of communication in an organisation and how constant this needs to occur as well as how I present myself, my ideas and opinions."

In answering these questions which caused her to feel "stressed .. due to the huge amount of university work" Lucy focused on her role as a learner

"In terms of my group skills I have mainly developed these through various group projects at university, however, facilitating focus groups with professional health providers in the community health project has given me a much deeper understanding of group techniques and how to draw out information in a relaxed and friendly environment.........

I have never been able to learn very well in a traditional teaching environment and therefore haven’t had a lot of confidence in naming concrete skills I have. School consisted of lesson-exam. Due to not learning this way I developed an inner critic saying I wasn’t intelligent to
be able to succeed in an exam or write a scientific report. This critic has
deflated somewhat, however, it has always been behind my lack of
motivation to write anything I see as straight academia.

She uses her art as "a bridge to my writing. If I feel stuck I draw a picture of my
'stuckness' and this seems to allow me to panic less and get on with it."

Being part of this group and undertaking some of the research tasks enabled
Lucy to use some newly acquired skills in a useful and productive way, "I
feel I have achieved a great deal through running the focus groups and organising times
and places with professional people. Full of youth and enthusiasm Lucy was clear
about what she wanted to do with her life. "My main ambition in life is to enjoy
myself. I do, however, have less herbal plans consisting of helping the less privileged than
I. This would be through teaching people how to communicate more effectively and
empowering them to speak out their beliefs and opinions. I would like to become politically
active and have my opinions respected by men as well as women."

This enthusiasm and belief that she could indeed make a difference was, for
me, a welcome breath of fresh air in a group of women who were becoming
tired of fighting the system. It was encouraging to know that there are
others, coming along behind, with the same passions and dreams, who
would take up the cause, albeit in their own way, and by doing so
alleviating the burden of responsibility from those who had walked, pushed,
struggled, their way down a similar path. Lucy's own way of walking the
path consists of "creating a different kind of awareness in people by a comment or an
act of kindness." Important and achievable steps towards equity and justice.

Maya

Maya was a speech therapist in community health. She was committed to
the principle and practice of community participation in both local and global
contexts. Her enthusiasm for doing something was infectious and inspiring.

Maya died during the early stages of this research.
When Pam commenced her time with this group she was in the position of community nurse. During the life of this research, she was promoted to Nursing unit manager and team leader of a community health centre.

Pam was trained and qualified in a number of areas including midwifery, gerontology and first line management. She has held positions of Director of Nursing in both public and private hospitals, been a Nurse Educator a Community Nurse, Pharmacy Assistant and Assistant Chef. She has enjoyed her career in nursing and feels that she has a number of skills and talents to offer.

"From my position I am honest, fair and able to see both sides. I work well with people in a community setting. I am a good community nurse and I have learned to work in a more holistic way. I think my work in the Community Links Project in Hazelbrook has improved my community development skills..... I have good people skills."

Pam sees herself as a survivor, someone who has battled enormous odds to keep going. She has achieved a great deal in her position and names these achievements as "surviving the last few years; my present position, teaching in nurse education, Community Links projects and present Healthy Villages project, improving the community health team spirit." Being first and foremost a practitioner with a wealth of experience, Pam keeps her feet planted well and truly on the ground, using her experiences to reflect upon and re-conceptualise her practice.

"[W]orking on Community Links Hazelbrook gave me the opportunity to see that a) community development is part of "nursing" as such. Coming from the old school this was difficult to accept as 'truly nursing'. b) Working as part of this community participation group was supportive to
me - in the context of added information of lots of people with loads of expertise. Also helped me to see that what I was attempting to do was and is OK."

Pam wants to "survive the health system for the next three years till I can retire" and is driven by the desire to make a difference for the people who use the health system, "I'd make a difference to the Lawson Health Centres approach to how we treat the public."

Pam felt that many of her struggles had been as a direct result of a difficult and traumatic personal life which has had a negative effect on her self esteem:

"I always see the bad side of things (the worst is always my first thought); stubborness. I try to please all people all the time; have difficulty thinking anything I do is OK, always knocking myself and my abilities. If I feel uncomfortable I laugh and make jokes when I don't mean to. Think everyone is better than myself. I am now learning to say that I can do some things okay but it's a slow process and many times the brick wall gets built up."

Through her contribution to this group Pam enabled me to see that there is an issue with 'naming' and 'ownership'. Pam had been practiseing community participation for years and had introduced many projects at work to strengthen people's involvement in decision making and service planning. However, she kept saying that she did not know if she was doing the right thing.

This led me to reflect upon what happened when a type of practice was 'named' by others. Maybe it led to those practising, questioning what they were doing. As they had not named their own practice, then what they were doing must, to them, be something different. This led the Inquiry
Group to researching what the staff in Community Health were already doing in terms of community participation, so that we could value and strengthen this.

Sue

Sue was the District Quality Manager, located at the local hospital. Her commitment to the group had always been strong, however her attendance and participation was more patchy than any of us would have wished. She had difficulties in her job and her management had requested that she not spend too much time with us. Sue left the group at the beginning of 1996 when she changed both job and community. Her words in 1995, on reflection, are slightly prophetic "I want something meaningful without disadvantaging my family... I am unsure of what’s ahead but I know it’s sound and worthwhile".

Sue was extremely committed to the idea and practice of community participation in health. She worked consistently with both the hospital and community health services to improve the services they were providing. And this was to the detriment of her health and peace of mind. Sue had a strong sense of personal integrity, which can be seen when she talks of her opportunities throughout her career.

"I have had many opportunities. Some like the opportunity to return to study, I seized and embraced. I guess, however, that perhaps I did not make the most of some:- Sometimes because I did not realise they were opportunities, sometimes because I would have had to sacrifice things I believe in, sometimes because I was in a particularly disempowered position, sometimes because it would have disadvantaged or hurt people I cherished and loved."

Sue also had an honest and open knowledge of her own skills and talents, which she listed as "Perseverance, tenacity, problem solving abilities of a high order,
lateral thinking, loyalty (given conditions agreeable with my value system), intelligent, caring, honest, hardworking, an aptitude for systems and an ability to perceive the ‘long term’ or global view.” Sue believed that these strengths were nurtured and developed through her experiences growing up in her family.

Committed to the idea of change and making a difference 'with' people rather than 'for' people Sue has achieved much in her career:

"I always choose jobs in organisations that needed change, and rebuilding or redeveloping and I thrived on them and gained many skills, learnt a lot and also gained a number of scars." While working in a hospital "I developed my staff into a 'real team' and we achieved much - fast and furiously and with enormous fun...introducing computerisation...I also helped many other department heads and staff to achieve .....I achieved satisfaction from my achievements whilst working as the Advisory Service Coordinator for the Australian Council on Healthcare standards."

Being at the forefront of a number of organisational change processes provided Sue with rich learning experiences, "I can say that the life experiences I have had have given me an incredible first hand knowledge and understanding of the imbalance of power and social, as well as other injustices in society."

Knowing about injustice and being committed to, and putting yourself in positions responsible for addressing some of these inequalities, can lead to pain and frustration. Family, friends and her strong spiritual beliefs have provided Sue with the strength and support to keep on going. Sue was a battler, a vulnerable battler, something she readily acknowledged "my greatest weakness is still, however, my tendency to be vulnerable to unjust criticism and to feel threatened by it- even when I know the criticism is unfounded or unreasonable.” For her, nothing had come easily. Many of her educational endeavours had been discontinued due to difficult personal challenges. She also experienced
many difficult relationships with the people she worked with. Sue explained these difficulties thus:

"the jealousy that other people have harboured towards me at different times. I was unaware that their actions were due to this basic human trait and being unable to accept that I could ever be of enough significance in any way to warrant people feeling this emotion towards me.... my reluctance to use the power at my disposal (as a result of my Christian beliefs) for my own ends and self preservation. My personality appears to be a threat to my professional life - 'people either love me or hate me'. Rejection by peers because I would not conform to what they perceived I should be. The fact that I think for myself, my reluctance to lie. Being a 'westie' and of poor background."

Sue always gave generously of her time, her skills and knowledge. She continuously challenged the aims of the project, the processes of research and what it was we were trying to do. This was extremely valuable for the group. It forced us to articulate clearly what we were trying to do and why. Being challenged, by someone is so committed to the project provided us with one way of finding our voices.

Rather than complete a questionnaire Ruth and Sandra were interviewed. For them, talking was easier to 'complete the task' than having to write down responses. This reminded me how much I enjoy the personal contact, the conversational approach to 'finding out'. A useful re-learning at this stage in the project.

Ruth

I interviewed Ruth just as she had finished running an Early Childhood Clinic. We sat in the tea room, at the end of the day to talk about these questions. Ruth felt that the last 11 years had been "very significant" in terms of her nursing career. Whilst she had a strong background in geriatric
nursing and an interest in palliative care she had spent the past four years in early childhood work.

She loved her job putting a lot of time and effort into doing it well: "I am a resource person for most of the team so I have to have a good level of knowledge and expertise and I use this consistently and willingly share this with others. I do my job well. I’ve been a nurse for 30 years and always done this job to the best of my ability. For the past 5-6 years I feel I do my job above the average."

Ruth accepted difference and individuality, was open minded and non judgmental, she often said wise things in a very matter of fact way and refused to see barriers to getting the job done. This ability enabled her to act, to get on with what needed to be done, for the families, couples and babies with whom she worked. She had a strong sense of who she was and appeared to manage the competing demands of family and work well. She knew what her priorities were and had the ability to "say no" and "leave the job at work - emotionally. I enjoy what I do and I enjoy my family and this is important. I put my family first and take time off." To me Ruth embodied 'common sense', which is not so common after all. This 'common sense' was summed up for me when she spoke about her dreams, "to always want to come to work. To not stagnate, to enjoy things or get out."

Education and further training were valued by Ruth: "getting the Lactation Certificate felt good" and she planned to pursue this love of learning further: "To be educated in domestic violence and sexual assault. To specialise in family and early childhood health. To always remain enthusiastic about life, to continue to be open minded and to always learn. To do a Graduate Diploma in Social Ecology and Masters - to learn as much as I can about families." Ruth was in the process of applying for post graduate study.

Ruth felt that she had been supported by the system and the organisations she had worked for, there have been many "opportunities for personal development in this job. if you wanted to develop an interest in part of your role you were
encouraged and supported to do this in forms of sponsorship." Ruth had also had the opportunity to "develop my strengths e.g. education, and have been supported in this by area management with plenty of input to help develop and improve skills....to be involved on committees ... to relieve Joan especially while she was on long service leave. This helped me see the bigger picture of community health from a broader viewpoint.... to work as a part of a multidisciplinary team and develop an ongoing interest in Primary Health Care and Health Promotion; if offered a course or seminar I never say no.

Not one to complain or dwell on the negative aspects of her working life, Ruth felt that although there had been lots of rapid changes recently she is now more assertive and able to cope. This previous lack of assertiveness was the result of "the hierarchy, I wasn’t assertive and was powerless within my professional life until fairly recently. Community Health has enabled me to develop assertiveness that I didn’t have before. I was too passive, the system, the way you were trained, you were the nurse the caregiver and you were responsible for the well being of the clientele. The training taught us to be handmaidens and this goes back to being the good little girl, obedient."

Sandra

I interviewed Sandra at her home, we sat on the deck overlooking the bush, drank numerous cups of coffee, ate breakfast and had a really good chat. I took copious notes whilst Sandra talked. Sandra was the Director of Community Health Services in the Blue Mountains. She was a registered nurse and has post graduate qualifications in management. She had pursued further study endlessly and voraciously immersing herself in areas such as: midwifery; psychiatric nursing; rehabilitation nursing; transactional analysis; gestalt; social anthropology; philosophy; politics; law and is a qualified real estate agent.

Although Sandra had breaks in her career for study she had been 'in nursing' for 23 years. She had worked in hospitals, with Aboriginal and disadvantaged people. Sandra saw her strengths as having a sense of humour, being able to see clearly and look at many implications. She was
patient with people who had not had many opportunities. She felt she was a good manager who maintained good relationships with staff, and she was happy to share power. She maintained a balance between feeling self-assured and vulnerable.

Sandra didn’t relate well to dominant men who misuse positional power. She felt that this was due to "childhood stuff". She tended to have a short fuse with people who don’t use their abilities and skills. Her strong commitment to her job and to ideas of social justice meant that Sandra found it difficult to switch off. Her work frequently flooded into her personal life.

Rather than believing that she has achieved her current position solely due to her own skills and talents Sandra feels that she has been lucky in her career, “there have always been people above who believed in my abilities and given me opportunities.” She had taken all of the opportunities offered and felt they led to interesting jobs. Additionally, "I got jobs through proving myself over long periods of time and handling difficult situations. I had good professional mentors."

Her achievements and what she felt good about included, representing enrolled nurses in their fight for award coverage and helping to establish a nursing course at Charles Sturt University, formerly Mitchell CAE. Sandra had also written an undergraduate program in rehabilitation for the University of Sydney and really valued working on research projects that had good outcomes in terms of relationships between nurses and clients.

Being politically active and “fairly up front” has meant that Sandra has not always been fully supported in her role. She was not a 'yes person' and would challenge decisions and people if she sensed misuse of power or social injustice. Both her sexuality and politics have been a threat as she was a “known left winger... having a political position was tolerated up to 1989, I will
dig my toes in around socialist issues, abuse of power, anything that is unfair. This upsets some people in the area as I challenge them around these issues."

Sandra appeared to have accepted that she would go no higher in the health system. In fact she was fairly disillusioned with the 'illness system' in which she had to work. She was extremely committed to Community Health but felt at the time that this part of the service would be better off in another bureaucracy altogether. "I am so divorced from health I wonder if I have any ambitions in health any more - I wanted to be the chief nurse in NSW up to 1989, it was a possibility, I would have been good for nursing and dragged it into the 21st century and changed it, especially the hierarchy."

It seemed a loss that such a person could become so disillusioned with the system. A person who had a strong sense of the social perspectives of health, a person with political 'know how' and strength of character to oppose take a position the hierarchy which employed her. The system needs to keep people like Sandra if it is to be a reflective and reflexive system, one that constantly renews itself. Any system will eventually stagnate and die if diversity is driven elsewhere.

'Debbie'

I thought about writing my story separately to that of the Inquiry Groups. In fact I began this way, but it did not feel right. I quickly lost sense of direction and purpose. Placing me, in with the group, somehow seemed to have more integrity, it was a better fit. My story is longer. I know more about myself. My task here has been to do even more theorising, conceptualising and reflecting. I am ultimately the writer of this thesis, and the only person of the group seeking a degree. It seemed only right therefore, that you should see, feel and know more of me.

I must have been ten or twelve years old when I remember, for the first time, that feeling of humiliation, anger and silence in relation to the medical
profession. I had a rash. My mother took me to the local doctor. Here I had to take off all my clothes and stand in front of him, naked, so he could look at the rash. I could not understand why all of my clothes had to be taken off, and he didn't explain. There was no more, or less, to it than that. I have no tales of inappropriate touching, but I certainly felt abused and ashamed.

In Australia, on holiday, I had to take my brother to see his specialist at the Children's hospital in Melbourne. I was sixteen or seventeen, he was thirteen or fourteen. For my brother it was part of a series of regular visits. Here he was treated as an 'interesting case'. While he sat pale and silent in his underwear on the bed, interns were invited to come and look at his 'condition', and they talked about him to each other, in front of us. Neither of us were acknowledged as people, neither of us was spoken to. Again I was silent. Angry, humiliated and hurt. I never asked my brother how he felt.

As a young adult, I worked with Julie. She had severe intellectual and physical disabilities plus scoliosis. She had rods in her back and frequently cried out and hit herself, in pain, frustration, anger? Bent in two, sideways, her parents and I believed Julie was in pain. We took her to see the specialist at Royal North Shore Hospital. After waiting two hours, despite making an appointment, we could now talk with this man. He told us she could not feel pain, that we were imagining it, and there was nothing he could do. This time I was not silent. I questioned his assertion that she could not feel pain. Mistake! From then on I was ignored. Furious, incredulous and hurt.

I didn't learn anything useful from these experiences except that I was angry. But I did not know what to do about this anger, how to speak out and be heard. And then, like many other women it was the birth of my two
children that acted as a catalyst for change, and where I began to learn how that knowledge is power.

James was born at a large Sydney metropolitan teaching hospital. My partner and I managed most of the labour on our own at home. When we arrived at hospital I was put in a wheelchair, put on a bed, examined and a scalp monitor was put on James’ head. We had lost control. My body was now a machine, connected to other machines whose sole function was to get this baby out. We could not get answers to questions and 'things' were done without us being asked or told why. Panic! James ended up being lifted out with forceps. I was convinced that it was the interventions that caused our difficulties.

With this conviction we were determined that it would be different with Jessica. What we needed was support, not to hand over control. I read books about natural childbirth and active birthing. By talking with other women I found a GP who was also an obstetrician and encouraged people to have an active, natural birth. Together we planned what we wanted, wrote it down and rehearsed how we would deal with the experience. We became empowered. We all had the birth that we planned and wanted, what a difference! Now I knew that it could be different and I had developed some strategies for making it different.

Be angry at injustice my friend and make changes. If not you, who, and if not now, when? (Parent of a child who had a disability).

My working life in Australia began at a residential hostel where children who had intellectual disabilities lived. I had no background in this area, my qualifications were as a teacher. However, I quickly began to question and change things. Why did the older children have to wear bibs? Why couldn’t
we close the doors when people went to the toilet? Why don’t we teach people to go to the toilet rather than keep them in nappies? Can’t we work out a way to communicate with these people?

At this NSW Health Department mini institution we also had case conferences. Here staff, parents and relevant experts would get together and plan the person’s life for the next year or so. It always puzzled me as to why the person was never there. There were other people asking the same questions and making the same changes. I attended courses, workshops, university, to try and find out some of the answers and to find a better way of doing. A way that saw the person first, that treated them with dignity and respect and a way that accepted that the person themselves could be their best expert.

I remember being delighted and relieved when I read the Richmond Report (1983) and the Report of the Handicapped Programs Review (1984). Here were the words I needed, and here were others who felt and thought the way I did. This was an exciting time to be working in this area. The federal Government legislation, the Disability Services Act 1986, had actually enshrined words such as respect, community, de-institutionalisation, in law.

Working next as a consultant with one of the largest charity organisations for disabled people in NSW, my work was focused on helping services change. I was to help them to provide more appropriate services for their consumers, to train staff and to set up systems that made the person and their family central. Here I learnt about the process of change and that no matter how right and just you believe the 'cause' is there is always resistance, fear, uncertainty and usually from people who believe just as strongly in their cause.
To succeed here, I learnt about collaboration and empowerment, about all of us owning the vision and the implementation. I learnt that the most successful advocates for change are often people themselves, and that to help people to find their voice and to support them in using it, is powerful indeed. I also learnt patience, as change can be painfully slow if it is to be sustainable. I learnt how to be an advocate and how to harness the anger to make it work for you, not against you. I also burnt out after ten years. I did not learn to sustain myself!

My anger and sense of injustice has stayed with me and now, as an academic Social Ecologist. Working in and for an institution, I work with another marginalised and disempowered group of people - students. Kept financially poor and reliant on our sense of justice and fairness there is an unequal distribution of power in these relationships. Academics have more power than students, this can be abused, and sometimes is. Remaining an advocate, supporting people to find their own voice is, I have found, more difficult when you are part of the system that is oppressing.

I have always been angry. When younger it was anger at our inhumanity towards each other. I could not understand why there was war, how we could intentionally hurt, abuse, silence each other. My anger came out as tears; torrents of tears. Tears of not understanding and tears of frustration and powerlessness. I believed, you see, that people were inherently good; that we basically cared about and valued each other and that violence was abhorrent and not natural. What I saw and heard around me directly challenged these beliefs. How could people behave this way?

I became angry with injustice. I couldn’t understand why some people were treated badly, or had less of the cake, just because they were a different colour or spoke a different language or worshipped different Gods. I could see no reason for this behaviour. And then I saw a film at school. I can’t
remember the title, but it was about an unmarried mother in the early
sixties, who had three children. One by one they were taken away from her
because she was supposedly unfit to look after them. It wasn't even that
overt. It was just that if you were poor and single, you lived in single
accommodation and, of course, single women did not have children! I can
still hear her cries of despair and hopelessness as her last child had to go. It
crystallised for me the sheer arrogance of those in the bureaucracy who
knew what was best for this family, who made inhumane decisions never
having to look at, to see and feel the pain of humanity on whose behalf they
made these 'for your own good' decisions.

As an emerging feminist and a woman enjoying the fact that I had both a
daughter and a mother, I began to see that there was something special in
this 'woman's stuff'. I started to make decisions that would help me explore
this 'something special but elusive quality'. I purposefully chose a woman
supervisor for my PhD. I also chose to give up my academic administrative
positions, and I from the School of Health to the School of Social Ecology
in the university. I moved to a place where women were overt and
comfortable with their feminism. I began to read feminist theory, feminist
poetry and prose, listen to feminist music. I wore purple more often. I
named myself as 'a woman'.

Part of this naming was finding my voice, of speaking out for myself as well
as for others. It is this voice which now asks to be heard. How did I get to
the point where I have dared to speak? Taking courage, speaking out,
having to believe that I have something to say. This has been the hardest
part of this thesis to write and I have to ask myself why? Believing that you
are the 'same as', can render you voiceless, about yourself. What is there to
say, why would anyone want to listen, surely we have heard it all before?
Imagine the terror that this 'same as' person feels when asked to be original
and creative.
I never knew I was 'other'. In fact I spent most of my time as a child trying to blend in, to become part of, the same as everyone else. This was not without its challenges. I was talking and reading way beyond my age before I went to school, plus I was tall. I stood out without trying, while desperately wanting to become invisible. Stooping, not working, playing up, 'going out' with whoever was deemed cool - even if I didn’t like them - smoking, all strategies I employed to become the same as. Now, as I look back I am amazed at how successful I was at convincing myself that I was no different to anyone else.

As a feminist Social Ecologist, my world view and my way of being with and working with people is deeply and profoundly influenced by feminism. I am ever more integrating my way of knowing and my way of being as a feminist. This can and does include how my partner and I share responsibility for parenting our children and household tasks. It leads to daily questioning of whether we are treating our daughter differently because she is a girl or because she is three years younger than her brother. It can and does lead to quite pedantic turn taking in asking friends and family over for meals, maintaining and strengthening our relationships with others. It influences our intimate life together as we struggle to throw off our conditioning about love and intimacy, passivity and assertion.

I include these examples to illustrate that for me feminism is not an intellectual exercise, it is truly a way of being in the world and it requires - in my case anyway - continual struggle and awareness in all aspects of my life. As it is a way of being, it is true, for me, that feminist theory and practice is the context in which this research has been conceptualised and implemented. To be different would be to not live my life. Researching is a 'lived experience', and it is essential that this lived experience is congruent with who we are.
CHAPTER 4

BOXES: THEORETICAL CONTEXTS INFORMING THIS STORY
"Most of us think that the space we live in is the most important space there is, and that the condition we find ourselves in is the condition which must be changed or else. That is only partially the case. If you analyse the situation properly, you will know that there might be a few things you can do in your personal, individual interest so that you can experience and enjoy change. But most of the things you do, if you do them right, are for people who live long after you are forgotten. That will happen if you give it away...The only way you can take yourself seriously is if you can throw yourself into the next period beyond your little meagre human-body-mouth-talking all the time." (Bernice Johnson Reason in Smith B. (ed.)1983:365)
Introduction

My question continues to be, how can I be self aware and act to make this world a 'better' place, "[h]ow can I intervene in the production of knowledge at particular sites in ways that work out of the blood and spirit of our lives, rather than out of the consumerism of ideas that can pass for the life of the mind in academic theory?" (Patti Lather 1991:20). What I aim to do in this series of essays - opinions informed by my concrete experiences, my reading and my reflections (Virginia Woolf 1922) - is to make my ways of knowing more transparent, to speak of what influences my practice as a researcher while at the same time trying hard to avoid the "consumerism of ideas".

I do this by constantly asking, 'is this useful to me and to the reader, does it help provide a context in order that the research itself can be more clearly understood?'

One must listen to her differently in order to hear an 'other meaning' which is constantly in the process of weaving itself, at the same time ceaselessly embracing words yet casting them off to avoid becoming fixed, immobilised. For when she 'says' something, it is already no longer identical to what she means (Luce Irigaray in Chris Weedon 1987: 64).

I ask you to listen to me differently. While I strive for clarity and authenticity, I am not always able to say what I mean and even when I do, I know that I will not always remain fixed to my position of the moment. At the same time, I am aware that "[i]n an era of rampant reflexivity, just getting on with it may be the most radical action one can make" (Patti Lather 1991:20).
Passionate about paradox: thinking the un-thought

'I saw an interesting bumper sticker the other day; instead of saying *don't just stand there do something*, it said *don't just do something stand there!*' A colleague of mine recently told this anecdote to a small group of us in a meeting. We all laughed. I wondered why we found it so funny, why did I laugh. Was it just the surprise of the reversion. Or was it because it so aptly summed up where we in the academy have arrived in this age of postmodernism? Standing there, in the moment, aware that there may be no ultimate truths (an interesting ultimate truth in itself); that difference is to be celebrated and accepted; knowing that all is fluid and ever changing; feeling the layers, the influences and understanding that nothing is quite as it seems, it depends on your point of viewing, in that moment. How does one reconcile this with acceptance of ethical universals?

Are we paralysed into inaction by our own abilities of analysis and critical thought?

How can one get on with it, if we are no longer sure what 'it' is, what is the struggle for, what is it about. To act, to struggle takes energy and to use energy surely requires some sort of conviction, a belief that what we are struggling for is 'something better' and what we are struggling against is unfair, unjust or down right ridiculous. Action requires passion. How can we be passionate about the paradoxes we know in this postmodern age?

To act we have to take a stand, to 'name' what it is that we are resisting and to name a vision of how it could be better. I do not mean a fixed utopia, but I do mean something different to the possible nihilism of postmodernism. Elisabeth Porter believes that 'stand taking' is determined by our "values, beliefs and ethical orientations" (1993:18). She goes on to
say that "[t]o be devoid of a value-orientation is to be devoid of character. Such orientations shape and guide our action, endowing life with meaning and dignity (Brubacker, 1984:63). This personal stamp of meaning is an essential property of human agency, endowing the concept of personhood with moral significance and "linking personal interpretation with overall narrative understanding" (Elisabeth Porter 1993:18).

This thesis is about action, about taking a stand and not just standing there but doing something. The research has enabled me to learn much, to dig deeper, to reach new understandings, to shift ground and to know my passion more intimately. It has also led to confusion, to a feeling of knowing too much, to becoming more humble, wondering what the point is, to paralysis at some moments in time. It has been about living a paradox, now it is about writing the paradox.

Here I wish to explore some of these questions and thoughts in an attempt to make visible my views of the world, of knowing and of living. It is not about justifying what I have done, it is not about untangling ideas, thoughts, passions and influences. It is about seeing the web of all these, knowing it, feeling it - in this moment.

I undertake this web spinning with hesitation, aware of the paradox involved in labelling oneself. Having worked in the area of disability for many years, I am only too well aware of the potential dangers of ascribing labels; the resulting expectations that ensue, the potential static nature of the label, the invisibility of the person compared to the visibility of the label. Furthermore, I know that if I deconstruct myself into the component pieces/influences/experiences, it will still not explain who I am. It is the relationship of all of these, the movements, the dance among and between that makes me who I am in this moment. It is a 'self in relation' (Elisabeth Porter 1991).
Labels, like all language constitute as well as describe and explain. In this respect I share the opinions of Liz Stanley and Sue Wise when they say "[w]e believe that so labelling beliefs and practices necessarily confine both the present and future experience and activities" (1993:58). We could also say that it is with the silken threads of our languageing and practising that we weave our own cages (Janet Turner Hospital 1991).

However, if we acknowledge the importance of reflexivity, the rigour and value of this research will be judged on how I make my way of seeing the world, and my beliefs about how people are in the world, explicit and visible. As Patti Lather says ""[o]bjectivity" means being aware and honest about how one's own beliefs, values and biases affect the research process" (1989:7).

In asking 'how do we know' we can see that knowledge is affected by our particular location in the social structure. Asking 'how we know' can also change the nature of how we know. All we can hope to do is to grasp the slippery bar of soap for a few seconds, before, plop, it has disappeared into the murky depths of the bath again. Our knowing is always partial, contextual and dependent upon our own history in terms of class, race and gender.

I began my adult life naming myself 'a socialist', supporting labour governments and the trade union movement. A lot of this came from my father, brought up as a working class boy, living in a council house, working hard to get an education and rising to the ranks of the middle class through his career. It always seemed to us that a great many of our 'social problems' could be solved through a redistribution of wealth, power and property, the inequities of which were only too apparent in England in the 1960's and 70's.
However, this alone was not enough as I began to realise that even with my 'socialist father' I did not have a voice as a woman. Being the child of a navy family, it became increasingly clear to me as I grew older that in this environment, a woman's role was that of support, of doing and saying the right thing in order that the men could get on with it. As we moved around and across the country every two years, it became painfully obvious that despite the popular saying 'women and children first' we were merely appendages who needed to constantly silently adapt.

Understanding inequities in terms of class structures did not help explain, and make sense of, my life and the life of my mother who struggled hard to be the good wife, keep quiet, forsake any hope of a meaningful career and constantly stunt herself for the sake of 'the family' and a predominately male institution - the Navy. I began to see that as a woman " [we] have never had a chance on the wheel of revolution : it revolves between father and son. We can neither turn it or ride it, because we are not on it. We have, however, been trapped inside it. We have been the hub that has held it together for the sake of our own misused and abused altruism" (Robin Morgan 1989:328).

It is against this personal background that I became interested in the women's movement and feminism. This helped me to understand my experiences and the role of women and children in capitalistic, patriarchal society. Feminism began trickling into my life.

The trickle became a torrent when I discovered the work of Robin Morgan, an American feminist, journalist, poet and political activist who maintains the rage in her work. She writes passionately and clearly and she wrote to me and for me. In her work she clearly articulates the oppressions of women around the world, while at the same time critiquing the
unconscious racism of white American feminist universalising tendencies. She also offers hope and a clear plea to shout out loud about oppressions when we see them and experience them. She clearly lives the Quaker and journalist mantra of 'bearing witness' (Robin Morgan 1989, 1992, 1994). She led me forcefully into reading more by women about women and so I stumbled across feminist theorising.

Towards a postmodern feminism?

At this point in time, my understanding of feminism is summarised neatly by Kate Pritchard Hughes:

[f]eminism consists of a comprehensive body of theory which deals with, among other topics, the gendered nature of language, sexuality, popular culture, psychology, literature and the arts, economics, health, the state, the family, education, the workplace, technology - the list is almost endless. It offers then, not only a set of strategies through which to improve women's material lives, but a critique and analysis of the very foundations of a society which uses gender inequality to organise itself (1994:2).

However, working in an academic institution and in the same faculty as the School of Humanities, I have found myself daily hearing about postmodernism. Initially my reaction was to resist this discourse, not understanding what people were saying. The little that I did understand, I did not like. There seemed to be no political content or desire. Yet I did pursue these ideas, partly out of a desire not to be left out, partly because I felt my criticisms were reactionary and not well grounded. In recent years I have come to read a number of writers, feminist and not, who spoke both with/in and with/out the discourse of postmodernism.
It was quite a relief to find that the tension between postmodernism and feminism, was inherent to the literature itself. Some of the tension revolved around the 'which came first?' question. If feminism did, then would postmodernism be merely another example of the men appropriating the creative theorising of women? (Somner Brodribb 1992). For other writers the tension revolved around issues of intellectual elitism and separatism. As Caroline Ramazanoglu writes:

I arrived late at a women’s meeting towards the end of the annual conference of the British Sociological Association a few years ago, to find some women expressing indignation at finding session after session of the conference dominated by men talking in terms of 'postmodernism'. These women said that they felt silenced, intimidated, excluded, put down and angry. They did not know whether 'postmodernism' was something they should take seriously, because they could not engage in a debate which made the issues inaccessible to them .... Much of the work in this area has been characterised by intellectual elitism and a level of abstraction from experience which makes it far removed from most English-speaking feminist work (Caroline Ramazanoglu 1993:1).

Other feminists similarly question postmodernism’s political positioning and usefulness (Patti Lather 1989).

My immediate concern is how useful is postmodernism in terms of embedding and embodying my participatory research? "The Modern-Day Dictionary of Received Ideas says of 'postmodernism': this word has no meaning. Use it as often as possible" (in Arran Gare 1995:4). Beginning
rather cheekily, Arran Gare continues in a more serious vein. He draws on Lyotard, to demonstrate that postmodernism is essentially about a loss of belief in progress, in the future and in modernity. However, postmodernity, while dependant upon modernity for its existence as a discourse, denotes more than a 'coming after'. Rather it "is more strongly based on a negation of the modern, a perceived sense of abandonment" (Mike Featherstone 1991:3).

At one level, all the discourse of postmodernism does is focus our attention on current changes in society and culture. This involves changes in information technology, art and literature where, Jean-Francois Lyotard would assert, we are becoming nations of re-producers. This indicates a shift from an industrial to a post - industrial order (Jean-Francois Lyotard in Mike Featherstone 1991:3). Lyotard further asserts that the "Post modern would have to be understood according to the paradox of the future [post] anterior [modo]" (Jean-Francois Lyotard 1993:46). The future comes out of, has its roots in, or is a reaction to what has gone before.

Postmodernism then, is a reaction to modernity, a reaction which comes from dissatisfaction and disillusionment with the conditions of modern life. Jean-Francois Lyotard’s answer to what he calls the terror of modernity is to "wage war on totality; let us be witness to the unpresentable; let us activate the differences" (Jean-Francois Lyotard 1993:46). At another level postmodernism can be seen as "a cultural image, a talismanic concept that incorporates images of disorder, dissolution, relativism, and fragmentation" (Mike Featherstone 1991:128).

Is it that a huge space has opened up in reaction to modernity? What will fill this space? Perhaps there will be a greater tolerance of difference and diversity; perhaps the creation of a new social order which is not gender, race and class based. Who knows? What is important is that the space is
there, that transformation is possible and that instead of a Phoenix rising out of the ashes of modernity, we can see Kookaburras, Wrens, Blackbirds, Vultures and Magpies. Each of these will have a voice, a song to sing. The beauty of each song will depend upon the listener. What is important is that in this space the voices of 'others' will be heard.

On the global level postmodernism not only signifies a revival of the neo-romantic interest in the exotic other, but the fact that the other now speaks back (Mike Featherstone 1991:147).

In her book, *Postmodernism and the Social Sciences* (1992), Pauline Marie Rosenau draws our attention to the light and dark sides of postmodernism. To do this she categorises people, a dualistic convention she insists that real postmodernists would deplore, into 'affirmative' and 'sceptical' postmodernists. Sceptical postmodernists are those who talk about nothingness, relativists to the extreme. They argue that rational judgement and any form of objectivity is to be shunned and is, in any case, impossible.

On the other hand, ‘affirmative’ postmodernists want a theory of reality that is enabling, that permits content, even though it is "soft, provisional and emotional" (Pauline Marie Rosenau 1992:111). While agreeing that there is a plurality of values, realities and experiences, affirmative postmodernists do not believe that this implies "ethical relativism.... Dissimilar sets of values exist, and it is perfectly legitimate to argue about which is preferable, given the alternatives. As the affirmatives see it, facts, meanings, and values cannot be considered independent of one another" (1992:114). Furthermore, while we may accept that relativism and subjectivity are inevitable it is "quite another to cultivate them as virtues" (Pauline Marie Rosenau 1992:116). Postmodernism of the affirmative kind, is useful to my own theorising as,
[a]ffirmative post-modernists frequently employ terms such as oppression, exploitation, domination, liberation, freedom, insubordination and resistance - all of which imply judgement or at least a normative frame of reference in which some definitive preferences are expressed. They hint that studying the local, the decentered, the marginal, and the excluded is superior to examining what is at the centre (Pauline Marie Rosenau 1992:136).

So, postmodernism, of the affirmative kind, values the local 'other'. Indeed 'other' now has a legitimate space from which to talk back. There is a rejection of universal, totalitarian claims to truth, against which all other truth claims can be measured. There is rather, a valuing and acknowledging of difference and the making visible of the story tellers self and experience in writing the story, as is the case in this thesis.

Other feminist writers such as Rosemary Hennesay believe that feminism is part of the postmodern discourse but "unlike many postmodern discourses, feminism grounds its critique of western knowledge in an emancipatory discourse" (1993:2). She goes on to distinguish between 'ludic postmodernism' and 'resistance postmodernism' arguing for a materialist feminism, "which intervenes in the crisis of knowledge by offering a way to make use of postmodern ideas of the subject in conjunction with a theory of the social which is congruent with feminism’s political goals" (1993:3). This position accepts that "social totalities like patriarchy and racism do continue to structure our lives" (1993:3).

What feminism and postmodernism have in common is that both have criticised modern foundationalist epistemologies and moral and political theories, exposing the contingent, partial and historically situated character
of what has passed in the mainstream for necessary, universal, and
ahistorical truths (Jean-Francois Lyotard 1993; Richard Rorty 1983). Both
have called into question the dominant philosophical project of seeking
objectivity in the guise of a "God's eye view..... which transcends any
situation or perspective" (Nancy Fraser and Linda Nicholson 1990:26).

While there is, undoubtedly, a tension between feminism and
postmodernism a critical coalescing of the two discourses, if one stands
with the affirmative postmodernists, could lead to an emergent postmodern
feminism which "integrates their respective strengths while eliminating their
respective weaknesses" (Nancy Fraser and Linda Nicholson 1990:20). This
stand leads to a more explicitly open, hesitant and partial scholarship, a
scholarship which does not strive for authority or closure. This position is
at once liberating and unsettling. As Donna Haraway says:

the further I get in describing the radical social constructionist
program and a particular version of postmodernism, coupled
with the acid tools of critical discourse in the human sciences,
the more nervous I get (Donna Haraway 1988:577 in Patti
Lather 1989:8).

For me, this is the point; this nervousness enables us to not fall into
becoming dogmatic. While nervous we can remain flexible and open.
Coming from a less than sure footing, we do not assert that ours is the only
path to follow, our footsteps the only ones to tread in. Clearly this would be
ridiculous. Being nervous, enables us to walk lightly on the earth with our co-
travellers and to respect their choices of different paths. Being nervous guards against complacency, staleness and authority. Being nervous enables
us to keep walking, to keep searching, to keep reaching out for and with
each other. Being nervous enables us to suspect "all that has been received,
if only yesterday" (Jean-Francois Lyotard 1993:44).
So, what has all this to do with passion? Is it that we need to learn to be passionate about knowing and understanding the constructions of our social institutions and social bodies, what the discourses are that shape our lives (our bodies too according to Foucault) while at the same time not falling into the trap of becoming a master narrator or a grand theoriser? Is it about being passionate enough to do something while at the same time knowing that the something is not perfect, that the something will change, develop, emerge in the process of our doing?

**The paradox of theorising**

Liz Stanley and Sue Wise (1990;1993) challenge us to 'do' feminism daily while at the same time highlighting one of the potential difficulties in theorising. Theory can become a way of interpreting others experiences, telling them what they mean and what they think. This problematic position is powerfully expressed by bell hooks:

> [n]o need to hear your voice when I can talk about you better than you can speak about yourself. No need to hear your voice. Only tell me about your pain. I want to know your story. And then I will tell it back to you in a new way. Tell it back to you in such a way that it has become mine, my own. Re-writing you, I write myself anew. I am still author, authority. I am still the coloniser, the speaking subject, and you are now at the centre of my talk (bell hooks 1990:15 in Naomi Scheman 1993: xiii).

As bell hooks so cleverly and confrontingly illustrates, 'theorising' can become an elitist activity, serving the interests of those few who already have greater access to knowledge and knowledge production than other
women, academics, me, for example. It is useful to be aware of this critique, to act with awareness, to seek to minimise the colonising effects of re-writing peoples' stories. We need to acknowledge our position as author and authority. We need to ask if, by abstracting and conceptualising people's lived experience, we are colluding with the governors of society. Does theory add peoples' own understanding or body of knowledge, in a way their lives? (Sandra Harding 1991).

However it is not terribly helpful for me to wholeheartedly take the position that theorising is elitist. It is certainly not helpful to the one who is writing the thesis where one must demonstrate an ability to both theorise and conduct independent research! Sometimes being a feminist can be disempowering in the moment. Perhaps we need to acknowledge that we are always standing on the shoulders of other women.

Chris Weedon offers an alternative way out of this dilemma:

> To dismiss all theory as an elitist attempt to tell women what their experience really means is not helpful, but it does serve as a reminder of the importance of making theory accessible and of the political importance of transforming the material conditions of knowledge production and women's access to knowledge (Chris Weedon 1987:7).

A radical feminist perspective (see for example Liz Stanley and Sue Wise 1990;1993, and bell hooks 1990) highlights these difficulties with theorising. Theory can be a way of interpreting other's experiences, telling them what they mean and what to think. In terms of our actions this position asks us to collaborate with others in the 'meaning making' of their experiences and the construction of theory and knowledge. It asks us not to
collect stories and do with them as we will, but to involve the story tellers in the theory and knowledge production.

Being informed and aware of the political paradox in theorising can, and does, transform our practice as researchers. This was so for me, as I constantly sought to co-labour in both the process and the product of the research which forms a substantial part of this thesis. I also found that I was able to share my concerns, my thinking and my dilemmas expressed here with my co-researchers who helped me to clarify my position. This was something they asked of me, not vice versa, and it was something they gave to me freely, pleased to be a part of the more 'academic' task of thesis writing.

The difficulties inherent in naming a theoretical position are further illuminated by the growing body of literature on a 'politics of difference'. This approach "means we each recognise that any standpoint that we take is necessarily partial and based on the way in which we are positioned in relation to class, race, educational background and any other number of factors" (Rosemary Pringle and Sophie Watson 1992:69). That is, it is not just our gender which positions us, but also our race, our sexuality, our age. All affect and effect our experience of and with our world. This sensitivity to 'difference' asks that feminism lose its innocence (Anna Yeatman 1993). It sees that oppression takes many forms : male/female; white/black; heterosexual/homosexual, for example.

This position enables us to see that being a 'woman' and identifying ourselves just as women is not enough. Within this gender category, there are Black women, poor women, white women, educated women, lesbian women, non lesbian women, old women, young women, disabled women. It also helps us to see that we cannot always speak for all women at once, we do not share the same experience, although we share enough to
recognise ourselves as 'women'. Women identifying themselves as feminist may also be racist women, or classist women. Furthermore, acknowledging, celebrating and working with - as opposed to merely tolerating - these differences can lead to creative, nurturing and affirming interdependency between women.

Only within that interdependency of different strengths, acknowledged and equal, can the power to seek new ways of being in the world generate, as well as the courage and sustenance to act in the world where there are no charters (Audre Lorde 1984).

So where do I stand? I stand in the paradox, knowing that I speak and theorise for myself and others, accepting the difficulties and dangers in this. I acknowledge, feel and experience daily, both my oppression and my privilege. My oppression as a woman in a patriarchal society and a patriarchal institution - academia - and my privilege as a white, middle class educated woman. I experience this privilege daily in my work with male and female, white and coloured students.

Out with the masters tools? Marxism and feminism

Postmodernism can enable us to see all our positions as problematic and provisional but at the same time we act in the world, we take a stand. This is where feminist and critical theory become salient, concerned as they are with social transformation. Marx can be described as the father of critical theory: "we do not anticipate the world dogmatically, but rather wish to find the new world through criticism of the old" (Karl Marx cited in Wilfred Carr and Stephen Kemmis 1986:137). Marx believed that by relentlessly criticising the current social order, humanity would be able to emancipate itself from oppression. However, there is an uneasy relationship between
Marxism and feminism, just as there is a tension between postmodernism and feminism. As this thesis is located within a critical social science framework, this tension needs to be acknowledged and mediated.

Marx assumed that men's interests were human interests. In this world view, women are 'other', considered only in relation to men (Mia Campioni and Elisabeth Grosz 1983:367). Furthermore, especially in the academy and sociology in particular, Marxism has become hegemonic, "in its position as the radical political theory, Marxism maintains a position of power which remains largely unrecognised and which negatively affects its relationship to other left political positions" (Mia Campioni and Elizabeth Grosz 1983:367). Mia Campioni and Elizabeth Grosz feel that Marxist discourse has a disproportionate amount of power in the academy, evidenced by the fact that I feel compelled to discuss Marxism, however briefly, to show that I am aware of the 'master' narrative in critical theory. It would appear that feminist theory is not able to stand alone in the academy - yet.

While it would be silly to say that Marxism is the only discourse which potentially silences us, it is certainly a huge barrier to women finding voice.

Either the 'other' valiantly tries to insert herself, her struggles, her knowledges within the master paradigm, expending all energy in the process; or, alternatively finds herself relegated to the status of heretic, playing the role of hysterical other to the cool of Marxist reason, thereby apt to be ridiculed, or simply ignored a hearing (Mia Campioni and Elizabeth Grosz 1983:371).

Risking this ridicule and silencing, rather than articulating "what the worker or the oppressed cannot know or say" (Mia Campioni and Elizabeth Grosz 1983:373), I attempt to let 'the masses' represent themselves, by

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focussing on people’s lived experiences of the health system in general and community health in particular. Rather than test a ‘theory’, of alienation for example, I first listened to, and heard, what people had to say. The theory, or explanations for their stories was developed out of their own presentations.

Marxism suggests one common enemy of the oppressed - capitalism - a similarity with some feminisms which suggest that patriarchy is the one common enemy of women. The difference which is now emerging - with the rise of a politics of difference - is that not all people, groups, communities, experience oppression in the same way, and indeed, as women of colour, like bell hooks and Audrey Lorde, have pointed out to us within the category of 'women' there are also some who may oppress and create 'other'.

In this current study, I have shown, through the words of people themselves and their lived experiences, that there are a multiplicity of powers, experienced differently and with different intensities by different people. It is this multiplicity, this complexity we/l seek to understand, to know, in order to change things. Struggles for change cannot take place on one front. There are many sites and no one should be privileged over the other. We need to insist on a "multiplicity of aims, practices and theories directed at revolutionary social change" (Mia Campioni and Elizabeth Grosz 1983: 374).

In relation to this thesis, Ernesto Laclau and Chantal Mouffe (1987) mediate the tension between Feminism and Marxism by positioning themselves as 'post - Marxist'. In their critique of Marxism they feel that new spaces are now opening up as sites for struggle. This is exciting, as we live in
one of the most exhilarating moments of the twentieth century: A moment in which new generations, without prejudices of the past, without theories presenting themselves as 'absolute truths' of History, are constructing new emancipatory discourses, more human, diversified and democratic (Ernesto Laclau and Chantal Mouffe1987:80).

Taking a constructionist position, they argue for a radical democracy where the "first condition ...... is to accept the contingent and radically open nature of all its values - and in that sense, to abandon the aspiration to a single foundation" (1987:102). Can we speak of a Postmodern Marxism supporting a multiplicity of 'anti-capitalist struggles'?

Clearly the system, or structure, that Marxists seek to subvert, is that of capitalism, in which the health care system is embedded (Arran Gare 1995). The Marxist answer is to overthrow this system and create a socialist society. But, the demise of capitalism - however utopian this may appear - may not mean the demise of patriarchy. In fact, some feminists have argued that in the heady days of the 1960’s when communism and 'the left' enjoyed more prominence than they do now in Britain, America and Australia, women were still expected to make the coffee and clean the toilets (Robin Morgan 1993).

**Pilfering the masters tools:**

**a postmodern/feminist/critical social science?**

While heeding Audre Lorde’s warning about the masters tools, many feminists have found that some of the master’s tools are worth pilfering (Joanne Meerham 1995: back cover).
The discourse of critical theory accepts that there are humanly constructed oppressive structures, which can be humanly deconstructed. The task becomes one of seeing these structures, knowing how they are built, so that one can insert oneself into the weakest points and watch them come tumbling down. In this way critical theory’s intent is political. It is concerned with action, and it is this intent and concern with which I resonate. While, this position recognises that there are some universals, such as patriarchy, what I have learned from a postmodern feminism and the politics of difference, is that these universals are experienced differently, that our context is important in terms of our experiencing. For example, patriarchy is experienced differently between women and within women.

Recently, I was working with a small group of postgraduate students. The discussion started with the one man in our group, Barry, saying that he could understand why men were getting tired of feminism. It was time to move on and look at people, not men and women. At this point Sam exploded. She talked of the fact that we could not move on until it was acknowledged that discrimination on the basis of gender happened, and until men accepted that they benefited from this discrimination. She used the recent haggings over Mabo and Native Title, to pursue her line of argument, being a Koori woman she took this position with force. Barry, an Irishman, then spoke passionately of the Irish and how the British had promoted genocide in the times of the potato famine. This was where these two people met, in the emotion of their stories, and their joint experience of oppression at the hands of the British coloniser.

Now, consider my position as a British, white middle class feminist! I sat there feeling, knowing my privilege as part of the British nation which had benefited from the oppression of both the Irish and the Kooris. I sat there knowing and feeling my oppression as a woman in a world defined by men. While I could not take individual responsibility for the atrocities of the past, I
could own the fact that I was the recipient of the 'spoils', and I could feel shame and anger. And, I could join with both of these people in a desire to make it different, to recognise and struggle against exploitation and domination.

I accept that there are some universals. I also know that these universals are experienced differently depending upon our context, our position at any given time. This is the context in which I set the following exploration of critical social science.

According to Stephen Littlejohn (1992) critical social science shares three essential features: firstly it seeks to understand the lived experiences of people to make explicit how they are oppressed; secondly social conditions are examined to bring structures such as power, to light; and lastly praxis, or theory and action are 'fused'.

Furthermore, "[a] common theme that seems to run through all critical theories, then, is giving voice to oppressed groups"1 (Stephen Littlejohn 1992:256). This can be seen as a utopian vision. However, if one takes a postmodernist stance then we would acknowledge that there are many oppressed groups, silenced voices. It is working at the margins of decision making with these people, that we struggle against oppression. I would argue that this is not utopian. There is no fixed sense of what society would look like, feel like, when we hear those at the margins. Rather it is, in Luce Irigaray’s words, a utopia in process (Luce Irigaray in Margaret Whitford 1991). The production of knowledge is grounded in process, human activity. It is the act of consensual knowing then, that is central and that enables us to act in different ways.

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1 This became the central theme of this thesis, as the title would suggest. It also enabled me to make central, the voices of those usually marginalised from the decision making processes in the health system.
It is with emancipatory knowledge that critical social science is concerned. Here we can see the connection with the experiential epistemology of radical feminists such as Liz Stanley and Sue Wise (1990;1993). We can also see similarities with the feminist idea of consciousness raising, based on the premise that many people have a false consciousness and cannot therefore see the cause/s of their oppression.

I believe that we need to proceed cautiously when talking of 'false consciousness'. We have to be careful that we do not hand a prescription down from on high in order that the oppressed can eliminate their oppression. We need to avoid simple recipes for the process of critical reflection, theorising and knowledge construction. I am not saying that reflection is neither useful, or necessary, if we are to improve our own practice and transform society. Clearly it is. I am though, arguing against the potential expert/novice dichotomy in terms of theorising and reflecting. Our task becomes one of foregrounding peoples’ own knowings and understandings. The people and the process are privileged, central. It is the theorising, the explaining, the critiquing which are empowering - not the theory, the explanation, the critique!

Jurgen Habermas is "the most highly respected proponent of critical theory in the world today" (Stephanie Short et.al. 1993:96), but, he is also highly criticised by some feminists as his theorising and model of communicative action is gender blind. On the other hand, he does offer us some sound places to start from. Firstly, he sees the self as a self in relation (Jurgen Habermas 1984). This is a view similar to that of Elisabeth Porter (1991). According to Habermas, the self is socially and culturally constructed and mediated:

Habermas contends that we are not first individuals and then social agents; personal identity is essentially socially
mediated, and the constitution of the self is concomitant with the establishment of relationships. Language functions as the medium in which identity is constituted. Identities are formed in webs of social relationships through the taking up of a myriad of social roles (Joanna Meerham 1995:3).

Jurgen Habermas (1984) believes that there can be, indeed should be, an ethical universalism. But instead of relying on the morals and ethics we have inherited from our Judaeo Christian past, which clearly serve the interests of a few, and not often women, he suggests that this ethical universalism be dialogically constructed and agreed upon. In this dialogic construction, it would be incumbent upon all of us that all voices are heard, none are silenced, each being accorded similar status and power. This implies a radical democracy, where competing claims are negotiated and consensus ensues (Pauline Johnson 1994).

Is this radical democracy a utopian ideal? What about power relations? Habermas is, after all, coming from a white, educated, male, middle class perspective, where consensus seems possible and power is not an issue. But how do we negotiate the fragmentation of contemporary lived experiences? A postmodern feminist critical theory makes these power structures and assumptions explicit in order that they can be negotiated by different social actors.

While humanism and critical theory may be no "longer fashionable in the world of deconstruction" (Jean L. Cohen 1995:80), I argue that critical theory/critical social science is a sensible progression of deconstruction. Deconstruction and an understanding of power relations are useful only if some sort of non utopian re-construction follows (Stephanie Short et.al 1993). What happens without this next step, this creativity, is that one slips into nihilism and a blank empty space with no place to go. Rather, if
we see the postmodern practice of deconstruction as being part of critical social science, then we have a sense of movement and fluidity. Furthermore, my understanding of deconstruction is that it aims to shed light, to uncover assumptions and world views - something it has in common with critical theory which "would aim...to shed light on the character and basis of such subordination" (Nancy Fraser 1995:21).

Critiquing Habermas's ideas, Iris Young argues that communicative action is wrong to presuppose that people can truly understand each other, that there can be transparency in the process of consensus building. In her view, we are strangers to each other and should use this as our starting point for communication. It is impossible for us to truly understand each other as we are constituted with different histories, cultures, contexts (Iris Young 1990). This, I agree with. But, does consensus mean that we fully understand each other, or does it mean that we fully accept each other, knowing that we are different? In my experience, it can mean both.

I find myself asking 'what would critical theory look like, feel like. What would one do, if one was a critical social scientist '? It seems to me that one of the things we would do is to make ourselves fairly unpopular with the decision makers and power holders in society. This is because critical social science is political, it seeks to understand oppressive structures, power structures and relations with the aim of transforming them into something else - a radical democracy. Someone engaging in research within this framework, places themselves at the margins too:

[a] critical social theory frames its research program and its conceptual framework with an eye to the aims and activities of those oppositional social movements with which it has partisan, though not uncritical, identification (Nancy Fraser 1995:21).
The danger here, is that critical social scientists can thus become marginalised, trivialised and misrepresented.

Critiquing the 'one-sidedness of critical theory' Brian Fay (1987) argues that critical theory and critical social science need to be expanded to include embodiment, tradition, historicity and embeddedness. Is this what a postmodern/feminist/critical social science would look like? Furthermore, Fay offers an ecological sense, where there is a "deep sensitivity to the interrelatedness of all things to each other" (1987:214) and where we are "aware of the unpredictable, fragile, and limited character of human enterprises" (1987:214). In embracing this view of critical theory/critical social science, traditional humanist ideals would move from adolescence to adulthood as we recognise and acknowledge that there can not be full self knowledge, power free of coercion and that our powers of reason are limited. We are, after all, only human.

Humans are forever in the middle of the way, forced as time passes to revise continually their sense of their origins and their destinations, and required to respond in only partially satisfactory ways to the ever surprising contingencies which they face.

Only a critical social science which is supplemented in the way I have indicated is capable of assimilating the inherently ambiguous nature of human existence (Brian Fay 1987:215).

It is my hope that weaving together affirmative postmodernism, feminism and critical social science offers the 'supplements' Fay speaks of. At the same time, a postmodern/feminist/critical social science enables us to remain undogmatic, and open to new possibilities, in terms of what societal
re-construction would look like. It enables us to see difference, to value diversity. It enables us to know that what we are doing is problematic, less than perfect, and as such it will enable us to embrace new and different ways of being with each other in the world.

It is an altogether different approach to the politics of knowing and being known which ... advocates for the creation of a more hesitant and partial scholarship" capable of helping us "to tell a better story" (Grossberg 1988:17) in a world marked by the elusiveness with which it greets our efforts to know it (Patti Lather 1989:28).

Some readers may worry that the ensuing plurality of social struggles, within a politics of difference, may weaken the total emancipatory struggle (Ernesto Laclau 1995). I assert that working at the margins, in multiple ways and at multiple sites, offers a new sense of hope. It is essentially an empowering position to take as it may be easier to begin our political journey by joining local and particular struggles. It is also hopeful as in the local and particular struggle we are more likely to be heard, to have a voice, to form friendships, allegiances and partnerships. The 'revolution' becomes small, individual, local actions multiplied many times. There is hope as, in this view of the world, we can believe that what we do matters and can make a difference. Having let everything else out of Pandora's box and let the furies run wild, it is time to let hope fly freely.
CHAPTER 5
THE VIEW FROM BELOW
"Wars and revolutions have outlived all their ideological justifications. No cause is left but the most ancient of all, the one, in fact, that from the very beginning of our history has determined the very existence of politics, the cause of freedom versus tyranny" (Hannah Arendt in Robin Morgan 1994:xviii)

"Transformation requires more than mere seeing: it requires all forms of perception, including remembering, imagining, hallucinating, dreaming, and emphasising. And transformation requires that we act, that we step off the wheel, outside the prescribed boundaries altogether. Transformation requires that we enter history on our own terms and audaciously place ourselves at the center of it" (Robin Morgan 1994:328).
Introduction

The research paradigm for this thesis is primarily informed by a critical, praxis-oriented paradigm concerned with both producing emancipatory knowledge and empowering both researched and researcher. As a feminist teacher and learner, it seems quite congruent and reasonable to state that my research efforts seek to "empower through empirical research designs which maximise a dialogic, dialectically educative encounter between researcher and researched" (Patti Lather 1991:70). This concern for empowerment, and an orientation towards dialogue, is one way of working with the potential difficulties of abstracting, rewriting and colonising others experiences for our own ends.

Feminist research

At present, I am in the processes of rejecting dualistic thinking. In a complex world explanations of the either/or type always fall short of the mark. Not that there is not a reductionist in here as well, trying to get out. After all, our long tradition of positivist/dualistic thinking is not so easy to shrug off all together. I do, though, find myself drawn to theories of social constructionism, probably because this way of seeing the world leaves me feeling more able to act. This does not mean that I reject out of hand the fact that our biology plays a part in constructing who we are. Biology constrains the construction of our-selves through socialisation.

However, feminists believe that the different psychological development of women and men is mainly the product of culture not biological differences (Margaret Whitford 1991; Liz Stanley and Sue Wise 1993). Therefore, the differences between men and women are not natural disasters for us (Dale Spender 1983; Shere Hite 1993). When we see gender differences as being the product of patriarchy, our struggle becomes one of trying to eliminate
the differences (Margaret Whitford 1991). This becomes possible if we can see 'femininity' and 'masculinity' as not fixed, but as constantly in process, changing, transforming (Chris Weedon 1987).

This position helps us to see our agency, rather than rendering us as mere objects. However, a difficulty with the social constructionist view is that it tends towards a 'grand theory' a cause/ effect dualism. For example, women are oppressed (this position being based on women's experiences) because of patriarchy (this is the theorised part of the equation). I wonder if we are falling into a masculinist trap by asking whys and hows and then coming up with an answer, a theory, something to defend. Is it more useful for us to be asking 'what is' and 'how can it be different'? Helen Roberts would agree:

All of these questions and assertions assume a model of linear causation. But what if the masculinist world view, which has depended on a logic of time lines, is also erroneous? What if the most fundamental error is the search for mono-causation? What if the world is really a field of interconnecting events, arranged in a pattern of multiple meanings? (Helen Roberts 1976:46).

The answer, because of patriarchy', closes the system, it says that this is the reason and how things are, the answer becomes the full stop. And who is interested in the full stops? Furthermore Liz Stanley's and Sue Wise's position is not that the search for answers/causes is meaningless but rather it is impossible, "the real world cannot be conceptualised in its totality within any theoretical construction" (1993:57). They posit a radical feminist theory, which for them is "that theory follows from practice and is impossible to develop in the absence of practice because our theory is that practising our practice is our theory" (Chester in Stanley and Wise
They do not see feminism in terms of biological essentialism, as some radical feminists do, rather they argue that the different psychological development of women and men is the product of culture. For them the body is seen in terms of "embodiment, a cultural process by which the physical body becomes the site of culturally ascribed and disputed meanings, experiences and feelings" (1993:197). As such any theory, they maintain, must be pragmatic, practical and everyday not esoteric and disembodied, as much philosophy has been (Naomi Scheman 1993).

Their feminist ontology which "sees self in relational, collective and collaborative terms" (Liz Stanley and Sue Wise 1993:197) is an experiential ontology and is "rooted in the acknowledgement that all social knowledge is generated as a part and a product of human social experience" (1993:192). This ontology leads them to an alternative way of seeing the world and our relations in it. A way that is creative and enables us to begin to re-construct ourselves through "collective relational systems of action and interaction" (Liz Stanley and Sue Wise 1993:195).

Working towards re-construction, or transformation of self and society, something that both critical social science and feminism have at their core, can lead one to become rigid and enmeshed in 'blueprints for the future'. Indeed in my experience one is encouraged to become like this. How often have we been told/asked 'well what is the alternative', 'what is your answer', 'what would an ideal society look like?' and how quickly we are dismissed when we resist providing the answer. What if we agreed that there is no such thing, or can be no such thing, as a fully liberated society free of struggle, antagonisms, tensions and history? What if there is no final point of arrival? "The myth of the transparent and homogeneous society - which implies the end of all politics - must be resolutely abandoned" (Ernesto Laclau and Chantal Mouffe 1987:106).
How, though, do we move if we don't have some idea of where we are heading while at the same time allowing space for flexibility, difference and creativity? Luce Irigaray (in Whitford 1991) provides a useful way of working with this paradox. She feels that we need to be wary of being utopian, our project is to critically analyse the unsatisfactory present. Her aim seems to be to set a process in motion, a process grounded in a dynamic vision, a utopia in process. This she believes is "the dilemma of feminism: we have to act as though the ideal future is both imaginable and possible, while yet knowing that the ideal is both incoherent and unreachable, and in any case subject to metamorphosis en route" (Irigaray in Margaret Whitford 1991:24).

For the research inquiry group, this was the tension we struggled to hold. We knew that we worked in an 'unsatisfactory present' yet we had some idea for how we could make a space, insert ourselves into current discourses, in order to change this. We imagined that change was possible while at the same time we had no fixed idea of what this change might look like, what people would do or say.

*The Subalterns Speak* tells the story of a feminist doing research. Much of this statement, it must be owned, is due to the fact that it is in the process of doing this research and writing the thesis, that I have 'come out'. Five years ago I did not name myself as a feminist, now I do. But I do so, in the manner in which Virginia Trioli talks of feminism:

There is no young feminist any more. There is no one movement. There are young women in Australia who call themselves feminists but who have almost nothing in common - politically, ideologically - with each other. Contemporary feminism has become a philosophical and political ethos so accepted by a younger generation of Australian women that
they don’t even bother to explain it. Feminism now incorporates so wide a spectrum of thinking and action that some older feminists clearly cannot get a grip on it (Virginia Trioli 1996:9).

There is no one feminism, rather there are feminisms (Virginia Kaufman Hall 1996). While there may be many sites and ways of struggling and resisting, the common thread that binds us together is the belief that discrimination happens on the basis of gender, in many societies. The differences though can lead to conflict and misunderstandings. These Virginia Trioli discusses in terms of a ‘generation gap’ and the sense of frustration and despair that many older feminists feel when they consider their younger sisters - frustration and despair that the younger generation is doing feminism their own way, a way which may not be the way of their mothers. Whilst I agree with Virginia Trioli’s position that feminism itself is pluralistic in this postmodern age, there are still some connecting threads, some common ground. It is the connections which bind us together despite our differences, that I wish to discuss briefly here.

I have been informed, and continue to be informed, by discussions about feminist research which I find both illuminating and confusing. Confusing in that while enabling me to articulate more clearly the methodology I have used, it seems that I both fit and don’t fit many writers descriptions of feminist research. I am interested in, and agree with, Maria Mies entreaty that women, concerned with the liberation of women, work with the view from below.

The vertical relationship between researcher and ‘research objects’, the view from above, must be replaced by the view from below. This is the necessary consequence of the demands of conscious partiality and reciprocity. Research,
which so far has been largely an instrument of dominance and legitimation of power elites, must be brought to serve the interests of dominated, exploited and oppressed groups, particularly women. Women scholars, committed to the cause of women’s liberation, cannot have an objective interest in a ‘view from above’. This would mean that they consent to their own oppression as women, because the man-woman relationship presents one of the oldest examples of the view from above and may be the paradigm of all vertical, hierarchical relationships (Maria Mies 1993:38).

This led me to initially name my methodology as grounded theory: that any theorising on my part could happen only in relationship with, and to, the concrete, lived experiences of the people with whom I spoke. While I used many of the techniques of grounded theorising, in coding and analysing the stories collected, I have come to realise that there is no such thing as a truly grounded theory. I take into the design of the questions, the focus of my inquiry, the people I relate with, a whole set of assumptions and ways of knowing. I have a priori theoretical constructs which I take with me into the research situation (Liz Stanley and Sue Wise 1991). This is not to say that these constructs or understandings are not subject to metamorphosis en route.

For these reasons, therefore, I do not claim to have done feminist research here, as I have not put the social construction of gender at the centre of the inquiry, rather it is a discourse which informs my inquiry. So, what is research that a feminist might do? Mary Fonow and Judith Cook (1991) reviewed the literature of sociology over a nine year period, and have distilled four major assumptions used when claiming that research is feminist. These are:
reflexivity
an action orientation
attention to the affective components of research
use of the situation in hand.

If I take these major assumptions as a way of evaluating my research, as a way of answering whether or not the research is congruent with feminism, I must answer that yes it certainly is. Participatory action research involves an action orientation and makes use of the situation in hand. It works with an issue of concern to the researchers, with the aim of enabling a better understanding of that issue and a transformation in the practice of the researchers. Additionally I have painstakingly, and often painfully, worked to make clear my dreams, hopes, biases and positions throughout this journey. I have clearly located myself and my interest in this process and have talked of the changes and learnings that have taken place for me.

Shulamit Reinhartz (1992) identifies three definitions of feminist research, one of these being: "Feminist research methods are methods used in projects by people who identify themselves as feminist or as part of the women's movement" (1992:6). A clear and simple definition and one which clearly situates my work as feminist. Furthermore, "at the core of feminist ideas is the crucial insight that there is no one truth, no one authority, no one objective method which leads to the production of pure knowledge...feminist knowledge is based on the premise that the experience of all human beings is valid and must not be excluded from our understandings" (Dale Spender 1985 in Shulamit Reinhartz 1992:8). These are insights, knowings, that have guided this thesis.

There is a great tolerance, of diversity in Shulamit Reinhartz's book (1992). Her broad definition of feminism, coupled with her broad definition of research has enabled an inclusive approach to both research and knowledge
production. In this approach, guided by some core beliefs, there is room for new and exciting approaches, there is room for imagining another way of researching, there is room for a multiplicity of struggles and resistances.

Another feature of feminist research and theory is the centrality of experience. As was seen from the brief stories of the women in the Inquiry Group, lived experiences have been extremely important in helping these women understand both themselves and their world and helping them articulate their own particular way of knowing "I can say that the life experiences I have had, have given me an incredible first hand knowledge and understanding of the imbalance of power and social, as well as other, injustices in society" (Sue 1995).

In talking of experience I, like Maria Mies, do not mean ‘one off’ things that happen to us, rather how a collection of experiences can help us to change, form and re-form our understandings:

experience is often equated with personal experience, with the atmosphere, the feelings which a woman has in a certain situation. In my opinion, however, experience means taking real life as a starting point, its subjective concreteness as well as its societal entanglements ... According to my understanding, however, this term denotes more than specific momentary, individual involvement. It denotes the sum of the processes which individuals or groups have gone through in the production of their lives; it denotes their reality, their history (Maria Mies 1991:66).

The experience of a days work in a health centre then, could become our starting point - as it did in The Staff’s Story. However, just describing this experience is not enough if it is to become part of a political struggle. We need to examine and scrutinise the experience in light of other’s
experiences, in light of the structures in which we work, and which work on us. We have to strive to understand the meaning of these experiences and why we act in certain ways if we are to begin to break the through the bonds of oppression.

Finally, feminist research is ethical. This is neatly summed up by Maria Mies when she says" [w]hat the scientist would not do to himself, neither should he do to any other being" (1993:51). While clearly directing this comment to those who do patriarchal research, it is a crucial guiding ethic for feminists engaging in research of any kind. This ethic is also part of our Judeo Christian heritage. I remember clearly learning at Sunday school the motto 'do unto others as you would be done by'. While we can critique and argue about many oppressions and conflicts that take place in the name of Western religion, this still remains a useful ethic by which to live one's life.

**Emancipatory research**

I am by trade, by experience and by desire an educator. My work is guided by an emancipatory interest. This interest is supported by the discourse of Social Ecology which sees learning and research as inextricably linked. In her book *Getting Smart* (1991) Patti Lather argues for research as praxis, responding to Gramsci’s neo-Marxist call in the 1940’s for intellectuals to become more politically involved and active in the world. Patti Lather speaks of 'research as praxis' having a transformative agenda, an emancipatory intent and using empowering approaches to the development of knowledge. The result can become "a constructive turmoil that allows search for different possibilities of making sense of human life, for other ways of doing justice to the complexity, tenuity, and indeterminacy of human experience" (Mishler 1979 in Patti Lather 1991:52).
Emancipatory research is, according to Patti Lather, the best method of researching within a critical social science methodology. However, as there are few clear strategies for linking critical social science and empirical research, the researcher often has to make them up. What is needed is "open, flexible theory building grounded in a body of empirical work " (Patti Lather 1991:54). The concrete forms of such a research methodology are "interactive, contextualised, and humanly compelling because they invite joint participation and exploration of research issues" (Patti Lather 1991:52). If we combine the concerns of feminist research and emancipatory research we can begin to fill in the details.

In feminist emancipatory research, those who participate may have input into the questions to be asked, may choose to answer different questions; may comment upon any data that was collected and may share the task of making meaning from the data itself. Participants may also be involved in writing up the results and conclusions, jointly constructing, jointly owning and being jointly responsible for the project. There is a need for reciprocity between researcher and researched, both become the changers and the changed. The conventional hierarchy of knowledge production is replaced by collaborative theorising.

In emancipatory research the researcher constructs meaning 'with' the participants, through a process of negotiation. This negotiation is a sensitive and tricky business given the relations of power that operate around and through researchers and collaborators. What this negotiation attempts to do however, is to address one of my concerns with critical theory, that is, people themselves work things out - together. Together they come to articulate how it is and why it is, and together they begin to imagine how it could be different. The only theoretical assumption that is at work here is, that collectivity, reciprocity and dialogue are 'good things' in
helping us make sense of the world. Theory building thus becomes dialogical rather than impositional.

There is, in this context, a responsibility on the researchers to look beyond the surface, the everyday, to analyse their findings beyond the common sense view or conventional understandings. This requires relationship and a level of trust between the co-researchers. One way of encouraging this trust is with reciprocity and an ability to negotiate and make visible relations of power within the group of researchers. We need to incorporate maximum reciprocity if our goal “of emancipatory research is to encourage self-reflection and deeper understanding on the part of the researched at least as much as it is to generate empirically grounded theoretical knowledge” (Patti Lather 1991:60).

In sum the development of emancipatory social theory requires an empirical stance which is open ended, dialogically reciprocal, grounded in respect to human capacity and, yet, profoundly sceptical of appearances and ‘common sense’. Such an empirical stance is, furthermore rooted in a commitment to the long term, broad-based ideological struggle necessary to transform structural inequalities (Patti Lather 1991:65).

The concern of this particular research project has then, been twofold. Firstly the Inquiry Group sought to hear the voices of those at the margins of decision making and power in the health system. We sought to make these voices visible and public, to insist that they get heard by those at the centre of power and decision making. This is one way we sought to change the status quo, to confront the system. Secondly we sought to better understand and change our own practice. To constantly strive for ensuring that our practice was congruent with our own rhetoric.
Participatory /collaborative action research

But to get back to our beginning, when the Inquiry Group began to work together we described what we were doing as participatory action research. Many of the women within the group had direct experience of doing action research, others were familiar with the term and what it meant. This description served us well. At the beginning it enabled us to have a clear shared understanding that what we were doing would require action as well as reading, theorising and reflecting. Using the term 'participatory' meant that participants in the Inquiry Group were all part of the planning, the actions, the making sense process.

Naming what we were doing in this way acted as an evaluative tool, we asked if what we were doing included all of us, were we sharing the work as best we could? Did we feel that all of us were involved in the action, the theorising and the meaning making. Were we jointly constructing knowledge and understanding? This type of research has been increasingly known under a number of names: participatory action research (William Foote - Whyte 1991, Robin McTaggart 1991, Susan Smith 1993), emancipatory action research (Stephen Kemmis 1985, Patti Lather 1991), qualitative action research (Bob Dick 1992), collaborative action research (Graeme Bird & Judy Pinn 1993). It includes substantial elements of co-operative inquiry (Peter Reason 1988, John Heron 1985) and soft systems methodology (Peter Checkland 1991).

Action research is all that these names imply. It is participatory, collaborative, democratic, consensual and emancipatory and has strong links with the writing of Paulo Freire (1970). It involves a group of people working together in search of critical knowledge of a particular issue, in order to effect transformation of the situation in which they find
themselves. This understanding evolves out of the actions and the reflections of the individuals and the group. The understandings of social interactions and contexts provide people involved with the opportunity to recognise constraints imposed on their practices from social structures and ideologies of domination and control (Shirley Grundy 1986). The wisdom generated by and of the group is paramount. Change can happen at an individual, group and societal level.

Action research is simple, yet extremely complex; it is systematic, with a clear cycle of stages to be worked through, yet chaotic. The cycle may not always, and should not always, be adhered to slavishly, each step in the cycle involves a life of its own. The process has clear, broad outcomes in mind yet is extremely flexible and may turn somersault at anytime. It is mature, first articulated by Lewin as a research methodology in the 1950's, and yet it is young, not widely known, respected or widely practised. The process is predominantly used within the area of education, although increasingly embraced in the health arena (Ian Robottom and Derek Colquhoun 1995; Yolande Wadsworth 1990). It has been called a 'fringe methodology' (Bob Dick 1992). It is personal, yet can be professional and political involving the public and the private selves of the researchers - valuing each.

Action research is an inclusive methodology and does not work easily with dualistic thinking. Action research is grounded in a constructionist epistemological tradition. Within this tradition, it is accepted that knowledge is created by participants in a given situation, nothing is absolute, that groups of people can and do create knowledge. Theory and practice are interconnected and interrelated, one informs the other in a continuous reflexive process.
Whilst this complexity may be understandable it makes the task of writing about action research as a method similarly complex and the task of doing action research risky, frightening, exciting and organic. Action research demands that each individual is engaged are "an aware self, willing to withdraw projections and offer a sense of openness and presence; risking, merging, separating, speaking our truth, deep listening, waiting, giving attention, having patience, taking a stand while all the time affirming and nurturing our collaborative process" (Judy Pinn 1993).

Finally, action research is informed by a stated ethical stance, it is not an ethically or politically indifferent methodology. Robin McTaggart illustrates this point well when he says "[i]t is my view that the fundamental impulse of participatory action research confronts the immorality of economic rationalism and its manifeststations in our institutional life work" (1991:53). Within this stance we work towards those things that are considered a 'better' way of being in and of this world. These better ways of being involve working towards democratic processes, not just to specific outcomes; social justice; honesty; authenticity; valuing and honouring of the individual, the personal of what it is that makes us human.

Each time a researcher writes about action research it is coloured by their particular bias, their experiences and the knowledge of the group and individuals with whom they have been working. People who undertake action research are not trying to lay down a set of procedures/tasks/steps/variables that if repeated may be replicated. They are not trying to say this is the Way, this is the Truth. That is not the point. People who do action research, in the terms in which I am describing it, are concerned with understanding and acting with the particular, the local in order to generate knowledge which will add to our understandings of particular issues in order that we may change them and ourselves.
In this way action research fits well within the postmodernist and poststructuralist theoretical tradition. We are concerned with what Foucault would call 'subjugated knowledges'. It is also part of the critical social science tradition which seeks to transform our practice through understanding. In this context, research contributes to our knowledge of people, society, relationships by saying: 'in this place at this time with these people we did this for these reasons. We found this and acted in this way to make a difference Have you found anything similar? Does this help you in your search for understandings? Is there anything that you can learn and/or use from this?'

However this does cause some tensions especially when the research is to form the basis for a degree awarded by a university, as is the case here. How do we demonstrate that we are capable of independent research when we work collaboratively? How do we value the collaboration of the co-researchers while at the same time claiming this work as our own? The system itself is set up to encourage individuation and competitiveness, not collaboration and shared constructions of knowledge. Knowing this, I chose to continue and to live with the tensions, after all this is the essence of doing Social Ecology.

Much of what I have been weaving a path through up to now is really the question of research. Action research recognises that there are always two equally important issues with which to struggle: the substantive issue and the research issue. The substantive issue in our case is public participation in the planning, delivery and evaluation of community health services. The research issue centres on questions such as: in whose interests is this research being done? How much do the researched know about the research? Do they enter into partnership? Are they entrusted with carrying out the research process, do they have managerial control, do they own the research? (Yolande Wadsworth 1982). If they do own the research: are we
sharing control, responsibility, power, knowledge; is the group working OK; are we able to be objectively subjective or subjectively objective enough about our own ideas, plans and actions?

On a number of occasions friends asked me what the outcome of this research will be, what model am I developing? I felt somewhat inadequate answering 'I don't know'. I also felt somewhat dishonest. Of course I had ideas, dreams and visions about what will happen but throughout this inquiry I purposefully kept these in the back of my mind. If they were to come forward then there was a danger that I would manipulate the group with whom I was working, my ideas may become their ideas, however subtly this happens. This to me is not collaboration. We need to jointly develop strategies, answers and models, if, and when, appropriate.

I realise that even now the terms action research are still somewhat cloudy and hazy. I have purposively left them so, this is how they are. It is going with the flow, trusting the process, and really believing that knowing can grow out of a passionate and emotional connection with others around an issue. Too often knowing is reduced to a set of skills and behaviours, a list of A to Z which if followed will lead to enlightenment. There is temptation in this approach, the lure of safety, of control of knowing what will happen next.

Orthodox research methods are inadequate for a science of persons, quite simply because they undermine the self-determination of their 'subjects'. Orthodox scientific method (particularly the formal experiment, but following this surveys, questionnaires, and observation) aims quite systematically and intentionally to exclude the subjects from all choice about the subject matter of the research, all consideration of appropriate inquiry method, all the creative thinking that goes into making sense; and therefore excludes from the field of research just
that aspect of being - self determination - which particularly characterises the subjects as persons (Peter Reason 1988:4).

With these cautions in mind there are some general principles and processes, some logical steps, which can be described when talking about action research. It is these that I now want to negotiate in some non-absolutist way.

A number of writers and researchers (Shirley Grundy 1986; Robin McTaggart 1991; Stephen Kemmis 1985; Yolande Wadsworth 1982; Susan Smith 1993) believe that action research is a political activity, not revolutionary but certainly injecting the evolutionary change processes with energy at certain points and around certain issues. In this way it is political and subversive, it is a methodology that seeks to understand the 'status quo', power interests, and systems which oppress, with the sole aim of doing something about it.

The action research process is informed by a fundamental interest in emancipation and empowerment to engage in autonomous action arising out of authentic, critical insights into the social construction of human society....When action research is informed by an emancipatory interest the possibility exists for the development of critical understanding of social interactions and contexts. Such understandings will allow participants to recognise the constraints imposed upon their practices from other social structures which are informed by interests in domination and control (Shirley Grundy 1986).

In a simplistic sense the tasks in action research involve identifying the questions or issues to be researched, developing models of practice, putting
these models into practice and recording what happens, reflecting on this experience and making sense of the whole process. The development of understandings, the 'making sense of', happens through a process of dialogue, it is a social process, the knowledge is explicitly socially constructed through individual and group critical reflection and dialogue.

For this thesis, and the empirical work it contains, an action research or Inquiry Group was formed. Their story is detailed in Chapter 6 where the actual doing of this research takes a concrete form. As mentioned above, the substantive issue we sought to understand, explore and act upon was that of community participation in health planning, service delivery and evaluation. Using this collaborative/participatory action research ensured that our method was congruous with our substantive concern.

**Grounded theory**

For praxis to be possible, not only must theory illuminate the lived experience of progressive social groups; it must also be illuminated by their struggles. Theory adequate to the task of changing the world must be open-ended, non dogmatic, speaking to and grounded in the circumstances of everyday life. It must, moreover, be premised on a deep respect for the intellectual and political capabilities of the disposed. This position has profound substantive and methodological implications for postpositivist, change-enhancing inquiry in the human sciences (Patti Lather 1991:55).

While the work of the research Inquiry Group was located within the context of participatory/collaborative action research, the other stories which make up a substantial part of this thesis were not. The people we spoke to via interviews and focus groups were not involved in deciding
which questions should be asked of them, which to explore. The staff of community health services were involved in the theory generation from their interviews; all other participants were kept informed.

The Inquiry Group believed that grounded theory would enable a complexity of issues, a variety of perspectives to shape the theory development which was grounded in, informed by the voices of the people we spoke with. It was, we felt, a method congruent with principles of community development - it starts where the people are at (Jane Dixon 1989). Thus we turned to the work of Anselm Strauss (1987) and Anselm Strauss and Juliet Corbin (1990).

Grounded theory aims to develop theory which explains the social conditions and experiences of those people involved in the study. A secondary aim (some may argue a more important one) is to generate theory which is applicable to other situations and contexts i.e. it is generalisable (Vera Irurita 1996). Grounded theory as a method is transdisciplinary, with its roots in philosophy, education, psychology and sociology - these being combined in social interactionism and pragmatism after the work of Herbert Blumer in the 1960's (Merilyn Annells 1996). Similar to Elisabeth Porter's (1991) ideas of a self in relation, social interactionism sees the self as constructed through social interactions. Grounded theory uncovers "the basic social and structural processes" (Judith Wuess 1996:127) which construct the self.

Judith Wuess argues that grounded theory is "consistent with the postmodern feminist epistemology in the recognition of multiple perceptions of reality" (1996:127). It is an emerging, flexible design which begins with the purpose of working out what is going on for people within a broad area of interest (Glaser and Strauss 1967 in Wuess 1996). The role of the grounded theorist, or in this case, theorists, is to find out what is going on,
to immerse themselves in the data from the field, to begin to understand what people are saying and to tease out through analysis and interpretation the influences of various power structures around class, race and gender. This way of researching enables pluralities and diversities to surface with the major question asked of the theory generated being 'does it work?' (Anselm Strauss and Juliet Corbin 1990).

In this way of working, we are not seeking a single objective truth. It is clearly a subjective method using people's experiences as the hub around which theory is developed. It also enables the researcher to be real and visible, to own a part in the process. Indeed Strauss and Corbin (1994) remind us that we need to "accept responsibility for our interpretative roles" (1994:274).

We did not conduct multiple interviews with people - a way of ensuring the flexible and emergent nature of theory generation - the process of analysis, interpretation and theory generation was done collaboratively by the Inquiry Group. This ensured that I, the primary researcher, was restrained in forcing the data to fit my own a priori assumptions. What is important in grounded theory is that while the researcher's world view influences what is observed and how, "only concepts which emerge from the researching data will enter the resulting theory" (Judith Wuess 1996:133).

Reflexivity - both a feminist and emancipatory research concern - is likewise vital to grounded theory practice. It enables us to critically analyse our own place in the interpretation and writing of both the story and the theory generation. It enables us to own our part in the process while at the same time ensuring that we develop theory that is located in people's interactions with institutional structures, in this case that of health. It also ensures that theory is useful, pragmatic and explains 'what is going on here ' to the people who tell their stories.
CHAPTER 6
THE INQUIRY GROUP'S STORY
"Who conducts critical social science, and in whose interests is it carried out? Institutionalised social research commonly serves the self interests of an academic research community or the sponsors of research projects. When this is so, social research becomes part of the establishment and the ideologically given framework of society. To escape enshament within the structured framework of self interests that constitute the established social order, a critical social science must first of all conceive its audience as wider than the community of social scientists and the managers of society. Second it must conceive its participants (the scientists) in different terms: while conventional social research relies on specialist researchers to carry out the research task on behalf of society (as part of the division of labour which is itself ideologically structured), a critical social science must engage ordinary participants in social life in inquiries whose function is to disclose the ideological processes and structures which condition their own practices" (Stephen Kemmis In Boud, Keogh and Walker 1985:154-155).
Introduction

This research project was conceived six years ago when I was teaching a subject called "Primary Health Care" to undergraduate nursing students at the University of Western Sydney - Hawkesbury. Primary Health Care is a set of principles which I could embrace easily as they are grounded in the ideas of social justice and equity. The focus is on the social construction rather than the genetic determination of health. Furthermore everyone has the right and responsibility to be involved in the decision making processes at all levels in terms of their health (WHO 1978; WHO 1986).

For some reason, it was this last statement that intrigued me. As I read more around the issue, I confirmed my suspicion that if people were involved in decision making then they tended to be healthier. This was further reinforced by talking with people I knew. Emma had late onset diabetes which the medical experts seemed unable to 'control'. In talking with her over a period of some months it became clear that she 'knew' what she needed, 'knew' why her blood sugar levels were fluctuating so alarmingly. However, she did not want to live a long and medically restricted life preferring a probably shorter but freer life. Although not an expert on diabetes she did know herself. When her doctor, after three years, actually listened to and accepted what Emma was saying, when the doctor handed over the control of the diabetes to Emma - her levels stopped fluctuating at such an alarming rate, they even stabilised after twelve months.

Similarly a friend's son who was on growth hormone treatments started to show a dramatic response to the treatment once the 'experts' let him decide when, where and how often he would take the medication. I played with the ideas of control and patient participation for a while, becoming more and
more intrigued, wondering how the health bureaucracy would be able to implement this principle in practice and not just in rhetoric.

In the middle of 1993 we invited the Team Leader of Springwood Community Health centre, Joan, to speak to students at the University about Community Health. During her talk she mentioned, as if in passing, the team's commitment to community participation in Community Health services. I pondered on this statement for a few weeks, could it be possible that we were on about the same thing? It seemed too good to be true, even more so, as I live in the Springwood area and had been wanting to do local research.

I spoke to a colleague of Joan's, Dot. She also happened to be the team leader of Lawson Community Health centre. I said I was interested in the idea of community participation and was exploring the issue as a part of my further studies. I was invited to meet with the Director of the Blue Mountains Community Health services and the two Team Leaders. We had a common purpose, and wanted to take action. We believed in the idea of community participation and agreed that there was not enough of it happening in our experience in the health system.

In practice action research begins with an imperfectly understood felt concern and desire to take action—a general idea that some kind of change or improvement is desirable (McTaggart 1992 p. 54).

I went to this meeting with reservations. I was not sure that working within a bureaucracy was a good place to study issues of participation. As I wrote in my journal, I felt that by working with the system I was "really accepting that the system is there and that working outside of it might be more effective, do I work outside of it with the aim of making it irrelevant?" I was not sure that I could

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work with nurses. However, I was also aware that "I needed to identify a group soon, to relate with one group so that my questions can become more specific" (Journal: March 1993). At this meeting, to my surprise, I found that Sandra, Joan and Dot shared many assumptions, dreams and desires; we all had similar critiques of the health system. I left the meeting feeling that fate had intervened.

We agreed that our collective aim was for public/community participation in health decision making, service planning and evaluation and that we sought a sense of partnership and democratic decision making. We were concerned with collaborating with 'others' and as such our research methods needed to be collaborative. We also owned the political nature of our inquiry, we stated from the outset that we wanted to change our practices and the system.

Living the research experience

The birth of the Inquiry Group and of the project. We committed ourselves to monthly meetings and went away thinking of who else we would invite at these early stages to be part of the group. The next meeting saw the group swell from four to eleven. This settled to a core group of seven, although the others continued to want to be informed of our progress.

This then, is the chronicle of the group story, it unfolds sometimes messily and slowly but, it is important. If, as Liz Stanley and Sue Wise (1993) say, 'our theory is that our practice is our theory' then my interest here is 'does the practice of the group demonstrate that our practice is indeed our theory?'

I included the 'raw data' as a way of telling the story of the group chronologically and authentically. I believed this to be important as it
demonstrates how we grappled with, understood and worked within a collaborative/action research paradigm. It shows that this is not an easy way of working.

For instance, there are the dynamics of the group to be worked with; individual needs and insecurities, lack of clarity about roles, ownership and power (Susan Smith 1993). We had to live with questions such as: who is responsible for which tasks: what if some of the group do not want to participate in all tasks, who decides what is important; how do you build trust and collegiality? In our case food seemed to play a large role, as you will see.

The group met monthly over the period of this project, from August 1993, to October 1996. The majority of meetings were taped. I wrote a summary of each meeting which acted as our record and summaries were distributed to each person in the group. I also kept a research journal. What follows is based upon the summaries, my journal entries and commentary from me and members of the group.¹

The Beginning

In August 1993 we held our first community participation group meeting. Here I gave a brief background to the meeting and obtained permission to tape the meetings.

Everyone was enthusiastic and supportive of the idea of community participation. ... some concern was raised in respect to the time involved when part of a research project. The possibility of applying for a research grant/industry funding was discussed.....it was suggested that we need to define and clarify before we inform and

¹ Journal entries are typed in *arial italic*, extracts from the group meeting summaries are typed in *courier italic*, commentary is typed in arial normal.
communicate with the community...the issue of group membership was discussed, in particular the possibility of inviting GP's and community reps to join us. As such it was agreed that we would come to the next meeting with ideas and thoughts on how to get the community involved in this part of the process.

Whilst an enthusiastic start we were not clear as to how the research was to be conducted. Many of us felt that some research funding would help speed the process up, as we were not sure how much time and energy we could commit to the project. This issue and the issue of group membership came up a number of times in the early meetings; they remained as floating issues and were never acted upon.

October......

We talked of the possibility of seeding grants ....lengthy discussion as to how we could get a person or some money to employ a person to help us.....we agreed that this project be seen as and talked about as a joint University and Community Health project...Debbie agreed to organise a literature search ASAP...Discussion regarding including others as part of the group...discussion of whether we do a pilot project or the whole of the Blue Mountains...agreed we needed to focus more, probably on geographical area and we need to include all the essential players in the health arena ..How can we best involve the community so that they can determine the issues so that health services bear some reality to them.

Refocus on health not illness - a lot of discussion in the system in NSW focuses on illness, we need to refocus on health and healthy people ... need to set the community up to succeed in participating, we may need to educate people so they can participate.....Agreed that we need to clarify terms and develop a shared understanding of what we mean by our project, this can be done and will happen as part of the meetings .. people happy to keep exploring the issues, no rush to start implementing.
The discussion regarding the need to educate people caused a reaction in me. As an experiential learning practitioner (David Boud, Ross Keogh and David Walker 1985) I believed that people learnt by doing, from the experiences themselves. I was also concerned that if we followed the model that we need to educate people so that they can participate, then it would never happen, it would become a form of gatekeeping. Additionally, it seemed to me that this model was based on the assumption that people do not have the skills to participate in decision making. Rather than voice these concerns, I walked on egg shells, and suggested the Freire readings (1970,1985; Nina Wallerstien 1988) and activities. I wanted to show by doing that there is another way of seeing education. This provided a focus for the next three meetings.

November ..........

Debbie has a copy of health participation from the National Health Strategy ....we agreed that we would all read this as soon as possible....Debbie had also started the literature search...we were surprised that there was not more actually happening given the number of articles written on it...It was felt that politics would be an issue for this group....the group talked about the fact that what we were engaged in was slightly politically risky at this point in time, but were happy to take the risk.

At this stage I was concerned that we should share the reading, the doing and the theorising equally. I did not want to 'own' the academic tasks, to encourage a division of labour.

We shared some of our thoughts and experiences in the area of community participation- how we could do it...we agreed that it would be useful to discuss the ideas of Freire and his 'problem posing methodology' at the next meeting.
November 30

Discussed the Freire articles (Nina Wallerstein 1988; extracts from Paulo Freire 1970 & 1985) ...We spent some time talking about his three step methodology which we agreed sat well with the current practice of people and the values of Community Health in general. We agreed that we would implement this methodology with the research group to enable us to get to the stage of a plan of action.....at the next meeting we will begin this process.

March 1994...........

Seems that we could be successful in getting money ... Sandra to keep pursuing this....Feedback on the community participation booklet ...feeling was that it reinforced what we were doing but was of little practical help...Debbie voiced concern re readings - if Debbie is the only one who is reading and feeding this into the group then the group will be continuously exposed to Debbie's bias. We agreed that Debbie would read all of the 'theoretical' material and cull the rest to some extent. Whilst this was seen as problematic, the literature search has been initiated by Debbie so is somewhat biased from the start. We agreed that other literature would be sent out in the minutes and people would undertake to read this material.

Despite my concern about equity, people were not willing to share the 'academic' tasks at this stage. This led me to rethink my role and to reconceptualise it as the primary researcher, the one with time and resources to read more. I was concerned about issues of power, it seemed as if I was going to get even more as all of the readings would be chosen and interpreted by me. I hoped that by having the awareness, recognising it as an issue would allow me to act with integrity. Additionally, as a group we discussed these issues and it seemed incumbent upon me to go with the group consensus, to trust that they did know what they were doing.
Talked about inviting a student in Social Ecology who is also a doctor and also interested in this issue...we also decided to invite the local neighbourhood coordinators ... discussed the need for all members of the group to start keeping a journal/record as a source of data...we agreed that we would begin doing this now. We then began the process of;
1. Listening to understand the felt issues or themes of the group
2. Participatory dialogue
3. Action on envisioned changes
taken from Freire's ideas (in Nina Wallerstein 1988). We focused on point one but found that we wanted to jump straight into point three.

This part of the meeting was transcribed, by me, word for word. The transcripts were then given to the group for validation and discussion. What follows are some excerpts from this transcript. I have included this rather lengthy section as it shows how we as a group grappled with issues fundamental to this research. It also shows our collective awareness of the complexity of the issues and the research task.

Dot: I'm very impatient ... when are we going to talk to people out there ...if we are going to have community participation shouldn't we be starting to ask people out there if they want to participate, how they want to participate?

Pam: I sometimes lose track of what participation we want the public to have .... I'm a doer so all the research and reading stuff is not my thing ...I get a bit lost in the meetings I'm not sure where we are ending up ....some things are starting to come out that are really useful but I'm still not sure that we've got a really clear idea of what the actual issue is.

Lesley: I can't understand how we get the community involved because most people are so apathetic.
Maya: For most of this century we've been very paternalistic.

Dot: We don't seem to be any nearer to me about having a clear thought.

Pam: What is the compromise then or are we thinking of small things that will grow into bigger things.

Joan: We need a process for making the public aware of the issues ... it's a long term process.

Debbie: Why hasn't it happened? everyone thinks it's a good idea in words - why isn't it happening.

Sandra: It's rhetoric

Debbie: Why is it rhetoric

Sandra: it's what they are expected to say

Debbie: who is expecting them to say it?

Sandra: pressure on people from community groups. There is no organisation - there has not been an organised push for it

Joan: Has a lot to do with society as a whole and the history, the have and the have-not's, the powerful and the powerless... people in power are not going to give it up.

Maya: We've gone past the point of whether or not it is a good idea. It is the HOW this is the most important and difficult part.

Pam: There certainly is a lot of conflict...people are not clear in their own minds, half want to do health promotion the others feel more comfortable doing the nursing sort of stuff.
Joan: The government has given no indication that they want the public to participate in the management or the setting up of how things are done.

Sandra: Yes the whole thing's just political ..... if you are talking about financial management there is no way, just forget it.

Lesley: I get the feeling that these people are not used to being asked their opinions, that they are quite happy to go along with what they are told they can have....... How do we get them involved to voice their opinions if they are not used to doing this?

Sandra: There are lots of small things being done and if we've got one fault it's ......communication of this.

Pam: Every little bit of health promotion that one of our staff does involves community participation.

Sandra: One of the major conflicts I have around participation is not giving the community false information in terms of what they can achieve given the real constraints.... I am also concerned with this issue of tokenism. And I don't know how to tell people and maintain employment that there are very real constraints.

Part of it is finding out where these people meet and approaching them on their turf.

The main issues for the inquiry group seemed to focus on the tension between feeling that community participation was a 'good thing' and scepticism of both people's and the system's capacity to sustain it. There is also at this stage a lack of clarity as to how we were going to do what we were really wanting to do.
April........

The last meeting was small but productive ....I took a directive and questioning approach - asking people to talk about what they see as the issues and their vision of community participation in Community Health ... people opened up quickly, sharing their frustrations and dreams...... I felt ambivalent about this role - it serves to separate me from the group, the researcher, the one setting the direction - but we did achieve a lot.... The meeting finished with a feeling of high energy and trust. We shared coffee and jokes before going home.

(I was unable to attend the April meeting. Minutes were taken by a member of the group).

A couple of people had skimmed the articles sent out .. lead to discussion that our ideas are good ideas but the how is really difficult. Discussed the nature of research and the tendency people have to make people statistics and to hand power over to the researchers.

.. some cake eating....

No-one except Dot kept their journal. Dot had written "the group suddenly seemed to come to life ... things started to move .. the Freire exercise was good although it was difficult".

13 April

"tension between pushing and influencing the group - how much do I let them find their own way ? How much do I go with the flow?

In the early stages I experienced a great deal of internal angst regarding my role with this group.

28 April
after spending hours transcribing meetings I wonder if there is another way? Summaries?
Listen to the tape and pull out key words and phrases so that I maintain the richness and
passion of what is said. You certainly get a clearer picture when you do transcribe, the
thing is that there are about 500 issues that could be taken up!

May........

We set the scene well with red wine, cheese and biscuits....discussion of the journals ... Debbie felt that there was some passive resistance happening in terms of the journals and the group agreed .. people made a commitment to try for the next meeting. People also felt that the biggest problem is that you never have time to reflect due to being too busy ... Felt that one of the clearest things seems to be the shared commitment of the group. We reminded ourselves that we had only met six times ... Pam felt that it was good and she was beginning to feel "comfortable, it is OK that I'm different to everyone else and that I look at it differently to Debbie " .. We all felt that it was good to have different perspectives and that "quite often when someone says something you think "now why didn't I think of that it's such a good idea".

We then took some of the key issues identified from the last meeting and rewoked them into aims and strategies.

28 May

the tyranny of the group - is this the most effective way to effect transformation or is it a few well placed individuals? On reflection I don't like this either/or, what about both?... could working with groups distract us from our goals? maybe collective groups really make us put our feet in concrete.

June........

although a small group the atmosphere at the last meeting felt good - lots of laughing - but also a high level of honesty, people clarifying with each other and able to say what they think. ... I'm beginning to feel itchy for some action now too - but also know that we are
not quite ready. We are just beginning to focus/converge and this process cannot be hurried along.

**July**

(I was unable to be at the July meeting).

We still need to educate people ... so that they can make decisions. We can't do customer focus, community participation if people are not aware of the issues... Discussion followed on how we could inform the public .... suggested that we form our own power groups - nibble away until success.

Phone call from Maya - to say hello and to check that the notes she sent me from the last meeting were OK. She also talked about her frustration with the group - that we have spent 12 months talking and no action.....she doesn't feel comfortable voicing her concerns in the meeting as the other people there are in fact her bosses.

**August**

Joan rang to ask whether it was worth holding the next meeting as a few people cannot be there. Coincidence that it comes so soon after Mayas call. We decided to cancel ... I am beginning to feel as if this is falling apart - a lack of commitment a 'lost the plot' - but how much am I projecting? ... I think I will make time to talk to each of the group about how they are feeling and what they believe we should be doing ... I also wonder if I am working with the right group - an underlying fear from the beginning - are these people the ones who are able to act or are they so trapped in the same pattern of behaviour as we have been critiquing - that the words are there but no-one is doing it?

I was feeling things slip away, people becoming frustrated and dissatisfied. I felt that it was time to clarify, to put forward some ideas regarding how we could proceed with the research. I spent August clarifying, reading the minutes and writing.
I also collapsed/escaped into reading (Foucault an escape?) and drawing lots of spaghetti like mind maps in my journal coming out with a few clear aha’s.

"What is reality anyway? A collective hunch" (Jane Wagner in Robin Morgan 1994)

"a good deal of the corporate planning I have observed is like a ritual rain dance; it has no effect on the weather that follows, but those who engage in it think it does. Moreover, it seems to me that much of the advice and instruction related to corporate planning is directed at improving the dancing, not the weather" (Ackoff, from David Russell 1990).

18 August

Find out what is already happening ... community participation as an outcome not a starting point ... Reframed, community participation will happen during the process ... the model for community participation becomes the research process it happens because we are asking the community and hearing what they say.

24 August

I’m still not clear on my questions and outcomes but I do feel happy about the process-which is a good start! ... I think that Andy was also right about my lack of confidence.. I think I am worried that once this takes off it will be big and I won’t be able to control it - back to my need for control!

September ..........

5 September

The more I go on the more I understand the saying "we will arrive where we were and see it for the first time" A lot of what I am saying, thinking and feeling has already been said - but I never heard it before!

I am also coming to really believe that a PhD is about learning and not changing the world. I have mouthed these words before but I am now beginning to hear them. This in itself is mixed with sadness at letting go of my desire to really make a difference and the joy of realising that I am learning so much that is new.
Prior to the September meeting I sent out a tentative action plan which had been informed by the discussions and meetings of the past 12 months, listing questions we needed to ask, outcomes and who we could interview. I suggested that we speak to 4 different groups:

- community health service providers; both community nurses and allied health staff
- service users; pensioners, parents, working men and women
- non service users or the 'public at large', and
- other service providers such as GP's and non government agency workers

We had some wonderful food to sustain us during the meeting ... feedback on the article sent out with the minutes .... Lesley spoke about the fact that she wants to develop some information for consumers about their service ..... Joan feels that community participation is being mentioned more and more.... we agreed that the language is shifting from consultation to participation ... but was still jargon and we wondered if people really knew what they were saying.

We walked through the ideas outlined .... People felt that most of the ideas were well grounded in discussions that had taken place in the group so they weren't new..... We agreed to focus on one Community Health centre.... we spent time talking about the ethics of asking people for information.... we talked about some ideas for making contact with non service users .... this led to a discussion of the community activist Fran Peavey. Dot had recently gone to her workshop.... Debbie agreed to send out copies of Fran's strategic questions.. people also asked for any 'interesting material' from Social Ecology.

We talked about the fact that we might find that the community doesn't want to participate.
well I thought it all went smoothly. Whilst I did most of the talking, I constantly checked individuals responses. The fact that Dot agreed to the pilot and Joan readily agreed to use Springwood as the starting service confirmed with me that they were comfortable with the process. People also asked repeatedly what they could do to help which was affirming... People liked the possible questions and added a few of their own. I feel quite excited at the level of support and interest- but still worried - they were not very critical.

21 September

conversation with Sue ... she asked for feedback about the meeting - did she say too much? Was I frustrated at the slow pace ? I probably need to give more feedback - suggests still, a level of dependence on my opinions.

October........

We talked about the issue of 'naming' that the bureaucracy seem to now 'own' the idea of community participation and this in effect seems to be disempowering for health practitioners as they are not sure what is meant by this term and whether what they are doing already counts.

We then looked at and agreed upon the sorts of questions we could ask the different groups ... We talked about the issue of labels and agreed that the word 'customer' was a little misleading as it implies choice and a different power base and information base than that which exists. In reality health 'users' are not in a position to effectively shop around. We agreed to stay with consumers.

We then went on to plan how we could access the community.

November........

Debbie let the group know that the proposal had gone through the University Ethics Committee....we spent some time filling in the
'roster' for the interview week ... we then spent some time planning the week ... we agreed to collect some demographic information from the people being interviewed ... we finished off the meeting feeling pleased with ourselves and our productivity. We felt that all of our ground work was beginning to pay off.

I had felt that I was putting forward my suggestions for action and had been reluctant to do so. I wanted group ownership of the processes, I didn't want people to just do as I said. However, the September, October and November meetings alleviated some of my concerns as people said that all of the suggestions were well grounded in our group discussions. It was as if we needed that planning, clarifying and reflecting time to tease out the issues in order that we could act. I was left wondering though, if I dragged my feet too long, if I was too concerned with issues of power and collaboration.

At the end of November 1995 my supervisor and colleague died, unexpectedly, while playing squash. I notice a difference in my journal from this point on. I seem to just get on with it for a while. The entries are less and apart from one lengthy entry, not very reflective. My interim supervisor was pushed me towards/into more academic theorising. We talked of words such as epistemology, ontology. I was resentful, wanting to only be part of the action. I was angry that Chris died.

December ......

In December I began interviewing Community Health workers. Their story, The Staff's Story can be found in Chapter 7.

We then had a photo session and discussed the aims and purpose of our research project for the Gazette [local newspaper] ad. and article.....Dot told us of a pilot project in another health area that was trying 4 or 5 community management committees, although the feeling was that our area was not supportive of this. This led to discussion
about the fact that we were taking a more 'community development' approach to what we were trying to do rather than impose a 'good idea' from the department onto the community.

January 1995.......

Caught up on last minute planning for the interview week .... two people are coming from Springwood hospital to help with the interviews .....we discussed what we needed to know to be able to conduct the interviews and what additional paper work we might need ... we decided that we needed a step by step guide... we also agreed that if people had an axe to grind then we needed a strategy. We agreed that Debbie would compile a list of 'who to complain to about what' to give to people ... we agreed to meet at Debbie's house for lunch for our next meeting.

19 January

up at six this morning to 'assault' commuters - Joan and I did Springwood, Ruth and Lesley, Blaxland. We had approximately 300 flyers to hand out. Standing there in the pouring rain, a never ending stream of sour faced people scurrying onto the station.... Back to Joan's for breakfast... If this isn't a sign of commitment about this project, some sense of ownership and responsibility - I don't know what is!

In January we spent 1 week interviewing the 'community'. We shared the tasks of interviewing, setting up the venue, providing tea and coffee, tapes and tape recorders. It all came together flawlessly.

I was amazed at this point in time. It seemed as if all of our, sometimes tedious, groundwork was now 'paying off'. People had no hesitation in becoming involved and acting together. There was a sense of shared direction and we each contributed what we could in terms of time and resources. We had acknowledged and discussed difficult issues such as 'community', 'participation', 'health' and had reached no answer, in fact we
were grappling with the complexities inherent in each of these issues, we were in many ways less sure of our own positions. But, we held this tension and acted.

*February*********

*Spinning the participatory web*

*What do you want?*
*Who ... me?*
*world peace, honest politics, a celebration of diversity, an end to oppression*
*clean air*
*clean water*
*love.*

*What do you want?*
*Why does that sound like an accusation?*
*It assumes I don’t have what I want*
*It assumes that by answering I will get what I want......*
*How can I find my voice?*

*As a child I have no memory of being asked what I want. As a female child why should anyone ask? Who cares? What does it matter? As I have never been asked how can I now answer? - the question fills me with dread; I’m supposed to have thought about this one, to sound intelligent and not idealistic when I reply. Is this the root of participation. Is this why this is a feminist issue? We are not used to saying out loud what we want and if we do say it out loud we don’t expect to be listened to, to be taken seriously - we are used to having our worlds and our words defined by others.*

*In this way could what I am doing be revolutionary? Facilitating the saying out loud of health workers (predominantly women) of service users (predominantly women) and those concerned with the care of the community (predominantly women?)*

*Is this why it is so hard to implement, why the reality lags behind the rhetoric? That to make it work we are working with people not used to saying and not used to being listened too - certainly no confidence that what they say matters.*
A great lunch provided by everyone .... feedback on the interviews of the community ... feedback on the interviews with Community Health workers ... Planning for accessing service users... we discussed how we could access other health providers ... we talked about what we would do with the data we were collecting and who wanted to be involved in analysing it. We agreed that we wanted to do this as a group ..... we discussed if and how we would expand this project to other areas.

March......

In March Lucy, a Social Ecology undergraduate student, joined the group as a research assistant.

Dot brought a cake .. we welcomed Lucy to the group and talked about her possible role and needs with this project......we talked about the process of getting consumers to be involved ... Debbie has, to date, only had one reply. People felt that consumers were a bit snowed under with the number of forms they are required to fill in and often language is very difficult and exclusively often targeted at white middle class educated people ..Debbie let the group know of the annual Primary Health Care conference ... we all agreed that this was a wonderful opportunity for us to present a paper.

Sandra gave us some feedback from the district meeting. Sandra had given the meeting feedback on how the project was going, she had told them that people were saying that the bureaucracy was totally out of touch ... the reactions from the district executive were either defensive or the feeling that we needed to do something about this.

It seemed as though we were taking collective responsibility for our 'findings'. We were distributing information as we went along, when and where it felt appropriate.
Staff are all feeling really overloaded and disempowered at the moment ... we felt that the power brokers were really out of touch with reality and, more dangerously, beginning to believe their own propaganda.

April........

Lucy spoke of her plans to run focus groups ..... We then talked briefly about how to access GP's. ...discussed the increasing pressures for change that are happening in terms of community health ..... discussion of the fact that middle management is also feeling very disempowered and frustrated and are beginning to voice these feelings..

We talked about the validity of qualitative data and how we would ensure this. Also that our methodology would be criticised by people who do not like what we have found....we agreed that we would spend most of the next meeting pulling out and agreeing on themes.

May........

I met with 'interested staff' from the [Springwood] health centre. They came to my house after having read the Staff's story. Overall they felt it was true enough for all of them. One said 'I've just come to tell you it will make no difference.'

June........

By this stage I was beginning to get concerned about the information we were obtaining - much of it critical of the health hierarchy. I was not concerned for myself but I did want the women in the group to be aware of the potential risks they were taking in being a visible part of this project.

We began by talking about the staff's story........we did talk about the dangers of making information public, that we had no control over what people would do with the information we give them and there may be
a backlash from people higher up in the hierarchy. People still felt that we needed to make this information public. People made a commitment to read the first draft thoroughly and provide feedback, written comments. We felt that this was important as this part in particular [the community's story] is a collaborative effort of the group and we all needed to participate in the production of the final write up.

...discussion of young mothers 14-15 years old and the difficulties in providing a relevant and accessible service for these people.

Debbie handed out a sheet of 'reflective questions' for people to consider and write responses to.

July

We discussed what to do with the consumer transcripts ... we also talked about the fact that this was a difficult group of people to access; the community nurses had been over protective ... discussion of the difficulty of accessing people other than those in the 'middle classes' and whether in fact community participation is really 'middle class participation'.

...middle classes are usually the ones to start any revolution, they are the starting point to open the system up ... the working classes tends to be disempowered and the upper and middle classes stand to lose power, influence and wealth ... this is a Marxist perspective of society and human nature ... women were still left out of the equation.....

Talked about how we would present our final report... discussed the alienating use of jargon and felt that it was really part of a power game ... we talked about the fact that we believed that meetings were set up to help communication but often resulted in people playing these power games and that these often bring out the 'little girl' in us. When this happens there is the 'illusion of democracy'... we talked about how aware people in power are of their power and how hard you
have to work to equalise power differences and hierarchy's. One of the first steps in this process is to make the differences visible, apparent, so that we can all see them.

The history of Community Health is such that it moved away from a fairly flat structure to a more hierarchical system. People felt that it was now much bigger and with growing regionalisation there is lots of duplication of tasks and function. People felt that more got done under the flatter structure, now people are weighed down by paper work and we are into survival mode. Flexibility and risk taking has gone and that people are being pushed back into being task oriented. This, we felt was part of wanting to control people.

I have included most of the record of this meeting as I felt it was one meeting where we spent almost the whole time 'theorising'. What was exciting was that it was clear that we were jointly constructing meaning, knowledge, based on our individual and collective experiences. This collective construction continued over the next few meetings.

August........

We spent most of the meeting cutting up the consumers transcripts and organising them around themes .......at the end of the meeting we talked about the feelings we had that there was a lot of implied dissatisfaction from people/consumers that they had not felt able to talk about. We also spoke of the fact that many of the consumers stories were profoundly sad and moving and that nurses often do not acknowledge this in their day to day work. In effect they can become desensitised to the humanness of the people they are working with....there was no built in structural support to enable nurses to be different, to debrief, to be sad...we started to talk about ways we could change this in Community Health.
September

Lucy brought her data..... and passed it around for us to look at. This prompted the following discussion.......GP's dissatisfied with the intake system and general lack of feedback from allied health staff ..... the data also pinpointed stuff that we already know and hear ... we also agreed that we give staff copies of the finished section so that they can know what is being said and can choose to take action on it... we felt that on the whole there was nothing new emerging now....we then focused on the outcomes we felt had been achieved from undertaking this research. This we did individually and then on butchers paper

Outcomes

It may seem strange to have 'outcomes' three quarters of the way through this chapter. However, it is true to the chronology of events.

The questions given to the group at our meeting in June 1995 (see Appendix 1) asked people to reflect upon why they were in this group, what their hopes and dreams for the group were and, as the research component for my PhD had been completed (or, so I thought) if they saw any future role for the group.

My interest in asking these questions was threefold. Firstly, while the group had been wonderfully active in terms of tasks to complete the research, in reflecting upon our actions and making sense of the data, I had felt that we were not so good on reflecting upon ourselves, in challenging our assumptions and our sense of purpose. I hoped that this process may allow us the opportunity to critically analyse the research group and our roles within it. I was interested in asking people to reflect upon whether being part of this research project had changed their practice in any way. One of
the aims of action and collaborative research being that change in practice will happen for the people conducting the research.

The following has been taken directly from the butcher’s paper we wrote upon in our group meeting. I have organised people’s comments around themes.

In terms of the reasons why people joined this group the answers polarised from:

"because I was put on it"

"Was asked to do so"

to a search for knowledge, understanding and change:

"I wanted to know more .... It was also an opportunity to participate in something that the community health team valued and thereby gave me the opportunity to develop links with them"

"I joined because I feel that the community MUST become more involved in the decision making for health issues... I wanted something challenging and positive to do ....... I hoped other staff would learn more about community participation and primary health care and become committed to working towards it..."

"To get a deep understanding of community health and different opinions by other group members."

Two people were also explicit in that they saw part of their reasoning to support me:
"I was quite prepared to help Debbie with her PhD project as I felt we'd all benefit from the knowledge gained."

"that it would be of help to Debbie"

People also wrote/spoke about the difficulties and successes in the group. The difficulties included peoples reflections on their contributions and feelings of worth in the group:

" I think a difficulty of mine has been not feeling as though I was treated as important or someone with valuable input."

" At first not knowing what I had to contribute and exactly where the project was heading"

talking of the struggle we went through at the beginning, working out a sense of direction, what we wanted to do and why:

" Was difficult at the beginning, seemed to take ages before we did anything, thought it was all going to collapse."

Two people felt that the research had not been as collaborative as they had hoped due to "competing interests" and

" I have been unable to contribute as much as I wanted to ... I guess if I'm really honest I have been disappointed at times, when we all needed to 'pitch in' and get some of the tedious and 'hard work' done and the 'sharing' hasn't happened and you [Debbie] have been left with more of the slog work than I think was reasonable for a joint project."

As to what people felt were successes or successful times for us:

" When we have all opened up, pitched in and got on with the decision making and tasks at hand ... when we have supported, listened and
nurtured each other, the way we have clung to what we believe is important; the joy and excitement following the interviews and the sharing of results; discussions of their significance and the getting of 'real information'.

"feel there have been times when we have achieved surprising levels of honesty and commitment"

"exciting once we got the interviews done ... could see the implications of what we were saying"

"Bonding of the group"

People were quite clear as to their reasons for still participating which, combined, talked of both the group process and expected outcomes:

"Because I want to see the results and feel a tie now to the group"

"I feel that there is still a lot to be learned and that as a group we still have more that each one of us can give to each other"

"Because I'm committed to seeing a community advisory committee body"

"As I believe its outcomes will be phenomenal for us, the community and Deb."

In terms of their input it ranged from "being part of a team" to people saying that they were not always as able to be involved as they would have liked "fairly minimal, would like to have done more than I did" to feeling that they were "a pain in the arse a lot of the time due to lateral thinking".

I am always interested in the 'so what' question, whether all the thinking, understanding and knowing in any way translates into changed practice. It would seem from people's responses that being a part of this research
group not only affected their practices but the practices of those around them:

"The research has affirmed my ideas about primary health care. It has also shown some staff members the benefits of doing community development including people in activities which can help improve their communities ... these staff weren't interested in community development before this project. It has also spurred us into more PHC 'projects'"

"I am questioning and challenging myself and the ways I and others do things and often find myself reflecting on things I am doing or have done .......It has also enriched my interactions that I have with other staff ... and I feel more confident in discussing and encouraging community participation activities."

"changed the management system, less hierarchical, people less threatened about opening up about things, it has affected the way we work"

"have started setting up a community advisory committee"

Everyone wanted the group to continue working together, to implement the suggestions and ideas that had grown out of the project and to continue supporting each other:

"that they could be used as resources in the rest of the area to carry out or rather support other staff in similar programs that the work will be published in as many areas as possible and would encourage others to have a go."

"That findings will be published and a revolution will follow"

"I wouldn't mind continuing this group even if we met 3rd monthly as a way of looking at ideas for keeping PHC a focus in our work."

---

PHC: Primary Health Care
"Want the group to keep going - PhD is a beginning not an end, we will
have to implement things, keep influencing changes in community
health - not let us become complacent."

All of these answers and discussions could have been pursued in more
depth but I chose, with the group's consent, to focus on the changes that
they felt had happened for themselves, others and the service. To this end
at the meeting in September 1995 we brainstormed on butcher's paper
what we felt the outcomes had been. This was then typed up and circulated
to the group with the question "do you feel that this accurately captures
what we said". We agreed that it did. As there were five typed pages I have
condensed and organised what was said. The outcomes are listed in figure
2.
Figure 2: Group identified outcomes of research project (September 1995)

Changes in own practice
• more conscious of empowering clients
• helped to focus on issues and to look at things constructively
• more going to the community
• a less arrogant, angry position
• now realise that community participation (CP) is hard due to dis-empowerment
• know that it’s an ongoing process, will take a lot of little steps to get people involved. This is a tiny little step
• people are so dis-empowered but now we try
• increase in knowledge of CP has given me strength to talk about it in executive meetings
• I am now working with the General Manager on the new business plan, taking a CP point of view

Changes in Community Health staff practice
• staff make comments that they can see changes happening
• two staff, normally quite reticent, are working with the community doing a needs analysis
• staff are getting more interested, they can see people looking at their dilemmas
• staff are motivated to initiate or lobby for change

Changes in the ‘system’
• established an advocacy system for marginalised groups leading to 11 advocates being given power to problem solve and make health more accessible for these groups. Management has committed to release people to do this. Four are currently in place
• it has introduced a theory base to change our way of operating/thinking leading to more empowerment for staff and changes in the management system. The system is now more open with more staff participation, ownership and increased interest
• CP has become a framework for practice in the centres
• now have stronger links with G.P’s and other community agencies

Changes outside of Community Health
• workshops [run by two people from the inquiry group] on CP at the major hospital in the area led to: people in Stores involving everyone in the purchasing procedure; triage and casualty nurses compiling a paper suggesting how bed allocation could be improved; discharge planning is moving towards a more cooperative process
• the smaller hospital in the area is now looking at more consumer involvement and working with community groups to focus on health promotion
• this is a social action movement, it will grow. We are acting as a catalyst. Community groups are asking about it. Gathering momentum from the grass roots and it will keep going.
• There is more honesty at Interagency meetings leading to other organisations collaborating with and advocating for Community Health in addition to joint problem solving around Department of Community Services funding cuts.

I was quite astonished by the information generated at this meeting. My focus had been quite narrow - the research project, my PhD - I had not really asked, or seen, how the research was changing people’s practice and their conception of themselves. While I knew that this was an inevitable
outcome of the methods we were using, I had neglected to provide the space for these issues to come into the limelight.

This highlighted the need to build in careful, considered and structured time for reflection. If 'reflecting' is not part of people's everyday work practices, we need specific procedures to enable this to happen.

**October........**

We discussed the list of outcomes generated at the last group meeting. Debbie asked the group to reflect on the process that had enabled us to achieve these outcomes the following comments were made:

- the process was slow and allowed for lots of different stages and enabled us to get our heads to a certain stage
- allowed us to incorporate a lot of information and know what we were doing
- it was a growth process - changed our thinking, enabled assimilation of other research, time to think and put our ideas together
- group became committed, as a group
- allowed us to be far more critical of others ideas and this was informed by our increased knowledge base

We then reflected on how our practice had changed

- more knowledge and more power to speak
- legitimised our practice in terms of PHC and given power to fly in the face of the push from hospitals
- become a lot more involved in decision making
- feel calmer, more empowered as a result of doing something useful and credible
Debbie distributed copies of the 'service users story' people..... felt that it was internally consistent and that the conclusions fitted with the themes.

November .........

In November Joan and I presented a paper at the sixth annual International Conference on Primary Health Care (Debbie Horsfall and Joan McKay 1995). This was an exciting moment for us, our first opportunity to go public and a good example of University and Industry collaboration.

By the end of 1995, the Inquiry Group had presented a paper and completed the Report, *From Rhetoric to Practice* (Debbie Horsfall et al. 1996). We had a concrete 'product' to grasp in our hands, a product which captured what we had done, a product which had been created by all of us. This 'product' is re-presented fully in the following chapter. As it is now a public document, having been distributed in 1996, this Research Report is included with both the same content and form as the one which was distributed. I have made no changes except page numbering, as I felt it important to maintain the integrity of our actions, our findings and our collaborative effort. The Inquiry Group's story continues after the Report.
CHAPTER 7
THE RESEARCH REPORT
FROM RHETORIC TO PRACTICE: THE SEARCH FOR PARTNERSHIPS.

Report of the inquiry into enabling promoting and enhancing community participation in service planning delivery and evaluation in community health in the Blue Mountains.

February 1996

Debbie Horsfall, Pam Hansen, Lesley Laslett, Sandra Longmore, Joan McKay, Sue Tansley, Dot Ward, Ruth Willic and Lucy Armstrong
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Acknowledgements.

A research project of this scope and depth could not have been achieved without the time, energy and commitment of many people. To all of the people that have shared their expertise, their experiences, their fears, hopes and dreams, we are extremely grateful.

We would like to thank in particular the staff of Springwood community health centre whose co-operation, interest and involvement in this research has been central.

We are indebted to those people of the lower mountains community who gave us their time, thoughts and feelings about health in general, community health in particular and their visions for how things could be better.

The people who use the services provided by community health in the lower mountains took the risk to tell us how they experience the service and shared with us what they valued and would like to see being done differently. We thank you for your courage and your insights.

In particular we would like to thank Lucy Armstrong who acted as a research assistant and was central to the conducting of focus groups and interviews with service providers in the lower mountains. We appreciated her time, energy and fresh approach to the research.

Jaki Nindle Taylor, who acted as the academic supervisor to this project in 1994 and ensured that our actions were grounded in theory as well as providing support and inspiration.

Andrew Horsfall for proof reading and editorial comments.

Finally two people who were integral to the commencing stages of this research and who died before its completion. Maya Lakshmi- Narayana and Chris Weineke: two women with passion and vision who struggled to make this world more just and humane. We are thankful that we knew them and hope that in some small way we have succeeded in carrying on part of their life’s work.
SECTION 1
PREAMBLE

For eighteen months we had been meeting together, as an action research group, exploring the issue of community/public participation in health. While our concern was, at times, a philosophical one grounded in our commitment to democratic and participatory decision making our aim had been to act, to discover, to hear and thereby improve our professional practice. We, the group, included personnel from the Blue Mountains District Community Health Service, including management and workers; a colleague from the Hawkesbury Community Health Service and a lecturer from the University of Western Sydney - School of Social Ecology (see appendix one for complete list of group members).

Towards the end of 1994 we decided that we had reached a major action phase of our project. We had discussed various types of researching, various ways of talking with people and read extensively in the areas of community development, health promotion and primary health care. We had deconstructed the ideas of community, the meaning of participation and were ready to start constructing, building links with people in the local area. So, after getting University of Western Sydney Ethics approval for our research, we began.

This is the story of what we did, how we did it and what we heard when we entered into a dialogue with the people among whom we live, work and play. It is truly a collaboratively created and inspired story. For us it records our collective leap of faith from planning, reflecting and talking - into action.
EXECUTIVE SUMMARY

Introduction.

The research project, which this report details, aimed to 'promote, enable and enhance community participation in community health planning, service delivery and evaluation'. It was based on the premise that community participation is desirable and achievable, a premise supported by key Primary Health Care Documents and Wentworth Area Health Service strategic plans and targets.

Our objectives were as follows:

- to find out what was happening in terms of community participation in community health centres
- to gauge the level of support and understanding of community participation from a variety of stakeholders
- to identify perceived barriers to participation
- to identify collective strategies for enhancing community participation
- to develop our knowledge and skills in the area of community participation
- to use a research methodology that was participative in itself

The research working party spoke with over 100 people via in depth interviews and focus groups with people from the lower mountains
community health service, community members, service users, community service providers and general practitioners.

This report captures a moment in the life of this research. The story and the process will continue as we begin to implement and work with what we have found.

**Overall findings.**

In terms of the 'big picture' what we found was at once affirming and depressing. We found that people were interested, willing and able to be part of decision making in health. The level of knowledge and commitment of people was at times quite inspirational. Our task now, is to harness this commitment and knowledge, to enable people to participate meaningfully in the long term.

What was depressing in its intensity were the major 'negative 'themes that emerged during the process of this research. Across all groups of people to whom we spoke the following key themes emerged:

- overall feelings of powerlessness in terms of their relationship with the health system at all levels;

- the perceived medical dominance of the health agenda and health services;

- community anger at its preclusion from decision making; and

- a feeling that there was a conspiracy by faceless people to maintain the status quo.
Findings linked to stated objectives

- To find out what was already happening in terms of community participation in community health centres.

Both the staff and service users interviewed identified that community participation was already happening on a day to day level. Both groups of people affirmed that service users were involved and participated in the type and nature of their care. Plans for interventions were often mutually designed and implemented.

However, in terms of evaluation little structured feedback was asked for from service users.

Furthermore it seemed as if service users were still cast in the role of passive service recipients overall.

- to gauge the level of support and understanding of community participation from a variety of stakeholders

Overwhelmingly the people who we spoke to supported the idea of community participation. This support was in terms of partnerships with health providers and the health bureaucracy. Many people also spoke of the need for active participation not consultation, which was often seen in terms of 'lip service'.

- to identify perceived barriers to participation

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1 A more detailed discussion of findings can be found in section 3
There were many barriers to participation identified by all people we spoke to. The largest barrier was seen to be the centralised and bureaucratic structure of the health system where people making decisions were seen as out of touch with the real needs and wishes of those they are paid to serve. This is compounded by the fact that health service staff are asked to work in partnership with their consumers and yet these same staff feel disempowered and voiceless in the system itself.

Furthermore there was the belief that the main focus of the service providers is still encouraged to be one of a curative service rather than in terms of health promotion and disease prevention.

Access to knowledge and information about community health itself and the decision making process in general was also seen to be a barrier with many people having limited knowledge of either.

Vested interests of those seen as being in powerful decision making positions and an accompanying lack of commitment to the practice of community participation were additional barriers. This could be seen by the lack of structural support for service staff to undertake more participatory practices and the perceived medial dominance of health care provision.

Staff, service users and other service providers commented strongly on the fact that community health staff appear to be both stressed and stretched. This was seen as a barrier to effective communication and implementation of community participation strategies.

- To identify collective strategies for enhancing community participation.

People identified a need for more ongoing information about current services; structures such as advisory committees, public meetings and
workshops so that they could be active in an ongoing manner. More participatory management structures and decision making within the health services; a bottom up rather than a top down approach to decision making and more resources provided in order to implement these strategies.

- To develop our knowledge and skills in the area of community participation

What we found here confirmed, to a large extent, what we already knew from our practice and our readings. There are no easy solutions, no quick fixes and no one strategy for community participation. People are sceptical and wary of being involved until a relationship is established. This takes time and commitment.

We did find that both interviews and focus groups were effective methods for beginning the dialogue, for letting people have a say. We also found that being part of a support group ourselves was necessary as it enabled us to experiment with ideas and to collectively develop innovative and creative strategies.

People who had no obvious link to the service, or who were employees of other community services were the most vocal while service users proved to be the most difficult to access and the most careful in what they had to say.

Overall, people spoke of a desire to be more involved but not at the exclusion of others. Interestingly we found a great tolerance and acceptance of the need for different views and opinions to be included.

- To use a research methodology that was participative in itself.
By asking people what they thought and taking seriously their thoughts and suggestions we undertook a process of participatory research. Our challenge now is to establish structures and systems that will enable a variety of peoples voices to be part of the decision making processes in community health.

**Recommendations.**

1. That community health centre staff be supported by both area and district level decision makers to implement participatory practices in their work and that recognition be given to the complexity and hard work required.

Strategies:

- emphasising promotion and prevention outcome measures
- providing in service training on these issues
- enabling staff time release from their case load duties to focus on health promotion and disease prevention
- to include staff in the decision making processes at the district and area level
- to ensure that funding is proportionally directed to these activities and not focused primarily on medical and curative programs

2. To establish advisory committees comprised of service users, community members, community service representatives and health department staff (this process has begun) and for this initiative to be supported by senior management. Tokenism should be actively worked against and non department membership must have the same level of influence as department membership. These advisory committees should work towards
the sharing of power and influence in terms of decision making in community health.

3. To make information and knowledge about community health available to the general public. To do this in an accessible and non-alienating manner that invites conversations and dialogue between various stakeholders.

Strategies:

- use of local media to publicise upcoming events, 'special features' on services provided
- strengthen links with other community organisations in the area
- holding of public meetings and forums to discuss issues, needs and concerns
- targeting of specific 'marginalised' groups of people to seek their input in discussion of issues in the area.

4. To establish and implement a system of ongoing feedback and evaluation from service users. This system to be designed in partnership with service users themselves. The focus of this should be the relationship between the consumer and the service; the quality of care, feelings of empowerment and control on the part of the service users.

5. For Wentworth Area Health to facilitate participatory management practices where the staff are an integral part of the decision making process. For senior management to model participatory practice and thereby enable staff to feel valued, worthwhile and trusted human beings.

6. To recognise the bureaucratic nature of the health system and either work to redress the difficulties for participation to occur within this type of
system or accept the status quo and cease demanding from the community, 
service users and staff strategies which the system itself cannot support.

7. That the research group continue to meet and work with the findings of 
the research project.
OVERVIEW OF RESEARCH PROJECT

Methodology.

The methodology for this project is grounded in poststructuralism, in particular the work of French philosopher Michel Foucault (1972-1977) and critical theory, predominantly feminist theory and practice (Liz Stanley & Sue Wise 1990; Shulamit Reinharz 1992; Deborah Lupton 1993). What both frameworks have in common is the valuing of local and particular knowledge.

We were also concerned with making visible, bringing further into the debate, the current discourses in health, particularly the competing discourses of the biomedical model and primary health care. Many of our findings and conclusions, based on the local knowledge’s of health workers, service users, the public and community service workers, illuminate the tensions inherent in the relationship between these two discourses.

Method.

When we began to work together we described what we were doing as participatory action research (Robin McTaggart 1991). This description has served us well, and continues to serve us well. It enabled us to have a clear shared understanding that what we were doing would require action as well as reading, theorising and reflecting. This type of research can be participatory, collaborative, democratic, consensual and emancipatory, the only way to go if researching participation!
We were also informed by grounded theory (Anselm Strauss & Juliet Corbin 1990). Our understandings and knowledge of the situation in hand were grounded in the data we collected through our extensive in-depth interviewing and focus group process.

**Our process - how we did this:**

We decided to undertake the research project in four phases. The first three phases used in-depth semi structured interviews, our aim being to enter into a process of dialogue with people and to really hear what they had to say (see appendix 2 for focus questions).

Phase 1: The staff’s story. We interviewed both nursing and allied health staff from Springwood Community Health centre to find out what they knew and felt about community participation and to acknowledge what they were already doing in this area in addition to understanding what their issues of concern were - what got in the way of community participation.

Phase 2: The community’s story. The ‘public at large’ were interviewed during one very intensive week in January. Here we wanted to know what they already knew about Community Health services and what their thoughts and feelings about participation were.

Phase 3: The service users story: We were interested in to what extent service users were already participating in the service, what their experiences of the service were and their feelings about community participation.

Phase 4: The story of other service providers. To tell this story we used focus groups and interviews. Again we wanted to know what people knew,
thought and felt about community health, what they thought the issues of service provision were and their knowledge of and support for participative structures.

**What we heard:**

Themes were taken from the stories of people who chose to find their voice and make public their experiences of and in Community Health. Individually and collectively the stories told of both commitment and concern; of struggle against bureaucracy; of being silent when they wanted to speak out.

They were stories filled with love, concern, compassion and partnerships. They also told of oppression and discrimination; of conflicting demands and expectations and of feeling stressed, powerless, helpless and frustrated. They were complex, powerful stories - ones we needed to hear (see table 1 for summary of themes).

As can be seen from table 1, there were a number of themes which said the same thing. For us this was sometimes surprising as the only thing all groups had in common was us and our questions. On the other hand, these commonalties provide us with some clear directions for action. For example it is clear that all people to whom we spoke, except staff, had limited knowledge of Community Health. We need to develop strategies to overcome this. In terms of primary health care and equal access to services this issue is of paramount importance.

In terms of community participation we are left asking the question - how can people participate in a meaningful way with limited knowledge and
information. We are also left asking 'whose interest does it serve to keep people uninformed and powerless?'

There was a very high level of support for participative decision making in Community Health and a high level of awareness of the complexities, difficulties and barriers to achieving this. The barriers cluster around issues of bureaucracy, sharing of power, real commitment by the decision makers, facilitating the involvement of marginalised groups and resourcing community health such that they can put these ideas into practice.

Overall, this was a story of 'community participation in action' as we asked people what they thought and felt and we listened with open hearts and minds to their answers. Some of what we heard was confronting to us in our professional roles; some was insightful, creative and confirming. Overall, what we heard confirmed that 'the people' are interested in and committed to the idea of participation in health.

People were well aware of the complexities and difficulties inherent in facilitating community participation, although there was a belief in the 'rightness' of this approach. Furthermore, people who had no identified involvement with community health at this time were only too aware of the power inequities in the health system and the inherently political nature of health.

If knowledge is power, then it is clear that the people to whom we spoke are powerless in terms of health. They knew relatively little about community health and next to nothing about the ways in which the decision making process in the health system actually works.

Furthermore, many people stated that they felt that they could not be involved personally as they 'know nothing' and they even discounted their life
experiences ‘that doesn’t seem to count for much’. We have, it would seem, been very effective in encouraging people to believe that they have no place in the decision making process as they have no knowledge that counts!

"Participation .... is a revered idea that is virtually applauded by everyone. The applause is reduced to polite handclaps however, when this principle is advocated by the have-not’s .... And when the have-nots define participation as a redistribution of power" (Sherry Arnstein 1971 in John McDonald 1993:96).

The people to whom we spoke complained of lip service being paid to public input. It would seem that they had in the past been consulted but had not participated in the decision making or problem solving process.

We are aiming for Partnership in Decision Making. While this is still a long way from total citizen control of the decision making process we believe that partnerships are achievable for both the community and the system itself.

If we are concerned with the art of gentle revolution which takes place within a climate of care and concern, then building, valuing and strengthening partnerships between health service providers, consumers and the people is an appropriate strategy. Any action in these terms is, indeed gently revolutionary. We do not believe that this community - or any other - deserves polite handclaps: we aim for thunderous applause!
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<tr>
<th>STORIES</th>
<th>Staff (n=7)</th>
<th>Community (n=40)</th>
<th>Service users (n=22)</th>
<th>'other' service providers (n=50)</th>
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<td><strong>The daily struggle of each person with their multiple and challenging roles:</strong></td>
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<td>* high level of stress</td>
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<td>* conflicting and diverse role expectations</td>
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<td>* medical practitioners useful to a point</td>
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<td>* partnerships - participative decision making at a local and day to day level</td>
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<td>* consultative not participative decision making by management</td>
<td>* hospitals - temples of death</td>
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<td>* being the 'pits of the system'.</td>
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<td>* too busy to listen</td>
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SECTION 3
GENERAL INTRODUCTION

Note on the text:

The following stories have been written to both stand alone and be part of a whole. They have been written to stand alone as, on most occasions, we gave a copy of the particular story to the participants.

In terms of the language used, for the staffs story and the service users story the interviews were conducted by the principle researcher and member of the research group, Debbie Horsfall. These two stories were written by Debbie with revisions, suggestions and comments from the research group taken into account after the first draft stage. As such they contain "I" which refers to Debbie.

For the community's story interviews were conducted, data analysed, themes decided upon and conclusions drawn by the whole research group. As such "we" is used throughout this story and it refers to all the members of the research group.

The 'other' service providers story also contains 'we'. Here it refers to Debbie Horsfall and Lucy Armstrong, research assistant. Interviews and focus groups were conducted by both these people. Data analysis and discussion of themes was also a collaborative process. Upon completion of the first draft input and inspiration was sought from the research group as a whole.

Most of the text in these stories includes the actual words of people to whom we spoke. This is a powerful convention as it clearly lets people
speak for themselves and the reader is able to feel the passion of the people concerned. It can also prove to be difficult at times. We are so used to reading sanitised and carefully constructed descriptions of events where often the person is written out of the story. Real words, and relationships, as they happen are often messy and uncoordinated while at the same time being powerful in their honesty and emotion. By using peoples actual words and not our reconstruction of their words then the 'data' remains true to the time, people and events (Margaret Somerville et.al. 1994).

Overview of methods used in interviews and focus groups.

Participants were usually given the choice to either be asked the questions or, to keep the questions in front of them and run the interview themselves. Most participants chose to keep the questions themselves and so keep more control of the process. This worked well for us as we could attend more closely to what they were saying and it provided more opportunity to interact without having to worry about when we were going to ask the next question. This facilitated a more conversational style interview which enhanced the open and honest exchange of thoughts and experiences. This approach can leave the research open to criticisms of bias and of being 'not credible', by some. However, we believe that by not also being frank and open with the subjects of the research we fall into the trap of objectifying and doing research 'on' rather than 'with' people. If the aim is for a mutual sharing and construction of knowledge then this can only be achieved if we allow ourselves to be part of the process too, to be questioned by the participants and not to maintain control and power by withholding, by keeping people guessing about where we were coming from. Conducting
interviews in a 'proper' and 'unbiased' manner conforms to the "values of objectivity, detachment, hierarchy and 'science'" (Ann Oakley 1981:38).

- **What we did with the stories - how the data was analysed.**

After the taped interviews/focus group each tape was transcribed. Themes and connections from the transcripts were pulled together following the strategy detailed in Anselm Strauss and Juliet Corbin (1990) for categorising and analysing qualitative data. Both open and axial coding were used. That is, the stories were broken down, examined, conceptualised and categorised. Broad themes were noted, analysed and checked against the participants words. A theme was identified based on the importance given to it during the interviews. This was reflected by the number of times each person spoke about it, the intensity of their feelings when talking and the length of time taken in talking about this theme.

The themes were then broken down into sub-themes and the data was cross checked to make sure that it belonged in the theme category in which it had been placed. The stories were then put together in new ways and conclusions/theories to explain the data were developed. These can be found at the end of each story.

This all sounds quite straightforward, the reality was that the themes and categories were not separate or exclusive, they all connected and interrelated. It was like a web of ideas, knowledge and feelings. The decision about where bits of 'data' went was made in terms of a 'best fit' and by asking what is really going on here? What is the strongest connection? Many of the themes overlapped and complemented each other while at the same time each had an integrity of its own and we have discussed them separately.
Validity

The staffs' story:

As the research group comprised people employed by the health system, including people in management roles, it was important that staffs' identity was protected from the group itself in order that no conflict of interest should arise and so that staff felt safe in talking freely. As such, interviews, data analysis and the writing of the story was undertaken by the principle researcher Debbie. The research group were given copies of the story once it was complete and when staff were confident that there was no identifying information in the story.

To enhance validity and remove interviewer bias, the staff themselves acted as co-constructors of the story. Once the themes had been identified and the individual stories constructed as a collective story, the people who had been interviewed were sent draft copies. We organised a lunch where we could talk about reactions to the material, the themes, how I had grouped and analysed their stories in addition to what they now wanted to do with the information.

Staff felt that the themes did represent what had been said during the interviews and felt that the collective story was both factual and powerful. They were also surprised that the themes were so consistent among the group and felt validated in their own thoughts and feelings. They felt stronger knowing that they were not alone.

The community's story:

As the participants in this stage had no links with community health services, the research group shared the task of interviewing members of the
community. This section of the research was the most collaborative. Following the interviews and reading of the transcripts a process of checking, discussing and rechecking among the research group took place. In this way we co-laboured with the transcripts and the themes until we were happy with the result and confident that the written documentation reflected both the process and the findings of the interviews.

As all members of the research group had been part of the interviews this ensured the validity of our documentation and enabled a richer and more creative discussion of events to coalesce.

Service users' story:

To protect the confidentiality and interests of the service users we again decided that they should be interviewed by the principle researcher who had no connection to the health service. To reduce potential bias and projection of the person doing the analysis, the initial part of the process of analysis was done by the Inquiry Group. Each member of the group had copies of the transcripts and were asked to read them, question or add to the themes already suggested by me and them to put segments of the transcripts in bags representing the theme. This then became the basis of the service users story.

The draft 'story' was further checked for reliability by the Inquiry Group and copies were sent to all participants asking for feedback, comments or ideas. In this way, although Debbie conducted the interviews and did the writing up, we co-laboured together checking, validating and questioning the analysis and interpretations of the transcripts.

Other service providers:

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The focus groups and interviews were conducted by Debbie and Lucy (research assistant). In order to minimise potential interviewer bias the data was discussed and analysed by both of us. Once we had written a draft document this was then given to the research group to read and check. We asked if our conclusions and discussion were grounded in the words of the people to whom we spoke.

The stories are presented here in the order in which the data was collected.
THE STAFFS' STORY
"You know", she said, "sometimes it feels like this. There I am standing by the shore of a swiftly flowing river and I hear the cry of a drowning person. So I jump into the river, put my arms around them, pull them to shore and apply artificial respiration. Just when they begin to breathe, there is another cry for help. So I jump into the river, reach them, pull them to shore, apply artificial respiration, and then just as they begin to breathe, another cry for help. So back in the river again, reaching, pulling, applying, breathing and then another yell. Again and again, without end goes the sequence. You know I am so busy jumping in, pulling them to shore, applying artificial respiration, that I have no time to see who the hell is upstream pushing them in."* (J.K. Zola 1970 in G. Jacob (ed) Patients, Physicians and Illness 1979).

* Male specific references have been changed.
Introduction.

This is the story of seven people from a Blue Mountains Community Health centre, who chose to find their voice and make public their experiences of work. What they loved, what made them angry and what they felt were the major issues for them, and community health in general. Individually and collectively their story tells of both commitment and concern; of struggle against bureaucracy; of being silent when they wanted to speak out. It tells of relationships with their consumers, with each other and with the system that employs them.

It is a story filled with love of their role, concern, compassion and partnerships with their consumers. It is also a story of oppression and discrimination; of conflicting demands and expectations and of feeling stressed, powerless, helpless and frustrated. It is a complex, powerful story - one we need to hear.

The story told here is a weaving together of the individual stories of staff and my words, a drawing together of themes, issues and concerns. What holds together the cloth, that we have woven, is the process, how these stories came to be told in the way that they have.

- How the stories were told - the process.

This part of the story began when I attended a staff meeting at Springwood Community Health Centre and invited staff to chose to make their voices heard as part of a larger research project. It seemed to me, if we were to look at, and understand an issue holistically, in this case the issue of community participation in health, then all people involved needed to have a voice.
What I asked for was approximately one hour of peoples time when we could talk together in a semi structured way, in a tape recorded interview. I also spoke about the issues of anonymity and ways people could feel secure in talking; that all steps would be taken to maintain the confidentiality of their words.

Five community nurses and two allied health staff chose to be involved. This included six women and one man, covering a variety of ages and years of experience in community health.

Staff were provided with copies of the focus questions prior to the interview. I did not want to spring anything on people and have the upper hand, and I wished to provide people with the opportunity to reflect upon the issues prior to the interview.

All of the interviews occurred during working hours at the staff members place of work, usually in their own offices which were away from the health centre. Where people chose to be interviewed at the health centre we discussed the fact that this could 'blow their cover' as people would know why I was there. Three people felt comfortable with this and still chose to be interviewed at the health centre. Having the interviews at the staff persons' place of work was important as it helped to ensure that the person was in a place in which they felt comfortable and helped to minimise any potential power differential between us. It was also important to talk with people during work time - in 'the thick of it'.

- **What I heard.**

The one hour interviews provided a rich and detailed picture of Community Health, from the workers perspective. Without exception I found myself drawn into their daily work and I left the interviews with feelings of great
admiration and warmth for the staff. I was moved by their strong feelings about the work which they do, the difficulties which they faced and their unswerving commitment to the community whom they served. I felt appreciation for the openness and honesty with which they talked, and their willingness to discuss and reflect upon issues which were at times difficult and confronting.

Whilst the focus of this inquiry was the issue of community participation, the open nature of the interviews allowed us to explore common issues of interest and concern and often I found myself contemplating issues that I was not aware of. On each occasion I was exhausted as I listened to the day to day experiences of these people, and wondered how they found the strength of character to keep going. The demands, both physical and emotional, of the work that they do deserves recognition and support. Unfortunately, as these accounts will demonstrate this is sadly lacking. As with a lot of 'women's work', in terms of caring and nurturing of others, the high level of care, commitment, and emotional strain experienced by these people, daily, was all too often invisible and unacknowledged.

Themes.

1. The daily struggle of each person with their multiple and challenging role:

* love of and commitment to the work;
* the high level of distress of the job;
  lack of basic resources;
  conflicting and diverse role expectations;
  unhelpful levels of accountability from the hierarchy;
  lack of understanding of the role of the community health worker from management, other services and consumers;
  team and relationship issues:
2. Powerfulness and powerlessness of community health staff:
* staff are powerful people at a local and day to day level;
* partnerships - participative decision making between staff and consumers;
* hopelessness and powerlessness in decision making;
  consultative but not participative decision making by management;
  being at the 'bottom of the ladder' in the health system.

3. Mixed understandings, feelings and practices of community participation:
* A range of understandings about community participation;
* belief that community participation is desirable;
  mixed feelings;
* It is already happening on a day to day level;
  room for improvement;
* there are a lot of barriers to overcome;
  peoples fear of alienation and loss of service if they speak up;
  the need to be inclusive, to hear the voices we don’t usually hear;
  people are not yet able to participate;
  fear of people pushing their own agendas;
  fear of conflicts of interest.

Theme: The daily struggle of each person with their multiple and challenging role.

Of the seven people who chose to be part of this research there were five community nurses and two allied health staff. Allied health staff include social workers, counsellors, speech pathologists, occupational and physical therapists and psychologists.

The first question asked the person to talk about their job, what they do on a day to day basis, and how long they had been in the role:
"What do I do on a day to day basis? Everything and anything! Every day is quite different."

"I do community development - not enough of it - and I see individual people and families."

"I've been around community health I suppose for 20 years."

"I've been working here for the last four years, previously I was in a hospital."

"I'm a generalist nurse and I've been involved for ten years now."

After briefly stating what they did on a day to day basis and the length of time that they had been in their current position, people went on to talk about their role in more detail. This was not a direct question asked of them but rather an extension of their own initial statements about their role.

"My role is across quite a few areas, it's quite a diverse role: early childhood, home nursing....immunisation clinic....family education....school screening, I would like to be involved in health promotion but rarely am and I've never been involved in any great extent with community development."

"What I am now is the meat in the sandwich, I have clinical work on this side and community development on the other."

"When you get a geographical area, that is your responsibility and you really make the decisions in working with your clientele, you can become really involved. You can decide to become involved in all sorts of groups or you can decide not to get involved in that at all and just do the basics."
When discussing their role in detail there was a strong feeling by most of the participants that there had been a number of changes in community health over the past ten years. On the whole, the changes were seen as positive and are best summed up by the following words:

"I mean like the way servicing has changed, hospitals have changed, services have changed, less money is available more services are needed, so everything has changed and the role needs to change as well. The career structure of nurses has changed, there wasn’t a career structure for a long time and there is now."

"I couldn’t believe the difference and the versatility of the role. I thought it was wonderful - the changes and the difference - and so I decided that this was what I wanted to do and I actually made up my mind to make it a career path that there was some way that I would like to be involved in community health and not ever look at going back into an institution again."

Whilst talking of their role, and their daily work, it became clear that people were committed to the work that they did, saw it as important and of value to the community.

"And it has been a wonderful ten years as far as I am concerned. I really do love my job."

"We have a very small turnover of staff here, we have a strong history I suppose because people want to do this job and they want to do it in this area, it’s a very popular area, it’s a nice area to work in, we have fairly well adjusted consumers out there and they are a joy to work with."

"I would rather be doing this than something else."
Despite these clear feelings of worth of the role and the love of their job there was also a high level of stress identified by each of the participants. The question of stress was not asked by me during the interview, rather these thoughts and feelings were volunteered by the participants as they continued to talk about their roles.

People spoke of their stress in terms of it stopping them providing the quality of service that they expected themselves to provide, it got in the way, and as such led to more stress and feelings of inadequacy and guilt. There was a sense of people rushing all the time with no space in their days for debriefing or taking time out, for nurturing themselves and each other.

"The reality is that grass roots level, they’re stressed, over the top, over the top stressed."

"I think that we have a very different level of stress because it is so intimate, we know every personal detail, the darkest corners of somebody, the greatest pains and traumas."

"Productivity, there’s a good one! with what? Just by increasing stress levels!"

"My main stress in the last few years would have been this feeling that the expectations of me every year are getting more and more and I am feeling less and less able to fulfil these, because of time and personal resources."

"You go into this house and you’ve got all this stuff going on with support for this family that is going through this really, really dreadful time and then five or ten minutes later you have got a clinic and you have got to see mothers and children."
People identified a number of factors which they felt were causing their stress, or adding to it. One of these was the lack of resources experienced in this Community Health Centre. The lack of resources applied to the number of staff available, access to vehicles, funding to support activities expected of them in their role and the poor office conditions that some experienced. This, in itself, was not surprising, we commonly hear the cry 'we need more resources' what is of concern though is that it would seemed that basic resources needed by people in order to do the jobs they had been employed to do were either scarce or missing.

"But because we have such a lack of resources, there is no pool car here, I can't do any home visits. If I have to go to a meeting I have to beg a car from somewhere."

"Like this room, I can only get in here four days a week."

"We have no access to child-care through community health. I cannot get funding to have kids minded and where is the room to have it here anyway...but I don't think that we can run a group without child-care. It's really basic day to day stuff, it's not about what you therapeutically do, by the time you get there you are exhausted.......It's the lack of resources that drives people crazy."

"there are not enough resources, there is a high expectation on staff and there is an incredible amount of skill and expertise among us but we are stretched to the limit."

By far the strongest reason given for the distress experienced by the community health staff was the feeling that they were expected to perform competing rather than complementary functions within their role. By this
they were referring to the tension between health promotion and primary health care activities and the more individual client focused services.

Whilst this was strongly felt by the community nurses it was also commented upon by the allied health staff, although with less intensity. There was a strong feeling by all the people I spoke too that they were expected to have, and maintain, a diverse number of skills and expertise in order to fulfil their day to day role.

"It's nice to have all of these skills but how can you keep each of them updated all the time, how can you make sure that you are giving the best, most up to date advice, in this broad amount of things? They want you to have early childhood skills, geriatric skills, palliative care skills, home nursing, counselling skills they want you to be a health promoter, they want you to be an educator, they want you to facilitate groups, they want you to be a resource person in at least one strand where you can educate your peers and remain updated on that. How much can you continue to do? I mean I can see value in all this stuff and I can enjoy it all but you only have an eight hour day and you have your other life as well!"

"We went through a period there a few years ago where nurses went crazy doing all that sort of health promotion stuff and at what cost to their nursing role? And it can be a very positive role, dealing with people in their own home, in their environment, but you've got to have time, you've got to have time for that."

"It is there as a theory and it is certainly meant to be the underpinning of what we do but there seems to be a distinct move to increasing our acute care role and treatment role rather than our primary health care role, with the early discharge programs in hospitals and such. I don't think that there is enough time to do the health promoting role and the primary health care focus that we
should be having. It has to do with staff and resources and certainly in the mountains with venue."

People spoke of the level of accountability required of them by others, in particular the amount of time taken for providing statistical information to Wentworth Area Health. People felt that they were being asked to do more, in terms of administration, with less. It also seemed, that whilst there was a general level of acceptance for being accountable, that the current demands were too high and not geared to the specific needs of community health. I believe in this respect, this reflects a generally low level of trust of the staff and what they do in addition to being time consuming, time which they stated they did not have.

"We are called to account much more for the things that we do. And that's OK. I mean we should be accountable, but the problem is that the accounting process then impinges on you, as far as the requirements are to do a lot of meticulous things, to keep records of what's happened. Then document that at certain times and pass that back to management. And in many respects it's very unrewarding, simply unrewarding, and quite frankly, in many respects I don't think that it makes a difference to the work outcome. Whilst outcomes and accounting practices theoretically should have some impact, it's very subtle if it has."

"In fact it has become a bit of a joke now, every time we turn around Claire has more papers for us, and they change every month and they wonder why we get confused. Too many trees are being wasted by Wentworth Area Health."

"I don't know whether it is intended but the messages that we get from the hierarchy..... means that we have to produce numbers about how many people you are physically visiting to show that you are doing a fair percentage of hands on work, and the diverse nature and
the amount of time that it takes to do all those things that you are expected to do across the area ...... means that we are not available to move off into health promotion, community development type areas. So whilst the idea is there the support isn’t really available, that I can see, to make it possible."

"The statisticians seem to want us to have little numbers on a piece of paper and really don’t understand the nature of our role and I suppose because everything seems to be basically centred in hospitals."

This lack of understanding of the staffs’ role and their needs was also reflected by both consumers and other services. It appeared that Wentworth Area Health, the consumers and other services added to the stress of the community health staff by placing what are seen as irrelevant demands on them and having unclear understandings of the role of the community health staff. While staff were often trusted with people in extremely vulnerable situations it seemed that they were not trusted to decide if a house needed cleaning or not. There were a number of 'mixed messages' coming from all directions.

" A lot of people are unaware of community nurses role unless they have had personal experience they don’t know much about what we do. There are still a lot of misconceptions, I find, in the community that the old role of baby health sister still exists and the mothers, no matter how young they are - 20, 22, 17 year olds - they talk to their mothers, their aunts, their grandmothers and they tell them how it was for them and they believe it is still the same."

While a great deal of the stress identified was directly related to their multiple and challenging roles and the mixed messages they received in terms of their abilities and levels of trustworthiness, these were
compounded by a number of team and relationship issues. As can be seen from the story so far, the role of the community health professional is challenging and stressful. As all people I spoke to recognised this, it was interesting to note that the staff had mixed feelings about the level of emotional support that they received from their peers and consumers. It would appear that while support is often given individually, there is not a strong feeling of cohesiveness within the team or of overall caring and concern for each other.

"So it gets down to everybody surviving the best way that they can and there is really no shared vision about what we are supposed to be doing. People are getting by day to day and I think good colleagues help in that."

"It's just a whole lot of people working in the same area doing their own thing."

"You need to get away for an hour, a couple of hours and relax yet their are still people around here who if they see you doing that they say 'hey you've got an easy job'. You know? God what a job! But they don't understand that you have just been through some horrendous grieving situation or whatever, it wouldn't matter that something has really affected you during the day."

"They don't understand how you can emotionally burn out with toxic people, they don't understand how stressed out of your brain, it affects you physically and emotionally, I mean these people are sick!"

It became increasingly clear, when listening to these stories, that while the health workers sometimes supported each other on an individual basis this was often negated by the general feeling of lack of support. Many people felt that the community nurses were in fact their 'own worst enemy' and
that the whole culture of nursing, being required to be doing 'busy work' all the time only added to their general feelings of stress and isolation. There was also evidence of a degree of horizontal violence perpetuated by community health staff on each other.

"While nurses continue to do what they do and stretch themselves to the limit, without lunch hours, without lunch breaks, or a bit of respite with their colleagues, it won't change. While they continue to do that it won't change."

"Historically nurses do not say no, nurses have been rescuing people, they have to learn that there is no written rule that says that you have to do everything."

In addition to a 'culture of nursing' impacting on how the community nurses in particular felt, there were a number of management issues which were raised, these were raised by both allied health staff and community nurses. It seemed that at the management level - centre, district and area - there was a feeling of lack of support, understanding and nurturance and that this got worse the further away from the 'grassroots' one got.

"There is no support from above."

'Do I feel valued by the service? I would say yes to that, sometimes, sometimes. I think that we get recognition to some degree of what we do, I think that Claire is as I have said, is quite aware of the difficulties of our role and appreciates what we do in our jobs. I think that Jill does too but I think that most of the hierarchy beyond that really have no perception of the peculiarities of community nursing, we are just a drain on their money."
"It is very annoying the lack of support the lack of appreciation involved."

It could be said that the above is not relevant to the main issue of this research, that is, community participation. I believe it is crucial. These are the people who are expected to be facilitating the participation of both consumers and non consumers in terms of service planning, provision and evaluation. It is relevant therefore to know where they are at, how they are feeling about themselves and their roles if we are to expect them to strengthen an aspect of their roles.

Additionally, in action research and community development - both of which underpin the way in which this research has been conducted - it is important to work with the issues of the people themselves. It is obvious that the issues of stress, lack of support, resources and conflicting expectations on staff were keenly felt by the people to whom I spoke. Furthermore, in terms of caring for and relating to other human beings, it is absolutely necessary to hear these concerns and issues.

Theme: Powerfulness and powerlessness of community health staff in decision making

In terms of decision making and control over their jobs it became evident as people told their stories that the general feeling was one of powerlessness, that decisions were made for and not with them, and they were 'told' what to do. However, the staff did seem to have a high degree of autonomy, control and power over their day to day interactions with consumers and there was evidence that they felt empowered enough to at least challenge decisions at a local, centre level.
“The clinical services director came down to a meeting we had at intake and she said that she really thought that Springwood people related to Penrith and that she thought that Springwood should be part of Penrith community health service. I thought that was extraordinary and I had only been here a couple of months, so I said to her, ‘look, I don’t know how you can think that. Clients are continually coming to me complaining that there are no services here that all the services are in Penrith, what they are saying is that they want some services here.”

“And then we get together as a group, like a small subcommittee and we work out how to map out the day, the timing and what to do first.”
“So you get feedback, so we say all right what can we put in place that will work for you, you are out there working with the youth, we are all in the health centre, so they are the experts, they tell us. So then we collect all the information and then we rewrite the program and do something else.”

In terms of how to provide the best level of service and care to their consumers on a day to day level people did speak of making decisions either collaboratively with their peers, or on their own.

"Now what we have decided today is to do a follow up on the non attenders and find out, if we can, why they are not attending. Did they have something else to do? wasn’t important, didn’t think they needed to, whatever the reason we need to know why they are not keeping their appointments."

“So I thought well… one of the ways I can help out is doing the school screening."
In terms of the central issue of this research, that of participation, I was interested in how, on a day to day level, the staff involved and encouraged people to participate in the service they received. I asked how they would react if someone did not want a service that they saw as important, would they in fact, respect that persons right to have a choice?

It would appear, from the following that they would. This demonstrated, I feel, a sense of security in their own role as well as the ability to support people in making their own decisions. In this way there was a sense of partnership (at least from the workers perspective) between health worker and consumer.

"I see my responsibility as one of support, all I can do is give them my spiel - immunisation is a spiel. I've got one mother who I have been seeing for two years, she is a naturopath and she told me up front that she was not going to do it, so I asked her about it but, it's fine we've developed a relationship she comes to me for advice on all issues but you don't say too much about immunisation she knows what it is for and she knows what it does."

"The bottom line is still that it is the parents choice."

At the local and every day level it appeared that staff felt empowered enough to make decisions either on their own, or collaboratively with peers or consumers. The story was different when we looked at decisions made by management. During this part of the interview I often sought clarification about the level of management people were talking about as it can be too easy to talk of a 'them and us'. So, I would ask if people were referring to centre, district or area level management when they spoke. It was clear that at the district and area level there was a strong feeling that the management had little concept of the role of the community health staff and their management practices reflected this.
"Management, I think management need to come out and refresh their memories. Do you mean at centre level, district level, area level? Both district and area, they were all nurses at some stage too. It's hard to remember I guess, if you don't use something you lose it and they've lost it having been out of it for a while. I think they need to put their ideals aside and look at things a bit more realistically."

"I think that there are a lot of people who make decisions out there who have no concept of what we are doing."

Staff spoke of a low level of participatory management in terms of decision making, people felt that decisions concerning them were made with little, or inadequate, input from them and this led to a high level of dissatisfaction, disempowerment and apathy. It seemed that there was often - but not always - a process of consultation, where staff were asked what they thought, but not often a process of participation, where staff had meaningful input into decision making, where they felt that what they had to say would make a difference.

"On a serious note, when anybody asks us then they're not going to take much notice and I think that there is a lot of lip service given to consultation."

"I guess the problem is that they [team leaders] don't have a lot of power, they have a title but not much power that goes with it and I guess that the managers feel a little bit powerless: they have things presented to them perhaps as a fait accompli and so they pass it on down to us."

"So do I feel that I can make changes? No!"
"I think that a lot of decisions in planning are made by a lot of people who do not understand what community health is about. They need to consult with the community health management more than they do as I don’t think that they have enough say. I think that the grassroots do not get enough of a say and I think that with the community it is just a token effort."

People felt that they often did not have a right to make decisions, if they did try and participate then they were labelled or 'told off'. The result being that they said nothing or only talked among themselves. A number of people were aware of this and the fact that this behaviour was not going to change anything. They talked of alternative ways of behaving but at the time of the interviews did not feel able to act differently.

"And we get hauled over the coals if we have not got all of our work done before we go, I mean this is health promotion ?"

"But it wasn’t long before that I noticed it was because this lady was assertive - and they need to do that - but they couldn’t handle it and all she did was refuse to do things that she felt were not right for her . ........ she said ’ I’m not going to do this, there is no way I am going to do this’ so now she is called a difficult woman ! "

"If we keep taking it all on board and grumbling only amongst ourselves then nothing will change. So what do you do?"

When talking of the health system and community health’s' place within it, it was clear that staff felt that they were at the bottom of the ladder in terms of funding and overall decision making. People felt that decisions were made which benefited the hospital - which they saw as far more powerful and better resourced - and community health often got what was left over.
There were also a number of references made of a power struggle between the hospital and community health, with community health coming out worse off as a result of this struggle. This led to a lack of support and commitment of the health workers role in community health. This was compounded by the fact that people felt that the mountains had even less 'political clout' than some other districts in Wentworth Area Health. This contributed to a feeling of hopelessness, that there was nothing that they could do to impact on this situation although it quite clearly impacted on them and the jobs they did.

"I don't know in terms of higher up the system because what people say to me is that on the area boards there are difficulties in power between hospitals and community health and there are a lot of things that people are directed to do in community health which seem to be more hospital oriented than community oriented."

"There is some way of accounting in the hospital that they can just haul money out from that and put it elsewhere......There is a very strong medical hierarchy in all these places and that is the power base!"

"Community Health is the pits of the system and you get treated that way."

"So that is why I think the planning never gets done in any integrated fashion and there is like this war going on between the hospital and community health and perhaps the director of community health. It is all about the battle and none of it is about long term planning."

"I value my consumers, the nurses certainly value their consumers, people are very dedicated. Often though when you look at the statistics, no, it's all about bums on seats."
"Somebody said to me 'don't you know that community health is in crisis?' well, yes I do!"

**Theme: Mixed understandings, feelings and practices of community participation:**

People were asked direct questions about community participation. There were a range of responses as to what this term meant, from people that had no clear idea to others who had a very thorough understanding of the term. This raises the question of how we can expect people to be implementing a certain strategy when they are not all clear of what is involved.

I also wanted to determine whether staff were already practising 'community participation', have they included and involved consumers and the general public to some extent in the planning, delivery and evaluation of their service?

"Community participation - getting everybody involved"

"Voluntary organisations working with paid people, community education programs. I'm not sure how the community could participate other than in fund raising in terms of what we do, in that what we do is specialised."

"I don't know what community participation is."

"OK, its the involvement of all levels of the community in deciding the direction that they would like to take in developing resources and services for the area that leads to an improvement in the overall health of the population."

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The question was then asked differently, in terms of planning, providing and evaluating services. Without exception the staff felt that all people should be involved, both service users and non service users.

"Who do you think should be involved in the planning and evaluating of community health? Everybody is the simple answer but it takes time to get around to all the people, to get them together."

"Planning and evaluation should include health providers - public and private providers. Consumers both individuals and groups. Expert impartial bodies such as university researchers and other health researchers. Perhaps special interest groups such as cancer council or asthma foundation."

One person had obviously given this question much thought and was able to outline a strategy for achieving community involvement and participation.

"For example if you wanted to have a general type of consultative process, say you would have a meeting in Penrith every 2 months where consumers of the health system could come and voice their concerns about the way the service is provided or, what they saw as being needs for the future. And more specifically if for example you thought that this service wasn't working properly then you would have to go straight to consumers of that service.... I mean if you were going to provide a service you would have to get to people who were going to use that service. You might advertise and have some sort of forum. So, I think you would have to use a multi pronged approach and in between that you could have, within the Springwood community, you could have a forum which would address the views from the neighbourhood centre, gp's, the nursing homes, anything; retirement complexes."
Yet another felt that the whole idea was a political manoeuvre to save the government money.

"There should be more government funding for community groups, it needs to be re-evaluated if they want to off-load these things to community participation and planning and all that sort of thing. They are opting out of their responsibilities otherwise, which they would love to do, the services that cost them a lot of money they now want to hand over to community organisations. Then they have got to be prepared to up the funding to those other organisations, not only the funding but recognition for people and employ people in those areas."

As with their understandings of community participation there were a variety of feelings associated from fear, to scepticism to a belief that it really is the way to go.

"I have some negative thoughts about community participation from that point of view, perhaps just a fear, a negative fear."

"So you invite people to participate in creating something else, yes that makes sense."

"I think that's good, the new primary health care concept that you go out and do projects and encourage the community to participate and create their own responsibility for their health and well being, getting away from 1:1 treatment."

"If community participation can mean that somebody says to me 'this is what the people in the area want - you do it' I'm quite happy with that."
After talking of their understandings and feelings people were asked to talk of the ways in which they currently facilitated participation of their consumers - part of the community - on a day to day basis. What can be seen from this is that people often bent over backwards to enable consumers to participate in making decisions about the type of care that they receive, but this is not always welcomed or easy with many consumers expecting to be told what to do by the 'expert'. Generally though people were concerned with providing a relevant, useful and effective service to people and they believed that this was best achieved by involving the consumers directly.

"I think with service provision we certainly try to accommodate on the whole, I always try to contract with them what they want and what they need and to work with them."

"Some people like to be told and are used to being told, I have some mums who say 'now don't do that, just give me a solution' and I say 'well you could try this, or you could try that, it's your baby not my baby. You make the choice, look at the options and away you go. I'm here and I'll support you but I'm not going to tell you what to do.' I guess it's about people adjusting."

"Certainly in palliative care we give people all the information about pain relief for instance, and they have to make a decision on whether they wish to use the medication in that way or whether they want to be more alert in their day to day lives, as long as they know what's involved in making a decision and we've given them all the tools to put it together then its up to them it is up to them to construct their best model."

Despite this belief in the value of participation and the practice of it in a day to day sense, there was also a recognition that things could be better and
that not all decisions made in terms of service provision were in fact made in partnership with the consumer.

"We provide the service according to the needs as they are seen by the health professionals not the needs that are stated by the consumers....So participation has got a long long way to go yet, it's all very top down."

"Early childhood would be interesting in that we went from the 'drop in centre' to appointments and I don't think that people were asked if they thought it was a good idea."

"You know there is $10 million and as much as the health centre has got a problem, is it what the community needs? And I thought, well I don't know as nobody asked them! And that is despite the fact that there is supposed to be health for all by the year 2000 and that we should have a primary health care focus and that we should have consultation and I saw that as fairly hypocritical."

Additionally a number of barriers to participation by consumers were identified. This was particularly noticeable when people spoke of their older consumers who they believed had learnt behaviours of doing what they were told, coupled with this was the issue of fear, that older people were fearful of losing their services and so would not rock the boat. There was also the feeling that the people to whom we really needed to listen, the people who had the greatest need for community health services were not able to be involved and that we had not found appropriate ways of including them.

"They {older home nursing consumers} are the hardest people to get to tell you what they really need, they will say 'oh, whatever you say sister' or 'whatever the doctor says is fine by me', whether that is
what they want or not and you have to work quite hard to get them to tell you what they feel they really want."

"The people who are least able because they might be from a non-English speaking background, illiterate people, people with a low income, people who work for long hours and have little time to devote to committee meetings. Elderly people who are quite fearful that the services will be cut from them or that they will be abandoned if they speak up. So I suppose I fear for them in terms of participation."

"Again the needy really aren't being heard, it's very hard to do."

"People were so bogged down in the way that they existed that they have no more energy left to do something about the services that they really need."

Staff also felt that people would be generally unable to be part of the decision making process at a planning level. This, they felt, was due to a number of reasons. Apathy, lack of awareness and education about community health services and a general feeling of powerlessness in terms of asking for what they wanted. There was a sense that people have to have reached a certain level of readiness in order to be able to participate.

"Australians feel that it is up to the government, 'the government ought to do this' and the 'government has got to pay for this' and 'I'm going to get all I can out of the government."

"How do we educate people to see that they have a role, or to feel powerful enough to reveal themselves to say 'this is what I think we really need'?"

"But the awareness, you've got to create the awareness. It's like people in the community who don't know about community health,
they can't ask questions about something that they don't know anything about, it's got to start somewhere."

"But for emotional wounds it's much harder for people to talk about that. Is somebody going to come and say we need more counselling for domestic violence, we need more counselling for sexual abuse? Now professionals will say it but will the person in the street?"

"do we suddenly expect the community to be educated to make these decisions?"

Another perceived difficulty, or barrier was the one of ensuring that you get the 'right' mix of people involved and minimising the effect of people who have their own agendas and possibly vested interests not supportive of community health.

"Therein lies the big problem too. Like who are you going to get, how are you going to get people with a balanced perspective; how are you going to get people who are in fact, genuine users of community health, who have some understanding? I also see groups who might have vested interests having a more excessive push than what the rest of the community would have."

"But in my own experience you will get a lot of people with their own agendas."

"I saw a conflict of interest, I should say a potential for conflict of interest. For example if you have GP's who, there is a big difference in GP's, so you could have a GP who had a very strong private enterprise philosophy, they might want to have nothing to do with a management committee, but if they did, they could perhaps use that forum for not giving a good community health service but in fact suppressing it..... I suppose that there is potential for chaos in that perhaps outside influences which in some respects don't have much
understanding from training or experience in community health might have some influence. But, that could be a good thing too because they have an outside perspective, they might have a perspective of looking at things which people inside the health centre wouldn’t."

Conclusions.

The Staffs' story began with a quote from Zola (1970) in which a person describes their sense of helplessness, exhaustion and the resulting powerlessness to make a difference. This is the overall feeling we get when reading this story. But why is this so, why do staff feel like this?

While staff are trusted daily, with sharing the life and death struggles of people in the community - often in the persons home - there is a sense of an overall lack of support and acknowledgement of what they do. This includes a lack of support for each other in addition to a lack of structural support from the bureaucracy in which they work.

Additionally, and quite astoundingly, while there is a sense of partnership, trust and collaborative decision making between staff and consumers in the most intimate and important times of peoples lives, there is not this sense of collaboration, partnership and trust between the organisation and the staff it employs. Instead, the staff feel strongly that they are not involved in policy and procedural decision making, rather they are the passive recipients of others decisions.

If one takes a Transactional Analysis perspective, in terms of analysing what people do and say to each other, we could say that the hierarchy in the organisation is acting as a critical parent with the staff being treated as - and behaving as - maladaptive children. As such, the organisation does not treat the staff as if they are capable of being involved in policy and
procedural decision making, they are often criticised for their behaviour, controlled by endless form filling in and are often discounted or unacknowledged (Muriel James and Dorothy Jongeward 1971).

When talking of these issues with the staff involved, and all of us as a group trying to make some meaning of these experiences and feelings, we concluded that much of this was due to three interrelated factors and the resulting discriminations experienced by community health workers. While I have separated these points in order to briefly discuss them, in reality each of these factors are more like layers of an onion, each relies on the other to make up the whole, and, like peeling an onion one weeps at the strength of the fluid which holds it all together. The three factors are:

- the nature of bureaucracies - structural discrimination
- gender and work - sex discrimination
- the competing discourses of the medical model and primary health care - 'scientific' discrimination.

* The nature of bureaucracies - structural discrimination:

Simply put, bureaucracy is a system of control, organisation and administration based upon impersonal written rules and a hierarchy of offices with a clear distinction between the 'office' and its incumbent (Alan Petersen 1994; David and Julia Jary 1991). It is widely accepted that the health system in Australia, and in most other 'western' countries, is constituted of a number of bureaucracies and that the administration of the health system is bureaucratic (Stuart Rees 1991; Gillian Lupton and Jake Najman 1989; John McDonald 1993; Ann Game and Rosemary Pringle 1983).
The bureaucratic nature of the organisations which make up the health system helps us to understand many of the thoughts and feelings in this, the staff's story.

"The structure and culture of bureaucratic organisation disadvantages less powerful groups and individuals; it denies them access to resources, participation in decision-making processes, and the validity of their own knowledge and experiences....... ....it is best to describe this process as 'structural discrimination'" (Alan Petersen 1994:90). The results of this type of structural discrimination are high levels of stress felt by workers who feel they have little control over their work, close supervision by superiors, and a feeling that one is unable to influence decision making. All of the 'results' identified by Alan Petersen can be found in the staff’s story and there can be little doubt that the staff in this community health centre feel structurally oppressed.

Bureaucratic organisations give great power to the people who control the bureaucracy, indeed bureaucratic domination is reinforced and supported by power structures evident in society (Ann Game and Rosemary Pringle 1983). Further, they are in conflict with ideas of democracy and participation. In terms of the central issue of this research, that is participatory planning, service delivery and evaluation in community health of all stakeholders, we need to recognise, understand and act to transform these factors of bureaucracy.

• **Gender and work - sex discrimination.**

"The development of nursing and various allied health professions.......is a result of nearly total gender stratification of medical work" (Peter Freund and Meredith McGuire 1991:274).
At the beginning of this story it was asserted that as caring is 'women's work' it is unacknowledged and invisible. The accounts of staff support this assertion. While allied health staff were important to this story the majority of employees in the community health centre are nurses, the centre is managed by a nurse and the Director of Community Health is a nurse also. As such it would be fair to say that within this community health centre nursing is the dominant profession and culture.

Much of the behaviour spoken about in these interviews reflect Florence Nightingale’s view of nursing which encourages quietness, submissiveness, endurance, obedience, selflessness and devotion (Ann Game and Rosemary Pringle 1983, Stephanie Short et.al. 1993). Florence Nightingale believed that nursing was a 'natural' occupation for women, indeed she wrote: "every woman is a nurse" (Peter Freund and Meredith McGuire 1991:275; see also Suzie Bates and Erica Linder Peitz 1990:194).

Whilst it is true to say that most of the people spoken to were angry, frustrated and concerned about their lack of control and power, they also spoke about their silence in meetings, their non speaking out; the fact that while they may not agree with many of the demands placed upon them they still carried out the tasks associated with these demands; the fact that they rarely took time out to look after themselves and maintained the sense of rushing to achieve all that they could and the feeling that while they had some issues with their work they loved their jobs. There was little evidence of assertion, of speaking out in terms of managerial decision making and policy development and implementation.

There can be no doubt, in terms of numbers, that health is a female dominated profession - in practice it is true, women are doing most of this 'caring' work. In Australia 79 % of all health workers are women, with
75% of the total health work force being female nurses. Of nurses 92% were women and 50% of 'other para professionals' were women (National Health Strategy 1993). This report of the National Health Strategy states further that, "Nurses, the largest sector of the health work force, can assert their interests but they are still largely excluded from the central debates" (National Health Strategy 1993:4), certainly a comment endorsed by the stories of the staff to whom I spoke.

It is difficult to interpret these comments and figures without seeing the issues of gender and the resulting discrimination of nurses and allied health professionals. This is compounded by the bureaucratic nature of health with the health bureaucracy reflecting and reproducing masculine dominance and female subordination. This is very clearly seen within the health system with over 90% of nurses being women yet there are relatively few women in high positions in the health hierarchy. The majority of those who are in the top positions tend to be white, middle class men (Ann Game and Rosemary Pringle 1983).

While this issue was rarely referred to directly during the interviews with the staff, when we met to discuss what had been said and what it might mean to us, the staff discussed the gendered nature of their work, felt that if there were more males employed in community health "they would not put up with it" and did feel that the stereotype of 'women's work' made what they did less valued by both themselves and the hierarchy.

Additionally there is the fact that caring for others, shares many features with women's work in the home, indeed that this is a natural extension of women's traditional work. This makes it difficult for both the staff and the hierarchy to fully recognise the work of these people as 'professional' (Stephanie Short et.al. 1993).
- The competing discourses of the medical model and primary health care - 'scientific' discrimination.

This final layer is supported by the preceding two. The dominant discourse in health at this point in time is that of the medical model, curative health, with its roots firmly in scientific knowledge and objectivity. "As has well been told in the literature chronicling its rise to power, the medical profession assumed sovereignty in the domain of health services. The profession based its authority on the esoteric, scientific knowledge which it commanded and on its exclusive mandate to apply this knowledge to the care and treatment of the sick" (Ann Daniel 1990:1. See also Betrand Russell 1952).

As this is the dominant discourse in terms of health "doctors determined what medical policies and practices were appropriate and persuasively required nursing and all ancillary services to converge with medical objectives" (Ann Daniel 1990:2). If we ask who are these doctors who are doing the determining we find that in 1988 75% of all general practitioners were male and 84% of specialist medical practitioners were male. The people being persuaded are the rest of the health work force, 75% of which are women (Erica Bates and Susie Linder Peltz 1990).

Primary health care does not have a curative focus, although no-one would say that curative procedures are unnecessary, instead its focus is on the maintenance of good health and the prevention of disease (Alma Ata 1978; Ottawa Charter 1986: Ann Daniel 1990). Community Health Centres were established with their principle features being primary health care and health promotion (Sydney Sax 1992). This discourse has as its focus wholeness and well being and is strongly informed by the understanding that health and wellness is, to some extent, socially constructed.
The stories of the staff tell of their awareness of the struggle between the two discourses of primary health care and the medical model, with its overlay of gender issues. People spoke of the battle between the hospital and the health centre with the clear feeling that the hospital had the most power and that community health was seen as the poor cousin. One person summed this feeling up eloquently: "community health is the pits of the system!". It is interesting at this point to note that 7% of the NSW health budget is spent on community health (Australian Community Health Association 1991). And, despite being committed to devolving financial responsibility to centres in the Blue Mountains district (Blue Mountains District Health Service 1993) staff still feel that the hospital controls what gets spent and where.

Furthermore, staff felt that many of the procedural tasks that they were asked to carry out had more to do with hospital procedures and there was the general feeling that those in the hospital had a limited perception of what community health was trying to do.

This is even more interesting when one looks at the Corporate plan for this area. Written in 1993 it states that "Community Health services are stretched to provide even basic treatment services, let alone undertake the substantial preventative activity for which they are uniquely positioned and based" (Wentworth Area Health 1994:14). In 1995, staff still feel 'stretched'.

The documents coming out of NSW Health, Wentworth Area Health and the Blue Mountains District certainly reflect a commitment to achieving a balance - in terms of resources - between prevention and cure. The corporate plan mentioned above (Wentworth Area Health 1994) details 4 priority goals. These four focus on: health promotion; treatment; service delivery and health status. Additionally one of the three primary goals of the
NSW Health system is "[t]o improve the health status of the community through public health services and prevention programs" (Tom Hamilton, C.E.O., in Wentworth Area Health Corporate Plan 1994:14). Staff however, feel that this balance is not there in practice, and they are not being structurally supported to undertake preventative and health promotion work.

In 1993 the National Health Strategy (NHS) working group held a series of workshops which looked at the issues of workplace reform. Many of the issues identified are reflected by the staff to whom I spoke. It seems as if little has changed, in this area at least, in the intervening two years. "In a real sense workers at many levels are too busy to think, communicate, and plan..... Workers and patients are sometimes alienated...once caught in the system" (NHS 1993:23).

In terms of participation the 1993 NHS report had the following to say: "Flatter organisational structures are increasingly common. Formal participation of the work force through representatives and unions sitting on bodies such as consultative committees are giving way to more genuine, daily decision-making rights for individuals and, particularly, teams of employees" (NHS 1993:30). If this is true then it is not reflected in any way by the stories the staff tell, they do not feel included or involved, indeed they speak of increasing feelings of alienation and powerlessness.
THE COMMUNITY'S STORY
"Health personnel form part of the community in which they live and work. A continuing dialogue between them and the rest of the community is necessary to harmonise views and activities relating to primary health care. Such a dialogue enables health personnel to acquire a better understanding of the community's feelings, the reasons for its views, the level of its aspirations and the pattern of its organisation and communications. For their part, the people will learn to identify their real health needs, to understand the national strategy for primary health care and to become involved in and promote community action for health. Thus, society will come to realise that health is not only the right of all but also the responsibility of all, and the members of the health profession, too, will find their proper role" (Alma Ata 1978:51).
Introduction:

"The people have the right and duty to participate individually and collectively in the planning and implementation of their health care" (Alma Ata 1978:3).

Starting at the beginning, this statement encapsulated our beliefs as a group while at the same time it raised a number of difficult questions: who are 'the people'? how do they feel about this right and responsibility? do they want to be involved? What do people already know and think of the health system in Australia and community health in their local area? how do you talk and listen to the people in an open and honest way? what if they say something that you don't want to hear?

This story is about our efforts to understand these questions at a local level. It is a story of 'community participation in action' as we asked people what they thought and felt and we listened with open hearts and minds to their answers. Some of what we heard was confronting to us in our professional roles; some was insightful, creative and confirming. Overall, what we heard confirmed that 'the people' are interested and committed to the idea of participation in health.

• How the stories were told - the process:

We believed that in order to truly listen and hear 'the people' we needed to look people in the eye, to talk with them not to them, to enter into dialogue and develop a relationship - however transitory - and to use a process which encouraged the sharing of information and knowledge. For these reasons we decided to have 'conversations' with the community, to conduct semi focused interviews. We also believed it important to make ourselves
personally visible, and not remain hidden behind our respective roles and the research itself, to become personally open and vulnerable.

There were many issues we needed to consider in order to maximise access and participation in these 'conversations' by as many of 'the people' as possible.

Venue:

We used the early childhood centre as our 'base'. The centre was in the middle of town, highly visible with a children's playground outside its front door, next to the town supermarket and main car park, and opposite two of the larger banks. Those of us who lived and shopped locally knew that this centre had a good flow of 'traffic' past its door. It also had the town centres one and only public toilet in its complex.

Times:

We ran the interviews in the last week of the summer school holidays, believing that most people would be back off holiday and spending this time catching up on shopping and preparing for the return to school, plus accessing full time workers taking a break. Times for the interviews were spread over the week so as to enable a variety of people to come to us if they wished. This included a weekday morning, two afternoons, one whole day, two evenings and a Saturday morning. In this way we hoped to be available to people who were in paid employment and commuters in addition to people at home with children, older people and people without paid employment.
Awareness:

As we had no established relationship with the people we wished to talk to, we spent a great deal of time discussing how we could encourage people to come and talk to us. An article outlining the research project was placed in the local paper. In the same edition was an advertisement telling people when and how they could come and talk with us.

One cold, wet, miserable morning, four of us spent one hour standing on the two major railway stations in the area, handing out approximately 600 flyers to commuters. The same flyers were distributed in local doctors surgeries, shops, library and neighbourhood centres. We also stuck them to telegraph poles, shop windows and toilet doors.

Each flyer invited people to "Have your say in community health", gave the times and location of the interviews and had a contact number for further information. Our aim was to get people to come to us, to drop in for a chat about the local area and community health.

Interviewer preparation:

Everyone who was part of the research group decided to be part of the interviewing process. Between us we had various amounts of experience in interviewing and talking with people. We had also invited people from the local hospital to be involved in the process and one member of staff made herself available for the week. In order to share our experience, reinforce interviewer reliability, and to prepare all of us for the interviews we held a two hour 'training session' the week before the interviews.

We agreed on a 'roster' that ensured that three people were at the centre for each interview session. Two people to interview and one person to make
people feel comfortable and provide tea, coffee or a cold drink. In total ten people were involved at one time or another during this week of interviews.

The interviews:

While our aim had been to encourage people to drop in and see us we found that very few people took this opportunity. A more effective way of encouraging people to participate was to stand on the street and hand people information about community health and the research. If they were happy to take the information we asked if they would like to 'have a say'. This proved to be most effective. It provided people with immediate face to face contact and enabled us to explain the nature and purpose of the interviews before they committed themselves to walking in the door.

At the outset the participant was given a consent form to read and sign, the research was explained in more detail and any questions, concerns or hesitations were addressed. We collected basic demographic information about participants at the beginning of the interview. All interviews were recorded with one requested exception.

Towards the end of the interview we asked each person if they would like further involvement, although we could not tell them what this might entail. Thirty eight of the forty people we spoke to agreed and filled in yet another form so that we could contact them at a later date.

* What we heard.

The one hour interviews provided us with a detailed understanding of how the community, those people who identified themselves as not being either community health service users or service providers, felt about community health services and the issue of community participation.
As we aimed at 'conversing' with people, having a dialogue with them about issues that they saw of importance many people spoke about their feelings of the local community, the state of politics in NSW, the health system in general and local issues that they were concerned about. This lead to a much deeper understanding of 'the people' on our behalf and, we believe was empowering for the participants as we were genuinely interested in hearing their views and opinions about what they felt was important.

We found that people came to talk to us for a variety of reasons. Some had specific issues they wanted addressed by community health; others were pleased to have the opportunity to participate, to be heard.

In terms of the context of these interviews, two things in particular stood out as being 'different than usual' in our community at this time. The interviews were held during the lead up to the NSW 1995 State election and many people spoke about issues in terms of the larger political context. Additionally, shortly before we began interviewing the NSW mobile breast screening unit, a brightly coloured and highly visible semi trailer, set up shop in the car park next to the centre. This could have had an influence on people's awareness of preventative health measures.

Most people we spoke to felt passionately about the local area, took the interviews seriously and were eager to help. They thought carefully about our questions and their answers.

- **Meet the people we spoke with:**

We were interested to find out who we had managed to access and who we had missed, how people found out about the interviews and whether
both genders were represented. Additionally, we thought that this would help you to put what we found in some context, to have an understanding of the people who were involved in the interviews.

Most of the people with whom we spoke were between 26-65 years of age with one person over 75 and one person under 18 participating. The number of women who came to talk with us was almost double the number of men, 27:13. On the whole we were quite pleased, feeling that we had done well to cover a variety of age groups. Additionally we were pleased that so many men did actually speak with us. We were concerned that societal stereotyping of health as 'women's business' would discourage men from being part of this process.

Nominating their 'area of work' at the beginning of the interview caused some interesting discussion, especially from people who worked in the home looking after children, running the household and maintaining the house and garden - mostly women. People often said 'I don't work'. However when we asked them what they did it became clear to both us and them that they did work but were not paid for doing so. These people then nominated their area of work as 'home duties' and they accounted for the largest group (10) of people who spoke with us, closely followed by people retired from the paid work force (7) and students (7). This is not surprising as we would expect people outside of paid employment to be in town, browsing, shopping, meeting friends and using the services more easily and more often than people who are in paid full time work.

While not surprising, it was disappointing. We do not wish to suggest that we were dissatisfied by these peoples input, far from it. Obviously women at home, working hard at raising a family, students and people who are now retired from the work force are an integral part of any community. In fact
we could argue that these people often hold the community together in an often unrecognised and undervalued way.

However, as mentioned earlier, we had distributed approximately 600 leaflets to people going to work outside of the local area - commuters. This was an issue for us as many people commute to work from this area and we wished to facilitate their participation. Additionally, we had scheduled interview time slots for two evenings and a Saturday morning. It would appear that this was a singularly unsuccessful exercise. People in paid employment who took part in this project tended to work in the local area eg. cleaner and scientist or at home; e.g. writer and potter; with one or two exceptions e.g. manager and journalist.

Our local population is predominantly white anglo saxon but we do have a number of people from non English speaking backgrounds (about 5% of total population) and a growing number of refugees living in this area (BMCC Community profile 1995). The majority of people to whom we spoke were Australian (31) with a small number of people from other English speaking countries (UK 4, USA 2) and 3 people from Europe. All participants spoke English at home. We did not access anyone who identified themselves as from a non-English speaking background.

Whilst the research and interviewing process was intended to be all encompassing we did not specifically target people from a non English speaking background, all of our awareness raising and advertising was in English. This was not because we wished to exclude people for whom English is not their primary language. In fact during the planning phase for the interviews we discussed how we could be as inclusive as possible, of all people. The the small, but diverse, mix of people from a non English speaking backgrounds in this area added to the complexity as there was not
one or two other languages that we could focus on. This is an issue that we feel we need to consider more fully in future.

In terms of our advertising it was important for us to know which of our strategies for involving the public was successful as one of our long term aims was to have ongoing community participation.

Most (19) people responded to our personal invitation to be part of the interviewing process with 10 people having read the article in the local newspaper. However, putting up posters and signs was also a useful strategy encouraging 7 people to take part. Four (4) people came as a result of talking to other people who had been interviewed. This combined approach was quite successful although in terms of longer term planning the logistics of approaching people personally will need to be carefully considered. However, it needs to be stated that we felt that given the total effort the overall response in terms of numbers, was low.

Themes

1. Community Health is difficult to access
   * lack of knowledge of community health
   * poor location of community health
   * negative attitudes of 'the system'
   * transport difficulties

2. Community participation - a noble aim
   * support for partnerships in decision making
   * barriers - people not empowered
     system won't change
   * strategies for facilitating participation
3. General Practitioners- too busy not meeting our needs
   * too busy to listen
   * the conflict of interest between care and running a small business

4. Health is a political business
   * health system or medical system ?
   * decisions are made to protect the powerful
   * the 'system' is out of touch with our needs

5. Requests for specific services.

   Not all parts of the transcripts have been used in discussing the themes that we found as this would lead to an often repetitive and extremely lengthy document. Rather we have chosen peoples words which most clearly represented the theme, covered the range of responses or stood out in their different-ness from others.

   **Theme: Community Health is difficult to access**

   Our first question to people was 'what do you know about community health services?' We had a wide range of responses to this question.

   "Nothing at all"

   "Community Health is more of a primary health sector with emphasis on treating people in the community rather than in hospitals."

   "Do you know any of the services that are available through community health ?
   No, just hospitals I suppose"
By far the majority of people knew nothing at all, had very limited knowledge or incorrect knowledge. When reading through the transcripts we found that a great deal of our time in the interviews, was taken in giving people information about community health services. This we did verbally in addition to giving them a brochure on the service.

Without exception people responded positively to this information and were frequently surprised at what was available.

"I think they should be advertised more often, I mean there are a lot of services in here that I didn’t know anything about, I didn’t even know existed and I think that’s a problem."

These reactions often led to discussions about how people could find out what was available in the area. People felt that tracking down what was around was an arduous business.

"If you haven’t been used to doing this sort of thing then it’s very hard to know where to start."

"It's a long haul finding out what is available."

"Unless you’ve been involved with them you don’t, you don’t really get a full understanding about what it’s all about, who they are available to, are they available to the general public, what’s the cost? all that kind of thing."

In terms of access the location of services is important, if they are invisible then this further limits peoples access to the service in a physical sense and in an information sense. If you don’t know that there then it is highly likely that you won’t know what it offers. It became obvious to us through the interviews that the community health service is, in fact, invisible.
"I think one of the big things is that people wouldn’t know that you existed, they don’t know where the place is."

"Where is the health centre?"

Access does not only refer to physical location and peoples information. It is important that a service is accessible in its day to day practice. That is, that people feel that they can use the service, that personnel are accessible and that the system is friendly and appropriate. As one person so aptly put it:

"I think that’s the biggest challenge that it is a place that looks and feels accessible...that it’s also a place where people feel comfortable coming to."

A number of people we spoke to had tried to make contact with the community health centre but, for one reason or another, had felt alienated by either the people or the system.

"I couldn’t get any contact, that would be the best word, we spoke, they gave me information but we didn’t get any contact between myself and for want of a better way of putting it - the organisation."

"a lot of the women are frustrated because they get to the stage where they actually want to speak to someone and then they have to go on the waiting list for six months. So they come away thinking the attitude is ‘well, you’ve waited 15 years, you can wait six months’."

"And they kept referring me from one girl to another, I think there were about three in the end and they said that they would have to get somebody down from Katoomba, well that wasn’t satisfactory, you thought twice about going in anyhow, I did......So we came out and I never went back again...when you are trying to make up your mind to
do something and you are balked by the very place which you think is going to help you by them saying ‘oh we’ll have to get somebody down from Katoomba’ or ‘we’ll have to refer you to somewhere, come back and we’ll make you an appointment, well it’s off putting.”

Other people who had not tried to use the service had some quite definite feelings about the centre.

"I definitely got the impression in the past, just being a building, people go in there and not much else happened. You didn’t see the people inside, you didn’t know who they were, you didn’t know what they did."

"The feeling I got was that you had to be in a nursing home, very, very sick to even be invited in the front door."

One person felt that the service was not there to meet his needs:

"it’s very difficult for me as a male to feel that the community health establishment is concerned about my health as they seem to be about the health of women, for example, and that saddens me."

In terms of accessing services the problem of transport was mentioned several times by people.

"The transport can be a bit of a problem."

"There are people up and down that I know of that don’t have transport, and it’s a little hard for them sometimes."

It is clear from talking with people that community health services, in this area, were invisible, difficult to access and poorly understood. As community health services seek to strengthen their focus on 'wellness'
rather than illness then the general population need to have access to information regarding its scope of activity and its location. If this is not done then the perception of community health is in danger of remaining as a sub-set of the hospital and firmly rooted in the curative model of health provision; that is people will use it when they need it, in times of crisis, not as a preventative service.

**Theme: Community participation - a noble aim**

We asked people a direct question regarding the decision making process and community health, 'who do you think should make the decisions about who gets what service and what services are available.' Most people found this question interesting and answerable. For some however, it made little sense, so we would reframe it and ask for example, 'if there was a new youth service going to be set up who do you think should decide what the service looks like, where it is located, what will be offered etc.?' This reframing helped make the question accessible for all participants.

We received a range of responses to this question. There was a polarisation from some participants in that they felt either the community/ potential service users should be the decision makers:

"The community, like the public."

"Well, I think the people who the services are for should definitely be involved and really kept informed of the planning process as well, maybe via the local paper. Like this project seems to be really good at actually asking people. But, maybe on a more ongoing basis as well."

"I think there needs to be a strategy put in place that says need a greater awareness from the community itself, now what their needs
are, what their demands are to a point that says they are exerting a somewhat greater pressure on the resource decider”.

or a range of ‘experts’ should be making the decisions:

“Doctors, for example, should be involved really.”

“I think that a lot of the local politicians should have a say.”

“Well it gotta be a medical man.”

“I suppose ideally the community nurses.”

“Well probably a neighbourhood centre group of people would be a good idea.”

“School associations where you really get people who live in this area and have children in this area, they are the sort of people who would be able to give you some sort of input as to what services would be best for this type of area.”

By far the strongest response spoke for partnerships. Where people in the system, the community and/or potential service users worked together to plan services and decide how scarce resources should be allocated.

“Well, obviously the administrators who determine where the money is going to should be involved, the local community health providers, that is to say the community nurse and other people that are involved at the local level so to speak, providing services to the people, as well, as well publicised invitations from concerned members of the public, if they’ve got something they want to say, so that they can, the residents themselves have the opportunity to provide input as to what they perceive the community needs.”
"Not one group can understand all the needs of a community, the people who are using the services, it's important that they are involved i.e., representative groups of people such as asthma foundation, heart foundation etc. plus general members of the community. It's also important to have professionals involved, district nurses, G.P's, I don't think it's very necessary to have hospital doctors involved because they don't really understand."

"People who are informed on health issues like community health experts, if there is such a thing, who know what kind of services can be set up and can be provided. Someone who has an interest in who knows about women's health needs, knows about children's health needs, aged health needs, I think."

No one suggested that people not from this area should be deciding what is needed or how it is provided. There was a sense of a need for dialogue and discussion around issues of concern and needs for the local community and that decisions should be made with a basis of fact and overall needs. The agenda should not be hijacked by 'outsiders and certainly not "the newspapers screaming headlines."

Whilst there was a high level of acceptance and support for inclusive decision making and partnerships, people also identified a number of barriers to effective participation in decision making. One of these was the lack of any feeling of community, that most people just got on with their own lives.

"People do like to keep themselves to themselves so everybody isolates themselves and I think that's the biggest problem."

"but you don't even stop to think about, about, you know what's lacking or what I can do."
"I'm a great believer in tribal life with I know it's got it's disadvantages and that's terribly idealistic but I think isolation..............there is not that sort of tribal support."

When asked if they would like to be part of the possible 'partnerships' the majority of people felt that they could not, usually due to lack of perceived expertise and/or knowledge.

"Having no knowledge I don't really know how I, or anyone like me, could help."

"I'm not trained that way, so I don't know how I could."

"I don't think that I could contribute anything because I don't know enough. You've got heaps of life experience. That doesn't seem to count for much."

This was an interesting phenomena for us as interviewers. Firstly most people had said that the community should be involved in the decision making process. Then when asked if they would like to be involved most people felt that they were unable to be due to their lack of knowledge and expertise. By the end of the interview, however, when we again asked them if they would like to be further involved, 38 out of 40 participants said that yes they would, and gave us their names and addresses so they could be contacted.

Something obviously happened during the process of the interview. It would seem that people left feeling more empowered than when they walked in the door. It could be that by asking people their opinions, really listening to their answers and engaging with them in discussion on issues that they felt
were important had enabled people to feel that they did have something important and valuable to contribute.

People also spoke about the 'system' being uninterested in change and that what we were talking about was really 'lip service' to a nice ideal. There was the feeling that if we are going to ask people what their opinions are then we need to be committed to change in light of these opinions. Otherwise there is a certain level of dishonesty in what we are trying to do.

"while a certain amount of lip service is provided for public input it rarely seems to be taken seriously."

"A lot of us have opinions and when the few situations come up where we’re allowed to express it there are so many people with pent up frustration’s that it’s a very difficult situation. I mean we’re asking for a major change in the philosophy of governments and bureaucracy."

"The organisation that has been doing the encouraging then has the responsibility of seriously considering the input they’ve gotten, and then doing something to let the residents know number one that they have been heard and that its been considered."

"It may be an outcome of well gee, we got a lot of input from a lot of people and now I’ve just got a lot more frustrated people because we can’t offer any more services it may require more resources or redeployment of certain resources from one group to another, so it’s difficult."

Still others feared that the agenda would be hijacked by 'the vocal minority' and that whatever systems and procedures we set up had to safeguard against this.
"I am sick and tired of reading the newspaper, how they take a selective sample and the majority of people say this and you think it’s funny but the group that I associate with, all the people that I come into contact with don’t agree with anything that comes up."

"It’s like the minority dictate the country whereas the average person doesn’t get stirred up enough."

"Each group is going to think it’s own problems are the greatest and they are going to be pushing, and it’s a bit unfair that the loudest voices get."

Everybody had ideas for how we could better involve people, how we could get information to people and how we could be more responsive to people in the community. The range of ideas and creative suggestions was quite inspirational.

"Have some sort of overall community sort of coordination."

"By word of mouth, that’s how I see you get to hear about things."

"Setting up ongoing, not just focus groups, but ongoing consultancy groups made up of not just people who work - they can be useful as they have a lot of networking knowledge - but by people who have an opinion in the community about it and you’ll get hundreds of those people."

"Well you are already doing it aren’t you, you’re interviewing?"

"I think the letter box."

"I suppose more of a workshop, that type of thing that could be presented and people may go along there, may not go on an individual
basis, but to go along and listen and they may pick up things without feeling too prominent and if those sorts of things are held on a fairly regular basis gradually people learn about them."

"Having meetings, yeah, having meetings, asking what they think of the ideas, just discussions."

"Use your local paper."

"The school I think, you can cooperate with one of the schools maybe, send letters home with students and a questionnaire, spread your questionnaire out, use your local paper."

"Use the networks that are already operating or services that are running."

"So you know your community nurses and the doctors to talk to people, not just about the specific issues that they are coming to see them about but to get them involved in a broader conversation say would you like to have more information and ask them if they can pass it on to you and, you know get them to help you."

It would seem that people are prepared to become involved in the process of decision making in a variety of ways. Some suggest quite direct strategies such as establishing ongoing consultancy groups while others would prefer the relative anonymity of workshops.

Theme: G.P's - too busy not meeting our needs

Questions were not asked about other service providers in the area. However a number of people commented on doctors in general and the local general practitioners in particular. Their comments were not very
complimentary. It seemed that people were not receiving the service that they expected from the GP’s that there was a feeling of being rushed and not listened to. This had the effect of discouraging people from going to the doctor, unless they felt they had no other option, and certainly not going to be listened too or have questions answered.

"I find the doctors round here are very, very busy, very brief and I go as little as possible."

"The doctor just zips in and out and says 'do this, do that'."

"As far as I can see everybody is scared of them."

"I wish there was somewhere you could go that you could ask for this, I mean I have got a lot of questions I’d like to ask but there is nowhere, no one to ask."

People were highly sceptical of doctors motives for seeing them and felt that there was a conflict of interest between care of people and running a small business.

"I think that if doctors were a bit more educative about when to come, when not to come and then again I suppose they want to make the best living they can, it’s better to have too many patients than too few."

"What’s the old saying? nature cures the illness, the doctor sends the bill."

"And they are just a cash laundering system really."
For us these comments caused a predicament. The interviews were conceived and conducted primarily by community health personnel, all women and predominantly nurses. This is not a group of people highly valued or respected by the medical profession (Ann Game & Rosemary Pringle (1983); Stephanie Short et. al. (1994)). What then, do we do with this information and how do we resist playing an adversarial 'them and us' game?

Theme: Health is a political business

Many people commented on the health system in general and again doctors in particular. There was a high level of awareness that health is a political issue.

People did feel that the powerful lobby groups in the health system had the system more or less under control and that this dictated the types of services we as consumers received. Additionally people commented on the fact that what we had as a health system is, to their mind, a medical system.

"In the health area we then have to confront the medical establishment which has spent at least a hundred years attempting to disempower the health recipient and to empower the health provider, principally doctors of course, the physician."

"This medical umbrella is a very all powerful thing and they're very threatened by anything alternative but the sad thing is, or happy for us, the alternative works. I mean I'm not saying we can do away with surgeons, or eye specialists, but the alternative does work and I know they make a big stink every time someone dies at a naturopath but the people that die from operations and from drugs, misdiagnosis is all
hushed up and there’s more, so really and truly I think this umbrella needs to be pulled down and restructured."

"They’re starting to run seminars now but they’re running it on totally medical model because …… they’re only getting people who have had extreme problems."

"I think doctors are a bit to blame because they, they cling to their professional secrets."

In terms of current decision making in the health system people also commented on the role of politicians. There was a sense that decisions were made to promote the interests of the holders of power rather than in the interests of the general community.

"I think there’s the old attitude that the government knows how to fix a lot of things in society, but if they did then they would never get elected again."

"Isn’t it a matter of politics and finances? You’ve probably got some unrelated do gooder who is after their own prestige and importance and future who, like a politician who basically answers to no-one and when the going gets tough we take away the money and we take away the services so obviously it’s a game we all play."

"I think there is a lot of misuse of the medical system that adds unnecessary expense to the health bill, that money could be spent elsewhere, where it would do more good."

People voiced a great deal of scepticism and disillusionment at how decisions are made currently. There was a feeling that nothing will change as people like to cling on to their power and money, coupled with the fact
that those making decisions were out of touch with what people really
wanted, or needed.

"I often find lots of things the people up there make the decisions, they
don't seem to make the right decisions."

"What I think is needed is for the high level administrators to be willing
to let go a little bit of their power, to be able to be open to feedback
from those below them."

"There's got to be a prevention line along the way and I think a
tremendous amount could be done on preventing these things
happening."

**Theme: Requests for specific services.**

A number of people, in particular those who came to us without us
contacting them first, made specific requests for services which they
believed community health should offer. As people gave us their time in
good faith we believe it to be important to include here all of the requests
made.

Interestingly, many of the requests for services included things that were
already being offered by community health such as: sexual assault services,
speech therapy, health screening and family support. This would suggest
that people are not aware of what already exists in the community, a point
clearly made throughout these interviews.

"I think that one of the big issues in the mountains, is all linked up to
do with family, family services and support for young mothers and
maybe offering ways that aren't so obvious, exercise classes or
something."
"I know you could offer a lot of seminars and financial planning.....more of a workshop idea for this transition [into retirement] which does have a sort of well, mental health as well as physical health."

"needle exchange {for diabetics}"

"get togethers for the people who have heart problems."

Other people spoke about services that they felt were needed in the community, these included health services and general community services which people believed were important to the health of the community.

"A medical centre it could perhaps be attached too the health centre, where you could just walk in."

"I think what we are sadly lacking here is somewhere, what do they call it down there, senior citizens centres."

Other specific requests were in the areas of: carers support, exercise classes, weight watchers and a heated swimming pool.

Conclusions.

This story is primarily about the beginning of a dialogue between 'the people' and community health staff. It reflects our genuine efforts at listening to many voices in our community in order to inform and transform our day to day practice.

The idea of participation, or community involvement in health, is not new and can easily be traced to the declaration of Alma Ata in 1978 where this
theme was strongly apparent throughout the document. However, the translation of this idea into practice is difficult and complex. Perhaps this explains why in 1989, Dr Hu Ching-Li, the then assistant director - general of the World Health Organisation, lamented the lack of initiatives which are working towards translating the rhetoric into reality (WHO 1989).

Much has been written about these complexities and difficulties (Jim Beresford 1992; Bryson & Mowbray 1981; Jane Dixon 1989; Wendy Farrant 1991; NHS 1993; Scott-Samual 1990; Iris Young 1992; WHO 1986; Williams 1991; Robin Watts 1991). It is now 1995; seventeen years have elapsed since the Alma Ata and we believed it was time to take some action, whilst at the same time acknowledging the difficulties and complexities involved.

As stated at the beginning of this story, what we did was 'community participation in action' within a community development framework. As such we were interested in starting where the people were at, not where we believed they should be, with beginning to address the 'expert provider/novice consumer' dualism and unequal power relations, and in using a process that was empowering for the participants (James A. Christenson & Jerry W. Robinson 1989).

It would appear from these stories that people were well aware of the complexities and difficulties inherent in facilitating community participation, although there was a belief in the 'rightness' of this approach. Furthermore, people who had no identified involvement with community health at this time were only too aware of the power inequities in the health system and the inherent political nature of health.

However it is clear that community health, for the people we spoke to, was invisible and inaccessible, and there was a strong feeling of the systems
inability or lack of genuine desire to really enter into partnership with local communities. We believed that these feelings could be understood within the following interrelated contexts:

- The medical model of health

  "According to the biomedical model, only the doctor knows what is important for an individual's health, and only he can do anything about it" (Fritjof Capra 1982:159).

The dominant discourse in health at present is that of the biomedical or medical model. As such, the emphasis of government policy, research priorities, the development of health technologies and media coverage reflect this dominance. Ask people about health, as we did, and you hear about hospitals and waiting lists. Everybody knows where the nearest hospital is but very few know of the location of the Community Health Centre. Given this dominance it is not surprising that community health, which is aiming to operate within a health promotion and disease prevention discourse, is invisible.

The people to whom we spoke felt that 'medical people' had set up the health system to suit themselves. This feeling is surprisingly supported by the Australian Medical Association when, for example in 1990, the then newly elected president of the AMA called for the "abolition of consumer groups and complaints units who offer comment on the performance of doctors" (AMA 1990 in Robin Watts 1991:91).
In terms of research priorities and funding it is clear that the curative focus is still highly regarded and highly funded. In 1988 figures regarding the funding allocation of NHaMRC grants show that $ 1 840 913 was allocated to genetically related research such as invitro fertilisation and embryo research while community health research was given $ 160 805 (Robyn Rowland 1992). Who of us has not heard of IVF programs which aim to cure infertility compared to those of us who have heard about New Parenting Groups whose function is to support new parents and prevent post natal depression, child abuse, isolation and poor child development?

Indeed "the great publicity given to such spectacular medical procedures as open-heart surgery and organ transplants tends to make us forget that many of these patients would not have been hospitalised in the first place if preventative measures had not been severely neglected" (Fritjof Capra 1982:134).

Given this, it becomes easier to understand peoples scepticism about the systems ability to change and the complaints of 'lip service' in terms of asking people their opinions. While community participation and public involvement in health are becoming increasingly popular goals identified in Health Department planning documents (Blue Mountains District health Service 1993; National Health Strategy 1993; NSW Health 1994) one senses a 'set up' of sorts.

That is, unless we are also prepared to consider changing our research and funding priorities then what is the point of asking people for their opinions and their input. In fact powerful lobby groups within the health system itself do not seem to support this practice." Some of the major obstacles to people's participation in health are to be found in the attitudes and practice of the medical profession" (John McDonald 1993:104). This can clearly be seen when one looks at professional journals. A review of the AMA journal
The Medical Journal of Australia, over the years 1989-1991 found that it did not contain any articles relating to public involvement! (Robin Watts 1991).

- **Power and knowledge**

  "Professional; power and prestige is contingent upon the acquisition of specific knowledge and skills which are exchanged for money in return for a service" (John Ashton & Howard Seymour 1988:37).

If power is knowledge, then it is clear that the people to whom we spoke are powerless in terms of health. That is they knew relatively little about community health and next to nothing about the ways in which the decision making process in the health system actually happens. Furthermore, many people stated that they felt that they could not be involved personally as they 'knew nothing' and they even discounted their life experiences 'that doesn't seem to count for much'. We have, it would seem, been very effective in encouraging people to believe that they have no place in the decision making process as they have no knowledge that counts! The more people who believe this, the greater the demand on 'others' having to provide health services.

The people who have the knowledge that counts - and therefore the power - are those people deemed experts in the health system, that is those people who support and co-create the medical model:

"In the history of modern medicine, the grasp of power by a male professional elite involved a long struggle that accompanied the emergence of the rational and scientific
There was, however, a sense that this is not how it should be. People felt that decisions should be made in partnership with the community and that power needs to be redistributed, to be shared more equitably. There were many suggestions as to how this process could be begun from the obvious to the more creative. What was clear though, was that there needed to be a series of strategies put in place to involve, encourage and inform as many people as possible. Interestingly, during the process of the interviews many people felt that they would like to be further involved in the decision making process. It would seem that something as simple as asking people for their opinions, thoughts and feelings, was in itself empowering and that through dialogue people feel committed to take action (Paulo Freire 1985).

There is however, an urgent need to act, now, and to stop hiding behind words (John Ashton & Howard Seymour 1988). The actors though, need to be aware of and plan strategies to cope with the potential fall out from their activities as it would seem that involving the people, the community, in the decision making process is an act of subversion as "despite the official rhetoric, government initiated programs in community health have not been about power sharing or substantial social change. Such change would threaten the basis of bureaucracy itself, including the power of the so-called experts who run the bureaucracy" (Alan Peterson 1994:122). These 'experts' may not take too kindly to having a more knowledgeable and more powerful constituency with whom they have to share (Erica Bates & Susie Linder Peltz 1990).

- **Consultation or participation?**

"Participation .... is a revered idea that is virtually applauded by everyone. The applause is reduced to polite handclaps
however, when this principle is advocated by the have-not’s
.... And when the have-nots define participation as a
redistribution of power" (Sherry Arnstein 1971 in John
McDonald 1993:96).

It is worth considering the differences between consultation and
participation, words that are often used interchangeably but actually mean
quite different things. Consultation means that we are going to ask you your
opinion, but decide what we are going to ask you about and furthermore
what we do with your advice. We could thank you kindly, say we have
consulted you and then continue on with what we are doing. Participation
on the other hand, is more suggestive of partnership and the sharing of
questions and answers. If we are operating from a participative framework
we might ask you what you think the questions should be and then how we
could work together at finding the answers. In this way we are beginning to
redistribute power (John McDonald 1993).

When the people to whom we spoke complained of lip service being paid to
public input it would seem that they had in fact been consulted but did not
feel that they had participated in the decision making or problem solving
process.

Sherry Arnstein’s (1969) ladder of citizen participation (in John Ashton and
Howard Seymour 1988:38) offers a useful framework in which to consider
these differences. The ladder moves through the least participatory method
of decision making to the most participatory. As we embrace the rhetoric, if
not the practice, of community participation in health, it may be worth our
while to decide which point on the ladder we are all talking about.
In terms of this story and the comments that people made during the interviews, we are aiming for Partnership. While this is still a long way from total citizen control of the decision making process we, and the people to whom we spoke, believe that partnerships are achievable for both the community and the system itself.
THE SERVICE USERS STORY
I wish I knew how it would feel to be free,
I wish I could break all the chains over me.
I wish I could say all the things that I should say,
Say them loud, say them clear for the whole world round to hear.

(From Nina Simone’s version of the Billy Taylor song In Robin Morgan 1984)
Introduction:

The service users proved to be the most difficult people to access in the whole research project. Whilst frustrating at the time this it how it should be. Issues of confidentiality and protection of peoples rights and privacy are even more important when people are dependant on the service of which we wish to ask their opinions. It was important to act with even greater care and sensitivity with this group of people than with non service users or other service providers.

- How the stories were told: the process

Initially I attempted to gain participation of service users by asking staff of community health, via the manager of the centre, to give all their clients a copy of a letter, introducing me, the research project and what contribution we wished them to make. This approach resulted in 1 response. Disappointing to say the least!

I then attended a staff meeting to ask staff if they felt there was another way that we could encourage service user participation in the project. We agreed that staff would find it easier to tell their consumers about the research project and ask them if they were interested in being involved. Telephone numbers of people interested were then passed on to me to contact the service users. This method proved to be more effective, with 26 potential participants.

I telephoned each person, asking them if they were still happy to be involved in the research. This phone call often resulted in another brief overview of the research, their part in it and the steps I would take to ensure confidentiality. It was also a good way to start making connections with people, of building a relationship.
Of the 26 people to whom I spoke 22 agreed to be interviewed. The other 4 either said that they had changed their mind or did not return my call. This I took to be an indication that they did not want to be involved. I did not pursue anybody, other than the one phone call, as I did not want to exert any pressure on them to take part in the process.

While relying on staff to ask service users if they would like to be involved did mean that I had a group of people to talk too, there was the possible negative effect of staff screening the consumers. I am of course grateful to the staff for taking on another responsibility, possibly one for which they could see no direct benefit for them and do not wish to detract from their effort.

However, personal conversations with some staff confirmed for me that they were consciously choosing people to whom I could speak. I was told things like 'well he is quite articulate and opinionated you will have a good talk with him', 'she is really sick at the moment I won't ask her but her friend is feeling OK I will ask her'. This was particularly true of home nursing, palliative care and counselling service users.

For new parents the staff person would often ask the new parents group, as a group, if they were interested in being involved. The risk of 'screening' was, therefore, less.

You could say that staff were exercising their duty of care, not wishing to stress service users who were quite ill, or not wanting me to 'waste my time' talking to people who they felt had nothing relevant to say. The effect though, could be seen to be patronising and by not allowing people to make decisions for themselves we may not have enabled all people who wished to speak to do so. Probably both are true.
Whilst problematic, this way of accessing service users seemed the least threatening for them, the most personal and enabled them to have as much control over their involvement as possible.

- What I heard:

The in-depth taped interviews which lasted between 30 minutes and 3 hours took place at the home of the participant at a mutually convenient time. They were as relaxed as possible following a conversational style (Janet Finch 1984; Ann Oakley 1981).

For many people I let them tell me their story, only asking questions at the end if they had not covered the particular issues I was interested in. I was surprised, delighted and at times humbled at the care most people took regarding the process. Many people commented that they had tidied up the house as I was coming, some had gone to the trouble of providing morning or afternoon tea. In all instances I was always offered a drink and somewhere comfortable to sit. It seemed as if we were both taking great pains to make each other as comfortable as possible.

This mutuality surprised me to begin with as I felt that the participants were giving primarily to me. However as the process continued I began to appreciate that many people valued the opportunity of having someone to talk to, someone who was interested enough in what they had to say to tape their thoughts and ideas. For one or two this was the first time they had been able to tell their story uninterrupted without anyone trying to fix things up, just someone who listened.

Many of the stories were full of joy, especially those of new parents, whose babies often got in on the act - and the tape recorder! Occasionally there
were traumatic stories of birthing, or difficulty with knowing what to do with the first baby in the house.

Other stories were difficult for me to hear, filled with pain, loss, trauma, courage, anger and for some people, impending death. Still others were stories of peoples struggle to overcome adversity in many forms.

All were moving for me, a stranger to these people who let me in to their lives.

Most of the people to who I spoke were full of praise for the services provided by community health. Many spoke of the fact that they would hate to see the services disappear, and sought reassurance from me that this was not my agenda. Those people who did have a complaint or anything less than positive experience were few and often chose to put the issue down to 'personalities'. None had ever given the health centre formal feedback of any kind.

People spoke to me for many different reasons. Some stated that they wanted to 'give something back' to the staff of the health centre. Others were keen to 'have their say'. Many were genuinely interested in the research project and helping me to conduct the research. Only one or two believed at the outset that they had interesting and useful things to say. A number of people said that they were not sure what they had to say would be of use, or that they couldn't understand why I would want to talk to them!

I felt privileged to have been in the position of the collector of their stories and of being able to explicitly value what each said.
• **Meet the people to whom I spoke:**

We, the inquiry group, were interested to know something about the type of service users who took part in the interviews. We wanted to know if we had only accessed users of more than one service or not, whether women and men were both represented in addition to age variations and ethnicity. Additionally, we believed that this information would provide you, the reader, with a richer context for the information that follows.

Overall, there was representation of all age groups, suburbs, and services which was pleasing especially the allied health service users, many of whom used the counselling service, as we had believed that these people may be the least likely to want to be visible in any way.

Eighteen of the people to whom I spoke were women and four were men. Most (8) were between the ages of 26 and 35 with four people in the 36-45 and 46-55 age groups. Three people were 66-75 and one person was in the 18-25, 56-65 and over 75 age groups. This reasonably reflected the ages and genders of service users expected as I spoke to 11 people who used the early childhood service - these being new parents predominantly women; 7 home nursing service and/or palliative care users and 4 allied health service users.

The majority of people (10) lived in the suburb of Springwood with the next largest group (4) living in Blaxland. The remainder were spread in ones and twos over the suburbs to whom the lower Blue Mountains community health service was responsible. Again, these numbers are not surprising with Springwood being the largest population centre of the area, followed by Blaxland.
In terms of occupation 11 people were in paid employment, 5 were retired and 5 worked at home doing home duties.

The local population is predominantly white anglo saxon with about 5% of the population coming from non English speaking backgrounds. Sixteen people were born in Australia, three in the UK, one each from New Zealand and Canada and one from Germany.

Whilst the research and interviewing process was intended to be all encompassing we did not specifically target people from a non English speaking background. It would appear that we did not enable people from these backgrounds to be part of this research and is an issue we need to be aware of in future. Indeed it raises the question of access to services more generally for people if, they are not targeted directly.

Themes.

1. Feelings and experiences of community health services
   * satisfied customers
   * an under resourced and undervalued service
   * room for improvement

2. Service from health?
   * medical practitioners - useful to a point
   * powerlessness in the system
   * hospitals - temples of death

3. Community Health - difficult to access
   * lack of knowledge and information about services
   * people at crisis point
   * waiting lists
4. Decision making
* day to day - a variety of experiences
* decisions are made by out-of-touch-'others'
* how it could be experts only or partnerships
* barriers to partnership.

Theme: Feelings and experiences of community health services about community health services:

The interviews usually began with us talking about the community health service that was used, how they felt about that particular service and community health in general. By far the strongest response was one of satisfaction with the service and in some examples people were pleasantly surprised at the level of care and attention they received.

"We were really amazed right from the word go at how much help was available I think for us and it's been great everyone has been really helpful we got considerably more help than we thought we would get when we left hospital."

"What we thought was going to be a bureaucratic visit turned you to be an incredible support network."

"They've been invaluable to me. Can't tell you what help they have been, so good and I really wanted to help myself, just before I couldn't."

Many of the participants had experienced both group and one to one support and service from community health. The one to one support in terms of counselling, home visits from community nurses or attending parent and baby clinics was seen as invaluable.
"I'm amazed by them you know I'm amazed at what is available when you actually need it and how you can get I guess individual assistance but that is tailored to what you need.'

"We had about 6 very close sessions ..... I also think that it is very valuable in my case I know I was very down and through her we sat down and we formed a mutual understanding on what I was going through and her efforts were very valuable to me."

"It's like a back up you don’t feel so lost you have someone you can ask questions to."

Additionally participants appreciated the group support that they received, either from self help groups or new parents groups.

"I wouldn’t really have met anybody not going to a mothers group and we are going to meet once a month to keep in touch so I just find that really useful."

"I have gone to the cancer support group which is a marvellous support group."

Many spoke of their feelings that more support could and should be provided in a group context.

"They should be saying, well I want you as part of your treatment is I want you to go to a support group and I want you to spend 3 or 4 visits to a support group and just see if that person improves."

"Say people like me come to a certain stage and they would sort of meet as a group or something, look I don’t know what I am saying, and well maybe what I am trying to say is that I would be frightened to think that these services would just disappear when it’s so necessary and I mean if there is a group that could get together and
support whatever field like counselling or even bereavement counselling."

"I just wondered did ask actually whether there would have been some sort of self help group that you could go to or you know, like, I can't for the moment just think, or even say for self esteem and things like that some of those other workshops that you hear of from time to time for women and helping you to understand yourself a little better but I was told that there is nothing really available."

Some participants who were using a service in the form of a group did feel that this could be improved.

"I would have liked to have seen firstly a lot more of the group and a lot more sort of, without being too airy fairy about it, more sort of introductions in the beginning, sharing the experience so that you had a good ground work and then reasonably structured information."

"There is not much interaction with other mothers or whatever it is just with the nurse, the community health nurse."

Although most participants were happy with the service they used, the majority talked about their feelings of community health appearing to be under resourced. This was not a question I asked of them, rather they volunteered this information, in most instances as soon as they had the opportunity.

"They do deal literally with birth to death it's certainly underrated."

"They are over worked and under resourced."

"I was sort of, have been under the impression that they are a bit stretched."
Participants made sure that they reiterated the fact that they were pleased with the service they used while at the same time talking of lack of resources. It appeared as thought hey were taking pains not to complain about their experiences of community health while at the same time knowing that there were not enough resources.

"They seem to be in the run the whole time ....... they are very caring professionals often overworked and underpaid from the hours that they seem to work."

"I think they do a wonderful job, I think they are pushed to the limit from what I've seen and they are all very dedicated and I think they do wonderful job but they are very thin on the ground"

Despite the general feeling of satisfaction, even pleasure with community health services a small number of people took the opportunity to voice some concern over the nature of the service

"It's good for people who are go getters but it just worries me that there's this gap there that people fall through it and I know, people like with this friend of ours, but it came down that she probably needed some help but she just slipped through them and I could see how if she went along she would answer the right questions ... she always answered the right things with us but you knew there was more too it than that but you know she was just having trouble coping."

or a particular individual in the service. When talking about particular individual experiences participants were careful to not mention any names of individual service providers.

"this district nurse took me in and had a chat about all other sorts of things and eventually got around to asking how I was and said ' I may as well write this down' so wrote it all down and I wonder, it's only my thoughts that she might write it down as a visit so I don't know that
that's true but I hadn't seen her and the other lady used to be so caring and so good but this one is only interested in holiday photographs wasn't really interested in my concerns, my anxieties."

"She actually mentioned her name and I know who it was but I'm not about telling tales but I fear for people who need better care and yes I have been tossing it around whether I should bring it to the attention and how I am going to do it. I don't think that you should have to put up with rough treatment when you are in a situation, I don't think anybody should."

"the first home visit was a bit disastrous."

In these instances I asked the participants if they had felt, or did feel, able to bring their concerns to someone's attention. None did, preferring instead to talk of the issues as conflicts of personality.

"It's a waste of my time and hers, she might be great for other people but not for me."

"I get along pretty well with anybody and there would be certain situations where patients clash with their nurses."

Theme: Service from health?

The discussions about feelings of community health services in many instances led people to talk about the health system in general. Again this was not a direct question asked of participants but reflected what they wanted me to know about their experiences.

A number of participants, particularly home nursing and palliative care users had stories they wished to tell about doctors, both G.P's and specialists. On the whole what they had to say was critical.
"I don’t dislike doctors but the majority, they are earning a living so they are looking at the easiest way they can earn the most money in the shortest possible time."

"The good ones {doctors} are really good, there seems to be a gap there, you know, and they get away with it, it’s just like it everywhere you know, you’ve got the guys they are just out of it, they just don’t seem to care they might have the bums on seats but."

"You might have the best surgeon and the best specialists in the world but if he has 50 patients a day, I don’t know 25, 50 patients a day to see and he’s running the whole time he doesn’t really give each patient what they need, the time they need ... I wouldn’t like to think that specialists are greedy, I mean that might be true in some cases."

Other people spoke of the fact that you used the doctor when you wanted to and for what you wanted - and nothing else.

"You go because you need antibiotics because you have got a cold but you wouldn’t let him touch anything else."

For some people it appeared as if they were not treated as a whole person, that the disease, not the person was treated.

"They did say that I would put on weight that’s all and I’d have a very big appetite and when I said to the doctor that my skin had broken out he said ‘that’s normal’ and I thought well, thanks for telling me. Now if I knew in advance I could cope. I guess it’s up to me the patient to ask questions, sometimes you don’t know what questions to ask."

"They don’t treat you they treat the cancer they don’t seem to be aware that you have got children to rear, you have got a husband and you want to continue on and your body does not want to be filled to the brim."
New parents spoke about their feelings that doctors were not always in touch with their issues and would rather access community health staff.

"I don’t think it is good if it is with a GP because a lot of the time they don’t have the questioning technique and then you know the ability to be in tune because they are not dealing with mothers all the time you know or fathers, who ever it is that are the main carers."

"For some things you don’t want to dive off to the doctor all the time and I think too what I have found is that they [community nurses] are more in touch with what’s going on with young children because they see so much."

Many people felt quite powerless in terms of the health care system as a whole. For some this was experienced as not being heard, not having an important voice.

"We haven’t got a big enough voice that’s why we don’t get the funding."

"It’s like the homosexuals today they are very political, very obvious lobby so there is lots of money spent. Well until now women have not been that way and heterosexual males are even worse, but women have to some extent not spoken out enough."

Others, particularly those who had a terminal illness, felt that hospitals were likely at worst to kill you and at best to be uncaring.

"In hospital they tend not to feed you .... they have made up their minds you are going to die."

"Most of us have realised that the last place you should die is in hospital ‘cause you do die, they stick you in a little room and make sure you die."
"I've got to know a lot of nurses in the hospital and I find, personally, with some nurses you get the feeling that they don't really care."

One participant was very sceptical of health department practices which they believed did not give people correct information, rather tried to convince people that their service was of use.

"They don't want to panic people so they rush around with their stupid looking caravans making people believe that they are going to be found out and cured and they are not well it is it's a way of stopping the community from panicking."

While the experiences and feelings of the health system in general was not the focus of this research these issues are those which people wanted me to hear and to know and as such are important to this study. Additionally, as we move more towards hospitals in the home via early discharge and more complex home interventions and treatments it is important to know who it is that people trust and which services they value.

Theme: Community Health - difficult to access.

Participants were asked how they accessed the service they were using and what other community health services they were aware of. People who had not been directly referred to community health spoke about the difficulties of finding out what was available and the general lack of information about community health services.

"It was really this business about not knowing where to go and who to talk to, or how to actually access the services and whether or not I qualified for them."
"It's nice to know, well then you know you can ask, you know, if you don't know it's available it's hard to ask about that sort of thing."

"You don't really have much idea of what is available unless you actually go out looking for it. It would be better if there was more publicity about what you can get help for if you need it."

"They say the services are there but accessing them is very, very difficult."

The general lack of information and knowledge about services available was seen to impact negatively on people in the community, people who often had to reach crisis point before they were referred to a service.

"I think they need to know more about what is available, you know people with sick relatives aren't aware of what is available you know they are at home with probably no one around to help until they really get to the stage of collapse before somebody does anything about it."

"I always question why it was necessary to allow a person to get into that state of health under the weight of it all when we were crying out for help, he was crying out for help and just nobody would come to your assistance when you needed it .... a little bit of assistance somewhere along the line would have been tremendous."

The majority of participants had very limited knowledge of other services offered by community health.

"Oh, they do physiotherapy as well, what else do they do? I know they have got a doctor there I saw a whole heap of stuff, counselling, physio."

"I've seen the notices for that on the notice board at the clinic for speech pathology and hearing but nothing for like drug and alcohol abuse."
Those who did have a good knowledge of community health were usually school teachers who had a community nurse located in their school or were extremely active in the community.

"I knew there were community health centres around and then I suppose that was because of my work."

"They do palliative care, they look after older members of the community who require things like help with dressings and well not older I guess anyone who needs minimum nursing care at home they maintain contact I guess with older members too even if it's from the sound of it sort of a drop in and check on medication and that sort of thing they do, when they are based at the school which I think most of them are they do kindergarten prevention and they test their eyes and ears and speech and stuff like that Paula helps me out with speaking to kids about health issues at times."

"Well I'm into a lot of things in the community so fortunately I am very community wise."

In terms of the services they were currently accessing many people were unsure as to what to expect and the nature and extent of the service. This lack of knowledge did, on occasion, act as a barrier to accessing the services.

"Like I said earlier I didn't know. The Mum's group was mentioned to me initially .... if I'd have known from the word go that what they basically do, they just give you showings of videos and talking about settling, teething, weaning and all the rest of it, but teaching you how to look after your baby I would have gone earlier instead of trying to struggle along I would have gone earlier."

"I didn't really know that they helped as much as they do."
"I don't know where it starts and where it stops."

A further barrier to accessing community health services were the waiting lists. This was relevant to allied health services such as counselling, physiotherapy and speech pathology.

"There is always a wait, a wait with getting in to see any of them."

'The only service I have used is the social worker and I 've been going there since I think it was February, early February and I was referred to that by a local doctor and I rang up Katoomba and talked to them up there and they said I might have to wait actually anything from 3 weeks to 3 months. And I thought golly, you know and I mean if you are feeling a bit like I was, a bit up tight and desperate what do you do in the meantime, just sit and chew your finger nails?"

This is certainly an issue in terms of health promotion and disease prevention. In these instances it would seem as if community health is operating well and truly from within the curative framework of treatment.

Theme: Decision making:

The major focus of this research was community participation in decision making in community health. Participants were asked direct questions about this issue. Many found these difficult questions to answer as to this point the interviews had been focused on them and their individual experiences and feelings. Additionally some people had not thought about this issue before " I don't know, nobody has ever asked me before."

To help ground the more general question about decision making we often began by talking about their experiences of decisions making in relation to the service they received.
These day to day experiences of participants reflected a polarity of involvement in decision making. Some people felt that they were encouraged and able to ask for what they wanted;

"There was also a lot of scope I think to ask for something if you had a particular interest or a particular problem that you wanted covered."

"Oh we could have said anything we wanted to really it was entirely up to us what we wanted .. what our problems were to what our solutions, what solutions we favoured."

Others spoke of instances where changes in services had been made with no apparent consultation of the service users;

"The immunisation is a bit tricky too because it was 3-5pm, now that's difficult for people that work and with children to pick up

Pick up children from school?

And I think it's changing. There was no contact, no contact with the service user. There was a notice in the Gazette which is the local paper to say that the Glenbrook one which is where we go is changing to 1-3pm or something

But nobody had been asked?

No but, and I've not seen anything from the health department. Anyway, you know these people, they all work for the health department and I suppose the cynic in me didn't expect anything but that means you've got to do something about it."

Still others were told what they would get and the manner in which they would receive the service.
"Actually I was just told that, I didn't know who I'd go to see at that particular time I just wanted someone to talk too and get some advice and counselling I didn't know who or what type of counselling it would be and I was told, you know, that I could ring and make an appointment with her and that she was a social worker and I presumed that that was chosen when they had their meeting because they explained that they had a meeting and everything so I presumed that that was what was available at the time."

Having discussed their personal experiences of decision making at a service level participants then moved on to talk about how they believed health service decisions were made. Participants reflected a belief that decisions were made by others, usually bureaucrats, doctors or politicians.

"I feel it's the health commission that makes the decisions at the moment in consultation with regional managers."

"Unfortunately when they talk to people about the health system they talk to doctors."

"Well unfortunately the politicians are making them and by building a great big hospital it looks as if the government is busy with health care."

If this is how people saw decisions being made they were not satisfied this process, often feeling that the decision makers were not in touch with the real needs of people.

"I suppose the administration of area health they make the decisions but I've felt for a long time, I know this mightn't sound good, I think sometimes they have been administrators for so long that they have forgotten and they do a good job I don't mean that, but I think they've just forgotten what it's like to be wanting the services."
"Basically they are too far removed from the day to day situations to be able to recognise things and even if they were to take up an issue the outcome wouldn’t ever be exactly what the people wanted because they would be looking at a different perspective."

"People who make decisions I think they have got to listen more to what people say and not just sit behind their desks and say well look we’ll draw up these little guidelines and this is what we’ll do and probably haven’t even stepped out of their little air conditioned office. I think they have to get around, talk to people in the streets, different walks of life and find out how they feel about it."

Many participants, while voicing dissatisfaction with the way decisions were made did have ideas for how decisions could be made differently. Some felt that only a certain type of person should be making the decisions either experts in the health system, the government or the service users.

"It must come from the federal government ... and you must have a strict control on that money."

"Doctors, medical people that are perhaps it would be a good idea to have input then I suppose you do have to have people in charge to make decisions."

"But it should be made by experts in the trade and I don’t mean doctors because they tend to look at things in a money way."

"Should be the ones that are doing the work."

"Yeah well I guess it applies particularly to people who are using the health system now, the community health system now people like me who are going up there and using the baby health centre and going to the new mothers group they are the people who are going to be interested in what’s available and who probably are going to have the best ideas about future needs."
By far the strongest response was one for a combined approach to decision making. An approach where health providers, administrators, service users and the community jointly made decisions.

"I suppose part of that is .. letting the community know about the kinds of services that do exist, raising awareness, having more dialogue between people and services so that people are then able to express what their needs are."

"I think the community should play a big role but a balanced role because the community sort of they are driven by their own needs."

"Probably a combination. You probably need the administration people because they know the right way and the right guidelines but yeah probably if they had some people from the community."

While talking about how it could be, in terms of decision making, participants identified a number of barriers that they felt did not encourage participatory or joint decision making. These barriers included the under resourcing of community health, powerful vested interests and the difficulty of culture change within organisations.

"They {community nurses} are overworked and under resourced they are not going to, it’s difficult for them to come along to the service user and say well what do you want?"

"Not doctors, not people, it really can’t be someone with a vested interest. You see doctors have got a vested interest, politicians have a vested interest, you know they want hospitals to look so big so that the community thinks oh well the government is doing something for us."

"They are going to have to change the culture of the whole organisation and that’s a worry because there are going to be people
there that aren’t suited to that and you’ll have to get rid of them if they are not won over.”

**Conclusions**

The consumers voices are extremely important, and sometimes difficult to hear. The participants gave their time and their energy in sometimes difficult times of their lives in order for us to gain a more complete picture of the services provided by community health locally, in addition to thoughts and ideas of decision making processes in health. Community Health is seen as providing a good service and people are more or less satisfied with the service they use.

The overall feeling that we got from sharing their stories was one of sadness.

Sadness that is not acknowledged or recognised on a daily basis. For many people, coping with illness of any kind or bringing a new child into the world involves struggle. The struggles were different for all the participants and related to their context, their supports, and the nature of what was different for and about them. We were able to see a glimpse of the whole person, as a result of this process and this glimpsing we were left with a feeling of pathos.

There is a subtext to this story, one which we as a group felt and became conscious of through reading the transcripts. In terms of their relationship with the health service, the people to whom we spoke felt powerless and were treated as such. We do not want in any way to cast the participants as victims, requiring our pity, or as people who are powerless in all aspects of their lives. Mostly these stories were of people engaged in some form of struggle and this struggle involved living their whole lives with relationships,
families, work, homes all being cared for and negotiated with - in an active sense.

We felt however, that many consumers were treated as patients and not people, that they were placed in the sick role, one of gratefully receiving a service that was decided for them and not asked for their input or feedback in any structural way. This was true for new parents as well as those people who were either physically, mentally or emotionally ill or in need of support.

While a number of people were critical of other health providers and hospitals they were not so about services at a local level. This could be because the more local services are meeting their needs more effectively, or because the relationship is more personalised and individualised.

Many participants saw the interview process as a way of saying how wonderful the service was, not as an opportunity to offer ideas, critiques alternatives. Whilst offering glowing praise, on the most part, they also said that it was under resourced. Yet how can they know this without it having some impact on them, without them experiencing this lack of resources. Did they feel rushed, not wanting to take up too much time or ask difficult questions. Is it a way of keeping people feeling guilty at taking, for themselves, some of this scarce resource? Is the service under resourced or is this climate created by the service in order to minimise contact with consumers in some way?

It would seem as if the participants were, to some extent, treated as passive recipients, not as active users with any choice and limited power in the relationship. The participants in this study were, I believe, systematically constructed (Victoria Grace 1991) to be 'passive consumers'. This was and is done in three ways:
1. Providing limited knowledge and information about services available and decision making processes. We are not advocating that given the correct information peoples behaviour will change (Alan Petersen 1993) but rather that information is a form of knowledge and that knowledge is a form of power (Robin Morgan 1994). By not having information/knowledge participants have limited power in their relationship with health services.

2. Having no structural support for feedback and input mechanisms. Any that are in place are limited. People are grateful for the service they receive and were fearful that it not disappear or be cut back. The services provided are mainly individualised, with the expertise coming from the staff to the service user. There is not a two way exchange of knowledge, experience, no reciprocity in the relationship and is hence dis-empowering.

3. 1&2 are reinforced by the health system and how decisions are seen to be made by 'others'. The rhetoric in a number of health department documents (Blue Mountains District health Service 1993; National Health Strategy 1993; NSW Health 1994) advocates for participation of consumers in the decision making process. What is unclear however is if this is to be a participation based on equal power relationships, or if this participation is to be controlled and constructed so that service users are maintained in their grateful and fearful positions. If this is so, the health department are engaging in a process of social control and regulation, albeit dressed up in the fancy rhetoric of empowerment, rather than radical social change (Russell Caplan 1993).
THE STORY OF 'OTHER' SERVICES
"Despite the official rhetoric, government initiated programs in community health have not been about power sharing or substantial social change. Such change would threaten the basis of bureaucracy itself including the power of the so-called experts who run the bureaucracy. ...... groups who are dependent on government funding are themselves vulnerable to developing those very same bureaucratic structures and processes which they set out to avoid."

(Alan Peterson 1994:122)
Introduction.

This part of the overall research study was a collaborative process involving a research assistant, Lucy, who undertook this work as part of her major undergraduate research project and Debbie, the principle researcher. In order to honour the collaborative process we worked together, with advice and input from the research working party, in the planning, implementation and writing up of this part of the project. It must be acknowledged, that Lucy undertook the majority of this work; organising and conducting focus groups, collating the information and taking the lead role in the eventual writing up of the story you are now reading.

Here we have focused on hearing the voices of people who provided important community services in the local area including neighbourhood centres, home care, migrant services, the council, GP’s and one paediatrician.

All community services in the local area were sent a letter explaining the nature and purpose of the research and asking for their involvement. This was then followed up with a phone call. Six services agreed to take part in the study. The service workers then took part in a focus group which discussed their relationship with community health, the issues for the local area and feelings about community participation.

GP’s and the paediatrician were approached through the local GP’s forum, where the research was again explained and people at the forum were invited to be part of the study. The GP’s and the paediatrician chose to be interviewed individually rather than take part in focus groups.
• How the stories were told: the process.

Each group and interview took place at either the community centre or the persons place of work. In the case of the focus groups, information was collected via butchers paper, where key ideas and issues were written down and validated by the group on the spot. Each meeting was also taped and later transcribed.

Interviews were taped and a summary of the interview was written immediately afterwards using the tape as a prompt. The summaries were then sent to those people who wished to receive them along with the question 'is this a fair and accurate summary of our conversation?' No one chose to change or add anything to their summary.

All people gave freely of their time, thoughts and feelings regarding the issues and we received important information about community health and the issues facing the people in the local area.

• What we heard:

Overall there was a great deal of support for the role and nature of community health services in the local area. People acknowledged the difficulties faced by this service and commented on the fact that many of these issues were the same for them. The increasingly bureaucratic nature of all service provision seemed to be a bone of contention for many people and was seen to hinder flexibility, creativity and genuine participation in decision making by the community and service staff.

We also found that this group of people were the most critical of community health services. This, we believe, was due to the nature of the
relationship. The relationship was more equal, than that say of the service users, in terms of power and knowledge. None of the people who took part were dependant on community health services and all had a good knowledge of the local area, services available and the issues facing the community. Additionally many people worked actively as advocates for sections of the local community who traditionally do not have a voice: the less advantaged, women, migrants, the elderly. As such they were used to, on a daily basis, speaking out against injustice and poor services.

**Themes**

1. **Access to community health services**
   - lack of information of community health
   - the inaccessibility of community health to potential users
   - access is only available in crisis situations
   - alienation and systems abuse of users

2. **Poor resourcing of community health**
   - impact on collaboration and communication with community organisations
   - impact on staff of community health
   - impact on health consumers

3. **Community participation**
   - participation not consultation
   - participation as partnerships
   - perceived barriers to community participation

4. **Strategies for change**
   - improving information from community health to the community
   - networking, outreach and collaboration.
Theme: Access

Participants in the focus groups and the interviews spoke of barriers to people using community health services. These perceived barriers included: lack of information, transport issues, the hours of opening of the community health centres and the fact that, for many of the services offered by community health, there are waiting lists.

Transport and the geographical location of the community health centres was an issue. It was felt that the centres themselves were not in accessible places for public transport. Furthermore, it was felt that often people were required to travel long distances to access services which participants felt should be offered locally.

"My issues with community health in the mountains is the location of the services and the lack of access due to transport difficulties."

"Community Health is only open 9-5. For working parents there is no access whatever for them, in fact community health is not catering to a very large group in the community."

"The waiting lists are huge."

"There's no point getting hoards and hoards of people in and putting them on the waiting list."

The participants felt that the community were not aware of the services offered by community health, indeed many of these participants did not have this knowledge themselves. As they were all in a referring relationship with community health this is a matter of concern.

"Community Health need to give out information about what's available. Doing a fair bit more promotion."
"I think it would be nice if community health regularly, at least annually, provided a list of their service."

This perceived lack of knowledge about community health can serve to maintain the medical model. People knew about home nursing, early childhood clinics, 1:1 counselling but had little knowledge of other, health promoting activities of community health. Participants spoke about "community nurses", "district nurses", "sisters". That people do not know what is available suggests that community health are not in touch, there is no apparent conversation happening between community health and its community.

Participants felt strongly that in order to access community health services people often had to be at crisis point. They are then labelled/categorised so that community health are in a position to provide them with a service.

"There is a lot of red tape around who community health can help and who they can't."

"She reached the crisis point that she was nearly on the verge of being put into St. John's and I had to get the nurse to come very quickly. But that need not have happened had they been given the help along the way that they needed. They were crying out for it and kept getting knocked back."

Many people commented on the alienation felt at the use of acronyms and jargon by community health services and personnel. This was specifically emphasised by the service which had the closest geographical and personal links with the health centre. They felt that jargon and acronyms alienated the community and further reinforced negative power relationships between service providers and service users.
"service providers separate themselves form the community by using acronyms and jargon."

Once people had managed to access community health, despite the aforementioned barriers, there was a strong belief that people who wanted to use the services, specifically the counselling services, had to go through a process of telling and re-telling their story before they actually received any service. The structures that community health put in place in order to match a potential consumer with a counsellor was seen as a form of systems abuse of people already in vulnerable situations.

"the intake system at times is difficult both from the point of view of that it sets up a barrier in a way that you go through the intake officer and the intake officer will decide who they will see...it is a big step to say 'I am having emotional problems' and they have to keep repeating the story...so that is the biggest problem."

Another type of 'systems abuse' spoken about included "health rush out and ask peoples needs, when it comes out it doesn't resemble the idea." That is, the 'system' asks people for their creativity, time and commitment and then abuses this gift by not integrating this information in the final product.

Theme: Poor resourcing of community health.

Everybody we spoke to talked of the state of funding of both their own and community health services. Funding was seen as insufficient and as having a large impact on the nature and effectiveness of the work community health do. Additionally, lack of funding was seen to have a negative impact on the workloads of staff.

"they have an in and out type of service because of their workloads."
The under resourcing was seen to effect the relationships between community health and other organisations in terms of the impact on the amount and quality of communication across and between services. Participants wanted increased communication with community health staff but stated that this took time and resources, both of which participants felt community health were lacking.

"difficulty in maintaining lines of communication with community health due to time and money."

"I feel that it is a resource issue more than anything."

One participant felt that this lack of funding could be addressed by reducing the amount of bureaucracy in the health system, "if you want my opinion the whole system is over bureaucratised."

The lack of funding was also seen to impact on the roles of staff and the hours they work. Participants felt that staff in community health were being asked to work longer hours as their roles have expanded. Part of this expansion is seen to be the extra demands placed on community health by the institutions early discharge plans leading to community nurses "having to do more of the medical role and monitoring."

"There is some problem with the way hospitals discharge people without putting in the services before they even get home ... and there has been very little communication between health and community health."

"There is not enough funds within community health services to be able to support them (people on early discharge) and I really see that as a health issue rather than a community service issue."

"There is real confusion about what does what, where, when and there is terrible communication between health. I mean the hospitals and community health centres and home care."
At the same time the boundaries of service provision have expanded. Staff in community health services are seen as being expected to have multiple roles and skills and not being structurally supported in this multiplicity.

"not equipping them to do the services.'

"they are very busy people."

"Government think they can give you $5 for something that costs $10, no acknowledgement of cost increases."

Part of the dilemma around the issue of roles was the expectation that community health staff incorporate primary health care and health promotion activities into their workload.

"I think for community health it's really difficult because when primary health care focus came in they literally said 60% primary health care 40% direct care. And when you try to do that in an environment that is not conducive to that sort of thing it makes it hard when you are not getting any recognition for community development."

"I think that it has been a very difficult process of change over from the medical model."

"There seems to be no health promotion in this area, no obvious health promotion ... but the district nurses wouldn't have time, you need a coordinator."

"people don't want to know about it, it's easier to do once people have something wrong with them, it is easier to work with the curative side of health. You could pour a lot of money into community health for health promotion and it would be a very slow process before you get any outcomes, but that is not to say that it shouldn't be done."
There is seen to be no structural support for health promotion in community health.

"policies are put in place that make it harder ... I have to provide you with a bill that says I have cured you, not that says I have assessed your health."

"there is a lot of counselling services but counselling quite often is because people say 'oh gosh, we're falling apart let's go for counselling' and I think that we really need to be looking for more projects that can mainly come into preventative care."

"I think that we would love to have preventative workshops and stuff here ... we have these wonderful meeting rooms where they could actually be held but they don't have the resources to be able to allow their people [community health] to come in and give talks."

**Theme: Community participation.**

Participants generally believed that community participation in decision making was desirable and to be encouraged.

"participation should be one of the key measurements [of health promotion]."

"involve people in the process of what and how peoples needs are going to be met."

"I do think that the general public does need to have some input but I do think that you need a wide range of health professionals."

Overall, participants were very supportive and were quite clear that this should take the form of participation not consultation.
"I also think that how community health can act on what people tell them is to actually involve, in not only saying what their needs are, but be involved in working out what and how those needs are going to be met and working n that."

"I think you have got to have all that local planning at the bottom and you have to say to people involved in the whole process and be able to make decisions and be able to say 'OK this is a need for me, it's a need for my next door neighbour and we want to work together to alleviate it.' And when those people own that they work on it."

"they can use the community like a resource if they are part of the planning they are going to understand that their is only this much money. Let the community prioritise. Like if their is a bucket of $90 000 then let the community decide what they really need."

Despite this stated belief in the desirability of involving people in the process of decision making in health there were a number of barriers identified.

"That's why I think there's a real gap in health in that they rush out and ask people what their needs are, grab all that information take it up there somewhere and develop the services. But when it comes down to the bottom it doesn't resemble what people wanted."

Participants spoke about the bureaucratic nature of health services and how that disempowers the workers in community health as well as the community. In wanting the community to be more involved in the decision making process the bureaucracy was identified as a barrier due to its perceived inflexibility.

"It is difficult for the larger organisations as we have a bureaucratic organisation and we do have to work under certain guidelines."

"Can I make a difference in the bureaucracy?"

"Don't want to feel tat you are banging your head on a brick wall."
"I guess my concern is when community health talk about participation it is hardly ever at the decision making role, it is at an advisory level and I don’t think that you can get past that in a bureaucracy like health ... no empowerment at all so therefore people soon get lost when they (community) get on to an advisory committee as they know that they can put up really good suggestions but if it’s not taken up further therefore there is no point as you are not being listened too."

Further barriers included lack of time and money, that if we are going to be serious about community participation then it needs to be structurally supported with resources.

"Community Health centres carry a huge range of services and I really think that they need to be better resourced if they are going to be there for the community as the name suggests."

"there is no support form government, they don’t give you money to advertise."

Some participants felt that only people who were users of the service could have meaningful and informed input. That people are more inclined and able to put their energy into decision making in health when they have an issue they are working through themselves. This view was most strongly stated by other health providers.

"In fact I know of a few patients who have started self help groups."

"You can’t go to the general public and ask them what they want form a community health centre if they have never used it or don’t know it existed."

"I think for a lay person it is very difficult to know what is available and what should be available and I think that that is part of the role of the health professional ... to see what sort of service is needed."
Theme: ideas for change:

Participants were forthcoming in their ideas for how community health could facilitate and encourage more involvement in decision making. Most of these ideas focused around providing people with information often via newsletters, flyers, letterbox drops, information and open days.

"Maybe a stall at the ivy market taking blood pressures etc. and then while you are doing that you can ask them what they feel would be the issues in the area."

"A newsletter which is warm and chatty, using people from the community to write it."

"I guess its all about slow change. You can’t change things overnight and I guess it has to be measured, but you can evaluate what is effective and how best you can do the next step."

This also generated discussion among the groups in terms of a raised awareness may increase demand for already over stretched and under resourced services.

People from community health need to meet and network with other service providers, to work together on community issues that are important to the community and to encourage collaboration across services.

"I think people underestimate the huge contribution that networking does to any project. It is just amazing what sort of things come out by just going to lunch with somebody or just going to a meeting about something completely different."
"Whereas if there was more of an outreach, a more mobile ... something that they [community] can access."

"We should somehow have something of an outreach where they [staff] spend time and maybe go to one of the other villages and have a day, or spend some time there so that people can access them rather than all the people having to come by transport."

It was a perceived need that community health should concentrate on health outcomes, what works and what doesn’t and put success stories in the newsletter.

"Giving out information about what is available doing a fair bit more promotion ... they could put out a newsletter ... a chatty newsletter ... and it might be an issue that they want to highlight but they can do it in a chatty way ... you could probably do that by using a group of people from ... the community ... do their own newsletter and community health resource it."

Another strategy that was suggested to overcome access issues in terms of what community health can and does provide was to employ a full time public relations officer in community health and that "funding for a PR person in the centres" would be necessary. In a similar vein people felt that doctors and pharmacists needed to be better informed about the services offered by community health.

Conclusions.

"That’s why I think there’s a real gap in health in that they rush out and ask people what their needs are, grab all that information take it up there somewhere and develop the services. But when it comes down to the bottom it doesn’t resemble what people wanted. I think you have got to have all that local planning at the bottom and you have to say to people involved in the whole process and be able to make decisions and be able to say ‘OK this is a need for me, it’s a need for my next door neighbour.
and we want to work together to alleviate it.' And when those people own that they work on it."

'Up there somewhere' is the bureaucratic structure upon which community health is organised (Stephanie Short et. al. 1993:33) which is seen as obstructing community participation in community health. The ways in which this happens includes lack of community centred information about services and decision making processes; poor funding which is often tied to medical, curative outcomes; perceived inflexibility of the 'system' and the use of alienating language and structures.

"Hummel refers to bureaucratic language as 'one directional language' because it offers no scope for talking back or inquiry. He contrasts it with everyday language which is 'two directional' because it involves communication and allows scope for communication and inquiry." (Alan Peterson 1994:100).

We believe that the time for action has come, action of which this project is a part. "Some feminists complain that research may be a way to avoid action. They advocate taking steps to stop doing research and start doing something about the problem" (Shulamit Rheinharz 1992:177). This action could take the form of empowerment of the community through giving them more information, by ensuring services are accessible, not abusing consumers and by valuing and strengthening the voices outside of the bureaucracy.

There was a general feeling of goodwill towards community health and a sense of collegiality and support for other service providers who were struggling to provide service with an ethic of care under the constraints imposed by poor funding and lack of structural support.
Additionally there was overall support for both the idea and the practice of community participation. As there is this support, and as it is not such a new idea (Scott-Samual 1990) it is time to begin actively putting in place systems and structures which facilitate community participation in health. Any research that is conducted in this area must be community based and participatory in its methodology.

"[T]he intention is to make power relations transparent or apparent in order for change to be possible" (Stephanie Short et. al. 1993:72).

We believe that everybody needs to own some degree of responsibility for why community participation isn’t happening. The community believe the culturally fed idea that people who use private health funds have a 'better' job or are in a 'higher' class than people who don’t. It would seem that the bureaucracy indirectly disempowers people through feeding or brainwashing them into this sort of thinking. Therefore making it harder for community participation to happen. People have to overcome an obstacle of potential public judgement before they will take action to be involved.

"it is evident that a more caring and just health care system can only occur alongside changes in other social structures and institutions...However, the difficulty of change becomes apparent when we consider how strongly consumption is bound up with identity" (Alan Peterson 1994:145).

A lot of disempowerment is to do with this sort of brainwashing and the main output is the media.
"There is little doubt that the media are important mechanisms in modern societies in shaping the dominant culture which links consumption with identity" (Alan Peterson 1994:145).

If individuals made more conscious decisions to be aware of what is being fed to them by mainstream media and other sources then this would, again, pose a threat to the government, and therefore start breaking down the power of the bureaucracy. This would, eventually, allow more people to take action on things like community participation.

"[T]he creation of more diverse media .. provides one possible avenue for challenging the hegemony of mainstream media representations" (Alan Peterson 1994:145).

There are many voices that can be heard throughout this document. The voices of staff and community organisations, the voice of the theorists and writers, the voice of the researchers. Our collective passion has empowered us to enable ours and other voices to be heard. Through the process of this project we have learnt strategies to value and strengthen all these voices and we have learnt that passion can serve to make an active difference.
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Appendix 1: Members of the Research Group:

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Appendix 2: Focus Questions for Interviews and Focus Groups

Focus questions for community health workers:

1. What is your role and how long have you been working in community health? Tell me about your work, what do you do on a day to day basis?

2. What do you understand by community participation?

3. What would you like to do/see being done differently?

4. Do you feel that you and the consumers are valued; do you feel able to make changes?

5. Who do you think should be involved in planning and evaluating CH services?

6. Is there anything you would like to say that we haven't covered?

Focus questions for service users:

1. Tell me about the health service you receive. How long have you been receiving this service?

2. Do you feel that you have any input into the service you and others receive?

3. Would you like to be more involved in the service you receive, if so how would you like to do this?

4. What do you think of Community Health Services?

5. Who do you think should make the decisions about who gets what sort of service?

6. Is there anything else you would like to say?

Focus Questions for other health providers:

1. What is your relationship with community health?

2. What do you feel are the 'issues' of the givers and receivers of community health services?

3. Why do people use/why don't people use community health services?
4. How can community health act upon what people tell them about community health services?

5. What do you see happening now in terms of community participation and how can we value and strengthen this?

6. Would you like to be involved in planning and evaluating CH services in this area? If so, how would you like to participate?

**Focus Questions for non service users:**

1. What do you know about community health?

2. Have you ever used community health services?

3. Who do you think should make decisions about who gets what CH service?

4. Would you like to be involved in planning and evaluating the community health services in this area? If so, how would you like to do this?

5. Is there anything else you would like to say?
CHAPTER 8

SUBVERSIVE ACTIONS: THE INQUIRY GROUP STORY CONTINUES
In early 1996, the Inquiry Group were made aware, quite clearly, of the subversiveness of our work. I include the following months to make clear what was beginning to happen, and how decision makers can often approve of an activity without in any way approving of the outcomes of this activity. The following also details another stage of actions as we sought for ways to ensure that our voices, and the voices to whom we spoke, were heard.

February 1996..........

Most of the meeting was spent discussing the draft research report....there needed to be more emphasis on what we had learnt about community participation .....the main themes needed to be emphasised more, these are: powerlessness in terms of health, medical dominance of the health agenda and services, community anger at its preclusion from decision making and a feeling that there was a conspiracy to maintain the status quo.

This feedback led to some important changes in the Research Report. The main themes suggested were given prominence, something I had hesitated to do, however the group desired not to pull any punches.

April 1996......

look at launching August/September as money is a major problem this financial year......Sandra to approach Dr Barratt [General manager of Blue Mountains District Health] ....Dr Barratt to approach Tom Hamilton [CEO of Wentworth Area Health and then the NSW Minister for Health about launching the report.

I received a phone call from Sandra about the report. She had sent a copy to Liz Barratt and Tom Hamilton (Wentworth Area Health CEO) as a precursor to the Minister. Tom had replied with a formal memo saying that this was not necessary and that he would be
pleased if we did not distribute the report further... in effect he was trying to quash the report.

It seemed at this stage as if the senior bureaucrat in Wentworth Area Health was trying to contain our 'findings', to control any 'damage' we might do if we went 'public'. Our only ray of hope at this time was that clearly he must have read the Report to realise the potential it had!

In May, I attended a Wentworth Area health workshop where I was introduced, by Sandra, to Jim Hyde, advisor to the State Minister for Community Services and Health. Jim was a the key speaker at the workshop, his talk focusing on the need for partnerships between the various stakeholders in health service provision. On meeting him, I spoke of the research the Inquiry Group had conducted, of the resulting report and of Tom Hamilton's response. He asked for a copy to be sent to him.

May 1996....

Talked about the report - Debbie will distribute. We talked about co authorship, felt that Tom might sack people if their names were still on the front ... we feel that his reaction is reinforcing what the report says....Debbie to attend a staff meeting at Springwood to talk about findings etc....Debbie talked about the stage the PhD is up to and her next steps....started to outline an action plan using the recommendations from the report.

Going public

Our task at this stage was to use the findings and recommendations and translate these into actions. As we were committed to the public nature of the stories we have collected and re-told, our task was also to distribute
this report to as many people as possible, including all those who told their stories - without risking peoples jobs.

June.......

Ruth informed us that Tom [Hamilton] had said 'no' to a submission asking that the team leader/num positions be separated. No reasons given as yet. People felt that the situation was only going to get worse especially with trying to set up the new health centre. We talked about staff taking 'class action' if all the nurses joined together then this could be a useful strategy. One cluster has already decided to take the issue to the next union branch meeting......

Debbie informed the group that Jim Hyde now has a copy of the report which he has agreed to copy and distribute (Jim Hyde is adviser to the Minister on Community Health issues).

We talked about holding a public meeting to talk about the recommendations from the report and to involve 'the community' in planning our next steps......

The fact that staff in one of the Community Health centres had decided to take some class action was exciting. I had talked with staff collectively and individually during the course of this research, encountering an angry, frustrated and despairing group of people. As with all research of this nature, it is difficult to establish cause and effect. We could not say whether this research had caused the staff action but it undoubtedly was one of the major influences. It confirmed in my mind that giving people the opportunity to speak and to be heard is indeed empowering. Providing them with the space to theorise about the constraints on their practice can, and did, help them to act.
July.....

Dot informed us that the Catholic [Health Service - Hawkesbury Area], had already held their first advisory committee meeting.

We discussed the Wentworth Area review which is currently underway. Dot is on the review committee and is getting rather impatient with the process as the doctors and surgeons who agitated for the review are refusing to be interviewed as part of the process....

Debbie handed out draft copies of 'the groups story' and asked for input, feedback, help for the next meeting. Copies of individuals stories were also distributed for comment...We decided that this group should now be part of the Healthy Cities umbrella [John Ashton 1992]

August.....

The August meeting was spent finalising plans for a 'participants meeting' to discuss the Research Report and for the group to seek direction for further action. All participants were to be sent a copy of the report along with a letter inviting them to attend this public meeting. Additionally we decided to invite key players from Wentworth Area Health administration. To this date we had consciously chosen not to let senior management in the Health Area have a voice in this research project. Our concern had very much been to work with the grass roots, to hear the voices of those not usually heard in the health debate. Now, however we wished to include the decision and policy makers. To begin conversations for change. (See Appendix 2 for list of people invited to attend).

At the same time the Inquiry Group decided that to minimise the risk of a 'backlash' from the executive of Wentworth Area Health I, being an 'academic', should publicly take responsibility for the report and the participant's meeting. In reality, Community Health organised the venue,
provided sandwiches, tea and coffee and printed 100 copies of the report. Springwood Community Health staff also provided administrative support in terms of being the RSVP number for people wishing to attend, or sending their apologies. As usual, the group contributed to the process in many and varied ways, demonstrating their commitment to our work together.

The request of the Inquiry Group, that I become the visible owner of the report caused me much internal angst. I had struggled long and hard to be inclusive, to be egalitarian and democratic. At one level, it seemed a tragedy that such strong women felt the need for public abdication. It was a strong and sorry reflection of the patriarchal system in which they worked.

September....

The participants meeting.

Eleven people attended the meeting. We received apologies from the CEO of Wentworth Area Health, the Director of Blue Mountains Community Health and four participants. Of those that attended four were participants in the research project; two were from the senior executive of Wentworth Area Health (Director of Nursing - Community Health and the Director of Planning); one was from the Blue Mountains Division of General Practice and the remaining three were from the Research Group.

People were seated in a circle with a flip chart being used by myself to record what people had to say.

We began with each person speaking their reasons for being there. These were:

* to see what we had to say
• to contribute
• interest (2 people)
• to see if what we had been doing would come to fruition
• to hear what people think of our work
• to show solidarity with the disempowered
• to see what strategies would come up (2 people)
• to ask questions

We then went on to speak about what stood out for each of us in terms of the research report. The following points were mentioned:

• that much of the input from consumers was 'controlled'. Many voiceless people are seen as not fit to speak
• that service users feel vulnerable
• the report is too long and uses difficult language
• people don't know about community health
• report looks like hard work to read
• the disempowerment of staff, consumers and management
• the separation of participation and consultation by staff and the community
• the issue of time, people are feeling rushed and processed by the system
• that G.P.'s comments are not clearly identifiable
• the lack of understanding of Community Health by the hospital and some consumers
• disempowerment - that equity seems to be frustrated by the powerful
• the distinction between participation and consultation

While we agreed that all of these issues were important ones, people wanted to move on to talk about the recommendations from the report.

We began working on Recommendation 1, talking of strategies and actions.
• It was suggested that Community Health [in the Blue Mountains] develop clear strategies for seeking funding based on evidence of need and possible outcomes. That Community Health develop a stronger voice, and case around these issues.
• We felt that a user's guide to Community Health be developed for staff, service users and the community. This guide to detail who makes decisions about what.
• Suggested that an action group be formed to lobby around the report. This group should comprise mainly of service users and the community. Suggested that we make contact with the Wentworth Area consumer reference group. Research group to do.
• We agreed that a letter be sent to Tom Hamilton, CEO of Wentworth Area Health, asking for a response from the executive. It was agreed that Debbie do this on behalf of the meeting.
• That the research group formally request a meeting with the General Manager of the Blue Mountains District, Liz Barratt, to discuss the report and look at outcomes. Research group to do.
• That the research group be widened to include community and service users, that the invitation to be part of this group be more definitive. Research group to do.
• We felt that support groups should be better used in terms of participation. That we could look at a networking mechanism for all the groups. That the area health service establish a system of consultation/participation from these groups.
• We felt that we should look at Nepean Catchment Management model of participation.
• It was also felt that Community Health management must own part of the 'problem' and come up with strategies to address the issues. Research group to do.

While the number of people attending this meeting was disappointing, to say the least, it underscored what we, as a research group knew - that people feel and are voiceless in the face of the NSW health system. One letter, one meeting, one report, while a start in the right direction, is not going to transform this reality overnight. There is much consistent hard work to be done to change this culture of powerlessness.
The people who did attend the meeting were enthusiastic and contributed their thoughts and ideas willingly and freely giving the research group some clear strategies for further action. Both of the senior executives seemed genuinely concerned with the information contained in the report and identified strongly with the feelings of powerlessness of both staff and consumers. They stated that they too felt powerless in the bureaucracy.

The Inquiry Group reconvenes.

We spent the meeting discussing the minutes from the community participation participants meeting.....We agreed to invite Liz Barratt asking to meet with her .... agreed that established support groups might like to network in order to have a stronger voice on some issues. This committee would be the appropriate one to work with......agreed to change our name to Community Participation Implementation Committee as this was now our role and made us appear less 'academic'....

The advocacy group is beginning to look at these issues and the older women's network is challenging how we deal with people. While some groups are becoming more powerful and demanding to be heard we wondered about those, the majority, who remain silent. We felt that this was an issue but too huge to take on, we could best help change along by supporting the groups that exist and helping these groups to network and become more effective.

Some clear tasks and directions were now emerging for our group. What was gratifying for us at this stage was that we felt these directions were informed and guided by our research efforts and those whose voices we had chosen to hear. That we were slowly, one step at a time, resisting the status quo by doing community participation.
A letter was sent to the CEO of Wentworth Area Health asking for a senior executive response to the report. No response was ever received.

Management responds

October....

One of the outcomes of the participants meeting was our invitation to the General Manager of Blue Mountains District Health, to discuss the report with us. This she agreed to do and our October meeting - lasting a mammoth three and a half hours - comprised solely of discussions with her.

She chose to work through each of the recommendations contained in the report From Rhetoric to Practice. What follows is a summary of her detailed response - the words and sentiments are Liz's not my interpretation:

Recommendation 1
All area corporate and strategic plans focus on health prevention and promotion. It is not happening due to other pressures on staff. Staff like the generalist role but it is becoming more and more difficult to do, part of the reason is that staffing levels have not gone up with the rise in population. "Stranding" is being tried to overcome this.

Staff appraisals should look at the balance of health promotion, community development and clinical work/treatment.

There is a need to meet with staff on a more regular basis. A three monthly meeting with all staff to be tried and reviewed after twelve months. Some changes in the system have happened. Jargon is being cut out of all documents and Community Health management meetings have been made more democratic and participatory.
Health promotion is wonderful but undervalued. Government pressure is on hospitals and medical programs. Wentworth Area Health is under-funded which impacts on Blue Mountains which has trouble funding its acute services at the most basic level. A comparison of staff across the district, especially allied health staff, shows the inequities.

People don't see Community Health as a health service. Signage needs to include all the services that are provided by the service.

Recommendation 2:
Advisory committees in essence are agreed with. The Healthy Villages advisory committee is constantly being expanded, the Aged Care and Advocacy advisory committees are working well. Lawson has tried an advisory committee to participate in the management of the Health Centre. It was difficult as members felt disempowered and not really listened too. It was tokenism and had to be disbanded.

Recommendation 3:
Public Relations Officer needs to be used more. Holding public meetings is problematic as we don't hear from marginalised groups. Advocacy group is working on a systems advocacy project, making the system more accessible, but this is a slow process.

Recommendation 4:
A user feedback system needs to be developed. This is beginning. Need to have both written and verbal feedback. Focus Groups could be used more, people are paid to come along two to three times a year. University students could be used for general canvassing say once a year.

Recommendation 5:
This recommendation could be used as the basis for discussions with staff at their meetings.

Recommendation 6:
Board is basically dishonest asking for area, district and local level to implement things that they don't. Board role has to change. The system is unsustainable at present and will implode soon, even the Minister is disempowered at present.

It was useful and frustrating to have this conversation. Useful in terms of the fact that the General Managers' attention was solely focused on the research report which she chose to take seriously. She dealt with each recommendation carefully, often asking for clarification and explanation of how we had reached such recommendations. She appeared genuinely interested and concerned while at the same time drawing our attention to strategies and initiatives which had recently been put in place to address some of the concerns in the report.

The frustration we felt was due to her agreement with us, that the health system is dishonest in its expectations of community participation and is extremely unstable. (It could be, of course, that she was sent to de-fuse the situation). Despite what we now knew, what we had collectively written I feel that we wanted an answer, that something could be done, now. Despite our knowing the complexity, the entrenched power relations, the overwhelming sense of powerlessness of staff, consumers and the community in terms of the health system, we still looked for the 'band aid' solution or, at least, a place to put our energies next. This was our last meeting of 1996.

Choosing the place to end is always difficult as there is so much more to be said. The Inquiry Group's story has only just begun, my role with them will continue for as long as I can be useful. It is time though, to close this chapter, to write our story, so that we too may be heard. It is important to make the space for our voices as all too often struggles around power and
empowerment can mean that we put ourselves in a voiceless position as we create the space for others to be heard.

Conclusions

We certainly 'followed the road less travelled' as part of this project. It felt at times as if we were laying the road brick by brick. Writing this conclusion now, some three months after the last meeting, I am left with some powerful feelings and equally powerful questions. I am reminded of the words of one of my students who simply asked 'how do we cope with the fact that this type of research throws up more questions than answers'? I had no answer then, and I have none now.

Those of us who choose to do our research in less than conventional ways, who are working with people, paradox and complexity are in the process of shedding our old skins. Twisting, turning, writhing free from reductionism and positivism, a skin which has held and contained us, for most of our lives. This old skin provided an easily recognised form and structure for our bodies, our ways of knowing and being. Part of our task is to re-define ourselves.

The quote from Stephen Kemmis (1985) which begins this chapter was chosen to reflect what I attempted to do in this phase of the research. It is to this quote that I return to reflect upon the methodology used. I believe that we did manage to move away from the typical division of labour often used in conducting research, that is I "engaged ordinary participants" and we did collectively and collaboratively "disclose the ideological processes and structures which govern their own practices" (Stephen Kemmis 1985: 155).
It is clear that we developed a critical understanding of the substantive issue we were researching, that is; community participation in health. It is also clear that through this process the people in the research group changed some of their practices. They felt more empowered and began to act in different ways. People began to clearly see the ideologies of domination, and control and the power structures which controlled their practice (Shirley Grundy 1986). I believe though, that we had to strive towards holding the tension between empowerment and powerlessness. Naming the demons is useful, one knows, can put a form to what needs to be struggled against. At the same time the sheer size of the demons can become overwhelming and suffocating. Accepting what you now know and continuing to act requires courage.

In answering Yolande Wadsworth's (1982) questions about action research it is clear from this story that the Inquiry Group were centrally involved. They shared the tasks of planning and conducting the research and more importantly they shared the task of analysis, of meaning making, of knowledge construction. This process of collaborative knowledge construction enabled us to critically reflect upon our own practices, to take action and make changes in our everyday lives.

For me, being part of a group to whom I had obligations and responsibilities enabled me to keep on going through those periods of self doubt and hopelessness. Whilst at times I also struggled with "the tyranny of the group" (Chris Weineke, personal communication 1994), it is clear to me that this research could not have happened without them. I learned much from this group of women who have dared, and continue to dare, to stand up for what they believe in spite of - or because of - the oppressive structures in which they work.
It has not been an easy journey. I learnt much about research, group dynamics and who I am in the process. In future I will begin the group process with more clarity about my role; I would own the technical skills that I bring to the group, valuing them rather than fearing them and I would accept that as an academic, as a white educated middle class woman I have positional power and privilege. I think I became somewhat muddled and confused at the beginning, thinking that for true, authentic collaboration we needed to be equal. This I now know is not often so and one of the ways of minimising some of the abuses of power is to openly accept the power, the skills and the privilege that you carry with you - realising at the same time that this is contextual. This links in with one of the major concerns of community (Iris Young 1990). That some efforts at community building demand homogeneity and attempt to make difference invisible, or exclude it. Whereas, in an ecological sense, it is our difference and diversity which makes the system, group and community, sustainable and adaptable - a living rather than dead entity.

I would also be more vocal about my struggles, distress and lack of motivation when this occurred. Reading this story one member of the group remarked 'Oh, I never knew you felt like that, like we did'. I tried to deal with these issues myself, outside of the group and by so doing I kept myself somewhat distanced and separate. Changing this pattern of my behaviour would in future lead to more authentic and powerful collaboration (John Heron 1985).

Reading this story, it seems to me that we set out to do, and in fact were engaged in, a three year cooperative inquiry project (John Heron 1985). One of our concerns had been to ensure our methods were participatory and collaborative in process. What this part of the story demonstrates is that this can be done and was done. It also shows that this was not without struggle for all of us. Our concern had also been an emancipatory one (Patti
Lather 1991). While it is not clear to me that any changes made have had a noticeable effect on the NSW health system as a whole, they have had effect at the individual, group and local level. We have created some ripples at the edge of the pool. Our hope is that these ripples will meet with those that others have created, at the edge, the margins, and will in the future lead to a tidal wave of change.
CHAPTER 9
ENDINGS?
"The writer of stories is always between the beginning and end of the world and she must write in both directions at once, back and forth, so that the past and the future coincide in one seed. And so create and cancel time so we may meet in the desert where I hear the spirits can live" (Metzger in Jahova 1986).
I do not really wish to conclude and sum up, rounding off the argument so as to dump it in a nutshell on the reader. A lot more can be said about any of the topics I have touched upon ... I have meant to ask the questions, to break out of the frame ... The point is not a set of answers, but making possible a different practice (Kappeler 1986 in Patti Lather 1991:159)

These words neatly sum up my state of mind as I write this, the final chapter of the thesis. The frame I sought to break out of was of my own making. The time was ripe for me to question myself, to re-search what I knew and to re-write myself anew. It was time I came out, found my voice and became visible. It was time for me to articulate what it was I believed in and why. And, as someone who always asks 'so what', who always wants to know what difference this new way of knowing will make, it is to the 'so what' that I now turn. For, if I am concerned, as a Social Ecologist, with critical inquiry and reflexivity, this re-searching and re-writing has to make a difference to how I see and act in the world. If I am concerned with collaborative and participatory re-searching, knowledge construction and meaning making, then my re-searching has to make a difference to my co-researchers 'seeing' and 'being in' the world.

While undoubtedly concerned with 'making a difference', with transformation and change the postmodernist in me has resisted dogmatic, outcome driven, 'master narratives'. Rather, I have located my standpoint. This resistance led me to locate this thesis, theoretically, within a postmodern/feminist/critical social science. In this, I join Brian Fay's modest search for

theories which were self-consciously local, particular, situated, experimental, and physical, theories whose values were not those of rational self-clarity and autonomy, but were
Erratum

Page 347, third paragraph, second sentence should read:

"This resistance led me to locate this thesis, theoretically, within a postmodern/feminist/critical social science."

Omit "Rather, I have located my standpoint"
something far less grandiose and mundane (Brian Fay 1987:212).

This standpoint has enabled research and action that accepts the multiplicity of feminist practices at different sites.

What now seems like a lifetime ago, when I was searching for a structure for this thesis, a way to write, to re-present this re-searching I remembered a conversation with a friend and colleague Hilary. At the time she had recently completed her Masters Honours thesis and was speaking to me of her writer’s block, of finding her own voice. She overcame this by thinking of her work as a story and chose to ‘just write the story, my story, as that is all it is - a story’ (Hilary Armstrong personal conversation 1994; see also Hilary Armstrong 1990). Such profound simplicity can be inspiring and empowering. The use of narrative let me discover my own way of writing the thesis and enabled me to find a voice in which to speak and be heard.

This thesis, while my story, is also the story of many other people. It includes stories of the Inquiry Group with whom I researched, the stories of Community Health service users, staff, members of my local community and the story of other service providers in the area. While I, as they, chose to move from silence to speaking, I continuously struggled an issue Philipa Rothfield (1994) identifies, that of speaking ‘about’ or speaking ‘for’.

If one moves beyond the dichotomy between silence and speech (whether to speak at all or remain silent) and into the problematic of representation, some particular problems arise. It is possible to distinguish between speaking about a group and speaking for a group...In practice though the two are not so distinct (Philipa Rothfield 1994:119).
The struggle to let people re-present themselves, to have their own voice, as much as possible given the genre of the thesis, led me to include many of the actual words of others in the text, academically, I have been supported by a multiple research method approach which combined collaborative/participatory action research (Robin McTaggart 1991 & 1992; Shirley Grundy 1986, William Foote-Whyte 1991) feminist research (Maria Mies and Vandana Shiva 1993), emancipatory research (Patti Lather 1991) and grounded theory (Anselm Strauss and Juliet Corbin 1991). Additionally, given that the substantive issue of my research was one of participation, it seemed congruent to me that the people to whom I spoke should participate by way of their words in this thesis. I think that it has worked. Their words are often powerful and moving and I am left knowing that what I have written and said is well grounded in their own 'speaking about'. This move from silence cannot be underestimated. Our stories must be told, our experiences made visible, our ways of being and knowing taken account of. This is one of the strongest convictions I now have as a result of this work.

In the beginning I thought that my work needed to focus on practical systems that we could put in place to facilitate community participation in Community Health (WHO 1978; National health Strategy 1993). Now I realise that I am concerned with something both smaller and larger than this. Critical social science, this thesis and, community participation meet in a desire to give people voice, people who are marginalised and decentered from health decision making. The continued marginalisation of service users and service workers ensures that the interests of surgeons, the AMA, drug companies and scientists are protected. Silencing marginalised ensures that only those in power continue being heard, keep dominating, and keep defining what health and illness is all about. And even with their 'God's eye view' they are not doing a very good job about it!
Our health system is sick, some may say dying. Those in positions of power, our present 'managers', do not have the answers. The interests in more technology, a greater focus on pharmaceuticals, and on the genetic causes of health, are not going to lead to a healthy, thriving, sustainable system. In an ecological sense, and a feminist sense, only openness to the full diversity of ways of knowing and being, can help us reinvent the health system. My research has confirmed, validated and expanded my knowing of these issues. People have shown themselves ready and willing to be part of this reinvention - despite their overwhelming scepticism about the 'system of health'. There is a fight to be fought by those that have only their voices as weapons and these weapons must be used. It is my hope that in the telling of their stories "[t]he story itself becomes the weapon of the weaponless" (Marina Warner 1994:412). In some cases this was so.

What is clear to me, and those in the Inquiry Group, is that the bureaucratic structure of the health service and the dominant biomedical discourse are patriarchal constructions and as such, powerful impediments to change. In taking a postmodern/feminist/critical social science perspective, we have lived with the tension of knowing and feeling these impediments while still being able to act. As women and as Community Health workers, we need to continue destabilising the institutions from/in the margins. Equally, an emancipatory framework asks us to transform our own practice as we seek to transform one of the largest structures in our society. This is what it means to speak of 'revolution' as small individual change echoed many times (Liz Stanley and Sue Wise 1993).

I began this research in the true spirit of an action researcher, interested in the idea of community participation in Community Health. Working with an Inquiry Group of people within the health system, using community development and collaborative/participatory action research frameworks, we began with a concern for social equity and a concern to challenge practices
which impede this equity. This concern grew out of a commitment to justice, and recognition of the unacceptable consequences of inequality in health and illness. During the first year of our working together the interest of the Inquiry Group coalesced around the questions:

- What is really happening in community health?
- Is the rhetoric translating into practice and if so how?
- How empowered do people feel in terms of their health?
- What are health personnel doing to empower and include their consumers and the general public?
- How can we, at a local level, establish systems and procedures to enhance and strengthen community involvement and participation in health?
- Does the health system support community involvement in health-in practice?

Together, over a period of four years, we sought answers and understandings. At one level, this thesis is about our quest to understand more about these questions. One of our most useful findings has been discovering and articulating the difference between consultation and participation. It seemed to us that the policy makers were tripping over their own feet as they struggled to implement participation via a consultative process. The two are not compatible as consultation serves to maintain and support existing power relations and structures, the novice/expert dichotomy is preserved. "Real participation means joint problem solving, joint decision making, joint responsibility" (Consumers Health Forum 1990:25). Real participation seeks to include difference and diversity of opinion and a sharing of power in a democratic sense.

During the process of our collaborative research our concern further crystallised around the tension between rhetoric and practice - the Health Department’s practice of community participation being woefully behind its rhetoric. At this point, we were proud to observe that we had chosen to be
methodologically congruent in our own theory and practice! That is, while striving to understand more clearly the issue of community participation, we used participatory and collaborative processes, struggling to privilege all voices - not just our own. Living the research process in this way helped all of us to know how difficult real collaboration and participation is. Through the process of interviewing and running focus groups with the people of the Blue Mountains, it became very plain to us that these values and practices were sadly lacking in Wentworth Area Health. Issues of trust, reciprocity, openness are vitally important to a dialogical and critical analysis. For community participation to move from rhetoric into practice these values need to be recognised as relevant to health care delivery.

A year after our report, From Rhetoric to Practice, was circulated we find that there are many local efforts and practices of community participation in place, which earlier were not 'named' as such. Naming is an issue linked with finding voice. If we let others name what it is we are to do, they remain in control and can continuously and continually define our practice for us. Naming what we do ourselves is part of the process of empowerment.

Through our researching we found that the day to day practice of community participation was not supported by the bureaucracy despite the rhetoric. Health practitioners were kept in alienated and powerless positions often taking their frustrations out on each other and themselves rather than working together. As already mentioned, this has begun to change.

Perhaps this change will happen from the bottom up. The Inquiry Group reported huge changes in their practice, their knowing and the meaning they made of the work they did. Many of them have been able to affect local structures. Other staff who were not part of the Inquiry Group also began to change in local ways, some embracing community development as a
theoretical guide for their practice; others going so far as to take a class action against Wentworth Area Health. A Healthy Villages Advisory committee has been established in the local area, modelled on the Healthy Cities concept, with a community participation sub-committee (John Ashton 1992). The health care system itself has changed, from a generalist community nurse approach to one of stranding - the aim being to release workers from being all things to all people. Nurses can now to specialise and not work daily with 'cradle to grave' issues. Many people have begun to transform their own reality as a result of speaking, being heard and listening to others.

We have also found that the public at large are ready, willing and able to participate in decision making about community health service planning, delivery and evaluation. Myths such as 'apathy', 'lack of skills' or 'awareness' were dispelled from the minds of the researchers throughout this process. If people did not know, did not feel empowered to participate, then it was often because they simply did not have the information to know. Instead of focusing on 'educating people to participate' - an exercise in gate-keeping that could mean people would never join in - we saw that our efforts should be directed at providing people with information, resources and opportunities. This community outreach will be a slow process as we break down the barriers, real and perceived, between the faceless people seen to be making the decisions at present, and 'others' at the grassroots. Service providers must stop treating health service users as passive consumers, stop overprotecting them and begin to see the whole person, with passions, dreams, desires and skills - not merely as one more 'case'.

While I have tried to be reflexive throughout this thesis, I have not yet articulated how this re-searching has changed my own practice. It is difficult at the best of times to stand apart from yourself and see how you
have changed. It is even more difficult when the journey has taken a long period of time. I have, no doubt, transformed my practice and my way of being in many subtle ways that I cannot yet see. One of the most vivid differences though, is my own sense of voice, of not apologising or silencing the fire in my voice, of speaking out, of daring to 'name the elephant' in the room that we all pretend is not there.

I work with people in helping them find their own voice in the classroom and their academic voice in the institution. We consider and analyse 'who speaks' and what that tells us of our construction of self and others and of the power relations inherent in this. I now know that there is no innocent, straightforward discourse of liberation or empowerment. And I now know "what it would mean to recognise not only that a multiplicity of knowledges are present in the classroom as a result of the way difference has been used to structure social relations inside and outside the classroom, but that these knowledges are contradictory, partial, and irreducible" (Elisabeth Ellsworth 1992:112).

I now know that we need to "refigure community, to include ways of disagreeing among ourselves" (Patti Lather 1992:132). Community has in the past been used in a romantic sense, implying that true community where we all are free can actually happen. Instead, I believe we should be talking of community as a verb, not as noun an end point or utopian ideal. We should instead embrace community as process, something that we co-create with others. Working with postmodern/feminist ideas such as the politics of difference, I now believe we must move away from expecting that we can ever fully know others in this community. By accepting our diversities and differences we work against the universalising tendency to homogenise or exclude.
These are the challenges which I now face in transforming my own practice more fully, in embracing and challenging my own rhetoric. Much of what I now know is not new. What is new in terms of the oft quoted 'body of knowledge' is that I now embody this knowing. What is new, is that the practice of those with whom I re-searched and my own practice has changed. And this, I contend is the point. A different practice has been made possible through the process of this story telling.

I chose not to call this, the final chapter written here, 'conclusion' as "the story of storytelling will never be done" (Marina Warner 1994: xxi). All we can do is to capture a moment in time and say: '[t]his is my story, I've told it, and in your hands I leave it" (Marina Warner 1994: xxi). I began 'Endings?' stating that I was looking for a structure for this thesis. Settling on the unifying theme of storytelling has worked well in providing a connecting thread throughout the thesis. It has, I believe, enabled me to weave a tapestry of many colours. The subalterns have spoken, and in so doing they transformed a reality.
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APPENDICES
Appendix 1
Questions given to Inquiry Group - June 1995

Dear All

As this group is a part of our research project the time has come for us to do some more formal reflecting of how we feel about the group and the project. Please take some time to answer these questions in writing and return them to me, in the envelope provided, by Friday 16 June.

What we have to say will be an important source of data, along with the minutes of our meetings. They are quite in depth and personal questions in some ways, but I hope that after two years of working together you feel OK about disclosing. If you don't then just leave the question blank. Naturally there are no right or wrong answers here, I am interested in your perceptions, you will not be judged in any way regarding what you have to say. It is also important that you are as honest as possible, if your answers are confronting for either me or the rest of the group then it is time we were confronted. This is all part of working together as a research or inquiry group.

Of course, responses can be confidential - I will keep your name and position apart from your responses if you like.

If you have any concerns or questions then please ring me on 541142

Please consider these questions as openly as you like.

1. Yes/no I am concerned that you protect my confidentiality from the group as much as possible.

2. Name

3. Age

4. Position

5. Professional/career qualifications etc. (this covers your qualifications and experience as you perceive them).

5.1 What are your professional strengths. How did they develop? Please include experiences that have enriched these.

5.2 What do you perceive to be your weaknesses? Why do they exist? What do you do about surviving/succeeding?

Adapted from 'Women Transforming the Workplace' Virginia Kaufman Hall 1995

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5.3 What opportunities have there been for you. How did you make the most of them?

5.4 What has threatened your professional life?

5.5 What have been your greatest professional achievements or things you have done that you feel really good about?

5.6 What are your ambitions, why?

6. Why did you join this research group? What did you expect to come of it: for you? for others? for Debbie?

7. Describe any particularly difficult and/or successful times in the group

8. Why are you still participating in the group?

9. How do you see your input?

10. Has involvement in this research affected your work in any way? If yes then please describe this.

11. What hopes and aspirations do you have for this group?

12. How did you feel writing responses to these questions?

13. Is there anything else you would like to say?

Thank you for taking the time and effort to do this

Debbie

Adapted from "Women Transforming the Workplace" Virginia Kaufman Hall 1995

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Appendix 2

People invited to Attend Participants meeting - September 1996

1. All people who had participated in interviews and focus groups.

2. The Inquiry Group Members

3. Tom Hamilton, CEO of Wentworth Area Health

4. Mike Smith, Acting CEO of Wentworth Area Health

5. Chris Lambert, Area Director of Health _ Community Health

6. Elizabeth Barrett, General Manager Blue Mountains District Hospital

7. Rufus Clark Area Director of Research and Planning

8. Diana Tricket Area Director of Nursing

9. Andrea Williams Director of Nursing Springwood Hospital

10. Alison Snedden Wentworth Area Health Promotion

11. Linda Macqueen Blue Mountains Division of General Practice.
The Subalterns Speak: A collaborative inquiry into community participation in health care

Debbie Horsfall, B.A, M.A
School of Social Ecology
University of Western Sydney-Hawkesbury

Ph.D Thesis
June 1997
PLEASE NOTE

The greatest amount of care has been taken while scanning this thesis,

and the best possible result has been obtained.
"I loved the vision-quest. Endless, conceptual, many hued bubbles jostled and wiggled and slithered meaningfully in and out of everyone's mouths. They did not mingle, they contaminated, infected, and changed the worlds of the bubble makers. Quality and questions and love mixed and mingled together in one reflexive spiral after another, and sense was made; and then another and another sense.... Time-less. Warm."

(Jaki Nidie - Taylor 1990:2)
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The Subalterns Speak:  
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Certificate of Originality

The Subalterns Speak: A collaborative inquiry into community participation in community health care

To the best of my knowledge and belief this thesis is entirely original research which has not been submitted for any other degree at any place of learning.

Every effort has been made to ensure that writings and ideas delivered in any medium, have been acknowledged and referenced.

Debbie Horsfall
Acknowledgements

How can one adequately say 'thank you' for the support, encouragement and love that one receives in getting to this point? How to make the bouquets; which mix of colour, perfume, texture?

For my mother and father I thank you for bringing me up to believe in others and myself. For encouraging and supporting me in 'getting an education' and for teaching me to ask questions and never simply accept what I am told.

My grandmother, a late thank you for loving me unconditionally, for showing me that being with others and giving can be a joy in itself and instilling in me a sense of collegiality and community and a strength to act, in small ways, for what we both believe.

Andy Horsfall my partner who has been with me since I was a child and who has never wavered in believing that what I am doing is both exciting and important. For his enthusiasm, his pride in my work, his constant urging to shout from the rooftops in my own voice and his meticulous and dogged hard work in editing, offering suggestions, ideas and inspirations. I also thank him for challenging me to work with my doubts and my fears and for helping me grow into the woman I now am, in this moment.

To my children, James and Jessica, for allowing me the considerable space I needed to complete this project. For their interest and support I am both grateful and humbled. I thank them also for the times they disturbed me for numerous hugs and 'how is it going?' They are both children with an immense capacity to give.

To my friends and colleagues in particular Judy Finn, Dr Virginia Kaufman Hall, Hilary Armstrong, Helen Kearins,
Karen Bridgeman, Jaki Nidie Taylor, Ana Smith and Maxine Wolfendon with whom I have shared numerous conversations, questions, laughs and tears along the way. Thank you for your support, your wisdom and your women's way of knowing and being. Thanks are also due to Lucy Armstrong whose youthful enthusiasm, uncompromising ability to say it as it was, and unstinting hard work in running focus groups and cowriting one of these stories is gratefully appreciated.

Special thanks also go to my supervisors along the way. Dr Chris Weineke who gently inspired and challenged me and who convinced me that I could write and had something important to say. For Jaki, Nidie Taylor who made me do the hard work of theorising my position, for standing beside me through the difficult times and challenges who never let me give up - ever ! And for Dr Ariel Salleh who had the difficult task of taking over in the final stages. I thank her for her meticulous hard work and for reminding me of my anger and passion.

This is a collective story, braided together out of the voices of many. It could not have happened without the support, generosity and courage of many other people. The women in the collaborative inquiry group deserve special mention - Sandra Longmore, Dot Ward, Joan McKay, Pam Hansen, Sue Tansley, Lesley Laslett and Ruth Willic - They stuck with me, and together through exciting, challenging and difficult times. I am thankful for their insights, their sheer hard work and their tenacity. To the participants who gave of their time in focus groups and interviews - thank you for taking the risk.
SUMMARY AND OVERVIEW
The tea is poured, the stitching put down.
The child grows still, sensing something of importance.
The woman settles and begins her story
(Eavan Boland in Marina Warner 1994:409).

This story is about change, community and the health system. It is about women. It is about challenging the status quo and advocating for and with the less powerful. It is about foregrounding previously silenced voices - including mine - valuing the subjugated knowledges (Michel Foucault 1972-1977) of people 'other' than those who make decisions on our behalf. In this story, which the thesis represents, I weave together many voices. My voice as the weaver, those of women and men who work in community health, of workers in non government agencies, of people who use the services of community health and of ordinary members of the public. These voices are marginalised, de-centred and disempowered from policy and decision making in multiple ways. Placing these voices at the centre of this work I provide the space and context for the 'subalterns to speak' in the hope that this speaking will transform reality (Paulo Freire 1970; Gayatri Chakravorty Spivak 1988).

True to the discourse of Social Ecology the thesis is transdisciplinary in that it integrates postmodern/postructuralist theory with feminism and critical social science. As I am concerned with working with people, constructing knowledge collectively, hearing and weaving together many voices the research is primarily collaborative, using emancipatory, feminist, action research and the methodology of grounded theory to tell the stories contained herein.

1 In 1988 Gayatri Chakravorty Spivak asked the question "[c]an the Subaltern speak?" (1988:284). Using the word subaltern "in its general sense of 'subordinate'" (Elsbeth Probyn 1990:188) Elsbeth Probyn refers "to those excluded from the multiple levels of empowerment as subaltern" (1990:188). It is in this sense that I use the word both here and in the title of this thesis.
In 1993, I was invited to work with a group of health practitioners, from the Blue Mountains of NSW, to research the substantive issue of 'community participation in community health'. This group became my Inquiry Group and we worked together for four years. Our inquiry centred on the premise that community participation is both desirable and achievable, a premise supported by key Primary Health Care Documents (World Health Organisation 1978, 1986 & 1991) and Wentworth Area Health Service (1993) strategic plans and targets. Whilst our concern was, at times, a philosophical one grounded in our commitment to democratic and participatory decision making our aim has been to act, to discover, to hear and thereby improve our professional practice. In deciding to listen and beginning to hear, we spoke with over 100 people from the lower mountains community health service, community members, service users, community service providers and general practitioners (see Fig 1).

This is the story, a narrative, of what we did, how we did it and what we heard when we entered into a dialogue with the people among whom we live, work and play. It is a local story, concerned with hearing and acting on
the voices of those we do not often hear in the debate on health. It is truly a collaboratively created and inspired story.

My thesis is that if we work towards partnerships in decision making in health - at all levels - then the system will, by necessity, change. However, during the process of this re-searching it has become astoundingly clear to me that while community participation is an idea being promoted by the NSW Health Department (1994), at present it is an idea that has not been thought through, is ill defined and lacks support in practice. Furthermore, it is clear to me that debates regarding health and illness take place within a medical discourse. A reorientation to viewing health as a social phenomenon must occur if community participation in decision making is to occur in any meaningful way. As long as the doctors and scientists are seen as the only ones who 'know' about health and illness, then there is no room for others to be part of the decision making process.

My hope, my imagining, lets me believe that if we can move towards partnership, then the debate, the relations of power, our collective knowledge about health and illness, and therefore our practices, will change as other voices get heard. This thesis re-presents one local attempt at hearing other voices and changing our practice in light of these other ways of knowing. It is "something of importance" (Eavan Boland in Marina Warner 1994:409).
Overview

Chapter 1

The purpose and context of this research is discussed. The reader is introduced to the notion of Social Ecology and the writer is situated. The substantive research issue, community participation in community health services, is discussed briefly in addition to an overview of the methodology and methods used.

Chapter 2

The context for the research is set within the current discourses in the health domain. The major competing discourses of the 'medicalisation of health' and 'primary health care' are discussed in detail. In this present moment, the discourse of medicalisation, which is informed primarily by biotechnology and economic rationalism, holds primacy. In this discourse, health and illness are seen as biologically and genetically determined. On the other hand, the discourse of primary health care - of which community participation is a major strategy - offers an alternative to the medical model. Here the social construction of health and illness takes a central place.

Primary health care and health promotion as concepts, are critiqued, and the theoretical frameworks of community development and empowerment are introduced. These serve as a guiding ethic for the research project. This chapter was written while I was doing the empirical research work and as such, my position was informed by the people to whom I was speaking at that time.

Chapter 3

A brief history and overview of community health sets the context for meeting the women of the Research Inquiry Group. The women, who were
centrally involved in the empirical research contained in this thesis, are introduced. The Story of the Inquiry Group is detailed in Chapter 6.

Chapter 4

I explain my position in the broadest sense. I argue for a postmodern/feminist/critical social science as a juncture which can be liberating, transdisciplinary and inclusive. Elements of both modernism and postmodernism are needed to understand the conditions we find ourselves creating, being created by, and struggling against. Using a critical social science, I adopt the emancipatory objectives of critical theory while drawing upon postmodern discourse analysis as a tool.

Chapter 5

A multiple method research design is used. Feminist research, emancipatory research, collaborative/participatory action research and grounded theory are discussed. These methods are congruent with the substantive issue, that of community participation in community health, and the methodological stance of a postmodern/feminist/critical social science. Sharing a concern with knowing, understanding and re-searching with, not on, people in an attempt to understand the unsatisfactory present and work towards transforming this through a concrete change in our own practices. There is an attempt to break down the more hierarchical top down re-searching which privileges those in the academy. Collaboration, negotiation, reflexivity, trust and openness are central to theory building becoming dialogical rather than impositional.
Chapter 6

Using collaborative/participatory action research as our method, this chapter details the four year journey of the Inquiry Group, drawing on records of our meetings, my journal entries and reflections. Here we can see the process of research come to life; the questions the group struggled with; the actions we took and our conversations together along the way. While primarily about process, the re-search and group process, it also details the changes in our professional practice that both individuals and the group believed happened as a result of our joint efforts to know, to understand and to construct meaning together.

Chapter 7

This formal research report From Rhetoric to Practice: the search for partnerships is contained within this chapter. The report was written collaboratively, by the Inquiry Group, and has been distributed to all participants in the research project and key players in the Health Department of NSW, it is a public document.

Section 1 and 2 of the report contains a summary and overview. Section 3 contains the stories of those we spoke to and the resultant theorising of the inquiry group.

The Staff’s Story tells of the experiences, understandings and frustrations of seven staff employed in the local community health centre. The story shows that while staff support the idea of community participation in health, they feel overwhelmingly helpless, exhausted and powerless. The Inquiry Group theorise that staff’s experiences are due to three interrelated discriminations:

- structural discrimination - the nature of bureaucracies
- sex discrimination - gender at work
* scientific discrimination - the competing discourses of the medical model and primary health care

The Community's Story resulted from the Inquiry Group interviewing 40 people who identified themselves as not using Community Health Services. It is a story of community participation in action. Again there was overwhelming support for the idea of community participation along with a great deal of scepticism about the desire, and ability, of the health administrators to enter into partnerships with the local community. This, the Inquiry Group, felt could be explained by the dominance of the medical model of health with its focus on the expert provider and the novice consumer, issues of power and knowledge and the confusion and lack of clarity about consultation and participation.

Twenty two Service Users spoke of being powerless within the system. Although grateful for the service they received, they were placed in the sick role, receiving merely adequate service, not asked for their opinions or fearful when they were asked. It was clear that community health service users were constructed as 'passive consumers'. They had little knowledge/information about services available and decision making processes, furthermore, there was no structural support for input and feedback to the service.

Using focus groups and interviews, the Inquiry Group spoke with local non government organisations and general practitioners in the Story of 'Other' Service Providers. While people were overwhelmingly supportive of community health and the struggle to pursue participatory practices, they were also highly critical of the bureaucratic structure of health services, alienating jargon used by health professionals and the dominance of the medical discourse in health.
Chapter 8

This chapter picks up the story of the Inquiry Group, after the publication of the Research Report. The focus is on the subversiveness of our work, as we pursued our commitment to making sure the voices contained in the report were heard.

Chapter 9

Endings? Primarily a reflective chapter, here I return to, and discuss, the key questions underlying the research in addition to drawing out the influence this research has had on my professional practice.