PUBLIC DISCOURSE PERSONAL REALITY: DISABLEMENT
AND A RE-SEARCH FOR CARING CULTURE

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This thesis is presented for the degree of Doctor of Philosophy
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PLEASE NOTE

The greatest amount of care has been taken while scanning this thesis,

and the best possible result has been obtained.
I declare that this thesis is my own account of my research and it has not been submitted previously for a degree at any other University or institution.

Michael E. Clear
For

my mother (Fay) who would have enjoyed the conversation immensely and to my father
(Tom) for the spaces he shared with her and

Mr & Mrs Gilbert and family who were generous carers and guides at an important time
and who I never properly thanked

Rose my companion always

To

enjoying our communion and our differences without any need for good or evil, normal or
abnormal, just a quieter mind and some affection.
Abstract

This thesis explored reflexively the lives of carers of disabled people, and the research process itself within the collaborative framework of a support group. This extended involvement with participants enabled an ethnographic-like methodology. It used as its data sources an extensive review of the literature, interview transcripts and fieldnotes from carer participants, participants from the local service system, and the records of meetings and activities of the Group over 5 years.

The study highlights the way the public discourse on deinstitutionalisation has so captured our consciousness on care of disabled people that the personal reality of care in which most disabled people grew up in the family home has been effectively lost. It traces the disordering discourses of disablement and their link with constructions of caring. The personal reality of care and the powerfully silent and isolating nature of this union of caring and disablement was the primary research focus. I suggest that these constructions result in a form of ‘career’ for disability carers. This may be characterised by social loss, and a lifestyle bound up with disablement which involves a search for a supportive or caring culture.

The isolation and exclusion of disability caring careers occurs behind the screens of apparently caring institutions such as marriage, family, community and the service system which are principally constructed around and produced by discourses of care. This is a central paradox of the research. At a broader contextual level of power and political economy I portray these discourses that produce caring and disablement as manifestations of patriarchy and capitalism.

In the search for a caring culture carers of disabled people routinely find their lives bound up with that of the state and service systems which offer some hope of a supportive response. Instead they invariably find that the culture is an alien one, and personal identification is reconstructed as diagnosis and programs of assessment and monitoring based on professional knowledge. Service system professionals themselves seek the support of a caring culture in performing their ‘caring’ work. They like carers perform their work within models and systems whose logic is inconsistent with a personalised care.

The research was also guided by personal experiences and in turn the research itself informed attempts of the Group to explore improved forms of caring culture, and more relevant public policy approaches. It is proposed that such approaches would need to highlight the complex ecological quality of caring not embraced by current public policy based on individualised constructions. The research story and the caring story are presented as reflexively intertwined, and overall the study attempted to bridge the gap between the process of knowledge construction and discourse, and the material experience of carer participants.
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ADDENDUM

page x - (Preface) change the sentence I have used this report as a basis for my brief outline of this earlier phase of the research in chapter 1 of this thesis. to read,
I have used this report as a basis for my brief outline of this earlier phase of the research in chapter 1, in discussion of the Child Disability Allowance and the Disability Support Pension process in Chapter 2 and the Family Support Project in Chapter 3 of this thesis.

page 12 - change the sentence I acknowledge that others may draw somewhat different lines of distinction around these ideas, but this particular distinction has proved useful for me and add references to read, I acknowledge that others may draw somewhat different lines of distinction around these ideas. This particular distinction has proved useful for me and it has been suggested by others (Boudon & Bourricaud, 1989; Kellehear, 1993; Marshall (Ed.), 1994).


page 301- addition to the bibliography - NSW Department of Health 1985. Policies for Development of Disabilities Services (Sydney, Government Printer)
Preface

I understand my purpose in writing this preface as more or less twofold. Firstly, it is to provide readers with a preliminary view of the purpose and scope of the thesis. Secondly, it is an opportunity to express gratitude to all those who I cannot so readily acknowledge through the reference list. I also hope it establishes a mood which engages and challenges with the substantive issues about caring and disability. A story about research into caring and disability is really very important because each of these themes has so much to say about the discourses and practices that influence our lives, daily.

So, with this pre-preface view, I want to help set the tone by ‘giving up’ as it were at this early point, what I believe is the more important and potentially ‘disruptive’ elements of this research investigation into caring and disablement. The power in the account lies in the meeting of the two human dimensions; a concept of caring and a concept of disability. Caring is ‘natural’, unconscious and comfortable. It is gently embedded, softly integrated, ordered, and an unspoken quality of daily life. It is beyond question and tends to occupy all the spaces that hold individual, family, community and society together. There is a sense in which it is everything we do (caring for ourselves, others and our world), except when we are uncaring especially of others, and then it is known, noticed; we know and it penetrates consciousness.

Disability could not be more different. It is ‘unnatural’ (although naturalised in biological discourse) and it is disability because of this. It is disruptive, jarring, unassimilatable, conflictual, and finally a matter on which we must consciously either act to exclude or include. It has historically been and continues to be a very uncomfortable presence in our lives. Our management and containment of this has been paradoxically linked with the naturalised caring construction.

The public discourse on institutionalisation and deinstitutionalisation has largely captured the entire deliberations about disability and issues of treatment and care. There seems little doubt that deinstitutionalisation has been a significant social phenomenon, and it is appropriate that it should be studied for its meaning and personal and social implications. Yet I will argue that there is clear enough evidence that institutional care was a small part of the overall picture of the treatment and care of disabled people. It is not just that this public discourse tends to render invisible the work of carers in the private world. There have been some very good accounts particularly from a feminist perspective, of the hidden quality of womens’ work as carers, and the way in which the deinstitutionalisation discourse
has accentuated this. I think it is appropriate however to go one step further back and call into question the broader discourse.

The thesis suggests that the precise numbers of those placed in institutional care are difficult to ascertain. Nevertheless there is sufficient evidence and a convergence of evidence both here and overseas to conclude that there may never have been more than 20 percent of the disabled population in institutional care, and probably for most of the time far fewer. This represents a significant number of human lives incarcerated in what has been well documented to be often highly dehumanising and destructive care regimes. Put another way however it may be said that at any one time probably 80 percent or more of the population of disabled people grew up and continued to live in the family home.

This is a very sobering reality to consider because when one looks at the public account, notwithstanding the recent social and feminist critiques which the thesis draws upon, there is very little told about the experience of carers of disabled people or the caring experience as a complex ecology involving at least two people and an immediate and wider social context. I have argued that carers' lives may be comprehensively constructed by their responsibilities and involvement with disablement, and that the depth, extent and nature of this carer experience and construction is largely absent from the public account.

A very important aspect of this story and a significant focus of the thesis is the link between the particular constructions of disablement in our society and caring. That we should have such an all embracing discourse around deinstitutionalisation should be indication enough that disability is, as I suggested at the outset, a very disordering and destabilising aspect of our lives. In the public discourse it consistently results in our consideration of the lives of disabled people in terms of the forms of inclusion or exclusion.

The hidden quality of the caring work of women then takes on new meaning when considered in conjunction with constructions of disablement which produce whole technologies and specialisations for managing and of course 'hiding' human lives. It is a very powerfully silent and isolating association that is made between women as carers and disabled people whom society does not want. This is the primary focus of this research.

In fact caring as a research and seminal topic has had significant attention in the last 10-15 years (Twigg & Atkin, 1994). This has reflected the strong feminist critique of the period. Nevertheless, it has been a more recent event that such critique has incorporated the complexities of the postmodern and poststructural view.

Postmodernism and perhaps more particularly poststructuralism have presented a challenge to modern empirical thinking and its methods of knowing and acting in the world. Numerous authors have reflected
specifically on the nature of this challenge (Weedon, 1987; Agger, 1991; Barrett & Phillips, 1992 to name just some). Personally speaking I too am grappling in my own way to fully appreciate how a postmodern view may change my sense of responsibility and action in the world, and that of those who form my world. Most particularly this reappraisal involves a rethinking about the nature and centrality of power, and the power of discourse to define realities which are multiple and changing. Perhaps more significantly however the story that unfolds here is an earnest, and at times quite personal attempt to understand how these perspectives inform our public actions, and our understanding of caring. I have in the thesis explored these challenges and tensions in relation to a particular group of carers in a local community. These actions include of course the inquiry or research action itself.

This study then is about my experience of understanding the constructed lives of carers of disabled people. I have presented their construction in the context of the production of a ‘normal society’. The ‘normal society’ has been presented as a discourse which operates in a number of ways to contain difference and the potential for social disorder. I have depicted disablement as the product of a number of discourses, economic, social, and predominantly as bio-medical. I have also portrayed the discourse of disablement as a paradox in its reinforcement of normality and an ordered world, by its construction of disablement as a threat to such order. In this picture the constructed body is paradoxically written and read as disabled in ways which deny difference, and then reconstructed in manageable and containable ways through normalising ideology and practices.

This interconnection of constructions of disablement and caring appears to work at multiple and interactive levels, and is in simple terms underscored by three socially determined and interrelated factors. I argue that these constructions result in a form of ‘career’ for disability carers. This may be characterised by social loss, stigma and a lifestyle closely defined by the involvement with disablement. This may involve a search for a supportive or caring culture. It is possible to view the public discourse of deinstitutionalisation and individual rights, which pushes out the complex reality of caring, as contributing in some degree to the isolation and exclusion experienced in caring for a disabled person. This isolation and exclusion occur behind the screens of apparently caring institutions such as marriage, family, community and the service system which are centrally constructed around and produced by discourses of care. I have identified this as a central paradox of the research.

The first construction of carers of disabled people identified in the study is that connected with the ideology of impairment to the human body itself. Linguistically this refers to loss or imperfection, but this is constructed as personal and social loss of wholeness for the person with an impairment, and by association or reflexively as it were as personal and social loss for carers. The second construction is the highly gendered ideology of caring based on constructions of womanhood and femininity. The third socially
determined factor of significance is the ideology of family which in paradigm terms is portrayed as a site of caring culture, but the research reveals may simply serve to disguise isolating realities within. At a broader contextual level of power and political economy I portray these discourses as manifestations of patriarchy and capitalism.

The association between the production of women as natural carers in discourses of caring, and the discourses of disablement as disordering and even monstrous is most important. The narratives of the study highlight the very silent and isolating fashion in which all this happens. This private reality takes place at the same time as a public discourse rages on more or less as if there was no private caring experience, an experience which for many carers is clearly central and life defining. The effect of naturalising caring and naturalising it to women within the construction of family as a caring environment is that we seem no longer to need to see or consider the issues and lives bound up by this constructed arrangement. It masks the very great personal pain and sense of separation experienced by women as carers, and their own significant needs for a caring and supportive culture. While carers themselves participate in the range of regulatory forms associated with marriage, family and service systems, they nevertheless both seek and construct caring culture and spaces of personal preservation.

Socialisation into this so called ‘career’ of disability carers begins within the cultural discourse of normality and the ‘normal society’ which is adopted as a paradigm from the earliest years. More specifically these learned perceptions are engaged by the carer at the point of ‘diagnosis’ and labelling of the disabled family member, and the carer’s experience of isolation from meaningful caring relations; the absence of caring culture. They grow out of the powerful conspiracy of silence and the unacknowledged loneliness of a carer’s association with disablement.

In the search for a caring culture carers of disabled people invariably find their lives bound up in that of the service system which offers some hope of a supportive response. Instead they almost just as predictably find that this is an alien culture that does not see their needs as they are, but redefines their desire for supportive connections into diagnosis (labelling) and programs of assessment and monitoring based on professional knowledge. I suggest in the thesis that in some respects this looks like a process of exoneration of parents by the service system, a modern changeling tale in which the service system relieves the mother in particular of the burden of responsibility it has placed upon her through the predominant discourses of caring and disablement. It can also be seen as a form of absolution for society in the absence of a personal care response. The complexity and irony in this is apparent when one appreciates, as the research suggests, that service system professionals themselves seek the support of a caring culture in performing their ‘caring’ work. They like carers perform their work within models and systems whose logic is inconsistent with a personalised care.
In the research process itself I have adopted an ethnographic-like stance and sought to facilitate locally and reflexively a different construction of participants as carers and a different concept of community. I did this by establishing processes in which participant carers wherever possible were actively part of the decision making, and processes that were essentially supportive in practical terms through information sharing and emotional and social support. The thesis may at one level be understood as a record and reflexive critique of the patterns of my changing understandings, and my position in relation to the community of carers with whom I have participated over this extended period. I have come to characterise this process in terms of a search for a more balanced ecology of care and praxis.

The research story and the caring story are presented as reflexively intertwined. In research as in caring the modernist propensity to rational, progressive action in the world as exemplified in the language of scientific control, professional intervention and strategic management may need to be tempered by a more reflexive effort to appreciate difference and a greater sensitivity to complexity of relations and an ecology of care. I believe that this is an important way in which the lives of participants in this research and critical and postmodern thinking have contributed to new understandings. I have suggested that this has implications for our formulation and implementation of public policy.

Overall, this collaborative and reflexive endeavour is informed by more conventional methods of quantitative and qualitative research such as literature review, interview surveys, and participative methods. I have adopted a critical perspective and discourse analytical approach to utilising these research methods and to ‘read’ and reconstruct data as required.

I believe that participants in differing ways have questioned societal constructions of themselves as carers, and their own involvement in this construction. In the process they have begun to construct a different view of themselves individually and collectively which challenges and transcends the certainty of dominant perspectives. The process has in some small measure allowed the constructed and observed to be the constructers and observers. Participant carers have in effect made a little room for other constructions of caring culture and community, and in the process informed the development of a more complex relational basis for the development of social and public policy. This calls into question the individualistic and dualistic basis of current formations of public policy which inevitably privilege powerful discourses, and result in alienating and isolating social and cultural forms.

The thesis is conveniently organised in three main parts. Part 1 consists of chapters 1 and 2. In chapter 1 I have sought to introduce a number of the key issues of the study, and in a style which to a large extent sets the tone of the thesis. I have built the thesis appropriately I believe, with my own assumptions and views as its foundation. In some respects this will look like a sleight of hand because this chapter was to be chapter 3, but I am happy
to acknowledge as part of the discourse and art of the thesis that it is made up of retrospective and prospective elements. I have suggested that this is testimony to the politics of the thesis project. Like research and the scientific process in general this is a political engagement, and part of defining a good scientific work is the ability to trace this aspect.

In gathering the literature and setting out the theoretical context, and the bigger picture issues which are substantially the tasks of chapters 2, I have permitted myself some latitude in the criterion of reflexive accountability. The presentation of this chapter was not so much uncritical, but I have largely suspended my personal and reflexive involvement with the text. This was in order to make room within these pages for other relevant perspectives, and to have space also for establishing the theoretical backdrop on the issues of caring and disablement.

Part 2 consists of Chapters 3, 4 and 5 which engage substantially with the story of the research process including my own reflexive participation, and the narratives of carers as participants in the Group and as individuals. Chapter 5 provides a perspective from professionals who were working in the local service system, and came in direct contact with disabled people and carers in carrying out their work. In chapters 4 and 5 in particular I have attempted to present a critical analysis of the narratives largely free of a theorising process, to which I return in the final chapter.

Part 3 includes the final chapter only, chapter 6, in which I have attempted to bring the narratives more specifically into an integrating conceptual frame and to some extent to encapsulate them. I have been cautious about this, recognising the threat of simply producing or reproducing another regulative category: a reminder of the Foucauldian message of the power-knowledge connection. I have concluded with an endeavour to reconnect the thesis with my material assumptions, and in no doctrinal or categorical way, I propose some tentative public policy guidelines that the research suggests.

Generally the acknowledgements appear at the front of the thesis, even though they are usually written at the end when all the hard work is done and the sense of appreciation and gratitude for support is most genuinely experienced and felt. Its position in the thesis presentation is testimony to the strong conventions which guide the scientific process of which this thesis is a part. It is to these conventions I want to convey my first debt of gratitude for without them I would have had to construct my own, and furthermore I would not have had the opportunity for critique that such convention provides.

It is it seems as Michael Mulkay in The Word and the World (1985) suggests, that the process of acknowledgement is a peculiar textual form "in which the author tells a third party that s/he 'would like to thank' a second party, but seldom actually says 'thank you' to that second party "(p. xi). That said, I can say that most of those acknowledged here have been thanked.
personally, and I therefore view this as an opportunity to recognise their contributions publicly.

In fact I want to make three sorts of acknowledgements. First is to the contributions of those who I refer to as participants. Their contribution is an essential ingredient of the story, and without it clearly the story would not be told. Many of those participants who are the Parent Exchange Group, have been part of this contributory process for approximately 5 years, and I thank them for sharing and exploring their experiences, and accepting me as a friend. I would like to mention each of you by name but I know many of you are happy especially in this context to remain anonymous, a quality of your lives I know which is not at all uncommon. The other participants I thank, most with whom I have only spent an hour or so, gave their time very generously, and shared their experiences with a quality perhaps beyond that deserved by the questioning.

The second sort of acknowledgement is to those who supported my work by being friends, making the space, enquiring about my progress and providing encouragement. Overwhelmingly this support has been that of my family, especially Rose. Ben and Rohan, and Matthew and Leigh, and my wider family too have always taken an interest, and offered encouragement, and I thank them for this.

I would like to include in this thank you my colleagues in the School of Health who took an interest throughout, and absorbed some extra work while I pursued my study during a six month sabbatical during 1996. I also appreciated my earlier attendance at the School of Social Ecology residential and the valuable process of sharing my research in progress with staff and students. The culture and ideas of Social Ecology and the ‘New Humanities’ are surely evident too. My gratitude extends to the University of Western Sydney for providing a research grant in the early period of the study, and the Faculty of Health, Humanities and Social Ecology for support with expenses in transcription is also gratefully acknowledged.

I want to offer a special word of appreciation in this context to Debbie Horsfall (Social Ecology) for her close interest, involvement and support in an earlier phase of this research from which the thesis has grown. Her support included the Group’s early development and collaborative endeavours which led to the report Living Together, Apart. The Experience of Disability in the Hawkesbury (Clear & Horsfall, 1994). I have used this report as a basis for my brief outline of this earlier phase of the research in chapter 1 of this thesis.

For the support of Judi Powis as a research assistant during the early phase, and for transcription work more recently, I am also most grateful. The UWS, Hawkesbury library staff were always helpful, and I thank Sue Venables and Di Roberts particularly.
Finally, and of course as we say 'not least', I want to thank Professor Bob Hodge (Humanities) for accomplishing with some considerable skill and insight, the often delicate balance of providing support and challenge throughout the years of supervising my research. On a number of occasions Bob's supervisory effort also quietly led me back to my own personal mission. This was especially important I feel in my striving for some reintegration of theory and action, and to make my research and theorising relevant and practical, locally. My commitment to this was evident in the development of the Parent Exchange Group. In my original proposal I had cited Robert Bellah (1970) in saying;

The radical split between knowledge and commitment that exists in our culture and our universities is not ultimately tenable. Differentiation has gone as far as it can go. It is time for a new integration (p.257).

In the end I believe the thesis provides a strong and personal account of the lives of carers of disabled people in a local community. In so doing it has within a robust research framework brought into sharper focus many of the discursive and material aspects of the lives of carers and less directly the disabled people with whom they share. It has sought to bridge the gap between the processes of knowledge construction and the material experience of the carer participants. It has attempted a reconciliation of sorts between a material and textual view. I am most grateful to Bob amongst other things for helping me stay with this purpose.
The terms disablement, disability and disabled people are used throughout to highlight the author’s view of the constructed dimension of such categories (see Hevey, 1992). In contrast the term “people with disabilities” can be seen to highlight disability as something the individual possesses rather than something society has made (disabled by society). In this thesis the terms generally refer to those who are disabled ‘developmentally’ and are likely to have experienced stigma because of their categorization and treatment as disabled people, and require particular support and care in order to participate in regular personal and social activity.

Many disabled people of course require no such particular support and care, and indeed may well be carers themselves. Carers in this thesis are those who take primary responsibility for the support of a disabled person.

I acknowledge that different uses are valid and given the context serve to emphasize different aspects of the ideas being discussed.
PART I

The breadth of the issues
Chapter 1 - A polemical introduction

The chapter to replace chapter 3

Not so long ago the substantive content of this introductory chapter was contained in a chapter on research methodology and research methods. This was to be chapter 3. Self evidently enough it followed chapters one and two, both of which introduced important ideas about the substance of this study. They laid the foundation which provided the research a certain logic, relevance and a credibility grounded in the wider world of science and the literature of my topic. It was natural enough to follow these ‘foundational’ chapters with an explanation of the research activities which made my thesis distinctive. I say “natural” because this is the pattern of research reporting everywhere, and also in the logocentric formula common to this process it was a logical point of explanation, prior to presentation of the “results.”

In the process of research orthodoxy and thesis writing that I have been describing, the pattern is clear. Firstly, one is engaged in the process of a carefully constructed logical argument. Secondly, the argument is presented in a scientific genre which is an authorless monologue, and whilst some notion of critique is permitted (by convention) within the argument, the opposition is one way. Thus, the non personalised author may (indeed is expected) to contest selectively the work of others, but the genre permits no
reflexivity or any real sense of an oppositional, contradictory or doubting voice. This personal and self contested quality, perhaps the experience of any learning, in the conventional methods of science (research) is written out. Thirdly, in the unfolding of the argument, the motivational impetus, the excitement of engagement with ideas (the personal attachments and message) that is really the fire keeping the researcher burning is withheld in order to permit the empirical evidence to reveal it. The implication here that the argument is carefully kept under wraps, is correct. The real message of the real author is suspended and hidden respectively to satisfy the conventions of a scientific discourse based on an epistemology of objectivity.

The assumption of this whole process is that its methods and conventions are such as to allow one to make a valid claim to truth about the material world of things and experience. An assumption from the outset of this current research (yes, that means ‘my’ assumption!) is that the issues of social dynamics and power with which this work is so centrally concerned do indeed have some material basis, but that knowledge of them is necessarily mediated by the language and discourse which produce them. From this I hold that no simple claims to truth can be made, although well defined and applied critical processes may produce revelations of the complex interests of power which produce ‘truths.’ In this I recognise and accept too that my explanation of these so called truths or revelations will become part of the complexity and the meaning of the phenomena being studied. This function of discourse in the production of knowledge is itself a challenge to the dominant paradigm which sees the function of language
and discourse as only to reflect reality. This is linked to a scientific method
the function of which is to reveal knowledge that exists objectively.

That I should hold these assumptions, and still be trapped within the
research conventions of an objectivist epistemology is a measure of the
power of the paradigm, and my training within it. It offered a degree of
security because it was familiar, but perhaps it was safe too, because I felt I
had some understanding of the very workings of power within the social
conventions of the academic thesis production process itself.

So it is that much of the concern of this thesis is the discourse and
experience of power in social relations. This is no less an issue because the
relations exist in research. It might be said that the discourse and experience
of power in the processes of knowledge production are more of an issue
than in other contexts because as Foucault (1977) argues, power and
knowledge are effectively a system and where one is, so exists the other. In a
world in which ‘normal’ science is defined in terms of the certainty of
objective knowledge, those who command some domain of objective
knowledge are permitted to be heard and to define problems and solutions
(Mendez, Coddou, & Maturana, 1988).

Where does this discussion and the confessions and concessions it contains
leave my thesis? Well, firstly it has provided me with the opportunity to
state some important assumptions up front as it were. These are no simple
ideas because they touch on the very matter of finding out, of producing
knowledge. Secondly, it addresses the taken for granted aspects of research and thesis presentation that are so reified and can be so hard to make explicit, as my own experience here suggests. Thirdly, it will probably be evident now that this chapter is not a simple presentation of the research assumptions and methods taken into the study in some fixed way and reproduced in the thesis write up. In fact the thesis write up, as I have learnt through this research process, is a complex part of the research and interpretative experience. After all, chapter 1 was to be chapter 3, and this is one of those sections of the thesis in which the structure and content is a mixture of the prospective and retrospective. Finally, it suggests something of the critical approach that I want to adopt to the thesis process throughout. In short, I am interested in the question of research, and not just particular research questions.

My stance in relation to the research process made it obligatory that I presented my thesis concerning the substantive concerns of this study at the outset. The Preface was used for this purpose, amongst others, and important ideas about caring and disability have been set out. The process of the research however is a transformative one. This I believe is true for me as the researcher and for other participants, and in the account of research this needs to be explained. This idea is evident even as I write, and it is perhaps well illustrated in this chapter. Far from a researcher being able to step outside him/herself, research is as much as anything else a journey of self discovery. It is autobiographical. Derek Colquhoun and Allan Kellehear’s (1996) observation is relevant. They suggest that,
research is always conducted by men and women who are confronted by an assortment of political, ethical and methodological pressures, which are seldom discussed in the more theoretical treatments of ... research. This is because personal experience is so often sanitized even erased ...(p ix).

So it was that the Abstract and Preface dutifully provided a view of the whole study captured as a compendium, up front. Even in this summary form the challenge of maintaining a critically reflexive paradigm is revealed. The careful reader will notice that whilst the researcher is positioned personally within these thesis introductions, the Note on the text refers to; “the author’s view,” as if to suddenly slip outside the process. In this case, having become aware of ‘falling’ back into old habits I have also chosen not to edit it, which itself says something of my attitude to the craftsmanship of thesis writing.

Methodological concerns and research methods

The discussion to this point has highlighted broadly my stance in relation to the question of research. It began an exploration of the important question of the role of the researcher and my position in the research process. I believe in this I was talking of the politics of research. My interest here is in the ability of the research process to not only create new knowledge and understandings from its explorations of ideas (compare this with the apparent function of any research), but to create opportunities for change or improvement, based on the ideas and understandings of those who are participants. The reference earlier to Foucault (1977), and the links between
power and knowledge as a system, and the power involved in commanding
some area of 'objective' knowledge to define problems and solutions was not
only a matter of interest in the professional world of the state service system.
It was central to the politics of research and the manner in which the balance
of power may be changed within and beyond the research process, and was
experienced by participants themselves. This was a concern then with
reciprocity of praxis in and beyond the research process itself. In the concept
of reciprocity the principles of reflexivity and the developing
understandings of research may become the concerns of all participants, and
not just someone designated as the researcher.

I have not however seen it as my responsibility to 'make' other people
(participants in the research) reflexive. Firstly, I do not see reflexivity as the
same as reflection on some object of one's thoughts. It was as I saw it a more
critically conscious experience at any one moment which itself reflects on
reflection. This has been described as a double loop of reflection on reflection
(Armstrong, 1995). It suggests being able to 'see' one's own position, the "I",
in any thought or action (Schon, 1985; Winter, 1989; Lather, 1986 & 1991;
Fook, 1996; Street, 1996). Secondly, my concern here as the researcher was
very much more with establishing opportunities for a particular group of
people to voice their interests and to be heard and not to tell them how they
should think. Nevertheless having said that this was my interest I can
report that the experience of providing opportunities was not simply benign
or uncomplicated, and chapter 3 explores something of the complexities of
reflexivity and reciprocity in my experience with the Group.
In the end the question of reciprocity was one of sharing at a number of levels and in a number ways. Like the issue of reflexivity it struck at the heart of power and the need for control of interactive processes, information, discourse and meaning, to be central and explicit in research (Lather, 1986; Fook, 1996; Young, 1990). It also needed to take account of others (“the other”) in a concrete sense not as abstracted or generalised others (Benhabib, 1986). The abstracted and somewhat impersonal position is common in conventional research, and reflected in references to the research “subject”. The language is seen to capture something of the objective position of the researcher, although I would argue it captures something of their impersonal position, not their objectivity. The inability or failure of the researcher to gain some measure of identification with others (participants), I believe makes reciprocity and some notion of shared subjectivity or community, difficult if not impossible. It makes the reproduction of extant power arrangements, and the inability to promote change highly probable. This latter point is one I feel more able to assert since my own experience in this research and the reflective process described in chapter 3 and subsequent chapters.

A process which presupposes the value and importance of change such as collaborative action research is by definition concerned with the dialectical connection of theory and practice and the way ideas are experienced and understood in everyday life (Carr & Kemmis, 1986; Winter, 1989; Robottom & Colquhoun, 1993; Street, 1996). Once again my interpretation was not in any simple sense of a project or a plan for doing and testing some ‘new’
action, although such projects in action research were possible and relevant. It was understood more in terms of the collaborative workings with the experiences of ordinary people. Participants coming together in some notion of community (sharing and reciprocity), sharing practical experiences, and repeating this over an extended period of time with a view to doing what they do better, and with an improved sense of its value and their own (Kenny, 1994). This reflected something of Habermas' (1971) practical knowledge interest, and the intersubjectivity of Schutz (1972) in which knowledge was generated amongst participants to inform everyday actions and in turn was informed by these experiences.

However, I was also guided by a Habermasian perspective in assuming a critical perspective was needed for the research process to deal more fully with the central issue of power, and to uncover and make explicit, contextual factors that regulated daily lives. His critical and emancipatory perspective argued for the construction of knowledge in communicative circumstances which are free of the distortions of dominant interests legitimations and ideology) and more open to critical scrutiny (Habermas, 1971, 1975 & 1984). Such a view was as I saw it strongly linked to a collaborative methodology, and one in which reciprocity and reflexivity in the terms I have discussed them were central. It also highlighted in a central way the constructed nature of realities, and the interests of power and social order that produced them. Knowledge creation and the process of critical analysis are linked to political engagement and the experience of ordinary people, and practice settings (Habermas, 1971; Agger, 1991).
The Habermasian perspective nevertheless relies on a view of a stable rational subject who through communicative action could achieve some kind of abolition of inequalities, critical subjects engaged in informed action (praxis), and hence a utopian world. I believed that the postmodernist perspectives on the importance of discourse in shaping and reproducing realities and a decentred subject gave a balancing quality to the critical perspective of Habermas and the critical theorists. It provided me with a more balanced approach in seeking a research methodology which recognised the centrality of power, the multiple and constructed nature of the social world and the function of discourse in this, and the political significance of the experiences of ordinary people.

My own developing perspective also included something of the Gramscian and feminist ideas of praxis and the link between the personal and commonsense and the social (Salamini, 1981). Sassoon (1987) captures these ideas and highlights nicely their links to the women’s movement;

The women’s movement has insisted that women’s personal experience is political, be it articulated in consciousness-raising groups or more informally through the kind of networks of friends and acquaintances which women have always established. It provides the raw material for intellectual and political work as well as solidarity. This coincides with a lesson from Gramsci’s writings. He argues that the necessary starting point for a better understanding of the world must be a critical analysis of people’s common sense (p16).

This coincided with and helped to bridge my own movement from a relatively uncomplicated feminism and a Marxist stance towards recognition of the value of critical theory, postmodern and poststructural
perspectives. At the same time and reflecting my professional interest in educational processes I had been influenced too by the work of Freire and his concept of dialogue and dialogical processes involving the active participation of those most connected with problems that they themselves had defined (Freire, 1970 & 1972). Here, ‘praxis’ was the real basis of revolution and change; “reflection and action upon the world in order to transform it” (Freire, 1972 p28). The processes of critical reflection and action for social change in the context of real settings with those most concerned seemed to provide a more practical basis for the theoretical suggestions of critical and postmodern approaches. I began to link these closely in my own way with my formal ‘training’ in research and the somewhat more academic approach to collaborative and action research methodology that this entailed. I believe I was in no doctrinal sense working with the ideas of community development and social change (Kenny, 1994).

Before connecting the discussion more to the research approach adopted I want to make a distinction between research methodology and methods. The distinction seems important, especially in the context of a collaborative and action oriented approach to research. It seems necessary to clarify these ideas also because of the degree of controversy that exists around the use of different methods in research, particularly along the qualitative, quantitative ‘divide’. In short, when I use the term methodology I am referring to the broad set of assumptions and values, in this case those theory, practice, critical and collaborative ideas about which I have been discussing. Fundamentally it is a reference to my ontological and
epistemological stance, and to this extent it might also identify broadly speaking, my affinity with one of the research ‘clubs’ or traditions. On the other hand I view methods as simply the range of data collection and analytical techniques commonly used in research. These methods include questionnaire surveys, interviewing, observation, descriptive statistics, discourse analysis amongst others, and are at one level simply useful ways of problem solving. I acknowledge that others may draw somewhat different lines of distinction around these ideas, but this particular distinction has proved useful for me.

In general I think these techniques of research are freely available to ‘members’ of any research ‘club’, and will be chosen to match particular research concerns at any given time. However, having said this it also seems clear that particular sorts of research methods may lend themselves better to particular broad methodological perspectives. Traditionally for example this might mean that interviewing is a preferred form of data collection for phenomenological methodology than a written survey instrument. My own position nevertheless is that whilst these traditional allegiances between methodology and method may generally hold there is no necessary link, and I am personally open to using whatever methods are appropriate given the research issues at hand. The qualitative, quantitative division around methods sometimes presents as simply another example of a debilitating dualist discourse which may simply contain and effectively disguise complex and important issues of paradigms and knowledge construction.
With these broad considerations in mind it is appropriate to turn to the study undertaken here, and to initially view it at the broadest level. The research took place within a collaborative framework defined by the Parent Exchange Group (PEG). By this I mean that the regular PEG meetings, developing contacts and networks of the Group provided a community of personal experiences, ideas and issues around which my own attention and reading focussed. It was the source of information for research and an impetus for the research activity. In specific relation to the PEG, I made a number of assumptions. Firstly, I believed that meaningful human connections and social interaction which was the basis of community was fundamentally important to all participants. Secondly, through the Group activity and the wider research activities (meetings, interviews and networking), of talking honestly about ideas, feelings and concerns, new things could be learnt about ourselves and our circumstances. In this participants could feel supported by others in a relatively safe (trusting) environment, and through all this learn how and be freer to make changes and choices in their own lives, differently. More specifically, I assumed that one may gain a keener understanding of how we were ‘made’ by cultural and social forces, and also develop from this a stronger sense of a personal ‘self’ (or selves), as distinct from a societally constructed ‘self’, and experience the benefits of this. This was the power of seeing the socially constructed nature of reality and pressing the daily taken for granted aspects of life a little harder than usual to see if they were really as ‘natural’ and unchangeable as they appeared. Within this context of regular meetings and ongoing
connections over an extended time practice and theory, experience and reflection, were ‘naturally’ bound within the research process.

I believed that a new sense of hope and the potential of things to change could come from the realisation that the burden experienced in disability and caring was in a significant way made and developed by society through accepted systems of thought, rather than being fixed and unchanging facts of life. The experience of disability caring could be different, and part of changing the experience was not just in getting better and extra support in doing caring work, as important as this undoubtedly was, but also in simply thinking differently about how these things actually worked, particularly in relation to the construction of disability and caring.

In this sort of research process participants were informing me and each other of issues about disability and their experience of caring. I was also endeavouring to do, at least, these things; (i) create a context, such as the regular meetings in which participants shared and explored ideas about disability and caring, but also about their life experiences generally and (ii) feed back ideas about the research as it proceeded so that there might be opportunities for new understandings about these things. Hopefully the outcomes were to do with a sense of support gained from sharing information and experiences which may have helped create and maintain some feeling of community amongst all participants and specific actions such as the Family Support Project (discussed in chapter 3) which may have worked to help in a material way.
Finally, but not least, the outcomes might be to do with a growing appreciation of the constructed nature of things, which often seemed fixed and natural, and just how they should be because we have thought about them and acted with them for so long as if they were. It seemed that this was how society wanted us to be with disability and caring. Chapter 3 provides a full account of this collaborative process and how it worked in practice. The following section sets out the research methods that were used in conjunction with this broad methodological framework.

Research methods and political interests

The research methods described in this section were always considered within the generalised methodology based on the collaborative framework of the Group. In other words the concept of a Group looking at its experiences as issues continually informed my decisions about what was important. This in turn influenced my reading and search of the literature and my focus on particular issues. In what I have come to call phase 1 of the research, my efforts in conjunction with a colleague and a seeding grant from the University (see acknowledgments in the Preface) was a study of the social support systems of disabled individuals and their families locally. The current study grew out of and overlapped with this research, and led into what I call phase 2 of the research. In phase 2 my focus became more exclusively that on carers of disabled people and their experiences.
It is not possible to neatly separate these two study phases of the research, and nor does it seem necessary or desirable to do so other than to clarify the primary focus of this thesis. In the context of its focus on social support systems of disabled people themselves, the Phase 1 study brought to light issues concerning carers and families. It was basically practical in nature, and did not attempt a fundamental and theoretical critique of the issues on which it touched. It was almost entirely unreflexive. A resource shortage meant that other than on two occasions the report that was produced from this phase of the research relied on fieldnotes and interview summaries, rather than full interview transcripts (Clear & Horsfall, 1994). Nevertheless, it was an important foundation for the current study and in many respects integral to it. It saw the early formation of the Parent Exchange Group, the establishment of the Family Support Project (FSP), and the development of a community worker model, that was proposed to government.

The current study phase (phase 2) then was built on, and extended and developed aspects of the earlier phase. With this in mind the following section draws on the research report of phase 1 to briefly summarise its aims and objectives, methodology and methods before describing the way these have been taken on in phase 2. It also provides another basis and reference point on which to observe my own changing relationship with the research process, and my consciousness and identification with the carer participants as the story of the following chapters unfolds.
Phase 1 research - the early patterns of research work

The aim of the study in this phase was threefold. Firstly, it was to prepare a demographic report on the nature and extent of disability in the Hawkesbury Local Government Area (LGA). Secondly, it sought to determine the nature of the social support networks of individuals living in the Hawkesbury LGA community who had developmental disabilities. Thirdly, it set out to use action research to plan, implement, and evaluate action, to develop the social support systems of people with developmental disabilities in their local neighbourhoods (Clear & Horsfall, 1994).

Whilst there was no strict or formal attempt as in conventional research to define the terms “carers” or “disabled” people, there was a broad understanding of who these people were. In fact carers defined themselves, by volunteering to participate, firstly in the activities of the Group and later in the interviews. However there was an interest in a particular group of disabled people who may be considered to share some functional needs and support characteristics in common. In its policy pronouncements, the New South Wales Department of Health (1985) provided a definition of developmental disability. The essential idea in the definition of developmental disability was a focus on the functional support requirements, severity and age of onset of someone so labelled. This represented an important shift away from attempts to define disablement in
terms of innate capacities and abstract constructs, such as scores on Intelligence scales (AAMD, 1975; Grossman, 1983).

This particular definition and focus tended to explain disability in terms of individual deficiency, rather than from a social and political perspective. Such definitions provided a more practical basis on which governments could make public policy determinations. They did not necessarily explain the 'true' nature of disability. The important point here was that the disabled people were constructed and recognisable by their label and categorisation as disabled, and a carer was someone who provided primary support, and was part of this process.

The relevant data for this region was accessed through Area offices of the Department of Community Services, Developmental Disability Service, Department of Social Security, Local Government Services and the Australian Bureau of Statistics. Initial investigations with Regional Officers of the Department of Community Services (Area Service Managers), supported the fact that data was incomplete in relation to both the nature and extent of developmental disability and the nature of the social support systems of the target population.

The study was viewed as a pilot study, as no similar study had been undertaken in the local area. In the literature generally the question of social support networks as a critical factor in successful community integration of people with developmental disabilities remained relatively untested.
Nevertheless there was an emerging view amongst researchers, that the difficulties experienced in successfully placing people into regular community employment and residential life may not just be a function of the skill levels of the people concerned, or the failure of support agencies in their direct support role, but a general failure to cultivate the usual social support systems upon which most people rely (Cattermole, Jahoda, & Markova, 1990; Clear & Mank, 1990; Todd, Evans & Beyer, 1990; Parmenter & Knox, 1989; Peck, Donaldson & Pezzoli, 1990).

I saw the failure to develop these social support systems, for example, as resulting in poor retention rates for people with developmental disabilities placed in regular employment, inability to function independently in regular and semi independent residential settings, with subsequent escalation in agency-provided support, and the significant cost inefficiencies which this causes. Further, isolation, loneliness and the general lack of benefits associated with companionship and friendship may be significant contributors to ill health, and to significant diminution in an individual's quality of life. (Greenspan & Shoultz, 1981; Halpern, Close, & Nelson, 1985; Hibbard, Liggett, & Shrestha, 1987; Hill, Wehman, Kregal, Banks, & Metzler, 1987; Noble, (Jnr) & Conley, 1987).

More specifically the study had the following objectives:
-to document the demographics of disabilities in the Hawkesbury local government area
- to investigate individual social support systems (family, friends, advocates and companionship patterns), by questionnaire and interview survey of a sample of individuals with developmental disabilities
- to develop and maintain links with individuals with developmental disabilities, their families and advocates, as a basis for future collaborative involvement
- to gain knowledge of the support requirements of individuals with developmental disabilities in the local community as a basis for informed advice and consultation with the local service industry
- to develop and maintain a working party to undertake collaborative action research to improve social support systems for these people at a local neighbourhood level
- to disseminate the results of the study in the form of a comprehensive report to assist local service providers, governments and people with developmental disabilities and their advocates, in developing the most appropriate support arrangements (Clear & Horsfall, 1994).

The design of the research study carried out during this phase involved 3 specific stages with each stage employing a different research method to match the research demands of that stage. All methods were employed within the collaborative methodology defined by the operation of the Parent Exchange Group, and this guided the research throughout. Whilst the design adopted here was specifically aimed at gaining new information and understandings at each stage, it was also designed so that each successive stage built and developed on the other. To this extent the multiple methods
approach of each stage viewed as a form of methodological triangulation as advocated by Denzin (1970).

The specific actions and on-going activities of the collaborative research Group were an integral and integrative aspect of the whole research process. The Group's support of the research took 4 forms, and these are discussed in chapter 3 as part of understanding the function and development of the Group.

In stage 1 the research involved data collection, document analysis, face to face discussions, and networking with schools, service providers and local government agencies as required for both gathering information, and clarification in order to establish the nature and extent of disability in the local community. These sources of information also assisted in gaining a better understanding of definitions of disability, the language used and roles of government departments and professionals in the lives of disabled people and their families.

Stage 2 of the study involved a questionnaire survey of 42 participants followed by a focussed interview with either parents or advocates of the person with a disability, or the person with a disability themselves. The questionnaire gained essential biographical information about the disabled person. This came from the disabled person themselves or more commonly from a carer about the family member with a disability. Participants were asked questions in six key life areas concerned with the issue of social
support. These areas were employment and/or educational participation; living arrangements and family connections; friendships; involvement in clubs or social groups outside the home; and transport.

The interview follow-up was designed to support participants' completion of the survey, especially where problems may have existed, and to gain information and understandings about the participants' feelings and values in relation to social support arrangements of the family member with a disability. Each interview took on average one hour and was tape recorded following agreement with participants. Interviewers organised time following each interview to listen to the tape and prepare a 1 to 2 page summary of the interview. These were viewed as critical in the event that resources did not extend to full transcription of the taped interviews.

Sampling involved a purposive, non-probability approach. Thus, participants in this stage of the study were a combination of those who volunteered in response to letters sent to families through schools and agencies, and others who were provided as contacts by "a word of mouth" or "snowball" method and volunteered to participate. As a contextual aspect of the thesis it is interesting to note that 72 disabilities were represented by the 42 participants. This indicated that more than one disability was involved for a number of people. Of the 72 disabilities intellectual disability was most common (29), physical disability (23) and sensory and behavioural disabilities (18). The age range of disabled people represented was 3-53 years. Personal details of carers was not information sought as part of the study.
The third stage of the project involved the selection of 3 members of the Parent Exchange Group, who participated in a series of open ended interviews (three, 1 hour sessions each, and a fourth follow-up session) with one of the members of the research team (the author and 2 others). These interviews were by way of a life story designed to provide a more fine-grained portrayal of the experience of disability, from the point of view of the carer. They were also seen as providing a form of credibility and validation to the questionnaire and interviews undertaken in Stage 2.

The three participants were selected by members of the research team (myself, an academic colleague, and a research assistant employed using seeding grant funds) after consultation with the Parent Exchange Group. Differences in the age, sex and the type of disability of the family member were the main criteria for selection. That 3 participants were chosen for these life stories merely reflected the time and personnel available for carrying out such extended interviews. It was seen as being the minimum number to provide a balanced picture for this stage of the project. Interviews usually took place in the home of the participant, but this was changed to an office at the University campus on a few occasions when this was mutually convenient to the interviewer and the interviewee.

Specific support procedures were prepared and communicated to each participant. This was in recognition of the fact that sharing, and reliving often painful personal experiences could be very distressing. The procedures clearly prepared participants for this possibility, and offered a process of
contact and support. Once again interviewers organised time following each interview to listen to the tape and prepare a 1 to 2 page summary of the interview, and as with Stage 2, these were viewed as critical in the event that resources did not permit a full transcription process to be undertaken.

The process of data analysis reflected the different types of data collected at each stage. Thus Stage 1 involved primarily a form of content analysis of the documents describing disability and in particular disability in the local community. This analysis focussed on words and ideas and tables and figures, to provide a description of the perceptions of disablement, its context, and the nature and extent of disability in the area.

Analysis at Stage 2 was in two distinct parts. Firstly, a database was established using the statistical package, StatView 512+ for the Macintosh. This enabled the basic descriptive analysis required of the questionnaire survey. Secondly, analysis of interview data was supported by the use of the NUD* IST (Version 2.3 for Macintosh) software package which was designed for coding, retrieving and analysis of qualitative data such as large amounts of text from interviews. This package permitted a well managed and systematic approach in efforts to identify patterns, relationships and constructs in the interview data.

The study was idiographic because it did not set out to define principles and laws about disability that might be testable and applicable in any place at any time. The aim was to focus on disability in a particular location at a
particular time. It relied on the ideas and perceptions of participants, including those of the researcher. The outline of the research design, its methodology and its methods make the involvement of participants including the researcher, at each stage quite explicit. This was not a critical process in the way it is developed in this phase of the research and in this thesis, however it was viewed as an important part of the context and credibility of the project.

The design sought to incorporate processes and actions which built on each other and reflect retrospectively on how things have been and seem to be now, and prospectively on how things might be (Grundy, 1986). The pattern of the project was both structured in its use of multi method triangulation (Denzin, 1970), and unstructured or differently structured in its reliance on the learning of successive stages to guide the project. To this extent it was more consistent with naturalistic and grounded theory methodology (Glaser & Strauss, 1969; Lincoln & Guba, 1985; Strauss & Corbin, 1990).

The common and integrating process throughout was the regular meetings of the Parent Exchange Group. This process taken overall constituted a strong form of validation for successive stages of phase 1 of the study, and a substantial test of emerging ideas and themes. The systematic and validating nature of the project is illustrated well in the way the interviews in Stage 2 were in themselves a validation process of the questionnaire survey that came before them, and the data emerging from the regular meetings contributed prospectively to the research planning, and reflected
retrospectively on the findings. In addition to these processes specific steps were taken to check the views of participants in the lifestories on the written summaries that were prepared following each session. The key question being asked at this time was, "Is the reconstruction of ideas and events in this summary accurate and fair?"

As I have already indicated the study was valuable in a number of ways and its basic findings, particularly those on neighbourhood based social support of disabled people have been reported elsewhere (Clear & Horsfall, 1994). It contained important limitations however and in the following section these are identified along with an explanation of the changing research methods and the focus of the thesis on carers and caring.

Research methods and the changing shape of research

The research methods of the phase 2 study included multiple levels and forms designed to inform understandings within the generalised methodology of the collaborative research group. These were more specifically focussed on the experience of carers locally, and the social construction of caring and disablement. These can be listed as follows:

- International and local search of the literature
- Interviews with key personnel in the service system
- Interviews with participant carers
- Records of regular meetings and contacts with the parent group; the Parent Exchange Group (PEG)- minutes and fieldnotes
- Data management and analysis using the software package NUD*IST (Version 3.0 for Macintosh) and discourse analysis of interview transcripts.

It will be evident from this list that during phase 2 the data base of phase 1 was built upon and extended. The literature search became considerably broadened and deepened to include a more critical review of the issues internationally from a decidedly more theoretical perspective. The phase 1 literature review was primarily concerned with policy and demographics locally, and the international experience of providing services to disabled people. In the second phase as previously indicated this focus shifted to caring and the carer herself. This shift in focus is taken up further in chapter 3, but suffice to say here that the involvement of carers in the Group and their extensive contribution to the earlier phase of the research, provided a powerful impression and a compelling case to better understand the 'other' story of the disabled lives that were being investigated.

The second development included a further 20 interviews of approximately one hour carried out in this phase. These could be described as semi structured or focussed interviews, although in reality they became more conversational. Appendix 1 highlights the broad focus of these interviews and issues covered, although this did not happen in any strict way. The interviews involved 10 participant carers from the Parent Exchange Group, and 10 professional participants from the local service system. Carers who were participants in the Group were invited to participate in the interviews,
and all who volunteered were included. Professionals from the local service
system volunteered, and were selected purposively by me on the basis of
wanting to gain a range of professional perspectives across the medical,
therapeutic and educational services. Appendix 2 is the letter distributed
locally to key disability services to gain volunteers. They were sent in
conjunction with telephone follow up calls by me to the various local
services.

Once again by way of a context it is interesting to note that of the 10 carers
interviewed in this phase a range of disabilities were represented. A focus on
the primary disability label only in each case as reported by the carer
indicated intellectual disability (5), physical disability (3) and both
intellectual and physical (2). The age range of disabled people represented
was 1.5 to 19 years and the average age was nearly 12 years.

Neither carer participants or those from the service system were asked to
provide biographical particulars. This was not considered relevant given the
research expectations and framework. In this regard I should also say that
given the local or provincial character of the study, it carried some not
inconsiderable risks to the anonymity of participants. In broad terms I can
report that carers were all women, eight of whom lived with a marriage
partner and two were single mothers, although previously married. At the
time of interview four carers had part time paid work in addition to their
unpaid caring work at home. Some general information of participants from
the service system is provided with the narratives in chapter 5.
The interviews with carers were carried out in their home or my office according to mutual agreement. The interviews with professionals were usually carried out in their work setting, although on three occasions it was convenient for participants to use my office. The questions provided a guide for me and served more as an aide de memoir, and the interviews themselves were mostly relaxed and informal. I had indicated to participants, carers and professionals alike, that I was happy for them to feel more in control of the process and to ask questions themselves of me if this was wanted. Oakley (1981) provides an outline of this approach to research which permits some equality in a dialogue or interaction. It suggests the two way process that is contained in the word interview, which might be more explicit in inter-view. The desire to conduct the interview process in this way was not altogether fulfilled in the interviews themselves, and this is discussed further later in my account.

The same ethical and support processes described for phase 1 were also put in place for phase 2 (see Appendix 3 for explanatory outline and consent form). Some carers who participated in the earlier phase were also interviewed in phase 2. They completed further consent arrangements in the knowledge that the focus of the study was now changed and involved a more direct focus on their lives and the caring experience, rather than that of their disabled daughter or son.

The Group continued to meet, and I continued to maintain records of the meetings. This was a process of some research significance, and with some
contact and networking taking place between meetings I was increasingly able to define myself as part of a community, and my research position was more ethnographic-like in that I observed and listened and recorded the experiences of a group of carers locally.

To some extent my choice of explaining and working with the data in this phase at the finer level of discourse analysis was my own personal desire to undertake a process of analysis which I was interested in, but not very familiar with. I was also encouraged in this through the supervision process. The fact that the interviews in the second phase of the research were fully transcribed also facilitated the choice of discourse analysis. However, perhaps most significantly the choice was also strongly influenced by the stage I had reached in the collection and analysis of data, and my own journey in the research including my interest in working with poststructural, critical and materialist approaches.

The organisation and management of data and selection for inclusion in the emerging thesis was a highly interactive and iterative process. As the chapter makes clear there was a range of important assumptions about the issues of the study and this combined with my continuing review of the literature and the interview experience interacted and fermented to produce what I was viewing as important categories for organising and thinking about the data. This process does not specifically and neatly fit any conventional qualitative moulds, although it clearly reflects broadly the processes of naturalistic inquiry outlined for example by Lincoln and Guba
(1985). I was supported in managing the transcripts and in the organisation and categorisation of data around substantive and methodological themes by the NUD*IST software program. Appendix 4 illustrates the organisation and categorisation that I developed in the process of analysis, using the NUD*IST program, and Appendix 5 identifies the scope of the issues as I had depicted them in a mind mapping form before beginning the interviews in this phase of the study.

I believe the development of the processes for managing and organising data was one aspect that highlights my personal shift in the research journey. In the first phase I had established a very tight and finely woven data regime, in which I sought to cover all bases with multiple methods and multiple levels. I was acting out what might easily be read as a masculine fetish for strategy and method. As someone with a particular interest in research methodology I was engaged in a test of my performance with the tools of trade. It has to be remembered that I am now reflecting on this earlier phase from deep within the current study, and in no way was I conscious of anything other doing the best research possible. However it was just the issue of consciousness which was all important here. In this phase of the study I believe I was beginning to consider the form of the data from a more reflective perspective and in a less predetermined way. Put another way, I was more responsive to the overall research context. This of course was an outcome that I may well have found easier because of the research foundation on which I was now building, including my developing links with the Parent Exchange Group.
The test of reflexivity

Within the framework of the phase 1 study I believe I saw myself as simply telling a story, to some extent as it was. I understood my research role as reconstructing as it were the constructions of participants, and telling their story in an interesting and certainly the ‘faires’ way. The structure of the study and my efforts to place the ‘microphone’ and the ‘camera’ at multiple places and angles reflected this. In the end the report contained an extensive mapping in statistical, narrative and thematic form of the social support arrangements amongst other things, of disabled people locally as seen primarily by carers, and some disabled people themselves. It revealed something of the lives of disabled people and their families, and their experiences of being separate from the community around them.

It was significant however that the early research was unable to explain in any critical way the personal, social and interdependent aspects that produced and reproduced the world that it described. It provided no insight into the influence of my role or anyone else’s in the process of the study. In retrospect I can say it lacked not only a focus on power as a central dynamic of relations, but it lacked a power of critical and reflexive analysis which could more explicitly challenge the data in terms of its paradigm contexts and the various discourses that produced the worlds being described. It lacked the power to critique the very processes of research which themselves were framed within particular power and paradigm interests. There was the very real pitfall within the action research model of simply reproducing in
actions the dominant discursive forms, and being ‘stuck’ in a present
because of an inadequate critical approach to uncover the forms of
construction and dominance, and moving on from there. In addition to the
other personal interests in discourse analysis, I came to view a poststructural
critique of language as a way of casting, in Agger’s (1991) terms,

doubt on ethnographies which rely on subjects’ accounts of their own
experience as if these accounts, like the accounts of experts, are not
already encoded with undecidable meaning (p41).

In a broad way then I was moving, and no doubt the process is continuing,
from the use in a general sense of a grounded theory and a naturalistic
inquiry approach to data collection and analysis towards an approach which
reflected more strongly the postmodern and poststructural interests in
power and discourse. The shift from the former towards the latter was not
simply improving my ability to critique, it was a more fundamental change
towards understanding the expression of power at a local and dispersed level
as the primary concern, and an appreciation of discourse in this
(Dant, 1991; Game, 1991).

The implications of this shift were perhaps quite profound, and I believe
that as I write I continue to appreciate the ways in which this shift
destabilises other basic tenets which are implicit in my earlier stance without
the influence of these postmodern and poststructural perspectives. It has for
example extended to a greater openness to the range of voices that may
constitute not only others but my own position. The perspective of a
’sovereign subject’, “me”, in search of, perhaps not so much a single truth,
but ‘truths’ of the political and social merits of one dominant ideological perspective over another is giving way to a different search. It is not merely that the subject becomes decentered and the world, predicated on essential continuities starts to break up (Foucault, 1977), but that one begins to understand and consider these issues differently.

With power and discourse as the main focus, and power viewed as dispersed (Foucault, 1977; Agger, 1991), the process of research and knowledge creation can look locally at ordinary voices and everyday practices. The complex intertextual nature of reality and relations, and the powerful paradigmatic contexts in which discourse is embedded can be brought to light through the texts of local participants, in this case carers and service system participants. The quest in a sense is right there, not just in any particular revelations that this brings to light, but in the relations of power that are constructed by discourse and might be constructed differently. Such new knowledge generated locally will always have implications for people’s daily lives, and their material well being. In the thesis I have tried to support this quest for a local and practical knowledge in research and to permit the power of ‘ordinary’ local experiences to more strongly inform my research. In chapters 4 and 5 in particular I have made a very conscious and concerted endeavour wherever possible to suspend abstraction, and allow local experience and practical knowledge expressed in the transcripts, together with my critical and affective response and analysis of them, to stand unaffected by extended theorising of the material. To a large degree although by no means
exclusively then, the theorising takes place in Part 1 (chapters 1 and 2) and Part 3 (chapter 6) of the thesis.

In the broad collaborative and action research methodology embraced here there was a specific intention to understand the relationship of experience and reflection, and how they worked together to inform each other and produce knowledge. This is speaking to the personal as political discussed earlier in this chapter. In so far as discourse always mediates our connection with a material reality, it can be understood that the relations of power and the construction and maintenance of particular realities, including the ideologically suffused practices of caring and professional service systems, can only be unravelled by examination of their discourse and discursive practices. It is in this sense only that I concur with the deconstruction position that there is nothing beyond the text (Derrida, 1976).

In my endorsement of a broad methodology linked to the daily experience of local participants, and my extended involvement with them, I am proposing a materiality and a reintegration of theory and practice. I am seeking to balance an over theorised, uncritical and disconnected science with the material concerns of ordinary people in a local community. It would be a mistake in discovering the power of discourse, and the discourse of power to disengage from the political thrust of my material roots. A genuine praxis here requires a democratisation of research itself so that it permits difference
to be seen and heard, and experienced. Agger (1991) in warning of the
dangers of an apolitical, trendy and commodified form of postmodernism
says,

(it) purposely replaces substance with style, installing ironic
detachment as the central social value. But neither cynicism nor irony
is an appropriate political posture, especially where so much is going
wrong. Both accelerate the venality of politics and the commodification
of public discourse (p202).

In another way the idea of a symbolic and material link is raised by Geertz,
(1973) in speaking of the purpose of anthropology. In this text Geertz also
highlights the important purpose of recording other ‘answers’.

To look at the symbolic dimensions of social action- art, religion,
ideology, science, law, morality, common sense- is not to turn away
from the existential dilemmas of life for some empyrean realm of de-
emotionalized forms; it is to plunge into the midst of them. The
essential vocation of interpretive anthropology is not to answer our
deepest questions, but to make available to us answers that others,
guarding other sheep in other valleys, have given, and thus to include
them in the consultable record of what man (sic) has said (p30).

Without this picture which views the material and the textual, it may be as
Freire in allusions to Lenin’s call for revolutionary theory to guide
revolutionary action, says; “a revolution is achieved with neither verbalism
nor activism, but rather with praxis, that is, with reflection and action”
(Freire, 1972 p96).
Framing the ‘caring’ thesis

Finally, the research process includes most importantly the writing about caring and reporting the ‘findings,’ in this instance in the form of a thesis. As I have already argued in this chapter, the format of conventional scientific genre, within the ethnographic tradition that I have chosen to work was not appropriate. Clearly, acknowledgment of this has meant that I was bound to choose my own form carefully. I needed to recognise the way in which the content of scientific reporting was linked to a form of writing. Basically, I accepted that the form needed to be consistent with the demands of the research process as I have defined them here. It also needed to be persuasive of my credibility as a ‘witness’ and participant, and also of the scientific worth of my work. An aspect of this was that it be interesting or capable of holding your attention. Lofland (1974) (cited in Atkinson, 1990), refers to the use of “conceptual frames,” and presents a case for the organisation of the research report, which uses the frame in a balanced way, which is both “elaborated” and adequately analytical, and also “eventful”. In summary;

First, the analytic frame should be ‘elaborated’- it should be couched in a text which ‘specifies consistent elements of the frame, draws out implications, shows major variations, and uses all these as the means by which the qualitative data are organized and presented.’ Further for many readers it should be ‘eventful’ - richly endowed with ‘concrete interactional events, incidents, occurrences, episodes, scenes and happenings someplace in the real world.’ (Atkinson, 1990 p15).
The format implied here seems appropriate, and is I contend largely the basis of this thesis. Perhaps in the final analysis, it is impossible to lay claim to a seriously different and more critical science, if I fail the test of my own reflexive account. Adequately tracing my own expressions of power, and authorial presence then becomes one of the major tests of the thesis. In this I wanted to avoid the practice of conventional science in which the “author is concealed lest science appear to be the fiction it really is” (Agger, 1991p53).

Given my own declared interests, perhaps there is no greater challenge, as Patti Lather in Getting Smart-Feminist Research and Pedagogy Within the Postmodern (1991) suggests, than to define the shape of a sociological project which does not reproduce the regulatory and oppressive forms it seeks to replace. I have a suspicion that in some way defining a sociological project may be part of the problem, although I believe a commitment to different discourses and practices is appropriate and relevant. It may be easy, armed with the considerable power afforded by poststructural insights to decide there is no project, and oppressive and regulatory forms will diminish when we finally come to a realisation of this. The challenge here is to understand how the project of equality, from a number of perspectives is indeed mutually inclusive with the broad view of postmodernism. In many respects it is this endeavour in relationship with the discourses of caring and disablement and the lived experience of carers, within the reflexive project to hold the activity of research itself somewhere close to centre stage, that defines my purpose, my thesis.
Chapter 2 - Concealing caring realities

Public policy private care

Behind the public accounts of the institutional treatment and care by state institutions of disabled people, silent or absent, is a larger story. It is the story of carers who play an intrinsic role in the care of disabled people. From the nineteenth century the public or formal account is rich in detail, providing either a story of growth and progress or in the case of the deinstitutionalisation narrative a critical account of care gone wrong (see Kanner, 1974; Celgelka & Prehm, 1982; Judge, 1987; Scheerenberger, 1987). In either case the larger story of care of disabled people in the family home is obstructed and untold.

Much has to be assumed on the basis of existing accounts of personal lives in general, and of institutional forms in government, community and family. Of course there have been many critics of the institutional narrative, for example Goffman, 1961, 1963, Szasz, 1961 and Scull, 1976, 1979 but it is significant that their critique did not extend to an account of informal or private caring.

The untold story may be described as the private or informal account as opposed to the public account, as if they were distinct entities. In this study however, I argue that the public and private spheres are not separate but
highly interrelated. Thus it is assumed that public policy decisions about the
treatment and care of disabled people have had, and will always have,
significant implications for other members of society involved in the care of
disabled people. I will argue that these “other members” have been and
remain overwhelmingly, women in the role as mothers and carers. The
disciplinary role of the state in activities of policy and practice which define
categories and set ideological agenda tacitly call upon these informal carers
to do much of the policing of their program.

In spite of the apparently impenetrable and unified view of the history of
care of disabled people as the difficult but steady march of progress towards
an enlightened egalitarianism, it is possible to bring to light important
perspectives which challenge this view. I argue that the form and language
of public policy have changed, but the ideological fundamentals of
controlling and managing individual citizens have not. These ideas may be
illustrated by a re-presentation of those historical responses to disability of
which we have records, and also by examining in a contemporary sense the
activities of the agents of public policy to better understand their ideological
and practice structures and processes. Also, by focussing analysis on another
aspect of the dialectic of public policy we may bring to light a different
narrative. The aspect to which I refer is that of individual carers and the
ideological and material reality which ‘sustains’ them. Some apparently
scattered fragments of history can be pieced together, and the established
historical monolith can be broken down to interrogate aspects of
disablement and care which have been hitherto less apparent.
When the Honourable Senator Don Grimes as Minister for Social Security introduced the Disability Services Act (1986), and guided it through the Australian Parliament there was widespread acclaim for what was seen as the essential goodness and reformist quality of the Bill (Ashman, 1989).

The New Directions Report was released in 1985. After the excitement of the Handicapped Programs Review and the consultations associated with it, the New Directions Report was favourably received. One of the major recommendations of the Report, on which the Hawke Government acted almost immediately, was to repeal the Handicapped Persons Assistance Act 1974 (...) The transition from institutional-to community-based services became a major purpose of the Disability Services Act 1986 and the policies surrounding it (Cocks & Stehlik, 1996 pp24-25).

The Disability Services Act was formulated following an extensive consultative process with disabled people, families, professionals and other community members across the nation (Australian Government, 1985: iii). It was underwritten by a statement of human rights and outcome centred goals and objectives which reflected a determined shift away from a medically driven approach to disability (Fulcher, 1989).

The same philosophical and policy shifts were being carried out in State legislatures across Australia and these reforms were symbolised and captured in support for a policy referred to as deinstitutionalisation, a movement from large State run institutions to State run community houses, hostels or the family home, of significant numbers of people with disabilities (Tully, 1986; Judge, 1987; Ashman, 1989; Cocks, 1989). The deinstitutionalisation policy, if one is to accept government
pronouncements, was driven by the philosophy of normalisation. In New South Wales this policy position was stated;

It should be remembered that the basic goal for all individuals with disabilities in the Department's care is the promotion of rights, competence and participation to the maximum degree possible (NSW Department of FACS, 1989 p7)

For over a decade normalisation as a social policy framework has been central to changes in government policy for people with disabilities in Europe, the UK, North America and Australasia. The Danish philosopher Bengt Nirje said;

Normalisation ... means making available to all persons with disabilities or other handicaps, patterns of life and conditions of everyday living which are as close as possible to or indeed the same as the regular circumstances and ways of life of society (Nirje, 1969 p181).

In North America, Wolf Wolfensberger a social scientist at Syracuse University developed the idea further in defining normalisation as

....the utilisation of culturally valued means in order to establish and/or maintain personal behaviours, experiences and characteristics that are culturally normative and valued (Wolfensberger, 1972 p28).

This policy purported and appeared to reflect the desire to create programs and services that supported the full citizenship and human rights of individuals so clearly deprived and denied them for generations. The policy initiatives by their nature seemed to suggest that the most obvious manifestation of this denial of humanity and rights were the policies which justified more or less total exclusion from mainstream life in institutions or in the private home. This process of exclusion and segregation involved
individuals from an early age and in every sphere of life for the whole of life; school, work, and 'home' life. The rights discourse on disability did not say that one of the significant effects of this historical exclusion was also the effective exclusion of those who were responsible for their care.

The purpose of the institutional structures that had flourished for 100 years, and housed those variously described as, "a parasitic, predatory class... and a menace and a danger to the community" (Fernald, 1912 cited in Nicholls, 1988 p24), were now being redefined. The so called deinstitutionalisation policy of the last decade or so was apparently reactive to the historical practices of institutionalisation and segregation, in a society now seemingly less comfortable with such a conspicuous challenge to the rights and value of a minority group.

The formal or public account of the treatment and care of disabled people is only part of the story, and its meaning can only be properly appreciated in the light of the fuller and largely interrelated private and informal account. From this perspective a question arises as to the extent that institutionalisation was the dominant reality which so characterised and symbolised treatment and care. We can ask: what were the proportions of people occupying institutions, and what was the experience of the un-institutionalised others? The public account gives a strong impression that most if not all people labelled as disabled were in institutions of some kind, so that the implementation of policies based on the philosophy of
normalisation, would mean that they were in the process of deinstitutionalising and taking their place in the community.

In the dominant public discourse on disability and care and its occlusion of the larger private care narrative, the notion of institutionalisation becomes synonymous with (all) care for disabled people. Deinstitutionalisation in so far as it is recognised in policy simply meant care for disabled people in a different non-institutional setting, the community. The community was constructed along similar lines to the former institutions only smaller and less formally managed. Care in the community seemed to refer to care in smaller units of houses or hostels. Any other form of care was only fleetingly recognised, if at all, as part of the deinstitutionalisation discussion. In histories of disability of the nineteenth and twentieth century comments like “Retarded individuals who could not be cared for at home continued to be maintained in institutions...” (Celgelka & Prehm, 1982 p50) were typical of the references to an unstated narrative of care in the family home. Such references clearly acknowledged the existence of ‘care at home’, but it existed as a given, a taken for granted natural arrangement of care which required little or no further explanation and no history. Of course it follows from this, that little further attention needed to be given to the carers or disabled people or their circumstances, or to the impact of public policy on these carers or their caring arrangements.

There is a significant absence of a narrative on care at home in ordinary family circumstances for most individuals labelled as “handicapped”. The
term used in Australian literature is *impaired, disabled or handicapped* consistent with the WHO, 1980 classification, or *developmentally disabled* (following Richmond, 1983 see chapter 1 for some explanation of this term). In North American literature the term generally used to refer to approximately the same client group is *developmentally disabled*. In spite of this absence of a narrative on care at home, in periods of institutionalisation and deinstitutionalisation alike, the significant majority of these people have probably continued to grow up and live in the family home.

Reliable figures on the numbers of handicapped people who have been institutionalised in Australia throughout this century are difficult to gain. It was said on the question of data in *New Directions* (1985) the report of the Commonwealth Government’s ‘Handicapped Persons Review’, a review which led to recommendations including the Commonwealth Disability Services Act (1986) that,

> there is a lack of statistical data concerning disabled people in Australia. The most comprehensive information available is contained in the survey Handicapped Persons Australia 1981, conducted by the Australian Bureau of Statistics (ABS) (p8).

Using this same ABS data the report goes on to say that the focus of the review was the 271,000 disabled persons between 5 and 64 years of age. Of this 271,000 it reports that “244,000 live in households; 27,000 live in institutions” (p8). This represents a rate of institutional care for this population of just under 10 percent (9.96%). It should be noted that as the report says these are based on ABS data reported in 1981. It is likely as is
usual with comprehensive ABS surveys of this kind, that the information was gathered by its personnel some 1 or 2 years prior to its published report. This is important because it would tend to suggest data focussed on a period when institutional rates were, if anything, higher. Further, it should be noted that whilst some deinstitutionsalisation efforts were under way at this time, 1981 pre dates key deinstitutionsalisation measures such as the Richmond Recommendations (1983), and the progressive implementation of ‘reforming’ initiatives flowing from the Commonwealth’s Handicapped Persons Review (1985).

Presumably using the same data as the Commonwealth’s report, and in so doing perhaps indicating its importance in this context, University of NSW researchers reported that “unpublished” ABS data from a Handicapped Persons Survey in 1981 says of all those under 65 years of age; “Eighty percent of all severely handicapped people ... live in private households” (Hardwick, James & Brown, 1987p10).

It is clear from official figures reflecting the residential environment of the mid 1970 period onwards (a time when institutional levels in Australia were still relatively high), that there was never more than perhaps 10 - 20 percent of the handicapped population living in institutions and perhaps as official data suggests far fewer most of the time (NSWADB, 1981; ABS, 1982; ABS, 1988). The Anti discrimination Board could say in 1980 that, “...most people with handicaps, both children and adults, live in the parental home...” (NSWADB, 1981 p179).
This pattern of institutional compared with non institutional care was also true for other parts of the world. Thus, even in 1967 at the high point of institutionalisation in North America there were no more than 200,000 handicapped people in institutional care which was "proportionally tiny" (Meyers & Blacher, 1987p14; Bruininks, Meyers, Sigford & Lakin, 1981pvii).

The picture from a range of cultural perspectives both past and present and in developed and undeveloped countries is the same;

...if mentally impaired persons lived, they lived at home or in the extended family and occasionally in the whole solicitous village, perhaps becoming beggars. (...) The majority of mentally retarded people live, as they have in the past, with their own families. (Meyers & Blacher, 1987p14).

In none of these accounts whether local or overseas is there any intentional or systematic attempt to present the case of the carer at home and that of a narrative of care which is historically elided. In these accounts any depiction of the historical reality of care in the family home is in general terms simply a sub text of the exposition of institutional history.

These historical details cast serious doubt on the public discourse, and raise important questions concerning the experience of the majority of people labelled as disabled, the nature of their care, and the experience of informal carers. It brings into focus the question of how institutionalisation as an historical phenomenon has so overwhelmingly eclipsed the more dominant experience of local and 'family' care as the majority practice.
The much acclaimed social and historical watershed of deinstitutionalisation may be understood quite differently when one appreciates that the experience of care was already primarily of a private or informal and non institutional kind. The creation of the ‘myth’ of deinstitutionalisation was possible because of the construction of institutionalisation before it, and the effect in either case seems to have been to mask the real site of majority responsibility for care which was the family home, and to disguise the meaning and effects of a public policy which rather than serving the interests of disabled people or their carers, may actually work to preserve an ideology and a system of relations of power.

The public discourse captured in the deinstitutionalisation frame made discourses on disablement a convenient diversionary focus for more complex realities of care, which were overwhelmingly part of the day to day experience of developmentally disabled people and their carers. It is also true that for those significant minority of disabled people who were institutionalised and often experienced appalling conditions and were subjected to horrific practices, deinstitutionalisation was an attempt to push some back to ‘family’ carers or to create a system of cheaper small-scale institutions.

When the public discourse extolled the virtues of normalisation, as it did in the terms already cited, it was clear that the “patterns of life and conditions of everyday living” to which it referred were in fact that of the family and
community, that is, “the same as the regular circumstances and ways of life of society”.

Histories of the construction of disablement

Prehistory and its myths

It would seem that historical records provide us with little insight into the personal lives of disabled people and their carers beyond the legislative and institutional story. Where such accounts exist they also need to be understood in the historical context, including the descriptive and textual fashions of the times, and the changing ‘rules’ of discourse and knowledge, that allowed people to explain their experiences. The discourse on the treatment and care of those labelled as disabled is a public one, and one that may be demonstrated to have highlighted an account to the exclusion of the main narrative. With the enlightenment of course most such story and myth was generated from the pursuit of a different rationality and explanation of ‘truth’.

A discourse with thoroughly scientific textual allusions captures another historical trace of the disability story. This is neatly framed by Solecki (1971) in presenting archaeological evidence in the form of skeletal remains of Neanderthal people believed to have lived some 45,000 years ago. These were collected in the early 1950s in northern Iraq near the village of
Shanidar, and are believed to present us with a picture of early people and their public or social stance in relation to their neighbours. With reference to the detailed study on one of the tribe Solecki suggests that “Shanidar 1 was a prime example” of “a case of rehabilitation”. He goes on;

Not only did he possess a disability from the day he was born, but he must have been blind in the left eye... examinations disclosed that the right arm, collarbone, and shoulder blade had never fully grown from birth. Furthermore, there was extensive bone scar tissue on the left side of his face. And as if this was not enough, there is evidence that the top right side of his skull had received some damage which had healed well before the time of his death. In short, Shanidar 1... was at a distinct disadvantage in an environment where even men in the best of condition had a hard time. He could barely forage and fend for himself, and we must assume that he was accepted and supported by his people up to the day he died. Any manpower must have been an asset to this ancient little community, especially since it undoubtedly took group activity to hunt the gregarious beasts of the wild. That “Nandy” made himself useful around the hearth (two hearths were found very close to him) is evidenced by the unusual wear on his front teeth. It presumably indicates that in lieu of a right arm, he used his jaws for grasping, while manipulating with his good left arm and hand. The stone heap over his remains, and the mammal food remains, show that even in death his person was an object of some esteem, if not respect, born out of close association against a hostile world (pp195-196).

Shanidar 1 may as Solecki suggests provide us with a very early and interesting account of treatment and care of someone who in a contemporary context would be labelled disabled. The skeletal remains record in perpetuity as it were an individual life, and Solecki painstakingly contrives to reconstruct its bodily form and social context. In so doing he reveals his two reference points as an individual body on the one hand, and a public or social discourse on the working life of the community on the other. It is a paradigm which allows a personal system of care to fall between the cracks, where it is buried without an image or a trace. The archaeological
remains fossilise and preserve a reality reconstructed by Solecki in the text
but this discourse produces a description, and the ‘naturalised’ caring reality
in the life of “Nandy” the Neanderthal character is beyond its perceptual
frame.

It is evident that in all ages there are dominant systems of thought and
practice locally, and it might well be said that recorded history is a record of
just such dominant systems. Of course the implication of this is that there
are other possible narratives and knowledges and other practices and their
apparent absence from the main discourse does not mean that they cannot
be found in a new reading. It may simply be as suggested, that the author
provides his/her own account from within a discourse which fails to
disclose realities of care and support that have been naturalised as part of
everyday behaviour.

The story of the changeling told in European folklore is very apposite here.
This story provided the parent of a so called ‘deformed’ or disabled child
with a convenient way to explain the birth of such an infant. It permitted
the sense of personal responsibility and the burden that emanated from this,
to shift from parent to the underworld beings, at various times either
benevolent or somewhat demonic, who were responsible for taking a child
and leaving another less human form in its place (MacCulloch, 1910, cited in
Haf ter, 1968).
The changeling (exchange child) was a pre-Christian, largely Celto-Germanic story which became Christianised. In the process the meaning of the changeling was redefined to reflect personal responsibility and it was transformed to represent the punishment for the evil ways of the parent. (Hafter, 1968; Ryan, 1980). The historical explanation of the changeling, its subtle complexity and changing character provide a valuable explanatory foil against which to view the local and bigger historical narrative of disablement. It highlights the way stories varied according to local custom, and also in a larger sense with the passage of time and the changing discourse of knowledge. It is relevant too because the story of the changeling reflects the dialectical paradox of disablement, and the way in which the construction of the parent (read carer), at least in Western and Christian cultural traditions was in the final analysis so finely bound to the meaning of disablement. The paradox of disablement involves the relationship between individual impairment and the body as the site of oppression on the one hand, and on the other the social attitudes and manifestations of these in society as the site of oppression (Finkelstein, 1980; Hevey, 1992; Oliver, 1990).

The economic production of disablement

In 1980 the World Rehabilitation Fund (Inc.) commissioned a monograph on issues concerning attitudes to disabled people. The resulting report provided an informed discussion of the social construction of disability, and
examined the oppression which defined disablement from an historical-materialist point of view (Finkelstein, 1980; Hevey, 1992). In developing the context for his thesis on attitudes Finkelstein provided a brief and valuable historical analysis of disability as a category.

Finkelstein argued that disability or the disabled as a category did not exist in pre industrial times. They were not institutionalised, serviced or segregated from society as we know it. This thesis is consistent with Foucault's account of the undifferentiated nature of madness in the pre enlightenment period, which Foucault (1973) described as; "the monologue of reason about madness." Rather "cripples", as Finkelstein referred to disabled people of this period were part of a broad lower socio economic class which consisted of low-paid workers, the unemployed, and others who might be referred to as mentally ill. Within the context of feudal economic production, social segregation or exclusion was not necessary. It could also be said that differentiation was not necessary or really possible in any meaningful way, although I believe Finkelstein's use of the term "cripples" is an attempt to screen a recognisable 'class' of disabled citizens from the wider population of those invariably referred to as 'incurables, mental defectives or the insane' (terms which include all of those individuals we currently label as disabled, handicapped, insane or mad). In fact Finkelstein's focus on employment and the segregation/integration discourse produces yet another account which leaves buried as it were a significant aspect of the disability support story connected with care in the family home. This should be considered relevant
even in a debate about employment, because so many disabled people were and continued to be unemployed. Where vocational and employment-like services have been established for disabled people these have overwhelmingly been the result of efforts by parent carers (Cocks, 1989; Cocks & Stehlik, 1996).

Finkelstein describes two other historical phases which followed the pre industrial period (phase 1), and it is in these industrial and post industrial periods (phase 2 and phase 3), that there is both a seemingly less fragmented account of impaired people, and a clearer picture of emerging categories of impairment and the legislative and institutional responses. This is consistent with the increasing pattern of discourse of differentiation and objectification uncovered by Foucault’s analysis as the creation of the subject in an increasingly studied and managed population. It might then be viewed as a particular form of differentiation and objectification, and this was associated, as Foucault (1975 & 1977) documented, with the wider scientific developments and differentiation of disease with populations and individuals, and the systematic diagnosis, treatment and practice regimes that followed from this.

Although Foucault’s interest was in the creation of the subject and the practice of power through the disciplinary technologies of knowledge specialities, he did not view these technologies as the result of industrialisation or the growth of capitalism. In fact he saw them as part of
the disciplinary formations that were a necessary precondition to the success of capitalist modes of production (Foucault, 1979). Nevertheless the onset of capitalist industrialisation and the progress of science tended to merge as a discourse of power increasingly focussed on objectification, and differentiation of individuals became common to the social and economic world (Foucault, 1973; Rabinow, 1984; Dreyfus & Rabinow, 1982). As Foucault documents in *Madness and Civilisation* (1973), the era of systematic confinement from the second half of the seventeenth century throughout Europe was associated with “the universal necessity of labor” (Rabinow, 1984 p136). The link between madness and “imaginary transcendencies” of earlier times was broken in the classical age in which,

...for the first time madness was perceived through a condemnation of idleness and a social immanence guaranteed by the community of labor. This community acquired an ethical power of segregation, which permitted it to eject, as into another world, all forms of social uselessness. It was in this other world, encircled by the sacred powers of labor, that madness would assume the status we now attribute to it (Rabinow, 1984 p136).

Of course as Foucault (1973) informs us, this economic imperative for confinement was sustained by the moral necessity for discipline and order, as the public decrees of the time made clear. He also describes the historical link of the period of confinement with the emergence and refinement of, “the isolation and observation of whole categories of people.” It was where “the first glimmerings of our modern medical, psychiatric, and human sciences are to be seen” (Dreyfus &Rabinow, 1982 p5).
Phase 2 in Finkelstein’s account was heralded by the emergence of the industrial revolution, and the production systems of the modern industrial era. This economic construction produced the need to construct categories of labour (the able-bodied workforce), and non labour. Here, Finkelstein’s account is in agreement with Foucault’s recognition of the emergence of the important discourse on ‘labour’. This differentiation process was reinforced by the Charities who defined categories of deserving and undeserving poor within the non labour category.

Historically these events were linked to the growth of asylums and institutions for those who were denied the benefits of participation in the economic production process, and a range of legislative forms for the determining who amongst the non work community was deserving or not of assistance. The story of the Poor laws and the eligibility tests of the eighteenth and nineteenth centuries provides testimony to the foundation of state managed systems for screening, labelling and segregating people, systems which have been elaborated and refined to the present day (Ryan, 1980; Stone, 1984).

Like Finkelstein, Stone (1984) saw the creation of the category of disability as an off-shoot of the changing economic system. In her view however it reflected the need of government to resolve what she called “the distributive dilemma”. In examining social security in Europe she referred to two systems based on work and need and the tension between them as
"the fundamental distributive dilemma" in capitalist and socialist societies (Stone, 1984 p17). According to Stone this distributive dilemma explains the creation of the category of disabled as essentially an administrative device by government to manage welfare payments, and the tension between these two systems. As Stone says;

Need-based distributive systems are no longer in the background, to be implemented only in cases of emergencies, but rather exist alongside work- and property-based distributive systems. The central political question is then how need systems are turned off or, more precisely, how they are constantly monitored and limited (p21).

Stone's account is interesting and based on a very detailed study of welfare and social security systems. It makes a valuable contribution to the social and material perspective on disablement. It shows implicitly the exclusion of the care narrative in the construction of a disability category as an object of the 'welfare' state. Stone's view should be considered as one element in the complex construction of disablement, although inadequate without consideration of the broader social discourse that is highlighted for example in the work of Foucault to which I have already referred.

In Phase 3 of Finkelstein's account the 'gaze' on the disabled person (of Phase 2) shifts decidedly to observation of society, and its disabling practices. This highlights the paradox of disablement described by Finkelstein, and in particular society as the site of oppressive practices. According to Finkelstein from a materialist perspective the emergence of new forms of industrial
technology and production systems have permitted significant numbers of disabled people to move into productive work. This view suggests we are now in a period of community reintegration of impaired people, and by a logical extension, “the elimination of disability” (Finkelstein, 1980 p.11).

Finkelstein’s account is a valuable expose of the social and constructed nature of disablement where this has been lacking (Abberley, 1989; Oliver, 1990; Hevey, 1992), but it is predicated on acceptance of the formal and public view of disability, and it is this which permits his conclusion that community reintegration is upon us. Given the complex historical and social context of disability, and the significant limitations of an argument built on the public discourse of employment and segregation/integration, such a conclusion is unwarranted. His unidimensional materialist explanation all but portrays production technology in this scenario as benignly contributing to the transformation of a multidimensional social construct. Even from a materialist perspective it fails to acknowledge that a significant majority of disabled people are not benefiting from new productive technology and engaged in “reintegration”, and many may well be just as or more disadvantaged than ever (Clear, 1989; Todd, Evans, & Beyer, 1990; Clear & Horsfall, 1994, McElwaine & Ford, 1994; Stern, 1994; Clear & Green, 1995; Patterson, Hanley & Auld, 1996).

The account also fails to recognise that community reintegration of disabled people involves an ecology of factors which often includes carers and wider
support systems. As important as the economic discourse undoubtedly is, community (re)integration is not just a singular economic phenomenon. Furthermore, in this argument the issue may be seen to be equally as important for women trapped in caring, as it is for disabled people trapped by the individual and personal tragedy discourse. They are powerfully interrelated.

Both the Finkelstein and Stone accounts ignore the complex re-alignment of power structures and processes which result in some marginal improvement in the rights and societal opportunities for some disabled people, at the same time as extending and shifting the points of surveillance and control of both disabled people and their carers through professionalisation of private lives (Foucault, 1977; Donzelot, 1980; Baldock, 1990; Cant, 1991; Bryson, 1992; Fox, 1993). Furthermore, the analysis fails to acknowledge that the same technological advances that appear to serve and extend the opportunities for ordinary people including disabled people, are deeply tied to powerful scientific and technological interests that in a broader sense have extended their control.

Medical and professional beginnings

Scull’s work on madness and insanity in nineteenth century England (1979) contributes to a constructionist picture also framed by Foucault, Szasz, Finkelstein and others, of the emerging sciences and professional and
therapeutic regimes, which led to progressively finer and finer levels of "differentiation". This is an important part of the care story and context. Clearly enough, Scull's work is not a specific reference to a modern category of disability. Although differentiation had begun, it seems clear as Foucault and Finkelstein suggest, that even in nineteenth century Europe where 'patients' were still relatively "undifferentiated, the asylums were filled by a vast array of societal misfits, 'cripples,' 'the blind' and 'mentally retarded' people too. The blurring of distinctions between the various categories of 'patient' here, and the lack of precision or untidy picture of the emergence of these social developments should not diminish the importance of the overall story.

The adoption of a more scientific and rational approach to the so called 'incurables, mental defectives or the insane' resulted in a great increase in their official numbers, and asylums to 'house and heal' them flourished across Europe and the western world (Scull, 1979). As illustration of the paranoia of the period, The Times (April 5, 1877, cited in Scull, 1979) could even report that, "if lunacy continues to increase as at present, the insane will be in the majority, and, freeing themselves, will put the sane in asylums" (p225).

Thus the period beginning in the eighteenth century, including that defined by Finkelstein's phase 2 to the present, was marked by the emergence and growth of professional specialities, particularly medical and educational
professions whose job it was to assess, cure, rehabilitate, educate and monitor the inmates of asylums and the range of institutional forms (Finkelstein, 1980; Hevey, 1992; Ryan, 1980). The proliferation, and increasing differentiation and specialisation of professionals, domains of knowledge and technologies, in medicine, para medicine, allied health and education, especially in the twentieth century were strongly suggested by Scull (1979) in describing the social production of insanity;

...it remains perhaps the most paradoxical feature of the entire reform process that the adoption of a policy avowedly aimed at rehabilitation and the rise of a profession claiming expertise in this regard should have been accompanied by a startling and continuing rise in the proportion officially recognised as insane (pp221-222).

In the eighteenth century medical science began to define the body as the location for disease, and established a system of knowledge which classified disease hierarchically into families, genera, and species (Foucault, 1975). The medical connection was not originally involved in the "confinement" process, but now in the developing differentiation of reason from unreason, the medical authority

...becomes the essential figure of the asylum. He is in charge of entry. The ruling at the Retreat is precise: "On the admission of patients, the committee should, in general, require a certificate signed by a medical person... It should also be stated, whether the patient is afflicted with any complaint independent of insanity. It is also desirable that some account should be sent, how long the patient has been disordered; whether any, or what sort of medical means have been used." From the end of the eighteenth century, the medical certificate becomes almost obligatory for the confinement of madmen (Foucault, 1973 cited in Rabinow, 1984 p159).
The process captured in this quote is remarkable for its current and extended operation across the entire state network of human service and professional activities. In fact it is possible to identify its current workings within the conduct of a seemingly remote area of medical provisions, such as employee sick leave and worker’s compensation claims which require the same medical certification process. More specifically, the account indicates the essential nature of the process used to determine and label those who are disabled in our society some 200 years on. The idea of the ‘certificate’ and the certifying process is central to the medical profession’s authority and to the legitimising and maintenance of a discourse defining the disabled subject. The language of “affliction” locates the ‘problem’ in the individual, and the reference to “dis-order” provides the social referent to the imperative of order in a normal society. Certification means a process of examination of an individual to determine (locate) a certifiable ‘quality’, and to objectify this in an authoritative record.

The invisible dimension in disability discourses

Defining the parts, renouncing the whole

In 1980 the World Health Organisation published a manual, which provided a means of structuring thinking and language, and understanding the rehabilitative needs of people labelled as ill, disabled or retarded. This was
more in keeping with the changing values and practices of the time (WHO, 1980). Thus, WHO defined three different effects of illness or disease;

- Impairment is “any loss or abnormality of psychological, physiological or anatomical structure or function;”
- disability is “any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being;” and a
- handicap is “a disadvantage for a given individual, resulting from an impairment or disability, that limits or prevents the fulfilment of a role that is normal (depending on age, sex, social and cultural factors) for the individual...Handicap thus represents socialisation of an impairment or disability, and as such, reflects the consequences for the individual - cultural, social, economic and environmental, that stem from the presence of impairment or disability” (WHO, 1980).

Whilst this classification system falls short of viewing disablement as purely a social and political construct, it was seen by many, particularly professionals; as a significant shift away from the focus on disablement as merely the pathology within an individual. It allowed for the way in which the environment might reinforce or mitigate the effects of pathology (Cocks, 1989; Fuhrer, 1987).

It seems the WHO’s (1980) classificatory system was also an attempt to adopt a sociological perspective in which ideology is laid as it were on the pre-existing scientific foundation of the biological body. Thus, “impairment” is the unproblematised biological foundation, which gives rise to the functional restrictions of a disabled person (a “disability”), and which may also result in a “handicap”, or the environmental (social, physical etc.) limitation placed on a person’s fulfilment of “normal roles”. This seems to
cater to the scientific and medical community (impairment concept), the professional and therapeutic interests (disability concept) and the social advocates and consumer groups (handicap concept).

At a workshop *Measurement of disability* in Canberra (February, 1994), participants, including a representative of the WHO, examined amongst other things the WHO (1980) classificatory system of *impairment, disability* and *handicap* (ICIDH) and its usefulness and relevance as a measurement tool (Australian Institute of Health and Welfare, 1994). At this workshop it was made clear that the ICIDH was developed within the context of “health experience” and as a “tool to classify the consequences of disease” (p10).

Furthermore, other papers showed how the needs of different groups such as the Australian Bureau of Statistics (ABS), the Department of Social Security (DSS), WorkCover Authority and those representing elderly people to name some, bring pressure to bear in shaping the definitions and labels, often to meet their particular survey needs, as much as any other reality. Thus, the WHO classificatory system on which so much apparently reformist public policy is currently based, was itself shaped within a *disease based* classification system, and was subject in its construction to pressures which reflected the measurement needs of a range of interested groups.

This account brings out the need for a the critical and postmodern perspective on the way in which scientific endeavour and knowledge production takes place within a social context and how this is reflected in
knowledge outcomes. It provides a valuable insight into how the complex and interconnected phenomenon, disability, may be reduced to separate elements in the process of satisfying equally complex social and political interests. It speaks to the decontextualised and individual perspectives, in which the often fundamental support context of disability as a social phenomenon is lost.

It is apparent, at one level anyway, that these recent social policy developments have opened up to challenge the scientific and medical underpinnings for the labelling and treatment of disabled people. In taking up the Human Rights Commission proclamations and locating the legislative and policy initiatives in the human and civil rights domain, policy framers have at least indicated that the social and environmental issues were the real source of the problem;

The problem is not one of individual impairment as the medical model would suggest, but rather of unnecessary dependence on professionals and relatives, of environmental barriers and unprotected rights, all of which limit the choices available to people with disabilities (Human Rights Commission, 1986 p29).

Implicitly at least, and to some extent setting the policy agenda, the Human Rights Commission identifies carers (“professionals and relatives”) as an aspect of the need for reform. In a clear reference to care of family and other care, “the problem” according to the Human Rights Commission is amongst other things “unnecessary dependence on professionals and relatives”. The
clear suggestion in “unnecessary dependence” is over protection and this occurs alongside the other problem of “unprotected rights”. This view needs be understood against the reality that for a very significant number of disabled people, professionals and relatives were perhaps all they could depend on. The state line and rhetoric of rights simply ignored this reality, and the certain prospect that informal carers and professionals would continue to be an essential support. State reforming discourse like that of human rights failed no less than the medical discourse it sought to replace to recognise that the protection of rights and extension of choice, involved and would continue to involve private and informal caring as the primary support for disabled people. Human rights discourse played an important part in deinstitutionalisation, but has failed to manage the complexities of interconnected lives.

In spite of the reforms disablement continues to be treated in policy and practice as fundamentally a medical process which focuses on the body as the site of the ‘problem’. It is managed by medical officers although increasingly the input of other professionals and professional teams is apparent. The public shift to the rights or social model in policy pronouncements scarcely masked a process deeply embedded in the medical and ‘normal’ discourse evident in the language of commentators some 200 years past.

The underlying process of social order and the moral purpose of confinement is preserved in the certification process whether this process is
concerned with admission to the contemporary mental health or disability establishment or to define an individual's eligibility for disability allowance. In the case of entitlement to the Commonwealth's Child Disability Allowance in Australia this moral 'gaze' would turn on the carer of a disabled child. The gendered discourse which produces the woman as carer who in the administrative discourse is sighted just long enough to permit the assessment and labelling process, renders her non existent in the individualised focus of the medical, and more recent human rights discourse.

In Australia there are two key processes which are relevant here although medical discourse is evident in the process of disability assessment and referral generally. The two key processes are assessment for entitlement to the Child Disability Allowance (CDA) and the Disability Support Pension (DSP) and it is important in the current context to examine these in some detail. The CDA is a benefit paid to the carer, usually the mother, of a child who is assessed to have a disability and who lives with the carer. A person qualifies for this allowance because of the extra day to day care and attention required, not because of the type and nature of the child's disability. Thus, the benefit is paid if the carer is involved in providing substantially more care to their child, because of the disablement.

It is clear that the process is to a large extent based on the medical model, with the diagnosis of the child's medical condition still at the core of the
protocols and process (DSS, 1994). The medical and professional 'gaze' extends to both the child who is the object of the disability assessment and the carer. In this process the carer is bound to the disability by definition of the benefit entitlement. Paradoxically, it is state managed assessment of the extra caring that produces the benefit. This stands in sharp contrast to assessment processes of the DSP, in which the carer is absent, even though overwhelmingly they constitute the primary support system for many developmentally disabled adults and a significant aspect of their ability to participate in community life, including of course work. At this point economic and labour market discourse override, and the informal caring role, in the complex structure of an individual’s life, is inconvenient, if not irrelevant. Like the rights discourse in its singular focus on the individual's protection and choice, it crushes out the informal caring role.

The DSP replaced the Invalid Pension in November 1991. Recipients must be over 16 years of age and have a continuing incapacity to work, as determined by a CMO. This incapacity to work is predicated on the level of the person’s intellectual, physical or sensory 'impairment'. Levels of impairment are calculated for each individual, by a CMO, using so called standard Assessment Tables (DSS, 1993).

The judgment in order to receive DSP benefit is based on three forms. The first form is completed by the claimant and requires basic demographic
information in addition to information on ‘medical conditions’ which could affect the person’s ability to work. Further questions are asked about the skill and educational level of the individual. The second form is completed by the treating doctor. The questions focus on the individuals’ “Diagnosis...Historical and Clinical Condition...Investigations...Treatment...Prognosis” in relation to the person’s ability to work. The final form is completed by the CMO and is based on a full examination of the individual. It is whilst completing this report that the CMO will make reference to the assessment tables. The report covers a medical history of the person and then details any “Medical Conditions” which would affect the person’s capacity to work, such as “Spinal condition, Limb Function” and whether or not the condition is permanent. If the CMO considers the person fit for work, they state for which category of work the person is fit (DSS, 1994).

Impairment is defined within this document as “any loss or abnormality of psychological and/or physiological function remaining after appropriate medical treatment and rehabilitative processes have been completed.” All impairments are measured in relation to the person’s ability to work and associated aspects of daily living (DSS, 1993pi). A ‘body systems’ approach is used in the tables. When considering the level of impairment the medical officer decides what effect the impairment has on the relevant body system and then converts this to “whole person impairment figures.” The impairment rating is then expressed as a percentage of the ‘whole person’
functional capacity (DSS, 1993p). The process for assessing intellectual impairment is a little different. In this section three criteria are assessed, “Intelligence, Behaviour and Capacity for Independent Living.” A score is given to each criteria, added together and then converted to a ‘whole person’ impairment score. For example, a person may be “Mildly impaired or worse (IQ 50-70)” have a “slight problem” with their behaviour and “needs regular help” in their capacity for independent living. In this example the person would score 5+3+4, a total of 12. On the standardised tables this would convert to a 55% whole person impairment score (DSS, 1993p22).

If the person has more than one impairment the “Combined Values Chart” is used to assign the impairment rating. For example, a person may score an impairment rating of 20 for Neurological Function: Impairment of Cognition, and 10 for Neurological Function: Impairment of Comprehension. This would lead to a total impairment rating of 44% using the combined values chart. This person’s functioning in relation to work and associated daily living tasks is impaired by 44%. The person would be eligible to receive the DSP (DSS, 1993p47).

The focus on capacity to work to the virtual exclusion of other areas of life is more apparent as one moves away from the biographical section. The questions asked of the person themselves cover whether or not the medical condition affects “the way you do things around the home...using public transport...driving a car”. There is no mention of these other areas in the
treating doctor’s report and only a passing reference in the CMO’s report where loss of ability at home and work are noted. Of course the intention of these forms is to enable a decision to be made regarding the eligibility of a person for the DSP, or whether they would be more appropriately served as recipients of another benefit. It is clear however that throughout this process the person is viewed in terms of body parts, and the extent to which these parts “function” or not. It is difficult to see the ‘whole person’ at any stage. Of course even less evident are the complex realities of support that define, amongst other things, a developmentally disabled individual’s quality of life, and specifically in this context, their ability to gain and sustain employment (Greenspan & Shoultz, 1981; Kochany & Keller, 1981; Bellamy, Rhodes, Mank & Albin 1988; Nisbet & Hagner, 1988; Clear & Mank, 1990; Clear & Green, 1995).

There are four important summary observations to be made about this process of assessment for the DSP. First, a person is judged solely in terms of capacity to work. In this regard the assessment process for the DSP highlights the construction of disability as a category as largely a creation of the industrialisation process, or as an outcome of the administrative requirements of an industrialised society. Second, there is an overriding reliance on medical classifications and terminology. Third, the process is based on standardised and normative scales which provide no flexibility in terms of an individual’s personal and social contexts, including their caring and support arrangements. Finally, the process is based on a body systems
Concealing caring realities

approach, which at no point views the whole as greater than the sum of the parts. The carer who was essential to the Child Disability Allowance is completely irrelevant in a process which reads the body and its parts as the essential and defining site of disablement (Clear & Horsfall, 1994).

Constructions of family, community and caring

The family

Ideology of the family has conservatively represented it from a functionalist perspective, and tended to portray family as a natural and universal 'thing' (Connell, 1987; Gilding, 1991; Mitchell, 1971). Gilding (1991) says that family is neither "natural nor inevitable - rather a product of history" (p.5), and Connell (1987) says of family;

Far from being the basis of society, the family is one of its most complex products. There is nothing simple about it. The interior of the family is a scene of multilayered relationships folded over on each other like geological strata. In no other institution are relationships so extended in time, so intensive in contact, so dense in their interweaving of economics, power and resistance (p.121).

Feminist and poststructural critiques of family not only draw attention to the diversity of family forms, but have revealed aspects of the fragile and conflictual structure of family which have been evident in high levels of domestic violence particularly towards women and children (Scutt, 1983).

The changing family has been characterised too from a Marxist perspective, in terms of the growth of capitalism, as coming more and more to represent
individualism; private and separate; a respite for an exploited workforce; and an important source of a mobile labour force and a unit of consumption (Mitchell, 1971). Donzelot (1979) also described the family as the cornerstone of private property, and a means for the reproduction of ruling ideology. The natural and inevitable quality of the family, which is no doubt supported by its association with the biological, reproductive and child rearing activities of society, makes it a profound source of social values. Whilst many feminists and marxists have viewed the family as a significant source or site of patriarchal and/or class oppression, often masked by its ideology, it may be seen as a choice which is "easily comprehended, indeed (a) highly rational choice, given the material and ideological privilege accorded to it in our society " (Barrett & McIntosh, 1991 p21).

Conventional marxist, feminist and critical perspectives have tended to view the rise of capitalism as the cause of significant changes in social relationships and conditions, specifically in the family. More recently this cause and effect relationship has been questioned, and explained in terms of a more complex view of the relations of economic and social phenomena (Foucault, 1979; Barrett & McIntosh, 1991; Bittman, 1993). Thus in relation to the family, the widely held view that the pre-industrial family was extended and the onset of industrialisation produced the nuclear family has been questioned. Bittman (1993) following the work of Anderson (1979) says that "the narrative of extended families, shrinking to a nuclear core under the influence of industrialisation," has been shown generally not to be true, even though the "quality of relations within the family" and of the family
with the outside world have changed significantly (p441). The separation of the production enterprise which became centralised away from home was also another significant change (Bittman, 1989; Bryson, 1992).

It seems that family not only offers powerful emotional and material support from within, but permits a degree and quality of expression and legitimacy which may be denied to those who are not part of family. This is both an expression of the essentialist conception of the family in which

it is as if we recognise variation in family forms as only the surface appearance of something that in essence is common to all human society, and an expression, perhaps paradoxically, of the individualistic and private quality of the family (Barrett & McIntosh, 1991 p39).

The way family preserves patterns of wealth, status and authority and the particular forms in which family is privatised and privileged in our society suggests an “anti social” form;

…it highlights very clearly how the family embodies the principle of selfishness, exclusion and the pursuit of private interest and contravenes those of altruism, community and pursuit of the public good (Barrett & McIntosh, 1991p47).

It is as if the family as normal and unproblematised is like the Foucauldian “docile body”; lying somewhere between the “normalised” subject, and a normalised social body, or society. It is shaped and transformed within changing historical economic and social contexts, by discourses of sexism, capitalism, able-ism, age-ism and so on, but its ideological and symbolic qualities persist. The more family as a category represents an acceptable
norm in our society the harder and less legitimate it appears to define life outside the category, or to conceive of it in some non family setting. The idealised and symbolic form of family and the model of care it prescribes is projected onto the greater social body in the construction of community. It is clearly difficult, if not impossible, to talk about constructions of family separately from the work of women and constructions of caring, and just as difficult to discuss the idea of community in a separate context. Each construction appears intricately caught up in the other, and whilst they take shape in a wash of gender ideology, they are each constructed by powerful discourse and metaphor of love, security, stability, friendship, communality, and inclusion.

The community

The focus on ‘community’ care raises, in itself, interesting questions concerning the meaning and construction of ‘community’ (Wilson, 1977; Finch & Groves, 1980 & 1983; Bryson & Mowbray, 1983 & 1986; Dalley, 1988). The structuralist functionalist perspective (Parsons, 1951) defines community in terms of a necessary and natural sub system, and other structuralist perspectives appear to leave community as some type of geo-social region, somewhere between the key structures of the state and the family.

As already indicated, feminists have also been critical of ‘community’
because of its use by government as a basis for social and public policy which shifts responsibility to the family, and by implication to women in unpaid and unacknowledged roles. It is most clearly seen in this context to be an ideological mask for family (Wilson, 1977; Finch & Groves, 1980 & 1983; Bryson & Mowbray, 1983 & 1986; Elliot, 1989; Graham, 1991; Stehlik, 1993; Skidmore, 1994).

Wilson saw community as necessarily oppressive because of its gendered nature;

The community is an ideological portmanteau word for a reactionary, conservative ideology that oppresses women by silently confining them to the private sphere without so much as even mentioning them (Wilson, 1982 p55).

Community care has also been seen as a flexible alternative to family care because it is essentially based on a family model. It can be 'rolled out' as it were when for example deinstitutionalisation is the order of the day, and the state simply provides a surveillance role over unpaid women carers (Dalley, 1988).

Skidmore (1994) suggests that community should be seen as part of the "lie of normality" (p24). Community really equates with the idea of society or the social domain, in which the idea of a normal society, like the idea of community reinforces a view "...that there is a natural and just order to the world". Community then, is an ideological and symbolic construct for maintaining a "lie of sameness" and providing security and control by managing and containing a reality of diversity and difference. An example
of this containment is the construction of "monsters and madmen" as stereotypes, which help us feel secure, but of course the process may also deny us the opportunity of learning to appreciate and develop "coping strategies" for difference (Skidmore, 1994 p21).

The symbolic construction of community is also taken up by Cohen (1985). The transformation of the reality of difference "into the appearance of similarity" appears to be its real function (p21). This Cohen argues is achieved by the attachment and commitment to a common body of symbols, which are most often understood at their boundaries and where they must be defended in the face of 'outside' threats. It seems that community works in relation to difference and diversity to "provide the means for their expression, interpretation and containment" (p21).

Community may be seen to embody something of our shared identity and common outlook where difference may be denied, but at the same time, perhaps paradoxically, it is imbued with a flexible and indeterminate quality, which makes it a politically active site for writing and re-writing public policy.

Caring

The caregiving role is perhaps, as much as any other human activity, associated with women and womanhood, and fundamentally gender saturated. This is not simply a strongly held popular belief, but is evidenced
by the traditional roles of women in the family and home, and reproduced in the social relations of the work place (Wilson, 1977; Finch & Groves, 1980 & 1983; Dalley, 1989; Elliot, 1989; Graham, 1991; Traustadottir, 1991; Bryson, 1992; Stehlik, 1993).

The functionalist and liberal view and its portrayal of caring as the separate, natural and unproblematic function of women belies its highly complex, cultural and historically embedded nature (Graham, 1983; Ungerson, 1983; Dalley, 1988). Caring can be seen as inextricably linked to the function and ideology of family and the very essence and basis of the family as a social construction and material reality. From a feminist viewpoint its intimate and unproblematic construction and connection with the feminine and with womanhood, motherhood and the family is intimately bound up with women’s oppression (Barrett & McIntosh, 1982; Wearing, 1984; Dalley, 1988).

The complex relational nature of caring amongst other things involves distinguishing the physical tasks associated with “caring for” someone from that of “caring about” them (Graham, 1983; Dalley, 1988). The latter Dalley explains is mostly the nature and extent of male caring, but for women it is mostly both “caring for” and “caring about”. This means that women are required to manage the complex process of reconciling feelings of love for those for whom they care with the potential sense of obligation, frustration and burden involved in the actual activities of caring (Dalley, 1988 pp 8-9).
Similarly, Hilary Graham (1983) has described caring as both “labour” and “love” where women are profoundly involved in both senses. Janet Finch (1983) acknowledged Graham’s reminder of the resistance of many women to the “socialization of caring”:

...the activity of caring significantly defines women’s identity, and it takes place in the private sphere where women are found. The experience of caring is the medium through which women are accepted and feel they belong in the social world (Finch, 1983 pp14-15).

She further recognised the complex relational nature of caring to which Graham (1983) had also drawn attention in cautioning against opting for non-family and non-community, because of their essential sexist family ideology:

...a recognition that caring about is frequently (although not necessarily) intertwined with caring for a dependent person should make us wary of any proposals for non-sexist forms of care which overlook the dimension of affection, which of course is not confined to people who are related through kinship or marriage. That is not to argue that, because I care ‘about’ someone I must necessarily care ‘for’ them; but it is to argue that I may choose to do so (Finch, 1983 p15).

This issue of the complex relational nature of caring was further developed by Keith (1990) and Morris (1992), who as disabled women and feminists questioned feminist literature and its failure to take account of the needs of disabled women, and for an undue focus on the carer at the expense of caring. Such a focus failed to appreciate the active consciousness and contribution of the ‘dependent’ partner in the caring relationship and resulted in social policy recommendations for institutional type care, which
deny to disabled and elderly women the sort of relationships and experience of home which non-disabled people take for granted.

In another article, Graham (1991) has drawn attention to another area of complexity and the need to broaden the thinking about caring and its gendered ideology to include issues of race. Graham shows how for many black women it has been a lack of private life which has been linked to their oppression, and acknowledging Glenn (1985) she says: “The struggle was, and is, to care for one’s kin and keep one’s family together” (Graham, 1991 p69). She argues that whilst family and ‘private’ care may be “useful in understanding white women’s experiences, it is less useful when Black women’s experiences are included in the analysis” (p69).

Although the literature appears to provide guidance only indirectly on this, these same points may also be relevant to carers of disabled children and adults (Wilkin, 1979; Glendinning, 1983; Cant, 1991 & 1992; Traustadottir, 1991). If they have experienced a degree of oppression in the public domain, either because of their connection with disablement and the negative and stigmatising aspects often associated with this, or through the sheer physical effort of providing care in an essentially access-less environment, they may well find home and family more attractive, even if this means merely the lesser of ‘evils’.

The experience of women caregiving with disabled children highlights the issues of loss of or difficulties with maintaining friendships and of
reciprocity in relationships and the significant disadvantage felt by disability carers in these transactions (Wilkin, 1979; Glendinning, 1983; Cant, 1991 & 1992; Traustadottir, 1991). Also indicated was the conflict between the cultural norms of a separate and autonomous experience associated with family ideology and the sharing and networking culture of women. It was noteworthy that in one study (Cant, 1992) based on interviews with women of disabled children, a mother might ‘turn down’ assistance when it was offered. Perhaps such instances may indicate something of the stigma and shame that may be experienced by carers of disabled children (or adults), and it could also indicate previous negative experiences of ‘neighbourliness’. It seems that the experience of reciprocity could be maintained however in the case where caregivers had similar caring demands, such as both having a disabled child (Cant, 1992 & 1994).

Amongst other things a recent study of caregiving and the wellbeing of women, involving a panel of 293 women randomly sampled and interviewed in 1956 and again many years later in 1986 (Moen, Robison & Dempster-McClain, 1995), found that the timing and duration of the caregiving role was positively related to mastery of caregiving in the 50’s and 60’s age group, but stress increased in those over 60 years, suggesting concern with the caregivers’ own health and ability to continue caregiving. Those with a higher level of self esteem and also those who had higher education levels had higher levels of well being in caregiving.
The study also indicated the benefits of social involvement and "connectedness" generally, and there were benefits with having an additional non-family role identity associated with employment or volunteer work, provided this did not extend to produce "overload and strain" (p269). The research was clear about the benefits of current employment and caregiving: "women... are better off in terms of their sense of mastery, self-esteem, and life satisfaction than those not employed" (p269). A reference in the study to "negative effects" on married women's emotional health, when caregiving was extended is a valuable pointer to the isolating and unhealthy potential of much of the private and invisible work of women. It suggests the potentially positive role of the Parent Exchange Group in helping to overcome this, and establish something of the "connectedness" that this study indicates was beneficial. The "benefits of current employment" when caregiving indicated by the study, demonstrate the power of career and employment to one's sense of self value and the fulfilment of many personal needs, not shared or acknowledged in the caring setting alone.

Intagliata and Doyle (1984) summarise the literature on the stressors for families and the carer in particular who are responsible for a member with a disability. These were described as;

... myriad and include periodic grief and chronic sorrow, strain resulting from the constant unrelieved burden of caretaking, shifts in the role expectations for individual family members, marital conflict, social isolation, sibling adjustment problems, and financial burden. (p4)
They also identify the range of service types provided to assist families and carers cope. These included information and referral services; self help parent groups; individual and family therapy; training programs in managing difficult behaviour and respite care (p4).

The ideological postures of government through its community care policy appear to have extended reliance on the family for the performance of the state's 'welfare' policies, but in a more qualitative change, they have also highlighted an increasing supervisory and surveillance role of professionals, as agents of the state, of the role of women carers and the function of the family (Ballock, 1990; Cant, 1994; Fox, 1993). The professionalisation of informal care through community care policies carries the undoubted potential for altering the nature of the caring relationship, and the introduction of normative processes based on an extended medical 'gaze' into family life (Fox, 1993). Through the professional expertise based model the informal, personal and idiosyncratic possibilities of caring relations may well be re-written in discourses which construct new subjectivities of the routine, impersonal, dependent and standardised carer and consumer.

Feminists have looked at the state as patriarchal either in its very structure and meaning or as historically constructed, and they have also examined its function in the construction of women and the family. This analysis has highlighted the way in which state 'welfare' policies depend on constructions of women as mothers and carers (Wilson, 1977; Finch & Groves, 1983; Bryson, 1992; Stehlik, 1993). These accounts also point to the
growth in state intervention in previously ‘private’ concerns, and in this public policy stance of ‘community care’ (Finch & Groves, 1980; McDowell & Pringle, 1992; Stehlik, 1993). When examined closely ‘community care’ in practice means living in smaller family styled models of institutional care or primarily increased care by family, and as feminist writers have observed for some time this really means care by unpaid women as wives and mothers (Wilson, 1977; Finch & Groves, 1980 & 1983; Bryson & Mowbray, 1983; Elliot, 1989; Graham, 1991; Stehlik, 1993; Skidmore, 1994). It seems clear that smaller government and reduced welfare spending by government based on so called ‘community care’ does not simply eliminate the power of the state in people’s lives, “it simply changes its direction” (Connell, 1987 p230). It increases pressures on the personal lives of women in particular, and the range of vulnerable people for whom they take most responsibility (Wilson, 1977; Bryson & Mowbray, 1983; Connell, 1987; Pusey, 1991; Gain, 1992).

The unpaid work of women in Australian families strongly reflects the sexual division of labour and the specialised embodiment of women’s tasks in supporting the emotional and physical needs of the family (Bittman, 1991 Bryson, 1992). These needs often present as more complex and more persistent when disability is involved (Balock, 1990; Cant, 1994; Clear & Horsfall, 1994; Williams, 1994). It seems that the role of the family is accentuated around the experience of disability, not only in intensity of involvement and commitment, but in duration (Parmenter, 1987;

In spite of any recent changes towards a more ‘symmetrical family’ in which men may take more responsibility, there seems to be unequivocal evidence (Bryson, 1985; ABS, 1990; Baxter & Gibson, 1990; Bittman, 1991) of the gendered structure of work in the Australian home. Accepting also the predisposition of government towards economic rationalist and ‘community care’ policies, it seems that the role of women as unpaid carers will be extended. These domestic realities, and uncertainties about the state’s responsibility and role, its levels of funding and support, and the complexity of the state administrative and bureaucratic processes, leave parents with difficult choices. The response of families with a disabled member, and women and mothers in particular, has sometimes been to extol the benefits of relying on specialised, segregated and institutional forms, even though their preference might be for more ‘normalised’ care at home. They are sometimes tentative if not resistant to the state’s attempts to carry out its ideology. Public policies of integration of disabled children into mainstream school education, and adults into competitive or supported employment and community care are sometimes resisted, not by preference but because parents know that these may really equate to greater workloads and efforts to manage resources on their own, and to much less certain forms of professional and institutional support (Barclay, 1988; Bowman & Virtue, 1993; Cant, 1994; Clear & Horsfall, 1994; Stern, 1995).
Poststructural deconstruction has exposed the weaknesses in modernist dualities such as public/private and this has confirmed what women have found in their personal experience of the reproduction of social and economic relations in paid work and at home (Weedon, 1987; McDowell & Pringle, 1992). Increasingly there is evidence that women's views about the merits or demerits of apparent changes in state intervention and their impact on the family are varied:

More recently, feminist scholars have re-evaluated the nature and impact of state intervention, suggesting that it may have contradictory effects for women: neither completely positive nor completely negative (McDowell & Pringle, 1992 p200).

These contradictory effects may include state welfare programs which tend to confirm inequalities of a structural kind and construct and reconstruct the work of caring in a discourse of dependency and need relative to a dominant primary, male role (Wearing, 1996).

Disablement and its caring context

Serious recognition of carers and of carers of disabled people in particular has been a very recent event in Australian public policy:


The policy and external context in which carers of disabled people in New South Wales do their caring in the 1990s involves an increasingly complex
mix of legislative and regulative forms, and government, semi government and non government systems of support (Bryson, 1992; Schofield, Bozic, Herrman & Singh, 1996). Financially, these include the Child Disability Allowance for the care of children up to the age of 16 years and the Carer Payment for carers of children over 16 years. Services may also include respite, home care, mobility allowance and some transport services of a limited kind (Bryson, 1992; Schofield, Bozic, Herrman & Singh, 1996; The Carers Association of Australia, 1996). These services are usually prioritized for particular categories of people in order to postpone or eliminate the possibility of institutionalisation. In the state managed climate of privatisation and user pays it is increasingly common for these services to be provided with a fee attached. In Beyond the Fog a research project conducted by Lyn Gain for the NSW Council for Social Service (NCOSS), 1992 it was reported:

Unfortunately (...) pricing policy does indeed have an effect on demand, in that people in need were now being denied or withdrawing from services because they could not afford to pay. These included child care and family support services, and home care for people threatened with institutionalisation (p14).

This direct assistance to carers may be seen as minimal recognition in response amongst other things to strong interest group representation to government over recent years. In the economic circumstances of the 1980s and 1990s they represent a form of social wage which should be viewed alongside a fall in real terms of lower and middle incomes. In spite of state initiatives to encourage women to join the paid workforce (eg affirmative action and equal pay legislation) these governmental supports may simply
have the effect of reinforcing the structural link of women carers with an unpaid caring role at home. This contextual sketch shows a picture of a wider and more complex service system, which includes the social wage and the broader collective services (health and education) managed by the state, and a diminishing government budget in real terms to support social welfare programs (Disney, 1991; Pusey, 1991; Gain, 1992; Bryson, 1992).

The seemingly reformist activities of government on the one hand in for example its equal opportunity endeavours whilst at the same time continuing discriminatory practices in employment and wages highlights a contradictory role of the state (Connell, 1987). Part of this ‘caring’ climate in NSW has involved state efforts to implement so called community care policies, including deinstitutionalisation. These may exert considerably increased pressure on women by reinforcing the function of women in the family context of providing care, at a time when other policy rhetoric of the state is encouraging a less gendered view of women and the family.

According to some social commentators there is evidence that the role of the family home, and in particular that of women as unpaid carers, has become increasingly important as the policies of ‘economic rationalism’, and ‘deinstitutionalisation’ take effect (Balock, 1990; Cant, 1991 & 1994). As Connell (1987) says;

Some of this is mere incoherence, to be expected from the sheer complexity of the state as a set of instrumentalities. But some is real contradiction (p129).
Nevertheless the idea of "the sheer complexity of the state as a set of instrumentalities" in itself is interesting, and perhaps sheds some light on its constructed meaning and role. The characterisation of the state as a complex set of instrumentalities shows something of its de-structured and fragmented existence, and suggests the possibility of the contradictory manifestations of its existence alluded to earlier.

The relevant disability policy framework of the recent era in NSW may be said to have begun with the Richmond Report in 1983, and the policy to separate developmentally disabled service provision from that of mental health and the Health department altogether. This included the program of deinstitutionalisation (Richmond, 1983). The era continued to be shaped to the present time by the Commonwealth Handicapped Programs Review (1983) which led to the Commonwealth Disability Services Act (1986), the NSW Guardianship Act (1987), the Barclay Report (1988) in NSW which was a response to criticism of the Richmond implementation project and deinstitutionalisation in particular, the Federal Disability Discrimination Act (1992), the NSW Disability Services Act (1993) and Commonwealth Disability Strategy (1994) (Tulley, 1986; Cocks, 1989; Annison, 1996). Overall, the legislative initiatives in their intention have been both protective and enabling. They have tended to reinforce the general policy of stronger individual protection of the rights and entitlements of disabled people, and enabled programs in employment, advocacy, recreation and accommodation which reflect the shift to a human rights and a social model of disablement (Cocks, 1989; Fulcher, 1989; Annison, 1996). In this process it seems clear, as
Cant, 1991 suggests, that forms of control over women's work and lives has been extended, both in the assumption of their role as carers and in the extension of the points of control. In assessing the implications of the Richmond Report she says that,

The surveillance of children within institutions, has not been withdrawn with deinstitutionalisation but has been broadened to include their families, principally their mothers (p121).

Throughout Australia following these apparently reforming activities of recent years, it is still the case that medical officers representing the Commonwealth are arbiters determining who will and will not be labelled as disabled children and adults in our community. Professional people working for the state make these decisions based on standardised, normative tests and scales and standardised ‘body systems’ assessment tables. As previously discussed in the case of children and entitlement to the Child Disability Allowance, it may also involve an assessment of a mother’s caring capacity. In the case of adults (16 years and over) the disability entitlement decision is made essentially as a judgement about one’s capacity to work. It is made with little information about an individual’s wider life and support context and more or less independently of any information concerning the personal and social context of those labelled (DSS, 1994). It exposes at a very fundamental level the quite fragmented, and often contradictory pattern of public policy implementation, and the ideological and constructed norms which underwrite it.
Whilst there is evidence of a greater presence of disabled people in the community, it seems clear that fundamentally little has changed, with most children still living at home, cared for by their mothers, attending 'special' and segregated schools and classes, with restricted recreation. Most adults are either unemployed or engaged in segregated employment or quasi employment activities (Ashman, 1989; Clear, 1989; Todd, Evans, & Beyer, 1990; Clear & Horsfall, 1994; McElwaine & Ford, 1994; Stern, 1994; Baume & Kay, 1995; Patetterson, Hanley & Auld, 1996).

The processes of measurement and the normative practices of science through professional practice have extended and intensified the gaze and points of control on the body and the social environments of disabled people at the same time as public policy ideology creates and extends the rights and opportunities for more 'normal' participation in community life. In this picture carers are constructed as essential to the defining character of disablement or irrelevant in accordance with changing needs of the social discourse at different stages in the lifespan.

Postmodernism and critical approaches provide the opportunity to disentangle disability from the supposedly 'natural' and commonsense world of individual biology and deficiency. This means dismantling too the link between specific biological differences and the construction of personal and social loss, and the generalised effect of stigmatising labels and categories which embrace the whole person for the whole of life. In this analysis a
social and holistic perspective allows us to appreciate other realities which construct disablement, and bring to light another narrative of care which the public discourse on disability hides. It compels us also to liberate caring from the ‘natural’ and commonsense, and therefore from its invisible and uncontested place in our consciousness.

The complex human and social implications of disablement and the normalising ideology and practices which produce and manage it can be seen to embrace and intersect with other constructed lives, such as those of carers most closely connected with disabled people. The process of exploring and explaining these complexities, against the backdrop of an accepted and naturalised narrative, is itself complex. In this chapter I have discussed the range of discourses which produce disablement, and in the process thoroughly elide a more holistic reality of disabled lives which includes very significantly that of women as mothers and carers. The chapter provides an important framework for understanding their powerful connections as a system of constructions. In this, a public and formal discourse around disablement and its treatment is manipulated to satisfy state interests at the expense of a predominantly private caring practice which it simultaneously constructs and conceals.

The management of disablement through normalising scientific and professional practices, no less for carers than disabled people, determines personal and social realities of daily life. Their constructions may be seen as a system in which the silent and embedded function of caring manages and
polices the disabled subject, on behalf of and in spite of a public discourse which is managed by the state as an active site for public policy discourse and power interests. The construction of disablement as a focus on the individual disabled body and discourses of care which define a state managed ‘caring’ system disguise and suppress the complex social and economic realities which produce disablement and construct carers. Their production and reproduction is confirmed and naturalised in the silencing and repressive quality of this public discourse, as it constructs a caring (‘welfare’) state supposedly managing a system of progressive and enlightened caring practices. The personal reality of disablement and the day to day management and care of lives dependent on other human support, continues to be quietly and ‘naturally’ that of women as mothers and carers in the isolation of their separate family homes, and largely non existent in the public account.

Chapter 3 discusses the substantive and methodological intricacies of seeking to foreground the unwritten narrative of caring and disablement, in the development of a collaborative group.
PART 2

Narratives of local knowledge
Chapter 3 - Coalition of differences: a collaborative research

A general and personal context

This chapter is concerned with the journey of the Group which became known as the Parent Exchange Group (PEG). It seeks to 'capture' the pattern of an emerging community of fragmented interests, and its conscious and not so conscious identification of issues of common concern to the participant carers. This view also takes in the evolving constructions of individuals as carers, and as members of a differently constructed community defined by the Group. It produces some images of participants as collaborators in the production of knowledge, and actions to create change locally.

I also examine my role as the researcher and my own changing consciousness of the issues including the research process, and my relations with the Group and its members. This has implications for the unfolding research process itself and the way in which it was designed. I have adopted a first person perspective as the only way to do justice to such a reflexive approach.

The changing research interests, and the constant movement and manifestations of control is expressed in the idea of the research 'gaze' and
the changing consciousness of group members, including myself as the researcher. The critical appraisal of the process reveals the complex ways in which the needs of participants, specifically those of carers and myself are worked out.

Although I am somewhat reluctant to indulge in a discussion of my personal history in the framework of my thesis, some personal sketch beyond the theoretical assumptions outlined in chapter 1 seems necessary in order to bring the reader fully into the research context. In fact there have in recent years been some valuable accounts of research of this kind (Atkinson, Shakespeare & French, 1993, Colquhoun & Kellehear, 1993 & 1996; Fook, 1996; Street, 1996 to name just some). Dorothy Atkinson and Pam Shakespeare put the case well:

The revelation of those hidden-from-view areas of research involves the book’s authors in a process of self-disclosure and self-reflection. (...) As we have written our various chapters it has become clear that our personal autobiographies are, in some sense, an important component of what we have to say (Atkinson & Shakespeare, 1993 pp1-2).

Even as I write I am coming to appreciate more that to some extent such personal accounts are a necessary part of a more democratic and humanised knowledge construction process. It is important I believe to make explicit at this early stage at least 3 aspects of the personal qualities I brought to this process, each of which could very reasonably be understood to influence my participation in the Group, and the research generally. My three concerns
are my gender, my employment as an academic member of staff at the university, and my strong history of involvement with advocacy for the rights and full citizenship of disabled people. I recognise the potential existed for gender to be the most confounding aspect here, and in reality it is pervasive and impacts on all elements of life. In this respect its influence is more difficult to assess specifically. I think the other concerns were more recognisable as they intruded on the immediate workings of the Group, and in this sense they are more important and a better way to construct the influence of the personal in this context. The power of gender to influence these personal dynamics is undoubtedly quite insidious, and I accept it as an underlying force and an aspect of all my relations.

For most of the research experience described in this thesis I was the only male. Thus, the support given in the first phase of the study was from a woman colleague, and although fathers participated in some key meetings the core group has been and continues to consist of mothers. With only two exceptions all 20 participants in the second phase interviews of the study were women. The two male participants were from the service system. In the earlier phase of the study of the 42 respondents most were woman, although a number of partners contributed both to the questionnaire completion and the follow up interviews. This sort of response and involvement seemed entirely appropriate given the significant responsibility of women relative to men in the day to day experience of disability and caring. Relations were comfortable at a personal level and
particularly in relation to the developing group, and over time infused with a healthy trust and balance in the ability of individual participants to contribute at whatever level they wanted or felt able. There did not seem to be a pressure within the dynamics of the Group which reflected specifically gender.

Nevertheless, my role as an academic and researcher employed by the university and the usual power associated with this position, and my own personal expression through this career work was more evident, and gender I believe was an aspect of this. At different points in this chapter this becomes relevant and as appropriate I have drawn attention to it. The third issue of my work and community action in disabled people’s rights and citizenship may have worked at a number of levels. It will be recalled that caring as a thesis topic grew out of, and was an extension of the first phase focus on the social support systems of disabled people themselves. During this research work, including of course the birth and development of the Group itself, I was personally confronted by a whole dimension of disablement that my history and allegiances had not permitted me to ‘see’. The point is most important, because even though I had a strong sense of family and community, a network of friends with disabilities and contact with their families, my strong commitment to the rights and citizenship of disabled people had to some extent ‘blinded’ me to the wider complexities of their lives. There have been over the last two decades times when in fact the public and professional discourse cast parents
and mothers in particular, as a significant source of the problem in liberating disabled people from lives of dependency and whole of life control.

In some way I believe I was indirectly part of that discourse, and can now more easily recognise how particular discourses, in this instance that of rights and equality, can hide other important stories. It would not be unreasonable to suggest the neglected and elided story here was the citizenship of women and carers themselves (Pateman, 1988 & 1989; Weeks, 1996). The accounts of mothers caring for disabled daughters and sons, and an emerging picture in the literature of the inadequacies, even failures, and unexpected effects of the deinstitutionalisation project have influenced the thesis. My loyalty to the rights agenda and commitment to disabled people's citizenship aspirations were initially matters of some tension for me in the context of a Group in which many carers were highly critical of social and public policy initiatives which espoused them. In this respect I have myself broadened my view to embrace a wider perspective of disabled lives, and I think it will be clear that the thesis itself is a statement of this.

To shift this discussion just briefly to include the theoretical framework outlined in the previous chapters it will reveal my interest in taking on a more critical and postmodern perspective in conjunction with the issues of modernity and an improved experience of personal and public life (Agger, 1991; Ferguson, 1991; Cox, 1995). Elsewhere this sort of thinking and task has
been explained in terms of the need to distinguish between the
"responsibility to act" and the "responsibility to otherness", and in making
this distinction Stephen White, 1991 has also drawn a parallel distinction
relating to language, between "its 'action-coordinating' function and its
'world disclosing' function". He says;

Understanding these distinctions, as well as why they are viewed
differently by the two sides, is the key to seeing what is at stake in the
debates over modernity and postmodernity (pp ix-x).

My experience of the experiences of carers, amongst other things revealed in
the earlier phase of the study, had awakened and challenged me to the need
to better understand this other story, and also to the nature of the tensions
of two broad intellectual positions. Of course, to return to my personal
positioning in the Group and in the research it be will clear as the chapter
progresses that issues of power and control could still be rather ambiguous
and messy ones.

Building a collaborative group

The Parent Exchange Group was a central element of this research. The
chapter describes its early development, the nearly 3 year period between
February, 1992 and December, 1994, as the first phase, and the period since
then to the present as the second phase.
The Parent Exchange Group was ostensibly established to create opportunities for parents in particular to share experiences and information with a view to understanding and strengthening local and neighbourhood supports of disabled people and their families living in the Hawkesbury area. It was supported at the time by the Area office of the New South Wales Department of Community Services, who recognised that carers in the Hawkesbury area received relatively less support and might experience isolation. Following consultation with the Department they distributed letters to families with a member with a disability who were on their mailing list as living in the Hawkesbury local government area (LGA). This of course preserved confidentiality, and provided families with a choice about responding and participating in the Group, free from any direct contact with me.

Following the first meeting at which 8 mothers of disabled children and young adults in the Hawkesbury area were present, it was agreed that meetings take place over lunch in the faculty meeting room at the local university campus on a monthly basis. It was also agreed that meetings record a summary in the form of minutes, and that they be distributed to participants prior to each subsequent meeting. The following extracts from the first letters to the community highlight the basic stated themes set out in seeking to establish the Group.
The project hopes to:
- encourage sharing of information at a local and informal level. This may include what services are available to you, and what you think should be available;
- contact as many people as possible in the Hawkesbury district and establish links between the university and the local community;
- provide you with the opportunity to talk to people who are not connected to any service provider or government body;
- collect information which will help improve the support networks of people who have disabilities in the local area;

In doing these things it is hoped that people with disabilities, their families and advocates will have greater information and contact with each other and the local community (November, 1991).

Basically the purpose of getting together on this first occasion is to introduce ourselves and discuss the information sharing and support ideas that we have. Any contribution of ideas will be welcome. (February, 1992)

These exemplars from the introductory letters make it appear that the aim in establishing the Group was a concern with local networking and support. Information sharing was a key aspect of this. In addition, it is clear that the stated intention was to permit the Group and its purpose for being to be something that was, in part anyway, able to be determined by participants themselves. A community of interests, informal, local and free of any professional oversight was most clearly part of the stated intent.

*Dynamics of control in the collaborative process*

Less clear perhaps was the unstated intention, as implied in the reference to “the project” and “collect information,” to set up a group which may support research of some kind. Certainly the subsequent application and participation in a funded research project points to this intention. It highlights the issues outlined in chapter 1 concerning a critical and reflexive
position of the researcher, and keeping in sight the ‘real’ purpose of the research, and the researcher’s consciousness of his/her own outlook. The idea that the Group would be an opportunity to meet without the impediments of bureaucracy and with those “who are not connected to any service provider or government body” brings into focus this aspect of the research process and my position in relation to the Group. Certainly these words appeared to acknowledge an important aspect of the carers’ experience, which was the perceived need to share their experiences at a personal and informal level, and for this to happen in a context in which they had some measure of control. This meant the opportunity to share without the potentially controlling presence of members of the service system. What was unacknowledged in this text was the position and interest of myself (and an academic colleague) as the researcher. The text assumes that I would not be viewed by participant carers as, “connected to any service provider or government body”.

On reflection such an assumption was perhaps unwarranted. Firstly, I had no personal involvement with any participants, and there was no formal or informal connection. Secondly, I was a member of an institution, and it was certainly connected with government. The two points taken together seemed to suggest a sound basis on which participants or prospective participants would be justified in holding some reservations about the ‘real’ interests of the University and a staff member setting up the Group.
It is possible however to take the two points above and to view the perception of participants entirely differently. Firstly, because I was unknown to them previously there was no basis on which to think adversely, and conversely there was grounds for being interested in something genuinely new. Secondly, the University was indeed part of the local community, but few would identify its interests in setting up a group of this kind as those of the bureaucracy, the service system or government in any conventional way.

In spite of these mixed messages of the text there were indications that the Group quite quickly established a comfortable disposition towards me and also to the idea of the Group. It was not long for example before the Group meetings were regularly attended by a core of 12 mothers of disabled children and young adults from the Hawkesbury area. In addition other prospective participants who were unable to attend due to other work commitments had asked that they be kept informed of meeting times. A mailing list was formed and approximately 20 families received either minutes of the meetings or a notice of forthcoming meetings.

Records referred to as minutes were maintained by me at each meeting and sent to all regular participants, as agreed by the Group (May, 1992 Minutes). As part of the information sharing these minutes often included items of interest (forthcoming workshops, service announcements etcetera) that meeting participants had brought to the Group and wished to have
distributed with the minutes. The status of the minutes was as a record of
the main discussion points of each meeting. They were not minutes in the
sense that the Group was formally constituted with a committee and
officially elected members who voted on ‘important’ recommendations.
Nevertheless they were accepted as a true account of the main discussion
points of each meeting. The issues recorded in the minutes often prompted
discussion at subsequent meetings. It was clear to me that they were read
and taken seriously because it was not uncommon for even small
inaccuracies to be pointed out at the next meeting.

Thus it was that the overall setting and responsibility for the meeting
including room booking, lunch ordering, tea and coffee set up, maintenance
of a mailing list, and the monthly preparation and distribution of meeting
minutes and notices was, and remains, that of the researcher (mine). Such
contextual arrangements may seem on the surface to be relatively
unimportant matters. However this was not how they were seen by me
from the outset, and participants have remained constant in their
expression of the sense of “freedom” they experience in being able to
participate in this particular group without being burdened by the
experience of further responsibility. I expressed this at one meeting as, “the
freedom of uncaring for 2 hours a month.” Such indications from
participants however were perhaps interesting indicators as to the Group’s
raison d’être, from the point of view of participant carers themselves.
The following extracts from Minutes of three of the early meetings provide valuable insights into the burgeoning interests of participants and the construction of the Group. They also indicate the emerging issues and brief for the research study that formed part of the Group’s focus during this first phase. It helped to move and maintain the focus and construction of the Group towards collaborative action and a more critical view of its own existence.

(...) Also, other information was distributed and discussed. We also discussed a number of local services, and the experiences of different Group members in using them. A few key points seemed to summarise our discussion;
- local services not responsive in crisis; have to go out of area.
- services exist out there, but you have to really work to find and tap into them. Almost like we need a locally based disability worker, as ... suggested.
- integration OK as long as properly supported, (...) reported on really good experiences with her child.
Discussion refocussed on the value of local supports and problems of getting support and schooling etc. outside the local area. In looking at this, 2 services were discussed as having local support value;
- Home Care and Host family system, although as (...) reported, this isn’t always straight sailing!!
We agreed to send material with these minutes. (PEG Minutes March, 1992)

We shared our experiences of the last month (since the last meeting).
Discussed;
(... ) Goals for the Group. What is our direction? Considered;
1. Initially value is as a support group; shared experience and information and networking, but could move to improving things for people with disabilities in Hawkesbury LGA, as we were able.
2. Mixture of disabilities represented was good
3. Send Minutes to regular attenders and minutes should just be usual summary. Others should get Notice of Meeting.
4. Use of Tape to assist in the Research project (...)
Started to look at some of the issues of Respite Care and Vacation Care raised at the last meeting.
Shared feelings about respite- difficulties in letting go when opportunities did present, doing it for so long and choices for so long so
few, and anyway lost interest in own personal development. Also question of guilt in some cases.
Other experiences included;
Being viewed negatively for putting son/daughter in an institution at time when no other options available.
Threats of suspension/ Time out at school because of difficult behaviour.
Some newer ideas and initiatives at schools, may be supporting younger students, not so helpful for adolescent and young adults.
(*PEG Minutes May, 1992)

Introductions: met(...) briefly explained the origins and purpose of the Group.
General discussion about the difficulties in dealing with the system.
Problems of access to... School. Especially problems of access because there are no ramps. Perhaps other reasons for resisting access of people with physical disabilities, and maybe ramps is just an excuse.
We all agreed how things usually only get done or changed when a parent fought for something and kept up the pressure until "the system" made necessary changes.
Problems too of professionals tending to support each other against the people for whom the service is established.
(...) gave some personal accounts of the real difficulties of being in the community with a child with a disability and how people can often be inflexible and unaware.
...distributed copies of the ad for the research assistant and we discussed the need for a member of the Group (...) to be on the panel... volunteered. (* PEG Minutes August, 1992)

These meeting extracts confirm that participants placed a high value on the need for information, and the obvious desire to share it. At another level however, and only formally captured by these Minute extracts, the sharing involved more personal concerns, and deeply felt experiences of alienation and conflict at the point of service provision and contact with the community. The entanglement of parents with service systems, primarily health and education, was often fraught and a source of great dissatisfaction.
In general the content and movement included in these extracts was most typical of the general content and tenor of the meetings.
During the early period of the meetings of the Parent Group it became apparent that funds could be available to support the Group in pursuing some of its interests in disability locally. This was put to the Group at one of its meeting (PEG minutes, May 1992) and following the Group’s interest and support for the idea a research application followed.

It might have been expected given the participatory pronouncements of the earlier letters that the Group would have actively participated in the preparation of the application for funds, but other than expressing their interest and support this was not the case. This raises a number of relevant issues. The first issue was simply a time deadline which meant the application was due prior to the next scheduled meeting. The second issue was that raised earlier in this discussion concerning the extent to which participants wanted to take on ‘extra’ responsibilities. It certainly seemed their involvement in the Group was in part due to the opportunity it provided to be involved with others, but free of specific responsibilities. On reflection it is most likely too that I was happy to maintain control of this key process, and whilst parents may not have wanted to take on ‘extra’ work, a different consciousness on my part may have facilitated broader choices of participation in this process.

The theme of more or less responsibility and/or involvement of participant carers was a source of underlying tension for me throughout.
On reflection it is possible to see that this was about control, the desire to maintain it, within the ideals and vision of a collaborative research endeavour in which sharing power was understood to be a hallmark. It was a context in which the boundaries were unclear. The Group was not primarily a research event, yet from the point of view of myself as the researcher, even though my intentions involved support for a broader concept of information sharing, support and local networking, research was never fully absent.

In the case of the application for research funds the opportunity existed which may have broken new ground in terms of carer involvement, and if appropriately constructed may have resulted in a higher level of engagement and contribution by participant carers, without actually adding to the burden of responsibility. However these events taken with the broader definition of the researcher (my) role, including minute taking, and responsibility for the whole communication process suggest a process more carefully managed and controlled than either anyone understood at the time or was necessary for the ‘success’ of the Group. Of course it may well be said as I have already suggested, that it prevented opportunities for participant carers, and restrained the manner in which the Group developed.

In part the personal tension I experienced may be explained by the question of the process/outcome demands of an experience of this kind, and the
apparent need to demonstrate something definable as an achievement, to justify the activity, and my time. It highlighted my sense of accountability to the School and the University and their control of me or my self control in this. There was an unstated need to produce something which more obviously resembled a research or ‘educational’ outcome. These tensions and concerns were recognisable at a subsequent meeting as the research project was getting under way, when I put the research study in the broader context of the Group’s actions and reason for being. Thus it highlighted the importance of not only having some specific outcomes like respite, which would be something that different people might take up as they wanted and are able, using the information and support of the Group, but it is also the sharing and support process of actually meeting together regularly. The survey and report on disabilities that came from the research could be used as the Group see fit. It is what the Group and individuals want to make of the project.

(* PEG Minutes, July 1992)

So in addition to these complex questions of control and clearly not unrelated to them the process raised important questions concerning the coexistence of research aims and the wider conception of the Group as a support process. This included the true extent of power sharing and the question of who really had control. An aspect of these emerging questions, issues and tensions then was in fact the way in which I appeared to be powerful as the convenor, researcher, academic and perhaps as the only male in the Group. Yet in spite of this seemingly privileged position I was feeling myself some sense of powerlessness in a wider system which itself exercised power.
Reflecting somewhat later on this, I came to the view that a great deal of the
focus of our meetings was on carer participants themselves sharing their
lives, good and bad, and from their continued attendance and interest
obviously benefiting from this. Increasingly, I was very much the
convenor/facilitator and listener. Both in relation to the experience of
caring life away from the Group and the experience of the Group itself, I was
in a sense quite separate from the particular experiences of other members
of the Group. Being with the Group and the various contacts which resulted
was rewarding, and our sense of an emerging community grew. I had issues
and concerns however which were not so easily included. I saw in this
experience complex contradictory even paradoxical elements which were
later evident in the experience (although not directly disclosed) of service
system employees. This is discussed in chapters 5 and 6. Suffice to say here
that it drew my attention to the complex capillaric and interstitial meaning
of power in relations locally, to which the work of Foucault takes us
(Foucault, 1982).

Some early collaborative efforts

A research study within a research study

Success in gaining a small University based grant was a boost to the sense of
purpose and confidence of the Group. At another level it could be
understood to be the validation of a community whose needs had been recognised as important in some way.

This idea is important because from the point of view of the University and the funders the research was about the discovery of important ‘truths’ concerning disability and social support systems in particular in the local community and perhaps beyond, and it was this potential that perhaps justified funding at all. Of course there may also have been some recognition of the importance of the links which were already evident through the Group, with the local community. Such links were part of the University’s mission. There is little doubt however that no-one understood that the Group was a community who met regularly, and celebrated in some measure a sense of human solidarity, and that this may have been more significant than any other aspect of the whole process.

What followed was an important research story which forms a significant part of the developing construction of the Group. As indicated in chapter 1, it was centrally although by no means exclusively to occupy its time over the next 2 years. It was significant in helping to define important issues about disability and the role of carers, the relationships amongst those most directly charged with the responsibility for conducting the study, and other participants in the Group. It laid the basis for the continuing study of which this thesis is a culminating point.
To summarise briefly, the aim of the study was threefold. Firstly, it was to prepare a demographic report on the nature and extent of disability in the Hawkesbury LGA. Secondly, it was to determine the nature of the social support networks of individuals with disabilities living in the Hawkesbury LGA, who had developmental disabilities. Thirdly, it was to use action research to plan, implement, and evaluate action to develop the social support systems of people with developmental disabilities in their local neighbourhoods. These were all issues central to the lives of the parents in the Group, and it seemed clear that their involvement in the unfolding study would provide significant insights, but also a uniquely personal view. It was felt that this was so, particularly because of the on-going relationship through the Group process (Clear & Horsfall, 1994).

As discussed in chapter 1 the design of the research study was such as to employ different research methods to match the research demands of the different stages of the study. It moved as it were along a continuum from a literature review and questionnaire survey at the objective end to follow up interviews and a small number of life story accounts at the other end. This might be described as a movement towards increasing levels of subjectivity. In the design all of the methods and stages were seen as held together within the flux like conception of the collaborative methodology defined by the operation of the Parent Exchange Group.
In fact the research activities and the unfolding process was central to the meetings and the inter-meeting communications, and this guided the research throughout. The specific actions and on-going activities of the collaborative research group were an integral and integrative aspect of the whole research process. The Group's support of the research took 4 forms. Firstly, they were directly involved in the selection of the research assistant, whose position was funded from a university grant. Secondly, at each monthly meeting of the group, the progress of the research was an agenda item for report and discussion. This meant the group was regularly updated, and their ideas could directly inform the progress of the research. Thirdly, members of the group (approximately 12 people, it varied around this number as a core group) were participants in stage 2 and 3 and actively supported the "snowball" or "word of mouth" approach to gaining volunteers for Stage 2. They assisted in making community contacts to fulfil the aims of Stage 1 of the project.

The fourth form of support for the research project was less formal and less direct. This support was the regular dialogue of the meetings which set the context of issues and concerns of parents as carers and advocates of people with disabilities in the local community. It was in effect a focus group on these issues and concerns and its language and dialogue were an important part of understanding disablement in the local community.
In December 1994 at the request of the Faculty dean the Group planned and implemented a launch of the report that resulted from the research study. From the point of view of the Group the research process had been a protracted event and the outcomes less definitive than they had expected. It seemed clear as the process unfolded and in the latter stage as participant carers read over and advised on drafts of the report, that they were touched to see their story told, and to read the explorations of human lives with which they could identify. Nevertheless, they had indicated too that their expectations of the study were that it would produce some specific recommendations for change, by which government might be influenced. These expectations directly influenced the study report towards the translation of the broad findings into a recommended model of service, which took the Parent Exchange Group as its starting point.

At this stage in the Group’s development and at this level of its understanding of itself, it seemed one could identify the shape and function of a more classical collaborative research design as proposed by Lewin, 1946; Carr & Kemmis, 1986; McTaggart, 1991; and Wadsworth, 1991 to name a few. A group with common local interests, met regularly and through this regular dialogue came to understand more critically the relationship between their personal concerns and the wider social context within which these personal experiences took place. Steps were taken in a more or less collaborative fashion to become informed of the local issues in a systematic way using conventional research methods, as described in chapter 1, such as
literature review, questionnaire survey, and interview and life story approaches. These were submitted to descriptive statistical methods, content analysis and grounded theory approaches to assist in evaluation of meaning and significance and to generate the report.

Whilst I maintained overall control of the process it was clear that participant carers who constituted the Group had considerable involvement at a number of levels, as the discussion has described. These were productive efforts and the consistent pattern of meeting attendance and the energetic and interested involvement of people was indicative of a strong sense of common purpose and sharing. It was a strong sense of partnership and community. The action research ‘spiral’ however included broader efforts to create change, and these too had already commenced as the research study within the research was under way.

*The Family Support Project*

In terms of acting as a Group to create change and improve things there were two important aspects of the Group’s activities. First, the Group met to talk about personal and broader local and social concerns. The personal and the social went hand in hand. The individual concerns of participants gave rise to discussion about the broader social issues of which these personal experiences were a part. Some level of empowerment came with being able to simply share and ‘unpack’ a personal experience of alienation; to see
something of the social and contextual forces that gave rise to it. It was not
difficult to appreciate how such a reflective process in a supportive on-going
framework could help in some measure to change the way one (they)
experienced those things and others in the future. Second, the Group made
decisions to take actions within the scope of its resources and abilities to
improve or change those things that emerged as priority concerns.

One of the Group's major involvements in seeking change was the
development of a respite cum family support project in conjunction with
the student community placement program conducted by the School of
Health at the university. The issue of respite was one that had been raised by
parents during the regular monthly meetings as the major support need for
parents and families. It was the single most frequently expressed concern of
participants in these meetings.

Within the context of specific action taken by the Group, such as The Family
Support Project involving students in placements with local families, other
data systems were established to monitor the effectiveness of actions, to
reflect on the experience, and to evaluate the worth of the ideas inherent in
the planned activities (see Appendix 6). Throughout this phase however
the primary evaluative and reflective process was the ongoing meetings and
sharing of ideas by the core of individuals.
The Project became the responsibility of the School of Health and managed jointly by the School and the Parent Exchange Group. Wherever possible the existing systems and structures used by the School of Health for student placements were used to manage the Project.

A component of the Bachelor’s program was student placement in services for disabled people. The placements were designed to provide students with experiences to assist learning about the support needs of people who have a disability and how they as health professionals may assist in meeting these needs. Traditionally these placements included large institutional settings, group homes, special schools and vocational programs across the Sydney metropolitan area.

The Family Support Project involved matching students in the Bachelor of Nursing with local families where there was a member with a disability. It was designed to provide students with valuable opportunities to learn about supporting individuals with disabilities and their families at the same time as providing families with some extra help. This help might involve providing respite, or assisting the disabled person in the family home or in making use of the local community.

Each student who participated in the Family Support Project was available to the family for 20 hours. The manner in which this 20 hours was spent was to be negotiated between the student and the family concerned. The
needs of the family and the availability of the student were the two key
factors. Students participating in the project could expect to provide support
in a number of ways. These could include participating with families in the
family home, participating with families in the community, participating
with a person who has a disability in the family home or participating with
a person who has a disability in the community.

The nature of the support and participation were naturally dependent upon
the individual needs of each person and their families. It may have
included talking or teaching/learning with a person, using local community
facilities, such as the park or shopping centre, providing companionship,
going on social outings, or involvement in a therapy program organised for
an individual.

The initial meeting of family and student of 1 to 2 hours was an opportunity
to get to know each other and to establish the main activity and dates and
times of the support. Of course it was also to be an important opportunity
for the student to learn about the support needs of the disabled family
member. Students were only permitted to make contact with the family
following a specific 2 hour orientation program in which they were ‘walked
through’ the elements of the project, and encouraged to consider and be
aware of the particular aspects of working with families and the range of
issues associated with disablement and the needs of families and carers.
The process/outcome dialectic was important in this experience as it was in the Parent Exchange Group experience itself. Students were familiar with placements in which their contact with disabled people was of an institutional nature, workshops, special schools and group homes in particular. This organisational experience was common to most placements for student nurses, hospitals being the most obvious and frequently used. The experience was largely pre-arranged, and the student’s job was to satisfactorily observe, learn and perform the role, which itself was pre-determined.

The Family Support Project challenged these basic elements of the placement experience. In contrast to a pre-arranged placement and a predetermined role students were expected to meet and negotiate with a family, usually a disabled child’s mother, about the needs of the child and the family, and the terms of the placement. In terms of the program goals and processes, emphasised to students in the orientation session, the student and the mother as carer were equals. This was an important component of the project, and there was no assumption of superiority either way. The student could come open and receptive to the opportunities to learn from a carer who had considerable experience and knowledge of the support needs of their disabled child, and they could be confident about their opportunity to make a valuable contribution to the support of the family. The process of the placement was as important as the specific learning outcomes associated with disableness and the support competencies.
Furthermore, in theory anyway, it was a process in which the ‘consumer’, in this instance the carer, could participate without feeling unequal at the outset, and where their knowledge and skills were recognised in the process.

Parents were asked to complete an evaluation format to assist in learning from each experience and in future modifications to the Project. It was not intended that evaluation be of the individual student, but rather the experience as a whole and its strengths and weaknesses. Of course this may have reflected on the student and the ways in which s/he may have done things well or differently or better. However the primary focus was not on the student, but the experience. In addition to this individual evaluation process PEG meetings allowed regular time to critically evaluate the workings of the Project, as the following exemplar so nicely highlights.

The following conversation was recorded at one of the Group’s regular meetings. It provides a valuable micro view of the operation of the Group, not captured by the meeting minute extracts. It illustrates effectively the working of the Group, and the essential process which was critical to an understanding of the gradual change in construction of individuals, and how we worked through some personal issues. It reflected something of my own interest in the group process for solving problems and coming to different understandings. Perhaps too, it revealed the influence of a critical perspective, a Habermasian and Freireian like interest in ‘freer’ contexts in
which praxis may result from relatively undistorted communicative experience (Habermas, 1971 & 1984; Freire, 1970 & 1972).

Specifically, the exemplar demonstrates the process of simply sharing experiences as a way of supporting each other and also learning about the range of ways of thinking and doing things in relation to particular life concerns. This was an important part of the Group’s activity. Secondly, it highlights the way a specific issue, in this case that of the Family Support Project, was discussed by the Group. Parents in relation to this particular program acted as consumers (of respite/support), providers (of opportunities for students to gain valuable experiences) and evaluators of the program. Thirdly, it highlights my role (Mike) in this process. In this instance I was an ‘equal’ participant in the Group, but not a participant in the Family Support Project in the same way as other Group members. Fourthly, it illustrates the power of such dialogue to draw out issues of concern in a critical and supportive way that may lead to informed change. Finally, critical examination of the text reveals important aspects of the individual experience of carers, their expectations and learned and preferred ways of handling the issues at hand, their feelings on important issues, and their experience of societal reactions. The meeting text is interspersed with my commentary on it.

Mike: I suppose if someone came along who you had absolute confidence in, absolutely comfortable with in terms of their ability to work with John, who you felt you could work with (...) It’s a sense of not being sure, of wanting to be around.
Rosemary: And that only comes with a period of time, and comes with anyone, like my homecare lady I'm relaxed with because I know she won't be fazed if he pulls some new thing.
Mike: How long did it take before you felt comfortable with her?
Rosemary: Oh a while. See they won't send me any homecare lady, I've got the best one. I've got two in the service who can come down and manage John. I'd refuse any others. I'd go without rather than have others. It's like building up a relationship with a child. Silence (...)

Rosemary is concerned about the suitability of the student who comes to do their family support/respite placement, and the ability of just anyone to manage her son who may present with difficult behaviour. Rosemary’s concerns appear to be more than just the practical difficulties of managing her son. She reveals her concern about other issues. Rosemary shows her sense of uncertainty about what expectations and experience the student may have of disability and the strength of her feeling seems to touch on the broader sense of discomfort that is often experienced by parents of a disabled child in the face of societal expectations and responses. She also reveals something of her interest in forming a relationship with whoever it is who comes to her home. The experience is not simply a chance for respite in the simple sense of being away from her son for a time, it may be an opportunity for companionship with someone who understands her son, and her predicament.

Mike: (to Margaret) So you see just going to the park, even though you're going too, you're not actually getting the same sort of respite (...)
Margaret: I'm getting away from hubbie so that's alright!
Mike: And you see that as useful, helpful?
Margaret: It's the only time to go out. I wrote in my little book that it was really nice to sit back and watch someone else occupy my children and I was a fly on the wall and I could sit back and watch them.
laugh instead of me having to be the one to think up ideas to entertain them. Just to sit back and watch them.

Julie: Just like the husband does. Laughter!
Margaret: Yes, that meant a real lot because I don’t get out very often. Anything different is good. I don’t mind having respite as long as the students don’t mind having me along ... because Trent won’t go out with just anyone. (...)

Like Rosemary, Margaret reveals her interest not just in having her child taken off her hands for a time, but having some change, different companionship, freedom to observe; “sit back and watch someone else.” Her ‘true’ wants are much more directly put, but Margaret is younger than Rosemary, and her disabled child presents much less challenging support needs which are much less likely to produce negative societal responses than in the case of Rosemary. Margaret does not have the obvious concern that Rosemary experiences of her disabled child’s behaviour, although she does suggest that he “won’t go out with just anyone.”

The reference to “getting away from hubbie” is an interesting allusion. It was one which was to recur throughout the study and is discussed further in chapter 4. Julie’s response and the Group’s laughter may serve to emphasise the point.

The discussion returns to Rosemary’s son, and incidentally touches on interesting questions about the student placement experience (compare with the earlier ideals) and Rosemary’s confidence (or lack of it) in the student professional to handle the difficulties she anticipates. Her anticipation of the
worst (or less than best circumstances) is really a key issue here. My sense of responsibility for what happens is also evident.

Mike: Any more issues. We can take on board the things you have talked about Rosemary, and think about them. I don’t know whether we can solve them.
Rosemary: I think it comes back to my child.
Mike: It’s also an issue of how we can construct the hours and how we can cater to individual needs. Maybe it’s something we need to think about before the next meeting. What about your involvement in the program in the meantime?
Rosemary: She’s supposed to be coming next Saturday - I think if I got another one where the car broke down I would just say forget it. I believe the other one was genuine, that she really had a problem with the car, I’m a little bit apprehensive on Saturday in the sense that I am not going to be there, she wants to take him bowling, I won’t be there, so he will already be out of sorts when he wakes up and finds Mum gone and I tried to explain this to her and she doesn’t seem very fazed by it. John has been on a similar outing with Barnardo’s to the bowling alley and John went off his head. Will she be able to handle him.

In the role of facilitator of the discussion (and this illustrates a position that I often had in the meetings), it appears that I am interested in bringing the discussion to some sort of close at the same time as being reassuring that issues of concern would not be forgotten (they were taken “on board”).

Clearly, Rosemary is anxious about how her son and the student carer will manage, especially in the public setting of the “bowling alley,” and in this anxiety may well be reflecting something of her own negative experiences in the same and similar settings. The “discomfort” to which I referred earlier can often be embarrassment and even shame in the knowledge of public expectations and reactions.
Mike: What is the worst possible scenario?
Rosemary: He’ll start hitting his head, he won’t hurt himself but it’s pretty distressing to see. He may try to scratch her on the arm, he can get really angry in the car and bash on the window, it can be frightening for someone who hasn’t seen it. I’d say she’s the sort of girl who won’t be fazed.
Mike: Let’s say there’s a problem. What does she do, where does she go?
Rosemary: Take him back home, take him to Frank. Sometimes when he’s screaming and carrying on it’s embarrassing. She’d get him into the car.

I have picked up on Rosemary’s anxiety and focussed specifically on the issue of the imminent outing with the student. Rosemary’s description provides some insight into the emotional intensity of an experience of this kind, which is obviously not unfamiliar to her. She alludes to the public and “embarrassing” nature of the experience revealing something of the fears she knows personally and projects to the student, even though she believes; “she’s the sort of girl who won’t be fazed.”

Debbie: So are you worried about her or about John?
Rosemary: No, I think John will survive but do we need to put her through it. Even when John hits himself he doesn’t hurt himself, bites himself sometimes, he’s like a tornado. See, then she’s got to cope with a public place.
Debbie: Sounds like she’s made an informed choice...you’ve told her that you’re not going to be there, that he’s going to be out of sorts. Sounds like she knows what she’s doing. The worst thing that could happen is that she’s going to be embarrassed.
Rosemary: Yes, it would be I suppose. (..)
Mike: It’s like you’re taking responsibility for her.
Julie: It’s like, we know how to deal with Tina, her brothers know how to deal with her, but does the student. Will she say NO. Joyce’s such a soft girl, I don’t think she could shout at the kid.
Mike: But Joyce can be quite firm though.
Julie: But she’s quite soft.
Judi: But she could be quite different when you are not there.
Debbie: Sometimes people are firmer when the parent isn’t there.
Julie: Yes, she’s been to Bridges with Tina twice.
Rosemary: I’ve seen her at Bridges and she’s managed very well.
Mike: We need to keep talking about it.
Julie: The type of disability makes a difference. The student really does
need to know something about the type of disability the child has (...
Mike: You might get in touch with us at any time if you've got a
problem that is of concern. (*PEG Minutes April, 1993)

Once again the "public" nature of the potentially disruptive behaviour is a
central concern. The whole segment illustrates the great strain and
complexity for the carer associated with what for most parents may be a
relatively uncomplicated experience. Of course these extracts also highlight a
pattern of quite critical and supportive dialogue, which was typical of many
meetings. The participants (Debbie and Judi) in this excerpt, were the
academic colleague and the research assistant respectively to whom I
referred in the Preface and chapter 1. They were participants in the earlier
phase of the research. Although their contribution here was a positive one it
might nevertheless be viewed from the carer's perspective as an unfairly
strong 'force' when, as was the case here we appeared to act as a team.
Overall this did not appear to be a factor of concern to the Group.

Beyond the dialogue as always there were material interests, and Rosemary's
son went to the bowling alley. Subsequently he was accompanied by
different students to Manly beach by train and ferry, to a Restaurant, to
another family's BBQ luncheon, and a full day trip to the central coast. By
and large these experiences passed without major incident, although not
entirely free of embarrassing moments.
In the context of the Group the wide ranging and individually shared concerns gave rise to proposals for solutions. Often these suggestions were for changes to existing service systems or the establishment of new ones such as respite itself, or the proposal for a locally based 'disability worker'. At a broader level then, the Group could be described as having only some interest in considering the purpose of the Group in a reflexive manner although they demonstrated a desire to share their personal experiences of disablement with others in the Group, an interest in learning of other ideas and solutions to their concerns, an interest in local solutions, and some satisfaction with the Group having mixed disability interests.

This latter point was a focus of some interest with the Group, many of whom had been involved with support Groups where the focus and reason for existence was specifically tied to a particular disability interest. By focussing on the broad common experience of disability rather than a specific diagnostic group, participants of the Group clearly felt that it more truly served their personal and communal interests. This idea, and the expressly felt interest or need in which it was contained, was a seed which provided the intellectual impetus for me to more consciously, albeit, on reflection, slowly and belatedly cultivate this aspect of the Group's existence. If the seed was planted by the Group consciously or unconsciously and took hold ever so slowly in my mind, it was often given a fertiliser like assistance through the sharing of the supervision process. What was becoming faintly evident was a mini-cycle, within the broader action and reflection process
(cycle) of the Group, and this was an important part of my learning and
developing consciousness of the issues.

The research and respite activities were important aspects of the Group's
life, and continued to be. The research report itself gave rise to further
discussion about the idea of disablement and also to new ways of
approaching the practical concerns of families and individuals where a
disability was involved. It was an important basis for reflection too on the
models of community support extolled and ostensibly practised by
government, and the possible alternatives.

Like all the issues raised the Family Support Project took place within a
context of interrelated concerns, and the School of Health with input from
the Group’s meetings reviewed its disability placement program within
which the project resided. The School supported by the Group felt that
changes were needed to facilitate greater student participation in the Family
Support Project. That greater student involvement was necessary in order
that the Group could extend the project as it (the Group) had proposed
beyond the participants in the Group itself to the wider community. This
occurred at the beginning of 1995.
Community development proposal

The Group's reflection on its own individual concerns was always related to the wider interests and concerns of the so called disability community. This extended following the research report of this first phase to the idea of applying for funds to establish the very model of support the study itself had proposed.

The model of interaction and communication, and the processes developed for planning and implementing projects and improvements for disabled people and carers such as the Family Support Project in the Parent Exchange Group itself, appeared to offer a valuable guide to the way in which government itself could provide support to local communities. It seemed clear that the study and activity of the PEG provided support for other documentation of the benefits of approaches to research which respect a theory/practice dialectic and closely engage the local community in implementing and validating actions for improvement (Carr & Kemmis, 1983; Winter, 1989; Fook, 1996; Street, 1996).

Taken as a whole the study of the first phase of the Group had suggested the possibility and merits of defining and implementing a different approach to service provision, designed to assist government in working with local communities and families to support, inter alia, the quality of life aspirations of disabled people and their families. In so doing it was thought
that it may actually define some notion of community which was so absent in the lives of carers and their families even though government policy as outlined in chapter 2 for a decade or so was built on an ideal (ideology) of community care.

In essence it proposed a community exchange group model, an outgrowth (or offspring) of the Parent Exchange Group in which a full time government employee (community worker) was engaged in a number of strategic locations across the local community. The role of the proposed community worker was not to solve specific problems in any case load sense but in a general way to be a link between government and other services and local communities. More specifically it was envisioned that the community worker would facilitate:

- systems of information sharing from government to community and community to government, including across government departments, and levels of government;

- networks of largely self sustaining community support which involved families where there was a disability, and the wider neighbourhood;

- a system of advocacy networks between the range of community forums and the community exchange groups in local communities;

- the broader inclusion of disabled people and their carers in their communities; and

- a greater and more appropriate use of the knowledge and skills that exist in local communities for defining and implementing government policy, and
contributing to neighbourhood based support systems (Clear & Horsfall, 1994).

It was believed that the community exchange group model had the ability to facilitate inclusions and links between disabled people and others in local neighbourhoods by encouraging information exchange, local contact and support through its regular local meetings and activities facilitated by the community worker. Such a model it was thought had the potential to overcome many of the structural problems identified by the study of disablement and social support systems.

The merits of providing local community workers who have considerable autonomy and flexibility in working with local communities, of supporting stronger links between formal and informal care arrangements, and encouraging stronger feedback and control by local service users has been supported in some form overseas (Bayley, 1982; Barnes, 1995; Wilson, 1995) and locally in Australia (Wadsworth, 1991; Kenny, 1994; Spindler, 1994). It was also recognised that to this extent it was not a new model but it was strongly generated from the experience of the Parent Exchange Group, and it included a serious commitment to inclusion and a focus on disabled people and their carers which was less well acknowledged.

The community exchange group concept and the role of the community exchange coordinator had only broadly been defined as outcome
recommendations of the research. If the community development project was funded an essential part of the implementation of this concept would be the task of defining and shaping more specifically the role of the community exchange coordinator. It would also involve ongoing evaluation and development as a model throughout its implementation. Initially it was proposed that these evaluative activities be carried out as an integral part of the involvement with the University and within the collaborative framework defined by the PEG.

The core group had continued to attend meetings regularly with few exceptions, and the Group had grown a little both in those who attended, and those who shared its interests and aspirations but were unable to attend. These latter people were on the mailing list and were kept regularly informed of meeting times and dates, and in particular of evening meetings which were held from time to time in order to facilitate participation of those who had paid day time work, and perhaps in particular, fathers.

The continued involvement of people seemed indicative of the Group's functioning to support people locally and of fulfilling some basic need to share. It was evidence that networking and informal contacts were being made. It strengthened me in the view that an appropriate solution was this kind of focus on building local supports amongst local people with common interests who themselves had some power to define, initiate and evaluate
changes. However, at this point the proposal was considered by government to be most "meritorious", but was not funded.

The changing construction of a community

The idea for the proposal had come from a parent in the Group. She had read of the New South Wales Department of Community Service's call for expressions of interest in the development of new programs to improve links between government, and families where disability was involved. She and others in the Group appreciated the extent to which the PEG was already building links between local carers, and making connections with information systems and other services through its meeting and networking process. It seemed the community exchange group concept could represent the next step to connect with the wider government service system.

Once again I took a significant responsibility for the development of the application and once again the time frame for the application's development was tight. Nevertheless, both individual parents and the Group were widely consulted and the model proposed in the application was that which had already been outlined in the research report. Also this was a report with which the Group was familiar. Whilst sufficient participants of the Group indicated their availability and interest in being part of a management committee process should the government support
the proposal, many were perhaps not surprisingly unavailable and less interested in this aspect of the idea. To some extent this was consistent with my view (discussed earlier), that parents were not inclined to take on any ‘extra’ responsibility, and also that it was difficult to envisage just how much of an ‘extra’ it might be or become.

The response to the proposal however seemed to indicate another aspect of the Group’s development which was more fundamentally important to the way it progressed beyond its establishment period, and the participation in key actions. The Group’s development appeared to reach a high point with the formal launch of the research report. Not only had it guided a research study, it had also participated in the exploration of ideas related to personal experience and the translation of these in helping to establish a system of student placement and its evaluative mechanisms. Further, it had assisted in the formulation of a proposal to government for a community development model of working with families with a disabled member, and the local community. Along the way it met regularly and shared experiences and information within a supportive framework. However some change was evidently underway.

There were interesting signs emerging of individual participants enrolling in TAFE college and university courses, and finding other work. These were interesting and noticeable developments, and I entertained the possibility that the Group experience itself could have been responsible for
encouraging them. Throughout the coming year there was more intermittent participation by individuals who had hitherto been regular participants. The focus of discussions broadened and some meetings turned to discussions of the ideal society and perspectives on human relations and social change. Furthermore, the extension of the Family Support Project to the wider community that was beyond the PEG itself had involved advertising the project locally. This resulted in an extended mailing list, now approximately 30 families, bringing in new participants in the Group. All these events were happening concurrently and there was a changing sense of the Group as community, and a growing sense of less certain ideas and forms. One seemed justified in thinking of this as a second phase of the Group’s life. This was not a second phase in the strict sense of a second cycle in the action research spiral described for example by McTaggart & Kemmis (1982). Nor was it a simple process of consolidation around the processes that had been put in place and the relations of participants which had become familiar and comfortable. It was characterised by a less secure feeling of the Group’s purpose and future. My initial response to this was to endeavour to structure meetings further and to seek more focussed dialogue at meetings, as if to try and maintain a certain rationality for the Group around a level of personal critique and social and political consciousness in relation to the disability issues at hand. I was, ironically it seems, trying to hold or recover something connected with the formal processes of research that I dimly understood were changing.
During the first half of 1995 as described in chapter 1, with the support of the Group I commenced the second round of interviews with 10 carers from the Group, and also of 10 professionals from the local service system. This was a clear focus on all aspects of the experience of caring in relation to disablement, compared with that in the first phase of the research which involved a focus on disability and social support although primarily from the perspective of the carer.

In the first phase I had worked as the principal researcher of a team guided by the PEG, including an academic colleague and a research assistant employed by the Group using a range of data collection methods as I outlined in chapter 1. In the second phase however I worked alone, interviewing carers all of whom had become part of trusted relationships within the context of the Parent Exchange Group. The research method was entirely by interview. These facts and the shift to a focus exclusively on the experience of the carer were to prove a potent mix in the research experience for me.

On many occasions the interviews resulted in the release of strong emotions, and it was not uncommon for the interview to be broken a number of times to allow for this expression of feeling. At no time did this appear to be an entirely painful event for the carer. Rather it seemed a combination of distress in recalling painful and hurtful experiences, and sheer release at telling or off-loading the story. As the researcher I
experienced a mixture of emotions. I was extremely surprised by the intensity of feelings released by what I believed were important and purposeful questions, but not likely to produce this reaction. I was distressed by the obvious pain that was so locked up with the experiences that I was being told about. Finally, and somewhat surprising to myself, I experienced a form of release too in which I felt perhaps for the first time that I could much more fully appreciate the carer as an individual. It was a realisation that I had in fact in some way been much more separate, objective and academic about my involvement throughout the whole process of the Group’s development to that point than I could ever either intend or understand. I completed interviews cheerfully and energetically, but I was thoroughly exhausted by them, and overall found the experience at the same time to be both stimulating and harrowing.

The discussion at this point needs to return to the wider changes taking place in the Group to which I referred earlier. In Foucauldian terms the research process was very much about my gaze as an academic and a researcher on a particular group of people. I believed that the collaborative methodology I had articulated and adopted was appropriate to shifting this gaze in two ways. Firstly, it validated a research stance in which I looked at my own thoughts and actions as much as anyone else’s (a reflexive stance). Secondly, recognised that carers too could become observers, that their gaze could be as much on me and the research process as the other way around. Once again a combination of my own albeit laboured assessment of
experience and writings and the process of sharing and clarification in the supervision process produced a fuller, richer sense of just how easy it is to deceive oneself about ‘real’ identification with the interests of others, even in a process designed to achieve just such a purpose. Concomitantly, it was clear that the powerful impact of the interviews themselves had made me receptive, and permitted the mists of academic or formal rationality to be lifted so that I could see ‘real’ people maybe for the first time, rather than subjects created in the discourse of ‘my own’ research. In reflecting on these experiences and the idea of personal identification I was taken back to the writing of Freire, this time with his allusions to Hegel’s *The Phenomenology of Mind*, 1967. Freire (1972) says:

> Solidarity requires that one enter into the situation of those with whom one is identifying; it is a radical posture. (...)The oppressor shows solidarity with the oppressed only when he stops regarding the oppressed as an abstract category and sees them as persons...(p26).

Such are the paradoxes of research. I felt these ‘realisations’ had shown me that careful design and method could play a useful and important part in the interrogative elements of research, but in an inadequately reflexive paradigm could be the very basis for learning nothing except a sort of formal reaffirmation of things already ‘known.’ It was not a call to do nothing or to abandon method: it is impossible to perform no action since inaction is in effect action. Nevertheless, it was a reminder for me of the need to simply be with those with whom I was, rather than construct them as objects of my research ends through the specification of goals and purposes.
Of course the experience is fundamentally personal, and it may well be the case that any number of other researchers may have captured and sustained a reflexive awareness from the outset. Even as I reflect now in writing I note that I say, "of course the experience is fundamentally personal," but such a concept in terms of research orthodoxy is perhaps monstrous. The idea that the Group in this instance might be seen as a community who met regularly, and celebrated in some measure a sense of human solidarity, and that in spite of all the other perceived research like virtues or meaning of the existence of the Group, this may have been more significant than any other, might also be a research monstrosity.

It must be apparent to any reader that the research processes described here involved a degree of design, system and rigour by the standards of social science. Yet I am compelled to say that as important as this may have been to producing praxis, there needed to exist a combination of factors, perhaps held at a little distance (arms length) by this ‘rigour’, in order to really ‘see’ things differently. I would argue that in this process, in addition to the construction of a range of carefully designed and interlocking methods in existence here, those factors included the Group and the extended involvement and relationship this entailed, the benefit of a critical (I use the word in its positive and constructive sense) external adviser/mentor (in this case my supervisor fulfilled this function), and finally a genuine and vigilant (perhaps conscientious is the best word here) desire to see it from the perspective of the ‘other’.
The PEG operated as a coalition of differences: it consisted of different individuals, different families and different disabilities, but it was also a coalition. The experience of family as the only real promise of community, the division of labour within it, and the alienating experiences of trying to connect with a wider community to find answers to pressing problems, and gain needed assistance were very common. It seemed the PEG offered some hope, the suggestion at least of another way of relating, another view of community, and the possibility of a community or coalition of interests for taking some small actions for improvement. It did this by establishing processes that were in some measure defined and managed by participants, and at an essential level supportive in practical terms through information sharing, and emotional and social support. There have not been any quick fixes or easy solutions to any problem or concern but individuals and the processes of the Group, have in some small measure allowed the gaze of the the constructed and observed to turn, so that carers for a time could themselves be the constructors and observers. Participant carers may have in effect made room for other constructions of caring culture and community. In the process they have begun to construct a different view of themselves individually and collectively. In their own way they have participated in a process of “resistance,” which challenged and transcended the certainty of dominant perspectives, and an uncritical acceptance of their circumstance.
Chapter 4 - Where caring and disability meet

In this chapter I present and discuss fieldnotes and interview transcripts gathered from carers over the period 1992 to 1996. These must be understood of course within the system of relations and ongoing dialogue of the Parent Exchange Group and its activities over this time discussed in chapter 3, and my own participation in the Group. I examine the experience of carers in constructing caring culture out of the experience of isolation which stemmed from their construction as carers, and more specifically in their isolation with disablement. Carers were isolated within marriage and family in a way which disguised the failure of marriage and familist ideology to support caring. It accentuated their oppressive isolation behind the screen of an ideology of caring as a natural and stable phenomenon. However within the context of a paradigm of normality and its powerful norms and expectations, a carers link with disablement posed more significant threats to stability.

In spite of altruistic discourses of steadfast friendship and neighbourhood carers learned early that disablement diminished their power for reciprocal participation as the basis for friendship and establishing neighbourly links. The patterns of disability caring, and the development of a career reflected in part the complex meanderings and convolutions involved in both carrying out caring work, and doing so in a way that optimised the personal
satisfaction and sense of worth that was experienced. This winding path started and finished with family, and in between the carer engaged where possible and to a greater or lesser extent with individuals and groups who held out hope of support and friendship.

My thesis is that there is a very large story about carers of disabled people who are overwhelmingly women. Their story is largely untold because of a public narrative of care concerned with deinstitutionalization and community care. Further, that when one examines discourses of disablement and caring they reveal powerful interests in social order. In disablement this involves the creation of discourses of disorder and fear. This is managed by differentiating and making visible a category (disablement), and by the use of normalising technologies from a range of knowledge interests derived largely from bio-medical discourse. In the case of caring, the carer is created through a highly gendered discourse which naturalises the caring role to women and results in a largely unseen role designed to fill the spaces of a market oriented society focussed on a discourse of production, consumption and the work ethic. These intersecting constructions of disablement and caring result in the complex patterns of control of an increasingly normalised and visible disability ‘threat,’ and the continued control of unseen carers.

The idea of a disability carer’s career derives not just from the sheer depth and extent of involvement with disability but from the idea of a career as a
significant determinant in an individual’s sense of standing for something, as encapsulating the work they do, and as providing a culture of support. This extends to the view that the gendered construction of caring and its embeddedness in familist ideology significantly isolates women as carers generally, but very particularly carers of disabled people. In this context the carer’s career is linked to alleviation of this isolation, with the search for a caring culture where one can be accepted, be supported, share and simply be heard; where one is valued. These are the unspoken and underlying personal benefits that come from any career.

The carers’ story then is told within the conceptual frames of career and the search for caring culture. I am aware of and cautious about the problem of collapsing years of research and data, and the multiple subjectivities of my participants (carers and disabled people) into frameworks which may be novel and interesting in some respects, but which may distort for evermore the diversity of experience that constitutes the lives of those with whom I have been involved. The complex and multiple discourses, often existing within a hegemonic discourse and practice, is one of the very issues on which the research has endeavoured to shed light. It is an issue for any research report, and any account by one of another. It is an observation about the textual distortion of any experience, even those (perhaps more those) framed so assiduously within the uniform conventions of scientific genre.
Where caring and disability meet

Caring is a complex relational phenomena and the role of a woman as mother and carer of a disabled child or adult is understood within this complex dynamic. The women in this study were strongly constituted by the caring work they did, mostly in the family home, mostly unpaid, and mostly supporting people who were in one way or another dependent on their caring work. This powerful personal identification with family and a disabled person was evident in the interviews themselves. Thus, even when the conversation concerned the feelings of the woman herself, it was not uncommon for her response to turn away from herself towards the people for whom she cared and to include their perspective as her primary focus.

The reflexive journey continues

Perhaps the most difficult aspect of this thesis development has been that associated with recognition and articulation of my own position in the research. On the surface of things this might seem a little extraordinary given my own stated case for the reflexive researcher. Yet the discussion of the reflexive researcher itself may simply take place within a formal and academic genre, and its ‘real’ application which increasingly I realise is within its own writing style, may be elided, or more accurately perhaps avoided within the authorless convention of academic writing. The current chapter represents a particularly challenging moment in this struggle with reflexivity. Firstly, in chapter 1 the issues of reflexivity, and the self
conscious location of the researcher and author (myself) were relatively easily addressed as academic concerns of epistemology and genre. I must recall nevertheless, that at the time, chapter 1 was a replacement for the formal declaration of my research methods and procedures, and indeed was a break through for me in the effort to position myself in my work. I was happy with the result but even now I can begin to critique its limitations. Secondly, in chapter 2 I was as it were permitted to move back into the genre of conventional research reporting, especially because the focus of the work was a review and outline of the scope of relevant discourses and literature on the issues. This does not mean that some other textual form would not be just as adequate to the task at hand, but certainly the more conventional framework is understandable given these demands.

In chapter 3 for the first time in the thesis I positioned myself fully in the research and additionally, in contrast to my stance in chapter 1 I reflected on my relations with participants, the Parent Exchange Group. This meant reflecting not only on my position in relation to the conventions of authorship in research (the formal and the academic) but also on my relations with the Group (the informal and dynamic). This brings me to my earlier assertion that “The current chapter represents a particularly challenging moment, (...) with reflexivity.”

In chapter 4 and chapter 5 I examine the texts of interviews and fieldnotes gathered from carers and from professionals from the local service system. I
want to critically analyse these texts, but relatively free of the theorising of the other chapters. Since the overriding concern of the study was the experience of carers of disabled people the chapters hold a central place in the research. The critical demands of reflexivity in relation to my position in the writing and in relation to the Group are extended in the current chapters to include my involvement in the subjective world of carers. This involvement took 3 main forms. We met (and continue to meet), as discussed in chapter 3 each month as a group (for over 5 years) and discussed a wide range of issues, sometimes of a very personal kind. From within this group we have undertaken joint activities such as the research and the Family Support Project. Between meetings there has been intermittent contact by telephone, post and directly of myself and other members of the Group. Finally, most participant carers took part in the two phases of the overall data collection process of the past 5 years.

As explained in chapter 3, during the second phase of the study the interviews were conducted only by myself, and the degree of trust and openness, and the strong feelings released in telling personal stories appeared to validate and express something of the benefits of my extended involvement with participants. The following sequence from one of the interviews illustrates aspects of this, although it also highlights the complexities here. This particular participant was only new to the Group, and this is perhaps the reason the issue of the interview process came up at all.
Mike: So you felt a little unsure today,
Bev: Mmm
Mike: Which is probably understandable I suppose
Bev: I didn't know what to expect today.
Mike: Right, it's a shame, [I] probably should've talked about a little more, should've been something that came through more in the group s, so there was more chance to feel OK about that.
Bev: I don't know the other women seem to be quite, I spoke to Fay about it and she said, "oh don't worry about it, it's OK, don't worry about it, you'll be right" and I sort of thought, oh, OK.
Mike: It's probably, some of these people have been coming to the Group for a few years I suppose (...).

The confidence of other members of the Group had helped Bev to overcome some anxiety about the interview experience. The segment provides an insight too into the communication that existed beyond the Group meeting itself. That Bev could speak to Fay about it, "and she said oh don't worry about it, it's OK," is important. In a small way these communications provide a glimpse of the nature of caring culture the absence of which may be so debilitating in being a carer. This exchange about "anxiety" was quite late in the conversation, and the next exchange perhaps provides a pointer as to the reason it became an issue when it did.

Bev: There's a lot of issues there aren't there? There probably aren't that many times when you'd sort of like been made to think through all of these...
Mike: It's not nice thinking things through? Isn't it...?
Bev: No.
Mike: You've found it hard?
Bev: Yes.
Mike: And hurtful too a bit, reliving sort of some of the pain, is it a painful thing too?
Bev: I don't think hurtful's the word, it's, I don't like living in the past basically. I think you know, things happen, you get over them, you get on with living. You can't look back all the time.
Mike: Right. Yeah, and I suppose that's a protective thing for all of us. When you do that, that's a protective thing, when you look back too much...
Bev: Well why should you continually look back. I mean we make mistakes in this world, we're only human, we make mistakes, you get over your mistakes and you get on with living.
Mike: Well, they're not necessarily mistakes...
Bev: No, sometimes they're good things too...
Mike: Sometimes you might have done things differently I suppose.
Bev: That's right. (...)

It seems Bev has found the experience quite difficult, and her explanation "that I don't like living in the past," may well have been Bev's way of communicating her discomfort at reliving earlier 'buried' experiences.

Nevertheless Bev also showed signs of wanting to share, and of being happy in talking to someone, as she said; "you hardly even know". My own observation that "Well, they're not necessarily mistakes...", and later "Sometimes you might have done things differently I suppose" suggests a somewhat detached even academic view. However, something of my own difficulties of dealing with the demands of the personal account may also have begun to show in the earlier questioning of Bev, "It's not nice thinking things through? Isn't it...?"

Bev: But that's learning isn't it, I mean that's experience, that's part of life, that's part of the learning situation.
Mike: Yeah, that's right. But sometimes it's opportunities to stop and reflect that gives you a chance to take something from the experience that you might not have otherwise taken, you might just have kept going on the same path. I mean it's quite difficult I think, it's asking a lot of someone to come and talk to someone else they hardly know about a lot of really personal issues.

Bev: But then again sometimes it's easier to talk to someone you hardly even know than it would be to talk to someone you do know. (...)

Public discourse personal reality: disablement and a re-search for caring culture
Like the experience of the Group itself of sharing often unspoken thoughts and feelings, and getting a sense of balance about your own stand on difficult issues, the interview process can be seen as very complex and perhaps opening up similar sorts of opportunities. It is clear now that Bev may well have been seeking to gain the same sort of reassurance from the interview process that participants often gained from the Group.

Mike: Yeah, mmm.
Bev: Is it time to go?
Mike: No. No, no.
Bev: It's half past twelve, half past eleven.
Mike: Half past eleven, what time, we started about..?
Bev: Ten o'clock (laughing).
Mike: Wow, we've done well haven't we?
Bev: Have we covered all your..?
Mike: Yeah, sure. It'd be good if you felt you wanted to sort of clarify something or impress something else on me that just gets to you when you go away or something, to give us a ring and just talk about it. I mean you should, that's not a problem.
Bev: You have impressed me because I do feel, I've talked about things which I don't talk about and I don't, I just do automatically. I tend to, I think perhaps I run... life too much after talking to you. (...) Mike: I don't want you to feel that, but if that's how you feel that's fine.
Bev: But if it's looking at yourself, and it's made me look at myself, I sort of think, I'll probably go back and do exactly the same as I've been doing for about ten years but at least maybe I'll be more aware, (...) Mike: Well, it's not the intention of the interview, this collecting this information is for people to go away feeling they have to change or that what they've done, it's not at all, that's not...
Bev: No, but if I get something out of it in the sense that I feel that I'm making a mistake or you know, that...
Mike: You could do something differently?
Bev: Yeah, yeah, I think that's good for me too.
Mike: Yeah, if that's how you feel that's great, but I don't, I suppose what I want to be, I don't have any expectation
Bev: You don't want to tell me that I'm doing something wrong?
Mike: I don't feel it, so I wouldn't tell you, but I don't even feel it, so I just don't have a strong feeling about what's right or wrong in these sort of circumstances.
Bev: I think that's sometimes something that I would like is someone to tell me if they think I'm doing the right thing or the wrong thing, and noone will do that.
Mike: (Laughing) Yeah, that’s interesting.
Bev: Even your friends, even your parents.
Mike: So you’re looking for that, you’re looking for that feedback, that sort of guidance?
Bev: I think so, I think everyone needs that guidance sometimes. I mean it gets to me, I just get fed up with being the whole thing, you know like the support person all the time. I mean I’m only human, I must make bloody mistakes, I mean there’s no way I don’t, but I never know if I’m making the right thing, and I suppose I’ll never know for certain sometimes if my decisions were right or wrong.
Mike: Yeah, well I suppose my sense is that there aren’t right or wrongs because most of the time people just do their best.
Bev: That’s right, and I think that’s all you can do.

I was not able to tell Bev that she was “right” which was it seemed what she was hoping I would say, but I was able to say that I did not think it mattered because I did not know anyway, and people “just did their best.”

However even now as I write, having said that “I did not think it mattered,” I realise with some force just how much it does matter. My suggestion to Bev that “I don’t feel it, so I wouldn’t tell you, but I don’t even feel it, so I just don’t have a strong feeling about what’s right or wrong in these sort of circumstances” may well have been part of the problem, and a strong statement of Bev’s inability to gain the personal support she needed. It was my inability to give it. In the context of the current study these observations are most powerful.

It took my engagement in this writing process to realise the importance of this extract, and the importance of the idea that Bev was actually seeking guidance and feedback; “I would like... someone to tell me if they think I’m doing the right thing or the wrong thing, and noone will do that.” In fact in the data collection, management and analysis process I had become only
generally aware that this idea might be important to my thesis. It was the struggle to communicate in writing a coherent meaning of what I had recognised as a link between the interview experience and one of benefits of the Group that Bev’s plea became more fully part of my consciousness.

Of course the implications of realising it in the writing process are that the structure of this report as a thesis was (is) being altered en route to take account of the newly emerging ideas or the changing value placed on ideas already drifting within the mists of the developing thesis. On reflection I realise that the experience I am currently describing is paralleled by that described in chapter 3. All of the rigour and rationality of research method had been brought to bear on the questions at hand and my involvement with individuals and the Group, but this in itself was not sufficient to produce a different view of relations. My conclusion then was concerned with the need for, “a genuine and vigilant (...) desire to see it from the perspective of the Other.” I identified some necessary combination of factors “perhaps held together by this ‘rigour’ ” that I was beginning to see as important to producing praxis, and knowledge, and “to really ‘see’ things differently.” I am now inclined to extend this list to include the writing process itself.

I am unclear about the extent to which this phenomenon of a connection between writing and reflexive insights is more generally experienced. It is not just a reporting event on an analytical process which has taken place
before and in a different space. It has become an increasingly important reality of my current experience, and the interpretative value of my research. This methodological interlude has highlighted both the power of writing in the interpretative processes of research, and also the way in which the interview experience may simply be seen as an extension of the social reality that is the centre of investigation.

Perhaps the conduct of the interview in the wider operation of the Group as a community, and Bev’s knowledge of my role in this opened up the interview to these complexities, but one suspects that the process always has the potential for this. This ethnographic-like position meant that I was to many participants of the Group, simply one of them. Nevertheless, notwithstanding a changing quality of consciousness and identification with participants I was not one of them, and in very real senses I was separate. I was, and am as I write looking or ‘gazing’ at their world of experience, most of which I am not a part. This means that I am relying on the texts constituted by my own notes and the transcripts of interviews to explore the social relations of power of this particular world of experience. My extended involvement as a participant and observer contributed I believe to the richness and complexity of the picture painted. This was true because of my own imagination of the contexts and nuances of participant’s lives not really captured by any specific set of records, but caught in me, and influencing my telling of the story. Of course it is also true because it may have permitted a relatively higher level of openness in sharing ideas in addition to any
benefit individual participants may have experienced in being able to tell their story, such as may have been indicated by the interview extract with Bev.

In the emerging thesis Bev’s desire for some guidance and feedback, by asking someone to tell her whether she was “doing the right thing or the wrong thing” was most important because it can be interpreted as an expression and effect of the particular form of isolation she, like many other participants experienced in their role as carers. It also highlighted aspects of the way in which the Group served to promote a caring culture which provided reassurance where otherwise it was lacking, and significantly it drew attention to my own position and tension as the researcher, and as a member of the Group. It was clear that for me there was not the same imperatives for support and answers, and this showed in my comment “well I suppose my sense is that there aren’t right or wrongs because most of the time people just do their best”.

Carers constructed by disablement

The earlier phase of the study undertaken within the collaborative framework of the Parent Exchange Group, and described as the first phase, opened up the world of carers of disabled people, and gave some indication of the extent to which disability construction and the construction of caring were thoroughly enmeshed. The extent of involvement and demands of the
caring role were combined with a clearly structured division of labour in these households. The ideology of caring as essentially a woman’s and mother’s task was clearly felt and experienced. The presence of disability in conjunction with the demands of caring also led to significant partnership strains. The following fieldnotes prepared during the first phase of the study raise a range of issues, but for the purposes of the current discussion exemplify and personalise these issues of personal and family relations. These were quite pervasive.

She feels that they had more "rockier" times than the average marriage would have had as a result of the extra demands of the disability. She also feels that if he had pitched in a bit more they may have been able to do more things together. She wanted to play netball but he was not prepared to mind... at the time and she could not ask people at the game to mind him so this avenue was closed to her at the time. [42/jp/5.93]

Her husband knows about the Respite program, but that's really all. He leaves things up to Denise and doesn't want to share. [148/mc/8.93]

Frank airs it as a worry but wouldn't do anything about it (...). Frank has no real knowledge of disability services/issues. [196/dh/6.93]

Talked with mother. Father doesn't have anything to do with the disability. She could rely more on the pre-school teacher and the Day Care mum and her mother to look after James than she could on Graham. This really hurt Sandra. Graham was not always reliable in picking up James on time or having planned days off. Sandra made contact with ...to get some support. She didn't know whether Graham was "working with her or against her". [45/jp/5.93]

These records were typical and suggested the complex personal experiences of carers in relation to caring, disability, gender, family and community, and they provided the impetus for making the discourse and experience of caring the primary focus of the thesis. The lives of those most responsible
for providing care for those given by society the disability label, themselves become emotionally and socially caught in the description and explanations of tragedy and loss, as if this really is the only meaning of disablement. It is not possible to understand adequately the experience of this particular group, and the patterns of disability caring careers without 'seeing' something of their powerful experience at learning of the disability "diagnosis" of their child. The socialisation and development of career took a number of different forms. Sometimes this occurred directly or closely associated with the birthing experience itself, and sometimes it was a progressive realisation in conjunction with visits to a general practitioner or other professionals. The exchanges with Carol, Danielle and Alison which follow highlight powerful aspects of the experience and the way it is bound in with the wider caring role, relations with husband, family and extended family, and personal and societal expectations of how things normally should be.

Carol: (...) they were all expecting him to look like some monster, like something really bad. But he was quite a good looking baby. He looked quite nice. Ahh, my father really took it hard. (...) Mike: (...)You mentioned earlier on that you have a large family and they were supportive and things, though your dad particularly was upset. Can you tell us a bit about how they responded generally as things went on beyond the birth?
Carol: Well, dad was quite good, you know, because as soon as, cos my husband had to take all the members of my family and his family in to actually have a look at the baby because they all had this image, thinking oh god, he's going to look terrible.
Carol learnt of her child’s disability at birth, and an earlier reference to her “dad” seemed important. It seems that the appearance of the child meant dad’s reaction was “quite good” even though the news itself was earlier taken “really...hard”. Everyone it seemed came to this extraordinary family event expecting “something really bad”. A birth in the family was usually the source of great joy and celebration, although clearly in this case the emotion was predominantly relief of some kind. Carol’s own reaction is absorbed in the expectations and reactions of surrounding family even though, as a later exchange reveals, these personal emotions were strongly felt as would be expected. Carol’s personal feelings in the face of the enormous experience seem unimportant, even lost as the family weighs up the extent of ‘loss’ entailed in the birth of the disabled child.

Danielle’s experience of learning of her child’s disability occurred in a progressive way over many months, and she and her husband were much less connected (than Carol) to family throughout this experience. They read a lot and sought the advice of professionals wherever they could. In this, it seems they were like Bev in the earlier account seeking some reassurance and feedback about their own feelings and actions.

Danielle: (...) we spent four or five blissful months thinking there was absolutely nothing wrong with ... . Then it was finding out that there were bits and pieces wrong with him, it was fairly traumatic, it was very tense (...) During this time you know, we were asking a lot of questions, we were both fairly tense, very upset. (...) finding out is like going through a grieving process and once I’d read that I felt a lot better, because I could associate what I was feeling with that exactly, because basically when a child is born you have all these aspirations,
you want them to grow up to a certain extent like you and if you have in inverted commas a normal child that's not an unusual expectation, not a bad one to have, unfortunately when you have a disabled child you have to completely change all those expectations (...) You're forever looking for a (...) point a base line somewhere to go from. We're going through all that again now. (teary) (...

Danielle: Yeah their intellectual learning so I was expecting to a certain extent that things wouldn't be quite right but when they said to me (...) "he has an intellectual age of 7 months". I found that very difficult to deal with. I still do, but I think what I sort of almost successfully managed to do was package it up, tie it in a bow and leave it there until I could talk to someone about it, because that's what you've got to do, it's very frightening.

Danielle's (and husband's) expectations of "a normal child" had been dashed, and this left them with feelings which were "frightening" and comparable to "grieving" in Danielle's terms. The allusion to "finding out that there were bits and pieces wrong with him" seemed to speak of the sense of break up and disorder, and the image contained in her words, "what I sort of almost successfully managed to do was package it up, tie it in a bow," suggested her desire to hold it all together or maintain the order that was so threatened.

Carol: (...) when I decided to have another child, it was to give myself, to prove to myself that I was OK. (...) Right up until... was born I was nervous that everything wasn't going to be alright. (...) Mike: You thought of all the worst possibilities?
Carol: Yeah, well that's right. These things they can't pick up with amnio. So, until I saw the finished product I thought (sigh) oh god, he's alright, thank god for that.
Mike: It sort of suggests that you were carrying some pretty deep feelings about, about ... birth.
Carol: Yeah. When I had (her disabled child) I had to be strong because (husband) didn't cope with it really well because (teary interlude), I'll go and get a tissue.
Mike: Perhaps where we were at was exploring some of those feelings that you obviously, or it appears you would have hidden and really managed...
Carol: I did, I did. I hid a lot of how I was feeling because (husband) didn’t take it well, I think because he had to take the brunt of it because I was in hospital. Like he had to go back to the families and say, “hey, ... has had a boy,” and they’d all go “great,” you know (expression of mock joy, delight). And then he’s sort of broken down and dad’s sort of, oh quick, get him a drink, get him a drink. They were very supportive of him but it was very hard on him, he took it really, really hard. So I think that made me stronger, you know, I didn’t want to show, I thought well, I’ve got to be tough. So I did that.

As evidenced in the previous extract, Carol has to absorb the whole drama of disablement, and it seems she pays the price of maintaining the order demanded by society’s view of normality. The price is her inability and non permission for expression of her own feelings at the time, and from that point onwards in being entirely responsible for the maintenance of order to preserve normality. In the birth experience this sense of fear and disorder were all around her, and Carol conscientiously and at great pain fulfilled the expectations of her. In the interview situation no such demand was made of Carol, and she had ‘permission’ and sufficient trust and confidence in the relationship to say what and how she felt. The experience as I have previously discussed in chapter 3 was very emotional.

The emotional impact of the birth of a disabled child was deeply felt and carried by Carol throughout her second pregnancy. It was a personal test “to prove to myself that I was OK.” The exchange reveals something of Carol’s own strong feelings concerning the birth of her disabled child although it was expressed most directly through a very tearful outpouring. She
explained her need to “cope” and “to be tough” in terms of her husband’s reactions, and once again the wider family to whom he had to report. There is a hint here of the extent of her own understandable distress when Carol refers to her husband, “it was very hard on him, he took it really, really hard.”

Alison’s experience of the birth of her first and only child was most dramatic as the following extract shows. Whilst the account of the experience itself provides ample basis for an appreciation of the trauma she experienced, her observation about her own carefree approach to life, which came later in the interview may have contributed something to her sense of “shock”.

Alison: (...) she had this terrible abnormality, she had this big growth out the back of her head, and a really strange shaped skull because of it, yeah, she just looked awful. I think at that point I must have gone into, I don’t know, some kind of shock I think, cos I don’t remember too much. Yeah, what, well. (...)

Alison: On the Tuesday I came home, I went home and I just sort of blotted it out so I didn’t see her. (...) And of course I wasn’t breast feeding her or anything, I didn’t even get any milk, none. I don’t even remember having enlarged breasts or anything. So they just said that what their tactics are, were that they’d give you a bottle and they’d get you to feed. So I started doing that and she, then it was, she was mine then (crying )and then the hard work started (laugh).I’m going to make a coffee, alright?

Once again the extraordinary experience of the birth of a disabled child produced reactions which expressed something of the deeply felt shock. Yet there is no evidence in any of these experiences of a sensitive or considered support for the person most centrally involved in the experience. Alison
was in shock, and "just sort of blotted it out so I didn't see her." The clinical response described by Alison as "their tactics ... were that they'd give you a bottle and they'd get you to feed. So I started doing that and she, then it was, she was mine," again seemed to depict the isolation of the mother's experience. This surely constructed and symbolised a symbiotic quality in the mother-child connection but it was powerfully constructed to the exclusion of everyone else. It tied mother and disabled child together, and from that moment onwards that is how it would be. The construction of disablement carried with it powerfully destabilising images as these accounts so vividly show. The construction of woman and her bondage to caring and the powerfully stabilising force this represented, appeared to provide the 'perfect' answer.

Even in the face of such great disruption to the paradigm (the ideal), once mother and disabled child were yoked there was the strong suggestion that nothing else needed to happen. As the thesis argues, in a very real sense nothing did happen unless there was an exceptional communal response or the carer made it happen through her own caring career efforts to find or piece together some expression of caring around her.

It was clear to me that the interview experience itself was one of the first complete opportunities that participants had for sharing honestly something of their own deep feelings about experiences that were in most cases years past. These were the revelations described in chapter 4 that had
so altered my consciousness and sense of identification with participants. Of course in reality these events were long past, but the experiences of disablement itself were a day to day reality for participants.

There was a profound reality and a symbolism of silence, non acknowledgment and of isolation contained in these early experiences which came to mark the lives of carers. The isolation was first and foremost that of the guilt and stigma and shame of bringing into the world someone that at the very least failed to meet the expectations of family and society, and at worst threatened to be or appeared to be a monster. The reactions and the tenor of the whole experience spoke of the deeply held expectations, and the way in which this was thoroughly disturbed by the birth of someone who did not appear ‘normal.’ Such expectations were simply held and known without any explicit acknowledgment, and when they were breached or broken by a ‘defective’ birth they were not easily understood or talked about or shared. These were very shocking experiences that could be clinically diagnosable and clinically described, but mostly not personally communicated and shared even with those family who were closest. Not only was this in itself a profoundly isolating experience for each woman in the construction of each woman as carer, it was buried beneath the reality of responsibility. It was revealed in the mother’s actions to support others in coping and maintaining a sense of the whole (family), the normal and the un-severed.
There were other discourses and patterns of experience in a child becoming disabled. These occurred later, and often became apparent when the child’s behaviour could be compared either incidentally or formally to developmental norms. These were also essentially isolating experiences for the carer although it appeared that they were less emotionally intense than the experiences that I have been discussing to this point. Dianne’s is one such experience.

Dianne: (...but then when she was probably around 2 1/2 to 3 (years) you started realising that she, well to me she developed normally till about probably two and a half, you just started to notice that she was very slow and forgetting things that she had already known like sitting down playing, she could pick that up quite easily, but the next time you went to sit down with her you had to reteach her to do it. So I think that’s when, I think that’s when also a pretty rough time I mean I was trying to get answers for “why” and nobody would say anything. So it’s trying to get the information out.
Mike: Right, who did you go to.
Dianne: Well (sigh) doctors.
Mike: Your family doctor initially.
Dianne: Yeah, and we went to neurologists, paediatrician, and you know all those sort of people because of the ...

The experience does not have the emotional intensity of the earlier accounts. It involves Dianne as carer closely engaged with and observing the progress of her child, but where a personal and communal culture of support was not evident. Dianne goes in search of information to a professional setting in order to gain some release from her isolation. The reference to “nobody would say anything” highlights more than a simple lack of accurate information.
Mike: That's right. So when did you learn about (...) Bev: I was absolutely devastated. (...) this specialist at ... Hospital, and there was no bones about it, he just sort of examined her and he said you know this child's retarded. (...) I mean she was 18 months and still not walking, she wasn't really sitting up properly. I put it down, I always put it down to the fact that she'd been so sick all the time and this is what'd put her behind. So maybe I wasn't, I was not wanting to see what was staring me in the face, I don't know, but um... Mike: So what was the response of others then? You were devastated, how were ...? Bev: Oh, I was a wreck for about a week. I went home and balled my eyes out for a few days. My best friend left me (sigh), she wouldn't have anything to do; she just sort of, I've never seen her since. My husband never accepted it for a long, long time. (...) as I've said it's absolutely devastating because I was also, she was physically handicapped as well. So it's some, you can't even explain it, it's just something you can't... Mike: Put into words easily... Bev: That's right, yeah.

Bev sees herself as responsible, and her "devastation" was not relieved by any particular support, although in a later exchange she does indicate that her own mother and father were understanding and supportive. Her husband, and her best friend may simply have added to the sense of "devastation" rather than relieved it. In part her feelings were due to the guilt and shame of not knowing, when the doctor carried out an examination and could say, "and there was no bones about it" that her child was "retarded". That she should say, "you can't even explain it" may not only reflect something of the extent of her feelings, but something of the lack of opportunity for sharing them.

In some cases there was the appearance that the emergence of a disability label for a family member grew out of the isolation and unsupported nature of caring. The caring experience may well have been isolated anyway, but in
particular cases this could be greatly accentuated. Such a case may have been that of Jane a single mother of 3 children. At the time of the interview she had recently separated from her husband who was in prison for abuse of one of her children. The experience was obviously traumatic and had gone on over some years. In addition her children were not strong academically and in particular all seemed to have language difficulties. In all other respects two of her children were described as developing without problems. Her third child however not only had language difficulties but his behaviour was sometimes uncontrollable.

Jane: I would say the first time I noticed anything from ... was when he was about 10 months old and I had him sitting on the floor in my family room and he was screaming and shaking at the time and it didn’t matter what I did I couldn’t pacify him and I went to the doctor and he said to me, “oh he’s just a highly strung child you know he’ll be OK don’t worry about it, get on with it.” I knew that something was different. And then I suppose after that as he got older he did things that I didn’t think were the norm and you’d sort of go and say to a doctor, “well what do you think?” and they’d say, “oh no no,” you know he’d mumble something about just being “overprotective” and “there’s nothing wrong with this child.” Because I’d had two really placid children and this child was really full on and when he was about, I don’t know 3 (years) I suppose he started pre-school and they just said, “Look this kid has got lots of problems I think you should go and see a paediatrician. “(...).

It is interesting that Jane went to the doctor for guidance, and not only was told to “don’t worry about it, get on with it,” but there was a suggestion that the source of the problem was Jane herself, and she was offered no specific help or support. The doctor was a preferred, or perhaps the only person to approach in a time of need, even when this was not specifically a medical concern. In cases like this when disability was not a birthing experience it
was not uncommon for entry to school to be part of the disability defining process, and this was evident here.

Jane: So I was basically running all over the place having all these different things happening with him and pre-school was really terrific and he was having a bit of help there and we sort of took it from there but things just kept getting worse up until the present day where just as he gets older I'm finding it a lot harder to control him because he's very strong and I think that comes from being other areas lacking. It puts more strength, I don't know whether that's true but to me I think they pick up on another area because something else is lacking. (…) Mike: So how old is …? Jane: … just turned 8 he's 8 and a month. (…) But as he got older more things started showing and I think I just sort of knew that there had to be some help. By the time he got into pre-school the help all just started happening.

The contact with school brought some satisfaction, in this case especially because of the disruptive behavioural focus of Jane's child, and the school's own need for support. In a course of action which was repeated many times over in the accounts of participants, Jane as an isolated carer of three children "was basically running all over the place" to bring together the supports she needed. In the end Jane did not just gain a single diagnosis of disability to her satisfaction, but three. After considerable difficulties in gaining the validation for her feelings concerning her son, with some varied resistance and acquiescence from medical and educational staff, assessments were given and labels ascribed.

Jane: (…) So she brought the Autistic Association in and they actually watched him in the classroom and did some assessments like did an assessment with me and basically told me that they felt that he was at the other end of the scale the autistic scale which meant he had autistic tendencies but really wasn't autistic. So that sort of explained some of the odd things that he was doing. So I had that. So I had the
intellectual disability, I had that. And then they actually said, to me "we feel (...) he comes in to ADHD." And then I had the answer I knew all this not being able to sit still and fidgeting and I knew that that was it so I knew that that book I had from Dr Serpentine all that time ago was actually I was on the right track. I think I was getting fed up with waiting for people to tell me what it was I wanted to find out for myself so I knew how to deal with it. So I now know that he is intellectually disabled. I know he has autistic tendencies and I know that he has ADHD mildly but he has it. So I felt with the paediatrician I was seeing that his attitude was ‘well I don’t believe in that. Too many people think that’s what the problem is.’ I gave him a miss (...) "

Jane wanted specific answers to the difficulties she experienced with her son, and the mere suggestion of a label (even the label or diagnosis that wasn’t), was claimed and held securely, “So I had that. So I had the intellectual disability, I had that.”

Jane’s experience here is both unusual and typical when compared with other participants in the research and the Group. Her personal circumstances as wife (before separation), mother and carer had tended to cut her off from family and supports. She felt particularly unsupported as the victim (along with her children, and daughter in particular) of sexual abuse and violence. To her it seemed that her ex husband as the person responsible for the violence, whilst certainly punished by imprisonment, was in many ways supported by the state. Jane’s pursuit of assistance was focussed on her son’s behaviour, and her doctor’s response not only failed to provide some validation for her claim to her son’s disablement, his response turned the problem around, in suggesting Jane herself was the problem. Jane could get no support from the state as the victim of considerable violence and trauma. From the state’s perspective it was as if a
family life would just go on unchanged. As mother and carer she would make the necessary adjustments, if indeed there were any to be made. The doctor’s training and experience did not embrace definitions of this child’s behaviour as disabled, and it did not it seems include the ability to interpret Jane’s own behaviour as the need for some validation for herself and her role as mother and carer.

The particular issue of whether Jane’s son should be ‘certified’ as disabled or not has been a controversial one in the context of a proliferation of categories and normalising treatment systems. It may well be that the medical versus social constructionist discourses at the core of this controversy need to take account in a more holistic way of the broader and complex social contexts within which the lives of the key players, particularly carers, are lived out. It highlighted at the very least the way in which the state service system redefined human support as concerns of individual and clinical treatment, rather than respond to Jane’s genuine experience of isolation and lack of support in sharing. It shows also how in the absence of a relevant human response Jane participates in this alien process. These are matters taken up further in chapter 5.

Overall it is obviously difficult to quantify or understand exactly how these early experiences qualitatively impacted on the lives of carers, however they were clearly acutely felt, and I believe it is difficult to overstate there significance in changing the lives of carers involved. If carers come to accept
and believe disability is a personal tragedy and a loss of human wholeness, it may be because the complex and powerful implications for their personal lives equates to loss of ‘self’, or the possibility or hope of experiencing a personal reality, beyond society’s construction of self. Society’s construction of self is predominantly tied to the caring role and family, and the ideology of womanhood. The daily experience of carers show how a carer’s life becomes bound up and lived through the experience and social explanation of disablement. These narratives show the great difficulty of extricating the lives of individual carers of disabled people from the complex personal and social world of disablement. Carer’s lives were enmeshed in that of disability and the range of meanings and experiences this entailed.

The isolation of disability caring within the family

Whatever the ideal of the family, its effects are often to further isolate and privatise the support role around one person (usually a woman) as carer. Support for the ideal of family may be support for the need of human connectedness, caring culture or community. Clearly the family as a consumption unit, constructed from a capitalistic discourse, and a form of shelter and material expression of patriarchal discourse, provides for some better than others (Mitchell, 1971; Dalley, 1988; Barrett & McIntosh, 1991; Bryson, 1992; Wearing, 1996). Whilst the ideology of family appears to provide a basis for viewing it as a place for nurturing the human spirit and fulfilling basic human support needs, as earlier literature identified, and the
current research highlights, the experience for many including many of the participant carers in this research was less personally affirming. Family was an isolating site for the performance of caring work, and caring culture was often absent.

The ideology of family is part of a complex intertextuality which includes the marriage relationship, and perhaps the quintessential ideal of a fulfilling partnership. The anticipation of emotional fulfilment and the promise of regular sharing in the direct physical tasks and emotional demands of day to day life are never far away. Yet the realities of which carers spoke were very different, and the picture complicated in a number of ways. In some cases they spoke as individuals who wanted and still had hope of realising these ideals of family in spite of their experience, and in others there was a great deal of cynicism. The object of this cynicism was primarily men and their apparent inability to take responsibility as husbands and fathers, and in varying ways the wider community, sometimes expressed as bureaucracy or some particular agent of the state.

Sandra: You sort of feel the assumption that husband should help and therefore you don’t like using other people. He’s able, there’s nothing wrong with him, it hurt to think he doesn’t do ordinary things what I take it as ordinary family things. (...) Can’t do this, can’t do that.

The “assumption” of course is a reference to the very partnership ideals of sharing in doing “ordinary” things. The idea of “using other people” alludes to the more pragmatic nature of relationships with others and
perhaps to the expectation of the more altruistic meaning of her partnership with husband.

Carol: (...) so I had my three kids there, (...) but (disabled child) wouldn’t go in there so he sort of sat outside the door while we were having the meeting, from 7 o’clock to half past nine. I don’t want to take my kids out, they should be home in bed. At half past nine I left. I thought oh well, I thought this would happen again, finding someone to look after the kids, so I thought, well, I’m not going to do it. I thought, well I don’t really want to go to this meeting when there’s no one here to look after my kids. Whereas, (husband) wouldn’t say well, I’m not going to go to the meeting, I’ll stay home. He’s got to go cos it’s a football meeting, so he’s got to go to that. It’s always back on us, on me, you know.

For Carol going to the meeting was more than simply making a contribution to the local community centre. It was a chance to make contact with her peers, to experience another aspect of herself beyond caring for her family, and Carol felt some degree of hurt at her husband’s failure to see this and be responsive here.

Mike: But primarily you’re taking responsibility and that’s how.... Fay: Yeah, oh yeah (...). But the actual, everyday rearing of the child, (...) He doesn’t see that as his role in life. His role is to come home and play with them for a few minutes and then he goes off to bed and the children should sit down and be quiet while he watches whatever he watches on TV (laughing) (...) he doesn’t take any active part in the working of it. (...)this is why I still say, yeah, despise him for it, yeah let’s say despise, is the fact that he’s never understood that sometimes I’d like to get out, go shopping without the children. But that’s part of him, nothing to do with the disability, and again it was a case of, if I was going anywhere, like I could go as long as I took the three kids with me. But if he was going anywhere he never took any kid with him, and that part I’ve never been able to accept, or will accept either. (...)

Mike: So is there any sense of that changing?

Fay: Oh. Well there is, when I leave him, when it’s easy enough to leave I will, that’s personal. And it will come, reason to believe it will happen.

Mike: So it’s not changing because he’s changing but is it changing because (disabled child) growing up.
Fay: Because I've changed. ... grown up and I won't tolerate any more, any stupid nonsense anymore.

Fay was bitter about her husband's inability (she said, "his disability") to accept responsibility for the children, regardless of the disability of one of them, so that she could simply have time to herself. In this case the time to herself still entailed the accomplishment of a necessary family task, and her husband "if he was going anywhere he never took any kid with him".

Alison: (...)Anything that I did, even now, he's had nothing to do with where she goes to school or in any way investigated anywhere that she might be able to go to school or offered that if a private school could do better for her he'd pay, or anything. But he would just come out with the question, "Is that school doing anything for her?" or "couldn't she get more?" Like it's just, yeah, like leave it all up to me, but just make the occasional comment that you just go, god, you know! Yeah, and it's, it hurts to not get that acknowledgment.

Mike: Yeah, sure. And over a long period of time too.

Alison: Mmm.

Where there was communication about the caring process as demonstrated here, it could have a remote outsider feeling about it, and said something of the distinction highlighted earlier in the literature, between "caring about" and "caring for". Alison's extensive involvement with her disabled daughter's schooling arrangements, is not only not recognised, but called into question.

Husbands sometimes seemed to become more involved as their children got older, especially when this resulted in a satisfying participation for the husband. In other cases where this occurred it simply seemed to reflect
something of a mix between necessity or last resort when his wife was
conspicuously run down by the caring work, and a genuine learning of the
benefits of sharing.

Mike: You’re the one who coped.
Carol: Well, I suppose now, because ..., he handles it, well it took ‘til ...
was probably about 2 or 3 I think, until they sort of had a relationship,
and then I was allowed to sort of let go. But then as the kids are getting
older he’s sort of taking over more (...) 

There is a suggestion here of a broader issue of control in Carol’s references
to being “allowed to sort of let go” and “he’s sort of taking over more”.

Sandra: Since (disabled son) has joined sports, (husband) has got that
different outlook on ... and his disability, because he realises that he can
do things, he always wanted his son to play football, so that was the
thing ... had to handle with his disability, hard on him I know but since
he’s been doing the track (wheelchair) work (husband) has been out on
the bike with him. At birth it was me getting ... into things (...)

Dianne: Yeah, well it’s mostly mine because he’s not there a lot but I
think he can get by when I leave, like Monday nights at tech. He didn’t
start off being really good but he is now.
Mike: So what’s changed?
Dianne: I think probably necessity (laugh).
Mike: What’s that, you’ve sort of demanded it going to tech and things
like
Dianne: Yeah. I think, I guess that over time that you knew that it was
a lot harder doing it and so I’d say well, I know you’ve been to work
and you’ve had a hard day or whatever but we’ve also got to do this, if
you’ll help me do this then we’ll (work) it out sort of thing. He
was the last one out of five kids, he was terrible when we first got
married, he never knew what housework was (laugh) because he was
like the baby of the family. He’s really good now.
Mike: You’ve trained him?
Dianne: (laugh) I don’t know that I’ve trained him but, yeah, I think
sometimes there were a lot of things where he just had to step in there.
There were probably a lot of things there where I was just so fatigued
and needed the time away.
In amongst all of this were the exceptional fragments of positive feedback and affirmation, that kept the spirit alive and provided some basis for continuing to believe in some notion of caring culture. In behavioural terms carers often seemed to exist on a surprisingly thin schedule of reinforcement or positive feedback, and the occasional rewards seemed scarcely adequate to counter the aversive nature of so much of the day to day experience of supporting others. So much of each participant's life was taken up with caring for others that any positive affirmation was likely to come her way really had to come from those for whom she cared most directly, her family and most specifically her husband. Despite this significant sharing need, and the ideal of the marriage partnership, it was uncommon that a quality of sharing was achieved about which carers could report great satisfaction. It was not uncommon for example that when husbands did reflect on their wives caring work, it was more by way of suggesting how it should be done differently. In other cases wives learnt to hide their feelings simply to maintain the peace with husbands who did not want to confront the emotional demands of their wife's isolation and caring work.

Mike: It's not so much being in a house on your own for long periods of time that you find the isolation, it's actually..
Alison: Oh, yeah, I'm quite happy by myself.
Mike: It's the sharing and that sharing can be the sharing of the responsibilities, but the sharing of what it means to do those things too?
Alison: Yeah, and sometimes you get a comment that, just like, ... would tell you that he feels I'm... I spoil (disabled daughter), he's trying to, I can't think of a particular situation but he would say that, "that's the world, that's how it is." I would get cross with his reaction to her sometimes and he would say that you, "you work it all around so that it doesn't affect (disabled daughter), instead of just confronting her and
giving her the education of learning that not everybody's going to be like you." Understand?
Mike: Sure.
Alison: But instead, I can see what he's doing, but it still makes me feel isolated in that that's how I believe that a parent should be, like I sort of say to him, "well OK the rest of the world might be tough toward her but at home she's got the, she gets the strength to cope with that out there," (...) but every now and then she'll go and put her arms around him and give him a hug and I think wow, that's great because it's making her, she is growing up and she is more streetwise (...) But I'd get upset because he was being tough on her. But I'm sort of learning that that's not too bad and maybe I'm changing a little bit like that too. Maybe that's why I can go to ... next weekend.

This exchange with Alison highlights the critical idea that she did not really feel dissatisfied with her work as a carer as such or even the fact that she worked on her own. Her real frustration and hurt was at the lack of positive affirmation for her work. Alison's capacity for seeing the best in her husband's suggestions, and their potential value to her daughter's development in spite of the failure to validate her own work, is evident in her remark,"I'm sort of learning that that's not too bad and maybe I'm changing a little bit like that too."

Carol: (...) There are kids in there with bandages on their head, stitches in their head, and he couldn't cope with it. So he would go for the first couple of visits and then he wouldn't come because he didn't feel comfortable. Then because he didn't feel comfortable I'd sit there and think, being really worried and thinking about how he was feeling. So in the end I said, well, I'll go on my own, I feel more comfortable going on my own. So I did.(teary)
Mike: That perhaps hurts a bit now when you think back on it?
Carol: Mmm.
Mike: So there's a lot of people who were sort of are good in different sort of ways but in fact, it doesn't appear as if these are really feelings that you could share at any point, you just carried them and coped.
Carol: Yeah, that's right, you do. But I think it's, it's not just because it's a disabled child. You find that with even with the other children you do a lot more with them because you've got the mother role, because you're the parent that's home with the children. Like, I'd quite
often say to ..., he'll come home and something won't be right, you know. I'll say, "there's lots of things that I don't tell you because I know you can't cope with them." I suppose some people cope with it better than others. He obviously didn't. (silence, teary)

The failure of the sharing process is poignantly captured in Carol's words, "So in the end I said, well, I'll go on my own, I feel more comfortable going on my own. So I did." This period of the interview was very tearful and distressing, and the power of Carol's feelings about the failure of sharing in this critical aspect of care was most evident. That her husband could come home and "something won't be right" is a further reference to the invalidating quality of the communications with husbands in a context where the isolating nature of the work made the need for a positively reinforcing interest more important. That she could tell her husband, "there's lots of things that I don't tell you because I know you can't cope with them" is perhaps a clear statement of the fragility of this partnership as a basis for emotional support in these things, and perhaps the basis for looking beyond the relationship for a stronger support of oneself and one's work.

Unstable relations, the family and beyond

The construction of woman as carer, and her responsibility for and inseparability from the experience of disability meant that in a significant way a carer's experience was determined by the immediate reactions of others to the presence of disability. Her relationship with disablement
brought about a degree of instability into every element of her life, and revealed the fragility of relations and connections which were meant to be stable and reliable. This was clearly apparent in the accounts of the early experiences of the mother and the expectations and reactions of family at the birth and ‘diagnosis’ of a child with a disability. Although less common, in particular cases and at particular times existing relationships appeared to be strengthened and understandings enhanced by the extraordinary nature of the disability connection. It was noticeable for example as these fieldnotes show that the carer’s mother could present as a confidante and friend, perhaps more reliably and intimately, than most other supports.

Denise talks to her mother though about the Group and also about the respite, and because her mum is interested, this satisfies her need to share these experiences with someone. [148/mc/8.93]

Connie saw Alex as having a very strong family network mainly revolving around mother, father, brother and grandmother. grandmother lives 1 km away. Grandmother (carers mother) very important. [3/mc/6.93]

(...) Ingrid’s mum sent lots of information on ... Syndrome. Ingrid’s mother lived in the country; she did visit and kept in touch - supportive from the distance. [15/dh/5.93]

Sandra’s mother used to come down...to be with Sandra and James at the clinics. It became a day out with Mum. [25/jp/5.93]

Her greatest support was and has been her mother. She feels guilty that she had to use the day care mum instead of relying on her husband, and recently she has not wanted to rely on her mother too much as her mother has a heart condition and is not well herself. [8/jp/5.93]

Nevertheless the experience for most was that of loss, being cut-off and of persistent uncertainty about the meaning of the experience in the present and insecurity and anxiety about its implications for the future. The
following interview fieldnotes introduce a range of the experiences which tend to further foster a sense of isolation, and influence the way a carer’s career moved in search of caring culture or some expression of community back to family, as perhaps ‘the line of least resistance’. These fieldnotes were from the first phase of the study in which the focus was on the social support systems of disabled people as seen primarily from the perspective of carers. This was important because the basis for some construction of community or neighbourhood for many families was the informal interactions of children and parents associated with the activities of children at local schools and social and sporting activities locally.

She had one experience at the local toy library, which showed how other children’s parents, ... can restrict opportunities for interaction between disabled and non-disabled pre-schoolers and also "punish" the parents of disabled children. [56/mc/7.93]

Tony often has friends over to play at his house because his mother encourages them, but Tony rarely gets invited to other peoples’ houses. This saddens mother. [107/jp/6.93]

In some cases because parents have "stopped" their children coming over to play. Other times it’s just the children themselves who choose not to come over and play. [65/mc/7.93]

Social attitudes of others also affect desire to venture out. Attitudes to Ian seem to be changing as he gets older - less cute. More difficult to accept disability. Tracey is really quite uncertain about the future. [50/mc/7.93]

Andrea and Ken have less to do with these parents and feel sure their social contacts and acquaintances are determined by Reg’s behaviour and peoples’ response to it. [16/mc/6.93]

One carer referred to this type of experience as to “punish” the parent for the presence of disability, which was certainly a powerful expression of the consciousness of some carers of their link with disablement. Fay in the next
extract touched on a sort of double think reaction from others to disability and its connection with caring.

Fay: *You get sympathy in a lot of cases, but you, because you’re coping, or you’re seen to be coping, and by the same token some people will always say, ‘oh I wonder if it’s catching,’ No matter what you say Down syndrome’s not catching but hey, ‘I won’t let my child play’.*

Here the use of the word “sympathy” suggests commiseration and pity, words and images very commonly associated with characterisations of disablement, and “coping” implies something of the hardship for which the “sympathy” is due. In fact Fay also says,”or you’re seen to be coping”, drawing attention to the discrepancy between the expectations in terms of the caring paradigm and the reality of caring which is unseen. The more explicit rejection however came in another parent not letting their child come to play because of the disability.

"Talking shop" and other no-nos

For most families the manifestations of connections with a local community are multiple and diverse and these fieldnotes simply provide a glimpse of the complex ways this was expressed in the interactions of children and adults from the interior site of home to the formal and informal exterior of school, library, shops and the spaces between. The sense of punishment and of being split-off however often came from much closer quarters than the general reactions of community.
Mike: So is there anyone, I was thinking about the personal, emotional support?
Dianne: It’s really just (husband). He’d be the only person really. I mean I do have a lot of friends but I really don’t think they really understand and I don’t even try to. (husband) calls it talking shop (laugh), if I talk about (disabled daughter) it’s like, maybe too serious a subject that people don’t like, you know they don’t really want to get all that involved, so it’s more casual comments that you make with your friends.
Mike: So you have a sense that it might actually spoil the friendships if it became an issue?
Dianne: Yes, it did, it did spoil one of them and I think I learnt from that the off-loading I do has to really be on (husband), (...) There’s a lady (...) I run off my ideas across her, and she will say to me, “oh well, we’ve done that” and blah, blah, blah, so you’ll just get a bit of feedback off her. So I find her really probably my most helpful person (laugh). Just another mum with a similar child.

The isolation described by Dianne was not that associated with having no friends at all. It was that pressure to only declare what was safe, and disability in spite of its personal significance in Dianne’s life, “it’s like, maybe too serious a subject” was not one of those areas. It seems even her husband wanted to declare disability off limits, referring to conversations about disability (their disabled daughter) as “talking shop”. This reference of course is highly symbolic and important in my representation of caring for a disabled family member as a career. As a colloquial expression “talking shop” is perhaps most commonly used as a reference to talking about work matters, often in the presence of someone who is not part of the work setting about which their is talk. In this sense it is a reference to their exclusion. In this case it was not appropriate for Dianne to be talking about her work, her caring career activities, and paradoxically this was part of defining her isolation, if not her exclusion. Furthermore, it was something
of which Dianne was clearly aware and had already experienced, and from which she had "learnt".

In the end Dianne's ability to share was preserved in two ways. One form of sharing was with her husband. The second form involved another mother with a child whose support needs were similar, "So I find her really probably my most helpful person (laugh). Just another mum with a similar child." Dianne's laugh spoke perhaps of her own incredulity even as she spoke and could hear herself, that "just another mum" could be "my most helpful person." This positively affirming contact contrasted somewhat with her earlier point that she had learnt, "that the off-loading I do has to really be on (husband)". This may well have expressed something of her husband's reluctance about "talking shop".

Dianne's friend who was "just another mum", could be supportive and accepting of Dianne's circumstance, because she had "a similar child". The friendship provided helpful "feedback" that was not evidently gained very comfortably through other means. It suggested something of the terms on which friendship and caring culture could be negotiated or orchestrated, and clearly disability in a child was significantly disabling for a carer in making and maintaining friendships. If friends could go so dramatically, then how much more difficult was it to construct a new friendship and a network of close support. The loss of friendship was common.
Bev: Oh, I was a wreck for about a week. I went home and balled my eyes out for a few days. My best friend left me (sigh), she wouldn't have anything to do, she just sort of, I've never seen her since (...) 

Helen: Well, my best friend, and we were really close we found out about ...when she was 18 months old and I told her, I've never seen her again.

Ingrid: That's what I'm saying, you get sympathy but you don't get support, you don't get help. I had a really good friend before I had (disabled son). We went everywhere. Since I had ... and (he) got to be difficult, I never saw her again either. So I mean to me that wasn't a friend, you know, because now I'm not able to do all the things I used to do, doesn't mean I don't want to do them. It just means I can no longer do them. Well I found that very hurtful.

A friendship lost in this way was undoubtedly “very hurtful” as Ingrid says, but it could as would be expected, set up an orientation and a psychology of uncertainty. It fuelled any preexisting fears of the community’s negativity towards disablement, and a carer’s anticipation of this in all their social participation. It was of course explicative of Dianne’s thinking when she indicated that she no longer tried to have her friends understand her predicament, and postulated that it was probably “maybe too serious a subject that people don’t like, you know they don’t really want to get all that involved,” and as a result she simply settled for friendships in which it was “more casual comments that you make with your friends.”

The experience of Danielle did not directly result in loss of friends, nevertheless she reported on feelings about the likely impact of disablement on relationships, and reflected on the way this alters her own social orientation.
Danielle: Friends, you don’t feel like, it’s a heavy burden, I don’t feel like, wouldn’t like to unload it. Family you always feel you can unload things on like if you have a death in the family your family is there for you, they’ll hold your hand, they’ll give you a hug, they’ll come and visit you, and when someone’s very very ill, you know, it’s the same sort of reaction. I think if they were slightly in denial, they weren’t there to give the help, to squeeze your hand, to give you a hug, the distance really didn’t help, yeah, they weren’t there.
Mike: But friends when you feel it’s a burden, it’s the emotional power of it?
Danielle: Yeah, cos it’s a pretty overwhelming for you and friends, you sort of, you’ve got to give them the information and then let them digest it and deal with it and then come back to you and if they don’t well then, they don’t. You can’t, I mean that’s just the way I feel.
Mike: It’s not anything that they’ve done particularly it’s your sense about how they would
Danielle: Cope
Mike: Is there something of, I mean is there something, is there a fear that you might lose them or that they might actually become more distant because you saddled them with that burden?
Danielle: Oh, definitely, definitely. I mean my closest friend who’s been going through some emotional hassles of her own, therefore if she hadn’t been going through the same emotional hassles, I probably would have dumped this one on her and said Di I need to come and visit you. (...) I’ve other friends that have been there all the time, but yeah there is a fear that they’ll just turn tail and flee and I think you feel so alone as it is. It’s a very isolating experience.

Danielle has not had a loss of friendship due to the burden of her experiences, but her aloneness was in not feeling able to share such a “heavy burden”. It extends as a threat and “a fear” on all future relationships, and she says, “you feel so alone as it is. It’s a very isolating experience.” The emotional power of the experience of disability is evident in Danielle’s words, and the experience is compared to that of a death of a family member. There are two aspects of the inability to share this experience. Firstly, family was usually an appropriate place on which to “unload” such experiences, “Family you always feel you can unload things on”, although
on this occasion they were some distance away and Danielle suggests that they may have been in “denial”, and therefore not available. Sharing in this case seemed to refer to the ability to say everything but also the intimacy, “family is there for you, they’ll hold your hand, they’ll give you a hug”. The second aspect of sharing on which Danielle reflects is that one needs to be much more careful with friends. The emotional trauma that Danielle experiences, if unloaded to friends could mean “they’ll just turn tail and flee”. Danielle’s reference to the need to give them time to digest the experience and come round to it may have reflected something of her own needs in coming to terms with what had been a very recent (to the interview) “diagnosis” of elements of her son’s disablement about which she had previously felt secure. However, it also highlighted the sensitivity and sense of risk involved in her ability to gain and sustain caring relationships.

Mike: So is that part of it, that it’s in a sense this is a burden that you can’t really share because noone really wants that so it means you’re even more alone than ever?
Danielle: Yeah, yeah it’s like the chore of cleaning the loo in the house, it’s the last thing everyone wants to do, most people I don’t like it, but yeah it’s that sort of, and I think the only way we’ve really gained support is through organisations of other mum’s and dad’s and people who are dealing with the same problem, they are the only people who can hold your hand because they’ve been through it, they know what it feels like (...)

The burden of disablement has often carried allusions to things defiled, soiled and unclean, and here it is conveyed with the image of complete domesticity in the caring role. The solution that Danielle is already offering,
remembering that her son is only now 18 months at the time of interview, and Danielle had only just had some latest confirmation of the extent of his disability, is the support gained through contact, “hold your hand” with others who have had the same experience. To some extent this was a direct reference to her involvement in the Parent Exchange Group, at which she had expressed the feeling that nowhere else could she so comfortably tell her story without fear, and gain the supportive feedback of others who knew first hand of what she spoke. It was assuredly Dianne’s own experience of “Just another mum with a similar child.”

The account of Alison which follows affords another view of the complex pattern of relations produced by the presence and close involvement of a carer in the life of a disabled person. Once again it was not necessarily the direct loss of friendship but the powerfully altered nature of a carer’s thinking and orientation to such relations, and in Alison’s case a personal choice to “abandon” them. In conjunction with this decision was a life now almost entirely made up of relations associated with disability.

Alison: I had, because of these friends, I suppose at the time my friends were mostly people involved in ... some friends I’d been really close to, very close to, for years. Their immediate reaction they told me she should be, the baby should be institutionalised, that I’ll ruin my life if I keep it. (husband) and I were both horrified by that. (...)

Alison: Cos I’ve given this a lot of thought over the years. Being a person who was probably fairly vain and fairly fashionable and fairly, and being involved in ..., the whole thing was like, beauty, like beauty pageants and (...) and then I had this sort of whole, such a change, such a change, that I had to be, I don’t know, become a different person. And then I’d give myself a whole lot of guilt about that too because I think when I was young, like lots of people do, cross the road, if there
was a disabled person down on the footpath selling pens, I’m not alone or anything like that. (...) 
Alison: Now I find myself, my whole life is people who have got disabilities or people that have got kids with disabilities or working with ... and that whole thing is disability, (...) 
Mike: You have nothing to do with them but do they have anything to do with you? 
Alison: No. Yeah, I’ve abandoned the friendships.

Alison’s prior connections were explicitly with things of fashion and beauty, and she is contrasting this with the unstated ugliness of disablement with which she is now inextricably bound. Her friends were connected with her previous life and acceptance of the realities of the present meant a quite dramatic separation with this “vain” past. There are thoughtful moral implications for Alison in what are undoubtedly significant life changes for her. Her self confessed rejection of disabled people in the past with the birth of a disabled daughter becomes the basis of a considerable transformation in her life stance so that she now can say, “I find myself, my whole life is people who have got disabilities or people that have got kids with disabilities or working with ... and that whole thing is disability, (…)”. This commitment is such that she feels herself able or perhaps compelled to abandon her old friendships. In this she is also reflecting on the development of a caring culture within a different set of symbols and virtues, namely those associated with the category of disablement and the caring sub culture that this defined. In this Alison had made a more consciously decisive and explicit statement of the search for caring culture that Dianne and Danielle had also made in their different ways. The
experience of a profound and extended involvement with disability was common as these fieldnote excerpts suggest.

The fact that they have never had the opportunity to do things together due to the demands of having a child with a disability so early on in the marriage. They have gone down different paths and she feels that it is 'too late to change', 'too set in our ways...lost too much.' [214/dh/9.93]

Shared feelings about respite and difficulties in letting go when opportunities did present, doing it for so long and choices for so long, so few, and anyway lost interest in own personal development. Also question of guilt in some cases. [87/pg/5.92]

Ian needs a high level of support and Tracey feels that to some extent she limits Ian, because she is protective. Also high support needs and complicated arrangements for Ian, make social outings for family with Ian difficult. [48/mc/7.93]

These fieldnotes capture something of the personal and social infiltration of disability in marriage and family life. These were viewed as significantly defining experiences in the lives of parents and mothers in particular. They could be associated too with positive routines of life and perhaps a unique knowing of one’s child that was borne of an intimate involvement, perhaps not so easily attained with “other siblings”.

Sandra had to “live with a lot of plaster” in the first 3-4 years. James was being splinted twice a week. Sandra developed a routine around this. [29/jp/5.93]

The constant involvement with James’s physical condition means Sandra knows James’s body a lot more than she does Anne’s, i.e. there is, of necessity, a lot more contact with a child with a disability than there is with other siblings. [72/jp/6.93]

Disablement often touched on issues of life and death in varied sorts of ways. This excerpt highlights the sometimes mixed and complex feelings
experienced by a carer, and in a specifically practical way the sort of challenges with which she is obliged to grapple.

People have asked in the past, "do you think he'd be better off dead?" Ingrid would never say this, believes that we are all better off for having known them, but would like him to die first as then she would know that he is ok and not have to worry about him. She thinks this comes from getting older. [194/dh/6.93]

The significant effect of these experiences was that carers were left further disconnected from those around them. The failure of family and marriage to significantly satisfy a carer’s need to share the demands of the caring role and to fulfil other personal subjectivities, combined with the absence of a natural community, resulted in a pattern of endeavours by carers to construct their own sense of a community. In most if not all cases it had left participants questioning their own worth as individuals, but there was significant signs that in most cases, even though there were often conspicuous hardships, and threats to health, that they were able to define ways for themselves of piecing together a semblance of caring culture. This however was a far cry from the paradigm ideals of family, community and care.

In the activities of women as carers of disabled people there were notable signs of 'resistance' or put another way, of the reformulation of a personal subjectivity within the caring work. This included as these accounts suggest, an appropriation of caring in such a way that it transcended caring as simply an extension of family. Family was generally present but it became their
caring work in a way that defined it as a personal vision, with goals for a disabled child and usually family too. It revealed the structure, pattern and something of the rationale of any career. Thus it was that increasingly it seemed the valuable business of 'shoptalk' was carried on as part of caring careers at a number of sites. These included most significantly the contacts with other parents, primarily 'mums' who represented a series of sites for caring culture. These were usually empowering experiences. This was their career work, and like any work site at which 'shoptalk' was common place it was not always a perfect basis for intimacy or the resolution of all one's needs, but it provided an important basis for 'checking things out' with others. These were people involved in the same caring career activities who "knew", and who could listen as equals and be responsive to the quality of your work. It also included frequent interactions with other workers, paid workers from the service system, and patterns of sharing information and expertise. These experiences were more often disempowering.

Family was close and familiar, and consistently the main site for performing caring work which could be joyous at times, and isolated and demoralising often. It was a haven when the ideal of community was shown to be the source of unfriendly voices. Family held out the promise of better more intimate sharing of work and emotions, which reflected both the persistence of paradigm perceptions in spite of contradictory experiences, and sometimes also new opportunities with the slowly changing face of family, and a husband's participation in it as children grew up. The carer's vision
for her disabled child was never separate from her family or the complex
interwoven patterns of other family members, but its inclusion was a reality
of conflict, often silent because of the array of isolating and exclusionary
forces from within and without the family.

Patterns of uncertainty

The potential for defining community through one's role and work as a
disability carer and from within a disability frame was evident in so many of
these accounts. The following fieldnotes are interesting because they
indicate that the arrangement was not unambiguously positive.

Margaret now at the stage in her life where she wants more in it than
disabilities, sick of hearing other people's problems but on the other
hand "I can still feel where they are at" and this is why keeps going to
the support groups. Margaret is ambivalent about these groups, the
younger mothers seem to actively seek her friendship and
support. Younger mothers still have a lot of hope which Margaret
doesn't have any more and she doesn't feel the need to give advice.
With (disabled daughter) some days are good and some days are bad.
Lives really from day to day. No-one can really tell you how to do it.
[189/dh/5.93]

Sandra misses the contact she used to have with the other mothers of
Cerebral Palsy children. These had been her main source of social
contact as the friendships she had prior to marriage slowly faded ...and
she didn't get to go out. Graham encourages Sandra to go out to get
some time for herself away from the family but is always surprised that
she goes to various committee meetings etc. rather than going to social
clubs, venues etc. If Sandra goes to social venues she doesn't want to
go alone but would rather Graham accompany her. [44/jp/5.93]

The satisfaction of caring relationships through involvement with other
mothers was evident for both Margaret and Sandra, but the potential for an
imbalanced reciprocity was also apparent. Margaret was a woman aged about 50 years. She had two family members with very high support needs. Her experience in managing these along with the responsibilities of a large family had resulted in her depiction within the Parent Exchange Group as a sort of elder statesperson, and to some as the really wise one of the ‘tribe’. Nevertheless, the satisfaction of providing advice and support about matters on which she herself already had a heavy caring role, when not able to be balanced by reciprocal support had begun to diminish. Her strategy of living from day to day was one adopted consciously or otherwise by most carers, and emphasised something of the uncertainty of lives connected with disablement.

If much of the career of caring was fragmentary and isolating of women from any sense of community and social connectedness, it was also full of uncertainty. This was uncertainty that usually began at the earliest point of a disability caring career. The caring role when linked to a disabled family member lacked many of the personal and cultural landmarks and models for a young person growing up and progressing through recognisable phases. This in itself was a source of sadness for parents, but had practical difficulties associated with simply not knowing just how much and what kind of assistance the family member may require, and this was a constantly changing matter in most cases.
The uncertainty was borne also of the very reactions of medical staff, other professionals and family at the outset, in which messages of hopelessness, sympathy, and instability were mixed with the promise of supports, hope, community, and a view of the carer as steadfast, courageous, and capable regardless of circumstances. It was fostered further by the substantially unreliable nature of supports at every level; immediate family, extended family, neighbourhood, and the service system. The following fieldnotes from the 1993 interviews on disablement and social support highlight the nature and complexity of these uncertainties, many of which touched on significant life events and decisions.

Joy is concerned about Alf’s response when his sister starts having friends of her own, when she starts school next year. Joy wants to establish a "foster family" set up for Alf with the Home Care lady i.e. someone who knows him and can offer him a loving relationship. [124/jp/6.93]

Fiona has concerns about the future, but generally is taking things as they come. She would hope that her son could participate in regular schooling, social and working life, but anticipates the need for special assistance and intervention in possibly all these areas. Fiona feels the issues are becoming more important as her son gets older, because his disabilities are more visible and the developmental lag greater. [55/mc/7.93]

Thoughts about tomorrow. Frank thinks about it. "In a joking sort of way I have thought about taking him with me". [193/dh/6.93]

Need to be planning where Alex is going to go. Can't take future for granted, need to keep looking at options and how to support them; "Nothing is ever automatic with him." [11/mc/6.93]

This Saturday will be the first time his parents will have gone out in the evening and left Bruce with a babysitter since he was born. Bruce is 19. They find it very difficult to leave Bruce with any one else although realise that this is an issue and they are starting to work on it. [213/dh/6.93]
When carers moved beyond family and friends towards the public system for support they were usually left with a pervading sense of unease about the real stability and reliability of government services and programs. The sort of questions people asked were; What do they really stand for? How long will they last? Do the personnel responsible for them really care and do they really understand? For many, the constant changes in departmental nomenclature, personnel, funding levels and program types was simply indicative of lack of connectedness to their needs.

Carers of disabled children and adults experienced a high level of frustration and stress in gaining appropriate access to even basic services that others took for granted, and the lack of local service provision was consistently commented on by parents. Even when services did exist in the local area one often only learnt of them by accident, or indeed by attending a forum such as the Group. There seemed to be no systematic and coordinated approach to providing information about services and supports to those who needed them most. Often this seemed to reflect the fact that when services were constructed by the state they were designed to meet the specific medical, therapeutic or educational needs of a disabled child or adult without a reasonable conception of such an individual’s life within a social system of supports. It appeared to reflect a focus on a service or a program rather than a person. Where services did exist, often outside the local area, there was a constant sense of frustration at the fragmentation and at other times duplication of services and supports. Parents believed that this lack of
coordination often extended to the groups of people lobbying for funding and support, who were similarly fragmented and weakened by the failure to "come together". It was further evidence of uncertainty and the powerlessness which was the product of a highly privatised, isolated and devalued social role.

Ideals and realities

Sometimes carers could only constitute self authentically or differently by being away from those for whom they cared intensely and daily, and when they were freed from the caring role itself, and the ideological demands that defined one's reason for being in the caring setting. To achieve this was often very difficult and only came after great stress. The fieldnotes below were made after an interview with Sandra in 1993. They are particularly germane because a week ago as I write, I learnt through a student who was involved with Sandra's family as part of her Family Support Project commitments, that Sandra was again in the same hospital, apparently "for a week's break."

Sandra reached a point where she needed a break, in fact she was on the point of a breakdown. At this stage she also had a daughter, ...who was about 4 years old. Sandra was already on medication, but a locum GP recognised her distress and arranged for her to go to hospital for a week's break. She stayed a month. This was a turning point for Sandra. James went to stay at ...while she was away, and Graham looked after their daughter. Sandra thoroughly enjoyed her stay at ... She learnt how to deal with relationships and how to stand up for herself, recognise her importance. She still uses the skills she learnt there to help her manage her life situation and her relationship with Graham. [10/jp/5.93]
These fieldnotes reveal another aspect of the absence of a caring culture for the day to day performance of caring work, the reality of its absence on a carer’s health and the seemingly small requirement of a carer for a one month’s supported break in a caring environment to achieve such positive effects. It also provides a glimpse once more of the small ways in which the Family Support Project itself might facilitate connections for people and some material assistance.

The broader picture then is brought into sharper focus. The vast majority of caring associated with disability is carried out in the family home. This caring primarily involves women. The apparent secret of their work is hidden further by an ideology of marriage and family where the ideals of a caring culture disguise a reality of loneliness and isolation. This isolation is not in the mere fact of being without others, because paradoxically this is often not true, but in the failure at the outset to declare the despair at disability and what it means, and the continuing silence of its impact. The ideology that produces and reproduces women as carers and disability as monstrous or disordering brings women and disablement together in a powerfully isolating union.

The fact that the caring role is so naturalised and naturalised to women, within the construction of family as a caring environment means that little awareness and effort is made to recognise that the ability to provide unrelenting support and care to others requires a culture of care which
sustains the carer herself. Where disability is involved these unrecognised aspects of caring may have an intense and powerfully destructive effect on the mother as carer because of the insidious and pervasive expectations of normality, which the mother understands she has severely disrupted. In other discourses of disablement the effects are no less isolating, although their impact may be less intense and destructive. In some cases of disablement the carer may herself directly participate in its construction as a means of having her own support needs legitimised or validated after a protracted period of caring without caring culture.

It is paradoxical, but carers often appear to ‘return’ to family as the basis of support for caring work, because efforts to locate community are in vain. The constructions of disablement and caring make the potential for community beyond family more difficult than usual, and chapter 5 explores further the disability carers’ experience with efforts to construct a caring culture. This exploration includes their interaction with the service system locally, whose functions involve an ideology of welfare, care and human service, but whose service is constructed and operates by a discourse with a very different rationality.
Chapter 5 - State systems of 'care'

As discussed in chapter 2 one of the major public policy initiatives of the last decade has been the so called deinstitutionalization movement and the policies to replace institutional care with community based care policies. Notwithstanding the distinction already set out between the public discourse and the personal reality of care in the family home, it was abundantly clear from these accounts that for carers there simply was no community beyond that which they themselves arduously stitched together from the fragments of family, friends, services and programs.

In this chapter I explore the experience of carers further in relation to their attempts to establish a supportive framework for their caring work. This includes a picture of lives constructed by their involvement with a professional service system and its normalising practices and technologies which were often alien and unfamiliar, but paradoxically held some hope of providing a form of personal validation and legitimacy that was otherwise unavailable.

Medicalized and Professionalised relations

The 'career' of a disability carer began at the point of 'diagnosis' and labelling of the disabled family member. This was a process deeply embedded in medical and professional discourse and paraphernalia and enveloped the
carer throughout the lifespan of the disabled family member. The carer’s life became determined by the relations of disablement and its interlocking with other social constructions connected with family and being a woman. Often the personal solution appeared to be in your ability to make meaningful connections with others who valued you beyond the complexity of constructed lives and circumstances; who valued you regardless of your association with disablement.

Through the apparatus of professional knowledge and systems of control and surveillance including assessment, monitoring, and a range of intervention techniques, the promise of state managed community care and support, gave way to state supervised professional control. These professional practices which were primarily administered by agents of the state or agents involved with the operation of state service systems were diffuse and pervasive. Such practices were modelled on and aided by the ideology of family. This was evidenced in the textual and the material structures of deinstitutionalisation. This included group homes and family styled living arrangements, which could be described as normalised. It was clear as indicated in chapter 2 that this meant the way other (most) people usually lived. This was ‘normalisation’. The involvement with state service systems often tended to saturate and to some extent defined the carer’s lifestyle. They contributed to the construction and maintenance of a disability carer’s ‘career’. Traustadottir (1991) based on her work with families of children with disabilities and identifying an “extended caring role” went so far as to suggest;
this role can provide opportunities for more flexibility than the traditional mothering role, and mothers of children with disabilities are sometimes able to extend their caring role to activities that are much more like a professional career than traditional mothering work (p217).

In relation to service provision in general both its quality and quantity were continually questioned by carers. From the point of view of quantity the evidence seemed clear; parents found they needed to go outside the area, often considerable distance to gain the essential services. This included appropriate education, health, employment and leisure and recreational support. As the following fieldnotes indicate this experience of a carer’s and disabled persons association with the service system began from a very early age in the life of the disabled family member, and continued throughout the lifespan.

Didn’t breast feed due to pressure of coping. Felt guilty as not breast feeding. Spent time trying to keep Toni away from this baby. At this time Ingrid was sent a letter from Dept. looking at mother being the cause of (the disability). Offered a place at (institution), although this had not been asked for. The first Ingrid had heard of this idea was the arrival of a letter which said, "your child has been offered a place at ...contact such and such a person, be there at such and such a day, if you do not want this place please let us know, there are other children on the waiting list". [160/dh/5.93]

There is always pressure to fit in with the rules of all the services she uses. Needs to use tact and diplomacy so that he can get the benefits. It suggests a situation where the services have the power to offer benefits on condition that the user obeys the rules. Sense of alienation in contact with professionals. [63/jp/6.93]

A health lady came to the school from the ... area and quizzed Sandra on James’s incontinence problem and how it should be managed at school, how staff could manage it. Sandra was made to feel incompetent and inadequate by these ...professionals, almost accusing her of not managing James appropriately without even finding out
about James’s personal history. Sandra was very upset by the entire incident. [52/jp/5.93]

Rohan spent his early years fighting to stay alive and life was one continuous round of appointments with specialists and therapy. All of this was out of the area in the city so there was little time for either mother or son to form friendships. [194/dh/6.93]

Denise recalls many experiences with doctors and specialists, who were not empathetic and who were poor communicators. A number said, "What are you looking for - false hope?" when Denise was taking Amanda for routine checkups. This lack of confidence is really due to the years of being given negative feedback from teachers, doctors and other professionals, all of whom sought to limit, control and negate any sense of confidence, vision and hope that Denise expressed in Amanda. Denise feels she now places these "restraints" on Amanda. [141/mc/5.93]

The story of a caring career and the search for supportive culture then included a picture of lives constructed by the involvement with a professional service and its normalising practices and technologies. It emphasised another dimension of the complex relational nature of the caring role, and as the fieldnotes indicate it went well beyond the boundaries of the family and the daily routines therein. It was illustrated by the complex and fragmented entanglement of carers with members of the professional service system and the state. The point of contact was either as carers themselves in search of support and some concrete indications of community and community based care, or when the legal and social ‘obligations’ of caring determined that a carer should fulfil other formal contacts with the state.
Professional processes disciplinary ways

If the needs and visions of a carer were associated with their disabled son or daughter in the context of their own family, and the search for a caring and supportive community then the focus and raison d’etre for professional service systems was unlikely to make them more than a little helpful and then only in very particular ways. As the fieldnotes indicated the engagement with professionals and service systems could be alienating, and rather than contribute to a carer’s sense of well being and the fulfilment of her career endeavours it could leave her feeling frustrated and diminished.

Jane: (...) One of them actually got me one day and said, “I took two things out of ... lunchbox today, because I thought that having a (disabled) child these would be unsuitable.” So she actually took them out of his lunchbox and when I got to school she gave me a forty minute lecture on nutritional values.

Jane as the mother and carer is assumed to have no knowledge of nutrition and the needs of her child at all. It was clear that the presumption existed that Jane’s view and indeed her feelings as the person who made the child’s lunch, did not matter. Jane as carer was unseen. The following encounter at the same school provides a forceful insight into the way Jane felt about her treatment, and the singular failure of individuals to recognise her competence and interests.

Jane: (...) We had a typical morning we got there at quarter to 10 instead of quarter past 9 and we walked into the school grounds and I got met by the Assistant Principal. She said, “... class is already in there” and I said, “oh well he misses out.” She said, “have you got a reason?” (Laughing cynically). Well I just lost it. I said, “Don’t you speak to me
like that” and I went around the corner. With that she was following me and I threw his bag in the classroom and I came back around. She said, “school starts at dah da dah da dah and he’s missed out”, and I just lost it. I said, “who do you think you are?” “You have no idea what it’s like to deal with this sort of a child. It’s a problem getting him to school blah blah blah blah.” (...) She said, “well I do understand”. Well that was it. I said, “you have no idea what it’s like to have a child like this. You think that he can just get up and he’ll just come to school and there’s not a problem.” I said, “you’ve got no idea”. I said, “I’ve been fighting with this child since he started school we might get to school twice a year on time dah da dah.” She said, “oh please don’t take him home.” I said, “I am sick of it you just don’t know what you’re talking about, you think you know what you’re doing but you just have no idea.” I said, “I’ll give you his bag with his clothes, you take him home for the weekend.” I said, “you’ll last one hour and you’ll bring him back”. I said, “because you have no idea.”

That Jane should feel the assistant principal, “had no idea” was not a comment on the assistant principal’s professional incompetence, but a statement about her failure to understand or recognise Jane’s place in the life of her child, and the nature of the work this entailed. The repeated reference to “you’ve got no idea” was a comment on the failure of the professional system to support her, Jane. Her comment “you think you know what you’re doing” however, was a much clearer statement of the view that as a system, it felt and behaved as if it knew best, better than Jane as the carer. The request, “have you got a reason?” suggested something of the staff member’s view of Jane as blameworthy, and was clearly so insulting that Jane in repeating it, as part of the interview, could only laugh with almost total incredulity and cynicism. It was in no way difficult to see this exchange as more like a person of authority talking to a child with none, and of course this is precisely one of the feelings that Jane experienced.
Danielle: (...) They wanted to assess (disabled child) initially between 10.30 and 12, a couple of months ago they made, at that time (disabled child) slept between 10.30 and 12 and when I said “he sleeps then it would be silly to assess him then” they said, that was a problem for them. They couldn’t cope with the thought of having to compromise. It was very difficult for her to come across and that gave me a very negative feeling about community services. I was thinking well, if you can’t compromise on something this basic this initial, how are you really going to provide any service for my (child), but after the assessment they were much nicer. Even when we turned up for the assessment she was patronising, she said, “when I come out I’m going to come out this door and this is where we’re going to go”, and I’m thinking ‘alright, I’m past 5, I don’t, you take me by the hand’, and I just switched off. I can’t stand being spoken to like that. I hate the thought that she’s doing that to everybody. I could just take her by the throat.

Mike: Sounds like … , a sort of programmed set of things.

Danielle: Yeah, which is really bad and I don’t know how to overcome it. Since the assessment she’s become much nicer and I even said, “look we had, personally we didn’t exactly get along terribly well”, but that’s finished, we’re getting over that. But if she speaks to me like that again she’s going to have another problem on her hands.

In an interesting, although for Danielle a painful reversal, the professional adopts the parent role and redefines mother and disabled child together as children. Danielle’s effort to represent her child’s best interests as she saw them exposes her to the impersonal boundaries which separate the professional service system from her experience of care. The experience here is perhaps a reminder of earlier painful experiences, “another problem” and the spectre of the first realisation of her child’s disability described in the previous chapter.

Overall Danielle’s experience here does little to either alleviate or even attempt to take account of the feeling of Danielle as the carer. She is entirely secondary to a process that will run it’s course in spite of the different needs of those who are submitted to it. Some negotiation and adjustment occurs,
but only after Danielle herself takes on the responsibility of pressing for change. It is most evident that the service system context is a space in to which it is expected that Danielle will enter appropriately, only if she leaves her own individual function and needs as a carer outside. It provides a picture of a service system that expects clients, even those experiencing some degree of trauma to adjust caring routines to meet predetermined system needs. It may in fact be more accurate here to depict the system as simply not recognising that Danielle had any needs at all. The focus is so clearly directed at a professional process and a client, it was as if she was a mere vehicle for the delivery of a client for assessment. Once again and in a very different system context from that experienced by Jane, a carer meets with a depersonalising system which appropriates a family model in which the professional-mother is repersonalized as a parent-child. In this context she does not even possess the usual rights and status of mother in a family.

Fay: I found with speech therapists, (...) they’re very good at pointing out what you should do and what you shouldn’t do and what have you, but never anything practical, and there was always sort of, why aren’t you doing this with your child, why aren’t you going through private clinics, and it was always the guilt trips they would send you on

The speech therapist is portrayed by Fay as providing a form of moral guidance which made her as the mother and carer feel guilty, but that failed to provide “anything practical”. Once again a mother as carer is reclassified as child, and there exists in the guilt the ever present sense of responsibility for disablement. The suggestion is that the therapist offered advice without a
context and a knowledge of Fay and in this sense could only point out, “what you should do and what you shouldn’t do”.

Alison’s experience was remarkably similar but highlights a great deal more of the important issues here.

Alison: Oh yeah, she’s I suppose to me she’d say things like, yeah, that had negative, I was saying negative things. (Silence while thinking ) I guess I’ve always felt that I’m not doing enough, that’s, you know, cos you have physiotherapists and you have all these therapists, and you have all these people say you should do this and you should do that. And you go home and you think, I’ve got to go to sleep, I’ve got to do the washing, I’ve got to be a single parent, I’ve got to do all those things. How can you fit in the amount of physiotherapy, occupational therapy, speech therapy, and whatever a doctor might have said to you, or go to hydrotherapy, you have other people who are telling you that you should go to, lots of people found things in newspapers about overseas schemes where you could take your disabled child and the miracle cures, and you start thinking, well maybe if I’d done that maybe (disabled child) be able to talk, maybe. So you always think that I should’ve been doing more. Pam would, she was really good, she’d say (teary)that I was doing a really good job, and (disabled child) was terrific, so, nobody else ever told me (crying, silence).

It is clear that even allowing for the possibility that the range of treatment suggestions from various therapists were of any value, the mere fact of presenting them to Alison without taking account of her ability to fulfil them was a source of pressure and guilt. The therapeutic regimes themselves would regulate Alison’s day to day life, but the broader caring role would see to that anyway, which left all the recommendations for treatment ‘free’ as surplus or residual concerns as it were, to occupy her mind, and in this way to ensure that she negatively regulated herself. Alison makes it clear that the treatment advice that came from “lots of people” was really no different in its effects.
The incorporation of Alison as carer, and as a person without a personal non caring existence, is absolute. Furthermore, the advice she gets appears to be totally decontextualised. Those who offer it do so from a ‘safe’ position, which reveals an objectivity and alienation from the real needs and demands of the caring context within which Alison must operate more or less all the time. Alison sees clearly that her personal life and caring career are separable in theory only because her daily experience makes them inseparable. She maintains some hope only in this other life and personal subjectivity beyond her caring career. Professionals and those who offer her advice from a similar stance in no way acknowledge a personal reality distinct from her caring career, and additionally fail to connect her caring work and role meaningfully with their professional advice.

The segment was a very emotional one because it touched on the raw nerve of absent caring culture. Alison is recognised as the carer, but her perspective is so little appreciated and respected that those who offer advice fail to identify a life, Alison’s life, in connection with their suggestions. It was a most telling moment when Alison concludes quite tearfully, “Pam would, she was really good, she’d say (teary) that I was doing a really good job, and (disabled child) was terrific, so, nobody else ever told me (crying, silence).” Pam in fact was “just another mum” with a child who was disabled. She was able very simply to provide the minimum essential validation of Alison as a person and a carer that no-one else seemed to be able to do.
During the interviews themselves and for me as the researcher these were some of the emotional exchanges that I experienced with some force, and discussed in chapter 3. They were part of my own changing perspective. On reflection I believe the interview process itself served as an initial impact on my consciousness. It was sharing this process in the academic setting and more specifically writing about it as part of the thesis development that produced a genuinely different view. I had in chapter 4 in relation to Bev for example, revealed my failure prior to writing to appreciate just how I was unable to identify with her in a way similar for example, to the position of Pam towards Alison in this transcript extract. To this extent as a researcher in my relations with carers I may have been only a little less alienated than those in the professional exchanges described here. This I believe simply reflected my disciplinary interests, albeit broader, and may be even transdisciplinary, but nevertheless the unspoken desire to construct a particular discourse on disablement and carers. Individuals with whom I was involved took shape within my subjective construction which was one aspect of my reason for being involved with them at all. In the case of the professionals who ‘appear’ in this thesis, their involvement with the same carers was more sharply defined by their disciplinary interests, and a less open and flexible process which might permit a genuine identification with the interests of carers.
Formal contexts and unfamiliar care

A more systematic view of the service system reveals that whilst the professional process is constructed from particular disciplinary interests, and therefore may focus on different parts of the body, a process or model of interaction with clients which is more or less common to all can be delineated. In a broad sense the process involved these common elements and steps; assessment and identifying problems; measuring the extent of problems; prescribing programs or regimes of treatment; monitoring the effects of such interventions; and evaluating by further assessment the status of an intervention and an individual body’s place in it. It may seem trite to identify and analyse this perhaps well recognised service delivery model in this way, however its importance when critically linked to the caring role cannot be overstated. The importance I believe lies in the entirely different focus of this essential professional process from that of the mother as carer, and the way in which the professional process proceeds to decontextualise its caring effort in complete contradiction to the mother’s efforts to find and advance a context which promotes caring endeavours.

A professional system which determines the social sub categories of disablement, and maintains them through its assessment and intervention activities is unlikely it seems to be interested in the broader concerns of caring culture. It may well show an interest within the discourse of community care in enlisting the cooperation and support of others including parents, and even others within the family or the community as
volunteers. In general however this appears to function as a way of controlling a wider group of people and coopting them in support of the decontextualised processes of professional intervention. It does not represent a serious effort to enable caring of the kind offered and needed by the mother as carer. Cooperation and the ordered compliance of carers in the professional process may be seen as the appropriate form of reciprocation in exchange for the professional expertise when the usual ‘gifts’ of reciprocation in caring were absent or not relevant. In so far as this process tended to defer to the discourse of community care these processes were apt to appeal to and reinforce the ‘normal’ and gendered discourses on caring.

The professional process involved a reading or series of readings of the body through assessment techniques which reflected the disciplinary foundations of the profession, and were connected to different aspects of performance in the life arena. The overriding principle for understanding these readings was that of normality. Given such factors as age and sex, how did an individual reading of the body through specific assessment techniques permit comparison of performance with others of comparable age etcetera. Thus, teachers read the body physically and intellectually in relation to its performance educationally, speech therapists/pathologists read the mouth and throat in terms of eating and communication performance. The case worker tried to gain a view of performance as a whole, but this latter role was not so much a holistic view of an individual in their context, but a view of all the elements of performance. Thus, the case management process was a way of coordinating both the various elements of the professional process,
but where more than one specialist was involved with the same individual it enabled one member of the professional team to coordinate and to assist the interventions of the performance specialists.

The following transcript extracts highlight aspects of the way in which a mother and carer begins with a view of her child and her/his needs and attempts to use these disciplinary regimes to provide support to the caring process as necessary and appropriate. This caring process may be contrasted with the professional process which began with the disciplinary techniques administered through the professional process described above, and coopted support from members of the family, particularly the parents and most usually the mother when it was suitable.

Mike: So you don’t get a sense of the doctor, or other professionals who might be responsible in this area, offering a great deal of help? Dianne: No, not really, no. Mike: Do they offer any help, I mean are they useful in any way? Dianne: Well, sometimes if I get stuck on something, you know, (disabled daughter) going through a thing where she ... at the moment, she’s ... all the time, and I sort of said to them, “well, you know, what’s this” and they say, “well that’s ...” and I think well that’s fairly helpful now what do I do (laugh). I guess I just get the picture that they just look at the (disability), they don’t look at the development or (disabled daughter) well-being at all, they just look at, well if we fix the ... then everything else will fall into place, like it’s been seven years and they’ve never been able to stop the ...

Dianne is clearly not reassured by the professional process. Basically she suggests that she manages independently. As a mother she has built up considerable knowledge of her child’s support needs, and it means she is looking for something more in-depth and special when she seeks professional assistance. She knows from her own experience much of the
conventional medical wisdom about the disability, and she knows too that the only meaningful progress for her child will require contextualised knowledge. Her laugh is clearly sarcastic because she already knows and has tried the advice, but also understands that its technical focus, designed to just “fix it” is misplaced. Her remark, “they just look at, well if we fix the ... then everything else will fall into place” seems to point to the failure of this process not just to see her child more holistically, but to see her role in the process. In fact the very idea of professionals simply giving advice, and doing so as if “everything else will fall into place” was as the earlier accounts emphasise, a significant carer refrain about their own vital, but unseen role.

Service system professionals involved in providing services to disabled people and their carers are to some extent spread across the community, although more usually they can be found working in specialised state operated and private systems. The focus on developmental disability as described in chapter 1, meant that the relevant range of specialised services was restricted primarily to the service operating as a multidisciplinary team out of the NSW Department of Community Services (DOCS). Such a multidisciplinary team will usually include at least a community nurse, a speech pathologist, a physiotherapist, a psychologist, a social worker, and a medical practitioner who is often a paediatrician specialising in disability assessment and support. It is not uncommon for smaller regional offices to rely on visiting and/or part time positions for some of these specialties.
In addition, post school vocational services, supported employment programs, residential services, recreational services and the Commonwealth Rehabilitation Service (CRS) also employ categories of staff who specialise in these different aspects of human service. Professionals who participated in this study were from a range of services provided locally or from outside the area to support local ‘clients’, including the multidisciplinary team, post school vocational services, a semi-private educational service, a local government integration and recreation worker, rehabilitation workers and a visiting medical officer. The transcripts which follow, themselves help to define aspects of these roles and their functions in some more detail.

Veronica (p)*: Yeah. So it’s allocated to a case worker first. They make the initial contact with the family, go and see them and work out what the issues are for the family and what sort of service we can offer them.
Mike: Would that always be true? I mean if a paediatrician referred someone as having a speech or eating disorder, so that the initial referral was entered at that sort of advice.
Veronica (p): Yep. It probably would still, we’d often do a joint visit at the initial meeting then. It would still have a case worker allocated straight away. Yep. But it might come to me at the same time.
Mike: In your case it’s fairly clear what your particular qualifications and expertise, but if you had to describe the sort of, I mean if you do this sort of work you must have a range of skills or strategies or, yeah knowledge base you work with. Could you describe that a little bit? I mean, what’s your strategy of becoming involved, how do you think about it and go about it?
Veronica (p): Well I guess depending on the area again whether it’s feeding management or communications stuff. Um. If it’s a feeding issue my initial contact would be to just talk about the feeding history with the family and what’s sort of presenting as the difficulty at the time and then observe the typical sort of feeding situation and just looking at the whole environment and what’s going on there. So looking at the baby’s skills or the child’s skills in terms of positioning and oral skills and coordination of whatever they’re feeding from, swallowing, whatever. Looking at how conducive the environment is

Note: The (p) sign is a way of more clearly identifying the interviewee as a participant from the service system, a professional.
to group feeding like whether it's very distractable, those sort of issues. And looking at the carer's skills or techniques that they use, how they hold the child and things like that. And then looking at the equipment, adaptive equipment that could be helpful for them so the type of bottle or teat or whatever it is that they're actually using, or the seating arrangement that the child's positioned in that sort of thing.

Mike: Yeah, that's really interesting. So a lot of it is observing.

Veronica (p): Observation and parent discussion like just, yeah, observation and observation checklists and things.

Veronica provides a very valuable insight into the important job of assisting with eating/feeding and communication. Of course the importance of such activities to the quality of life hardly needs stating but it may be less obvious that some physical support needs of eating/feeding in particular may at worst be a question of serious obstruction to breathing, and therefore Veronica's interest is in the safety of the child.

Veronica illustrates something of the case worker role which in this instance is like an initial reconnaissance or probe into the family setting to establish some of the important benchmarks for the subsequent intervention. The more specialised work of the speech pathologist centres on observation of the oral actions of feeding, the carer's techniques and interaction with her child, the family and environment as they impact on the "difficulty".

The "environment" here is a reference to those elements, human skills and behaviours, and equipment and apparatus which immediately impact on the feeding action. This is clear in Veronica's references,
observe the typical sort of feeding situation (...) Looking at how conducive the environment is to group feeding like whether it's very distractable, (...) carer's skills or techniques that they use, (...) And then looking at the equipment, adaptive equipment.

The central elements in this entire process are that of observation and recording of observations and discussing these with the parent. It is important to note that even the discussions with parents themselves may become part of the observational process in which the professional takes evidence to support the intervention. This is most clear in the extract which follows when Veronica says, “With the interaction stuff it's probably a bit more informal in that it's mostly my observations. Yeah it's just discussions on how they interact but no sort of standard tool.”

Overall the focus is on the feeding action and the immediate and directly relevant environmental factors. In this process the carer within her own home becomes one of the environmental factors under surveillance. There is an unconscious link of carer skills and involvement with equipment. Her behaviour may impact directly on the quality of the eating/feeding behaviour of her child, and finally it is she who will listen to the advice and apply it as part of her caring work.

Mike: (...) you obviously have some sort of assessment tool or some sort of recording device for when you're looking at the child, do you have something when you're looking at the parent or some way of reporting on how they're managing or how they're doing things?

Veronica (p): Fairly, with the feeding stuff it's fairly formalised on checklists and things, there's almost as much attention paid to the carer and the environment as well as to the individual. With the interaction stuff it's probably a bit more informal in that it's mostly...
observations. Yeah it's just discussions on how they interact but no sort of standard tool.
Mike: So will it get reported or recorded in some way, would you build that in somewhere?
Veronica (p): Yeah, I build that into my report, yeah, and look at it in my programing, or you know, therapy sort of plan.

Where a carer and/or a family were seen as part of the focus on an individual body or function, it was primarily in terms of how they might be a part or all of the cause of the problem, how they might assist in the intervention or assessment itself, or in fact how it may serve to support the carer herself who otherwise may not be able to fulfil a supportive role in the optimum fashion. The carer's role becomes intertwined with the therapy and programing for the child, "I build that into my report, yeah, and look at it in my programing, or you know, therapy sort of plan", and in a very real sense inseparable from it.

Only very occasionally was it evident that the real interests of the carer regardless of the professional process were valued and permitted to be heard or seen. It was even rarer that her significant, primary and vital role were acknowledged because within the context of the professional process and its disciplinary identification she was neither an expert or even expected to know, and the broader caring function as a naturalised function was not at issue. The latter point was true unless of course it was perceived through the observation process that there was evidence of neglect or the failure to perform caring to a standard considered 'natural' or 'normal.'

Mike: Perhaps you could tell us about your role, what it is that you actually do, and I suppose, what you feel that you want to achieve.
Kylie (p): Well, I guess our role, well, my role, I'm a registered nurse, but I work as a community nurse within the Disability Team. I guess first off our role is to support the family, a family who has a disabled child and they usually have to fall into a category where they come in within moderate to severe range of intellectual disability (...). Supporting the family, taking referrals, organising assessment to diagnosis, um.

Mike: You don't actually carry that out, you organise it?

Kylie (p): We have assessment and diagnosis here, however, my role as a ... doesn't really come in to it I guess, in a practical sense, there are paediatricians, speech pathologists, occupational therapists, physiotherapists and psychologists, whereas the role of (community nurse) is more for support, moral support, and perhaps explaining medical terms, that often doesn't actually come into it, chromosomal abnormalities, going a little bit into genetics, very briefly, just after they've been perhaps for a specialist appointment, you know, (...)

Mike: (...) You sort of broker and find, sort of mediate and find the connecting points with someone out there.

Kylie (p): I sometimes look at us like we're a coordinator or something like that, or we help organise people's lives in a sense (...)

Kylie's role is not so much that of the specialist but as a community nurse she makes the links between specialists. It may be the parallel of the case manager in any individual case. She identifies families more than a specific disabled family member as the main focus of her role. Nevertheless her role of supporting the family is part of a professional system, and her supporting role is linked to the organisation of this process and holding it all together from the families point of view, "for support, moral support, and perhaps explaining medical terms, (...) chromosomal abnormalities, going a little bit into genetics (...)"). These supportive activities reflect something of the obvious stress, if not trauma that many families experience as an outcome of the assessment process.

In the following relatively lengthy extract Kylie spells out one aspect of the professional process in more detail. It draws out further the nature of her
own family support role within the context of a professional process. The system Kylie describes was one which operated for certain categories of disablement, but as Jane's experience in the previous chapter suggested there were often barriers and other points of entry to the system of assessment.

The departmental systems within which the processes that Kylie describes unfold are complex, and it is important to appreciate as part of the background here, that this particular service defined its target group as those who were classified as moderately to severely disabled. Thus, the experience of Jane discussed in chapter 4, appeared to involve a considerably greater individual effort in hustling to gain answers than the systematic approach that Kylie describes. This was because in the complex categorising processes of the department, and it was clear that these were not fixed categories, either officially or in terms of professional discretion, Jane was not eligible for service because her child was not considered to be sufficiently disabled. These broader contextual components of the professional process were often a barrier to entry into the service system, and a source of considerable anxiety and uncertainty for a carer. Cracking the code of departmental classifications could at a macro level be seen as part of the assessment as it were, of a caring career, although as the extract which follows suggests, there were also trials at the micro level.

Mike: With that assessment process, what do you see it's doing, what do you understand it to aim to achieve?
Kylie: Well, trying to give the family some answers on why their child has a disability. They're basically little children because we have a paediatrician and an early intervention service, 0-5, for that service, the assessment and diagnosis, and from what I hear from the parents
it's all these unanswered questions. What went wrong, why, what does the future hold, what help can I get, what's going to help anyway, who can help me organise for my child to support my child in the long run, schooling, you know, education, recreational activities, and then going on to employment and housing and things like that. In the assessment and diagnosis we try to answer all questions that's why I'm there as well, we always attend. (...) They come to the office, because they know me, they've seen my face, it's a little comforting I hope for them. I bring them in, I introduce them to everybody who's going to be there. Prior to that we've already sent them out a letter stating what's going to happen on that day, how many hours it's approximately going to take, bring something to eat for your child, all the rest of it. They come in and then the therapist gets the child to usually play with some therapy toys to try to get an idea of the child's development, ask mum and dad a lot of questions. The paediatrician usually does some basic collecting of data like heart rate and things like that, chest sounds to see if there's any congenital cardiac problems and respiratory problems etc. She just looks at muscle tone and joint movements and things like that. And then, what happens after that, the therapist and paediatrician go out the back, discuss what they've found, what their findings are, write it all down on a report each. In the meantime I've given the family a cuppa and a biscuit and I've gone back out and had a chat with them as well, hurry them [professional team] up a bit, then we move back into the room, we sit there and discuss the findings, and what the therapist can provide in the future, weekly therapy, fortnightly therapy or we don't believe the child needs it at this time or, yes I can offer this or whatever.

This process takes some hours and is clearly very arduous on all concerned.

The process described by Kylie highlights the need to smooth out and coordinate a complex professional event. There is no acknowledgment of the integral role of the mother as carer and no meaningful or personal identification with her. It is fundamentally an applied scientific process with a team of applied scientists collecting data, taking time to assess it, and providing on the spot answers of the findings to the subjects. The subjects are comforted where possible by Kylie who has been part of the process as a member of the team, and her role here may extend to the provision of information and explanations of scientific terms that may not be so clear. In
the end the process which has read the body from a number of different therapeutic perspectives using mostly reliably normative based measurement devices, has resulted in a scientific explanation and prognosis of a child. In this process Kylie can be seen to move between a more personalised caring and the professional caring of a service system driven essentially by a scientific rationality. It provides a hint of the contradictory elements, boundary (personal/impersonal, carer/professional) weaknesses and splits, and human dimensions beneath the scientific rationality of care.

For the carer this process may provide some sense of exoneration because as the earlier narratives show the sense of personal responsibility and failure, at not fulfilling societal expectations on ability can be intense. In this respect the elaborate scientific discourse might be compared to earlier discourses of the changeling described in chapter 2. Paradoxically, the process may simply have provided some sort of official societal absolution for the inability to provide the sort of caring culture that most carers were seeking. The assessment and diagnostic processes, and the range of inter-therapeutic referrals and re-assessments which occupied such a significant part of a professional's time became part of a disciplinary driven response to the basic care demands of people and their carers, who the same disciplinary processes had categorised in the beginning.

The process defined the rules and quality of societal care and support from the outset, “early intervention”, and carers whose real needs were often for personal recognition and the reality of a supportive community, when
confronted by a service system often alien and out of touch with their real needs, sought at least to use it to gain something of a ‘break’ from caring work.

Fiona (p): Well, yeah, I’ve been thinking about that lately because I don’t sort of know where we stand, I mean we’ve got parents saying we want this babysitting service and then you’ve got DOCS saying well, you know, you’re servicing the client and then the case worker’s role within the community team is the family support, and us at the moment are providing both, I think, but when you get, essentially for the client with the parents’ needs in mind as well, so if you’re looking at disability standards and if we need to change our service to comply with those, I need to find out who is, who are we servicing, who are our clients, is it the family or is it the client, because if it’s just the client, well, this is what we need to do for the client, but you can’t really isolate that person who lives in the family unit I don’t think, you know, it’s something I’m tossing about at the moment.

Mike: Sure, yeah, I can see what your saying.

Fiona (p): But at the moment I think we’re, I mean the client is the client but, yeah, I mean we provide some sort of support for the family

Mike: Because of the family

Fiona (p): Just to make things easier I guess.

Mike: So, and that’s, what you’re really talking about there is the respite role

Fiona (p): Mmm

Mike: that you perform, that’s the primary

Fiona (p): Yeah, (...)

Fiona was struggling with contradictory elements within her role. It was as though she could see the complex ecology of care and support, which included ‘client’, carer, family, in addition to the “disability standards” and the need “to comply with those”. The logic of the service system was at odds with the needs of carers and families who for all intents and purposes spoke for the disabled clients. This logic involved adoption of some versions of individual training and educational discourses and practices as the most appropriate social policy response to the needs of disabled people
themselves. Yet the resourcing of such services made these individual goals and standards for disabled clients unrealistic and unattainable. The model of individualised program and training goals was at odds with the complex ecology of support required. It highlighted the support needs of carers for respite from the day to day responsibility for care which became more apparent, but within the social policy framework of the department, not legitimate. Fiona reveals something of these complex and ostensibly conflicting human needs as she tries to balance the demands including her own personal feelings, policy and the “standards” requirement with the day to day realities of her service work. In the process, she reveals some antagonism towards parents for using her service merely as a “babysitting service”.

Mike: Do you think the pressure out there is really for a place to put people for the day and that’s it, that’s basically it?
Annette (p): Oh, Mike, honestly yes. This is what demoralises me in my quiet dark moments is why the staff and I are pushing for structure and development when I’ve not seen one of these parents in the five years, they couldn’t give a stuff what happens during the day, as long as they’re not in their hair. So and I’ve had very interesting discussions with service, with residential service providers when I’ve been recommending that we reduce the number of days of somebody’s placement because they’re desperately unhappy here, they’re don’t join in, they don’t want it, and they say we can’t do that because of our staffing problems they’ve got to stay here. So the dynamics that inform somebody’s placement are often skewed and not needs based and not about the person but about the service needs and I find that really irritating. Obviously you end up with a very miserable person. So, I mean you get good hearted parents who are genuinely trying to find something for their family member that means something to them and they’re terribly terribly rare. The majority of people are not. So if we do the toilet and tea routine all day

Mike: That’s respite
Annette (p): Well
Mike: And they’re looking after them the rest of the time
Annette (p): It’s respite (...)

Public discourse personal reality: disablement and a re-search for caring culture
Annette reveals the same apparently conflicting service and support demands, although she had taken a strong stand in support of a needs based client program and was clearly, like Fiona antagonistic towards parents, “I’ve not seen one of these parents in the five years, they couldn’t give a stuff what happens during the day, as long as they’re not in their hair.” Both Fiona and Annette disclosed at later points in their interviews a degree of sympathy for the situation of parents they appeared so critical of in these excerpts, and it was clear their real target of frustration was their departmental employer, and the unworkable logic of their service systems. Their sympathy revealed another aspect of the contradictory and alienating structures within which they worked and carers and disabled ‘clients’ entered. Their antagonism towards parents/carers who they saw as simply using the service, could be seen to be the result of the efforts to balance the contradictory forces of the personal with the impersonal and the individual and the ecological within structures and models which simply did not enable such a balancing. Any ‘natural’ disposition on the part of Fiona and Annette to provide a personalised care and to identify with carers and ‘clients’ at another more humanised level was thwarted and negated by the disabling constructions and models of the service system.

The accounts uncover further something of the taken for granted nature of the informal caring role, and the assumption that unlike any other parents, parents of disabled people, in this case adults, should further give their time to the effective operation of government programs. Even allowing for the fact as suggested by Fiona and Annette that some parents may have simply
shown no interest in their disabled family member’s well being, (an issue to which I will return) the genuine need for support for the carer was not apparent or explicit. It may be that the real purpose of public policy in this post school area was quite ambivalent. Thus, it was neither to provide seriously for the training needs of disabled people because they were not considered a serious labour market potential, or a serious respite program for carers, since this would be some kind of official recognition of the extent and economic value of unpaid caring work. These programs therefore often ‘hover’ uneasily, and were subject to periodic changes which reflected the changing political context, the power of lobby groups (significantly these were usually made up of parents), and the underlying and unstated dynamics of the labour market, disablement and care.

With reference to the issue of parents who appeared to some professionals to be uncaring about the welfare of their son or daughter there are at least three points which can be made. The first is that for many parents after 18 to 20 years of caring career work, like any other parent there was the expectation that in terms of societal work and social ethics, that they might be free of the 24 hour a day caring role for their children. Public and social policy rhetoric tended to reinforce these expectations in spite of the realities of continually very high levels of unemployment, and a dearth of post school alternatives for disabled adults. The second point is that many parents, as the thesis has highlighted, experience considerable economic and social loss and stigma associated with their caring role of a disabled person. If the opportunity existed to be separated from this often socially negative
connection as their son or daughter moved into adulthood then this was perhaps entirely understandable. After all, it was clear from the evidence of the thesis that the choice to be separate from the socially negative connection with disablement was one that most people made, within the context of a social paradigm that legitimised just such a stance. Finally, it was most apparent from the research that parents in seeking caring culture often found they had to establish its various, and pastiche like formations themselves. The existence of and regular participation of parents in the Parent Exchange Group was one manifestation of this.

Parents often went to extraordinary lengths to try to establish appropriate services and basic supports. This was reflected in the efforts of one mother in the local community whose son had major support needs and was leaving school soon, who together with her family organised a number of public meetings locally to gain support for post school services/programs for disabled people. This parent with the support of her family has not only continued to provide the support and care her 18 year old son needed, but worked tirelessly to gain some appropriate post school programs. This story was repeated in varied forms on many occasions, and my notes from earlier interviews highlight some of these.

She attends a local public school and is in a special class. Mother has had to work hard to have the special class established in the local school. [251/dh/7.93]

...feel strongly that John should be fully integrated, as segregation leads to more problems. Have spent time since John was about two (years of age) checking out the local school situation, levels of support for children, attitudes of the staff etc. Are not Catholic, but found this
school to be accepting and welcoming of children who are different. [225/dh/7.93]

Mother organised a local epilepsy support group; feels fairly unsupported by professionals in this. [257/dh/7.93]

Within the service system models, most particularly during the early intervention and school years it was quite common also for professionals to have high expectations of parent support for their professional work.

Mike: So are all the parents involved?
Tina (p): With the physio programs yeah.
Mike: Right OK. So it’s a condition of their doing it?
Tina (p): It’s very important because if the parent doesn’t know what you’re doing with the child then the parent can’t do it at home and that’s one of the conditions that we impose upon them is that we like them to do therapy at home as well because we’re not miracle workers, we can’t provide the cure unless the work is done at home as well, you know, collaboratively, we can work together as a team and we may be able to lessen the disability.
Mike: OK, so you understand disability to be some sort of structural change or dysfunction that can be mitigated for through the treatment, through the therapy?
Tina (p): Well that’s right. The ultimate aim is, if possible obviously fix it, if not possible to fix it then definitely to lessen it by continuous work and the more you do therapy wise then you are going to get a result if you expect it. If your mind I guess tells you that I’m doing this but I know I’m not going to get a result, then we believe that the child can pick up that you don’t expect a result and so therefore we tend to sort of work with the families as well and sort of explain to the parents that you have to want it, you have to believe that you’re going to get a result, not necessarily fix the child but a result and by doing this, it may only be a small result but there will be a result.

The therapeutic focus on the child with a disability, “we can’t provide the cure unless the work is done at home as well” and the disability within the child, “fix the child”, embraced the family in such a way that the child’s future basically rested on their commitment of time to the regime set by those at the service. It was consistently reported by professional people in
this study that it was the mother who fulfilled this commitment within the family. In this instance the process of control on the carer is quite subtle and pervasive, and suggestive of a moral imperative;

Mike: So a result would be that they could do a particular function better than they could have otherwise have done it, walking or...?
Tina (p): Yes because if you believe that you can’t do something then you can’t because you believe it. No matter what you do you’ll never do it properly. So, whereas if you believe that OK I’ve got a problem with doing it but if I practice, and practice makes perfect, and so if I keep trying and trying and trying to do this thing well then I’m going to have a better result than if I didn’t try at all.
Mike: So what sort of form does the counselling take? You’re counselling parents, you have that initial
Tina (p): We have that initial consultation. Basically if you can, I work with the families all the time as well so you learn to read them, the minute they walk in the door you’ve sort of worked out whether or not today is the day, (...) So we’ll do that on an individual basis, on a one to one, but as I say, everything that we’re doing is we’re working on a positive light the entire time and encouraging that family to say hey, come on, get your act together, pull together as a team, we need you, you know, the way it is at the moment you’re not quite with it, you know. (...) If the parent doesn’t fully believe then it’s our job to get them to fully believe.

The elements of the professional process were evident again and at no point were the family or the mother in particular free of the careful scrutiny of the therapist. Her life and the progress of her disabled child were closely bound, and within the process the family and the mother are “read” in counselling. There exists the hint or the possibility of a supportive identification with the carer, “we’re working on a positive light the entire time”, but as was the case in earlier exchanges the language of “collaboration” and a holistic view was often only understandable in the context of professional or therapeutic process, and “If the parent doesn’t fully believe then it’s our job to get them to fully believe”.

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Mike: Are you able to make those sort of distinctions through the assessment processes you have?
Tina (p): Yes. And again that's because you've got parent input and you're consulting with the parents all the time, and you're getting sort of little stories. I've always got an ear on everybody all the time, trying to, not necessarily to know what's going on, but it's important for us so that we can know exactly what is going wrong with your child and if we've got the whole picture then we've got more hope of doing something for the child.

The moral penetration of the observation and assessment process was extensive. Having "an ear on everybody all the time" was revealed as the need to "know exactly what is going wrong with your child". For the carer this may well translate as, 'judging how poorly you are doing your caring job'. This was shown to be most paradoxical when Veronica indicated something of the relative difficulties she experienced in observing the work of other professionals.

Mike: So you think this role, I mean is it generally, I mean is your experience that you're generally viewed in a cooperative way or would some parents actually in some respects resist that sort of involvement, just something?
Veronica (p): I haven't experienced it from a parent's perspective, they're mostly fairly cooperative and look at it as a cooperative role. Teachers is where you sometimes get some resistance or
Mike: So one professional viewing another's work?
Veronica (p): Yes, I think so, yeah, I'm not really sure what the issues are but probably just threatened by someone else sort of coming to them saying they should be doing things I guess.
Mike: You don't see that in parents and carers?
Veronica (p): No. I have a lot more success working with families, a lot more effective
Mike: What would you put that down to?
Veronica (p): Probably, I guess the families are obviously have a lot more at stake in wanting to help their child. I think teachers probably lack that a bit. Teachers are really busy as everyone else is and don't have the time. A lot of the things I ask people to do are fairly time intensive, yeah, and a bit difficult especially if it's an augmentative form of communication such as a communication board (....)
Veronica’s account touches on the question of the different rationality of care of the mother and the service system in this case the school, and the way in which disciplinary thinking may facilitate construction of boundaries which close off the potential for supportive connections. Carers of course were not generally constrained by disciplinary discourses, “and look at it as a cooperative role.” The reference to the possible lack of time available to teachers may well indicate by implication, another aspect of the taken for granted and invisible role of carers who apparently did have time.

For mothers, who in many cases had been informed by medical and professional people at an earlier point that their child was more or less worthless and likely to be a “vegetable” these moral injunctions from professional people to “believe” and work harder to get results sometimes seemed unbelievable. The public policy shift from institutional to so called community care was exposed in chapter 2 as only relevant for a relatively small group because care continued as invariably it had, to be provided from the family home. However in the context of changing discourses, albeit, unchanging ideology in public policy, there was also a shift in the management discourse on power and control towards devolution, collaboration, and greater consumer and community participation in major areas of state services such as education, health and social security. Once again carers found evidence that such discourses meant that no real transfer of power or change in the nature of caring culture took place. Just as community care policies had meant the persistence, and in some cases the extension of care by unpaid carers at home, these discourses offered no ‘real’
change in practices that would benefit them. In fact in the context of the study there was further evidence of state managed service systems extending control over informal carers.

Mike: The professional, I mean does the service system, and professional people (...) reflect the same sort of lack of connection with you, where you’re coming from, (...) Alison: Mostly they’re just so matter of fact (...) Yeah, like so much is given to you, so much of the responsibility is given to you as the parent, (...) but it’s sort of now if you’re the mother, say at school, if that’s what you want us to do you’re the mother, they’re not telling you, you know? ... educated guess, they’re not giving you the instruction for you to sort out and then say well I’ve looked at all the possibilities and this is what I’d think’d be the best. They’re saying well what do you think, you’re the mother? Then if things aren’t going right then you’re the cop out, you’re the one, oh you didn’t tell us (laugh).

Mike: Yes, that’s interesting, that sounds like a sort of reversal of the past where parents weren’t taken into account at all. Now Alison: It is a way, it seems to be a cop out in a way.

Mike: Right. So in some respects you lose control but by a different sort of process. Before ... they had everything and you had no say in it. (...) Alison: Yeah, I find it most, very interesting. (...) I can see what’s worked and what hasn’t worked over the years and I can, like in a physiotherapy session or something like that, I usually know more than they do. And so many of the things that have been any help whatsoever for her have been things that have been my suggestions.

Mike: Probably largely unacknowledged?

Alison: Well, yes, yes. One that does stick in my mind, (disabled daughter) was going to ... School and with her knees and ankles I thought that an exercise bike would surely be a good piece of equipment. All they had was the old fashioned, you know, like where the physiotherapist actually sits there and pushes the kids legs up and down but if they had an exercise bike, they see these things on TV and all the fitness stuff, so yeah, every kid in the place wanted to have a go, so I got this exercise bike for ... , it went over to school, she used to do a few minutes on it when she arrived at school. Before long they had a row of them. They all thought it was great and all the kids’d have these competitions, how long they could do these exercises for, nobody ever said, ‘hey what a great idea of yours, ...’.

Alison’s experience again highlights the different approaches to care and the influence of the professional setting in defining boundaries which made
acknowledging valuable contributions from an ‘unrecognised’ participant in this case ‘just another mum,’ difficult. The interpretation of policy initiatives and their implementation on the ground appeared to result in another form of ‘punishment’ of parents by the shifting of unreasonable levels of responsibility to them.

In this instance Alison was able to demonstrate the benefits of her extended involvement with a range of specialised therapies, in recommending in an educational setting something of her learning from a therapeutic setting, and interestingly perhaps constructing herself in a para-professional role. This extensive involvement and learning from different specialties was one of the interesting caring career benefits that many carers of disabled people gained from their work. In fact this facet of the disability caring career often played an important part in the way in which carers could support each other in the context of the Parent Exchange Group. The sharing of scientific information and a wide variety of applied science from a range of disciplinary contacts was a valuable feature of the caring culture established by the Parent Exchange Group. It was also one of the supportive aspects of the inter-meeting connections between carers. It was in effect another newer basis for reciprocation, often cultivated ironically from the isolationary experiences of professional discourse and settings. It emphasised the earlier reference to “the extended caring role” and the way a disability caring career took on something of the professional (Traustadottir, 1991).
The 'scientific' and competitive rationality of professional service appeared to work against supportive connections, and a genuine identification with the needs of others. Alison's experience in this setting almost perfectly mirrored her experiences described earlier which in themselves were repeated many times in the accounts of other carers that, "nobody ever said, 'hey what a great idea of yours, ...'."

The personal and the professional

These accounts open up and provide a view of contradictory and alienating elements within models and systems of care; professionals as personal carers and mothers as 'professionals'. So paradoxically it would seem that professional individuals themselves sometimes revealed their own sense of isolation within an alien system, and from a genuine connection with either clients and their carers or even with their own nearest colleagues.

Mike: Can you tell us what sort of strategies, in terms of your expertise, what sort of strategies, what sort of expertise you have that you specifically use in your job, just generally, not just in that circumstance. So you're a registered nurse, that's your primary background?
Kylie (p): Yes, and I think knowledge of the physiological system is obviously a help. I think though we more align ourselves with counselling. We have a social worker here as well and I almost feel I'm doing more that sort of a role. Of course, there's no clinical skills involved but a lot of skills that I've certainly learnt. Communication being the most. You know, I question myself sometimes. I go away sometimes and think, gee, did I say the right thing? And that worries me. But you've got to just keep moving on. (...)

From the discourse of "physiology", and communication from a
"counselling" perspective in a somewhat unexpected way Kylie's personal voice comes through, "You know, I question myself sometimes. I go away sometimes and think, gee, did I say the right thing? And that worries me". This is a professional service and setting, and no sooner does she hear herself in these words, but she returns to her other self, "But you've got to just keep moving on."

Mike: You're the sort of expert from day one as it were?
Veronica (p): Pretty much, (...) I think we've developed, I guess out of necessity, we've developed quite a good peer support network,
Mike: What with other people, speech..?
Veronica (p): With other speech pathologists within the area.
Mike: How do you manage that?
Veronica (p): Just through... Well I was based at ... when I was first employed and there's another speech pathologist based there as well so that closeness was good for networking and stuff when I first started, but the area had already established regular speech pathology support meetings and things like that where once a month we'd meet with all the speech pathologists in the area and discuss those sort of issues. But, yeah, as for having a senior or, yeah, someone to sort of authorise I guess what you're doing or just verify that you're doing the right thing, there's no support like that. So they're probably the two biggest areas of issue.

Veronica acknowledges the necessity of "a good peer support network" or in the vernacular of the thesis, a caring culture for carrying out her work. She also identifies that this can sometimes simply mean regular meetings with other speech pathologists to discuss their work "so that closeness was good for networking and stuff". It was one of the "biggest" issues. The comparison here with the caring careers of mothers of disabled people, and the needs for regular caring contacts and supportive networks, is striking. The function of the PEG in providing this same support for parent carers,
"so that closeness was good for networking and stuff" was very obvious.

Mike: OK. Just one last question. Is there any particular way that you would characterise your relationship with clients, whoever you see clients as whether it's the person with the disability or the family or mother, is there some particular way that you want to be remembered for or characterised in the way in which you interact or relate to them?
Veronica (p): I guess it's followed on from we're a voluntary service so a family has to want my input, yeah, so I guess then just as you know, helpful sort of role in that, you know, I've made something easier for them or improved the quality of life for their child and for their family and life, that sort of thing. That's probably, it's really difficult in terms of accountability a lot of the time identifying what it is that we've actually achieved so I think probably just care giver satisfaction a lot of the time is what we use to judge how effective we've been. I guess that's really important.
Mike: So that's your, that's the sort of feeling you have about the relationship with the carer, is that what you mean, and you get a sense from that, as to whether in fact, what you're doing has been good and worthwhile?
Veronica (p): Yeh, I guess the carers willingness to accept what you're implementing and has to carry it on, the feedback they sort of
Mike: How well they carry it on?
Veronica (p): Yep, and the feedback they give you about that, yep.

This exchange with Veronica seems to illustrate a tension between a more personal statement of her work and the more usual objectivity of the applied scientific discourse of the professional. The questions were framed in such a way as to presuppose a personal connection with a client, and

Veronica appears to move towards this personal identification with "their child" and "their family life" in seeing herself as being "helpful" and "making things easier". So it was that Veronica indicated that it was all a question of accountability and caregiver satisfaction. It is most interesting that the weight of all the assessment activity and evaluative processes was
'reduced' to this. The ever present need of being valued, and in this context having the carer on side, which was reflected in "feedback they give you about that" was a powerful reminder of the complexity of relations that made this personal affirmation so difficult to achieve for those who in this setting were expected to provide it.

Suturing a caring culture

In the end it seemed carers themselves took an overriding responsibility for stitching together a network of support that justified some claim to feeling and being part of some community or communities. The effort and the tasks seemed to define a career role inextricably bound up with disablement.

The accounts provide powerful insight into the lives of a group of individuals in a local community who were caught up in the discourses of caring and disablement. These discourses created a concerted reality of excluded lives, a reality which was met by personal efforts from isolated sites to produce meaningful connections. This resistance was in the form of a career devoted to both the creative vision of a connected and included life for a disabled family member and for the family as a whole, and the construction of a caring culture to preserve and support a personal reality, and the realisation of the broader caring career aspirations. On occasions this effort to achieve caring goals within more stable and predictable caring culture could be supported by individuals from the service system.
Alison: Oh, yes, I don’t think you would expect that a person could take that responsibility but if they have the, it’s a genuine interest, it’s a genuine caring, it’s almost, say (a local service provider) has got that sort of, it goes just that little bit further than just doing what she’s doing, but you know, there’s something else there. Those sorts of experiences it seems certainly do help to dull that sense of isolation a bit. But there’s lots and lots of others that just sharpen it up (Laughing).

The point of course was that it was a particular individual and not any particular system that helped “to dull that sense of isolation a bit”. This was in some respects another case of “just another mum with a similar child”, although in reality she was someone employed to provide services to disabled young people. It seemed she was able to step out of the seemingly alien and unfamiliar culture of the professional service system to meet and fully recognise the personal realities of the carers such as Alison with whom she had contact. That point of contact was a site for caring culture that linked carers with each other across the yawning spaces of isolation to other varied sites including the PEG which together framed a fragile network of caring contacts.

The accounts show that mothers as carers, and professionals operating out of state service systems worked within systems and models which were incommensurate with a personalised and holistic experience of care. Family, friendships, community and the state service system were themselves disclosed as an unstable array of social supports none of which provided a natural or reliable form of caring culture, but all of which may offer up some
fragment of such human connection, sometimes it seemed in spite of themselves.
PART 3

Caring conceptions and conclusions
Chapter 6- Relations of power and sites of change

In the heart of the thesis, chapters 3, 4 and 5, in which I examined my relations with, and the experiences of carers in the local community, I have ‘framed’ their story as a career in search of caring culture, a career which is deeply shaped by and embedded in the lives of the disabled people for whom they care.

The movement from chapter 5 to chapter 6 is an emergence from my engagement with the subjective world of the accounts of participants from the local community. It seems appropriate that in chapter 6 I attempt to reconnect these stories and my discursive analysis with the wider theoretical discussion introduced in chapters one and two.

Representing the lives of carers

Overall my thesis highlights the powerfully gendered constructions of the caring role and the experiences of carers which produce and reproduce this. It provides insights into the complex experience of the carer in the context of the family, the network of stitched up connections in the local community and the experience of involvement with the complex construction of disabled people locally. It depicts the isolation that characterised caring, usually experienced in the absence of any naturally occurring culture of support. This helped to sow the seed of a particular type of caring career or
working life. This was a career that was understandable amongst other things in terms of disconnections, and a search for caring culture.

It is important to emphasise that the idea of constructed lives was not just of itself the issue here. I would argue that all lives are constructed whether they be those of carers, disabled people or not. A critical point is that they might be constructed differently. Understanding the constructed nature of human lives as distinct from the ‘natural’ or fixed provides a dynamic perspective on the possibilities for social change, and this has been an important feature of this research. The appeal in the constructionist position is in the plausibility, the chance for change. Eva Cox in her 1995 Boyer lectures expresses something of this in referring to change; “In the possibility of change lies ‘hope’, the final figure from Pandora’s box of troubles. Without hope, we are discouraged from trying” (p7).

I am not necessarily assenting to the view that some essential aspect of the carer’s life was unconstructed and any constructed aspect was ‘bad’ per se. There was no evidence that women who were carers did not want to care, or that they simply rejected their construction as carers. There was however abundant evidence that they sought a culture for appropriately sharing the caring work they did, and also for recognition that their lives could be constituted by more than caring. The thesis then has addressed particular constructions which seemed to produce lives characterised by a propensity to social isolation, if not exclusion, and by patterns in Foucauldian terms of resistance to this (Foucault, 1977).
The idea of resistance here was concerned with carers shaping a career from their constructed lives as carers of disabled people. It was a career substantially formed by discourses of isolation and control, that marked the construction of caring and particularly caring associated with disablement. There was not however just a single story to relate because there were different traces or 'songlines' revealed on the landscape of carer experience. For many the powerful conspiracy of silence surrounding disablement was the starting point and for others it seemed the story began with the unacknowledged loneliness of caring within the complex intertextual links of marriage and family.

In spite of these differences I have chosen to characterise their stories as a search for caring culture which helped to shape, and was in turn shaped by a caring work, a career linked to disability. This is not the assertion of a theory about carers, or a single fixed narrative which can be tested and re-tested in research to distil a truth about a particular people's life. It is as I say my chosen way to characterise a range of complex stories, and in one sense it is no more than a metaphoric reference with valuable integrating qualities. It can be seen as a rhetorical device and a textual method in order to persuade (Atkinson, 1990). Put another way it is as Geertz (1993) has said of anthropological writings, that they are "themselves interpretations, and second and third order ones to boot (...) thus fictions; fictions in the sense that they are 'something made,' 'something fashioned' " (p15).
The idea of a metaphor here is most important. From a critical and poststructuralist point of view it is argued that this is the level at which we deal with reality, and at the extreme that there is no other reality (Derrida, 1976). For my purposes it provides for a subjective and mediated view of the material world. It is not simply the same as the sense in which we say, 'that the map is not the territory', because this implies that the text or the discourse merely reflects an external world. My broad assumptions which I set out in chapter 1 involved the discourse in the construction of reality in complex ways which reflected relations of power and resistance (Foucault, 1977). It is in this sense that my metaphoric portrayal of carers, in this case as embarked on a career and involved in a particular kind of search, should not be seen as more than a valuable integrating theme, and my own subjective reading connected with my research material. In fact my critique of conventional positivist research is its link to particular discourses to become predominant claims to truth about human experience and the material world. This of course reflects the system of knowledge and power bound up in disciplinary interests of which critical perspectives and postmodernism has so much to say.

With these ideas in mind and in the spirit of my own reflexive journey I have come through the research itself to a stronger appreciation of the meaning of multiple discourses. I have for instance a stronger consciousness now in chapter 6 of my own earlier subscription to something of an anti-medical discourse. By this I mean that I now believe that part of the purpose of my research and study at the outset was to find a stronger case for
reducing the power of this dominant medical view in the disability
discourse, and the replacement of it with something else. While I had
defined a thesis based on my experience with carers in an earlier phase of the
research, I have with some tenacity held on to a well developed writing and
theorising about disablement. This will not be too apparent in the current
thesis (the final version) because I did finally let go of a chapter entitled
‘Discourses on the construction of the disabled subject’, of which only textual
traces remain. The chapter perhaps reflected a hidden agenda, and older
allegiances and antagonisms were caught up in this.

At this point in time I would express a much greater sense of ease with a
medical discourse as such, and now express my concern and dissent with its
powerful hegemony and links to a techno-scientific discourse to the
exclusion of other valuable narratives. Chapter 2 presented an account of a
range of discourses which I believe drew attention to the wider contextual
influences of patriarchy and capitalism in the constructions of caring and
disablement. This reflective moment may seem like a small point in a
relatively large research project, however I think it is fundamental. It strikes
at the very heart of the issue of power and control and regulation of which
this thesis speaks. It is part of the wrestling with isolation and exclusion
which so depicted the lives of carer’s and disabled people. It talks to the links
between discourse and practice because the discursive dominance on the one
hand is the exclusionary practice and alienated culture on the other.
The penetration of economic and scientific discourse and patriarchy into every facet of life was very evident in the lives of carers in this study. These dominant discourses become bound up in institutional forms like family, community, and service systems which seem to offer caring culture as an integral and stable feature of their processes and operation. Paradigmatically speaking they are naturalised in our thinking and living, and we enter the living spaces of these forms with unnoticed expectations and knowledge about how they should be, and how we should 'behave'. If the discourse and experience are not one, then it seems we rely on our moral codes, also highly naturalised, to question only our own failings. The controlling force of these naturalised discourses and practices is by definition subtle and persistent, and so naturalised we tend, 'naturally' enough, to accept the discrepancies and disharmonies as our own. In a very real sense they are, and this is part of the complexity of the 'matter'. We might say as I implied earlier in this chapter, that we are our constructions. This brings me full circle, to the idea that part of the 'solution' may simply (perhaps not so "simply" really) be the need to diligently work at 'hearing,' and yes to avoid any aural dominance 'seeing', multiple discourses. This might be some version of my effort to hold in tension the medical and professional discourse along with the social and cultural.

In this context such a view of a solution to the presence of too much power might also be applied to the way in which carers at home were so thoroughly squeezed out of the public account of care of disabled people in the discourse of deinstitutionalisation and community care. Dominant
discourses eliminate or dismiss the ‘other,’ often through containment and management, and in the way of things produce exclusionary practices. There was in the research a strong sense that the caring culture to which women in particular are more attuned was rendered absent or alien by discourses of another culture. There was in fact a strong indication that the women, carers who participated in this study, were trapped in an unfamiliar cultural context which was not constructed to hear their voice. As Turner (1990) in referring to Goffman’s, Gender Advertisements (1979) reminds us, “women entering a masculine world both suffer from, and cause something of, a culture shock” (Turner, 1990p161). Carers were left to go in search of their ‘own’, and in this particular context it was not so much found as constructed, negotiated and orchestrated. Also it was often, perhaps paradoxically, experienced through the common disability connection. I say paradoxically, because the disability discourse was largely a medical, professional and economic construction which produced much of the sense of alienation and isolating stigma.

I believe then that the experience of women in this study was comparable to a sort of cross cultural isolation which supported by the accounts told here, included not only a break down of communication at the personal level, but the systemic dislocation with structures such as family which simply did not fit the paradigm ideal. This was never absolute, and carers were given hope that even where alienation existed in personal relations or in a system’s operation one day it could be different the next. Notwithstanding the uncertainty that this and other aspects of disability caring produced, usually
the experience was more predictably isolating. It was difficult to overstate the powerful and pervasive way the paradigm of normality worked to make any connection with disablement problematic, and it was because of this that the forms of ‘resistance’ adopted by carers were from within a disability frame.

**Careers to preserve intimacy**

Resistance then may be understood in this context in at least two interesting, and not altogether unrelated ways. The first expresses something of Deborah Tannen’s idea of life as a community and “a struggle to preserve intimacy and avoid isolation”, and this may also be viewed in relation to Carol Gilligan’s idea of an “ethic of care” (Gilligan, 1982). In these words Tannen (1991) was describing the world and life of women as distinct from men for whom life, “is a contest, a struggle to preserve independence, and avoid failure” (p25). In fact Tannen specifically refers to the different experiences of women and men as “different worlds,” borne of their different socialisations, and their communications as more or less “cross cultural”;

If women speak and hear a language of connection and intimacy, while men speak and hear a language of status and independence, then communication between men and women can be like cross-cultural communication, prey to a clash of conversational styles. Instead of different dialects, it has been said they speak different genderlects (pp 42-43).

The link of these ideas with the evidence of the thesis appears strong. Whilst the thesis has been very much a story about women it has reflected on the role of men throughout. Just as the idea of “a struggle to preserve
intimacy and avoid isolation” will seem consistent with the accounts of carers and my portrayal in this thesis of caring careers in search of caring culture, the “... struggle to preserve independence, and avoid failure” will strike a cord when considered along-side the stories of men in this thesis. It may well be seen that men too are often to be found in search of a culture of independence, and one that expresses their peculiar desire for “contest”. In the study it may have been expressed in their inability to connect with a disabled son or daughter when they were young and their dependency levels were high, but in some cases becoming much more actively involved when they could strike up an independent relationship and participate in a shared sporting interest, even if this was wheelchair sport. It was perhaps more common though that the presence of disability seemed to seriously ‘impair’ a father’s ability to relate to his daughter or son at all, and in some cases the threat to his independence or status or both was such that he denied any connection with disability at all.

It should be noted that in one case there was in relation to a father’s reaction, what seemed to be an inversion of this denial, and a sense of kudos from the connection with disablement. This is reminiscent of what Goffman (1963) discussed as a sort of wisdom that is perceived by others, about someone experienced or associated with deviancy such as disablement, and are acclaimed in some way for being in the know, “wise person” (p 43). The same father in no significant way participated in the care of his daughter, but appeared to enjoy the attention that the family gained because of the disability of one of its members.
Of course men too seek intimacy, and avoid isolation just as women seek independence and appropriate recognition for the value of their skills. In the constructionist discourse of this thesis I interpreted these differences as reflecting significantly the particular gender constructions of women and men in our culture. I acknowledged too, that other discourses including the discourses of biology and economy were also relevant.

Chapter 2 provided an introduction to theoretical perspectives on caring. In the normal society of the Parsonian model the caring role was natural and natural to women. More critically speaking it was constructed by a number of discourses, and very significantly in western culture by patriarchy and gender. The discourse of gender was a particular reading of the sexed body, but it may also be understood as bound up in an ethic and deeply embedded in moral and cultural understanding of womanhood and motherhood.

When Carol Gilligan (1982) in her *In a Different Voice*, challenged the Kohlberg justice based view of moral reasoning, she was challenging the idea of a “single mode” of human and social experience. It was a challenge to the limits placed around a view of moral behaviour which had in Kohlberg’s work reflected the masculine view of the impartial, public and universal. For many feminists however, it appeared as though she was defining how women are ‘naturally’ carers. It looked like a confirmation of the functionalist perspective which had assigned women to fixed roles based on a particular ethic of care. This was the morality of care for others and for
human connectedness in contrast to that of "justice" and human rights. Of course, as the discussion has suggested if women had a different moral voice it may be seen as due to different socialisation and a different social construction than any innate quality. This was society’s construction of womanhood tied to care. It meant that to be a whole person, a woman would have to take account of an ethic of care.

The work of Tannen and Gilligan suggest different but parallel ideas about the different construction of women and men, and the relative interests in connection and community. Resistance for women, and for the purposes of this discussion carers might be seen in one of two important ways, and both ways. It could be seen as either the ability to achieve a more balanced life by embracing the independence of the male construction that both Tannen and Gilligan seemed to discuss in different ways, or by achieving a caring culture in spite of the isolating independence discourse of a patriarchal world. Within the framework for understanding resistance (like power) as micro-physical concerns of any social setting, rather than as grand revolutionary projects, I am cautious about either overstating or simplifying the nature and form of resistance that I observed. The current study appeared to provide evidence of both these forms of resistance, and also it seems possible to consider a third because they were synthesised in the lives of carers. Thus, earlier chapters showed quite clearly I believe that carers shaped caring careers in ways which appeared to embody both an aspect of independent action with a strong sense of justice and the rights of their disabled son or daughter and the probity of their own treatment, as well as actions
committed to forging links and reliable relations with others. Carers it seemed demonstrated resistance in both the search for a fairer world and through connections with others.

If the currency of exchange or reciprocation in the professional process was some form of cooperation or compliance on the part of disabled person and carer in return for the benefits of professional expertise, then there was some evidence that this was not simply accepted uncritically. So, as earlier chapters show their response to the scientific and alienating culture of service systems and the rationality of professional processes was often to challenge both openly, and in the personal adoption of contrary approaches. This was not usually in any indiscriminate or reactionary way, that might unnecessarily preclude them from the useful advice of an alternative discourse, but commonly showed all the hallmarks of a highly pragmatic approach.

The idea that care and justice are not mutually exclusive is not new. Such philosophical concerns touch on the wider question of the enlightenment ideals of impartiality and the search for definitive and universal principles, driven by a logic of identity (Adorno, 1973). Such logic may be seen as that underpinning the cultural and scientific processes which construct and sustain discourse on disablement, and the professional disciplines and processes which define the sphere of public care. It confronts and abstracts the particular experiences of individuals including carers, in order to normalise, contain and manage their differences. In the process and in
conjunction with other discourses such as patriarchy, it constructs the forms of dominance and subordination which might indeed value the universality of principles of justice and independence over particular expressions of care and intimacy, and in this sense promote subcultures within dominant.

The logic of identity expresses one construction of the meaning and operations of reason: an urge to think things together, to reduce them to unity. To give a rational account is to find the universal, the one principle, the law, covering the phenomena to be accounted for. (...) The irony of the logic of identity is that by seeking to reduce the differently similar to the same, it turns the merely different in to the absolutely other. It inevitably generates dichotomy instead of unity, because the move to bring particulars under a universal category creates a distinction between inside and outside. (Young, 1990 pp98-99)

Marilyn Friedman in a paper called ‘Beyond Caring: The De-Moralisation of Gender’ says;

Like care and justice, commitments to particular persons and commitments to values, rules, and principles are not mutually exclusive within the entire panorama of one person’s moral concerns. Doubtless, they are intermingled in most people’s moral concerns. (...) At any rate, to tie together the various threads of this discussion, we may conclude nothing intrinsic to gender demands a division of moral norms which assigns particularised, personalised commitments to women and universalised, rule-based commitments to men. We need nothing less than to “de-moralize” the genders, advance beyond the dissociation of justice and care, and enlarge the symbolic access of each gender to all available conceptual and social resources for the sustenance and enrichment of our collective moral life (Friedman, 1993 pp269-271).

Friedman’s focus here is the moral philosophy of Gilligan, and the tendency to “moralise” along gender lines but it is clear that the major descriptive dividing lines of care and justice and the various personalised and universalised characteristics that pertain to these respective divisions are not viewed as “mutually exclusive”. Porter (1991) observes similarly that we
tend to be so conditioned to dualistic thinking, "that we still approach many of these issues as if traits are essentially masculine or feminine" (p169). In responding to Gilligan's concept of different moral voices Porter proposes another way out of the care/justice dialectic;

What I am advocating is a synthesis of voices and a notion of identity viewed as a self-in-relations. This synthesises individuality and sociality (Gould, 1978; 1988) in that it takes into account the self, others, the context, and the contextual self. What Gilligan has construed as 'different voices' cannot be simplistically combined in the development of a strong sense of self. As a vision for future relations, I support the emergence of self-in-relations (A↔B) rather than self-and-relations (A+B), or the relational-self (B+A). Where the emphasis is on the last two combinations, it is very difficult for one side of the convergence not to dominate... (p169).

This approach begins to look very like the synthesis in practice that carers in the study embraced as a regular part of their lives. Discourses construct reality, and if as Tannen proposes women and men grow up with different discourses they may also grow up in "different worlds". It begs the question about how it is that women in this study for example could seemingly cross the divide. In a patriarchal culture the sense of being unheard, at a personal level becomes for many women a sense of being part of an unfamiliar even alien society. The compulsory and often extended involvement of carers in this study with private and state operated systems around the support needs of a highly devalued person, may help to explain something of their ability to cultivate an identity which looked something like Porter's self-in-relations. As Minnow (1990) suggests, a social relations approach
presupposes a basic connectedness rather than an essential autonomy of the individual.

The research has shown that the construction of women as carers, and their assumed role in the performance of caring duties in the private world of family and home, was the essential reality for participants. The impact of a disabled family member both qualitatively and quantitatively on the life of a carer involved her in powerfully isolating experiences. Her caring experience could be described as a career devoted to the realisation of her personal goals for a disabled family member within her aspirations for a family. Like any career there was evidence of adjustments and changes over time in response to changing demands of the work, changing personal competence and changing opportunities for the expression and performance of one’s work in the environments with which one interacted.

The opportunities provided by a career in the more usual sense, included significant contact with a group of people regularly, and systems for understanding and evaluating one’s ‘performance’ of duties which are both formal and informal. Usually a career develops within work settings which a worker chooses, and which permit some degree of common understanding of the purposes and processes of the work, and development of a culture that is personally and socially satisfying for participants. It is not uncommon in this depiction of a career for there to be little distinction between the personal and career identities of an individual, although clearly there is ample evidence that many people develop a personal and social life
of family and friends quite separate from their working careers. They fulfil varied aspects of their being (or becoming).

The caring careers of women caring for a disabled person contrasted sharply in a number of ways with this typical account. Overwhelmingly however, in these local narratives it was defined and formulated out of adversity rather than a ‘simple’ choice. It might be characterised as a form of resistance in itself rather than an expression of power, and perhaps as a mark of courage, and the indefatigable ‘nature’ of the human spirit it developed and grew, in often highly alienating and even hostile environments. It was further distinguishable by the way in which these carers composed from the fragments of more familiar connections, a caring culture to support their caring work. It was a form of community, where no such reality of community existed.

Caring and ‘self preservation’

This brings me to the second idea for conceptualising resistance. In a not unrelated way of understanding resistance in this context, and perhaps shedding further light on the nature of the caring careers of carers in the study is a wandering sort of divergence from Goffman’s idea on the ‘preservation of self’. This idea was described by Goffman in relation to the experience of inmates under the conditions of a total institution (Goffman, 1961). My interest here is most specifically in the idea of the ‘preservation of self’, although there is also some relevance in the idea and circumstances of
the “total institution”. Goffman’s examination of how inmates preserved self may not be dissimilar to the way carers looked after themselves in the caring career. For Goffman ‘self’ was the set of adult roles constituted in the everyday ‘outside’ world, the character of which was threatened by the oppressive qualities of the ‘total institution’. Superficially at least it shares something of Tannen’s idea of “a struggle to preserve intimacy and avoid isolation”, and as I present carers’ stories here, doing this in association with individuals who themselves were as strangers in their own land.

In the wider issues of this thesis on care (and returning to the issues raised in chapter 2) it is interesting to note that Goffman’s work on institutions, and Asylums (1961) in which his ‘total institution’ thesis was pivotal, contributed to the movement for deinstitutionalisation (Fox, 1993; Cheek, Shoebridge, Willis & Zadoroznyj, 1996). It is argued from a critical and feminist point of view that his perspective represented a humanistic discourse appropriated by the state to abandon its responsibility for care and to shift it back to ‘community’, and unpaid carers at home (Hudson, 1991; Lloyd, 1992). To talk of this shift back to community, the family home and privatised care as the site of oppression, emphasises very well my own case for considering Goffman’s ‘preservation of self’ and ‘total institution’ narratives as relevant to the experience of carers themselves. It also underscores the Foucauldian position described in earlier chapters on power and its complex expressions in disciplinary, regulative and normalising discourse and practice, which might be just as relevant to the family as to Goffman’s institution (the asylum).
As I mentioned in chapter 4 women in this study did not indicate that they
did not want to care, or that they rejected their construction as carers. They
did however strongly indicate that they wanted a different culture for their
caring work. They also sought recognition that their lives could be
constituted by more than a caring role. It is in relation to these ideas that I
believe Goffman’s idea of the ‘preservation of self’ might be seen as relevant.
I am representing the carer’s of my study as individuals who were
significantly oppressed both by their construction as carers in the first
instance and more especially by their construction as carers of disabled
people. Their careers as disability carers represented an important re-
construction of the oppressive quality of disability caring, in which they
attempted to re-define for themselves a personal subjectivity which
accommodated their sense of obligation and caring responsiveness to a
disabled family member. Because the overriding hallmark of disability
caring was the personal and social isolation associated with the profoundly
devalued character of disablement, the career itself was both impelled and
constrained by a search for caring culture. It was possible to think of this re-
constructive process on the part of carers as both a form of resistance and
also as a preservation of self, a self which unavoidably embraced the social
construction of carer, and some ideal of a personal self acting independently
in the world. The latter point touches on the idea that participants wanted to
be recognised and enjoy lives that were greater than that constituted by
caring. In the disability caring career participants showed they could establish
some sense of an independent identity, and although it was always within
the caring frame it was not a mere acting out of an oppressive discourse of
care. What may have been evident was women creating a space, not merely to regain something lost, a Lacanian “desire” (Lacan, 1977), but a positive affirmation of themselves, often through their own rejection of alienating forms and their arduous manufacture of caring culture. This looked more like the positive form of resistance and “desire” of Deleuze and Guattari (1984).

In fact this was a matter I alluded to in chapter 2 in drawing attention to Janet Finch’s cautionary note about seeking non-sexist forms of care, and in the process abandoning caring of affection and choice (Finch, 1983 p15). Further, Hilary Graham (1991) referred to Glenn (1985) in highlighting how in the case of some black women the private sphere and family was not a form of oppression as it is for white women. They were oppressed by the lack of a private space. Also, Keith (1990) and Morris (1992), speaking as disabled women and feminists stressed the complexities of focussing just on the needs of the carer rather than the caring relationship, and rejecting family forms because of the sexist ideology which maintained them, in support of institutional forms which may be less desirable.

Given both the physical and psycho-social stressors that may accompany caring for a disabled family member in the public space and the often unshared and lonely experience of caring in the private arena it is not surprising that women may piece together in their own way a patchwork-quilt-like form of personal and connected lives (Balbo, 1987). Balbo says;
(...) in our 'service society' contradictory trends are emerging. Not only do women 'value what they are doing', as the quilters did, there is widespread awareness that we only survive as human beings within capitalism and patriarchy because of servicing work, however unrecognised its worth might be in enhancing the quality of our lives (p56).

Where the response of service systems was alienating and the threat to the personal and familiar care by formalised measures and means loomed large, women as carers resisted and picked their way around, carefully compensating for these caring deficiencies, and putting in place as best as they could a supportive life. They did this for themselves and for their family including the disabled member. Clearly, in these diverse ways they constructed worlds to connect for themselves and their family, and to gain independence, personal space and the means for preserving and cultivating other senses of self.

There is a sense then in which the career was born out of adversity, and a set of oppressive experiences which were loosely speaking common to disability carers. These do not add up to the "total institution" of Goffman's asylums. Nevertheless it is worth identifying the general conditions out of which such careers may emerge, because it may help to better understand their attributes and development. To some extent this has already been done, in so far as I have referred to a number of key aspects of the disability carer's experience, and their formative qualities.
Other texts, some of which have already been discussed in chapter 2, and only some of which were specifically relevant to disability caring, have convincingly outlined the nature and extent of caring work (Oakley, 1974; ABS, 1988 & 1990). More specifically, Bittman (1991) has shown in the Australian context how families use time, and specifically highlighted the continuing role of women in household work. Also in the Australian context, Cant (1991) offers a most valuable and detailed account based on time use studies using personal diaries (a quantitative measure) and interviews (a qualitative perspective) of the caring ("tending") work of mothers of disabled children. The sample for the study included only mothers of physically disabled children (spina bifida and cerebral palsy), and as Cant points out this aspect of the sample may be important, "so that differences in the tending work required to meet children's special needs can be readily understood" (p17). Although my thesis has not involved a detailed focus on the activities of caring in any measurable or comparative sense, chapter 1 did provide by way of a basic context the disabilities represented by carers in the study. There were a cross section of disabilities represented, although broadly involving developmental disabilities according to the definition outlined in chapter 1, and intellectual disability was most common. I make the point here that the evidence of my thesis is that regardless of the specific disability label, there were a range of extra caring duties associated with a family member having a disability, and the complex interdependencies that accompanied this. Indeed, without just the sort of study undertaken by Cant it would be difficult, if not impossible to measure their complex impact on caring. Furthermore, as this thesis has
emphasised the impact and isolation associated with disability caring is intimately connected with the very silent and unshared quality of the association with disablement. This is more closely aligned for example with the perspectives of Goffman on stigma and its ‘spread effect’ and debilitating results (Goffman, 1968 p43), a point to which Cant also alludes (Cant, 1991p264).

It is clear from Cant’s work that women as unpaid carers of disabled people spend a significant portion of their time involved in the work of supporting other members of the family, including but not only a disabled family member (Cant, 1991 & 1992). Typically, as my thesis indicates, and Cant herself found, they carry out this work in extended periods of isolation in the private space of the family home, even though as the evidence suggests there are increasing demands from the state through professional service system interventions. This sense of isolation is intensified when disability is involved because as Cant suggests; “friendship networks are disrupted by the extended dependency needs of children with disabilities” (p218).

A feature of the conditions of the “total institution” outlined by Goffman (1961) included daily life carried out in one place, in the company of large numbers of others, where individuals were treated in most non individual ways. Under these conditions typically experienced by inmates of asylums, boarding schools, prisons and orphanages individual identity was at risk and inmates developed ways of preserving self.
A Total institution may be defined as a place of residence and work where a large number of like-situated individuals, cut off from the wider society for an appreciable period of time, together lead an enclosed, formally administered round of life (p11).

For carers of disabled people most of whom lived and worked in the family home, the notion of the total institution appears totally irrelevant. However, what is important and useful here in Goffman’s concept is the idea that under particular sorts of conditions, particular sorts of practices and career patterns may be evident. In particular he proposes that inmates develop unofficial and informal practices which constitute an “underlife”, and a form of “secondary adjustment”. This is distinguished from a “primary adjustment”, which refers to the inmates’ normal fulfilment of the disciplines, expectations and obligations as a participant in a particular social arrangement (institution). Goffman (1961) describes “secondary adjustment”,

...as any habitual arrangement by which a member of an organization employs unauthorized means, or obtains unauthorized ends, or both, thus getting around the organization’s assumptions as to what he should do and get and hence what he should be. Secondary adjustments represent ways in which the individual stands apart from the role and the self that were taken for granted for him by the institution (p172).

Goffman provides an example of prisoners using their rights to library facilities and ordering books, “the minds of prisoners being something that can and ought to be allowed to profit from reading”, as a means “not for self-education, but to impress the parole board, give trouble to the librarian, or merely receive a parcel” (p172). “Secondary adjustment” then was used according to Goffman, by patients and other inmates, as a means of
preserving a sense of self and as a form of resistance in the context of a particular set of conditions, and may he suggests be more generally observable.

The practice of reserving something of oneself from the clutch of an institution is very visible in mental hospitals and prisons, but can be found in more benign and less totalistic institutions, too. I want to argue that this recalcitrance is not an incidental mechanism of defence but rather an essential constituent of the self (p279).

Carers of disabled people as the evidence of earlier chapters makes abundantly clear often operated under conditions which superficially appeared stable, familiar and customary. Carers were highly cooperative participants in a range of regulatory rituals of marriage and family. Their construction as carers was very complete and practised and reinforced daily within a normal paradigm and its disciplines, which was rarely challenged in any open sense. This sort of cooperation might reflect social role conformity to the caring role expectations of the wider world, but the extent to which the family can be seen as ‘total institution’ this would in Goffman’s terms constitute a “primary adjustment”. Indeed, in Goffman’s words and bearing in mind carer experiences described in this study, family may be viewed as a “more benign and less totalistic institution”, but nevertheless a site where a carer might stage actions of self preservation, “secondary adjustment”.

These cooperative appearances often disguised an intense personal struggle in Tannen’s words, “to preserve intimacy and avoid isolation”, and through
a caring career to establish a sense of caring culture. This struggle was a common feature although as I have indicated in earlier chapters, it sometimes arose out of different discourses of disablement, and the different patterns of alienation associated with lives that were thoroughly devalued. The ‘silence’ surrounding the unexpected and monstrous quality of disablement, the inability to be heard and to share at a personal level, and the segregated and isolated burden of care within the family, contributed to a sense for carers of being imprisoned in an unyielding and insensitive culture. This sense of entrapment and of alienation was not removed by establishing relationships beyond the family. The link with disablement often resulted in the dramatic loss of regular friendships, a significant breakdown in the usual reciprocal power for neighbourhood relations, and a loss of the usual opportunities for social relations associated with one’s child participating in local school and out of school activities. Carers lacked a culture of care for their own caring work, and for the development of any other personal life.

It is in this context that one may begin to understand that Goffman’s concept of the “preservation of self” through practices which resemble “secondary adjustment” may have some relevance to the carers of this story. I think the value and relevance in his observation on this is not in the “secondary adjustment” per se, but in the idea that individuals who are disciplined and regulated, denied choices and individual expression in extended and repressive ways may continue to ‘cooperate’ with ‘arrangements’, whilst seeking other forms of expression.
Carers were shown by the accounts to have cooperated with 'systems' in all respects at the same time as using them in a way that they themselves saw fit. Furthermore, they also demonstrated an ability to be significant critics of these systems and openly challenged them at different times. I believe these were opportunities in the public sphere which were more difficult to express within the relatively more repressed environment of family and home.

Excursions into the public space of the service systems was in itself an opportunity for an 'escape' from the discipline and repression of family. It was in this context that the following extracts from one of the Parent Exchange Group meetings reveal something of the way practices of manoeuvring to find space and express self took place, usually from within the acceptable limits of caring work.

Bev: *We do sacrifice ourselves for these children.*
Helen: *But who wants to think about it.*
Sandra: *Well sometimes we do because then we wallow in self-pity.*
Helen: *That's why I don't like to think about it.*
Sandra: *Sometimes, like what's the alternative, if you don't wallow in self-pity, what's the alternative.*
Bev: *Where can I get the gun.*
Ingrid: *I could have done with one on the weekend.*
Bev: *So maybe making the sacrifice bit, like Alison doesn't realise that the sacrifice thing to a degree when she's got an opportunity to be a little bit selfish is because she's used to sacrificing so much. Just takes it in her stride.*
Carol: *Alison is so busy with (disability social club) and (disability sporting club) and Helen: *But you must get something out of going to (social club) and (disability sporting club) and all this sort of thing, get something out of it for yourself.*
Carol: *You feel like it don't you.*
Helen: *You probably got a lot out of ... .* Alison: *I didn't in the beginning when it was getting going and you could see that that was a good thing for the kids to have, I wouldn't like to do that now. It just that it happened so that (disabled daughter) can just go and enjoy ... . And I don't.*
Carol: Once you're in no one wants your spot, I mean we get something out of it because we're giving something, but Alison's job is quite, it's worse than mine because she's the treasurer, got to go in and do the wages and
Alison: I probably quite enjoy it. That side of it, like tomorrow I'm going to a seminar thing, ... community ... and being treasurer of (disability social club) entitles me to go to that and that's fine because that's work skills.
Helen: But you're going in there, you're seeing people and you're mixing with people so in a way it's giving you a bit of a social life or whatever.
Alison: I feel that the work (for disability sporting club) is actually a social, basically a social outlet as well, so we all, and it's something that (husband) can be socially involved with as well. (...)

It seems like “self pity” might be the only form of self indulgence for Sandra, and Bev appears to be feeling something of this in her references to “sacrifice”. She suggests that Alison cannot take the opportunity to be “selfish”, she's so used to self sacrifice, and perhaps also cannot tell which is which. Many of the carers however were involved in activities and committees associated with their child’s disability, and the question of these representing a social outlet for Alison in particular, and also Carol was the focus. The exchange is about personal space and freedom to be oneself, but it feels very constrained within tight boundaries, and Alison can only concede, “I probably quite enjoy it.” Of course this restraint about the pleasure that is experienced in being involved in activities away from home may express something of their limited personal value, and the continued connection with caring and disablement. It may also speak of sense of guilt associated with doing anything for oneself.

Sandra: But that's how I look at it. To me it's a social outing, this.
Ingrid: Oh yeah, I enjoy it but I was just saying today I could have quite easily, if I thought oh they'll be there, but it's just that sense of commitment, the same type (...)

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Fay: Well I have to, or otherwise I'd be a wreck. 
Mike: (to the Group as a whole) What sort of things do you do to? 
Carol: Well getting involved in doing P and F at school (...)

The "this" at the end of Sandra's opening line is a reference to the Group meeting itself. Whilst there is a general feeling in the Group that the meeting is socially indispensable and Fay suggests she would be "a wreck" without it, Ingrid draws attention to its limitations and how she may see it as part of the commitments. The "commitment" may well be a reference to her sense of the burden of her constructed self and the inability to simply do something for herself as a change. Carol then returns the discussion on "social outlets" to the extra-familial, but nevertheless caring context of the school P&F meetings.

Carol: Well I'm starting to do things that I want to do, like I do ceramics every Tuesday, and if one of the kids is sick on a Tuesday I'm so angry, if I have to miss out on ceramics I'll say you're not that sick, he felt that bad... You start to take back some of your time. 
Mike: Does anyone else have an equivalent of ceramics. 
Helen: Yeah I have my massage. 
Mike: Where do you go? 
Helen: Yeah you've got to do it because sometimes I think, it's the only thing I've got. 
Sandra: Why don't you think about taking up a pottery class? 
Helen: At the moment I prefer to do something where I can get out and 
Alison: Yeah, you need to get out 
Sandra: I'm going to aerobics tonight, take her ... so that gives me even an hour. I can appreciate what you're saying cos I got rid of the boys on the weekend because of (disabled son's) sport so that was, (husband) will take (disabled son) away to sports. He won't just stay home and mind him while you go out for a while or something like that. I had the benefit of that but I know what you mean about searching, you just want to be 
Dianne: I want to be my own person. I mean even if I go to the hairdresser's
In this exchange the discussion seems to have loosened up somewhat, and there are indications of a more open expression of feelings. It reveals the small but significant actions of carers to “get out” and do what might be “the only thing I’ve got”, and to get “even an hour”. The exchange also illustrates more closely something of the “secondary adjustment” practices. Thus, Sandra was able to ‘organise’ her husband into taking care of their disabled son, paradoxically by getting “rid” of them because “he won’t just stay home and mind him while you go out for a while or something like that”. It was clear that in Sandra’s family sport was the one reliable basis on which her husband would be responsible for their disabled son although it was equally clear that Sandra ‘managed’ this experience overall, and in this case in order to gain some space. Dianne suggests that any experience of this kind offers the potential for just “being her own person” in this case the hairdresser fulfils the need. This may have been a good portent for hairdressing business, and suggestive of potential marketing strategies, but more specifically here it was illustrative of the ways women must organise their lives to achieve some form of personal expression.

These exchanges took place within the context of the support group. It highlights its function in providing some space, a supportive culture of like minded people who may not always declare all their ‘true’ feelings even if they new them. The following three participants suggest you could be heard without fear of non acceptance, gain valuable insights to support caring work and people support each other. It was a measure of caring culture.
Jane: I just think this is good because I can say whatever I want to say and if somebody comes in and they’re upset and I can listen and I think, ‘God that’s happened to me. Oh terrific.’ And they did this and that and I keep it all in me mind and I’m going, I could try that I never thought of that. So I find it really helpful, because no-one is really dictating to you. They’re listening to you. You can ask whatever you want to ask and people don’t look at you and say, ‘Well why would you want to ask a stupid question like that?’ You can say whatever you like basically. I enjoy it.

Carol: Yeah, so I don’t tend to tie my time up too much now. I enjoy going to the PEG meetings, the only meeting that I go to, because it’s a casual sort of meeting. I don’t have to take minutes and all that sort of stuff. I like to spend my time at home. (Carol had indicated earlier in the interview her strong personal choice to be at home while the children were still at school) If the kids have got something on at school, then I’ll go in and get involved in that. I work at the P and C of course and I enjoy it, but that’s starting to get me down as well because that’s another thing that ties me down as well. And I know that when he goes to this school, over here, you have to be obligated to do stuff over there as well.

Mike: So is that the benefit of PEG, that Group in some way. Danielle: Yeah, yeah it is a huge help just to realise that the fact that your own parents just can’t cope with what you’re telling them, it made me feel less isolated, yeah, you gradually feel better when you realise that you’re not the only one feeling that way, you’re not the only one feeling isolated, you’re not the only one feeling alone, you’re not the only one feeling you’re miserable and revolting and, yeah, it makes you feel a lot better.

Discourses on caring create and re-create the caring subject and this was constantly patterned and reinforced by the ideology of family, community and state operated systems and professional practice. It was evident too, and the various exchanges highlighted here illustrate this, that in a Foucauldian sense carers themselves and their peers, reinforced their ‘subject’ status, in a way that showed both an ‘identity’ integrally involved with caring, and their frustration and dissatisfaction with the way this constructed role limited any other personal expression.
Caring embedded in the ‘normal’

To a significant degree the isolation and exclusion of disability caring careers occurred behind the screens of apparently caring institutions such as marriage, family, community and the service system that were as highlighted in chapter 2, centrally constructed around and produced by discourses of care. This was a central paradox in a research that often seemed permeated with paradox. The construction of caring and the construction of disablement involved a complex intertextuality with some discourses, particularly a gendered and economic (capitalist) discourse of women as carers, and of disability as non productive and medically (biologically and thus socially) disordering, predominant. It is interesting that it can be seen that capitalist economic discourse has constructed and consigned (in spite of any recent appearances to the contrary, see references in chapter 2 supporting this) both women and disabled people to the non-economic and non-productive realms of the private non-economy; the family. It is in these expressions of patriarchal control and finally through control of labour, that women and disablement are brought together.

These discourses were in a very real sense more than the meaning and effect of their separate constructions. There was a personal and social solitude around the meaning and effects of giving birth to a disabled child and the isolation of caring which was often accompanied by energetic and active (“I was basically running all over the place having all these different things happening”) carer lives. The power of the experiences to define a carer’s life
appeared to be masked, and understanding and supportive connections, and spaces to experience oneself beyond caring did not come easy. This was in spite of the fact that carers were surrounded by these apparently caring structures of marriage, family, community and the ‘welfare’ state. It seemed these structures were simply an integral layer of the mask.

They took shape around the array of seemingly simple commonsense ideas, and the natural and taken for granted. They appear so simple, but their complexity and the realities that they conceal, lie comfortably embedded in the paradigm ideals of care, family, community and what we facilely understand as ‘normal’. The construction of caring when linked in the disability carer to constructions of disablement bring the carer face to face, or more accurately perhaps pull the carer in to the wash of abilism. The normalising discourses and practices of a modern society mask and manage the fear of disorder and difference with modern scientific and professional ideologies and practices such as labelling, special education, rehabilitation and integration.

The discourse of the ‘normal society’ works in these ways to contain difference and the potential for social disorder. It highlights the discourse of disablement as a paradox in its reinforcement of normality and an ordered world by its construction of disablement as a threat to this order. The constructed body becomes paradoxically written and read as disabled so that difference is denied, and then it is reconstructed through these normalising professional practices so that it is regulated, managed and contained.
Furthermore, the paradox extends to include those associated with marginalised individuals, such as carers of disabled people themselves who because of their association may experience loss of opportunities for personal expression, social acceptance and become isolated from the usual forms of social connection and exchange.

These outcomes meet with different and sometimes paradoxical responses by carers. They may turn further inward to fulfilment and seek community in family, in the private sphere with husband and children. Sometimes the relationship with a disabled family member became the most valued and rewarding. It was the strongest indication of caring culture. They become involved in disability groups and define community around the relationships defined by the common experience of being carers of disabled people. Finally, for most it involved cultivating a number of one off contacts and acquaintances where reciprocation was either not the issue in any direct sense (like in the casual telephone contact) or it was achieved simply through shared words and hearings. These were supplemented by a range of contacts and acquaintances associated with disablement, some of which included the professional service system, particularly where an individual professional person could identify personally with a carer. A carer’s life already constructed to sustain family, became caught up in a category which was ideologically constructed to define and regulate difference. In this complex process of alienation, carer’s invisibility, isolation and solitude became all the more deeply experienced, and the search for caring culture all the more relevant and meaningful.
At the centre of these paradoxes was an ideology of family and friendship, which concealed important differences in the experiences of men and women within. Carers hidden within the discourse of family were apparently involved in positive sharing relationships, when in reality they were despairing at their isolation, personally and socially. The acceptance of ‘normal’ discourse on friendship, family and community, like caring, may often limit our ability to think of or to construct these discourses differently so that the range of experiences that are part of the realities of ordinary lives and the people themselves can inform the development of other practices and to construct other more supportive and inclusive ways.

The search for caring research

In the research process I have tried to understand and move cautiously with this complexity and these personal experiences, and increasingly this has meant simply being with people. The experience of the research itself was that the most valuable support and learning was associated with the personal identification that came from listening and being with people. There was more to good social research of this ilk than this, but without it, it was difficult to recognise the real value. This at least seemed like caring research, and in its absence it was easy to see how this approach to research itself could simply become another layer in the construction, regulation, and disempowerment of women as carers. In this a scientific discourse sustained
within gendered models of knowledge and research seemed most relevant (Harding, 1987; Lather, 1986 & 1991; Reinharz, 1992). My earlier reference to Freire (1972) with allusions to Hegel (1967) and the idea of solidarity in praxis, were now being informed more by feminist critique on masculine forms of knowing.

This discussion then concerns my role as the researcher and author in terms of its complex link to the participants in the research and the idea of caring. Through this reflexive account I have attempted to describe and understand my position in relation to the individual participants, the research and the caring experiences they relate. This included and was inseparable from the caring culture that the process of the Parent Exchange Group cultivated. In conducting the interviews I did not temporarily suspend my sense of this purpose and meaning in the function of the Group. This involvement with the Group was undoubtedly a qualitatively important aspect of the research which contributed to the willingness of participants to share their experience, and interestingly perhaps further contribute to nourishing a culture of support.

Based on my experience of the research it was difficult to see how social research generally could contribute to a process of change, without the benefit of a reciprocal praxis and a highly reflexive approach. It appeared on reflection just all too easy to simply permit with this approach to research
for it to become one more framework of concealment for the exercise of power. There needed to be some system and a systematic process in place for unmasking where possible those practices that appeared as liberating, but really served as regulatory. In my experience a mere reflective attitude was not enough. If it was that in the final analysis, I was able to come through the process of research having myself enabled more than disabled, then as I observed in chapter 3, it will have been the careful workings of a system of processes. Amongst other things this would allow others to be heard (provide for reciprocity), and the researcher’s voice to be checked and balanced in a process where otherwise there may be undue control.

If part of better understanding the workings of care is an appreciation of the relational complexity, and the caring and support needs of everyone involved, then the support process in collaborative research itself was not exempt from these complex social dynamics. I believe the professional narratives told here showed something of these relational complexities, in so far as service system providers themselves revealed somewhat paradoxically, their own needs for care. They worked within systems whose logic was often irreconcilable with the needs of those for whom it provided, their own needs, and within a culture that seemed inherently antithetical to caring.

Kari Waerness (1987) in advocating greater theory on caregiving work suggests, such systems based on scientific rationality and professional authority and power contrast with that of informal care based on experience and local knowledge. In an allusion to Gilligan’s (1982) “ethic of care” thesis,
Waerness proposes the need for a different rationality of care based on an image of the “sentient actor” who is both “conscious and feeling”, rather than the dualism of the conscious, cognitive actor (the professional) and the image (and debt to Freud) of the unconscious, emotional actor (pp217-219). I think this indirectly says something about the role of the researcher in the context of community work and the collaborative processes that I have been describing.

The question of research action and how to be involved in the process actively without simply reproducing the very patterns of power and control that one is investigating speaks to postmodern meanings of power, not just the broader contextual power of society and economy. These postmodern ideas encourage us to view power more in terms of everyday life and relations. These are the Foucauldian relations of power which are not necessarily chosen or part of conscious actions (Foucault, 1982). An important point to be made here is that in this sense power is not necessarily oppressive and it can always be resisted (Solas, 1996). It is part of the substance of all human relations, the basic substance of action, including caring action in caring relations.

This postmodern perspective contrasts the modernist “responsibility to act” with a postmodern ethic of a “responsibility to otherness” to which I alluded in chapter 3 (White, 1991). The idea of informing our political engagement, and drawing on feminist and postmodern theories I would maintain that all engagement is political, with a counter balancing ethic in this way seemed to
provide an extended perspective to the combination of factors I identified in chapter 3. These factors included a range of interlocking methods such as those used in this research, the participation and extended involvement with the Group, the critical (I use the word in its positive and constructive sense) contact with an external adviser/mentor (in this case my academic supervisor fulfilled this function), and the conscientious desire to see it from the perspective of the other. In chapter 4, I also suggested that the writing process and the way in which it was integral to reflexivity and thesis construction should be included in the model of research that I was constructing for myself as part of the necessary conditions for ‘seeing’ things differently.

In Stephen White’s words a sense of “grieving delight” informs a responsibility to otherness: “delight in otherness”, stopping short of grasping and owning, grieving or mourning for “the fragility and momentary” character of the other (White, 1991p129). In this portrayal of the issues White is influenced by Lyotard (1984) in his references to a “mood”, which represented something of the change from modernism to postmodernism, “... the dimension of grief might resensitise us to injustice. The dimension of delight likewise might manifest itself in a deepened concern for fostering difference” (White, 1991p129). Such a perspective seems to create a space for the other in whatever setting we are in: to be more the well informed listener and respondent, and in some sense perhaps as a guest in the company of others, sensitive to human strength, fragility and differences, and an active ‘harmonious’ participant in human becoming (White,
A “responsibility to the other” to otherness could balance the dominant modernist ethic of a “responsibility to act” and the sense that in research like every other human endeavour we must seemingly master and control a process and outcomes to have accomplished anything. To inform our research actions and I would suggest our caring relations and our public policy by such an ethic may create a more balanced praxis where a little space for reflection tempers the rush to act and smother difference (Fox, 1993; Deleuze & Guattari, 1984).

There is something relevant too, in more ancient wisdom of the Taoist saying, “wu wei” which has been variously translated to mean acting in accordance or in harmony with the nature of things or the context (Needham, 1956 cited in Capra, 1975), and “no monkeying around” or without combativeness or egotistical effort, and “no ado”, which can be read as, “not-acting, an action responsive to the demands of the context” (Hoff, 1982, cited in Flemons, 1991p72).

In the research process Habermas’ s theory of communicative action along with the conscientization and dialogical processes of Freire were valuable critical guides for interaction with research participants, in ways that gave effect to a more balanced praxis (Habermas, 1984; Freire, 1970). This was the balance of theory with action in the more conventional readings of action research and community development, and the desire to create opportunities for change which was produced from a critical and emancipatory consciousness that guided the times that we worked together.
as a group. Something of this quality is contained in the extended meeting exchange included and discussed in chapter 3. I am suggesting here that this may be supported by a postmodern perspective, and that there is the need to balance this modernist compulsion to do things and make changes towards some notion of a better world with a responsiveness to the ‘other’, and the need to carefully work over discourse in order to disclose its hidden hegemonic interests. I believe these ideas are closely linked to my own experience in this study and the need for me to step back, and quite simply identify more with participants, rather than simply work so assiduously to apply research processes and re-construct participant lives through research. Equally, I believe they speak to the problem of service systems and models of charity which seek to provide care and support from thoroughly disconnected discourse and practice.

Far from identification with research participants being a problem for good social research, I suspect it may be a necessary condition of the sort of social research undertaken here. Identification here could refer to at least three aspects which involves looking inward at one’s own position, and outwards at others, and at the same time at the relationship itself. I believe Gregory Bateson (cited in Flemons, 1991) captured something of this relational complexity and necessity in the words “it takes two to know one”, as does Porter’s “self-in-relations” discussed earlier in this chapter. At one level it may suggest that there should be no undue barriers that prevent a researcher seeing it from the point of view of the ‘other’. It means in a critical and
reflexive sense the researcher has to identify with her or himself and participants.

This approach may well involve applying critical perspectives at two levels, and broadly speaking this has been the approach I have adopted in the present study. Firstly, at a more personal level and the level of language, it requires the basic self and ‘world disclosing’ tenets of the poststructural view referred to earlier (White, 1991), and also feminist methodology (Harding, 1987; Lather, 1986 & 1991; Reinhart, 1992) to see the sexism, ablism, racism etcetera that may prevent understandings. Secondly, it also demands examination of the context of political economy and structural elements such as patriarchal and capitalist discourse and the material grounds which underwrite and enable particular contexts and relations of power.

This idea of personal identification as an important condition of this kind of social research may provide some component of a research framework which helps to overcome the potential for perpetuating power relations. In this process of identification the researcher does not need to assume the status of a ‘native’. As I suggested in chapter 3, my own extended involvement and developing friendship with the participants of the Parent Exchange Group did not alter the fact that in quite fundamental ways I was not one of them. Finally, and with these latter points in mind, it seems to me to be well worth being reminded of a view expressed by Clifford Geertz (1973):
(...) what we inscribe (or try to) is not raw social discourse, to which, because, save very marginally or very specially, we are not actors, we do not have direct access, but only that small part of it which our informants can lead us into understanding. (...) So far as it has reinforced the anthropologist’s impulse to engage himself with his informants as persons rather than as objects, the notion of “participant observation” has been a valuable one. But, to the degree it has lead the anthropologist to block from his view the very special, culturally bracketed nature of his (sic) role and to imagine himself something more than an interested (in both senses of that word) sojourner, it has been our most powerful source of bad faith (p20).

Public policy: an ecology of care and contexts for change

In spite of demonstrable forms of resistance carers operated within ‘normal’ paradigms of science, medicine, economy and gender which themselves underwrote the disability and caring constructions. Carers were often challenging and resisting those manifestations of these paradigms such as the impersonal and impartial treatment of their son or daughter (and indeed themselves) within the professional process, and the isolation of their consignment to the private realm of the family home without a public presence or voice. The challenge to the paradigms that gave rise to these manifestly unreasonable experiences required the opportunity to link the personal to the wider social context. This was evident in the Group’s meetings in which personal issues gave rise to explorations of contextual layers which became a ‘natural’ process for trying to understand something better, for foregrounding the taken for granted aspects of daily life which may have been thought about differently.
In chapter 2 it was disclosed through review of the literature that the level of institutional care for disabled people in western countries including Australia was not always easy to quantify because data collection was not always adequate. It was clear nevertheless that institutional care was only ever a relatively small part of the care story, and that of those disabled people who survived infancy most grew up and lived in the family home. The research undertaken locally in this study which reveals the carers of disabled people as highly cut-off and isolated in their caring work raises the most fundamentally important questions about the discourse of public policy and practices of state service systems, which in their acceptance of ‘normal’ discourses have not considered these realities part of the care story.

Carers can be included in the public debate, visible and heard, not through service system models based on principles of applied science, which amongst other things, monitor and exercise surveillance under the guise of providing family support or community care. The potential exists for opening up the options of care and for the creation of caring environments by viewing human support needs as part of differences produced by social contexts, and a reflection of the predominant interests of the social relations in those contexts. As I carefully set out in chapter 2 discourses of disablement, as with those of care and a wide range of social policy are based on a model of the individual. They assume the existence of a separate individual, indeed in disablement a separated body. They focus on defining human problems, with the aid of scientific ‘objectivity’ as belonging to individuals. The act of knowing in this context is the act of bringing forth a
definable and treatable condition which inheres in individuals, as if they were contextually disconnected. The essential logic of problems belonging to individuals, and difference as an individually distinguishing quality, remains the basic premise, even though in recent decades there has been a shift in the state providing more equal access to society for people so defined, based on principles of individual rights (Minow, 1990; Pateman, 1988 & 1989). Such logic determines a response which is largely focussed on the autonomous self or individual, and individual problems disconnected from social contexts and social relations. The ‘care’ response of state systems whether at the level of initial ‘assessment,’ or service provision, and increasingly in the discourse of prevention is focussed on the principle of the individual separate from context and relations, a context which from a constructionist view is integral to a holistic understanding of the cause and the response (care) that society can offer.

A serious shift in social and public policy would involve seeing the individual in some way similar to Porter’s “self-in-relations”, and understanding so called social ‘problems’ as just that, the ‘problems’ or differences in adapting to the demands produced in and by complex social contexts. It would be a move away from the concept of a separate self or individual. The care and support response would be correspondingly associated with the contexts in which these different support demands were experienced. It would make it easier (and logically more consistent) to make a concept of inclusion and avoidance of social isolation a central concern in the development of policy. This must be true for all of those involved in
what can only be understood as complex relational experiences. This would be a significantly holistic view of public policy and the human relations involved. In a typical caring arrangement it would view the needs of all the participants, such as mother, father, disabled child and other family members as important. It would understand the value and complexity of a relationship which itself unfolds within a complex set of discourses, relations and practices. It would challenge the conventional wisdom which involves simply focussing on the separate and discreet clinical needs of a diagnosed person. It would challenge models of care based on paradigms which see disabled people or carers, as separate from the social relations that constitute them, and fail to recognise that no-one thrives when they are unduly isolated or disconnected. Within such a model carers of disabled people for example, would be visible, heard, and valued as part of understanding disability and the social context which defines its existence. Valued too, as part of understanding caring as social, contextual and ecologically woven.

Within the research, and discussed in chapter 3, three applications of these exploratory and caring forms have been taking shape. It will be quite apparent that at one level there is nothing new about these activities, and yet in their context and taking account of the range of particular individuals involved they are of course unique. They represent both tentative and evolving endeavours such as the PEG processes, and the Family Support Project that in themselves as yet have not been well evaluated, and the proposal informed by the experience of the Group, for a community worker.
They have been generated out of and in turn tended to inform a research and support context. All of these aspects are as they have evolved inseparable.

Each tries to include and redefine relationships of power in notions of care, and understand care around people in relations with others in a ‘real’ experience of caring culture. There is a fundamental endeavour to work with the material circumstances of participants as the basis for change. Explorations of the context which seem to shape and construct personal experience are grounded in that same personal reality. In each is incorporated some notion of a flexible model which enables (it cannot ensure) a basic respect and interest for hearing the voices of others, and in some way especially those who might not normally be heard, who might be vulnerable and hidden. In the emerging processes there has been an acknowledgment of a critical equality (equality with awareness, and awareness of our different contributions) between participant carers and myself as the researcher and convenor of the Group, and students and family members.

The research and these processes highlight the complex and ecological quality of caring. It highlights the manner in which public discourse both constructs and conceals a private reality. The deinstitutionalisation story and the private disability caring realities revealed in this account provide extraordinary demonstrations of these relations and the workings of power that produce them. Public policy can only really do justice to both carers and
those disabled people who are part of such caring relations when it views them holistically. For women who still overwhelmingly provide care in our society (Russell, 1983; Bryson, 1985; ABS, 1988 & 1990; Baxter & Gibson, 1991; Bittman, 1991), equality seems to lie in both the ability to make a more genuine choice about this career, and in choosing it, to be visible, acknowledged and supported. The business of sharing the work of caring is not a simple private matter. It requires a fundamental public response and the endeavours described here and their public policy implications need to be connected. This has not been a primary focus of the study, nevertheless there are ideas and implications here broadly suggestive of improvements, and about which future developments locally, are likely to contribute. The community worker proposal is one such example. They are I believe strongly suggestive of the need for further research with carers to understand better how they apply in practice, and how they might be integrated with public policy initiatives.

People exist in relationship with others which help to shape complex contexts of care. Their lives including their caring is complexly connected with others and our knowledge of them is formed in terms of their relations. The development of social and public policy on the abstract construct of the separate individual disabled person or carer facilitates the construction of alien sub-cultures, where people are lost and lonely behind their individual labels and their assumed meanings. It is most obvious that there is an urgent need to minimise the isolation of regular caring settings, including the isolation that may be experienced in the family context. Thus,
in spite of the ideology and appearances, families were oriented around highly individualistic values (Barrett & MacIntosh, 1991). The search for caring culture and the process of preserving or finding other personal realities were central in the lives of women, who were exceedingly isolated by their caring work, largely in family settings. If service and support arrangements genuinely reflected a shift to a social relations model, which itself incorporated a notion of basic rights for individuals, there are likely to be a greater variety of service options available to reflect the complex range of human and support differences in the community. This implies a system which is able to be more responsive to individual needs, and more accommodating of complex ecologies of caring relations.

Representing the current public debate on care as merely a rhetorical and contrived dualism of institutional versus community care, reveals the potential for a fuller public debate about who really cares, and for whom. It provides an opportunity for building public policy on a more open and honest basis, and seeing the range of options for caring as they really exist rather than within the false dualism of institutional and community care. If for example caring and the formation of neighbourly relationships are really not outcomes of some discourse of individual altruism and the spontaneous events of community, but require some complex workings in the reciprocal power of exchange, then we need to understand such power and the complex contextual aspects that shape it as fully as possible and consider in our public policy ways of supporting those who may not have access to it (Abrams, 1977 & 1979; Bulmer, 1987; Wellman, 1990; Cant, 1991 & 1992).
Joan Tronto (1995), has provided some important ideas which seem most relevant in finalising the link of this current study with public policy thinking. She has suggested that to overcome the 'hidden' quality of care, care and caring relationships need to be made central in social and public theory and the basis of political judgement. Care is defined as;

a species activity that includes everything that we do to maintain, continue, and repair our 'world' so that we can live in it as well as possible. That world includes our bodies, our selves, and our environment, all of which we seek to interweave in a complex, life-sustaining web (Fisher & Tronto, 1991, cited in Tronto, 1995 p142).

Using a model of care that is grounded in the connections and practical realities of ordinary people implied in this definition, Tronto's analysis of care demands that we attend to the real sites and processes of day to day care, and use the most vulnerable in these settings as our guide. Leaving aside now the difficulties of determining just who are the most vulnerable in any setting, clearly this contrasts with public policy models which are built around patriarchal abstractions of the individual, the economy and justice as the basis for action. As Tronto says,

(…) care provides a radical basis for rethinking political judgements. (…) what most recommends care is the practical, daily, concrete way it forces us to think about moral and political life (p146).

There is fundamental need to change the discourse and practice of public policy to take proper account of this knowledge, that is, the knowledge grounded in the experience of those who care daily in contexts of relations with others. The social relations model must be viewed as part of the
changing context and the context for change in which carers and disabled people are publicly supported.

This research has consistently highlighted the way in which those things closest to us and the most certain and embedded in our everyday lives are often the most problematic and the most difficult to 'see' and change. It is these influences that are perhaps more regulatory of daily life than anything else, and I would contend that one of the more valuable observations of this study is that caring is one such phenomenon. This will not seem like any profoundly new idea and yet it must be said, lest, like carers themselves it simply goes unnoticed. Caring culture it seems does not just happen: it is cultivated care-fully, and it would seem that we could all benefit, and very especially women, if this was a much more actively conscious dimension of public discourse and response.
Bibliography


Public discourse personal reality: disablement and a re-search for caring culture


Bibliography


APPENDICES
Appendix 1 - Interview guides

Phase 2 Interviews - Parent/carers

Question Prompts only:

* Experience at time of learning of disablement
  - personal feelings
  - response of others - change over time

* Type of caring activities

* Feelings about caring work and caring relationship(s)?

* What about support for you? How do you feel? Sources of?

* Experience of Govt. policy and its effects
  Has it and How has this changed?

* Experiences with professionals - medical
  - educational
  - others

* Examples of loss of control? - loss of self?

* Experiences of empowerment?

* View of others (acceptance/non acceptance)?

* Opportunities for change/improvement?
  If so - what are these?

* Feelings about the Gr’p (PEG) / Uni & students? - sense of community

* Describe/feel about relations with disabled son/daughter? About disability?
Appendix 1 - Interview guides

**Phase 2 Interviews** - Service system / professionals

Question Prompts only:

* Establish role in system
  How is role understood?
  Describe activities and purpose encompassed by the job?

* Who gets a 'service'? Who are the clients?

* What sort of support is provided?
  Main strategies/processes for defining job?

* Understanding of disability?

* Impressions of Govt. policy and its effects?
  Changes over time

* Understanding of the support role (general)?

* Opportunities of improving service?
  How?

* Defining relationship with clients?
Letter of Introduction to local service system

To whom it may concern,

I have approval from the University of Western Sydney, Hawkesbury Human Research Ethics Committee to conduct research entitled *Constructions of Disability and Implications for the Caring Role* (Approval No. HE......). This research is being conducted by me. I am a member of staff at the University and a PhD student in the Faculty of Health, Humanities and Social Ecology.

The primary data collection method involves taped interviews of approximately 1/2 to 1 hour following discussion and signing of formal consent. I wish to conduct these interviews with selected members of the professional service system (community, medical, educational and therapeutic) whose work is associated with disabled people and their families. All information will be maintained in a strictly confidential way.

If you require any further information please feel free to contact me on Phone: 045-701920 or Fax: 045-701420.

Sincerely,

Mike Clear
CONSENT FORM

UNIVERSITY OF WESTERN SYDNEY, HAWKESBURY
FACULTY OF HEALTH, HUMANITIES AND SOCIAL ECOLOGY - PhD
RESEARCH
RESEARCHER: MIKE CLEAR

A Study of the Constructions of Disability and the Implications for the Caring Role

I have been asked to participate in the above research project and give my consent by signing this form on the understanding that:

* the research project will be carried out in a manner conforming with the National Health and Medical Research Council code of practice and the University of Western Sydney Human Research Committee terms of reference.

* the general purposes, methods and demands and the possible risks, inconveniences and discomforts which may occur during the study have been made known.

* I am volunteering to take part in this study and may withdraw at any time or refuse to answer any questions.

* data obtained in the study may be used in publications but my name and data will not be specifically identified.

* data obtained will only be available to the researcher and to me.

* this research project has been approved by the University of Western Sydney Human Research Ethics Committee HREC Approval #..................

* A confidential mechanism exists to deal with any complaints or concerns you may have about your participation in this research. You may make a formal complaint or discuss these matters informally, by contacting the following person.

The Manager
Research and Development Unit,
University of Western Sydney, Hawkesbury
Locked Bag #1 Richmond NSW 2753.
Tel:(045) 701259

Your full name: ...............................................................

Signature: ................................................................. Date ....../...../......
(of participant)

Researcher's name ....................................................

Signature: ................................................................. Date ....../...../......
(of researcher)

(one copy of this form to be given to each participant) (one copy to be retained by the researcher)
EXPLANATION OF RESEARCH AND ETHICAL CONSIDERATIONS FOR ALL PARTICIPANTS (TO ACCOMPANY CONSENT FORM)

To be explained (in writing and verbally) to each individual participant in the interview survey or parent exchange group meetings

1. the purpose and anticipated benefits of the project
   - to understand the way society constructs disability and the implications for the caring role

2. the procedures and possible demands involved in their participation
   - voluntary participation in one interview of approximately 60 minutes with the possibility of follow up contact for clarification purposes. Voluntary participation in parent exchange group (PEG) meetings. A tape recorder will be used.

3. possible risks to participant
   - there are no anticipated physical risks. If participation causes any stress or emotional discomfort the participant may end their participation at any time, and assistance will be offered (see below).

4. threats to confidentiality
   - beyond the researcher, participants will not be identified by name. Data will be recorded using code names and all information will be held in the strictest confidence and securely kept in an office file under lock and key.

5. that participation in the project is at all times voluntary
   - participants are free to withdraw at any time.

ACCESS TO ASSISTANCE IN CASE OF DISTRESS

I recognise that sharing experiences with someone, especially if it reminds you of painful experiences or any experiences about which you have strong feelings, may be disturbing or even distressing.

I have thought about this and want you to know that I am available at other times, other than the interview or our regular meeting times, to talk and share your concerns, if it would be helpful in any way.

Of course you might want to stop the interview at any time because of how you feel and this is quite OK.

I am available on the following numbers and can arrange to talk with you personally too. If there is any other way I can support you eg by providing contact with a counsellor, please let me know.

Mike Clear - telephone (w).............. or (h)....................

Public discourse personal reality: disablement and a re-search for caring culture
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Public discourse personal reality: disablement and a re-search for caring culture
Appendix 4- Data management categories

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Appendix 5- Mind map

Public discourse personal reality: disablement and a re-search for caring culture
STUDENT / FAMILY PLACEMENT AGREEMENT

STUDENT:

FAMILY MEMBERS INVOLVED:

START DATE:
COMPLETION DATE:
DATES AND TIMES OF PLACEMENT:

TYPE OF SUPPORT / RESpite EXPERIENCE PLANNED:

MAJOR AIM OF THIS SUPPORT:

SPECIAL CONSIDERATIONS / REQUIREMENTS:

SIGNED / DATED STUDENT:

SIGNED / DATED FAMILY MEMBERS:
UNIVERSITY OF WESTERN SYDNEY - HAWKESBURY
SCHOOL OF HEALTH

STUDENT PLACEMENT EVALUATION

STUDENT:

FAMILY MEMBERS INVOLVED:

START DATE:
COMPLETION DATE:

WAS THE MAJOR PURPOSE FULFILLED / HOW ?

IDENTIFY ANY PARTICULAR STRENGTHS OF THE EXPERIENCE:

IDENTIFY ANY PROBLEMS OF THE EXPERIENCE AND HOW THESE WERE HANDLED:

ANY OTHER COMMENTS:

SIGNED / DATED STUDENT:
UNIVERSITY OF WESTERN SYDNEY - HAWKESBURY
SCHOOL OF HEALTH

FAMILY PLACEMENT EVALUATION

FAMILY MEMBERS INVOLVED:

STUDENT:

START DATE:
COMPLETION DATE:

WAS THE MAJOR PURPOSE FULFILLED / HOW?

IDENTIFY ANY PARTICULAR STRENGTHS OF THE EXPERIENCE:

IDENTIFY ANY PROBLEMS OF THE EXPERIENCE AND HOW THESE WERE HANDLED:

ANY OTHER COMMENTS:

SIGNED / DATED FAMILY MEMBERS:

PLEASE RETURN IN THE ENVELOPE PROVIDED WITH STUDENT OR AS SOON AS POSSIBLE - THANKS