Punters and Providers in the North of Scotland: a study of shared experiences.

Barry Gault

A thesis submitted in partial fulfilment of the requirements of The Robert Gordon University for the degree of Doctor of Philosophy.

October 2007

“So we beat on, boats against the current, borne back ceaselessly into the past.”

F Scott Fitzgerald

The Great Gatsby.

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Abstract

Name: Barry Gault.

Submitted for the degree of Doctor of Philosophy.

Punters and Providers in the North of Scotland: A Study of Shared Experiences.

The research was carried out during a time when residential provision for people with learning difficulties in the north of Scotland was changing from being hospital based towards being community centred. The aim was to utilise an understanding of the dynamics of past provision to shed light upon present practice and planning for the future: focussing upon that form of 'difference' which has been given the name 'learning difficulty'.

The research utilised records, interviews, narratives and discussion groups to explore the experiences of providers of services, service users and those who were close to them. The research sought to go beyond description; to facilitate respondents in sharing their understanding of the organisation of care services and how it had an effect upon their life chances and self concept.

The design of the research, which made use of multiple sources of evidence, was qualitative in its approach. It was undertaken within four 'sites of interest':

- The archive or the historical record of provision at Lhangbyde Hospital..
- Through semi structured interviews with 'Providers'
- A 'Punters' discussion forum located within a self advocacy group.
- A set of 'Intimate Narratives'.

The method had its roots in constructivist, reflective and post modern currents of thought which confronted the difficulty inherent is making an epistemological distinction between what is out there in the world and the categories of meaning which are resident in the human mind. The goal was to produce texts which promoted dialogue rather than monologue, were evocative rather than definitive,

utilised participants in the research in a manner which empowered them, rather than simply extracting knowledge.
Qualitative frameworks of analysis were used to extract themes of meaning from the data which emerged from records, transcripts of interviews / groups, and the narratives relating the experience of respondents. The Nvivo qualitative data processing package was used primarily to manage the data, although it was anticipated that at least some of the analytic categories would emerge directly from the discourse employed by respondents.

In the five substantive findings chapters, the 'what' and the 'why' of provision for people with learning difficulties was explored. In chapter 4, entitled 'Searching the Archive' findings were set out relating to the naming of 'difference', the roles of providers, the practice of 'grading', visual stigmata and the transition from a county asylum to a mental handicap hospital.

In chapter 5 under the title 'Recurring themes in Provider Discourse', in pursuit of the 'what' and 'why' of provider experience, the findings arising out of the semi-structured interviews with 'Providers' were gathered together into eight explanatory 'themes'. These themes included the process of encountering the institution, everyday needs and routines, gender, sexuality and reproduction, the hospital economy, status and hierarchy, the sick role, activity inside and outside the hospital and finally the process of change.

In chapter 6, under the title of 'Providers Tales' the experiences of three key informants within the 'Provider' group were examined, in order to provide a more detailed and holistic account of their journeys within the institution.
In chapter 7, under the title of 'Punters Tales' the 'what and why' of punter experience were examined. Some similar themes to those brought out by the providers were examined in the context of community living. Additional findings, particularly those relating to the importance of 'having a voice', were set out, and providers introduced their own concepts such as 'negativity and small mindedness' and 'Overpowerment'.

In chapter 8 some ‘Intimate Narratives’ from the researcher’s own life experience as a father and as a facilitator and adviser within a self advocacy organisation were presented directly as stories of everyday experience.

In the final two chapters of the thesis an attempt was made to synthesise the overall findings of the research, and to assess their implications for future policy and practice. In chapter 9, under the heading of ‘Reading the Chart: understanding the past and present as a foundation for future planning’ the findings from the four ‘sites of interest’ were gathered together under seven explanatory themes, with the section entitled ‘Gaining a Voice’ achieving an overall pre-eminence.. The last chapter in the thesis (Chapter 10), under the title of ‘The Future Course’ detailed a plan for change and development based on a synthesis of findings. In addition the role of future research in promoting change was examined. The thesis concluded with a ‘plain language’ summary of recommendations.

Key words: Learning Difficulties: Self Advocacy: Narrative: Power: Inclusion: Residential Care.

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In the discussion of the application of the identified themes relating to 'difference' which follows, both discourse and the power relations within which they subsist will be examined. At the end of this examination a short commentary will attempt to make a general point about present grand narratives and their links to those of the past and future. 294

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CHAPTER 1: INTRODUCTION

This chapter provides an introduction to the thesis and makes explicit the overall orientation of the research. The chapter is structured in 6 sections, which aim to contextualise the thesis both personally and with regard to the changes in policy and practice taking place at the time the research was conceived and executed. The fundamental approach of the research is outlined, and the reader is provided with a sense of the boundaries of the enquiry.

Section 1: The rationale for the research.
Section 2: A discussion of language.
Section 3: The research questions.
Section 4: An overview of the nature and scope of the enquiry
Section 5: Sequence and Synopsis; a document map.
Section 6: A personal reflection.

Section 1: The Rationale for the Research.

The origins of the research stem from an experience of change over many years, and on a number of levels. As a child of around 11 years I had been driven past Lhangbyde hospital and had said to my sister; “Look … we are passing the nuthouse”. My sister scolded me saying that I should not use such language to describe the people who lived there. At that time I knew nothing of the distinction between mental handicap and mental illness (as it might have been described at that time), but I did have a strong sense, derived from an early television adaptation of ‘Jane Eyre’, of the menace that attached to mental impairment, and the need for the confinement of sufferers in order to protect the wider population. Fast forward over twenty years to the birth of my son, Spinner: some of the theorists of grief and loss are eloquent in describing the feelings of

shock and disorientation which accompany the form of loss that a diagnosis of Down Syndrome could be said to entail, drawing a parallel to the loss of a loved person (Parkes 1998: Tschudin 1997) However, as Spinner grew into a personable young man, it became clear that, like any other parents, our role in life was to facilitate his development in the best way that we could; and supporting his interest in self advocacy was one part of that task.

At the time that the research was conceived, in the late nineties, such personal change was taking place within a wider context of policy development. The nature of provision for people with learning difficulties, and the manner in which 'difference' was conceptualised (see section 2), was going through fundamental change (Scottish Executive 2000). It had *always* been the case that the majority of people with learning difficulties lived with their families or in the community, but residential provision in the North East of Scotland, was focussed mainly upon two hospitals, both of which closed in the early years of the 21st century. (Council / NHS 2002) The people who had lived in hospitals were largely 'resettled' into small, community based residential units,(Ark Housing 2007; Cornerstone Community Care 2007; Real life Options 2007; Inspire 2007), though in the later years there was less emphasis on 'bricks and mortar' and more effort to support people with learning difficulties in their own home. The initial aim of the research was to compare the experience of those who had resided in Lhangbyde hospital with that of people who had been 'rehabilitated' into the community (Emerson and Hatton, 1994; Booth, Simons and Booth 1990). However, as a result of the experience of undertaking the historical research and the punter interviews, and bearing in mind the long experience of the researcher as an adviser to a self advocacy group, it was decided to widen the scope. The research task now aimed at eliciting from punters and providers their views about the *nature* of learning difficulty, and the experiences which flow from carrying the label of learning difficulty (Stalker and Cadogan et al 1999)
The overall rationale for the research has thus become an attempt to understand something about the *nature* of change as experienced by both punters and

providers; both at an organisational and policy level, and on a more personal level.

Section 2: A discussion of language.

Within this section it is proposed to look at the issue of language and terminology from three points of view. Firstly there is the whole question of which name to give that form of difference which is variously called mental handicap, learning disability or learning difficulty. Secondly there is the question of the terminology which is used to denote the status of service user and that of the service provider. Finally there is the fact that the everyday language employed by many of the respondents is a local dialect which has been given the name 'Doric'.

A name for 'Difference'

The terminology which is used to both describe and define that form of 'difference' which is the subject of this research has its roots in statute and in professional (often medical) usage. Such terminology has often passed into wider societal usage. Thus the first attempt at a consistent terminology within Scotland was contained within the Mental Deficiency and Lunacy Act (Scotland) 1913 where statutory definitions of the terms 'Idiot', 'Imbecile' and 'Feeble Minded' were provided. It is significant that the concept of 'deficiency' was utilised in the title of the statute; this was a concept which went on to have a lengthy legal and professional 'shelf life'. The terminology of this early statute has gone on to acquire a pejorative connotation in our wider language.

Terminology has varied both over time, and between cultures: In the United Kingdom some of the more commonly used terms have been 'Mentally Handicapped', 'Subnormality', 'Learning Disability' and 'Intellectual Disability', and they have all been sustained within a variety of professional contexts for varying reasons. The latter term is enjoying something of a renaissance in recent years (Gates 2005) with the name of an influential journal being changed

from ‘Learning Disabilities’ to ‘Intellectual Disabilities’. In the United States the term ‘Mental Retardation’ has had a wide currency and the word ‘retard’ continues to be used as a noun. It is important to retain a focus on the nature of the relationship between those who use the terminology and those who are the subject of such use. It is a reflection of the *power* (principally medical) to socially construct difference in a specific manner (McClimens 2007). Indeed it has been noted that such labels are ‘sticky on one side only’ (Swain and Cameron 1999), insofar as the negative consequence of such objective categorization has the effect of disempowering people with particular mental or physical attributes.

Given this variety of terminology, it is important to say something about the manner in which it will be utilised in the chapters which follow. Terminology is sometimes used in a way which implies that it arises ‘naturally’ from some form of organic, bodily or psychological state:

> “An intellectual disability expresses itself primarily through differential cognitive and adaptive skills,”
>
> Russell and Mammen 2005 pp 190

For many terminology is a concomitant of power (Luckasson 2003 cited in Gates 2005), and the researcher would argue that the significance of the manner in which it is utilised depends to a degree on the social and organisational position of the person who is using it.

Goodley presents a persuasive case for a critical challenge to some of the terminology employed and makes the case for such a challenge being mounted upon individual, social, political and epistemological grounds. His paper

> “attempts to reconsider the *epistemological orientation* of the social *model* of disability, wherein impairment is considered as equally social as disability and therefore includes people with ‘learning difficulties” (emphasis in the original)
>
> Goodley, 2001 pp210

He then goes on to deconstruct the concept of ‘impairment’, to show the importance of story or biography in promoting understanding of impairment, to make an attempt to relocate impairment within its own culture or collective identity, and finishes by making clear the impact on peoples lives of epistemology or the process of naming. He talks of the necessity to view ‘impairment’ with ambivalence because even this seemingly neutral concept is undoubtedly social in its origin. In the view of the researcher the concept tends to minimise the importance of such positive skills and abilities which are set out in the ‘Intimate Narratives’ chapter below. In an ideal world the goal might be the abolition of the category ‘impairment’ or ‘disability’, and promotion of universal access to all services and activities in society. For example there would be no such thing as special education, instead a recognition that all children are special, and that they should get that level of support that they need to achieve their goals; in other words truly comprehensive education. Such universality would apply to all services (Bolderson and Mabbett 1991).

However, in the real world of practice and care, a variety of socially constructed terminologies have been utilised. It is important to state in this introductory chapter that the researcher, because of his background in the self advocacy movement prefers the term ‘learning difficulties’, although it is acknowledged that even the self advocacy movement has its hidden agendas and vested interests (Apsis 2002). The term ‘learning difficulties’ is, in the view of the researcher less likely to separate out people into some form of ‘naturally determined’ category, and more likely to draw a parallel between the difficulties they face and those encountered by other social groups. Given this preference, it might be thought that the term ‘learning difficulties’ would be used throughout the thesis. However, the findings, and especially the excerpts from transcripts are drawn from a number of time periods and professional orientations. In the process of describing and analysing activity the language and terminology utilised in the particular context under consideration will be employed, and will

thus be inconsistent. This is acknowledged, but is seen as a concomitant of the breadth of the research activity which is undertaken, and reflects the way in which language is used in practice.

Denoting the status of the service provider and user.

During my training and socialisation as a social worker, within my subsequent employment in a school of nursing and midwifery, and during the present research, I have encountered many and varied names for the status of service user and service provider. At the time the institution was opened in 1865, the dominant discourse was that of the poor law, so the service users were referred to as ‘Pauper Lunatics’. Although people who were regarded as ‘Defective’ had the same status as service users, they were referred to in the case books in the terminology of the 1913 Act as ‘Idiots’ and ‘Imbeciles’. At this time and right up until the second world war, the service providers were known as ‘attendants’.

In the post war period medical discourse gained in ascendancy, and the term ‘patient’ began to be the most frequent appellation for service users. During the movement towards rehabilitation, and eventually closure of the hospital service users became ‘residents’ and this terminology was transferred to the ‘new’ service providers.

Terminology within community based services is a complex matter. Nurses who worked in an institution which declared itself to be a hospital, even though the huge majority of service users were not in any sense ‘sick’, (Parsons 1951),were comfortable with the term ‘patient’. Responsibility for the commissioning of the ‘new’ services lay with a joint ‘resettlement action group. (Council 2000) where the discourse employed by the social work department was influential, so the term ‘client’, which reflected the professional aspirations of social work, was common. Later, when local authorities began to employ the discourse of

business the term ‘service user’ came into vogue, and during the wilder excesses of managerialism, ‘customer’. Service providers were sometimes given the name ‘carer’, although this made it difficult to distinguish them from family and friends who also regarded themselves as carers. One way round this was to call people who provided facilitative services ‘assistants’.

For the purposes of analysis within this thesis, the researcher has decided to use the term ‘provider’ to cover *all* those who provide service, be they social workers, social carers, medical professionals or any other persons employed in a caring capacity. This term is reasonably neutral, although it is acknowledged that any terminology carries with it some degree of value judgement. It has been said that one defining characteristic of membership of the ‘disabled’ community is the fact of having someone who is paid to care for you. (Mason 2000). The term ‘punters’ has been chosen because it avoids some of the pseudo-therapeutic connotations of other terminology; and it also gives some sense of the experience, that the form of service which people with learning difficulties receive is often a matter of chance, depending on the vagaries of varying practice within different geographical or professional jurisdictions. As was the case with the term ‘learning difficulties’ discussed above, consistency would seem to demand that the term ‘punter’ should be used throughout the thesis, but the *context* of particular pieces of description or analysis, will often imply the use of one of the other terms outlined within this section.

A local language.

Within the excerpts from transcripts which form a large part of the evidence in chapters 5, 6 and 7, the reader will notice that many of the respondents utilise a local form of language or dialect which is known as ‘Doric’. It has been said that a language can be thought of as a dialect which possesses a navy, and it is beyond the scope of this thesis to make a hard and fast distinction between these two concepts. Suffice it to say that several respondents, be they ‘punters’ or ‘providers’ naturally expressed themselves in the local dialect; so no attempt was made within the transcription process to undertake a running translation. It was felt by the researcher that the language employed transmitted shades of meaning which would have been lost in translation. Sometimes respondents utilised standard English to express themselves; where respondents did this, the transcription remained faithful to their usage. In appendix 1 a small glossary has been included which provides definitions of some of the terms used.

Section 3: The Research Questions

When the study was planned, the researcher had some idea of deriving the central research question from one of the major theories which posited a desirable direction for change and development in the provision of services for people with learning difficulties. Examples might have been theories of normalisation (Wolfensberger 1972) or person centredness (Sanderson and Kennedy et al 1997) The aim would have been to evaluate the changes in services, and to see how far they measured up to these theoretical ideals. However, as the research interest grew, and as archival material was explored, a wider question emerged:-.

> How does the lived experience of the ‘provider’, the ‘punter’ and others inform our understanding of that form of ‘difference’ variously described as ‘subnormality’, ‘Mental Handicap’, ‘Intellectual Disability’ or, in this study, ‘Learning Difficulty’?

This most abstract of research questions leads on to two further questions:-

1. What can be learned about the dynamics of identifying and living with, learning difficulty by examining archival records of past provision, the experience of providers of service, the experience of punters and finally the intimate narratives of individual experience?
2. What forms of policy and practice development could be derived from examining these experiences.

Section 4: The nature and scope of the enquiry

In the light of what has been said about the extent and the levels of change in the ‘rationale‘ section above the research aims to examine the dynamics of change on a number of levels. In chapter 2, entitled ‘Past Discourses’ the concept and practice of self advocacy will be examined through the medium of a discussion of the evaluative studies which have looked at the changes in provision for people with learning difficulties in general, and the practice of self advocacy in particular. In this chapter a sociological perspective upon the process of change will be employed, and the relevance of the concept of discourse analysis will be explored. An attempt will be made to synthesise some of these past approaches to the understanding of the nature of learning difficulty in order to underpin the methods which will be employed in the body of the wider study. In chapter 3, entitled ‘Research Design and Methods’, the major research questions are set out and the process of finding respondents is described. The process of data collection and analysis is detailed, and the issues around methodological rigour are explored., as well as the ethical challenges inherent in research into the area of learning difficulty

In the five substantive findings chapters, the ‘what’ and the ‘why’ of provision for people with learning difficulties is explored. In chapter 4, entitled ‘Searching the Archive’ the results of archival research which examined documentary records of provision of residential care at Lhangbyde Hospital are set out. Some of the themes which underpinned the process of change are gathered under five headings, and the nature of these themes are set out diagrammatically.

In chapter 5 under the title ‘Recurring themes in Provider Discourse’, in pursuit of the ‘what’ and ‘why’ of provider experience, the findings arising out of the semi-structured interviews with ‘Providers’ are gathered together into eight explanatory ‘themes’. These themes are derived directly from the accounts provided by providers of the routines of daily living within Lhangbyde, and the changes which took place over a time period from the end of the second world war to the closure of the institution in 2003.

In chapter 6, under the title of ‘Providers Tales’ the experiences of three key informants within the ‘Provider’ group are examined, in order to provide a more detailed and holistic account of their journeys within the institution. Explanatory themes from both these chapters are combined, to present a diagrammatic representation of the overall explanatory categories derived from the provider interviews.

In chapter 7, under the title of ‘Punters Tales’ the ’what and why’ of punter experience are examined. The results of the initial and follow up punters discussion group and the resulting individual are set out. The explanatory themes, all developed from an initial open ended are will be brought together under eight headings. These are represented diagrammatically in terms of ‘Life’s Voyage’

In chapter 8 some ‘Intimate Narratives’ from the researchers own life experience as a father and as a facilitator and adviser within a self advocacy organisation are presented.

In the final two chapters of the thesis an attempt is made to synthesise the overall findings of the research, and to assess their implications for future policy and practice. In chapter 9, under the heading of ‘Reading the Chart: understanding the past and present as a foundation for future planning’ the findings from the four ‘sites of interest’ are gathered together under seven explanatory themes, with the section entitled ‘Gaining a Voice’ achieving an

overall pre-eminence. These overall findings are represented diagrammatically, under the heading ‘A Chart which Maps our Understanding’. The last chapter in the thesis (Chapter 10), under the title of ‘The Future Course’ details a plan for change and development based on a synthesis of findings. In addition the role of future research in promoting change is examined. The thesis concludes with a summary of recommendations.

Section 5: Sequence and Synopsis

Figure 1: A Document Map

Diagrammatic Representation

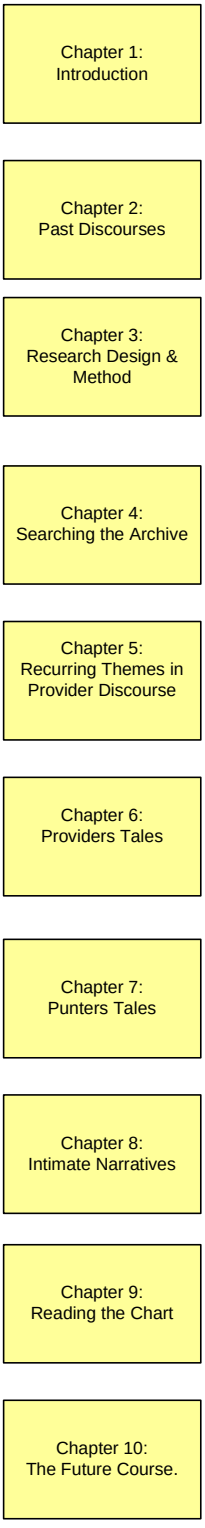


Figure 1: A Document Map

Figure 2: An Approach to Synthesis.

Figure 3: Research & Practice

Figure 4: The Analytic Hierarchy

Figure 5: The Research Question

Figure 6: Model Building and Testing

Figure 7: A voyage into the past

Figure 8: Lhangbyde: Providing a Shelter from the Storm.

Figure 9: Life's Voyage

Figure 10: Gibb's Reflective Cycle

Figure 11: A Chart which Maps Our Understanding

Figure 12: A Plan for Future Practice; Gaining a Voice.

Section 6: A Personal Reflection

At the time of writing the spirit of the age seems to demand a universal commitment to the promotion of change, almost for its own sake.

> "Part of the process of being the agents of change is admitting that we have not done enough"
>
> Ed Milliband ; Cabinet Office Minister. Guardian 23.07.07

In the 'rationale' section above the researcher attempted to describe the beginning of a journey of understanding. (Benner-Carson, 2000) In this section, I will seek to make clear the general orientation that I brings to my understanding of the process of change within policy and practice relating to the process of meeting the needs of people who have learning difficulties. This is done in an attempt to avoid the trap of espousing a rhetoric of change without firstly defining the nature of such change, and secondly being explicit about the position of the researcher within that process of change.

With regard to the nature and direction of change it is clear to the researcher that there has been, in Scotland, a major shift in policy and practice towards de-institutionalisation. Apart from one or two instances of 'village communities' for people with learning difficulties surviving within the voluntary sector, the trend has been towards much smaller institutions, or towards supporting people in their existing homes. The researcher, in general approves of the direction of change which has occurred, but strongly suspects that many of the issues which are currently engaging present day providers and punters were also influential in earlier years.

The second 'caveat' to be expressed within this personal reflection relates to the *position* of the researcher within the process of change. The researcher sometimes refers to himself as 'marginal man'. Having trained and qualified as a social worker, and gone on to practice and teach in this area, he

went on to join the staff of a school of nursing and midwifery, and in this capacity had a limited amount of professional contact with providers based within the hospital, or community based settings; although not enough contact though to claim the knowledge and understanding of an ‘insider’. As well as patrolling the boundary between two professional groups, the researcher, because of his status as the parent of a young man who lives with Down Syndrome, has day to day contact with both the able bodied and the disabled world. Although this affords some limited insight, it also provides an understanding that the experience and interests of able bodied professionals will *always* be different from those who carry the label of learning difficulty (Apsis 2002) In another capacity, the researcher has worked, part-time for over ten years as an ‘adviser’ to a local self advocacy group for people who carry the label of learning difficulty. Self advocacy groups can be said to keep their advisers ‘on a short leash’ (People First Scotland 2006); the position of adviser to such groups requires an acceptance of the fact that voting and decision making powers lie with the membership rather than the advisers. In addition, the adviser role does have an authority which derives from such activities as day to day administration and dealing with funding bodies.

A third ‘caveat’ has its roots in the marginal cultural position of the researcher, who was born within a fishing community in the north east of Scotland, and brought up in a family where both grandfathers were fishermen. His family migrated to England, but he returned during his adult life. The quotation from F Scott Fitzgerald reflects a belief in the influence of the past on present behaviour, and the forms and titles of some of the diagrams reflect a discourse which is drawn from the influence of fishing upon the lives of significant people within his life. The researcher shares this cultural heritage with many of the respondents within the study, which may mean that there are many unspoken understandings which are shared.

The final role which the researcher has to acknowledge is that of 'researcher' itself. The demands of professional rigour and ethical practice will be discussed later. It is important to recognise that the roles of 'Professional', 'Parent' and 'Adviser' are influential upon the role of researcher in the present study. In the view of the researcher, his 'marginal' status has influenced the manner in which this study has been carried out. The thesis aims to generate explanatory themes as it progresses rather than testing hypotheses derived from wider theories. It is constructivist in its' overall approach insofar as we

"Do not find or discover knowledge so much as construct or make it"

Schwandt 1994 pp 125

It is also profoundly influenced, by the 'Grounded Theory' approach, but recognises the influence of wider experiences in forming the explanatory themes which have emerged. Its overall aim is to give a voice to both punters and providers in a manner in which past research has not achieved, but recognises that the very particular experience of being 'marginal man' in the sense of occupying several social positions which could be seen to conflict, will greatly affect the manner in which that voice is both identified and expressed.

Chapter 2: Past research and present literary discourses.

“What those old Greeks…….took to be the task of a whole lifetime…….keeping the balance of doubt in the face of all inveiglements, fearlessly rejecting the certainties of sense and thought, incorruptibly defying selfish anxieties and the wheedling of sympathies- that is where nowadays everyone begins”.

Johannes de silentio (Soren Kierkegaard)

Fear and Trembling: Preface.

This chapter is structured in ten sections.

Section 1: Introduction
Section 2: Self Advocacy
Section 3: Evaluative Studies of Provision for People with a Learning Difficulty.
Section 4: Evaluative Studies of Self Advocacy.
Section 5: A Sociological Perspective
Section 6: Discourse Analysis.
Section 7: One Approach to Synthesis.
Section 8: Further Approaches to Synthesis.
Section 9: A unifying perspective.
Section 10: Conclusion and the Link to method.

Section One: Introduction

Conventionally, at the commencement of a research project, a primary task is to outline the current state of knowledge within an area of interest, to examine the theoretical and conceptual frameworks which have underpinned understanding of the topic thus far; to identify gaps in knowledge, and to make a judgement concerning the extent to which the methods employed within previous research activity promoted true understanding in the past, and remain likely to do so in the future (Grbich 1999). For researchers working within the Grounded Theory tradition there is, to say the least, ambivalence concerning the advisability of surveying previous literature. For Glaser (1998) P.68

> "To avoid reading the literature beforehand is a strategic grounded theory pacing; it is not neglect or anti-scholarship or anti-contributory to a literature. Not reading the literature is part of the grounded theory empowerment. It is one more dimension of freedom to discover. It gets the researcher started faster."

This does not imply an injunction to avoid reading the literature *entirely*. Glaser (1998) strongly advocates at the sorting and writing up phase of the study the treatment of past theoretical writing as data to be examined, and included in the study through the medium of the constant comparative method. Strauss and Corbin (1998) also counsel against becoming so steeped in the literature that the researcher is constrained and stifled by it, sometimes to the point of analytic paralysis. Glaser (1998) advocates reading “vociferously” (P73) in other fields in order to promote theoretical sensitivity. His feeling is that this ‘keeps the researcher supersensitive to emergence with no preconception’. The present researcher would describe the benefit of reading which has theoretical breadth in terms of the possibility of transferring concepts derived from a variety of subject areas to the research in progress. Strauss and Corbin (1998) acknowledge the contribution of knowledge of wider theoretical frameworks in certain circumstances, insofar as they sensitise researchers to alternative perspectives towards the data which is emerging from the study.

In the view of the researcher it is helpful to make as transparent as possible the influence of wider theoretical frameworks upon the study. This presents the reader with the opportunity to make a judgement as to whether substantive and formal theoretical categories have indeed emerged from the data, or whether they have simply been transferred from other sources and applied deductively in the present study. In the chapter which follows the researcher identifies three distinct theoretical traditions which have been influential. The first of these is the self advocacy movement which argues that people with learning difficulties have the right to exert a determining influence on both the strategic and day to day planning and provision of the services that they use. This world view has run in parallel with a movement from a medical / treatment model towards a consumerist view which would seek to evaluate service not on the basis of treatment of a condition, but upon satisfaction levels of service users, and other stakeholders. The researcher would also argue that much of, particularly the earlier writing which advocated the inclusion of people with learning difficulties

into the mainstream of life, had its roots in a second and distinct theoretical stream, namely that of symbolic interactionism, particularly as applied to the study of total institutions. Wolfensberger (1972). The third category of theoretical influence acknowledged by the researcher relates to the tradition of discourse analysis which emanated from the writing of Michel Foucault. Although the main focus of this tradition was historical, the researcher will argue that the understanding of the insights gained from the interview based section of the study has also been informed by this perspective. At the end of the present chapter the researcher will attempt to construct a theoretical model which blends the insights gained from these three perspectives.

Section 2: Self Advocacy.

The existence of a 'human rights' approach to the planning and provision of services for people who have been given the label of learning difficulty or any of its previous incarnations, is a necessary precondition of the emergence of self advocacy. If people with learning difficulties are not thought to be capable, or entitled, to speak up on their own behalf; then there is no soil within which self advocacy can grow. Emerson (1992) locates the effective origin of the concept of normalisation, which seeks to maximise quality of service for people with a learning difficulty by granting them the right to the same patterns of life as any other citizen, in the 1959 Mental Retardation Act in Denmark. However although he identifies such rights as necessary he concedes that they might not be sufficient to ensure provision that is integrated with that for non-disabled people, and is truly inclusive . He cites the argument of Bank-Mikkeson (1980) P56 that

> "While normalization is the objective, integration and segregation are simply working methods".

A further step in the development of a social environment in which self advocacy as a principle could gain ground was taken by Wolfensberger (1972) when in addition to a rights based approach he formulated a principle which focussed upon the *means* which were used to achieve such rights. It is a common misunderstanding to think that the principle of normalisation has as its aim to transform all service users so that they act in a 'normal' fashion. Apart from the epistemological difficulties of defining normality, there is the empirical problem of how to promote and monitor it, and how to change people if they should stray from the path of normality. In his formulation of the principle he defined it as;

> "Utilization of means which are as culturally normative as possible, in order to establish and / or maintain personal behaviours and characteristics which are as culturally normative as possible"
>
> Wolfensberger 1972 P28.

Thus Wolfensberger with an emphasis on *means* could not, unlike earlier Scandinavian thinkers, countenance a rights based approach to provision of services which tolerated segregation of people with learning difficulties. It is important to say that the Scandinavian countries have now remedied this omission, and in Sweden a human rights approach to provision was incorporated in the Social Services Act 1982 (Socialtjanstlagen). This was further refined in 1994 with passing of the Lag om stod service for vissa funktionshindrade (LSS: A law about state service for particular functionally disabled people) which provides for a *right* to ordinary living for disabled people which provides an ombudsman whose role is to ensure compliance by service providers. This dilemma is still apparent within Scottish services. In the field of residential care, the commitment to a movement towards provision which is as culturally normative as possible has been has been unequivocal. The recommendations of an enquiry set up in the early nineties under the auspices of The Scottish Home and Health Department and the Scottish Health Service

Advisory Council examining the future of mental handicap hospital services in Scotland, made the issues of principle absolutely clear.

> "In the future, it should be the norm that people with a mental handicap who are unable to be looked after at home, should be cared for in small, locally based residential facilities. The facilities should be developed by the NHS, local authorities and voluntary and private organisations"
>
> Scottish Office Home and Health Department 1992 P82.

A commitment to this principle continued after devolution (Scottish Executive 2001) and also in the wider United Kingdom (Department of Health 2001). It could be argued that the movement along a continuum towards culturally normative care has gathered pace with an increasing commitment to support people with a learning difficulty in the places where they live, rather than in specially constructed provision. (Choices Care 2007). In education provision the commitment to the normalisation principle is less apparent. There has been a trend towards inclusive provision contained within specialist units sited within ordinary schools; (Scottish Office 1998;Mason 1998) although there has been something of a backlash under the banner of 'choice' which urges the retention of segregated education (Birrell 2005).

Thus far the changing social policy context, and the theories which underpinned it have been outlined, but the human rights and the normalisation movements appear to be predicated on a description and analysis which can characterise people who carry the label of learning difficulty as being passive recipients of changing and developing services. Such theories concentrated on the development of services which were culturally normative, and, by implication, thought that the question of agency on the part of the users of services was a secondary consideration. In a variety of countries, people who carried the label of learning difficulty, or the label which reflected the history and culture pertaining at a particular time, began to let it be known that they had an opinion,

and wished to express it. Goodley (2000 P9) describes a group in Stockholm, Sweden, composed of 'persons with mental retardation' and university students meeting in the late sixties. As a result of a discussion of their experiences the members of the group decide that individual members might not wish to be seen simply as members of a group with a circumscribed function; and that they might wish to develop their own agenda for their social and cultural activities. Williams and Shoultz (1982) describe a 'brainstorm' reported by a man called Ray Loomis who had lived in a state hospital in Nebraska, USA for 15 years. After living in the community for seven years, he realised that interdependence rather than independence or dependence is the norm for most people. In 1975 Ray developed a self advocacy organisation called Project Two, which insisted that the organisation had to be run by people who had been defined as having a mental handicap, with non handicapped people acting as supporters or helpers but not leaders. Williams and Shoultz (1982) also describe the parallel growth of an organisation called People First in Oregon, USA which was the result of a convention held in October 1974. This organisation spread its influence and ideas through the USA and Canada and has been influential on the development of a world wide People First movement. There is a sense in which the chronology and *geography* of the development of the movement is of secondary importance. The key issue is the development of the principles behind the movement which were well expressed by Ray Loomis in the early days.

> "If you think you are handicapped, you might as well stay indoors. If you think you are a person, come on out and tell the world"
>
> Williams and Shoultz (1982 P24)

This quotation captures the dual nature of self advocacy describing both an individual process of empowerment through learning to speak up for oneself, and a more collective form of empowerment which groups get together to

support one another in the process of voicing their shared concerns (Simons 1992).

Just as there are degrees of normalization, there can be said to be a continuum of self advocacy. Goodley (2000) sets out three alternative models of a self advocacy group. The first is *Autonomous Model,* where the group is independent as regards time, organisation and finance from public or non statutory service providers; where advisors or facilitators are independent of service providers; and members are free from conflicts of interest which might prevent them from freely voicing their opinions. The *Divisional/ Coalition model Model* is one where the self advocacy group has emerged out of an existing parent or professional organisation; for example ENABLE in Scotland. It may well be the case that self advocacy has developed out of another form of advocacy such as citizen advocacy. The third and final characterisation is the *Service System Model* where the self advocacy group is located within a service delivery system. In hospitals this may have taken the form of a patients forum or council, and in a day centre a service users group.

On reflecting upon the nature of self advocacy, and examining the effect of this developing and changing theoretical context upon the research, and also upon the manner in which it was carried out; it became clear to the researcher that professional and personal views about the nature of learning difficulty are shaped by contact with both people and institutions. The researcher trained as a child care social worker, and in accordance with the spirit of the times became a ‘generic’ social worker during the 1970’s. At that time it was routine to segregate people who were defined as suffering from ‘Mental Handicap’. The researcher has a vivid memory of visiting a ward within a large mental handicap hospital where 30 or so people appeared to be in the care of one nurse who sat at a desk with a small transistor radio. A few years later the researcher was the social worker for a young woman with learning difficulties whose elderly mother had died, leaving her alone in the world. No consideration was given to finding out about her family or social network, and she was placed in a private

residential care home about fifty miles from where she had lived. Subsequent more personal experience has, however, lead to a link with the self advocacy movement through assumption of the role of adviser to a local self advocacy group

In terms of Goodley's typology, the self advocacy group to which the researcher belongs could be thought of as aspiring to the 'Autonomous' in terms of organisation. Some finance came from the local authority in grant form, with the balance coming from the group's own fundraising efforts. There was no direct day to day involvement of the local authority in the running of the group, which was overseen by a committee where only people with a learning difficulty had voting rights. The researcher acted as an adviser and could be regarded as independent: (apart from the fact that his employment as a lecturer in a school of nursing might be thought to involve some identification with the caring professions). It was the case that all the members of the group had, in the past been users of local authority learning disability services, but none of them attended day centres or used any residential facility. The researcher, over a ten year period had been present as an ally, as the group, and the individual members within it, had grown in confidence with regard to self advocacy. It is the judgement of the researcher that the group could be regarded as autonomous, but the experience of working with the group, and subsequently interviewing them about their experience and conceptualisation of learning difficulty had led to the belief that there was a sense in which people with learning difficulties were co-dependent with professionals.

Professionals were all dependent on the existence of people with learning difficulties as a means of earning their living, and in their turn, group members had all gone through a process; firstly within the education system, and then within the care system, of being defined as someone in need of specialised help and support. Their individual identity and their identification with the group was thus largely determined by the definitions that had been conducted by others. The history of their development as a group was one of growing confidence that

they were people first, and service users only incidentally. One interesting effect of this was that they were able to make an input to the planning of services as being bona fide service users, but if they denied belonging to any particular category whilst taking part in this process, professionals on the planning body began to question the legitimacy of their presence. The experience of being both a spectator and a participant in these dynamics made the researcher to seek out a method of enquiry which made no assumptions about the nature of theoretical explanations of the nature of learning difficulty.

Section 3: Evaluative Studies of Provision for People with a Learning Difficulty.

In the view of the researcher, the growth of a human rights approach to the provision of services has encouraged people with learning difficulties to speak up for themselves. It has combined with a trend towards an underpinning consumerist metaphor (Baggott 1998)) to produce a series of studies which seek to examine the successes and failures or residential and support services in terms of both process and outcomes. One of the first of these was the study of daily life within a traditional mental handicap hospital originally published in 1980 in England (Ryan and Thomas 1980; Ryan and Thomas 1987). The fieldwork for the study was not based on a consciously articulated methodological choice, but consisted of participant observation by one of the authors who was working as a nursing assistant in one ‘villa’ or ‘ward’ within the hospital, who simply kept a diary of day to day life. The second author provided background study in relation to wider issues of social policy etc

The description and analysis undertaken, focussed around the routines of daily living similar to those which underpinned the ‘provider’ interviews in the present study. The author describes patients having to be out of bed at 7 a.m. whatever day of the week it was; strict segregation between staff and patient eating and drinking utensils; mealtimes where residents are continually told to ‘shut up’ because the staff did not like the noise of conversation; the consternation

amongst the staff caused by a proposal to offer a choice of meals, bath times consisting of a queue of patients waiting to use the same bath water; and everyday clothing which was communal. Some of the policy issues which emerged related to the patients as objects rather than subjects including the valuing of control above care. Medical dominance in setting the objectives and standards of the care system was identified as well as a relatively stable population of patients cared for by a constantly changing and insufficient population of nurses. At least half of the patients being prescribed major or minor tranquilisers and nurses were admonished for talking to patients rather than getting on with their work. There was very limited contact on the part of patients with the outside world.

In the chapter dealing with the policy implications of the study, the authors refer to a description by two nurses of the advocates of normalization in terms of their "emasculated humanitarianism" and their view that "the imposition of normal environmental demands is not the function of a subnormality hospital" (Ryan and Thomas 1987 P136). The chapter goes on to describe the imperative for nurses and doctors to defend the dominance of their own professions in the care of mentally handicapped people. Other issues covered include the tendency of large institutions to provide inflexible and dehumanised care; and the most challenging issue of all was the assumption that people with a mental handicap should be grouped together at all. In the final chapter of the revised edition of the book (Ryan and Thomas 1987) the authors report little systematic change in services for people with a mental handicap. Provision within the community is seen as patchy and under funded, and medical dominance has not been effectively challenged. Opposition to the closure of hospitals is seen to be rooted in ideology (the desirability of segregation) and occupational self interest (loss of jobs and status). In summary, there had been some progress towards ordinary living, but there was still strong institutionalised opposition to a long term commitment to normalization.

Despite evidence of such opposition there was, in the late 1980's and early 1990's a movement away from hospital provision and towards the development of community based services. In the Kirklees area of England a group of 39 'movers', their service providers, and their relatives were asked to evaluate the effects of the change of residence (Booth, Simons and Booth 1990). The 'movers' were rated by staff according to an 'Adaptive Behaviour Scale' which was designed to assess their competence in daily living skills. The researchers decided not to use a second part of the scale which was designed to assess 'maladaptive' behaviour because of problems of validity, and of moralistic overtones within the criteria of maladaptive ness. With regard to outcome, there was a 4.3% overall improvement in the adaptive behaviour scores, although there was considerable individual variation. Staff commented upon the increased confidence, independence and maturity of service users who had moved to a new form of care. Service users, particularly those who now lived in ordinary houses, were almost universally enthusiastic about their new homes. The freedom to undertake domestic tasks, such as cooking and housework in a manner which they planned for themselves was particularly symbolic of a changed life. Those who lived in shared accommodation sometimes reported difficulty with their new housemates. Families tended to concentrate upon the visual transformation with regard to such things as dress and hygiene, and also made reference to improvements in self awareness and social skills.

A review of research published between 1980 and 1993 in the UK into the impact of the move from hospital to community based care upon the life experiences and quality of life of people with learning disabilities, (Emerson and Hatton 1994) concluded that they were materially better off, were more satisfied with their services and their wider life, and had more opportunity to use skills they already had and to develop new competencies. They had more choice and a wider circle of contact with others, and were less likely to engage upon stereotypical behaviour such as rocking or self harm. They made more use of ordinary community facilities particularly in relation to being well accepted customers of local businesses. The downside remained that in comparison with

the wider community, though they were better off than they had been in the past, they remained relatively poor. With regard to the strategic choices of life; i.e. where to live, they remained at a disadvantage, and even in their daily lives they had less opportunity to exercise real choice than others. They remained somewhat passive, insofar as they relied on others to organise activity rather than being able to initiate it themselves.

The same authors, in company with others later examined the quality and costs of differing forms of residential support for people with learning difficulties (Emerson and Robertson et al 1999). They found that village communities may be associated with better access to health care and to routine day activities, whilst dispersed housing may be associated with greater social integration and homelier settings. Compared with more traditional small-scale provision, supported living was associated with greater choice, and greater participation in community- based activities.

In Scotland, an evaluation of the impact of social work and health services for people with learning disabilities in terms of their outcome for service users and their carers came to some interesting conclusions (Scottish Executive 1999). Researchers organised twenty five focus groups and six supported interviews with respondents who had disabilities which caused communication difficulties across Scotland; talking to 124 people in all. The focus of the study was not on the transition to community based services as such; it looked more generally at levels and types of community participation. The findings painted a picture of social isolation with a distinct paucity of friendships outside the family or service system To be sure, there *was* use made of community facilities, and to this extent the respondents had much richer lives than those who lived in institutions; but participation was usually mediated through family members or support staff. Younger respondents seemed to have the highest expectations with regard to meeting people and going out; they wished to lead their own lives rather than relying upon their parents or other family members. There was also an unfulfilled wish for full time employment in *real* jobs. This was seen as an opportunity for

interesting occupation of time, and an opportunity to meet people. The respondents did not so much identify gaps in services as gaps in access to ordinary aspirations such as those outlined above; but they did recognise that if they were to achieve access to ordinary living they would need more help and support than was available at present.

Section 4: Evaluative Studies of Self Advocacy.

The evaluative research reviewed mostly used individual interviews and focus groups to ask various respondents about the outcomes of community based services, and how they compared to residential care within a hospital setting. Implicit in the evaluation of achievement is a valorisation of certain rights for service users. These include presence in the community, support in the process of making choices, the encouragement and enhancement of service users' competence, the encouragement of respect for their personhood and of active participation within the community (O'Brien 1987). Proponents of self advocacy elevate the enhancement of one competence or right; to be heard, to speak up for oneself, to a pre-eminent status. The punter interviews within the present study concentrate on the dilemmas inherent in the exercise of this right. It is interesting therefore to examine some of the attempts that have been made to evaluate endeavours aimed at promoting self advocacy.

One of the first evaluative studies of the dynamics of self advocacy on a day to day basis was carried out under the auspices of the Norah Fry Research Centre in Bristol (Simons 1992). The study involved a total of 79 service users, of whom 54 were members of self advocacy groups, and 25 were not. Three methods of data collection were used; unstructured tape recorded interviews; discussion groups ranging in size from five to ten people, and participant observation by the researcher in relevant settings such as day centres and self advocacy meetings. Sympathetic approachable staff members were seen to be central to the impact of self advocacy in the sense that they were willing to listen to the concerns expressed by self advocates. Advocacy conducted through the medium of

centre committees was seen to have a limited impact. The larger People First Groups were seen to have increasing influence, often through direct contact with interested professionals. This growth towards political influence was sometimes inhibited by accusations that self advocacy groups were not representative of service users as a whole. Interestingly, one of the key benefits of self advocacy identified by service providers was its positive impact upon the individual service users who participated in it. They were not so sure that it had any great influence upon the service system.

In a publication which drew upon the Bristol research outlined above, and contributions from self advocacy groups throughout England and Wales, including one which operated within a mental handicap hospital (Sutcliffe and Simons 1993) some adults with learning difficulties identified the power differential between themselves on one hand, and staff, parents and carers on the other, as the key issue. They contrast the feeling of being treated like a child, being told what to do by professionals with the protection and safety which derives from having a voice which enables them to take responsibility for themselves and share responsibility with others. There was a tendency for staff to see the primary influence of self advocacy as being upon very practical concerns such as leisure facilities and poor quality food. and they would seek to encourage service users to be more demanding and less passive. This was particularly true when self advocacy groups were connected with service providing institutions such as day centres, but the more autonomous groups, such as People First had ambitions to become a pressure group influencing the planning of provision. Some examples of activities and initiatives that one group had undertaken were: the writing of a policy on sexuality; participation in steering and planning groups, management committees; providing workshops at conferences; involvement in the training of diverse professional groups. Such activity was sometimes problematic, being tokenistic in the sense that professionals encouraged input from consumers without taking responsibility for changing and developing services in the light of what they had learned.

A later study, which focussed on self advocacy in Wales (Whittell, Ramcharan, et al 1998) was based upon replies to questionnaires circulated to 58 self advocacy groups thought to be operating within the country. Forty six of these were completed and returned. Information gained from this source was supplemented by a group discussion with members of a county wide self advocacy forum based in Cardiff. When this was transcribed, a draft of a chapter based upon what had been said was written and audio taped, and sent back to the group for checking. In these groups the fact of belonging to a self advocacy group encouraged a sense of self respect, ownership and identity. In the Cardiff area there was a multiplicity of groups, and this was seen as being important because it gave service users the chance to choose a group where the atmosphere made them feel comfortable, valued and respected. As well as giving them the opportunity to speak up for themselves, members also felt that they developed the ability to listen carefully to the problems expressed by their peers, and offer advice rooted in their own experience. As well as these individual skills, respondents also mentioned the promotion of confidence at a collective level with the group telling others about their rights; being involved in training and the development of new self advocacy groups, and representing the views of people with learning difficulties in a wide variety of forums within the statutory and voluntary sector.

Another method of understanding the individual and group processes which take place within the self advocacy movement is for the researcher to collaborate with experienced self advocates in the production of a narrative about their experiences (Goodley 2000). Analysis of these narratives was then undertaken in the light of themes which had emerged directly from the content of the stories that had been told. This analysis was then used as the foundation of an evaluation of the impact of self advocacy upon the participants and others involved. Four fundamental themes were identified. The first, entitled ‘Pre self-advocacy group days: the making of a self advocate’ traces the effect of such formative experiences as the influence of a ‘defiant’ parent who urged their disabled child to claim their place in the world. The experience of being excluded

and forced to enter institutions such as boarding schools and day centres, seemed to create a capacity for resilience in the face of adversity, and sometimes the outside community also acted to exclude them, and this capacity for resilience had to be drawn upon once more. Despite this, friendship often provided a key support in the further development of resilience (Bayley 1997). A second theme outlines the process of being in self-advocacy groups and coming out as a self advocate. The membership of a group clearly enabled narrators to "recognize, understand, clarify and develop their resilience" (Goodley 2000 P120). The groups seemed to offer a context for the development of self empowerment rather than normalization as such, giving narrators the confidence to define themselves, rather than being defined by others,

A third theme explores the process of learning from the experience of being in the group and deals particularly with the role of advisers. It is not just the independent or staff status of an adviser which can lead to tensions, it is the fact that they are involved in so many roles and interactions which can lead them to assume power which should belong to self advocates. Thinking more widely, for self advocates, the feminist slogan that the personal *is* the political aptly describes the direct effect that the politics of everyday group activity has on self concept. Learning takes place not as a result of academic endeavour, but through the medium of intense personal experience; and throughout the vagaries of such experience, self advocates comfort themselves with the thought that they are preparing the ground in order that the next generation can find their voice. The fourth and final theme makes a very general point about the essentially storied nature of self advocacy, and the centrality of the influence upon self advocates of the accounts of others. Such stories are fundamental, because they illustrate the fact that self advocacy is not just something which is learned through participation in organised groups, but emerges out of past experience of both adversity and opportunity within a wide variety of institutional contexts, including families, the education system and organisations devoted to caring.) He uses the concept of 'resilience' in both a descriptive and analytic

manner to characterise nature of the journey undertaken by the self advocate, and the mind set which is utilised to face the future. (Goodley 2000 P 130)

Section 5: A Sociological Perspective

Thus far the influence of a human rights base, manifesting itself in the goal of normalising the means of service provision, and valorising the right of service users to speak for themselves has been acknowledged. In the view of the researcher the theory and practice of the normalisation movement can be said to be underpinned by that current within sociological theory which is termed symbolic interactionism. In the early chapters of his very influential book, (Wolfensberger 1972) one of the key writers makes the links between the sociology of deviance and the manner in which mentally retarded people are regarded and managed. He cites the suggestion of Wilkins (1965) that

> "Our attitudes toward deviance derive from the Platonic notion that goodness, truth and beauty are related to each other, and that any deviations from norms are 'errors' which, by analogy must be related to evil and ugliness"
>
> Wolfensberger 1972 P14.

Wolfensberger then goes on to take a historical approach to the symbolic meanings attached to mental retardation such as sub-humanity, being an object of unspeakable dread or being ascribed the role of the holy innocent. The definition of symbolic interactionism goes beyond this historical approach and Blumer (1969) identifies three elements. Firstly what defines the nature of being human is the capacity to act on the basis of meaning. Meaning is ascribed not only directly to the behaviour of other people but also to artefacts; as in the case of a wooden cross to Christians; and to abstract ideals, such as chivalry in the case of medieval knights. Secondly meanings emerge directly from the very process of social interaction with other human beings. Thus the most common association of the term 'Madonna' has changed from being concerned with the

depiction of a saintly woman in the art of the renaissance to that of a post feminist popular music icon. Thirdly, everyday social life consists of a process of negotiating meaning through the medium of a personal interpretive process. Thus a person of more mature years seeking to understand the musical tastes of a younger generation would need to understand that the word ‘bad’ is a term of approbation when applied to the latest musical offering.

The present study, especially in relation to the archival section, and to the experiences outlined within the provider interviews, is very focussed upon the dynamics of residential health and social care institutions, and their effect upon the life chances of those who have been defined as ‘deficient’, ‘handicapped’ ‘disabled’ or in possession of ‘special’ needs. Indeed it could be argued that all the respondents in the study, including those who had *always* lived within a community setting, lived under the shadow of these institutions. For this reason, it is apparent that the ‘theoretical sensitivity’ (Glaser 1978) of the researcher has been much influenced by the work of Erving Goffman, and at the later stages of the analysis process many of the more abstract categories employed echo the concerns of his work on the nature of total institutions (Goffman 1975).

Goffman added to the symbolic interactionist current of thought by focussing on the manner in which experience is organised on the basis of ‘frameworks of understanding’ whose function is to make sense out of events.

> “Frameworks are not merely a matter of mind but correspond in some sense to the way in which an aspect of the activity itself is organised – especially activity directly involving social agents. Organisational premises are involved, and these are something cognition somehow arrives at, not something cognition creates or generate. Given their understanding of what is going on, individuals fit their actions to this understanding and ordinarily find that the ongoing world supports this fitting. These organisational premises – sustained both in the mind and in activity – I call the frame of activity. …… activity interpreted by the application of particular rules, and inducing fitting actions from the interpreter, activity, in short that

organises matter for the interpreter, itself is located in a physical, biological, and social world."

(Goffman 1974 P158)

In his application of frameworks of understanding to the dynamics of life within a total institution Goffman (1975) examined the respective worlds of the staff and the inmates outlined the particular rules that governed their behaviour. The staff for their part have to deal with the demands and needs of inmates at a face to face level. The expectation is that they will carry out their tasks within a particular moral climate. The management of inmates is typically rationalized in terms of the ideal aims or functions of the establishment. Thus when patients in a Mental Handicap Hospital have to be segregated from others because their behaviour is unmanageable within the confines of an ordinary ward, they might be taken to a 'Special Treatment Unit'. Their behaviour is thus characterised with the aid of a frame of reference derived from medicine. For patients, their self concept is modified in the light of their experience of life within a total institution. In the absence of the ordinary reflections of life (family, friends, workmates) the inmate undergoes a process of mortification of the self, and has to adopt a number of modes of adaptation in order to survive the assault made upon the self by the institution.

From Goffman, the present study derives its understanding of the centrality of the links between the practices of the institution and the self concept of both punters and providers. This is not to say that the responses of the punters, and to some degree the providers, will be identical to those identified (Situational Withdrawal, Intransigence, Colonisation, Conversion and Playing it Cool). It may be, for example, that the 'grading' system for patients, which was common within mental handicap hospitals, had implications for both the manner in which providers organised their work, *and* for the self esteem of the punter. However the insights provided (Goffman 1975) may well provide some clues as to the level and nature of generalisations which providers in a hospital setting and

punters who live in the community, make about the nature of day to day living, both in the hospital and within the community.

Section 6: Discourse Analysis.

The data which has been produced in the present study consists almost entirely of discourse recorded in a written form. Archival evidence is in the form of quotes drawn from official records, and the semi structured interviews conducted with punters and providers have been converted, through the medium of the transcription process into written records. It is acknowledged that insights have been gained from other sources such as the stories recounted in the 'Intimate Narratives' chapter; and it is the view of the researcher that anything which can be read with the aim of deriving meaning, can be regarded as text (Thompson 2003), and forms part of the content of the study. Consequently, whilst examining theoretical context, it is important to provide an account of some of the writing which has influenced the manner in which the researcher derives meaning from such texts.

In the process of examining and assigning meaning to text, it is the belief of the researcher that the reader is faced with two sorts of choices (Traynor 2004). The first relates to the nature of the individual as a subject. Here, at one end of the continuum, can be found the autonomous individual as a sole originator of meaning; in religious thought such a person is created as a person with free will and absolute choice, although that person may be tainted with original sin, and in political thought has ultimate self responsibility since there is no such thing as society. In examining the text produced by this perfectly autonomous being, there is little point in looking for the origin of meaning, since the experience is unique. At the other end of the continuum is the view that the human subject is only made possible as a result of discourse. Self concept is entirely the result of our internalisation of the views of others about us. (Mead G.H. 1934) The second choice relates to the view of the nature of language held by the reader. On the one hand language can be regarded as a neutral medium through which

the author of text conveys facts and concepts to the reader. At the other end of the continuum is the view that language is simply the material enactment of the social, political and philosophical structures employed by individuals and groups to exercise power.

For Foucault (1992) the utility of examining discourse lay in making explicit how systems of language shape the experience of people, and determine what can be said, in what form, and perhaps more importantly, what cannot be said. In the commonplace usage of the term discourse is usually taken to describe the process of communication or interaction between two or more actors. In its Foucauldian usage the term is defined more widely and is used, in combination with an archaeological method to describe individual acts of language or statements. The significance of such statements goes far beyond the merely linguistic, and have been described in the following manner:

> "For Foucault discourses are made up of statements that set up relationships with other statements: they share a space and establish contexts; they may also disappear and be replaced by other statements"
>
> Danaher,Schirato and Webb 2000 pp35

The contexts referred to above define the conditions of possibility within which the statements subsist. For Foucault it would be impossible to give meaning to statements outside the particular period of history within which such discourses were dominant. It is, of course, possible to attempt to define such a discourse by its internal elements or its external context; but the depth and subtlety of the description required by a Foucauldian view is almost impossible to convey. After excavating the discourse from the soil of a particular historical period, it is of crucial importance to analyse it within the context of the worldview in which it was originally located.

Another important element of Foucault's account of discourse relates to the linking of knowledge and both the form and content of its expression to power. The concepts of power and knowledge are inextricably linked. Where there exists a power relationship, there will also exist a related field of knowledge, and any existing field of knowledge both presupposes and constitutes at the same time power relations. (Heartfield 1996)

> "Power relations serve to make the connections..... between the visible and the sayable (the two poles of knowledge) yet they exist outside these poles"
>
> Kendall & Wickham 1999 pp48 .

Knowledge is what is thus used to select and justify the forms of power that are utilised in one particular historical period. It should not be assumed however that power operates in a uni-directional manner. The relationship is better characterised as being a dialectical one.

> "As power operates primarily through discourse (ideas, assumptions, knowledge, frameworks of understanding) such domination can be challenged through acts of resistance, through the use of countervailing power to undermine dominant discursive practices."
> Thompson 2003 P 57

With regard to the two fundamental choices to be made in pursuing an understanding of text which were outlined above it can be seen that the influence of Foucault has inclined the researcher to a theoretical view which acknowledges the formative effect of discourse upon the human subject and the impact of structural factors upon the material enactment of language. The researcher's theoretical sensitivity is grounded in a notion of discourse which posits an intimate and dynamic link with issues of inequality, discrimination and oppression. The determination of self advocates to find their own voice which was described above represents a conscious effort to develop power which is

sufficient to countervail dominant discursive practices; especially those undertaken by professionals involved in the health and social care systems.

Section 7: One Approach to Synthesis.

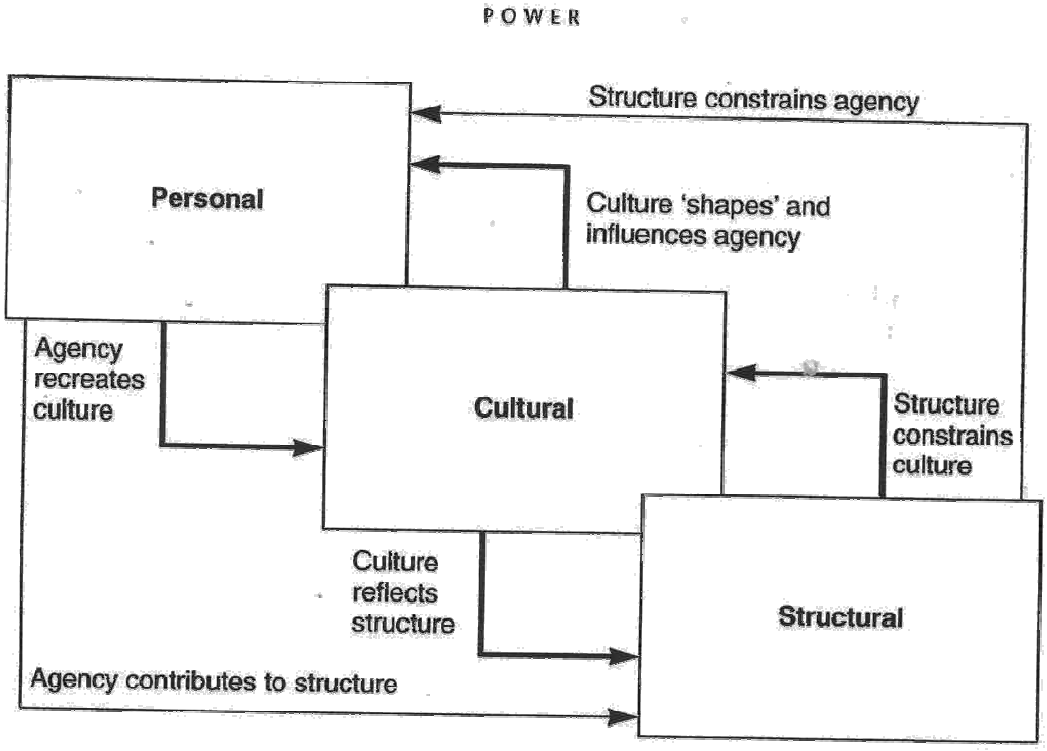


Figure 2.1 The interactions of the personal, cultural and structural levels

Figure 2: An Approach to Synthesis. Source: Thompson (2003) P69.

Thus far the influence of three theoretical currents, and some of the evaluative endeavours that have emerged from them, have been acknowledged. However, if the relationship between theory and methodology is not one where the latter is deduced from the former then the nature of the relationship must be made clear. In terms of the conventional purpose of a literature review alluded to in the first paragraph of this chapter, a necessarily brief outline has been provided of some of the theoretical and conceptual frameworks employed within these influential

currents of thinking. In order to identify gaps in the knowledge base, and to evaluate the extent to which the methods employed by previous studies promoted a good understanding of the issues involved, it is the view of the researcher that some explicit synthesis of the impact of influential sources must be attempted.

A primary consideration when attempting to summarise the overall impact of past theory upon the present research is to consider the *level* of analysis at which such theory has sought to operate, and the nature of the relationship between the levels of analysis. Thompson (2003) in thinking about the everyday operation of oppression and discrimination distinguished three levels of analysis. (Fig 2) The first was the personal level where individual agency is identified in terms of the attitudes and motivations which inform the behaviour of people who act in a discriminatory manner, or are affected by the oppressive or discriminatory behaviour of others. Taking the example of self advocacy, the self concept of a person who carries the label of learning difficulty may well have been greatly affected by the definitions employed by significant others (such as professionals and carers). Such definitions may be contained within a culture, (for example that of disability being evidence of sins of the past being visited upon the present), or they may be a result of structural factors, such as the adoption of segregation as a primary means of providing for disabled people. The next level identified by Thompson is the cultural one. Culture is conceptualised as operating from a group or institutional level; examples being the family or religious bodies. Taking an example from the symbolic interactionist perspective, treatment or care organisations often develop strong cultural norms about the boundaries between service users and providers which are reflected in cultural conventions about the manner in which members of either group should be addressed by the other. The terms utilised having a strong symbolic importance within the process of status ascription. Individuals can be influential in changing culture, for example a disabled person who becomes a cabinet minister, and it is also true that structural influences can determine the limits of cultural change.

The third and final level of analysis is the structural one which operates at a society wide level. An example of structural analysis could be the transformation of the British economy from being predominantly manufacturing to being a service based economy at the beginning of the 1980's. It can be argued that it was this, and the influence of globalisation within a service economy that has led to the transfer of services to the private sector rather than any individual or cultural change of heart (Glyn 2006). Once again, the causal relationships do not run wholly in one direction. An individual Prime Minister can have a great effect upon the design and functioning of political and economic structures; and the movement towards a multi-culturalist view of service provision can lead to it being acceptable for rail passengers to make timetable enquiries to a call centre in India.

With regard to the application of Thompson's schema within the present research; it is anticipated that it can be adapted to shed light upon the processes of archival work, the interviews with providers and groups of providers, and the storying process reported within the intimate narratives. Within all of the 'sites of interest', a response will be obtained from punters, providers and others which tells a personal story. In line with the patterns of interaction between the levels set out in Figure 2, *each* of those levels has some form of influence on the others, and the aim will be to present findings which make those relationships explicit.

Section 8: Further Approaches to Synthesis

Having thought about the *content* and *level* of the theoretical influences upon the present study the researcher takes the view that there has to be some discussion of the epistemology of synthesis. There is a need to examine the degree of certainty in knowledge, and the difference between knowing (with certainty) and believing (without being certain). One approach to the task of synthesis is to simply combine the insights gained from a multiplicity of approaches. Faced with the complexity of examining how and why auditors

interact with their clients, (Beloucif 1996) the first task was seen to be to specify a framework based on relationship marketing based on exchange theory, interpersonal relationships theory and interorganisational relationships theory as a basis for understanding interactions between service providers and their clients. Then grounded theory was used in an exploratory manner to facilitate the emergence of the dimensions of the audit-client relationship. Finally systems theory was used to build a holistic model of what was happening in the audit market. The researcher was attracted by the simplicity of the aggregation process involved, but was not convinced that the theories were epistemologically compatible. The question occurred as to whether the researcher deduced some of the categories from the foundational theories rather than allowing them to emerge from the data. Also it would be interesting to know whether the categories which emerged from the grounded theory were usable to establish causes and effects under the auspices of a systems based approach.

Another approach (Walsh and Downe 2005) makes an attempt with the aid of a process called 'Meta Synthesis' to integrate results from a number of different but inter-related qualitative studies. It seeks a model which provides an explanation of the findings of such studies, but distinguishes itself from the meta-analysis of quantitative finding by saying that its task is not to seek certainty in cause and effect conclusions, but to utilise a hermeneutic aspiration to understand and explain. The merit of this approach is expressed in the following terms.

> "bringing together qualitative studies in a related area enables the nuances, taken for granted assumptions, and textured milieu of varying accounts to be exposed, described and explained in ways that bring fresh insights"
>
> Walsh and Downe 2005 P205'

By analogy, the process of naming and enumerating theoretical influences outlined above is not seeking to examine the totality of alternate theoretical

possibilities and somehow make clear the gaps in the perspective of the study. The task is rather to display an interpretive intent, and to detail the empirical insights and tentative theory which have been derived from previous writing in the area of difference and disability.

Section 9: A Unifying Perspective.

Within the approaches to synthesis discussed above the key issue appears to be the extent to which it is possible to combine subjectivist and objectivist views of the world. Is it possible to link the personal and the structural, or are these levels of analysis governed by opposing epistemological frameworks? Is it possible to root a grounded theory approach to questions about audit in a systems based theory? Is the process of Meta synthesis capable of producing a whole which is more than the sum of its parts, is the result a mere checklist of influences? It can be argued that this opposition between objectivism and subjectivism is destructive of any true process of understanding within social science, since it leads to alternative epistemologies which are, by definition likely to be partial, and unable to truly represent the practices and experiences of the social world in a dynamic manner. (Bourdieu 1992).

Bourdieu puts forward a in his 'Theory of Practice' a sociological view that rather than studying individual behaviours, the key is to examine *actions* which contain within them influences from the cultural and structural levels of society (Rhynas 2005). Bourdieu describes and explains these influences with the aid of three concepts.

The first of these, the *field,* is analogous to Goffman's frameworks of analysis.

> "It can be described as a series of structures, institutions, authorities and activities all of which relate to the people acting within the field. It is not a static entity, but changes as practices or power dynamics challenge the boundaries of the field. . Every person acting within the field is capable of

> producing effects upon it……. It is the *relationships* within the field that are important" (Researchers emphasis)
>
> (Rhynas 2005 P181)

In the present study one field of interest may be the residentially based care of people who have the label of learning difficulty. Insights derived from the early experience of providers may point to total determination of the parameters of punter's lives because of the power of total institutions. However, notions of human rights, emanating from other sources, including the growth of a consumerist culture challenged the boundaries of the field.

The second element of Bourdieu's system is the notion of *Capital.* Although the influence of economic capital in the Marxian sense of a factor of production is acknowledged, the concept is widened to include social and cultural capital. Exchange of capital is the process through which reconfiguration of the field takes place. During this process authority is transferred, and the participating groups seek to maximize their capital. Traditionally very little capital has been assigned to Punters, they were expected to adopt a passive role, and do what they were told. One of the key tasks of the self advocacy movement is to build a stock of capital for service users within the process of planning and providing care services, and ultimately within the wider society. When self advocates take part, in partnership with professionals, in the planning process, they are, as well as helping to make plans, making a bid to increase the amount and worth of their capital. That might not have been their intention, but the effect of their activity has been to change the nature of their relationship with the care system; a process which often creates personal and professional dissonance within the ranks of providers.

The third element *Habitus* incorporates the cultural level of analysis into his theory of practice in a manner which manages to capture the fact that the nature of reality is often totally unproblematic because it is seen to be somehow inherent. Such features of social life can only be understood by going beyond

the combined behaviour of individuals to the historical and cultural base which is rarely made explicit. It is a commonplace that some cultural items are explicit and formally taught, for example American schoolchildren being shown how to put their hand on their heart when the national anthem is played. Bourdieu shines the spotlight on that form of transmission which seems to occur on the basis of a form of cultural osmosis, perhaps via imitation, but in the view of the researcher more likely on the basis of once making a mistake, and being determined never to make it again. Bourdieu characterised his theory of practice on the basis of an equation (Bourdieu 1984)

[(habitus)(Capital)] + Field = practice.

In the form of the equation there is an attempt to capture the sense that individual social beings in pursuit of their capital are constrained and 'internally regulated' by their habitus. But

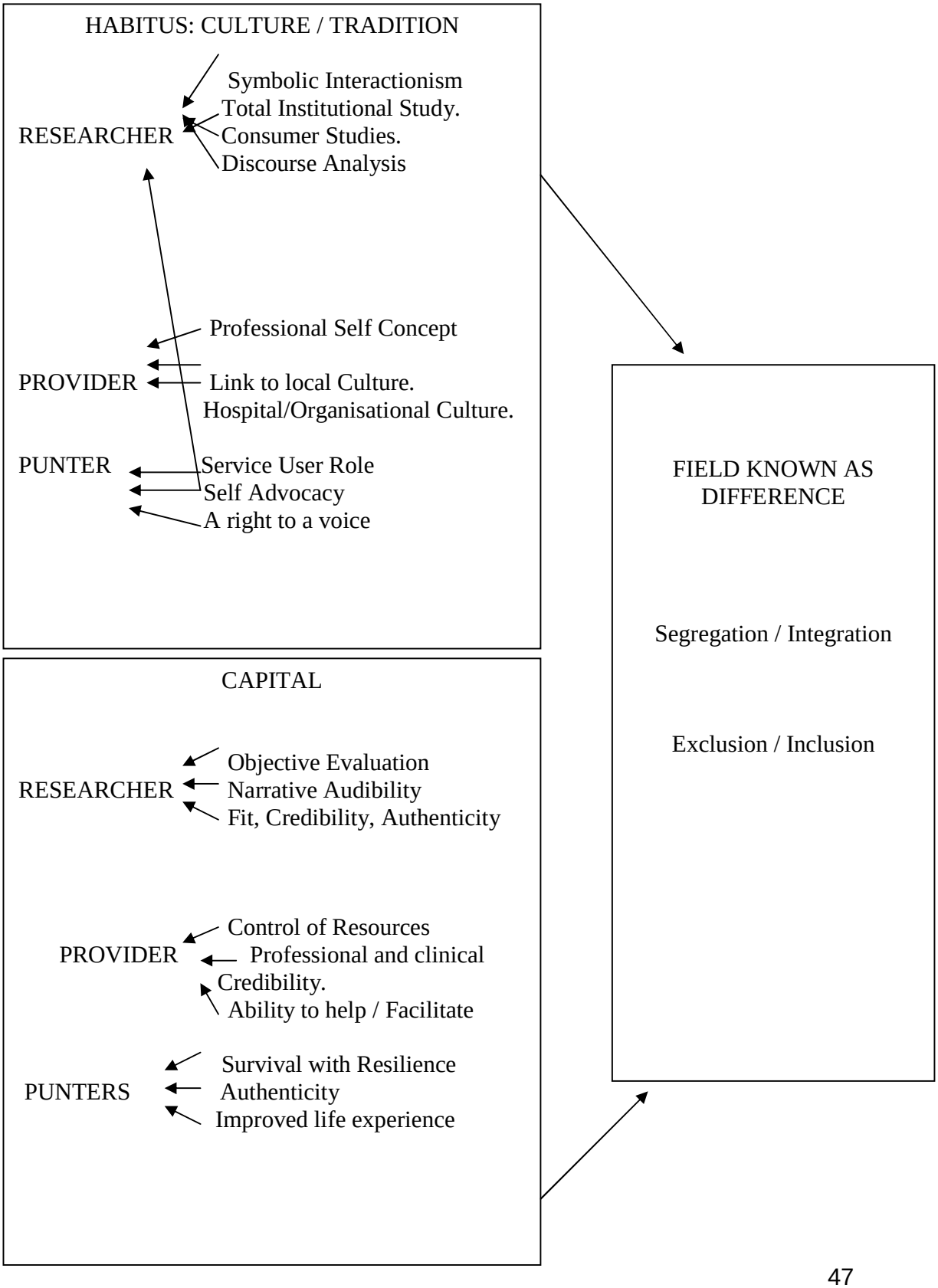
> "the influence of the field is crucial as the action is both constrained and given meaning by the context in which it takes place"
>
> (Rhynas 2005 P182)

The theory is useful in understanding the relationships between punters and providers because of the centrality of the notion of practice. It provides a conceptualisation which is capable of encompassing process and the dynamics of change, for example the interaction of habitus with the restraints imposed by a total institution or a market driven consumerist economy. In terms of its method, it is attractive to the researcher because of its emphasis on reflexivity. The researcher has to locate their own position within the field of study in a transparent manner; because Bourdieu is in no doubt that the researcher is a product of the social world within which the research takes place.

In Figure 3 an attempt has been made to characterise the elements of the present research in terms of Bourdieu's system. The 'habitus', outlining in the culture and traditions which might be thought to be influential upon punters, providers and the researcher is set out, along with the components which the

three major parties might bring with them. A very crude attempt is made to speculate about the components of that field which has been given the title of ‘difference. Clearly the purpose of the research is to add content and detail to this schema.

Figure 3: Research & Practice – Adapted from Bourdieu (1992)



Section 10: Conclusion and the Link to method

The central research question for the present study is a very widely drawn one, namely the nature of the category of difference which is variously described as ‘Subnormality’ ‘Mental Handicap’ ‘Learning Disability’ ‘Intellectual Disability’ or, in this study, ‘Learning Difficulty’. It necessitates enquiry over a great breadth, taking in historical documents and records, and interviews with punters and providers. Its basic orientation is influenced by grounded theory, and to that extent the intention is that theoretical categories will emerge from the data.

The theoretical currents which have been set out above are influential upon the present research in two senses. Firstly that the theoretical sensitivity of the researcher has undoubtedly been sharpened by exposure to these currents, and secondly that during the process of abstraction which takes place when formal theory emerges, some of the findings and perspectives will be treated as data. Conceptualisations of influential factors, such as Thompsons’s and Bourdieu’s schema are NOT to be utilised as the basis for hypotheses within the current research. There is a sense in which the empirical findings which have been examined in relation to consumer satisfaction are only of background interest inasmuch as the research question pertains to the theory *behind* provision rather than expresses curiosity directly about experience of the care system

The overall aim has been to make the theoretical context within which research practice as transparent as possible; and it is anticipated that representing that practice with the aid of Thompson and Bourdieu’s terminology and theoretical system is helpful to that process.

Chapter 3 Research Design and Methods.

"There must be a reason for the person who hastens off into the desert; if something is not running after her, she is running after something"

Yoruba Proverb.

This chapter is structured in 15 sections.

Section 1: Introduction.
Section 2: The research question.
Section 3: A general approach influenced by Grounded Theory.
Section 4: Sources of Data
Section 5: Building evidence across sources. .
Section 6: Ethical considerations.
Section 7: Data Collection 1: Searching the archive.
Section 8: Data Collection 2: The provider interviews.
Section 9: Data Collection 3: Punters: The group Discussion / interviews / intimate narratives.
Section 10: The Structure of interviews / group discussion.
Section 11: Interview / group discussion content.
Section 12: Data analysis.
Section 13: The pursuit of rigour.
Section 14: Further considerations regarding rigour.
Section 15: An evaluation of the research design and methodology.

Section 1: Introduction.

Decisions about research design have been eloquently defined as a sort of *anticipatory data reduction* and the orientation of the researcher at the commencement of a project characterised by the phrase,

> "Something is known conceptually about the phenomenon, but not enough to house a theory" (Miles & Huberman 1994 P 16-17)

At the commencement of the present project, the researcher thought, on the basis of both personal and professional experience, that ideas about the nature of learning difficulty were inextricably linked to the culture of the surrounding society. There was no doubt that there had been a seismic shift in central and local government thinking about the best form of provision for people with a learning difficulty who needed support; going from segregation and control aimed at reinforcing boundaries against 'pollution' (Brigham 2000) towards small local units, inclusive in nature, where the aim was to promote integration with ordinary communities (Scottish Executive 2000).

The problem was to evolve a design which could address the *breadth* of perspective required to document changing experience with regard to both punters and providers. It has been said that those without an understanding of history are destined to repeat it, so an element which looked at past experience was essential. The interview based element of the research was, at first, also planned to be historical in its perspective; examining the parallel experiences of punters who had lived in hospital, and those who had provided services for them. However, the researcher found that decisions about who to interview, especially with regard to the punters, were greatly influenced by the process of understandings which emerged during the actual research process. Glaser's (1998) description of theoretical sampling characterised this process very succinctly.

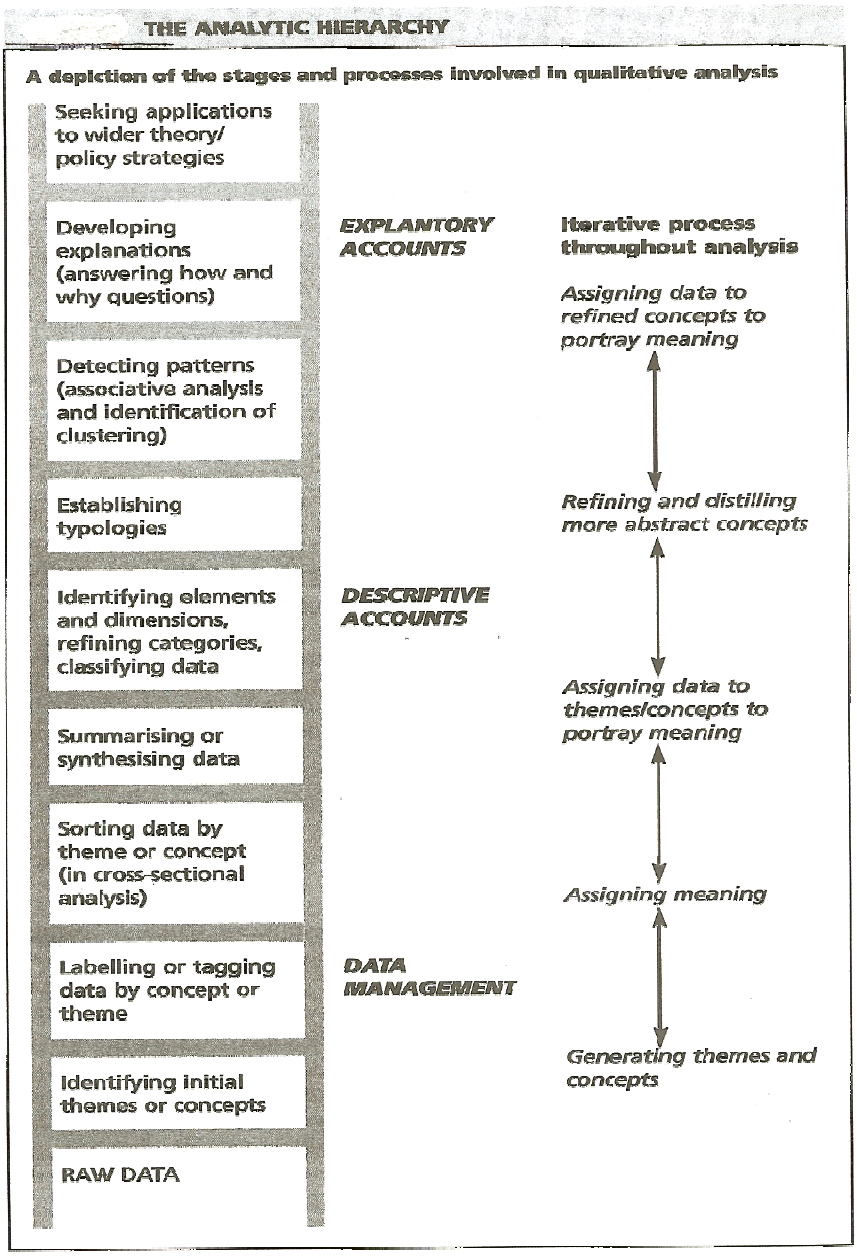
> "… the prime mover of coding, collecting and analyzing data. It is both directed by the emerging theory and it directs its further emergence. It is the "where next" in collecting data, the "for what" according to the codes, and the "why" from the analysis in memos."
>
> Glaser 1998 P157

Also influential in making choices about overall design was the analogy of a ladder used by Spencer, Ritchie and O' Connor (2003) to describe the progress of the iterative process throughout analysis, where insights gained in doing the research make it

> "Possible to 'look down' on what is emerging and to reflect upon how much sense this is making in terms of representing the original material"
>
> Spencer, Ritchie and O'Connor 2003 P213.

Thus, as the research happened, so the ways of interpreting and understanding the evidence changed. One can characterise this process by utilising the language of the 'Analytic Hierarchy' set out in figure 3. The management of data in both the archival research and the provider interviews provided descriptive accounts which led the researcher towards a modified explanatory account. Specifically, the theoretical explanations of the nature of that form of 'difference' known as 'learning disability' which emerged from these two sources of evidence led to a change of direction. Instead of focussing upon a historical account of those 'punters' who had lived within the institution, it was decided to utilise the discussion group to ask current punters about their experience of difference whilst living in the community.

Figure 4: The Analytic Hierarchy.
Source: Spencer, Ritchie and O'Connor (2003) P212



One key realisation therefore was that both punters and providers take part in an active process of theorising about the nature of learning difficulty, and consequently the researcher sought to modify the design to take account of this knowledge.

This chapter seeks to make explicit the nature of the research questions which the study aimed to throw light upon, and the choices that were made with regard to methods of enquiry. Parahoo (1997) p 142 defined 'research design' in terms of a plan or strategy which

> "Describes how, when and where data are to be are to be collected and analysed"

The elements of the current research strategy will be described in the light of a general approach which owes its orientation to grounded theory, and will further describe the time frame, place and source of the data, and the methods of data collection and analysis.

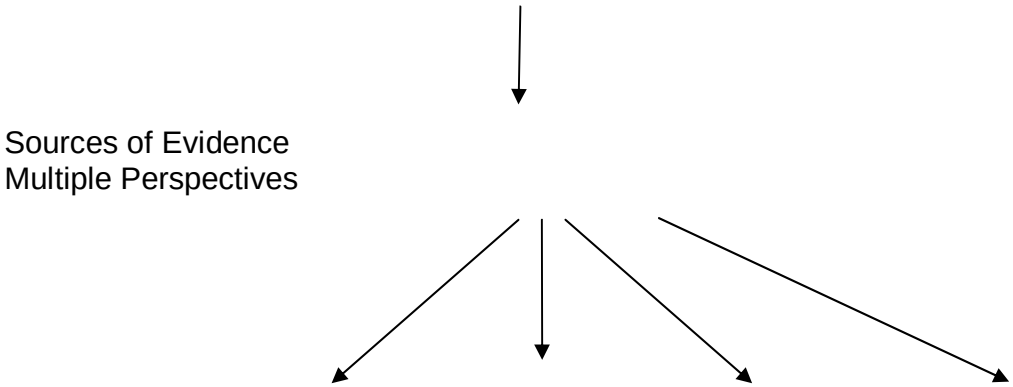
Section 2: The Research Question.

The nature of the research question changed and evolved during the early stages of the study. The researcher initially considered deriving the primary research question from one of the major theories espousing an overall viewpoint concerning the direction of change to be pursued in designing services for people who had been defined as having a learning difficulty (Wolfensberger 1972; Sanderson and Kennedy et al 1997), or from one of the empirical studies of the process of moving towards community based provision (Booth, Simons and Booth 1990). Hypotheses derived from these sources would have been couched in terms of the progress or otherwise towards the normalisation of service, or inclusion of people who had been defined as having a learning difficulty within the mainstream of society. However, the experience of

undertaking the archival work, and conducting the provider interviews pointed to definitions of the nature of learning difficulty which were changing. These changes were apparent in the discourse which was employed within both the archival and the interview based sources to describe the activity of everyday living. At the same time, the researcher's reading around grounded theory had pointed towards a research question which allowed the maximum scope of enquiry inasmuch as its parameters were not limited by the dictates of a pre existing theory. For these reasons the research question was widened to one which was focussed on the nature of difference. This difference had been expressed in various ways as Mental Deficiency or Subnormality, as Mental Handicap, as Learning Disability, Intellectual Disability or, in this study, Learning Difficulty. Whatever language was used, the research focussed on the discourse employed by those who lived and worked within the care environment, and the social and psychological forces which influenced them. In chapter 2 entitled 'Past and Present Discourses' the researcher has briefly outlined some of the theoretical currents which influenced its genesis, but the task of the research is to understand the nature of difference with the aid of insights gained directly from the archive, from those who provided services in the past, from present punters, and from a number of 'intimate narratives'. An alternative way to characterise the research question is in terms of its focus on a *description* of the experience, and an enquiry into nature of the *theory* which conceptualises the experience, of those who live and work *inside* the care environment, rather than an enquiry which derives its agenda from outside theorists. The research question and overall structure and content of the study is represented diagrammatically in Fig 5.

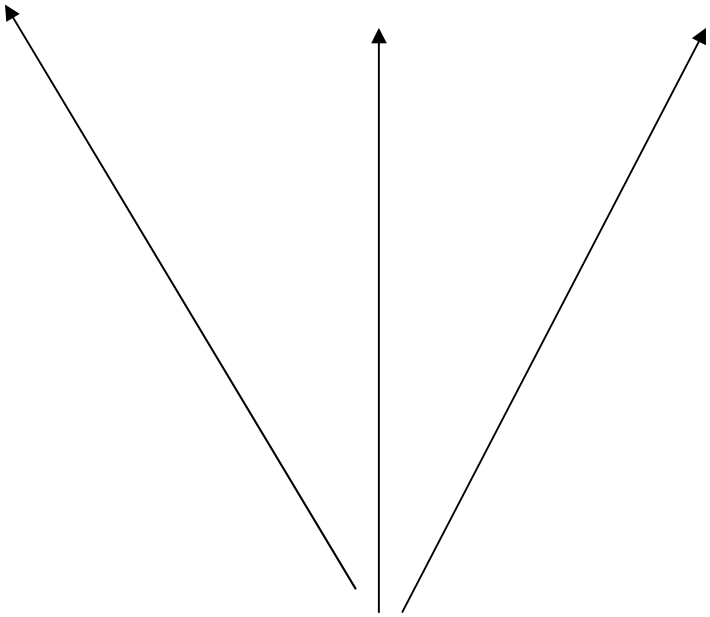
Figure 5: The Research Question

Central Research Question: How does the lived experience of the 'provider', the 'punter' and others inform our understanding of that form of 'difference' variously described as 'subnormality', 'Mental Handicap', 'Intellectual Disability' or, in this study, 'Learning Difficulty'?



Sources of Evidence
Multiple Perspectives

Official Records Provider Interviews Punter Interviews Intimate Narratives



The day to day experience of living both within an institution and within the Community

The social, cultural and organisational context

Section 3: A General Approach Influenced by Grounded Theory.

The co-originators of Grounded theory in contrasting it with speculative or logically deduced theory defined it in the following manner;

> "Generating a theory from data means that most hypotheses and concepts not only come from the data, but are systematically worked out in relation to the data during the course of the research. *Generating a theory involves a process of research* .By contrast the *source* of certain ideas, or even "models", can come from sources other than the data" [emphasis in the original]
>
> Glaser and Strauss (1967) P6

In this original statement of the nature of grounded theory it is significant that the title of the book points towards the *discovery* of theory within the he process of analysing the data. In a later work, Glaser set out of a very firm dictum:

> "Do not do a literature review in the substantive area and related areas where the research is to be done" (Glaser 1998 P67)

Theory was not, initially at least, to be imported from outside sources. Through the use of the constant comparative method and by moving from substantive or open coding of individual words and phrases on a line by line basis, the process of research moved towards the emergence of categories by condensing a number of substantive codes into a higher level of abstraction. (Benton 2000). By posing questions about the categories that have emerged from the data, a limited number of theoretical constructs or categories will emerge, and through further interrogation of these constructs a number of core categories will emerge. At this point Glaser (1998 P67) acknowledged that a literature search in the substantive area could be carried out and woven into the theory as more data for constant comparison.

This method was attractive to the researcher, because of the potential for the theories to emerge directly from the responses of punters and providers, and also from archival data that had been collected. One of the effects of the movement towards self advocacy for people with learning difficulties had been a desire on the part of disabled people to be included in the planning and undertaking of research (Apsis 1997; Ward 1998). Particularly in relation to punters, the emphasis within grounded theory upon constant comparative analysis of the data meant that the respondents set the tone for the development of the content of substantive theory, and that the theoretical constructs would be greatly influenced by their concerns. For both punters and providers, the injunction to the researcher to be someone who

> "Moves in with abstract wonderment of what is going on that is an issue and how it is handled".
>
> Glaser 1992 P22

This would ensure that predetermined categories, from whatever source would not be used to characterise their experience.

Another major reason for the adoption of grounded theory as a general approach relates to its goal of generating theory rather than findings. Its purpose is not verification but generation of hypotheses. It offers

> "A rigorous, orderly guide to theory development that, at each stage is closely integrated with a methodology of social research" Glaser 1978 P2

The central research questions outlined above relate to a period in the history of provision for people with learning difficulties when it appears that the principles guiding provision are changing. A key purpose of the research is to use the responses of punters and providers to generate theory which reflects these changing times. It can be argued that qualitative interviews with a small number of providers and punters cannot be thought of as representative of the general

population of those who fall into these categories. This point is conceded; the purpose of this research is to generate theory about the nature of the experience of those who have been defined as having a learning difficulty, and those who provide services for them. It is for others to verify whether such theory has application to the lived experience of others.

Having acknowledged the formative influence of Grounded Theory it should not be assumed that the research was undertaken in a manner which conformed totally to the methodological strictures of one proponent of the theory. Indeed, the methodological paths of the co-originators of Grounded Theory diverged in later years, with one author maintaining that theory rises directly and rigorously out of the data, (Glaser 1992) and others (Strauss and Corbin 1990) turning towards a

> "Conceptually descriptive approach, that encourages directive questioning and supports an interpretive stance"
>
> Boychuk Duchscher and Morgan (2004) p605.

In the detailed description of the methodology which follows, it should be clear that the general approach based on Grounded theory was modified to take account of the aims of the study, and the context within which the fieldwork was undertaken.

Section 4: Sources of Data.

When making the choice of a setting, population or group of individuals to study, the researcher was looking for characteristics which were like to be both compelling and interesting to those wishing to think about the past, present and future provision of services to people who have been defined as having a learning difficulty

> " A realistic site is where (a) Entry is possible. (b) there is a high probability that a rich mix of the processes, people, programs, interactions and structures of interest are present (c) The researcher is likely to be able to build trusting relationships with the participants in the study: and (d) data quality and credibility of the study are reasonably assured"
>
> Marshall & Rossman 1999. P69

Bearing these in mind, data was gathered from four main sources.

Archives: The first was a period of archival work undertaken during the year 2000. In the light of the historical inclination of the central research questions, the researcher was keen to seek out documentary evidence which had the potential for setting out both descriptive and explanatory accounts of the nature of past provision. The researcher approached this archival work with a naïve view that it would consist of sifting through piles of dusty records. It was a relief to find that past records relating to institutional care provision in one hospital context had been indexed, and in some cases microfilmed, and there was an archivist on hand to give advice about the best way to access them. The records covered a time period from the opening of the hospital up until the late 1980's.

The records consulted were retained under three main headings.

- Case books, mostly dating from the time when the hospital was a county asylum (from 1865 onwards). These were useful because they contained written descriptions of people who had been admitted, and it was possible, because of the language that was used, to concentrate upon the patients who in modern times would be regarded as having, in the current medical parlance, a learning disability. The distinction between this group and those with a psychiatric label is a thread which runs through the discourse of both punters and providers up until the present.
- Minutes of meetings: in the early days these included the minutes of the county lunacy committee, and in later years the minutes of mental

hospital boards of management and regional hospital boards. These minutes often contained explicit statements about changing policy; an example being the reasons for the redesignation of Lhangbyde as a mental handicap hospital in the years after the inception of the health service.

- Microfilmed files relating to the management of the hospital. These were particularly important in documenting the development of bricks and mortar provision during the nineteen sixties which were necessary to facilitate the change in function from asylum to hospital. They were a revealing source of professional and managerial discourse because the files tended to reflect the nomenclature which was current at the time. For example: the distinction between 'High Grade' and 'Low Grade' villa's, which referred to the classification of the patients who lived within the ward.

Providers: The second major data source related to the 'providers' who had worked in Lhangbyde hospital. The only qualification for inclusion was that they had worked at the hospital for at least two years. The first method of contacting possible respondents was to approach university colleagues who had worked in the hospital. This produced three interviews. Another route was to approach people who were working in other organisations and interview them if they met the eligibility criterion. This produced three interviews. One doctor was interviewed while the hospital was still open. Earlier interviewees were used to establish contact with people who had worked in the hospital in the past, and this 'snowballing' procedure resulted in a further 5 interviews; making a total of 12 in all.

Interviews took place within a number of locations, the deciding factor being the convenience of the respondent. Venues included Lhangbyde hospital, other health service premises, The Robert Gordon University, and in the case of

providers who had retired or moved on, some interviews were conducted in their homes. Interviews lasted between 45 minutes and 1 hour 20 minutes, and were conducted without interruption. The interviews were tape recorded, with the aid of a small machine, which was placed in a convenient spot between the interviewer and respondent. On one occasion the motor of the tape recorder had become worn, and drowned out the respondent's voice, so with his kind permission the interview was repeated at a later date. The respondent was convinced that this was a sophisticated methodological ploy, but the researcher was able to convince him that this was purely because of mechanical malfunction!Of the 12 providers interviewed 8 were nurses, two were medically qualified, and one was a psychologist; the remaining respondent had started as an administrative officer, but had moved on to become a manager involved in the organisation and provision of services.

Punters: The final source of data was a series of group and individual interviews with punters. The criterion for inclusion changed as the research went on .At first the plan was that anyone who had lived in Lhangbyde hospital for two years or over would qualify. Even this was not as clear cut as it seemed, because there was no guarantee that someone who had been admitted to Lhangbyde would necessarily, to use the medically based terminology, have a learning disability. One interview was completed with someone who had been a patient at Lhangbyde, but, as the research progressed, the emphasis shifted and it was decided for reasons to be made clear later, to focus on membership of the self advocacy group. Membership of the self advocacy group was confined to people who conformed to a recent Scottish Executive definition of learning disability.

> "…A significant, lifelong condition that started before adulthood, that affected their development and which means that they need help to: understand information: learn skills and cope independently"
>
> Scottish Executive (2001) p3

All punter participants had been in receipt of services, either in terms of education, health or social care, which were provided for people who fell within the above definition.

6 people took part in the two group interviews. 5 of these respondents were also interviewed individually, and two additional individuals were interviewed. One follow up interview was undertaken with a couple who were part of the discussion group. This made a total of seven individual interviews, one interview with a couple and two group interviews. The group interviews lasted for around an hour and ten minutes, and the individual interviews lasted for anything between thirty minutes and an hour. Group interviews took place within the 'drop in' centre run by the self advocacy group, and individual interviews took place at respondents' homes. In the discussion group five out of the six respondents were male, and one female. In the individual interviews three out of the eight respondents were female, and one woman who was the partner of a man who took part in the group discussion happened to be present when the follow up individual interview took place.

Finally, there is a sense in which the people who are the subjects of the 'Intimate Narratives' could also be regarded as a data source. Because of the nature of the narrative method it cannot be said that these were selected with any thought of rigorous or objective criteria. They appear in the narrative simply because they have played an important role in the life of the researcher as a parent and self advocacy adviser.

Section 5: Building evidence across sources.

Since the primary purpose of the study was to enable both providers and punters to describe their experience, and to articulate some of the theories which enable them to attribute meaning to that experience; the strategy for locating research participants put aside the question of whether the responses

of punters and providers were likely to be representative of the opinions of a total population. The fundamental choice of a qualitative method and the experience of the researcher led to a belief that the research should seek out cases which are likely to be information rich in terms of the breadth and depth of their experiences. That is not to say that the research anticipated anything about the nature of the *content* of their responses; simply that their experience of being a punter, or working as a provider of services, was likely to enable them to have something to say about provision and experience in the world of learning difficulties.

The overall approach to gathering information was utilised to differing degrees both *between* and *within* the three evidence sources; namely the archives, the provider interviews and the punter interviews. During the work in the Northern Health Services archive, early reading of the casebooks shed light on the categories of diagnostic classification employed by those who were charged with the management of the hospital. This informed the nature of the data which was sought out during searches of the microfilmed files. The categories which formed the working language of these files provided an orientation to the minutes of various meetings which enabled the strands of developing policy to be teased out.

When the next data source was approached, the researcher was still in a state of ‘abstract wonderment’, insofar as there was no real awareness of what it was like to provide service on a day to day basis within a hospital based residential care setting. However, there was a degree of awareness of the geography and topography of the hospital, and of continuity and change within the categories of classification, and this enabled the researcher to listen to the accounts of providers with a modicum of understanding. Thus, in the language of grounded theory, some substantive theory had emerged during the archival work, and some more abstract formal theory also emerged covering such processes as the journey from lunacy to mental defectiveness, the respective roles of different

provider disciplines, the grading and classification of residents, and the influence of visual stigmata. This formal theory did not influence the questions asked in the provider interviews, which tended to adopt an open ended approach to the biography of the respondents and to the routines of daily living within the institution, but they did provide some background understanding.

This process could be described as a process of utilising codes that have emerged within different contexts as a basis for further exploration (Strauss and Corbin 1990) although a strictly Glaserian approach would demand that theoretical sampling would be based solely on codes which had emerged during an earlier stage of data collection. (Boyscuk, Duchscher and Morgan 2004) It is the view of the researcher that substantive and formal theoretical codes which had emerged during the archival work were influential upon the provider interviews, but that other contextual factors, related to the biography and experience of the researcher could not be discounted altogether.

The process of past theoretical coding determining the course of future data collection can, however, be seen most vividly in decisions that were made about data to be collected in the punter interviews. At the commencement of the study, the plan was to look for a group of punters who had been through the experience of living in a residential hospital based environment, and had then moved on to live within the community. However the process of moving from substantive to more abstract theoretical thinking during the process of coding data from the provider interviews, and the experience of providing ‘memo’s’ which formed the basis for continuously modifying explanatory categories, led to a fundamental change of direction. Some substantive theory had emerged from the provider interviews relating to such issues as motivation and vocation, the effects of the institution, the economy of the hospital, and the changing relationship and boundaries between punters and providers. The last category was particularly influential, inasmuch as a number of providers had spoken eloquently about the journey from encountering a huge undifferentiated mass of

disability when they first worked at the hospital towards a realisation that they might be able to learn from patient experience.

This led to a fairly fundamental line of enquiry, as to whether punters might have some well formulated views about the nature of disability, and the relationship between themselves and the wider society. These constructs *did* emerge from the data which had already been gathered; and *did* point the researcher towards punters who had developed the ability to communicate in an abstract fashion about the nature of their life experience. However, although the overall strategy of gathering information started with a purposive outlook and moved towards theoretical sampling, it cannot be denied that the orientation and past experience of the researcher with regard to self advocacy was influential in the choice of a sample of punters who had a pre existing commitment to the efficacy of speaking for themselves.

Section 6: Ethical considerations.

An ethical approach to the undertaking of research requires attention both to the protection of participants and of their rights. (Grbich 1999). Attention to the protection of rights implies a responsibility on the part of the researcher to contribute to the empowerment of the respondent, and the researcher would argue that this is particularly applicable to research in the area of learning difficulty. Polit and Beck (2004 P 143-150) identify three principles upon which to base this protection. These include:

- *Beneficence* which encompasses the maxim of doing no harm, facilitating freedom from exploitation and positively striving to maximise the benefit to the respondent of taking part.
- The second principle of *respect for human dignity* which produces a responsibility that sufficient information is disclosed to enable the

potential participant to make well founded decisions about the costs and benefits of participation. .

- The third broad principle of *justice* which requires the researcher to take cognizance of the participants' right to fair treatment and privacy.

In order to ensure that these principles were put into effect application was made for full ethical approval from the Research Ethics Committee, and this was granted on 1st June 2000. With regard to the archival section of the research, a written undertaking was given on 11th May 2000 that the researcher would 'neither publish nor make known any specific personal information relating to any specific person or patient discovered during the course of my research into the archives. Privacy of all participants was ensured by the use of pseudonyms in all transcripts, and changes were made to descriptions of locations etc to ensure that participants could not be recognised. This was done in such a manner as to ensure that the veracity of findings was not affected. This is particularly important in the context of the research, because the 'learning disability' world is a small one, where both punters and providers may well recognise others on the basis of description, even if they are not specifically named. At the end of the research project all tape recordings will be destroyed. In order to ensure confidentiality during the lifetime of the project, all the research material will be stored securely away from the researcher's place of work.

Access to providers of service was attained via a letter or telephone call which outlined the aims and objectives of the research. An information sheet for professional participants and 'research advocates' was produced (Appendix 2) but this had to be amended later when the emphasis in the punter interviews was changed to focus on a self advocacy group.

At the beginning of each provider interview the researcher repeated information about the nature and purpose of the research. Providers were free to refuse to

take part at any time, and one provider did decide that she did not wish to take part after the initial contact.

The ethics of research into the experience of people who have been defined as having learning difficulties raise particularly complex issues. There has been a traditional assumption that people who fall into this category are vulnerable to exploitation because of a lack of capacity. This assumption has its roots in the Helsinki Declaration (World Medical Association 1964) which posits the existence of research populations which are in need of special protection. Undoubtedly the punters in this study are entitled to the same level of protection as any respondent, but the researcher would argue that their aspiration towards self advocacy should entitle them to be empowered to put their own point of view. One way of doing this would be to cast the researcher in the role of 'supporter' much in the same way as a BSL interpreter aids a deaf person taking part in a hearing person's event (Walmsley 2004). The researcher would prefer to characterise this role in terms of being an adviser or facilitator to the self advocacy group. This endeavour has been described elsewhere:

> "We constantly try to embrace, respect and value self-advocates insider perspective, initiative, ideas and expressions as a necessary fair intention in workable dialogue. In our shared experience this balancing act can eventually result in an elusive although inclusive sharing of power"
>
> Roets, Van de Perre et al (2004) p55

Particular attention was given to the question of possible exploitation with regard to the punter interviews and the intimate narratives. At the beginning of the project an information sheet was drafted, and plans were made to appoint a research advocate to safeguard the rights of potential respondents. With the shift of focus to the self advocacy group as a vehicle for the organisation of the research, different considerations came into play. Permission to undertake and record the group discussion was sought and given at a committee meeting of

the self advocacy group, and before the individual interviews respondents gave their written permission. (Appendix 3). Also both group members and individual respondents were reminded at the beginning of the interview of the aims and objectives of the study, and this was reflected in the transcripts.

The researcher would argue that the organisation of the 'punter' section of the study, with the plans for the research being discussed collectively, and the individual participants giving individual permissions showed respect for their right to self determination. Additionally it is argued that the influence of grounded theory, and the open ended nature of the research questions, meant that the punters were empowered to evolve substantive and theoretical categories which reflected their ideas, rather than theories imposed from outside. The research design further empowered punters by going back to them in individual interviews, and a final discussion group to ensure that the preliminary coding of data had represented their ideas authentically.

With regard to the 'intimate narratives' the stories relating to the experience of the researcher as facilitator were the shared property of himself and the group members. It would not be possible, from the narratives themselves to identify individual members; and the general issue of using the experiences of the group had been well aired at committee meetings. The issues relating to Spinner's stories, including those where the experience was shared with the researcher, were more complex. Spinner was used to sharing his experiences in public, because he had undertaken a number of joint teaching sessions with the researcher, where role plays were utilised in order to promote discussion amongst first year nursing students about the nature and dynamics of disability. The narratives in their final form were read over to him, and there were some which he was not happy to share. These were not used. It is worthwhile saying that Spinner does not regard himself as being 'vulnerable' in any generic sense of the word. He would expect that the researcher would show him respect by asking his permission, and discussing issues with him; but he would feel somewhat insulted if he thought that he needed to be protected in any generalised fashion.

Section 7: Data Collection 1: Searching the archive.

In the archival work, data was collected by reading through casebooks, the minutes of meetings and microfilmed files. The researcher has in chapter 4 made use of the Foucauldian metaphor of an archaeological approach to the gathering of data. The period of archival work could be seen as a 'dig' where the artefacts of past caring activity are retrieved, classified and interpreted. However, the metaphor does not bear too close an examination, because physical artefacts are usually located in the soil where they had been previously abandoned or hidden. Unless they were located in line with a specific purpose (a burial ritual for example) it is only their temporal context that can be established through such devices as carbon dating and their position within the soil. The records unearthed by the researcher in the archive had to be contextualised in other ways. Who had made the decision to retain records and for what reasons? It has already been acknowledged above that the records were indexed and stored according to a classification system which had been imposed by archivists, past and present. It would be interesting to know what principles had guided such decisions. Perhaps the one parallel which does exist with mainstream archaeology is that, by definition, the researcher has no way of knowing about records that did *not* survive. The categories of meaning that were evolved rest upon a necessarily partial evidence base.

There was some crude sampling of records, especially case records to take account of the need to sample within a number of time frames. Consequently records from the turn of the century (19th / 20th) were examined to get a flavour of the discourse of the long past. Then attention was paid to case records for the period just before the commencement of the health service (1930's) One set of records which have not been examined are those patient records which are stored in 'dead files' in the hospital. Attempts were made to characterise another level of discourse by looking at the minutes of the North Eastern Hospital Board, especially around the time of the changeover of function of the hospital. At the suggestion of the archivist, the microfilmed files relating to the development of

Lhangbyde as a mental deficiency institution were examined. Quotes from the records utilised were recorded on to index cards.

The process of historical research has been aptly described as a

> "Voyage of discovery or a journey without maps"
>
> (Rafferty 1996pp 172)

The author spent some days trawling through routine records which shed no light on the question of the nature of discourse around learning difficulty, and then, on occasions almost stumbled upon gems of discourse, which shed enormous light upon the manner in which managers and administrators thought about people who had been defined as having a learning difficulty.

Inevitably, when examining official records the author is at the mercy of those who took the decisions to retain some records and discard others. There is no particular reason to suppose that the records which were examined would fall short in the key areas of authenticity, representative ness and credibility (Gilbert 1993): but it must be acknowledged that there exists no complete list, or sampling frame which would enable the researcher to make an estimate of the proportion of existing records that it has been possible to examine. It is instructive to draw an analogy with the employment of non probability techniques in qualitative research. (Grbich 1999). The primary purpose is to seek out information rich cases, and such techniques as theoretical sampling which seeks to identify concepts and particular situations are permissible .If one is looking at the content and patterns of discourse, the raw data is of interest in itself, even if it might not be representative of the whole spectrum of records which were kept by those who planned and operated the services. The key task of this research is to facilitate interpretive understanding, one approach being the semiotic which has been defined as a science that studies the signs within society (Barthes 1968). In the present research the aim is to use a Foucauldian approach which, in the view of the author, goes one step further, insofar as it

sheds light on the relationship between the concept of learning difficulty (or Mental Deficiency, or Idiocy) and the prevailing rationality of the time. The artefacts which are reproduced below will, it is hoped , convey the flavour of what it was possible to say if one was a provider, manager or administrator of institutionally based services for people who had been defined as a having a learning difficulty.

Data was recorded by noting verbatim sections of written discourse upon index cards. Where there were records of meetings which seemed to the researcher to be of particular interest, photocopies were made, with key sections highlighted. Later in the research process archival data was re-examined to make links with the theoretical categories which were emerging from the interview data, and the codes which had been recorded on paper were linked to those nodes, trees, attributes and memo's which had been recorded with the aid of the Nvivo package (Gibbs 2002).

Section 8: Data Collection 2: The Provider Interviews.

In the light of the contextual factors described above, the researcher approached the interviews with the providers with an aspiration to ask them generally about their day to day experience of caring within a hospital setting. There were no pre-existing hypotheses about the *content* of such experience, or whether care was undertaken in a particular *organisational form*. The aim was therefore to ask providers about there everyday life. Consideration was given to constructing a questionnaire concerned with activities of daily living, which would contain a number of closed questions, the answers to which would either be yes / no / don't know, or perhaps expressed through the use of a scale. The answers to such questions would have produced generalisable findings, but the personal and professional experience of the researcher had led to the belief that when asking about a caring role it is difficult to know what is not known. In other words

the researcher wanted to give respondents the space and opportunity to provide their own description and analysis of their day to day experience.

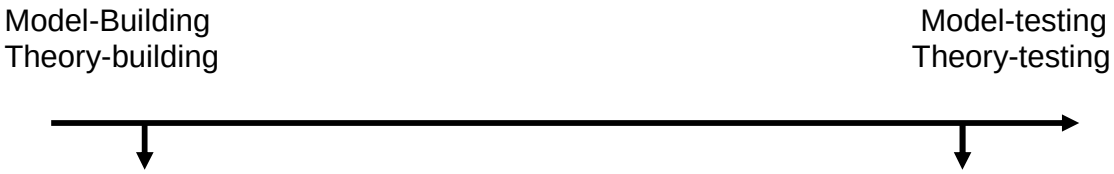
For this reason the researcher approached the interview with a 'script outline' which detailed some of the areas to be covered, but was not followed rigidly (See appendix 4). This allowed the researcher to ask open ended questions, based on a What / Why / When / Where / How framework, but to alter the order of the questions to suit the dynamics of the interview with the particular respondent. The outline included two open ended questions which were always asked at the end of the interview: these related to changes that the respondent had seen during their working life and the respondent's opinion concerning the best and worst things about working at Lhangbyde.

One justification for adopting this approach to data gathering was related to the biography of the researcher. There was a sense in which the process of preparing for the interview went much further than simply drafting the 'script outline. The researchers experience as a social worker and as a facilitator in the self advocacy movement, lead to an emphasis on improvisation in a planned and partly structured manner. The researcher was aware that when it came to describing and analysing the process of caring, individual respondents were likely to frame their answers in widely differing terms, and to present a variety of 'threads' to follow up. Also their responses within the interview had to be handled in a manner which balanced discipline with spontaneity and creativity. The semi structured interview appeared to offer the space to engage in high risk, high gain interaction with respondents which promised, under the right conditions, a product which was worthy of high analysis.

Another justification for the employing a semi-structured approach relates to the overall purpose of the research. It has been made clear above that the research was aimed at model or theory building rather than the production of replicable findings about the characteristics of punters and the people who provide care for

them. Wengraf (2001) represents this spectrum from unstructured to fully structured interviewing and possible relationship to phases in the development of a theory in diagrammatic form.

Figure 6: Model Building & Testing.



Wengraf 2001 P61

In the process of interviewing the providers, it was thought the use of a semi structured interview format was more likely to provide the space and flexibility to enable the respondents to give an indication of their own particular approach to care .The content of the questions asked of providers were inspired by the life experiences checklist produced by the British Institute of Learning Disabilities (Ager 1998). The checklist was developed to provide a means of finding out whether service users enjoy experiences common to the majority of members of the general population. Items were chosen to reflect a broad range of life experiences, focussed around five central themes of Home, Leisure, Relationships, Freedom and opportunities. The methodology employed in BILD application of the outline was to facilitate the completion of a questionnaire which asked service users either individually or in groups to respond to questions which detailed their experience in relation to the broadly defined themes. The experience of the service users was then compared to that derived from a sample of 410 members of the general population in order to make an evaluation of the extent to which the people who had been defined as having a learning difficulty enjoyed a lifestyle which approximated to the 'normal' in the general population.

In the present study the use of the categories was more indirect. They were used to provide a structure for asking the staff about their experience of the way that punters needs were met. They had to be adapted for application to life within an institution. Thus the questions about 'Home' related to the physical layout of the space in which patients in the hospital lived and slept. One deficiency in the themes identified by BILD related to 'work', and providers were asked about the opportunities for work available to the punters after the category was added to the outline.

Most importantly the use of the categories in the present study had a very particular purpose. Clearly it would make no sense to ask a sample of 12 providers for second hand information about the normality or otherwise of punter life experience. The framework was used as a 'prompt' for providers to indicate the shape of the model or theory relating to the care of service users during the time they were working at Lhangbyde. Whether it was successful or not can only be judged by evaluating the quality of the responses.

Section 9: Data Collection 3: Punters: The Group Discussion / Interviews / Intimate Narratives.

The self advocacy group were accustomed to taking decisions as a group. Their committee, which met fortnightly, was at the heart of their day to day activity; making decisions about everyday matters, such as the decision to order a new door for their office, and also acting as a forum for exploring more strategic matters, such as the decision to mark their 10th anniversary with a conference devoted to employment policies and practice. It was for this reason that the decision was made to use a group interview or discussion as the first data gathering method.

The term ‘focus group’ was used to describe this first step in the data gathering process, but such groups are usually very formally organised, with the subject of the group interaction determined by the person who is moderating or facilitating the group (Morgan 1997), and are often utilised to discuss very specific issues such as the marketing of a product or the identification of current political issues. Also it is often the case that focus groups are brought together for a very specific purpose. Perhaps the term ‘Discussion Group’ would have been more accurate because the pre existing ethos of the group led the researcher to believe that the product of the group interaction might be more than the sum of the viewpoints of the individual participants. Because of the commonality of experience within the group, the members were adept at evaluating the authenticity and veracity of the accounts that were being presented, and on a more positive note were able to help other members to initiate and develop accounts of experiences and concepts which described them. The role of the researcher within the group was also influenced by the existing ethos in the sense that in a focus group the role of the facilitator often seems to revolve around the setting of an agenda for the group. In the discussion group the researcher fell into the role of adviser / facilitator, where the task was less about setting the agenda, and more about picking up currents of discussion within the group, and endeavouring to clarify them, and reflect them back to the group for the purpose of development. (Worrell 1988; People First, Scotland 2006)

A great advantage of the group discussion was that it was possible to gather a lot of material over a limited period of time (Morgan 1997). It was not just the *quantity* of information which was important. One of the central questions to be addressed by the research concerned the manner in which punters, theorise about the nature of learning difficulty. The density and quality of the discussion which occurred within the group enabled the researcher to make links to wider questions of disability and difference, and it is the view of the researcher it was the interaction between the respective members of the group which provided a fruitful context for the development of such ideas.

All the participants in the group discussion were interviewed individually during the weeks which followed the original meeting of the group. The purpose of these interviews was to see whether they could provide depth and detail on topics that were only briefly discussed in group interviews (Morgan 1997). Also, in the data gathered during the group interview there was a sub theme which identified the fact that sometimes one needed to be on one's own to think about one's situation, and this led the researcher to think that there was a need to explore individual opinion.

The interviews took the form of picking up the themes which had been identified by punters in the group discussion, and reflecting them back to the individuals. On one level such interviews constituted a useful validity check insofar as it was interesting to see if the same issues were thought to be important, whether what had been said within the group was added to, or qualified in any way; and whether completely new issues were raised. However such claims about validity should be treated with caution, because it may be the case that issues of context may be at least as important as issues of validity. Thus adolescent boys expressed rather different ideas about sexuality and gender during individual interviews than they did whilst in the company of their peers (Wight 1994). It might be that punters also are influenced by the group process to express views which they would not formulate individually, or vice versa, insofar as it might be more comfortable to express themselves in a one to one situation.

During the course of the interviewing process it occurred to the researcher that it might be useful to include the views of punters who had not taken part in the group discussion process, but were peripherally involved with the group. This decision arose out of the view of group members that such additional interviews might provide information rich sources.

It is difficult to say anything systematic about the gathering of the intimate narratives, since they are a distillation of a life experience. They have been reflected upon, but in the wider sense of the word. They have not been structured with the aid of a 'model' (Gibbs 1988). By their very nature, they have been interpreted, and linked with wider experiences in the process of telling. Since they all describe an experience of interacting with others, both their form and their content sometimes reflect the concerns of others. All that can safely be said is that some have been excluded on the basis of a lack of permission on the part of one of the subjects.

Section 10: The Structure of Interviews / Group Discussion.

Having identified informants, and decided the approach to be utilised in facilitating the gathering of data, the researcher gave some thought to the question of structuring the interviews. One of the primary research aims was to facilitate the punters in the identification of some of their underpinning theory, defined as

> "A scheme or system of ideas or statements held as an explanation or account of a group of facts or phenomena"
>
> Shorter Oxford English Dictionary 1983

In order to enable theory to emerge from the data, the intention was to utilise an inductive approach which would rely on a dialogue between the respondents and the researcher. This ruled out a structured questionnaire with predetermined questions and a limited number of alternative answers. The provider interviews had been conducted with the aid of an interview outline, structured around the work history of the respondent, and the daily routines of living within the hospital. Since the punters did not share common daily routines a different method of providing an outline structure was developed. The group discussion was semi structured in the sense that it started from a very general question about what

made life worthwhile, and then relied on clarificatory questions and probes to bring out the important issues. The individual interviews were semi structured on the basis of the themes which had emerged from the group discussion. Semi structured interviews have been defined as being those:

> "where research and planning produce a session in which most of the informant's responses can't be predicted in advance, and where you as interviewer therefore have to *improvise* probably half—and maybe 80% or more—of your responses to what they say in response to your *initial prepared* question or questions. [emphasis in the original]
>
> Wengraf (2001) P5.

Thus in terms of the degree of potential for control over content to be exercised by the researcher, the provider interviews were more structured than the those relating to the punters. Both were, however, aiming for depth of coverage in terms of both a detailed level of knowledge and of getting beyond surface realities towards more complicated causal factors. Wengraf (2001) classifies the information to be gathered through the medium of unstructured in depth interviews under three headings.

- *Discourse*: Where the endeavour is to

> "Identify the systemic nature which enables certain sorts of things to be said, and make other things difficult to say"
>
> Wengraf 2001 P8

The researcher thought that a semi structured dialogic approach would be more likely to enable punters to bring forward some of the rules which governed their interaction with the wider world. For example in what circumstances is it permissible or expected to identify oneself as having a disability.

- *Objective Referents.*: There are the factual elements of a story; for example where punters had lived, what professionals they had met; which members of the public they interacted with and which professionals they had encountered.

- *Subjectivity*: defined as

> "A model I construct of what I see as some of the permanent or transient characteristics of the subject who is acting as an informant in the interview…… the interplay between my and your subjectivity in an interview interaction is a matter of research" Wengraf 2001 P 9

It is the contention of the researcher that the strength of the semi structured interview that it is likely to facilitate access to all three of these elements, and that it is therefore well suited to the task of facilitating access to both the factual and theoretical opinions of punters.

Section 11: Interview / Group Discussion Content.

In the original research proposal there was an assumption that there would be an equivalence between the questions asked of the providers and the punters respectively. With regard to the providers, questions were structured around the 'routines of daily living' (Ager 1998). They were open ended in the sense that the first question which related directly to the interaction between providers and punters asked about a typical working day in the hospital. Although the ultimate intention was to get providers to both describe services *and* explain the reasons *why* they were organised as they were, the starting point was a focus upon daily routines. Although the ambition of the researcher was to start with a clean sheet, it is acknowledged that professional experience had instilled the notion that institutional practice tends to be built around routines. It was thought that these routines would provide a fruitful route for exploration of day to day experience, rather than being of interest in themselves. Whilst undertaking the research, this

did prove to be the case, and questions about the routines of daily living did produce data about the hospital as an institution *and* about the individual experience of the providers who worked within the institution.

When formulating interview questions for punters the starting point of routines of daily living proved to be more problematic. Potential respondents mainly lived independently, with some still living within their family of origin, and so the likelihood of their being common routines which could serve as a starting point for the group discussion seemed slight. The search began for a beginning question which would be as open ended as it was possible to get, and which could be used, in conjunction with probes and clarificatory questions to enable punters to identify what was important *for them.* The following question was used:-

> "When you wake up in the morning, what would make you think that this was going to be a good day?"

All the themes which emerged from the discussion group and from the subsequent individual interviews had their genesis in the answers from various group members to this question.

Section 12: Data Analysis.

Although data has been gathered from two archival and two interview based sources, the researcher sought to utilise a common overall approach to the task of analysing it which draws its inspiration from grounded theory.

The records of the archival work, held on index cards and photo copies, were transcribed into a file which was suitable for processing with the aid of the NVivo package, and were sorted into nodes so that they were suitable to be included in the process of constant comparative analysis.

All the punter and the provider interviews had been recorded on audio tape. Because of their centrality to the study, both the punter discussion groups were also recorded on video as a back up measure. All of the punter and provider interviews and discussion groups were transcribed by the researcher. In the early days of the study the researcher had thought that it should be possible to save time by using a secretary, who was able to understand the dialect that many punters and providers employed, to transcribe the tapes. This proved to be an expensive (in terms of time) mistake, because the researcher found that any outside transcriber who was used tended to edit the transcription in order to conform with what they *thought* the respondent had said. When the researcher compared the tapes with the transcriptions with the tapes it was found that some important elements had been missed out, and on one or two occasions, the transcriber had ascribed the opposite meaning to that which had been intended by the interviewee. That is not to say that the researcher did not sometimes find it impossible to understand what had been said on the tape, but a consistent rule was developed to listen to it five times, and then mark the transcription as being indistinct at that point. Also it was probably easier for the researcher to understand what was being said, because of pre-existing knowledge about the context and terminology of the subject area, and, of course, being present at the time. Needless to say the process of transcription was a laborious one, and, because of the demands of full time employment it was often not possible to fully transcribe the interview until some time after the event. The researcher found that the process of transcribing an interview tended to take around seven to twelve hours of work.

Although the aim of the researcher was to conduct the analysis in a manner which is compatible with a grounded theory approach, it has to be said that Glaser (1998) advised strongly against the use of transcribing of tapes, on the grounds that theoretical completeness was not predicated upon descriptive completeness. There is a danger that

> "The researcher is overwhelmed with unnecessary data for generating instead of rapidly delimiting it"
>
> (Glaser 1998 P 108)

Glaser was in favour of note taking within a few hours of the interview in order to achieve a meaningful mix of interview and observation. Other researchers have admitted that the pen and paper method can be, by comparison with recording and transcribing

> "…extremely inaccurate; much that is spoken is lost, and much that is recorded is no doubt altered. At the same time however, it does enable the relatively easy study of a very large number of cases, and it is this which justifies its use in the present study"
>
> (Strong 1979 P227)

If the present researcher had been able to undertake the project on a full time basis, interviews would always have been scheduled for the morning, so that notes could be written up on the same day. This would undoubtedly have been a more economic and efficient method of data recording. Unfortunately the demands of full time employment, and the fact that punters especially seemed to be easier to contact during the evening hours made this difficult. Apart from these practical considerations, the researcher often went away from an interview with a strong impression about what had been said, and when the interview was transcribed in detail, realised that the punter or provider in question had been articulating concerns that had not made a strong impression upon the researcher. Since the transcriptions will be stored electronically and available to the reader of the research approach, it should be possible for the reader to come to a conclusion as to whether the coding of the data was justifiable. However, this should not be taken as an infallible validating mechanism for reasons which will be explored below.

Section 13: The Pursuit of Rigour.

Those who seek after rigour in both quantitative and qualitative research often define such rigour in terms of *Validity* which refers to the extent that an instrument measures what it purports to be measuring; and *Reliability* which relates to the degree of consistency or accuracy with which the instrument measures the phenomenon or attribute which is the focus of study (Carter and Porter 2000). Underpinning both measures to some extent is a notion of *replicability* insofar as if an instrument measures a characteristic at one point in time, then it should be able to achieve the same goal on another occasion under the auspices of another investigator, given identical conditions. Similarly an instrument should be able to maintain standards of consistency and accuracy on subsequent occasions, and in the hands of different researchers. There are those who would argue that validation cannot, in the social sciences occur via the medium of subsequent replication because, by definition identical social circumstances cannot be recreated in the real world (Bloor 1997).Thus the central dynamic of Grounded Theory can be located in the dialogic interaction between the researcher and the respondent which results in the production of data. By definition this interaction is a unique event, and cannot be replicated in a different time or place. In this section the researcher will examine the methods that have been used to gather information within the study, to see whether they approach the fundamental research question in a credible and justifiable manner.

Given the debt that the researcher has acknowledged to Grounded theory it is noteworthy that the founders of the theory had a very particular approach to issues of replicability, and to criteria for judging validity. For Glaser

> "The rigor of grounded theory is as stringent as it is in the more forcing or quantitative methods of survey and control oriented research. In grounded theory interpretations of hypotheses are constantly checked by the

> constant comparative method. They are as much a part of the theory and as grounded in it, as the main concern and its continual resolving"
>
> Glaser (1998) P11

There is a sense in which rigour is built in to the method. Because Grounded Theory is concerned with hypothesis generation rather than the production of findings rigour cannot be judged on the basis of replicability, and so other criteria must be sought. These criteria are identified as fit, workability, relevance and modifiability. (Glaser 1992). By 'fit' is meant that the categories should express the pattern in the data rather than being forced to fit preconceived or pre existent categories (Glaser 1978) For example in the current study one of the first categories to emerge from the punter discussion group was the notion of 'activity'. If the category had been imposed from elsewhere, rather than emerging from the data, it might have been thought of a hobby or interest, but an examination of the transcription shows that it has a much more abstract meaning to do with the importance of activity as a goal in itself.

By 'workability' it is meant that the theory has predictive or interpretive value in the area of substantive or formal enquiry under consideration. The formal theoretical category which emerged from the provider interviews of 'safety' contains within it some substantive categories concerned with gender, sexuality and reproduction. It works quite well within a hospital setting, but it may or may not be possible to widen it to account for the experience of punters who live within the community.

There is a sense in which 'relevance', or the applicability of an emergent theory to particular social processes, is a function of whether it fits and works. (Glaser 1978) The process of induction of theory from the data makes it likely that it will not stray too far in terms of relevance from the social processes under examination. It could happen if the preconceptions of the researcher have been allowed to unduly influence the coding process. However this is much more likely to happen under the auspices of the deductive paradigm.

In the ‘Intimate Narratives’ chapter the researcher, working as a facilitator, and influenced by definitions of learning difficulty based upon IQ; had deduced that someone who carried the label of learning difficulty would not be able to think abstractly. The experience of having this rudely contradicted by experience led to doubt as to whether the original theory worked or fitted in that particular situation. More fundamentally, it led to doubt as to whether behaviour can be predicted by intelligence quotient in everyday social situations: in other words whether the original theory was relevant at all.

The acknowledgement that a credible theory is one which is ‘modifiable’ is of key importance within grounded theory: the foundation of the paradigm upon which it is based is that truth cannot be seen as fixed and immutable, inasmuch as

> “Generation is an ever modifying process, and nothing is sacred if the analyst is dedicated to giving priority to the data.” (Glaser 1978 P 5).

Provision for people who have been defined as having a learning difficulty has moved away from specialised buildings and institutions towards supporting people where they live. If a study was undertaken in ten years time, focussed upon the concerns of punters living within that system of support, it may well be the case that categories which worked, fitted and were relevant in the past would have to be modified in order to rigorously explore the new situation.

Furthermore Glaser (1992) identifies two general indicators of successful inducted scientific theory: parsimony and scope. That is to say that a useful theory is one which combines breadth of coverage of variation in behaviour within the population under study with the utilisation of as few categories and properties as possible. In the present study, the category which illuminates the issue of the boundaries between punters and providers is one which covers insights gained from a wide variety of data sources with the aid of an economical approach to categorisation.

For Glaser the application of the criteria of fit, work, relevance and modifiability to the conceptualisation which emerges from the constant comparative method is the basis of a rigorous approach. Other theorists working in the Grounded Theory tradition (Strauss and Corbin 1998) would wish to add criteria specifically related to the development and density of the categories, i.e. having many properties and dimensions. This density and the development of tight linkages between categories are seen as good indicators of the explanatory power of inductively developed theories. Strauss and Corbin (1998) also would seek to ensure that the conditions under which variation is found should be explained by weaving both micro and macro conditions into the fabric of the analysis.

This is undertaken with the aid of dimensional coding which seeks to lay out the properties of a code and their dimensions. Punters who talked about the characteristics of their carers or assistants identified the issue of flexibility as an important one, and rated their abilities along this dimension. Carrying on this process Strauss and Corbin advocate the organising of data in such a manner as to make explicit the connections between a category and its sub-categories with the aid of 'axial coding'. In order to facilitate the emergence of highly developed and dense categories they make use of an analytic diagram of a conditional matrix where the emphasis is

> "that both micro and macro conditions are important to the analysis. Events that occur "out there" <u>are not</u> just interesting background material. When they emerge from the data as relevant, they too should be brought into the analysis" (Emphasis in the original).
>
> Strauss and Corbin 1998 p 183

These additions to the Grounded Theory approach first set out by Strauss and Corbin (1990) are dismissed by Glaser (1992 P97) as being imposed on the conceptualizing of data in a manner which amounts to "preconceived, forced conceptual generalisation" .In the present study the aspiration has been to

enable theoretical formulation to emerge from the text of written records and the responses of responses of punters and providers. However it seems inevitable that wider contextual factors, emanating from both micro and macro levels will become a significant part of the story at some point in the analytic process. It is the contention of the researcher that the methods of gaining information which have been utilised have enabled the voice of punters and providers to be clearly heard, and that it is this emergence that is important rather than the precise timing of its appearance.

Section 14: Further Considerations Regarding Rigour.

In considering other methods of ensuring methodological rigour within this qualitative study, the researcher has considered three approaches. The first is that of triangulation. Denzin (1989) cited in Flick (1998) distinguish four subtypes, which include *data triangulation* which advocates studying phenomena at different times and places, and hearing the accounts of different respondents and types of respondent. *Investigator triangulation* recommends the investigation of the influence of different researchers both on the categorisation of data and the wider approach to the research in question. *Theory Triangulation* relies upon the comparison of the utility and explanatory power of alternative theoretical starting points; and *methodological triangulation* advocates the use of different techniques within methods (such as both open ended and closed questioning) or between methods. (An example being the use of interview based and textual analysis within the same study.)

Within the present study, it could be argued that the inclusion of both interview based and archival research and the interviewing of both punters and providers imply the promotion of a rigorous approach via the device of triangulation. This view needs to be treated with caution for two main reasons. Firstly Bloor (1997) makes the point that there is a logical error involved in attempting to replicate chalk by studying cheese inasmuch as data are shaped by the circumstances of

their production, and that data produced by procedures based upon different paradigmatic assumptions as to the nature of knowledge. A second and more radical objection (Richardson 2003) is that in valorising triangulation there is a danger of making similar 'domain assumptions' which posit the existence of a fixed point or object that can be triangulated. Richardson sees the triangle as a rigid, fixed two dimensional object, and prefers to substitute the crystal as a governing imaginary, because of its ability to reflect externalities *and* refract within ourselves.

A second device aimed at increasing the level of rigour is that described by Bloor (1997) as member validation. Defined as a set of techniques through which the researcher aims to validate analytic categories by seeking to check them against respondent's descriptions of their social world. In interview based studies the most common method of achieving this goal is to take the results of the analysis back to the field, and ask if the respondents recognize and concur with the distillation of key concepts which have emerged. It could be argued that the constant comparative method outlined above would imply that codes should be checked and verified, and this could be taken further by acknowledging the potential for misunderstanding or expressing poorly a respondent's intended meaning (Chiovitti and Piran 2003). One method of combating this tendency would be to endeavour to use, as far as possible, the respondents' language and terminology in the naming of categories, certainly at a substantive level, and perhaps at the level of formal theory. One important application of this validation technique has been the identification of culturally competent knowledge as a basis for authentic understanding of participants' categories of meaning. (Mill and Ogilvie 2003: Meleis 1996). The researcher identified this as a particular issue in relation to the punter interviews. There exists without doubt, a disability culture which has grown up in response to negative social definitions on the part of the able bodied majority.(Mason 2000) and people who have been given the label of learning difficulty have had to work hard to maintain their self esteem in the face of pervasive attacks upon their self esteem. (Goodley 2000 ; Roets, Van de Perre et al. 2004)

The researcher did not use this checking technique in the case of the provider interviews, except insofar as a large numbers of probes were utilised during the process to ensure that the respondent's meaning had been properly apprehended. The interview process for the punters was different insofar as the initial categories of meaning derived from the group discussion were checked out in the follow up group discussion and the individual interviews. However some of the same logical and epistemological caveats which applied to the triangulation process also apply to member validation. Semi structured interviews are very susceptible to the influence of context. It might be that opinions expressed within a group discussion might not be validated by participants on an individual basis. There is a different atmosphere in a group discussion, and the passage of time might lead to changes in emphasis or perhaps even changes of content of opinions. The best that can be said is that the method of recording the group discussion and individual interviews aspired to accuracy which was checked out by returning to the punters for checks on authenticity and some elaboration.

A third and final method for the promotion of rigour has been to evaluate the 'confirmability' of analyses by establishing and following audit trails (Cutcliffe 2004). The process of following such trails includes a number of steps (Lincoln and Guba 1985). The primary one is to make a judgement about whether codes and categorisations can reasonably be said to be grounded in the data that has been produced. This is based on a judgement about the content of the data, and the nature of the linkage to categories. The next stage is to evaluate the logical status of the inferences which are made in linking the data to the categories which are said to have emerged. Might it be, for example, that the reasons for the emergence of a category are apparent to the researcher, but not easily apparent to a reader who is involved in a formal or informal auditing process? It may be that a finding could be explained by reference to another category or variable entirely. On the basis of such considerations an auditor can make a judgement about the effects of researcher bias or orientation. If the researcher

displays a consistent tendency to construe categorisations in a particular direction, then it may be reasonable to be sceptical about the overall confirmability of the findings of a study.

On the face of it the recording of interviews via the medium of transcription, and the organisation, processing and analysis of data with the aid of the NVivo computer program provides a firm basis for auditability. Transcripts are stored electronically and can be provided on disc in tandem with written description and analyses. The process of evolution of 'nodes' and 'coding trees' is recorded and can be traced by an auditor, as can the progress towards the evolution of core categories and overall findings. (Gibbs 2002; Morse and Richards 2002). However the existence of such clearly marked trails may lead the researcher to believe that the epistemological foundations of the notion of confirmability are more solid than is actually the case. It would appear to be based on positivistic underpinnings, insofar as there is an implication that there is an objective reality which can be studied, and that if enough people can be convinced of the confirmability of categories or findings then the nature of such a reality can be reliably established. (Cutcliffe 2004). The researcher has made clear above the influence of past professional orientations and present involvement in the self advocacy movement, and perhaps the best that can be expected from the notion of auditability is to give the reader or prospective auditor the information that they need to make a balanced assessment of the influence of such orientations upon the data analysis. One further source of such information can be found within the appendices which set out the research instruments which were used in the study.

Section 15: An evaluation of the research design and methodology.

> "I argue that rigorous implementation and explication of method alone never explains the process of abstract knowing, regardless of which paradigm the scientist espouses and which method is chosen"
>
> May (1994) .P13.

Throughout the study in framing the research question, in the location of informants, in planning the manner of gathering information and the subsequent analysis of the data gathered, the researcher has pursued a general approach which acknowledges its debt to the grounded theory tradition. In its original form grounded theory seeks to facilitate the emergence of theory from the data by asking very general questions. What is this data a study of? What category does this incident indicate? What is actually happening in the data? (Glaser 1978 P 57) Through a process of concurrent data collection and analysis first and second level coding takes place leading to theoretical sampling which leads to the emergence of core categories and the emergence of theoretical hypotheses. For some these are the defining elements of grounded theory and

> "If all the data in a study are collected and then the analysis is done, then this cannot be considered as grounded theory. If a number of discrete themes with no interlinkages are reported, this is not grounded theory; it is probably more appropriately termed thematic or content analysis"
>
> Webb (2003) P544.

The researcher, whilst acknowledging theoretical influences is wary of the almost theological tone of the emergence versus forcing debate, and prefers the view that

> "Whilst some ways are more appropriate than others, at certain times, under certain conditions or for specific target groups, it should be remembered that this does not necessarily mean that the researcher using a different approach or method than her colleague is doing a less satisfactory job"
>
> Van Teijlingen (2003) P436

Specifically the researcher shares the frustration of Morse (1997) P 24 that the cognitive struggle of model or theory construction, and the overall process of theory development is rather cursorily summarised as 'emerging form the data'. Morse (1997) goes on to identify four cognitive processes integral to all qualitative methods under the headings of comprehending, synthesising, theorizing and recontextualizing.. The experience of the researcher as an adviser to a a self advocacy group, and the perceptions outlined in the 'Intimate narratives' chapter, have brought home forcibly the fact that these processes take place within a context. Charmaz (2003) makes a useful distinction between 'objectivist' and 'constructivist' approaches to grounded theory and makes clear that the latter approach

> "Recognizes that the categories, concepts and theoretical level of an analysis emerge from the researcher's interactions within the field and questions about the data"
>
> Charmaz 2003 P271.

Thus the process of undertaking the provider interviews, interacting with the background awareness of the researcher resulting from past experience, led to a changing and developing approach to the design of the subsequent punter interviews.

More radically the researcher has some sympathy with the view expressed by May (1994) that

> "Intuition and creativity are as much a part of scientific work as are careful observation and description"
>
> May (1994) P17.

The researcher would extend this insight to the process of developing substantive categories and formal theory. It is true that the initial codes emerged from the discourse employed by punters and providers and the language of official records; but the manner in which issues were followed up, and probes formulated owe something to much wider experience. May (1994) draws a parallel with the approach to the development of expertise in nursing set out by Benner (1984). In qualitative research the development of the skill of pattern recognition and the ability to make linkages with a range of theoretical frameworks is the result of progression from novice to expert within the process of analysis. The researcher would argue that familiarity with the history of changing approaches to care within the area of learning difficulty, and involvement in the day to day development of self advocacy helps to sharpen the ability to pick up patterns and formulate theoretical categories on the basis of insights gained during the process of undertaking research.

In concluding this review of the complexity of the process of establishing criteria which facilitate judgement on the question of rigour, the researcher would argue that the methods employed have been well suited to the consideration of the central research question of the nature of learning difficulty, and the identification of the theories which punters and providers utilise in order to understand the concept, and the experience which they have. In summary the researcher would agree with Chiovittti and Piran (2003) that it is important to let the participants guide the inquiry process by checking theoretical construction

against participants' expressed understanding, and also to articulate throughout the perspective from which the researcher was viewing the research in as transparent a manner as possible and practicable. It is left to others to make the judgement as to whether these ideals have attained.

Chapter 4: Searching the Archive.

"That men do not learn very much from history is the most important of all the lessons that history has to teach"

Aldous Huxley, Collected Essays , 1959.

This Chapter is structured in five sections.

Section 1: Introduction.

Section 2: Historical approach

Section 3: The legal and policy context.

Section 4: Patterns of Provision and Change; five explanatory themes.

Section 5: Conclusion.

Section One: Introduction

In this chapter the aim is to make sense of the context within which the service users or punters, and the providers of the care at Lhangbyde Hospital lived their daily lives. It is the contention of the author that in order to understand later narratives it is important to be aware of the history of Lhangbyde, particularly from the inception of the health service onwards. The practice experience of the author has led him towards the belief that the theoretical concepts which inform the practice of those who provide help for people who have been defined as having learning difficulties have a long 'shelf life', and the primary purpose of examining the records of past practice is to evaluate whether there were themes within such everyday practice which would be recognisable to present practitioners.

The aim of laying a foundation for the dissertation with the aid of a historical perspective goes far beyond the merely contextual. A major purpose of the dissertation is to shed light on the processes which lead to the formation of identity amongst people who have been characterised as having a learning difficulty and amongst those who care for them. For the latter group the question is to some extent a secondary one, since their 'professional' identity is only one part of their overall self conception. For people with a learning difficulty, who have spent a considerable proportion of their life living within a residential institution, the role that the prevailing material conditions and the governing discourses of the hospital play in the formation of their selfhood will clearly be crucially important. In making the link between the historical context and the process of identity formation, two distinctive theoretical traditions will be drawn upon. The first of these has been characterised as the 'subject of language' approach (Du Gay *et al* 2000) which has as its basis an idea that

> "Identities are constituted through the reiterative power of discourse to produce that which it also names and regulates"
>
> (Du gay. 2000 p2)".

Thus if patients have lived for a considerable period of time in an institution which characterises both buildings and people as ‘high grade’ and sometimes converts this specialist adjectival phrase into a noun, then it is unsurprising that they incorporate the concept into their own view of themselves and others.

The second tradition has its roots in a

> "Thin historically and contextually informed understanding of the limited and specific forms of personhood that individuals acquire in their passage through social institutions"
>
> (Du Gay 2000 pp4).

Within this tradition people retain their own identities, but adapt their behaviour to the constraints imposed by the institutions within which they find themselves. An example of this might be an acceptance of the rules governing the days upon which they are permitted to leave confines of the hospital on visits to local towns.

Later in the thesis whilst applying these theoretical traditions to the experience of people who have learning difficulties an attempt will be made to counteract the past tendency of professionals to minimise the degree to which such subjects play a role in the authorship of their own destiny. Thus within Chapter 7, under the heading of ‘Punters Tales’ some of the individual, organisational and social factors which influence identity will be set out, as well as some strategies of resistance employed by people with learning difficulties.

Section 2: Historical approach

A first task is to give an indication of the general approach to historical endeavour and analysis which was adopted, and to make transparent the links between that approach and the methodology which was utilised whilst examining various sources of information about past practice at Lhangbyde. It is the view of the researcher that any event becomes history the split second after it has happened; so the concept of history to be employed has to exhibit the capacity to take cognizance of the long past history of Lhangbyde, and also to inform an understanding of the relatively recent experience of punters who have been defined as having a learning difficulty. If disparate periods of history are to be united in this way, then the reflexive and constructivist approach which is present in the later chapters of the research inevitably has a parallel in this foundational chapter.

The purpose of history has, in the past been characterised as :

> "To enable man (sic) to understand the society of the past, and to increase his mastery over the society of the present"
>
> (Carr 1986) P13

It is difficult to argue with such objectives, but it is important to consider the *manner* in which such objectives are to be pursued. One approach is to gather together evidence about a particular sector of society within a particular time period, and endeavour to relate the experience to a wider theoretical system. Carter (1979) made an analytical distinction between peasant production (crofting, small farming) and capitalist agriculture (Muckle or Large Farming), using a Marxian theoretical framework (mode of production, relations of production, class formation): to argue that variation in the size of farms in the North East of Scotland, enabled ease of social mobility and advancement , because of gentle social gradation within the agricultural community. Another example of a 'broad brush' historical approach is to be found in the work of Hunter (1976) who used an even wider perspective to chart the transition from feudal to a capitalist economy within the Highlands, and to characterise the function of the crofting community as being to provide a pool of reserve labour for capitalist industry or agriculture. However it is not essential to turn to a Marxian theoretical perspective to exemplify this manner of looking at the past. It can be argued that the current governmental attachment to the desirability of 'inclusive' services (Scottish Executive 2000) implies a view of the history of the development of services for people with learning difficulties which posits an almost inevitable progression from 'diagnostic' services based in institutions towards 'needs led' services located unambiguously within a community setting. The goal for the development of 'modern' high quality services is seen to encompass a movement towards "social inclusion, equality and fairness, and the opportunity for people to improve themselves through continuous learning" (Gray 2000). It is important to avoid simply making the *assumption* that all history is progressive.

"The past as representing *progress*, while psychologically gratifying, prejudges the past, and forces it into a mould which empirical research may contradict"

(Rafferty 1996 pp174)

Also if this 'progressive' view of history were to be utilised to inform an examination of past forms of service provision, it might constitute more than an epistemological error. Looking at it from the point of view of the design of the present study as a whole, it would be difficult to square the use of such an approach with an examination of the recent history of service provision. The process of looking at recent history will seek to use a general grounded theory approach as a means of eliciting what the punters and providers *themselves* identified as the key issues in understanding the experience of providing services, or being defined as a service user. It would require a researcher to draft questions which had their foundation in an all encompassing world view, and to interpret their answers in the light of that theoretical framework. It is for this reason that an alternative methodological approach, informed by the work of Michel Foucault would seem to offer more hope of providing a framework which could unite past and recent history. The method could be used either in a modified or radical form.

In a modified form it would be possible to outline the three elements which Foucault suggested as symbolising society's structures and values, and which contribute to the medicalisation of madness:-

- Family -- child relations centred on the theme of paternal authority;
- Transgression -- punishment relations, centred on the theme of immediate justice;
- Madness -- Disorder relations, centred on the theme of social and moral order. (Foucault, 1971 p274, cited by Tudor1996 pp19).

These elements could then be used as a basis for an explanation of the manner in which people who have been labelled as having learning difficulties have been understood, explained and ultimately controlled. However any such plan would in the view of the researcher be antithetical to a truly Foucauldian view of the purpose of historical endeavour, since it would involve confining our

understanding of the discourse employed by punters and providers within the boundaries of explanatory categories which emerged from historical work which was undertaken for another purpose. It is intended, both in the archival work which provides the long past historical data, and in the later interview based data collection, to use a method of analysing and processing which enables categories of meaning to emerge from the data itself.

In this more radical interpretation of the Foucauldian project there will be no attempt made to locate the history of learning difficulty provision within a total history which looks for the

> "Overarching principles which govern the development of an epoch"
> (Kendall and Wickham 1999 pp24).

Rather the aim will be to concentrate

> "Instead on describing differences , transformations, continuities, mutations and so forth"
> (Foucault 1972: 9-10 cited in Kendall and Wickham 1999).

It is acknowledged that although the use of grand theoretical models will be eschewed there is a place for four 'ordering tools' which will help to structure the process of examining a number of archival data sources.

The first of these is 'Archaeology', which is used by Foucault to describe the process of locating and then analysing the occurrence within the archive of particular practices and discourses. It is worth making clear that Foucault is using a much wider than usual definition of the term 'archive'. In the research undertaken for this dissertation the author has indeed sampled records contained within an actual formally organised and structured archive, but Foucault describes the archive as being

> "The general system of the formation and transformation of statements"
> (Foucault 1972. Cited in Kendall & Wickham 1999)

The archive is thus the soil, rocks or foundations within which the historical researcher conducts a search for artefacts which provide evidence of the nature of previous discourse(s). Thus whilst conducting a 'dig' amongst a set of microfilmed files the author came upon a record of the commissioning, design and subsequent unveiling of statue at Lhangbyde hospital which will form the basis of a non interpretive description of regularities, differences and transformations which were taking place within the hospital in 1969. (GRHB, A1/8/1/8/1/9/26)

The second ordering tool to be utilised is that of 'Genealogy'. If the archaeological task is to uncover the bodies of past discourse(s), that of genealogy is to uncover the historical relationship(s) *between* them. It should be noted that this does not imply that grand theory is needed to facilitate the description of such processes. Thus there is documentary evidence in the minutes of the District Lunacy Board of the pride which the managers of the former District Asylum took in the fact that it charged the lowest rate to parish poor law authorities in the whole of Scotland. After the transformation of Lhangbyde into a 'mental deficiency institution' in the early 1950's there is also documentary evidence in the minutes of the Board of Management for Mental Hospitals of the importance attached to agriculturally based self sufficiency. A

genealogical perspective does not seek to prove that there were causal links between the two facts; but simply to record that the two items of discourse existed within the same geographical space, and within the lifetimes of one set of providers.

In order to make use of the above it is essential to provide a description of the third ordering tool, which Foucault also widened to improve its descriptive and analytic power; that of 'Discourse'. In the commonplace usage of the term discourse is usually taken to describe the process of communication or interaction between two or more actors. In its Foucauldian usage the term is defined more widely and is used, in combination with the archaeological method to describe individual acts of language or statements. The significance of such statements goes far beyond the merely linguistic, and has been described in the following manner:

> "For Foucault discourses are made up of statements that set up relationships with other statements: they share a space and establish contexts; they may also disappear and be replaced by other statements"
>
> Danaher,Schirato & Webb 2000

The contexts referred to above define the conditions of possibility within which the statements subsist. It is thus possible to locate and identify within the archive(s) statements about the condition of 'Mental Deficiency' from the administrative records that refer to the time when Lhangbyde was converting from an asylum and to a colony. For Foucault it would be impossible to give meaning to such statements outside the particular period of history within which such discourses were dominant. It is, of course, possible to attempt to define such a discourse by its internal elements or its external context; but the depth and subtlety of the description required by a Foucauldian view is impossible to convey if, after excavating the discourse from the soil of a particular historical

period, it is not analysed within the context of the worldview within which it was originally located.

The final ordering tool which will inform the historical description of the development of Lhangbyde is that of power / knowledge.

> "Power relations serve to make the connections..... between the visible and the sayable (the two poles of knowledge) yet they exist outside these poles"
>
> Kendall& Wickham 1999 pp48 .

Knowledge is what is often used to select and justify the forms of power that are utilised in one particular historical period. Thus in a 'Mental Handicap' hospital in the central belt of Scotland patients who were allowed out of the hospital on parole had to wear clothing which had a small label on it upon which was written "Property of ..... hospital" . The label in this case was not the invention of an interactionist sociologist; it was visible in every sense. All that was sayable, (at that particular time) was that it was a rational method for keeping track of the hospitals clothing stocks. One benefit of this final ordering tool is that it can be used to describe the strategies of resistance that punters might use to minimise the impact of such a dehumanising practice.

In summarising the historical approach which underpins the archival section of the dissertation it is instructive to quote one passage from 'Madness and Civilisation'

> "In the serene world of mental illness, modern man no longer communicates with the madman: on one hand the man of reason delegates the physician to madness..... on the other, the man of madness communicates with society only by the intermediary of an equally abstract reason which is

order, physical and moral constraint, the anonymous pressure of the group, the requirements of conformity."

Foucault 1979 pp xii.

The purpose of the historical section of this dissertation, and of the qualitatively based research which follows, is to shed some light upon the processes by which people who had been defined as having learning difficulties were separated from the ordinary world of the rational: to identify the form(s) of abstract reason which were put in place within hospital based residential care, and later within the community, in order to mediate between people who have been defined as having a learning difficulty and the wider society.

Section 3*:* The Legal and Policy Context.

In comparison with other groups of people who were looked after in places which were termed 'hospitals' people with learning difficulties came fairly late to institutional care. Until relatively late in the 19th Century it was not thought necessary within a predominantly rural society, to make special provision for idiots imbeciles and the feeble minded. It was the twin processes of industrialisation and urbanisation which required much more sophistication in terms of social and other skills and led to calls for the segregation of those who could not cope with the demands of the more complex society which was evolving (Hunter 1987). The first attempt to build an all encompassing care system was made through the medium of the Mental Deficiency and Lunacy Act (Scotland) 1913, which provided a statutory definition of the terms 'Idiot', 'Imbecile' and the 'Feeble Minded', and also assigned responsibility for their care to various bodies.

This long past history is important to understand because:

"The present pattern of services for the mentally disordered is not only a product; it is also a prisoner of the past. Paradoxically our nineteenth

century forbears in their deeply concerned search for order, stability and permanence, may, in some respects, have presented the generations succeeding them with patterns of care which have proved difficult to adapt to the turbulent environment of the twentieth century"

(Hunter 1987 pp332--333)

In specifying the legal and policy context within which the 'archaeological' endeavour advocated above is to take place, it is the view of the author that three interrelated elements have to be taken into account.

The first of these is the complex relationship between institutional provision for those who have been defined as mentally ill, and those who have been defined as having learning difficulties. In Scotland as a whole the first institution for the treatment and education of defectives was opened in 1852 at Baldovan near Dundee, but the foundation of 'colonies' for defectives at Larbert, Gogarburn and Lennox Castle had to wait until after the first world war . Thus the asylums (both Royal and County) had since the date of their formation inmates who were defined as defective rather than demented. Thus the casebook of the Banff District Asylum for June 1903 records the admission of Billy Geddes (name changed) who is described as an

"Imbecile, very nasty temper! Occasionally, when roused, he uses the most filthy language" (GRHB 35/4/2).

This mixture of categories of patient continued until the period of the formation of the health service in the North of Scotland when the Mental Hospital was transformed into Lhangbyde Mental Deficiency Institution in 1953. In May 1951, when the planning of the new hospital function was being undertaken, the minutes of the medical services committee of the Regional Hospital Board showed that there were a total of 2,113 patients in psychiatric hospitals. Of those 317 were 'certifiable as mental defectives'. (GRHB A1/4/8/1/8/2/9/2)

Even after the change in function, the process of sorting and separating the two categories took a long time to organise and operationalise. A provider who started his career in the early 1970's at Lhangbyde recalls a patient who had been admitted in the distant past after an episode of post puerperal depression, but who had grown to be dependent on the institution, and had become a long term resident.

A second element concerns the pervasive influence of the poor law upon provision for people who had been defined as having learning difficulties. Section 2(5) of the Mental Deficiency and Lunacy Act of 1913 identifies the "duty of the parish council .....to ascertain what persons of sixteen years or over within their parish (not being persons who can be dealt with as lunatics under the lunacy acts) are defectives subject to be dealt with under this act....., and to take steps for ensuring that they shall be dealt with by being sent to institutions or placed under guardianship in accordance with this act". (In the days before the health service, defectives and lunatics utilising institutional services both came under the ambit of the poor law).

The ethos of the poor law was always to make provision which made as little demands upon the public purse as possible. The local District Asylum was opened upon 1st May 1865, but in June 1880 a 'succursal asylum' was opened less than a mile away. The likely reason for this was that Institutions which had more than 100 patients had to have a medical director, and this was a luxury that the Banffshire District Board did not see as necessary (Ferguson 1981). The report of John Fraser, commissioner in lunacy dated 20/8/1900 (GHRB 35/1/2) notes that

> "The rate of board charged for the patients is £18 5/- , the lowest in Scotland, and this low rate is mainly due to the profits derived from the farm'.

This ethos had a direct effect on the day to day lives of patients, whether they were lunatics or defectives. The Lunacy and Mental Deficiency Committee of the County Council meeting on 13th April 1931, considered a complaint from a doctor about the failure to admit his patient. The doctor

> "Entered in the petition the various details required by the public assistance officer, who was waiting at Seatown to complete the petition. The asylum was also notified, but contrary to instructions the car went direct to the asylum, and when the patient arrived there the schedule was found to have no petition, and in spite of a request that the patient should be made comfortable, the whole party, including the patient was dispatched back to Seatown, causing a further hours exposure on a wintry day"

In a further letter the doctor reported that the patient had died. The committee found no fault with the asylum, saying that the proper documentation proving the eligibility of the patient should have been completed. (GHB 35/1/5)

A third element which set the context for service provision was the relative lateness of institutional provision for people with learning difficulties in the North East of Scotland. As has been stated above, the impetus for the building of colonies for defectives came from the 1913 Act; in England (Stevens 1997) and in central Scotland the building 'boom' occurred in the 1920's. In the North East there was no specialist hospital for people who had been designated as mental defectives until after the health service was inaugurated. The North East had always boarded out its patients in institutions in southern Scotland, or utilised places within the asylum system. With the regionalisation of hospital services within the NHS the area could no longer board out its patients, but had to make provision for them in the area (Ferguson 1981).The decision to designate Lhangbyde as "institution for adult mental defectives of both sexes" was made at a meeting of the Medical Services Committee of the Regional Hospital Board on

2nd May 1951, although it took a number of years to fully implement the decision. (GRHB A1/ 1/4)The area was not alone in this tardiness in providing specialist centres. New mental deficiency hospitals were built in Dunfermline: (1968) Inverness: 1969 and Renfrewshire in 1975. (Hunter 1987)

Section 4: Patterns of Provision and Change; Five Explanatory Themes

The above legal and policy context could be seen to constitute the 'soil' within which archaeological excavation took place and will take place throughout the research. The archive, following Foucault could be seen to be the concrete record of the manner in which the discourse(s) involved in the implementation of law and policy took place. The artefacts which are reproduced below will, it is hoped, convey the flavour of what it was possible to say if one was a provider, manager or administrator of institutionally based services for people who had been defined as a having a learning difficulty. From the archive five explanatory themes emerged.

The naming of difference: This process provides one example of the relation between the visible and the sayable; the "dynamic, mutually conditioning relationship between words and things" (Kendall & Wickham pp27).When Lhangbyde changed its function in the early 1950's one of the first tasks was to solve the problem of what to write on the sign outside the hospital, and on the letterheads. Central government was asked for its opinion. At a meeting of the regional hospital board on 3rd March 1954 it was reported that;

> "A reply from the Department of Health stating that as Lhangbyde Hospital did not operate under a certificate from the general board of control, they agreed that it would not be appropriate to include the words 'certified institution' in the title. A mental hospital or mental deficiency institution must be so described in statutory documents; but they saw no objection to

> the use of some other name such as 'Lhangbyde' or 'Lhangbyde Hospital' as a heading to the official notepaper, especially for use in communicating with patients' relatives or friends"
>
> (GRHB /A1/1/ 4)

At a later stage in the transformation of Lhangbyde, in the late sixties, the physical layout of the main building changed in order to meet the perceived needs of the new clientele.

> "Demolition work was kept to the minimum , and was solely influenced by the need to open up the circulation within what had been a prison like layout for the original 'pauper lunatics', and the later mental patients , whose home it was up until the mid twentieth century"
>
> (GRHB 8/1/8/1/9/26) .

Perhaps one of the clearest indications of the prevailing spirit of the transformed institution was expressed in the briefing notes for the unveiling of a free standing sculpture which coincided with the official opening of the extended and remodelled main building on 20th November 1969. In the notes for the opening ceremony the sculptor says that,

> "This group is principally designed to evoke two main ideas suggested by the purpose of the hospital. Firstly the feeling of advancing--a moving eagerly towards some goal. It is a quest. Secondly it is a community of souls. The goal is achieved by mutual aid. This interdependence is and essential ingredient in the progress for these people. The more able are the pace setters bringing the others along, and maturing with that, responsibility. Each individual figure shows a slightly different attitude to this forward surge. The leader is thrusting forward without hesitation, while the others vary in their degree of commitment. This, I feel, indicates the range of type and attitude the staff of the hospital meet with.

> Considering all the circumstances I felt that a child group with its unsophisticated, receptive eagerness was a suitable symbol of that positive quality upon which the staff at Lhangbyde build"
>
> (GRHB/A1/ 8/1/8/1/9/26)

In the view of the researcher, the sculptor concerned had been very perceptive in picking up a discourse which pervaded the world of the hospital, and remains influential up until the present; namely that the status of people with a learning difficulty can be equated with that of a child. It is not uncommon, when a person with a learning difficulty is being described in the popular press, to read that they have the mind of a (3, 4 or 5) year old, even though the subject of the article is an adult.

The Roles of Respective Providers: The records that are quoted give some indication of the relation between one statement and another, focussing upon the ordering of statements into a workable system (Kendall & Wickham 1999). In the time of the District Asylum, providers of care were termed 'attendants': but with the coming of the health service, and the growth of a service dedicated solely to the needs of the 'mentally deficient', a system of care evolved which was based around the medical model of care. The minutes of the board of management for the Mental Hospitals for their meeting on 14th September 1949, set out

> "General rules for management under the Mental Deficiency and Lunacy Act 1913". (GRHB ,B3/1/1)

The rules were drafted by a consultant psychiatrist who was the overall medical and was influential in planning provision for the mentally deficient at the level of the regional hospital board. His rules are worth quoting at length, because they give a good flavour of the prevailing atmosphere of care for those who were termed 'mentally deficient'.

Medical Superintendent:

"He shall visit the patients frequently, and pay such extra visits as may be considered necessary to patients requiring special care and attention."

Matron:

"She shall do her utmost to promote the physical and mental welfare of the patients, and shall encourage order, cheerfulness and kindness among the patients and nurses by every means in her power. She shall satisfy herself that the meals for the patients and staff are properly cooked and served at the appropriate hour."

Nurses:

"are placed in positions of responsibility, having the care of persons who, by reason of their mental deficiency, are unable to care for themselves. They must constantly remember that the institution exists for the benefit of the patients, whose comfort and well being must always be the first consideration. Nurses are absolutely forbidden to strike or threaten patients, to use any form of harsh treatment, or to deprive them of any privilege. Ill treatment of a patient is an offence at law. Nurses are not allowed to give medicines to patients, to employ seclusion, baths or any other remedial agent except by the instruction of a medical officer"

Mealtimes

"At all meals, the utmost order and decorum must prevail and patients must not be hurried into taking food .No article of diet, spoon or other utensil shall be taken from the dining hall."

The discourse employed in the drafting of these rules displays a degree of clarity and certainty which suggests a system where all who took place would know

very clearly the boundaries of their particular role. It will be interesting, in the later part of the research to see whether the 'coal face' providers, and the punters they looked after were possessed of a similar level of certainty.

Grading and accommodating Mental Defectives: a search for guidance.

That the people who came to live at Lhangbyde were graded, and that the verb was commonly transformed into a noun (i.e. individual service users were referred to as a ‘high grade’ or ‘low grade’), is a commonplace. In the planning documentation for the expansion that took place in the late sixties, projected buildings were routinely referred to as a 'high grade villa' or a 'low grade villa'. This did not refer to the quality of the fixtures and fittings, but to the epistemological status of the individual human beings who were to occupy them. When the building programme was in full flow, there was a need to be clear about the rules which made the statements about grade repeatable, "to be part of the true" (Kendall& Wickham 1999 pp27)

In a letter to the Scottish Home and Health Department, and in connection with hospital building note number 30, the secretary to the regional health board asked for

> "Guidance with regard to provision which should be made for mental defectives. The point on which we should particularly welcome your advice is as follows: Should beds for high grade defectives be spaced at 7 ft centres, allowing approximately 70 sq feet per bed.”
>
> (GHRBA1/8/1/8/1/9/2)

Apart from seeking a formalised central government ruling as to the variation of treatment *between* grades, there were more informal boundaries which marked out those who were graded from those who were not. However those who

patrolled the boundaries of the graded system had to be kept separate. In a letter dated December 1969 to the Scottish Home and health department about a proposed new form of residential provision a group who

> "could reasonably aspire to transfer to a community life within a reasonable time..... could then be allowed to live in conditions much less like hospital, and more like home. Such privileges could not be granted to patients who were not separated from others because of the jealousies aroused"
>
> (GRHB A1/4/8/1/8/2/9/2)

Another signifier of the border between those who can be graded and those who are not revolves around the issue of whether or not they are paid the going rate for their labour. The group secretary of a local Hospital Board writing in October 1964 complained that

> “The opening of the unit has resulted in the transfer of ten high grade patients from Lhangbyde, and their replacement with very low grade patients from elsewhere. This has caused a serious domestic labour shortage, and my board recommend that the staffing establishment be increased by two general maids to compensate..... this work has previously been undertaken by patient labour”.
>
> (GRHB A1/4/8/1/8/2/9/2)

This gives a clear indication of the borderline between those subject to grading and those who are not. More worrying for the categories employed, and to be employed throughout this thesis, it calls into question the nature of the boundaries between ‘punter’ and ‘provider’, and whether even this most basic of categorisation / division is a useful explanatory tool. In later chapters we may find that the rules of repeatability / truth go beyond the service user / service provider dichotomy.

Visual stigmata as a signifier of punter status:

Another facet of the archaeological task is the

> "Attempt to analyse the positions which are established between subjects in regard to the statements focuses on the way statements produce subject positions"
>
> Kendall & Wickham 1999 pp 27.

A text book which was reprinted in 1959, and thus would have been familiar to providers at Lhangbyde gave the following as one of the general characteristics of mental defectives.

> "The physical defects that may accompany mental deficiency are called *stigmata of degeneration* (italics in original) and usually the lower the grade of defective the more pronounced the stigmata, although this is not always so. It must be emphasised that the presence of stigmata does not necessarily mean that the affected person is a defective, although their incidence is higher among defectiveness than the normal."
>
> Bailliere . Tindall & Cox 1959 pp269 ...270.

Within the clinical records reviewed, subject status was often signified by description of the punter's visible stigmata.

Thus in October 1914 a local doctor writes of a candidate for admission:-

> "He has the appearance of an idiot, his limbs are deformed and there is paralysis on one side. His saliva dribbles from his mouth and

he endeavours to answer simple questions asked him by a very imperfect
form of speech." (GRHB35/4/6)

A punter admitted over twenty years later in January 1937 is described as

"A small deformed idiot of dull, vacant expression"
(GRHB. 35/4/4)

It will be interesting to see if punters and providers mention similar stigmata as a signifier of subject position or status in the interview based section of the research to be undertaken later.

From lunatic asylum to institution for the mentally defective; In the section headed 'Legal and Policy context' above, it was noted that provision for people with learning difficulties, and people who have been defined as having psychiatric problems was historically intertwined. The period of the early 1950's is interesting because it is possible to trace within the records 'surfaces of emergence', and to follow the manner in which the transfer of function led to a new 'domain' of expertise for Lhangbyde. (Kendall & Wickham 1999 pp 27).

The key meeting, from the point of view of the emergence of the new function for the hospital was that of the Mental Health Sub Committee of the Medical Services Committee which met on 12th October 1950.(GRHB A1/4)In the minutes of the committee it was stated that:

"These mental defectives gave little trouble, and ought rightly to be cared for in an institution for mentally deficient persons where specialised facilities existed for educating and rehabilitating defectives whose presence in a mental hospital was detrimental to recovering psychotic patients. Furthermore their presence constituted wastage of beds so far as the mental hospitals were concerned. Dr ---------- had estimated that 650 beds were required for adult

> defectives in the region, and there must be at least 200 cases in the of mental hospitals in the region, besides others in local Authority beds. There was the further problem of adult mental defectives in the community, a great number of whom required institutional care of the proper type..... It was readily understood that Lhangbyde could be readily extended to form, ultimately the adult deficiency colony for the region."

Within the minutes of this one meeting the seeds of three patterns of discourse are apparent. Firstly that provision for mental defectives should be different from that for psychiatric patients, focussing on 'educating and rehabilitating' rather then 'treatment'. Secondly, by implication, that successful provision would be that which would remove 'Mental Defectives' from the community, and treat them within an institution. Thirdly, that the best form of institution would be a 'colony', with all the connotations of self sufficiency that the term implies. It is the contention of the researcher that these forms of discourse manifest themselves in a number of the records of the management and day to day administration of Lhangbyde in the following three decades or more; and are present in the dialogue with the more modern forms of discourse which emphasise the benefits of community based provision. (Birrell 2005)

Section 5: Conclusion

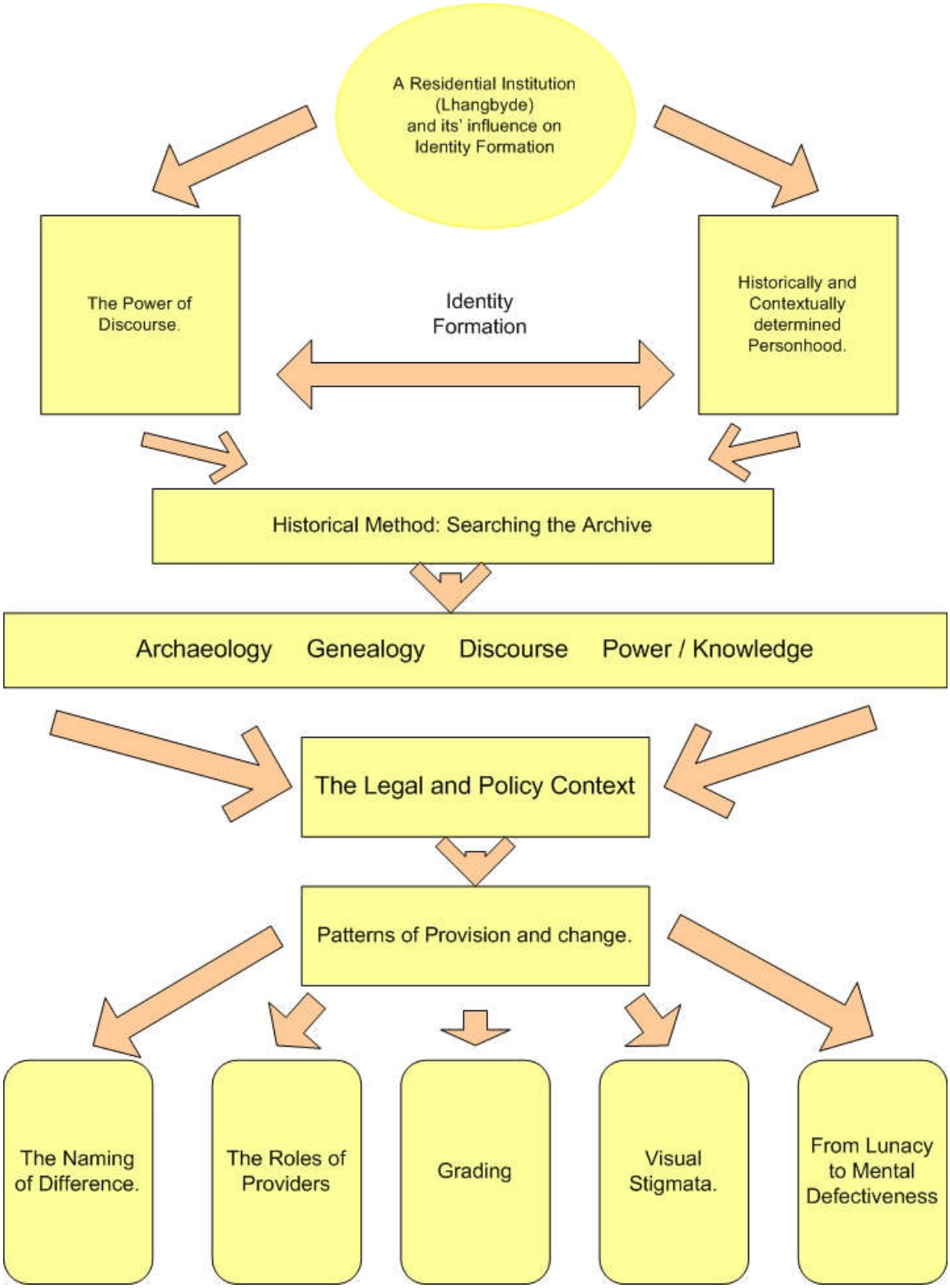
In summary the purpose of this foundational findings chapter has been both to provide a context which aids understanding of the experience of the punters and providers are be interviewed later in the research, and to make a start on the process of understanding the role of institutions in defining the identity of both punters and providers.

Methodologically an attempt has been made to excavate historical artifacts in such a manner as to make it possible to compare the discourse of the 'long past' which is contained in the records with the discourse of the 'recent. It may be that

within the interviews which will underpin chapters 5, 6 and 7, whole areas of discourse will emerge which have not been discovered within the formal records of service provision. Because the records have been retained in the form of quotes written on index cards it may be that quotes which have not been used in the foregoing chapter will be used later in conjunction with transcripts of interviews, if common themes emerge within the discourse of both.

In any event it is anticipated that both the interview based, and the historical sections of the thesis will be influenced by a Foucauldian interest in the rules which govern the formations, continuities and mutations of the discourses employed by both punters and providers in their descriptions of their experience of living and working within hospital based and more community based care systems. The themes which have emerged from this exploration of the archive are summarised in Figure 7.

Figure 7: A voyage into the past.



Chapter 5: Recurring Themes in Provider Discourse.

> "Thomas was surprised by how much he had come to tolerate, even to like, the asylum. The vast lateral folly was hidden from his view by the elms at the edge of the cow pasture, and he could briefly view it with detachment. The things he had seen inside had seared his soul. But 'sear' was perhaps the word, he thought, like 'cauterise': he was burned, but he did not bleed."
>
> Sebastian Faulks. 'Human Traces' P182

This chapter is structured in sections.

Section 1: Introduction
Section 2: A brief profile of respondents.
Section 3: Encountering the Institution.
Section 4: Everyday needs and routines.
Section 5: Gender, sexuality and the spectre of reproduction.
Section 6: The hospital economy.
Section 7: Status and hierarchy.
Section 8: The sick role.
Section 9: Activity inside and outside the hospital.
Section 10: Change and Development.
Section 11: Conclusion.

Section 1: Introduction

In this chapter the emphasis will be upon the categories of meaning employed by the providers who were interviewed to both describe and understand the experience of working at Lhangbyde Hospital (Lieblich and Tuval Mashich 1998). A distinction can be made between the *form* of a category, how it is named, what forms of language are utilised to convey its meaning; and the *content* of a category. In what follows the emphasis will be overwhelmingly upon the *content* of the categories concerned, although readers of the findings reproduced may be interested in the influence that an institution has upon the

form that categories take. Where this is apparent it will be commented upon. Gibbs (2002) forcibly makes the point that the categories that are employed in the analysis of data should reflect the data but not merely reproduce them. The categories employed below have emerged directly from the data (Glaser & Strauss 1967), but it is undoubtedly the case that both their form and their content will have been influenced by the areas of questioning which were included in the semi-structured interview outline. Having acknowledged this, it should be noted that the formation of the first level categories, or 'free nodes' was directly influenced by the words spoken by respondents. Indeed, in some areas of discourse respondents answered questions which had not been asked, and in some cases the name of the category has emerged from the language of the respondent) Also the formation of the second level categories or 'tree nodes' was directly affected by the amount of attention given to them by respondents. For example, when setting out the interview outline, the researcher had thought that 'Gender' would be a relatively unimportant classificatory category. It was the responses of the providers interviewed which led to it being identified as a major determinant of the nature of the everyday experience of work.

Section 2: A brief profile of the Respondents.

Lochinvar: A male respondent who started work in January 1981, and who had seven years experience in the hospital as a nursing assistant, a registered nurse and a first level manager. He moved on to work in the community in 1988.

Planter: A male respondent who started his career as a nursing assistant in 1973, did his training and became a registered nurse. He moved to another hospital to be a first level manager in 1979, but had subsequent contact with staff at Lhangbyde in his capacity as a trainer and educator.

Solar: A female respondent who started work as a nursing assistant in 1963 and progressed through training to the role of registered nurse. She worked at Lhangbyde for twenty five years and retained contact with the hospital in her later role as a trainer and educator.

TopDoc: A male respondent who is a psychiatrist by profession. He worked at the hospital from 1992 until the hospital closed in 2003, but had undertaken placements there during his training in the 1980's.

DayNurse: A female respondent who joined the staff in 1964, and worked her way up from nursing assistant via training to staff nurse and later first level manager. After a break for childrearing she worked in the hospital for 20 years, and continued her contact with staff as a trainer and educator.

TopNurse: Joined the staff of the then County Asylum in 1945, as an 'attendant' ; qualified as a registered nurse and became a top level manager. He spent his entire working life at Lhangbyde Hospital.

Pavlov: A male chartered clinical psychologist who joined the staff of the hospital in 1966, and worked there until his retirement.

StalNurse: A male respondent**;** he commenced employment as a nursing assistant in 1966 and worked his way up to the position of senior manager. He retired after 34 years service.

PurpleHeather: A female respondent who came to the hospital as a registered nurse in 1980, and worked there until 1988.

TradNurse: A female respondent who commenced work in 1964 and progressed via training to the role of Staff Nurse and then Charge Nurse. She left in 1974.

SideDoc. This respondent was a male psychiatrist who divided his time between hospital and community responsibilities. He commenced work there in 1976, and remained in contact until the hospital closed in 2003.

Crossover: A female respondent who joined the hospital in 1986 as a clerical worker in the centre which provided a form of industrial therapy for patients. She was transferred to the Occupational Therapy Department when it opened, and became a senior manager on the administrative side. When the hospital closed she became a provider of residential care in her own right.

Section 3: Encountering the Institution

In this section a picture will be painted of the provider, over a period of time, encountering and coming to terms with the pressures and requirements of Lhangbyde as a social institution. There have been a number of moving accounts from ‘punters’ of their experience of encountering residential institutions (Cooper 1997. Rolph 2000. Andrews and Rolph 2000.) but few accounts of the daily lives of ‘Providers’ within a hospital setting.(Ryan and Thomas 1987). Goffman portrayed vividly the impact of the power and pervasiveness of the total institution (Goffman 1975) in the manner that it regulated the everyday lives of those who lived and worked within it. Feminist writers have coined the phrase “the personal is political” (Hanisch 1970) in order to draw attention to the process by which the very structure of our thinking, and the categories which we employ to facilitate our understanding of the world, are shaped by our experience within such institutions. To be sure human actors retain a degree of choice and agency within such a setting (Giddens 1993), but the experience of those who were drawn into the world of Lhangbyde was that it had a profound effect upon the manner in which they understood the world. In the sixties and early seventies,, when much of the expansion of Lhangbyde as a mental handicap hospital was taking place, the North East of Scotland had yet to feel the impact of the discovery of oil, and the dominant cultures had their roots in the world of fishing and agriculture. These were cultures which had a long history, where individuals would have been the carriers of a tradition that they derived from their parents, grandparents and beyond. (Miller 1999; Hunter 1976) Clearly the move into work within a hospital which cared for large numbers of people who had been defined as vulnerable represented a massive transformation. One respondent talked about his shock at the scale of the hospital and of being in the farmyard on a Saturday and in the hospital with a collar and tie on the Sunday (Stalnurse) the shock being that much greater

because he lived relatively near, but had no notion of the nature of daily life within the hospital.

It might have been the case that if providers had come to the hospital with a very clear sense of motivation, and some clear objectives, then they would have been more prepared for the process of acculturation. In the case of the doctors and psychologists, they did come to Lhangbyde with a fairly clear sense of purpose, usually related to the development of their professional career (TopDoc, Pavlov and SideDoc). It was unusual, however for nursing staff to be motivated by such clearly instrumental career goals. The experience of Lochinvar of fatalism in the face of a range of personal and social pressures was a more usual story. Another respondent freely admitted to no great calling to the role of nurse, it was simply a fact that the prospect of employment there had always existed, and had already been taken up by several members of his family, and it was there if needed if other forms of employment did not live up to expectations (Planter). Indeed, in the case of another respondent whose life's work had been at Lhangbyde, he had given up an apprenticeship in a local city, because his remuneration was less than the cost of getting to work, and once he commenced work at the hospital, because of wartime labour mobility regulations, he was unable to move employment in the early years of his career even if he had wanted to. (TopNurse)

Once providers started their employment, they reported something of a shock to the system. Sometimes the biggest shock was the lack of dignity, the lack of privacy, and the lack of the basic human rights to go out the door and have a walk (Solar). As others had described, (Lochinvar) they experienced some of the routines as being bizarre, but also, especially if they worked in a ward where patients had a need for a great deal of basic support, the presence of so many disabled people in one confined space had a profound impact upon them. One respondent got to the point of telling his sister and brother-in-law, who both

worked at the hospital, that he did not think he was going to be able to continue working there (Planter).

The stress emanating from the transition from the outside world lessened with time in two senses.

- Individual providers got used to seeing the patients on the ward, and perceived both their individuality and their humanity.
- Secondly, in later years, social change outside the hospital, with disabled people being encountered in schools and in the wider community came to mean that beginning staff members experienced less of a culture shock when they entered the hospital situation.(Day Nurse)

During the early years of the careers of providers, the method of transmission of the culture of the institution tended to be verbal rather than taking the form of procedure manuals or written objectives being specified. One provider put it in the following way:

"It didn't need specified. It was Dr A says and Dr B says and Matron says, and you don't argue."

(Solar)

Consequently there were a variety of sources, both informal and formal from whence the rules of the hospital could be gleaned. There were occasional briefings but mostly it was seen as a matter of watching what other people did, and symbolically signalling understanding through such activities as handing on and receiving the keys (Planter). Indeed one provider remembered that on his first day he was handed a key, and told that if he lost it he would lose his job. He thought at first this was an exaggeration, but came to realise that without his key there was no way that he could move through the hospital to do his job (StaNurse). The point was that learning about the rules emerged during the routine of caring for patients.

One important aspect of the encounter with the institution related to the rules about relationships across the provider / punter divide. After the phase of initial shock and disorientation, most providers came to recognise the 'personality and character' (Planter) of the patients that they were working with. On the surface there relationship was strictly a professional one which was reflected in roles with strictly defined boundaries, but providers expressed a feeling that their relationship with punters was sometimes more authentic than other relationships in their lives because the patients were fairly direct in expressing their feelings, being less prone to artifice and game playing. One provider respondent was eloquent in describing the dignity displayed by a particular patient, and the effect that encountering him had on his notion of what it was to be a patient (Planter). It was recognised by providers that, sometimes, there were patients whom they worked with who evoked a special interest within them, but for some providers, especially those who worked on wards where the patients had few support needs, it was hard to see any hard and fast distinction between the personhood of punters and that of people in general, so they accordingly related to them much as they would any other human being that they encountered. (Purple Heather)

There was recognition that the institution itself was sometimes a source of pressure to maintain the punter within a patient role. It was as though the institution needed to incorporate the patient into the administrative and financial structure of the hospital, finding it difficult to accept that a patient might be in need of some rapid, focussed help followed by a swift discharge back into the community (TopDoc).

Section 4: Everyday Needs and Routines

The everyday life of the ward was structured around functional and temporal considerations. In looking at the functions which providers undertook on a day to day basis the life experiences checklist which was used as a guide for the semi

structured interview (Ager 1998) was of limited use insofar as it tended to concentrate upon fairly abstract categories such as home, leisure, relationships, freedom, and opportunities. The interview with service providers commenced with a question about the nature of a typical day, and it was thought likely that the answers provided by respondents could be conceptualised in terms of these categories. This was only true in a limited sense, because the responses were more likely to be couched in much more basic terminology relating to such issues as sleeping and waking, ablutions, feeding, clothing and occupation during the day. To be sure it is not possible to say anything concrete about the higher order life experiences until one understood the manner in which the more basic needs were met (Maslow 1968), and it was the case that the categories employed in Ager's work often underpinned the probes which were used to clarify the meaning of responses which focussed at that more basic level.

In order to understand the centrality of the temporal dimension, it is important to reflect upon the universality of the shift system, at least in relation to the nursing staff who provided the face to face care. The day was divided into the night shift, which went from 19.00hrs until 07.00hrs, and the day shift which occupied the rest of the day (TopNurse, StalNurse, TradNurse). It is true that, in later years at least, the precise dimensions of the shifts may have varied, but their role in structuring the day remained constant. Caring functions always took place within these parameters, and it was often the case that days of the week were designated for other, less basic functions, such as 'parole' outside the ground of the hospital, or nail clipping / hair cutting (Solar, Planter).

Once these temporal dimensions have been established, it is easy to make the link with the tasks which have to be accomplished during the day. The first task, at 07.00hrs would be to get people out of bed, and to get them to breakfast. Prior to the opening of the new 'villas' in the 1960's breakfast would be taken at a central dining hall. There were strict time limits upon breakfast time, because the providers needed to move on to the next task (Lochinvar, Planter). Those

who were capable might have washed themselves, but upon return from breakfast those who were not self sufficient would need to be bathed and shaved. Baths were characterised into ‘normal’ baths, which might not be needed everyday, and ‘special’ baths which would have to take place daily for such reasons as urinary incontinence. (StalNurse) The process was described by one respondent in the following terms:

> *“the male side it had three locations. The nurse who was in charge issued out razors, for shaving and ablutions and one group went down to the bathroom to get a bath. This was a sheep dip system, because there was insufficient hot water to bath the patients. The demand for the hot water was for the kitchen”*
>
> (TopNurse*)*

The mention of the importance of the needs of the kitchen is very interesting. It could be argued that apart from the shift system, one of the most important influences upon the temporal structure of the day emanated from the kitchen. Both lunch and tea (Supper or Dinner in more formal language) came relatively early (11.00-11.30 in the case of lunch, ‘Tea’, the sole evening meal, at 15.45). This was to enable the kitchen to provide staff lunch and tea at a time which would enable them to finish cooking at a reasonable hour. (Planter) After bathing, which could be a protracted process; if there were large numbers of patients who needed to be bathed and shaved; patients were moved to the sitting area for the rest of the morning. In later years a proportion of patients, depending on their support needs might be involved in some sort of centrally organised activity. Increasingly the ward staff relied on activity in ‘the hall’, which later became occupational therapy to take the pressure off ward based staff during the daytime, although there was some ambivalence about the increasing power and influence of centrally based staff.(Crossover).

For reasons referred to above, the period between mealtimes during the day were relatively short, with tea taken around 4 o’clock. The period up until 19.00 hrs was spent watching TV, and then, with the changeover of shifts it would be

time to prepare for bed. Early preparation ensured a smooth handover to the night shift. In the very early post war years, before the hospital was officially designated as being for the mentally handicapped, staff slept in rooms near to the wards and were on call during the night (TopNurse). In later years, the separation of responsibility for night and day shifts became more formalised, although a particular staff member might do both during the course of his or her employment.

One of the key routine daily functions for care providers was to provide for the clothing of patients. In order to understand the challenges involved, especially during the period in the seventies and early eighties, when the population of patients was at its height, and wards may have contained up to 50 patients, it is important to appreciate that the clothing system had to be both comprehensive and simple to operate. An essential distinction was made between 'Hospital' clothes and 'Good Clothes'. (Solar, Planter, TopNurse, PurpleHeather, StalNurse, TradNurse)

The main reason for having 'hospital' clothes, which were communal rather than individually owned, was to simplify the process of laundering and allocating clean clothes to individual patients.

> *"Well everything was in house washed in the main laundry, all…..all clothing from actually bedding to personal clothing went to the actual laundry. It came back from the laundry to the individual ward area, by name, by ward name at that time…… ward name…….not residents name…….in that early days. Obviously it had to be separated into various cupboards where everything was kept. At that time……. maybe the word to use.....it was communal..... clothing."*
>
> StalNurse.

There was some evidence to suggest that the 'hospital clothes' system had a redistributive function, insofar as those patients who had an income, either from their families, or from certain kinds of state benefit, contributed to the purchase

of communal clothes, which were then also used for other patients who did not enjoy these sources of income (Crossover, Lochinvar)

In contrast to the widespread use of ‘hospital’ clothes, there were occasions where it was appropriate for patients to wear more individualised clothing of a better quality. These were given the name of ‘Good Clothes’

> *“Yes. / and then they had their good clothes, which were doubly locked away in plastic wardrobes in a room upstairs these tall plastic things..... all……those that went to church would put their good clothes out on a Sunday, and for when they had anything special, a bit like what we would do ourselves, when we have got nice clothes we keep them for special occasions..... They were kept safe there as well; they had nowhere else to put them, they had no wardrobe space beside their beds.”*
>
> (Solar)

The ‘something special’ referred to in the above quote included occasions when patients were likely to come into contact with people from the outside world, such as outings and visits to and by relatives. It also referred to special events such as dances within the hospital. In later years there is evidence that patients had more say in choosing their own ‘good clothes’ with the aim of promoting self respect and dignity (Crossover) and by the nineties, when hospital and ward populations were much lower, it was possible for all patients to have their own clothes (TopDoc). There were rational reasons for the distinction between ‘hospital’ and ‘good’ clothes, the interview extracts quoted above suggest that the institution couldn’t guarantee to protect the ownership of everyday clothes, and so restricted the ownership of clothing to a relatively narrow range of clothes which were used on special occasions. The effect in practice of the distinction between ‘good’ and ‘hospital’ clothes was to provide a form of uniform to distinguish the punters from the providers within the hospital setting, which set them aside as a stigmatised group (Goffman 1968). In a world where the lives of the punters who were given the name of ‘patients’, was constrained by routines which emanated from the need for both functional and

temporal predictability, clothing was thus a powerful indicator of status. One provider respondent emphasised this point outside the interview situation (Planter) when he described preparation for taking punters on a bus outing. Nursing staff were told that they should wear ties, which were not obligatory in the hospital, in order that people outside the institution would be able to clearly distinguish punters and providers. This was not necessary in the hospital, because everyone knew who belonged to which group.

Section 5: Gender, Sexuality and the Spectre of Reproduction.

In drafting the provider interview outline, (Appendix 5) the researcher had included a heading called 'Rules about gender', expecting some organisational differences concerning the manner in which services were provided for males and females respectively. What was completely unexpected was the sense of complete separation of the genders within the institution, especially in the early post war years. Reference was made to this separation within almost all of the interviews, and its nature and significance are perhaps best expressed with the aid of two extracts from interviews.

> *"I knew that there was ... you know... male and female.....but one of the biggest shocks that I hid was the hospital. It was one hospital, but there wis clearly male and there was female... that wis.. and it took a bit a.'.. and in some cases ....it was very.. and that was for staff as well by the way. You know only males could work on the male side and only females could work on the female side.. quite a...The male side was run by the chief male nurse and the female side was run by the Matron., and there wisna a lot a' .../// [INTERJECTION 'Contact'?] ... and even in the .... I'm coming up a couple of months... in actual social events like.. the actual mixture of male and female residents wis closely guarded.{ Laughs} even at dances, when they went back to their wards the males went oot a' one door first , and then the females.. vice versa. That ..you know... it is a shock til ya,"*
>
> StalNurse

Q " Somebody else said to me that in a way the male and the female sides were in a way almost separate hospitals"

A "They told us..... you were a sex pervert if you went near the other side"

Q [LAUGHING] "Did that apply to the staff as well as the patients?"

A " Yes... as far as the staff were concerned..... you would soon die if you were caught near the female patients"

Q "When you say 'you' do you mean the patients?"

A "Well me... the nurse"

TopNurse

These respondents seem to be suggesting that there were almost two hospitals subsisting within the boundaries of Lhangbyde. There was some suggestion that, in addition to the formal separation, there were differences in atmosphere, with the female wards being much more formal in their working relationships; male nurses could call the charge nurse by his first name, whereas in the female wards the first level manager had always to be referred to as 'Sister'. With the progress of time, and the opening of the 'villa's' in the sixties, the sense of complete separation was loosened a little insofar as began to be acceptable for male and female staff to work within the same ward. This was described in the following manner.

. *"I think probably when the people that lived there moved to the villas. I seem to remember that it was an open approach. There seemed to be more integration. There was a lot of leisure type things. They were trying to drag themselves into the 19th century"*

TradNurse

Despite this liberalisation in the relationships between genders within the hospital, there were still practical implications arising out of the separation. One of the most significant areas was that relating to 'Parole' and 'Ground Parole' ; There were certain areas of the hospital where members of the respective

genders were forbidden to go (Lochinvar) and as well as geographical separation there was temporal separation inasmuch as males and females were only allowed to go outwith the hospital on specific and separate days. This geographical separation led the researcher to speculate upon the reasons behind such rigid demarcation. The answer emerged from the respondents themselves as was evidenced by the following quote:

> *"the chances are that, if there were males at that time, in places where they shouldn't have been, they would have been the more able, and I daresay those who probably didn't have a learning disability who were getting up to those sorts of tricks"*
>
> TopDoc.

The requirement to control sexuality stemmed from a number of concerns. One word which was often used in this connection was 'safety'. There was some concern that people who had been placed there in order that they should be protected should not be exposed to others who might exploit their vulnerability. (TopDoc, Solar, Planter, SideDoc). It was thought that some of the males who had been sent to the hospital by the court system, who were often more able than the average patient, might take the opportunity to exploit more vulnerable female patients, and the staff had an obligation to protect these women. If this did happen, it might be that the Mental Welfare Commission or the Police would become involved. On the other hand, especially in later years there was a recognition that male and female patients were bound to have some sort of contact, and that the philosophy of normalisation required that such contact should have a role in the encouragement of authentic social relationships. The organisational dilemma was to facilitate such contact in a manner which did not encourage exploitation. A system of girlfriend / boyfriend visits with one patient visiting another in their 'home' ward was inaugurated, though under strict supervision. In later years, it was recognised that there were a group of both male and female patients who were in a position to give informed consent to having a sexual liaison, of some description; and that sexual relationships did take place between consenting adults. This relatively liberal approach to the expression of sexuality meant that education was needed in relation to such

concerns relating to acceptable sexual behaviour in public places, and also in relation to contraception (TopDoc).

Despite the development of such liberal attitudes and practices, it should be remembered that in the Sixties, there was still a good deal of general controversy about changing sexual mores as is illustrated by the following quote:

> *"Yeah……In terms of I think the morality of the time plus the fact that they were at Lhangbyde to be cared for and not to be interfered with, and certainly not to enjoy themselves having sexual relationships with somebody else; they would you know"*
>
> (Solar)

Interestingly the same respondent had talked about the restrictions that were placed particularly on female staff by the management of the hospital. They included having to apply for a late pass if they wanted to be out later than a certain hour; and being locked in the nurses' home with a glass fronted box which had to be broken to get the key in the case of an emergency. Clearly the protective role of the hospital extended beyond the patients.

Although it was the case that in the wider world, the link between sexual expression and reproduction was becoming increasingly weaker, there is no doubt in the researcher's mind that the spectre of potential reproduction underpinned many of the rules governing the control of sexuality.

> *"I think it was a great fear aboot peoples sexuality / particularly nae si much expressions of sexuality but particularly pregnancy there was a great concern that these folk in Lhangbyde……. they were ostensibly in health service care and were being looked after by qualified nurses and professional doctors shouldna hae the opportunity to become pregnant"*
>
> Lochinvar

The issue of the control of sexuality, and the avoidance of pregnancy was a complex one, perhaps reflecting the complexity of changing sexual mores outside the hospital. One respondent used the word ‘horrific’ with regard to the possibility of patients becoming pregnant (Solar); this response was probably linked to the issue of sexual safety referred to above. It may well have been the case that some female patients may have been admitted to the hospital on the grounds that they were ‘moral imbeciles’ and thus susceptible to sexual exploitation. It was the case that persistent sexual misbehaviour attracted sanctions such as being ‘grounded’ within the ward for a period of time or transfer to a locked ward. Other remedies such as termination of any resulting pregnancy or sterlisation (SideDoc, Lochinvar,) could be used to ensure that reproduction did not take place (Craft 1994 :Lothian 2006).

On the other hand, at least three respondents shared memories of couples marrying as a result of meeting in Lhangbyde (PurpleH, TopNurse, SideDoc). They were provided with separate accommodation, usually in the main block; and such a marriage was often a precursor to leaving the hospital. One respondent offered the view that such couples often complemented each other, with one partner making up for the other’s deficiencies (SideDoc) .In at least one case a child was born as a result of the marriage, and because the family lived locally the respondent was aware that they enjoyed a happy and fulfilled family life until the early death of the male partner. In the mind of the researcher, this rather begged the question of why this woman needed to be accommodated in a hospital situation in the first place

In reflecting about the direction of policy relating to gender, sexuality and reproduction, it seems that the injunction to protect, operationalised in a fairly benevolent manner which took account of the inevitability of punter’s sexual activity was the dominant force. There was an implied commitment to a fairly traditional view of the place of sexuality both outside and within marriage, and

perhaps surprisingly, a small minority of patients were able to enter into long term relationships which were long lasting and stable.

Section 6: The Hospital Economy

In carrying out the archival work which formed the basis of chapter four it was found to be the case that the hospital, in its' earlier days, before it became a mental handicap hospital, had been proud of the fact that it charged one of the lowest rates in Scotland to the Poor Law boards which placed pauper lunatics in its care. This was because it was more of a 'colony' than a hospital in the strictest sense of the word. It followed the pattern adopted by other such 'colonies' which have been defined in the following manner:

> "The colonisation of so-called 'inferior peoples' being an already established and popular British policy at this time. ..... With the ultimate aim of maximum self sufficiency, colonies were based on a village layout with a central administrative block surrounded by pavilion homes (later known as villas) and various amenities such as workshops, a school, a recreation hall and a farm. For the local authority there was the advantage of allowing the addition of buildings as funds became available. Consequently, as the institution grew, it became increasingly insular and cut off from the community."
>
> Fido and Potts (1997) pp39

Lhangbyde Hospital fulfilled several of these criteria, and it is clear that one effect of this 'colonisation' was that the much of the economy of the hospital benefited greatly from the labour of punters. (Lochinvar, Planter, Solar, Crossover). There was, up until the seventies a fully functioning dairy farm, which supplied milk to the hospital and to others in the area. There was a laundry which took in work from surrounding hospitals, and many of the

tradesmen such as plumbers and carpenters had assistants who were drawn from the punter population.

As well as the work that went on in the wider hospital, it was usually the case that the day to day running of the wards depended to some degree on the labour of people who carried the label of 'patient' as is evidenced by the following quotes.

> *"most wards had a able patient from another ward, that worked in the ward and they were a volunteer. They were involved mainly in helping the cleaning side, and the domestic side; washing dishes and laying tables. I mean they obviously felt it was a great boost to them, and the strange thing wis that any of the patients that worked in the wards were in the ward for a long long time."*
>
> (StalNurse)

> *" the four domestics that were employed, they really did do the lot, they did all the work, we worked alongside them, to make sure they were safe, especially with boiling water. They were mostly very sensible ladies anyway."*
>
> (Solar)

This work sometimes involved undertaking some of the routine tasks involved in caring for less able patients. One respondent describes the work of a more able patient, whose role was to cut a hole for the head of a patient in a long strip of green paper in order to make a bib to protect his clothing at mealtimes (Planter).

Another sort of work for punters consisted of unsophisticated manufacturing of items such as pot scourers and wooden chairs. Members of the public came into the hospital and purchased them (Crossover). There was also a more formally organised department which manufactured concrete blocks which could be used for the construction of paths and so on. The respondent who described this process said that there were around forty people working on it at any one time, but its tedious and repetitive nature meant that it was hard to see it having any therapeutic value. However, other respondents said that punters' work,

particularly when it involved domestic and caring endeavour was rewarding for the patients involved; sometimes in a monetary sense, and nearly always in the sense of adding to their self esteem.

Ironically, when *providers* were at the very beginning of their careers, they often had to work alongside punters. Solar describes her first job in the morning as filling the milk jugs from the churns which were delivered from the farm, and making the tea in huge teapots. A number of respondents (Solar, PurpleH, StalNurse) describe a process of progression from what was essentially domestic work right at the beginning of their careers, towards the adoption of a more conventionally professional role once they had served a form of apprenticeship.

> *"When you went to the ward first you started at the bottom. You did the cleaning. There was somebody who did the upstairs and someone would do the living room and some else would do the kitchen and some one else the dining room. The kitchen / dining room was at the bottom rung of the ladder; that is where you started."*
>
> TradNurse

Responsibility for the most menial of tasks such as tea making and table setting tended to be allocated to whoever had started their caring career most recently. Having said this, jobs like tidying out cupboards and giving the ward a 'spring clean' were undertaken by all of the basic grade nursing staff. It is interesting to speculate whether this joint labour sometimes undertaken by both punters and providers was useful in bridging the gap between these two categories of people which was described above in the section entitled 'Encountering the Institution.'. There is a sense in which it is hard for providers to see punters wholly in terms of their classification under such categories as 'Patient' or 'Handicapped Person' if they worked alongside them during the formative years of their caring career.

Thus far the micro-economy of the hospital has been examined; the work that was assigned to both punters and providers within the hospital. It was also the case that the hospital subsisted within a macro- economy of care, where providers of care within the local area, and countrywide entered into complementary and sometimes reciprocal relationships. These came to light when a number of respondents (TopDoc, SideDoc) brought up the notion of 'trading' with other institutions. It might be an external institution agreeing to take a patient from Lhangbyde in return for the hospital taking one of their patients. One example was a patient from the London area who came to the hospital after a patient who should have been the responsibility of the hospital had been admitted to a London hospital. It should be noted that this sort of trading happened largely in regard to the less dependent patients. Respondents who worked in wards with patients who had very high support needs (Lochinvar, Planter) reported that there was seldom any turnover of patients.

The nature of this trading system developed and changed for a number of reasons. Historically speaking, the transition, at the beginning of the health service from being the County Asylum to becoming, in 1953, a hospital where Mentally Handicapped people were accommodated involved, throughout the sixties and seventies many transfers of patients who were in need of care within a psychiatric hospital. During the war years a local psychiatric hospital had been transformed into a naval hospital, and patients needed to be transferred back after the war ended. This process of deciding which patients really needed to be in a hospital dedicated to the care of Mental Handicap / Learning Disability went on for a number of years ; one of the medical respondents described a situation where

> *"An awful lot of people who had been in hospital in '84 of course didn't have a learning disability at all. They had all sorts of social problems, nothing particularly current but they didn't actually have a learning disability"*
>
> TopDoc

This respondent and another (Pavlov) saw it as being central to their role to ensure that only patients who needed particular *hospital* services remained there.

Another site for 'trading' revolved around the age of the patient or potential patient. Traditionally there was a division of labour between Lhangbyde and a city based hospital which involved that hospital admitting children, and transferring them when they reached adulthood. The division wasn't absolute, inasmuch as Lhangbyde had a 'boys unit' which lasted until the late eighties (TopDoc) accommodated in an old staff house within the grounds. One respondent (SideDoc) identified the decline in the transfer of children reaching adulthood as a major factor in the decline of the hospital's overall population. In his view the decline in transfers was in its turn related to the fact that from the late seventies, the education authorities were given the responsibility for the education of all children, including those who in the past had been deemed 'ineducable'. Because children were attending school in the day there was less pressure for them to be admitted to hospital care, and there was therefore less pressure to transfer older patients.

One of the biggest areas of trading was the 'forensic' area. These were patients who had been committed to hospital by the courts. There was some trading with the State Hospital at Carstairs (TopDoc, SideDoc).This sort of trading also went on with respect to mainstream psychiatric hospitals. Another area of trade related to respite care, with pressure from GPs and social welfare organisations to take patients in order to relieve short term pressure on families.

In the last decade that the hospital was open, the trade changed direction with the movement of policy towards accommodating people in small, community based residences, usually run by independent contractors. A 'Resettlement Action Group' was set up to facilitate the planning and provision of these new services. The internal micro economy of Lhangbyde was greatly affected as

wards closed, and staff and patients were transferred within the hospital to take account of the declining numbers. Relationships within the wider macro economy changed fundamentally as was evidenced by the fact that a great deal of the comment upon the closure of the hospital in the local press focussed upon the disappearance of a local employment provider. However it could be argued that the caring functions of Lhangbyde were transferred rather than abolished; with many staff transferring to employment with the new service providers, taking with them many of the therapeutic and organisational practices which had grown up within the hospital.

Section 7: Status and Hierarchy.

That there was a well defined hierarchy of status within the institution was well illustrated by the following excerpt from an interview.

> *"The patients would prefer to come and speak to the staff rather than to each other.....*
> *I think because the staff had high status.... the patients were just patients and knew ... there was a pecking order....they used the terms 'high grade' and 'low grade' suggesting a pecking order which was part of the same; if patients wanted to insult each other, they would call each other low grades'; there was a clear pecking order throughout the ward.. the patients themselves would show most respect to the charge nurse, and would show lesser degrees of respect...down the line.. that was just the way it had to be."*
>
> Planter

In trying to understand the nature of this 'pecking order' it became apparent to the researcher that a number of elements had to be taken into account. The first of these related to the fundamental division of patients into the categories of 'high grade' and 'low grade'. It probably had its origin in the use of the measurement of intelligence quotient to classify patients in terms of their degree of disability. The term was often used for those who required a high degree of support in order to accomplish everyday tasks (Solar), or experienced difficulty with communication or mobility (Pavlov); but providers reported that although it

was used for classificatory purposes, it was not a term which would be in everyday use by staff. In later years medical staff in particular came to regard it as a less than helpful term, mostly because it was not reliably predictive of functional ability or potential, and respondents reported that from the eighties onwards, it fell into disuse. This is not to say that it did not survive within the language of punters, especially in the context of argument or disagreement where 'low grade' might well be used as a term of abuse. A patients self classification, or classification by others might have quite profound implications for their self esteem, as is evidenced by the following extract.

> *"We stupidly had a high grade party and a low grade party. Now, as far as patients were concerned, if they went to the high grade party they were better, the low grade wasn't so good. There was a mongoloid boy who used to come to me in my office to say he should get an invitation to go to the high grade party and he was very upset about this, because he had been helping me at the dance with the high grade people, so there was a pecking order sort of situation taken up by the patients"*
>
> TopNurse

The second and perhaps more formal element in the status hierarchy related to the relationships of rank within the provider population. For nurses the first level of management was the charge nurse or deputy charge nurse who was responsible for the day to day running of the ward, making decisions about the everyday care of the patients who lived there. There was a charge nurses meeting, where they had access to the higher management in order to discuss the everyday working of operational policies and procedures. Respondents reported that the decisions of these meetings were seldom transmitted in writing. In the early years the management structure of the hospital was divided along gender lines with the male side reporting to a chief male nurse and the female side reporting ultimately to the matron. These divisions declined and disappeared in later years. In a similar manner relationships became less deferential over the years. The rank above that of Charge Nurse was entitled 'Nursing Officer', and one respondent who started work in the early seventies

reported that the custom was to stand up when a nursing officer entered the room (Lochinvar). This custom petered out in later years.

A third and once again fairly formalised element related to the relationship between medical and nursing staff. Medical staff had responsibility for overall case and care management, deciding such things as how patients were to be treated, and whether they could be discharged or transferred. Nurses, on the other hand, had the responsibility for day to day care of the patient and were likely to be more familiar with their individual needs and foibles. Medical respondents had clear ideas concerning the levels at which it was appropriate to make requests of nursing staff (TopDoc, SideDoc). If it was a particular task that needed doing they would address basic grade staff directly. If it was a fairly important thing a matter of liaising about possible discharge for example, then they would go to the charge nurse, if it was a policy thing, like the way a ward had been run, then they would probably speak to the nursing officer.

A final element in this system, although to some degree separate from it, was the figure of Matron.

> *"And then there wis matron. Matron wis God!.....Matron controlled everything she controlled the wards, the catering; she had her finger on the pulse. I would have said!"*
>
> PurpleHeather

In Chapter four a description of what it was to be a perfect matron from the first decade of the 20th century was reproduced. From what was intimated by a number of respondents the job description and person specification for the role of Matron had not changed much over five or so decades. She represented an essentially conservative force, with well defined ideas of how staff should be managed, which did not contain much space for ambiguity. In the later years, when the strict gender division of the hospital came to an end, the role of Matron was merged into that of chief nursing officer.

If you asked respondents who was at the head of the status hierarchy, they would identify the medical superintendent as fulfilling this role. The senior medical staff were consultants, and were psychiatrists by discipline, but there were GPs who did sessional work within the hospital, taking responsibility for the physical well being of patients and undertaking such roles as the renewal of certifications.

In amongst this fairly structured status and hierarchy system there was one figure, Pavlov, who was consciously attempting to loosen the rigidity of this system. He institutionalised a multi-disciplinary staff room, where senior staff from all disciplines, both caring and support staff could interact informally. He also suggested that instead of sitting on the 'Sister' or the 'Consultants' tables in the canteen, staff should make a conscious effort to mingle. He reported that the most resistance to these initiatives came from the senior female nursing staff, who were accustomed to dining with their peers. There is evidence that in later years the status hierarchy became less rigid, and that there was more inter-disciplinary, as opposed to multi-disciplinary work undertaken. It became acceptable, for example, for basic grade nursing staff to talk directly to medical staff without utilising the charge nurse as an intermediary. This tendency towards a more flexible approach reflected changing ideas about the care of people who had been defined as having a learning disability, and also had to be seen in the context of changing social mores in the wider world.

Section 8: The Sick Role.

It is one of the central paradoxes of the care system for people who have been defined as having a learning difficulty or disability, that they were resident in a building which had a sign outside it which identified it as a hospital; when, in reality only a small proportion of them could be thought of as suffering from an illness in the accepted sense of the word. (DHSS 1971) This goes to the heart of our concept of what it is to have a learning difficulty. In the main, Lhangbyde was a large scale residential unit or colony where people who were defined as

having a learning disability (or the equivalent term in earlier years) lived their day to day lives. However, it was the case for a number of reasons that some wards were designated as 'sick wards', and the dynamics of that designation process emerged during the interviews with providers, although the issue had not been thought to be of particular interest at the time the research was planned. One respondent understood the distinction but confessed her inability to remember much about patients being ill in the conventional sense of the word.

> *I wouldna have said that I remember aboot people having medical conditions ken like cancer or...//..I cannae think 'o anybody...I aye feel its a kinda recent thing.....Lhangbyde as it wis...people getting cancer.. it wis something I hidna really heard aboot, folk being ill like that..I suppose like sort of* normal *illness*" (Emphasis in the text)
>
> PurpleHeather

There was some evidence of a lack of clarity in the early definition of the sick role, which made for difficulty in the provision of day to day nursing care.

> *"The sick ward … where was it at the time? Yeah the sick ward patients were in there….. The sick ward patients were severely disabled, or patients who were ill, a physical illness. Some had diabetes, some were terminally ill, a fair mixture, some hid behavioural problems. Your sick ward was a mixture, not people that were terminally ill. It was a horrendous place to be in."*

Clarificatory Question *"Why horrendous?"*

> *"Well, later on , you could be nursing patients who were dying, at the same time you could be restraining severely disturbed patient you had to physically restrain them from getting near patients that were dying in their beds. It terms of that it was quite horrendous."*
>
> (Solar)

However the majority of respondents did make some important distinctions between various definitions of the sick role. The fundamental distinction was that which was made between the sick ward downstairs, and the sick ward upstairs.

The sick ward downstairs cared for patients who had particular conditions upon admission , or developed illnesses later, which required medical and nursing interventions which were essentially similar to interventions which would have been employed in the care of patients who did not fall into the category of 'Learning Disabled' or any of the equivalents. The patients accommodated therein have been described in the following manner.

> *The sick ward…..I think people would mostly mean the ward downstairs which was a ward of less able people, a ward which afforded better observation in dealing with people who were physically ill perhaps they had a stroke, didn't require care in the infirmary, could be accommodated later in their stroke in Lhangbyde.*

SideDoc

Sometimes the processes which had led to people becoming patients in the sick ward downstairs were not particularly transparent or understandable.However, it was clear that in relation to most patients, they had been assigned to a role, which encompassed being fairly dependent, and needing medical and nursing services which were fairly mainstream. However being assigned to the sick ward upstairs implied the possession of very specialised and particular characteristics.

> *"But there was the sick ward upstairs, which was really a misnomer because it was a completely different type of ward: a high observation ward, locked accommodation, for a population who were offending... and it was very very different from the sick ward downstairs,..... Extreme challenging behaviour, someone with a history of offending"*

Q "Was this a particular ward where people who were on court orders would be?"

> *"Traditionally that would be, but they wouldn't have to acquire them. If people came with a very sinister record for example, … there would be transfers to a state hospital for example occasionally, that would be the ward where they come to, but it was a quite separate ward to the sick ward downstairs; separately charged*.

Thus in an institution which was given the title of ‘hospital’ there was a tacit recognition that the huge majority of the residents were not ‘sick’ in the widely accepted sense of the term. The sick role was then constructed in two quite divergent ways. The first and most consistent with a commonly accepted understanding of the sick role (Parsons 1951) referred to people who had become ill with conditions such as diabetes, or a stroke which would be familiar to the general population. The second, and more specialised construction of the sick role referred to people whose behaviour severely challenged the norms of the wider society, often resulting in them appearing in court and being made the subject of an order. However it also encompassed people whose behaviour might be characterised as ‘sinister’ either within or outside Lhangbyde, who needed to be kept separate from the wider population whilst they underwent treatment.

Section 9: Activity Inside and Outside the Hospital

In his discussion of the difficulty of constructing measures of the quality of life Ager (1998) acknowledges that it is sometimes difficult to justify the choice of certain experiences which are valued. Whilst evolving the guidelines for the semi structured interview the researcher went along with the identification of ‘leisure’ as an important category, but as the interviews progressed it became clear that this category was expanded to cover the more general field of activity. This on the basis that once the interview got beyond asking about the more basic needs of punters and how they were fulfilled, there were questions to be asked about how they related to the wider world, both within the hospital and outside it.

The more restricted questions about leisure produced answers relating to organised activities within the hospital.

"They had a very full programme of varied activities in the hospital for a start, and then they had a full programme of bus trips outside...with coming out of the bus and going to tearooms...theatres, cinemas, halls, going up into the hills, walking……..all sorts of things while they were in hospital...always under supervision, but sometimes with quite light supervision. Ehh. They would go into shows in Aberdeen and the theatre, they would go down to the beach, they would go to football matches. Depending on their interests; quite a lot didn't want to go out..... we wouldn't force them to.."

Pavlov

One of the key elements of the provision for leisure activity, particularly after the building programme which took place during the sixties, was the 'Hall'. The researcher only developed an understanding of the meaning of this term as a result of undertaking the early interviews. The 'Hall' was a central place where punters went to engage in leisure activities on a daily basis, and was also the setting for such activities as dances and the showing of films.

" The hall was……. again I hinna that good a grasp on't because I didnae often get involved in it, but there was a central kinda therapeutic area, it was a massive community and everything within the hale place what was loosely known as the hall was the big complex in the middle where which also included the kinda staff dining facilities, but there was a big hall that was used for dances ,pictures played bowling there was cinema once a week, there was carpet bowling there was full size snooker table there was an awful lot of maist of the social life of the hospital as a whole happened in this kind of central area. There were dedicated hall staff whose job it was to dee entertainments dominoes and jig saws and a' that kind of stuff and worked more traditional 9-5 kinda hours as well as people that were in the wards and some of the folk in the hall and places were nursing staff as well some of them were recruited as kind of therapy staff others were nursing staff."

Lochinvar

From the point of view of the staff, this kind of activity contributed to the promotion of community spirit and a good level of morale (TopDoc) and in later years some forms of activity were formalised and formed the basis of occupational therapy. (Crossover). One respondent went as far as saying that

he thought the level and quality of leisure activities within *Lhangbyde* surpassed what could be achieved in community based provision.

Many of them who I saw afterwards regretted going out into the community and wished they were back in Lhangbyde, because there was a very full social programme thanks to Bill Geddes (pseudonym) *mostly; a range of activities where they weren't put at risk of being demeaned by others, which was a major factor where somebody threw a fit or wet themselves, it wasn't remarked on, it was just dealt with"*

(Pavlov)

These interview excerpts contain the seeds of a dilemma about leisure activity within the institution. They illustrate that there was a lot going on, but make clear that activity was provided under certain conditions. There is a distinct sense, particularly in the last quote, that punters may be assumed to be at risk, and in need of being protected by professional staff. This approach was also evident if a wider definition of 'activity' is accepted when other life experiences are examined.

One experience which might be legitimately considered as a leisure activity concerns the freedom mentioned above to simply go out for a walk, either within the hospital grounds, or outside.

> *"There was ground parole for those who were deemed unable to go out of the grounds. They had ground parole they would go and wander round the hospital area itself, they were capable of that. There were others that had* full (Emphasis in the text) *parole it was called where they could go to W or B on a Friday afternoon, after they got their pay…their money but it was every second Friday, they weren't allowed out the same time as the men were allowed out , it was consecutive days.. They weren't allowed out together. It was the same for the ground parole. It were the men who were out on a Monday on ground parole, it was Tuesday for the women. So men and women weren't allowed to wander freely in the grounds on the same day."*
>
> (Solar)

The terminology employed would seem to imply that the freedom to go for a walk was not a right, but was a privilege that needed to be hedged round by

conditions relating to time, space and gender. The distinction between 'full' and 'ground' parole were mentioned by almost all respondents. One respondent mentioned that parole was more of an expectation on the part of male punters than it was for females (Lochinvar). Because it was a privilege, the withdrawal of parole could be used as a sanction if people misbehaved.(TopNurse) There was a sense in which the remit of the hospital extended to some of the local towns.

> *" If onybody was seen as misbehaving in Seatown* (Pseudonym) *sometime members of the community would phone up and say one of your people is making a nuisance of themselves / but by and large the relationship was awfy good. Lhangbyde was the major employer in the area and maist of the local people recognised that a lot of the shops got a lot of trade from there, maist o' the local community depended on it a lot of local people worked there and I think the atmosphere was very tolerant"*
>
> (Planter)

As well as the stated rules which governed parole, there were more informal pressures that could be placed upon punters who did not use the privilege wisely.

> *"I can think of one chap who liked a drink..... and he smoked, and he went out every week once he got his money. I have a feeling it was a Thursday when he went out, and ...ehh.. I did something unethical. He used to spend a' his money, and he wisnae living we....nae cigarettes for the for the rest of the week, so I said gie me a fiver ...I'll keep a fiver, and then you will get it when you come back. Well it wisnae Thursday night... it wis Friday morning that he would get the money back, so that he would have enough cigarettes and tobacco to last him for the rest of the week. He would go down to Mackays* (Pseudonym)*……. Mackays pub in Seatown. .... The Kings Head* (Pseudonym) *it is called now... it is still owned by one of the sons.. the Mackays"*
>
> PurpleHeather.

Another activity which took punters outside the hospital was the annual or semi annual bus run, described in the following terms:-

"It was always very highly organised. They always tended to go to places where there wasn't a lot of the general public around..... They didn't get told, neither did the driver, we only ended up somewhere. We leave about 8.00, drive for hours and drive home again. Very little contact with the generally public. They would stop at some hotel for lunch, there were limited outside the bus, it was a bus run. Eating out was a fantastic experience for everybody. It was very organised and a member of staff had to stay with it. There were two buses from each villa."

TradNurse

Several respondents described the bus runs as being very institutionalised concentrating on the bus ride itself rather than going somewhere and doing something. They described travelling the same routes, and visiting the same hotels for lunch. One respondent talked about the innovation of a boat trip on Loch Ness, but reported that his colleagues thought this was a risky endeavour, involving a great deal of responsibility on the part of members of staff.

Another activity which could be seen as a primary experience for most people was having contact with one's family. For patients it would also be an activity which would reach over the boundaries between the hospital and the outside world. Hospital staff saw it as being very desirable, and put a lot of emphasis upon facilitating it (TopDoc, SideDoc, Planter, LochNurse,TopNurse, TradNurse). Contact with families did not seem to be evenly spread, there were some families who were conscientious in their visiting patterns, but there were some who did not visit at all, making it difficult at the point of discharge of some patients from hospital to make realistic plans.

" Well that varied, and you would have to go through all the patients individually to say how much interest some relatives took; some took a very keen interest in their relatives in the hospital , and in other cases there was absolutely no contact at all. We had an awful job trying to track down some relatives, and some people were discharged showing no birth date and next of kin. Which was ...rather a shame, but that was the way of it. There had been no contact with any member of the family in a very long time"

(TopDoc)

It is reasonable to make the point that sometimes staff were, to say the least, ambivalent about contacts between patients and their families.

> *"there were some relatives who visited faithfully, it always tend to be a Sunday. There were some families that rigour sly visited every Sunday. They could visit anytime but they tended to come on a Sunday. They tended to come from all over, not the local area."*

Question. *"What did staff think of families?*

> *A bit of pain, especially, they used to pick on staff about what they were doing or not doing. They didn't say exactly what for ----- the clothes they came back in, they had to be hand washed. You had to be nice to the locals*
>
> (TradNurse)

Another reason for staff ambivalence related to the fact that they had to live with the disappointment of the patient if promises were not lived up to.

> "*I can think of one parent who didn't come when they were supposed to come, and you would get the patient ready, and even though he wis blind, I think it was twice that I got the patient a' ready, thinking that they would come; and they usually come, I got him a' ready, bonny dressed, and they didna come; and he went absolutely loopy. He wet himsel, made a mess o' himsel, screeching; so eventually I learned that if they didna come we would go out anyway; I would take him out, even if it was a walk in the grounds, or a trip out. I suppose that there would have to be transport."*
>
> (PurpleHeather)

The relationship between the 'inside' and the 'outside'; the hospital and the community was a complex one, and those organising cross boundary activity had to take that into account. It has been stated above that the relationship between the hospital and the community was a tolerant one, especially in the light of the importance of the hospital in the local economy. However, the following interview extract shows that the issue of 'rejection' was always around, sometimes overt, and sometimes hidden.

> *Q "When you said that they were rejected...what did you mean by that?"*

A "Well I mean't that the patient was never accepted in the community...[INTERJECTION : *"Right"] and that created problems within families. There was a baby here that was hidden away and nobody realised it until the mother died"*

B "And when you say 'here' you mean Seatown (Pseudonym)*"*

A "Seatown ……..yes"

B "And that was during the time when you were working?"

A " Yes"

B "And how old was the baby when the mother died?"

A "It was about nine..... "That actually happened quite often, there was quite a few of them..... and when you placed a patient in the community here....some people .....you are never quite clear of it..."

(TopNurse)

It appears as though, on the basis of what this respondent, who was both a key figure in the staff group and someone who had an insiders knowledge of local culture, was saying, that although people were prepared to be tolerant to the presence of punters within the community, there was, on occasions, a feeling of shame, leading to rejection of family members who had been identified as having a learning difficulty.

Section 10: Change and Development.

One of the key problems associated with both description and analysis of life within Lhangbyde on the basis of interviews with 'providers' relates to the difficulty of accounting for the process of change over time. When the oldest respondent interviewed commenced employment in the hospital it functioned as the 'County Asylum'. It was only later that the Hospital changed its mission in the to become a hospital which specialised in the care of people who were then termed 'Mentally Handicapped' and later became defined as having a 'learning disability'. Many of the respondents were present during the sixties when the new 'villas' were planned and built, and care shifted away from the original main

building; and were also there during the time when the population declined and the locus of residential care shifted towards small units within the community, and away from large residential hospitals entirely.

Consequently some of the themes which have been abstracted above, such as the separation of the genders, or the routines of daily living, have to be qualified by consideration of the time period at which they took place. The analytic process is further complicated by the fact that changes did not take place at a uniform speed within all parts of the hospital, and there may have been staff who were strongly influenced by notions which were more relevant at the beginning of their career, such as grading on the basis of intelligence quotient, or eugenicist ideas which would have placed the avoidance of the reproduction of disability at the centre of the carers role, than modern concepts of care based upon such principles as human rights and normalisation.

Accordingly in this final section of the providers tales, it is important to detail some of the forces and processes which made for change within Lhangbyde as seen from the perspective of the people who worked there. It should be noted that the characterisation of change reported in this section largely derives from that part of the interview where respondents were asked very open ended questions about the nature and causes of change, or the best and worst things about working at at the hospital; so the categories of meaning derive directly from provider experience, rather than the phrasing of questions within the semi-structured interview. On this basis 4 themes have been identified.

The first of these relates to **changing ideas**.

> *"Yes I think there was some changes in ideas, the place had grown so quickly, new blood came in, the surrounding area alone could not cope, staff came from a wider area, and the whole place was opening up to people who could see a career. So I think that opened up the whole scene. The whole ideas changed."*
>
> (Solar)

Such changes took the form of a changing climate of opinion reminiscent of the wider changes of attitude which were taking place in the wider society in the sixties and seventies. As was the case in the wider society there were those who sought to resist such changes. Those who saw themselves as conscious promoters of change (Pavlov) identified both allies and opponents within the hospital, to the extent of using such descriptive terms as 'staunch supporters' and 'reactionary'. The above quote is descriptive of a process, but does not attempt any analysis, although another respondent did speculate that an influx of staff who had trained elsewhere did lead to exposure to new ideas, often through the medium of in service training. .Changes in ideas were reflected in changes in attitudes; a respondent describing a later period, the early eighties described a growing effort to promote the dignity of punters.

> *" Attitudes changed greatly over the time I was there; people were treated with more respect, and there was more effort made to promote their dignity; one example is that the standard of their clothing improved a great deal all that changed massively..... it allowed them to express their personality, they were allowed to go out and choose their clothes rather than simply being given them."*
>
> (Crossover)

A second area of change related to the improvements in the **physical facilities** at Lhangbyde. During the sixties and early seventies patients moved out of the original 'asylum' building and into newly constructed 'villas' built in the grounds of the original hospital. Moving away from the original 'Big Hoose' towards a more decentralised, campus like environment.

> *" First of all the facilities.. improvements in the facilities.. the new buildings; the identity gained by individual patients because they had been shut away, restrained, and they weren't anymore*"
>
> TopNurse

In listening to the accounts of these times the researcher gained an impression of there being something of a new dawn, with both new ideas and new facilities

coming on stream, although one is inclined to wonder whether the 'confines' were physical or conceptual boundaries. Another medical respondent described a nursing officer who imported more homely furniture which he had acquired from house clearances. (SideDoc) The doctor was doubtful as to the usefulness of the initiative, but once he saw the effect of the change upon the atmosphere of the ward he was converted to the idea. It also led him to an understanding that nurses who spent almost all of their working life within the ward situation were likely to be more sensitive to the nuances of atmosphere which could be influenced by changes to the environment. Other physical improvements were achieved by partitioning ward space, particularly within the sleeping areas with the aim of promoting a less 'institutional' ambience.

As well as identifying allies and opponents in the promotion of change, respondents who saw themselves as innovators identified a more subtle but pervasive third area of influence upon the change process. The presence of **kinship connections** between members of the hospital staff was seen as an essentially conservative force. The presence of kinship connections was inevitable, given the fact that Lhangbyde was such an important employer in the area, and because nursing staff especially had often been steered toward working at the hospital through the medium of peer and family grapevines.

> *"Well....it was a clique system... whoever you have spoken to, they would verify..... The first thing I did when I took command was to take staff off wards. There were some staff sitting in easy wards, and some in difficult wards, and these members of staff shared something with the matron, my predecessor. She had a sister, she had a brother, a brother in law, a sister in law. Now, when I started off meetings with charge nurses, to try and establish some sort of rapport between folk the meeting was more or less... you were speaking to the family.. you got nothing past... most of the charge's .. they were not happy to talk freely because of this situation*."
>
> TopNurse

This extract brings out a number of important issues. There is an implication that kinship considerations influenced decisions concerning deployment of staff, tending to lead to rigidity of practice. Some of the issues which have been

referred to above, including the ending of the strict gender separation with regard to the staffing of wards, and the implementation of charge nurse meetings where the development of policy and practice was discussed, were part of the wider process of change, but a respondent who was a senior manager implies here that in order to promote such change the essentially conservative power of the established kinship networks had to be confronted. The kinship network acted as a sort of sponge which absorbed the impetus for change.

> *"The husband the wife I think that was very much encouraged by the … I forget the reasoning, but I heard an old employer at Lhangbyde, but she went on to be a senior nursing officer here in Aberdeen, I remember her talking about the reason why the authorities liked that, having a husband and wife both in the hospital, both aware of the dynamics perhaps an element of one keeping an eye the other even; it was deemed to be very useful"* SideDoc

It thus seems as though family relationships were thought of as some sort of a medium, within which the norms and rulings of hospital management could be transmitted.

Finally, in the discussion of the macro economy of the hospital outlined above, it has already been established that **changes in policies elsewhere**, such as the transfer of responsibility for the education of disabled children from the welfare authorities to the education department in the late seventies, had a profound effect on the level of admissions to the hospital based care system. Indeed one respondent argued that this was the key reasons for the decline in population within Lhangbyde, which in its turn led to an increased ability to provide individulised services. (SideDoc, TopDoc). However it has always been the case that policy changes in the wider world have impacted very directly upon Lhangbyde life, but it may be that far from being a part of continuous progressive change, variation in the pace of external change was reflected in the progress of change within the hospital.

Well there has been a … latterly towards the rundown there was a rush with regard to discharge, but there have been maybe two or three phases of a lot of people being discharged and a lot of time in between where there has not been any sort of change at all. well has been a … latterly towards the rundown there was a rush with regard to discharge, but there have been maybe two or three phases of a lot of people being discharged and a lot of time in between where there has not been any sort of change at all.

(TopDoc)

Thus it appears as though there had been a recognition of the desirability of movement towards community based provision over a long period, but the level of impetus to transform this into discharge from hospital varied, until the time came when closure of the hospital was in sight when this was transformed into a 'rush with regard to discharge'. Paradoxically, the process of change which had at its goal the ultimate demise of the hospital had the effect, at first, of greatly improving the day to day living experience of punters, but there was a recognition by staff that the hospital did not have along term future.

"*the real change, and the best change .. that wis good, especially for the patients .. the residents at that time...there was a lot more choice available for residents.. It was also quite clear that the future..ehh...care of these actual patients...residents wisnae long term. hospital .., it wis something else and community care ..you can break that doon into whatever it was.. but it wisna in the old fashioned institutional care. I think that was quite clear…….it wis quite clear because that was government policy. How that happened, was difficult to accept by a big majority of staff. And I say that there because they knew nothing else; it wis... we had always done it, nae only wis it.. they also knew that they widnae be caring for them while they were in the community. I say that there because it was a big issue.. health and social work.. social care..nurse and social worker.. there wis a lot of political fixing there"*

StalNurse

At first, it was as though the policy goal of movement of patients towards the community was an abstract goal which, although it was beneficial for those who had moved out, did not have a great deal of effect on the overall life of the hospital. However, once the total number of patients slipped below a 'critical mass' it became clear that it was not economic to continue to have a range of

wards open, and the benefits of lower patient numbers began to be transformed into a process of instability and uncertainty for the patients who were left.

> *Also there was a sad moment when, for example you saw the first wards being closed. Although it wis preferred to be called decommissioned, it wis closed, that wis maybe the start of the decline, and staff.....it really sank in and unfortunately when the ward wis closed it was locked……..that wis it……..and anything that was needed in another ward……it was beg borrow or steal, it was moved. It wis also at the time whereby motivation wis jist non existent..you know..because there wis no funds available for redecoration purposes. It was quite clear that the hospital wis closing and if you wanted to make your ward look better you had to dee it within yourselves etc .. limited budgets. And so that perhaps the beginning , and you could see things were limited and you could see that the best way was really out and intae something better..... we had spent a' these years having residents in wards that were compatible to one another, had good relations and then somebody jist... that disnae happen in a normal family.....And it wis something that unfortunately the staff couldna control, it was the system that there wis , and that happened maybe twice a year., and it caused a the bigger movement of residents within the hospital...you know there wis so many moves.."*
>
> (StalNurse)

Section 11: Conclusion

In the final analysis, changes of policy in the wider community led to the closure of an institution which had started life as the county asylum, which catered for a range of people whose diagnoses covered a range of clinical specialisms, from learning difficulty through to acute mental illness. The institution had, after the inception of the health service, become an almost self sufficient community which had sought to focus its' mission on a closely defined client group, and to provide a more humane and individualised service to that group, but it had been recognised in the end that it was a contradiction in terms to seek to be inclusive within an institution which kept people separate from the wider community. The movement to community based services was accepted by the majority of providers, with many of them transferring to employment within the new provider services. In the opinion of the researcher, at the time of inception of the new services there was an atmosphere of new beginnings, almost the movement from the darkness into the light. The providers who were interviewed for this

study recognised that services for punters inevitably developed and changed over time, but notwithstanding all the acknowledged deficiencies of Lhangbyde, were aware of the positive and caring work which was done. It seems reasonable to end with a quote from a provider who had long working experience:

> *"Yes, you might have gained the impression from what I said that this was a pretty oppressive place to be...eh.. for staff ..... but looking back on it now I can see that the great majority of staff were well intentioned…….. poorly educated…..as to the nature of learning disability and perhaps how you should be with them..... the nature of the service that needed to be provided, and there was just a lack of awareness of what people were doing , but in the main people were well intentioned. They did want to help, but they……..you know……..it might have appeared that they were not encouraging respect, but that was not a conscious thing. The point I am making is that people were doing their best, that they could……given their own socialisation, at that point."* Planter.

Chapter 6: Providers Tales.

Lhangbyde was known as 'the big hoose', and among the local folk, they would say, 'if you dinna behave yourself you will be off to Lhangbyde. And the other thing significant was that the main building was hidden when you came in.. You went into the drive past the gate house, and you gradually went round so you wouldn't see where you were going, there were rhododendron bushes growing on either side. And all patients came in that entrance. You would eventually see it... but before you got there...."

(Top Nurse)

This chapter is structured in 5 sections.

Section 1: Introduction.

Section 2: Choosing key informants.

Section 3: Key informant; Lochinvar.

Section 4: Key informant; Solar.

Section 5: Key Informant; TopDoc

Section 1: Introduction.

In chapter 5 above the emphasis was upon the process of deriving categories of meaning from the descriptions and analyses of their experience provided by all twelve respondents. The categories were derived from the 'nodes' which result from the first stages of such a categorising process which takes place within the NVIVO qualitative data analysis software. (Gibbs 2002) The intention was to explore those nodes or categories within which responses from several providers have been recorded. Some of these categories emerge directly from the language employed by the respondent. The 'sheep dip system' of bathing patients is an example of one of these. Others are more 'concept' driven insofar as responses regarding a particular area of life experience, such as 'gender' or 'sexuality' , have been abstracted by the researcher, but always on the basis of a direct , low level categorisation of what the respondent said within the interview. There was very limited use made of verbatim quotes from the transcripts in that chapter because the prime aim was the categorisation of common responses. They were used to amplify meaning, and reference was made to the transcript within which they occurred.

In this chapter an attempt will be made to focus upon a more holistic form of analysis, where verbatim extracts from the transcripts of interviews with three key informants will be set out, with the aim of providing detail from their experience with the aid of as little interpretation as is consistent with structuring the presentation of the material. It is acknowledged that these extracts have

been chosen from the interviews as a whole and framed in a particular manner, but the aim has been to present a range of content, sometimes having to do with similar categories, but from different occupational and gender perspectives. The aim is to provide a sense of the depth of both the continuity and change which occurred within the working lives of individual providers.

In his discussion of the dynamics of 'Total Institutions' Goffman 1975 examined the 'staff world' and outlined the particular orientations and skills which are associated with the role of staff member engaged upon 'people work'.

> "The special requirements of people work establish the day's job for staff: the job itself is carried out within a special moral climate. The staff is charged with meeting the hostility and demands of the inmates, and what it has to meet the inmates with, in general, is the rational perspective espoused by the institution"
>
> Goffman 1975 P80

The providers who were interviewed had to be guided by the rational aims of the Hospital which were, in most senses, relatively simple. Namely to provide for the day to day needs of the patients to whom the researcher has given the title 'Punters', to co-operate with other professionals in evolving a professionally based assessment of the long term needs of those punters, and, especially during the later history of the institution to work towards their rehabilitation to ordinary living within a community setting. Although the aims of such an enterprise have been characterised as being relatively straightforward, the career of the provider within the hospital was affected by such influences as their own previous personal and social history, by the effects of such variables as kinship and gender within the hospital, and by the changing and developing expectations placed upon the hospital by external governmental bodies.

The Shorter Oxford English Dictionary (1986) defines the act of narration as “the action of relating or recounting or the fact of being recounted”. The employment of narrative seems to the researcher to be a potentially fruitful method of recounting, in relation to the providers, the manner in which stories about their individual, organisational and collective histories recount the formation of their professional identities, and the manner in which they invest their working lives with meaning (Gardner 2002).

Having thus identified the potential benefits of a holistic and narrative approach, especially in situations where it is useful to access ambiguity and multiple meanings, the researcher is not suggesting that the narratives set out below represent in any sense a ‘true’ account of historical fact. (Lieblich, Tuval-Mashiach et al 1998) put it succinctly when they say that a life story derived from an interview amounts to one instance of the life story, which is in itself a reconstruction on the part of the narrator, often with a particular purpose in mind, of a core of facts which are selected from and interpreted.

Section 2: Choosing Key Informants.

In choosing the three key informants the researcher made an attempt to pay attention to what has been termed ‘holistic form’ *and* ‘holistic content (Lieblich, Tuval-Mashiach et al 1998). It is recognised that, within this context, form and content are two ends of a continuum and shade into one another. The holistic-form mode is more focussed upon the *structures* employed in the telling of narratives. It could be said that the semi structured interview outline employed within the research determines the form of these particular narratives, but it was often the case that respondents heard the questions, but framed the answers in a narrative form which had its roots in forms which were prevalent either within their professional grouping, or their culture of origin. Thus in choosing TopDoc as a key informant the researcher took account of the fact that his narrative was

informed by a perspective which derived from a medical / professional / rationalist outlook. For example he answered questions about his reasons for coming to work at Lhangbyde in terms of his professional progression and development. In choosing Solar as a key informant there was a recognition that her gender position may well have led her to prioritise a form of narrative which emphasised questions of vulnerability and safety, for both punters and providers. Lochinvar told his story in a form which demonstrated the depth of his cultural engagement with the surrounding area. His answers to the questions about motivation focused upon his relationship to the fishing industry, and the limitations that this placed upon his range of choices.

The holistic-content mode of reading focuses on the wider life experience of a respondent and seeks to establish *meaning* on the basis of the content narrative as a whole or the context within which it takes place. (Lieblich, Tuval-Mashiach et al 1998). It is difficult to draw a precise boundary between form and content, since they both influence one another. TopDoc was a useful key informant because he tended to see the process of development and change in terms of a drive to ensure that only those who 'truly' had a learning disability should remain as patients. Solar, because of the length of her service, was able to bring to the interview a perspective which was informed by a strategic understanding of the changes in attitude and practice which had occurred over a long period; both within the hospital and in the surrounding society. Lochinvar, perhaps because of his class and cultural background, was articulate in detailing the dissonance that he felt existed between the 'real' outside world, and the 'bizarre' and enclosed world of the hospital.

In summary, there is no sense in which these three key informants could be said to be 'representative' of either the whole staff group at Lhangbyde, or even the totality of respondents within the study. The hope is rather that their occupational and social diversity will enable them to illuminate a wide range of meanings or explanatory themes.

Section 3: Key Informant; Lochinvar

Lochinvar was brought up in a fishing village around 15 miles from the hospital. On the 'pre interview' form it was recorded that he was known to the researcher through his employment in a community based 'not for profit' company. The researcher was a director of the company, but played no part in the day to day management, and so did not have a close working relationship with him.

Beginnings, Expectations and Reactions

One of the first issues to be covered in the interview was the question of how the respondent came to be employed at Lhangbyde.

> *Q " What were your reasons for seeking employment at L, why did you, if you think back to when you first went as it were?"*
>
> *A " I jist totally drifted into it Barry, my* fathe*r was working at L, and my* girlfriend *was working at L (*emphasis in the original) *"I was working as a fisherman, in a seasonal occupation and it was finished for a four month period // (*Prompt *"Uhuh") went to the job centre to sign on and look for a job, and he said there was nothing much going at the moment but the only thing I can tell you is they are recruiting at L." (*Prompt *"Right") "So it was something I had been determined that I was* not *(*emphasis in the origina*l) interested in but wi my dad there and my girlfriend there and the job centre pointing me there, it seemed to be eh… the only thing that was the only opening that was around."*
>
> *Q "You used the phrase just now that you were kinda 'determined you weren't interested in', tell me a little bit more about that." "Why is that?"*
>
> *.A " I"* ('I' said in a regretful tone) *"had a real problem with my dad going to work there, I found it quite sort of difficult my father wis a fisherman wi his ain boat and I hid hid my life mapped oot: that I was going to go to sea with him and we were going to buy a new boat : and that was all part of growing up in a fishing village I think" (Prompt 'Yeah') "I think my father abandoning a' that and going away to work at L was something I found very difficult to cope wi." (*Prompt *'Right') "It gave me a life away from the fishing which was probably to my advantage but I certainly didna see it at that time / so I suppose I kinda resented his mid life change of direction."*

On reading through this section of the interview, the researcher gets a sense of choices being somewhat predestined by circumstance, and fatalism in the face

of these pressures. Having started work at Lhangbyde, Lochinvar was struck by the routine nature of much of the work.

> *"we started at 7 O' clock in the morning and as I said it was a lot of physical care you wid be helping people get oot of bed helping them get breakfast, helping them wash, bath, get shaved"(*this was said in a tone which suggested someone reading out a list) *" it wis… and that took up most of the morning essentially then the people would be getting their lunch and again. at a fairly unusual sorta time I thought folk would startin getting lunch at quarter ti eleven which seemed to be geared roond aboot allowing the staff go for their lunch at a mair traditional kinda ..kinda.. meal time ///. eh… and then in the afternoon there wid be… it would be a bit mair relaxed and their wid be things to dee like tidying out cupboards and things that were expected to keep busy preparing clothes and things for the following day / and then you would be helping people get ready for bed, again remarkably early they had tea and would be helping people get ready for bed sorta back a' 6 some people would be in bed by the time night staff came on at half past seven."*

Whilst answering a question towards the end of the interview about the positives of working at Lhangbyde, Lochinvar qualified what he was saying with the aid of the following observation.

> *"a lot of what was happening; doing of the routines and things, were frankly bizarre; When you went there you couldna believe what was happening; within two months of being there you kinda had accepted it as……. A kind of normality; you got kinda acculturated to it very quickly but there were a lot of good times."*
>
> *Q: The other side of that question was really what was the worst thing about working at L for you?*
>
> *A : "Ehhh …I think I had a recognition that it wisnae part of the real world.*
>
> *Q "You used the phrase 'it wasn't a real world.' Would you like to say anymore about that.or……?"*
>
> *A: "Aye, that kinda idea that it was slightly bizarre never entirely left ma; ehh….something surreal about L that eh.. you couldna quite put your finger ont but a stranger coming in the door could spot it within ten minutes.. But the Staff had almost become part of it, theyd become part of this strange world; so I dinna think I ever quite got awa from the idea that it was a bit abstract; a bit unreal ".*

To summarise this section, it conveys an experience of coming to work in the hospital without a particular vocation for this kind of work, with choices having been determined by other influences. Once established at the hospital the work was routine in its nature and time was structured by the nature of the routines of daily living. The routines were experienced as being somewhat bizarre; particularly the timing of meals, but the respondent recognised that providers very quickly became acculturated towards accepting them as normal.

Meeting the Needs of Everyday Living : Clothing

At the time Lochinvar started working at Lhangbyde, there were around 650 residents. One of the most important tasks was to ensure that they were clothed appropriately.

> *Q "OK a minute ago you said that you helped in preparing clothes; how were clothes stored, were they individually stored or was there a kind of a central pool?"*
> *A (A very fast rejoinder) " There was communal clothing and people got bundles made up for them for next day wi their name on it / so you would try and select a pair of trousers and a jumper, and appropriate clothing for that person that you thought would fit them and wrap it in a bundle wi an elastic band with a piece of paper on topa that wi their name on it and they kent it was for them for the following day Ehhhh // purchasing of clothing was again quite similar, bizzare, in that folk that hid the maist money seemed to buy most of the clothing they were a' shared people didn't have individual clothes it was a' shared from a central point."*
> *Q "explain that to me again, that business about people having the most money bought the clothing, how would they have a different amounts of money?"*
> *A " people would have their own individual accounts / and again as a nursing assistant I didna hae a great deal of contact with that a lot of that was very sorta confidential but I can remember a big purchase of clothes being made and people didn't go and select clothes, the van came out from a big shop in B, it wis A, I cannae remember a' that, that supplied maist of the clothes to L so they would send out a van and you would get sorta 20 polo shirts in one colour and 20 polo shirts in another colour and then 20 pairs of trousers of one size and 20 pairs of trousers of another size / but .I can remember folk working out who could afford to buy new clothes rather than who was actually gonna get them."*

However, there were special occasions when this collective approach to clothing was not appropriate, and at these times a separate category of clothing (usually called 'Good Clothes') were issued.

> *Q "Right, OK, was there such a thing as good clothes?"*
>
> *A :" yes" // (Prompt; "Right") " folk wid hae their ain good clothes the people I wis workin wi good clothes wernae particularly relevant / ehh… good clothes were for ootings special things, parents coming to visit and things like that.....ken"/ (prompt "aye") "Maist of the people I was working with as I said were elderly men and they had the communal supply of clothes a' the time good clothes were very very rarely used, but they had locked wardrobe units that they had good clothes in "*
>
> *Q "Right and …For those rare times when those were used what sort of occasions were good clothes be used"*
>
> *A : "well again the folk that I wis workin wi used them much much mair rarely , but ither folk would be using good clothes for relatives coming to visit if they were going away home for a couple of days to visit their relatives, or if their relatives were coming to visit them you used good clothes. I can remember being involved wi folk using good clothes for court appearances and things like that kind, If they had been charged wi offences then they could wear good clothes but as I said ,my experiences as I said that we're thinking back to the first time working as a nursing assistant was that the folk I was working wi very rarely, if ever used good clothes."*

It seems as though these special occasions revolved around contact with the outside world; visits to and from relatives, court appearances etc. It could be argued that these were occasions when outsiders could be present. The other interesting point about Lochinvar's recollections was the inverse relationship between the degree of dependency and the likelihood of contact with the outside world which would require the use of individual clothing.

The Sick Role

One of the distinctive features of Lochinvar's early career at Lhangbyde was that he mainly worked with patients who had a need for close support. This led him to think about the nature of the sick role within the hospital, and to address the paradox that all of the people who lived there were called patients, and resided within an institution which was called a hospital; whilst at the same time there

were wards which were set aside as ‘sick wards’ implying that the rest of the residents were not designated as being sick.

Q “O…K / One thing I wanted to pick up from what you said earlier you were talking about ….the part of my questions about the lifestyles…you said that in the wards you worked in first, really they didn’t take much part in leisure or work activities because they were sick . Is that…”

A “Yes (prompt: “right”: the answer had interrupted the question) *“they were not necessarily given preference, there were the terminally ill and some of them were, but there were other people who had had minor strokes and were not really ill in the traditional sense of the word but were not ..eh… not physically well enough to take part some of the ither things that were happening in the hospital. We took people in that ward that for instance hid diabetes and needed regular injections of insulin because the folk in the sick ward were dealing wi it all the time, they were seen as the folk that were maist appropriate to deal wi insulin dependency, so they took people to this ward purely because they were diabetics, rather than “*

Q “ It sounds as if the implication of that is in order to live in the main body of the hospital in a way you had to be quite independent and self reliant in one sense is that a fair thing to say”” “ .”
A “ Aye… there were some ither wards where people had sorta profound disabilities and profound physical disabilities / there were some people in other places that used wheel chairs some people in other places who wid have hid cerebral palsy for instance or would have needed quite a degree of physical support / again I suppose they were predominantly kinda younger people and it had been a life long condition /Maist a the folk that were in the sick ward were people who had developed (emphasis in the text) some condition at some later point in their life people had been more physically able, we had one man who had worked maist of his life and had taken a stroke and for some strange reason he had come to L instead of going tae the local cottage hospital / he had worked in the local brick works at W for 20-30 years before I was in contact with him”

So it seemed from this answer that the sick role was defined largely in terms of illness in the conventional sense rather than upon the degree of support needs. Also, one of the defining characteristics seems to have been that they had developed the condition in later life, rather than being born with it.

Q “OK… So that leads me on to saying you have been quite careful to say that this was a very particular experience because of the nature of the patient group, in later places that you worked in L did you have a different experience?”

*A " I hid a very different experience..I hid a different experience on various short occasions during that first year at L as well / I mean above which was known as the sick ward upstairs, which was the locked unit, previously known as the STU special treatment unit : apparently there was a charge nurse known as Smith and it used to be nick named Smith's Torture Unit at one point" (*Researcher laughs at this bit of folklore) *"the STU special treatment it had been deemed as being* nae *an acceptable term so they changed to the sick ward* upstairs. (Emphasis in the text) *So very occasionally I would be shifted if there was a shortage of staff so probably over my year I had done a couple of weeks in the sick ward upstairs and that was a very different experience because you were it was predominantly locked although there were some people who were under supervision all the time they were there as they were deemed as a risk to ithers I suppose and there was a lot of coming and going so.*

Here Lochinvar makes it clear that he has been socialised into two different uses of the term 'sick'. The first, being a description of the development of an illness used in a manner which would make sense within mainstream society. The second usage, more akin to behaviour which would be described as 'Challenging' in modern discourse, might be thought to be mere euphemism; a method of describing with the aid of therapeutic language the process of locking up people who had either broken the law, or had transgressed widely held norms. However it appears to the researcher that this kind of usage was quite consistent with the practice of calling a large scale residential unit a hospital. It seems strange that the category of 'sickness' was so malleable as to encompass both.

Gender, Sexuality and the Spectre of Reproduction.

Particularly in the early period of his work at Lhangbyde Lochinvar worked in high dependency wards, where the patients, because of a lack of mobility, had very little opportunity to interact with members of the opposite sex. Despite this, he had a very clear understanding of the rules relating to contact between the genders within the hospital.

A " there were // nae mixed wards at that point at L at all."

Q " This is in 1981?"

A " yes everything was segregated in fact there were certain areas of the ground that females were not allowed into, certain areas of the grounds that males were not allowed into, and some of the villas I worked in would hae a map on the wall telling you in which parts of the grounds it was acceptable for males to be at and people were in trouble if they were caught in female parts of the grounds. // (Prompt "Rig…ht") *"There was a central area that was mixed that wis acceptable for both males and females to be in but there was a female side and a male side "*

. Q "OK and.. what kinds of sanctions were there if you got caught in a place where you were not supposed to be".

A " Ken.. I wasn't really involved wi that cause as I said it was elderly men that were ill and quite often in the sick ward for the finish of their lives //ehh…so I didn't have a great deal of involvement with younger people that …/ would have been there looking for opportunities tae meet with females. // ehh… things would have been like withdrawal of privileges, privileges like a day oot in B . the mair able folk sometimes I wis workin wi, would have what was known as a parole day in B once a week, and you could lose your parole day if you were caught where you shouldn't have been. /
You could also lose some of your money and that money was based on a incentive scheme / there was payment for, a basic payment, and the payments were worked out by psychologists and by psychology department to try and motivate people and equally punish folk so I suppose there was a kinda basic payment that everybody got / there was work related payment that you got for performance at your work depending on what kind o job you did within the hospital and there was an element of payment for behaviour as well, so people could lose the part of the payment which was dependent on their behaviour."

In following up the efficacy of the sanction relating to 'parole' (A system where selected patients were allowed the privilege of leaving the grounds of the hospital on particular days of the week) it becomes clear that the objective is to cover the eventuality that male and female patients might meet somewhere which is outside the operational control of the hospital. The unspoken risk being that there might be contact of a sexual nature. Geographical and temporal segregation was the safest method of preventing this.

. Q "OK…..and on these….. parole …. could men and women have the same parole day ?"

. *A " men and women were generally different parole days // eh..I think men were a Thursday I'm nae sure when women were but I think my memory was I didna work much wi females, parole was a much mair unusual thing for women than it was for men, it was men that were more looking for parole expecting a parole day."*

. *Q " Why do you think that might be?"*

. *A " Don't know, // I might be wrang / as I didnae work with females, I didna think there was the same interest in I think in a lot of ways a lot of the men were abler at that point a lot of the men that were people that were there through the courts.*

It seems as though there was a predisposition towards thinking that women were less likely to be eligible for parole. It may be that they were regarded as being more 'at risk', or it might be the case that men who came through the court system were likely to be more able, and thus have more ability to benefit from parole.

Q "Alright…/ Can I just ask you a general question about that separation of the sexes which is backed up obviously by a number of rules, / what do you think was the reason for that / why did they want to keep the sexes separate?."

A "I think it was a great fear aboot peoples sexuality / particularly nae si much expressions of sexuality but particularly pregnancy there was a great concern that these folk in L they were ostensibly in health service care and were being looked after by qualified nurses and professional doctors shouldna hae the opportunity to become pregnant"

Q " Right ....OK.... did it ever happen that they did?"

A " yes" (a very fast rejoinder !!)

Q " yeh….and what would happen to somebody who had responsibility for that person that had been found?" (Didn't get a chance to finish the question)

A " Nothing" (Emphatic) *" there werenae any* real *sanctions because I think there was a recognition within the hospital that keeping folk totally apart wisnae possible // realistically they could hae certain rules to try and keep them apart but in practice it wisnae always going to happen the sanctions were much* mair *there for the people who became pregnant than the*

people who allowed (Emphasis in the original text) *them to become pregnant"*

Q "What was it you said…. what sort of sanctions would they be?".

A " Well there was a lot of pressure on people who became pregnant to ehhh…and their families to have an abortion for instance / generally people would be convinced that an abortion would be the only route to go / if folk in the hospital became pregnant wid have an abortion, /
Folk that became pregnant a second time or were deemed to be sexually active after haen an abortion were quite often again persuaded, or their families were persuaded, that they should be sterilised / so still in the 1980's they were sterilising people if they didna want them to become pregnant"

When the respondent used the word 'convinced' he was alluding to an active process of persuasion on the part of the staff to influence individual patients and their families to terminate individual pregnancies, and if sexual activity continued, to use sterilisation to prevent even the possibility of future pregnancy.

Hierarchy and Camaradarie

In this final extract from the interview with Lochinvar the researcher seeks to convey some of the sentiment he expressed looking back on his experience. There were some aspects of life as a nurse within the hospital which he clearly did not regret leaving.

A"I think it is often quite difficult to stop me voicing an opinion I would get myself in trouble wi that at various points. Do you want to hear aboot this?"

Prompt *" Yes, I do"*

.

A "One particular incident, it was nothing to do with the folk we were working wi, we had an air bed which was to prevent people having pressure sores and the idea was certain parts of this bed it was almost like an air mattress / certain parts of this bed inflate and then other parts inflate and the first parts that were inflated go down so it is to rotate the pressure on someone's body if they are lying prone ,some folks who were ill. The charge nurse was the charge nurse, nae the deputy that I worked with, the

man on the opposite shift who occasionally I had some contact with was trying to persuade the nursing officer that we needed a new one and would they buy a new one. I came in fairly late into this conversation to hear him saying "look at this air bed here it disnae really work we have a real problem with it" so I wandered along "it does work a' yiv got ta dee it push this bit here and turn this bit here and it will work awa fine. So in the next few days, I got a bit of a row after the nursing officer had gone that I had the audacity to speak up and explain things to folk that were seen as my bosses"

Q " Right That kind of brings me on to my next question, you said the nursing officer was the sort of middle management was he or she?"

A " Yes"

Q " And would you be expected to speak to them directly or not?"

A " No very very rarely, ehh…up to a point that I stappit spikking and stand up when they came into the room We didn't always it would depend who they were but the expectation was if a nursing officer arrived the nursing staff would get on their feet."

On the other hand there were aspects of his working life at Lhangbyde which he looked back on with some affection

Q "All right, I think I have asked most of things I wanted to ask you about your experience. As a kind of an ending and a general question what would you say was the best thing about working at L."

*A "Camaraderie" (*Questioner echoes *'Camaraderie'?)*

A" yes I am a big fan of community care and I really believe that people should be living independent lives in their own houses, in their ordinary street somewhere, rather than living in a group but, there was a great deal of fun a great deal of laughter a great deal of gentle teasing in all sorts of directions a lot of quite enjoyable sort a times there quite a close knit staff group, lots of strong links with the patients as well, they formed a lot of friendships and a lot of enduring relationships.

Q "Right do you think there were enduring relationships across / between staff and patients and patients and staff?"

A "Aye..There wisnae probably so many ehh… as there could have been or should have been but there would have been some folk took special interest in some of the people they were working with . but you had things

within wards as well I can remember a young lad that used to go up to one of the wards that contained older men and play draughts wi an older man on a regular basis and it is the kind of things that other folk in the community might dee, you might go to an old people home and spend a bit of time playing draughts with somebody that you previously known or regularly. So there were there wis a pleasant kinda feel to it a lot of the times.

In summary, within these extracts from a transcript of the interview with Lochinvar, it is possible to develop an understanding of some of the forces which impelled him towards a career at Lhangbyde. After making the jump from 'the outside' to 'the inside', and becoming a 'provider', he makes clear the impact of routine both relating to time and the nature of the tasks of daily living, including the system for the provision of clothing.. Despite having little to do with female patients, or male punters who might have had contact across gender boundaries, he had a good understanding of the rules relating to gender separation, and the sanctions which might be deployed against those who transgressed them. Despite the rigours of hierarchy and status, Lochinvar was able to identify, and make explicit the nature of the satisfactions which resulted from working as a provider.

By looking at his experience in this holistic manner it is possible to recognise someone who was embedded in the local culture and language who had a well developed ability to appreciate the surreal side of institutional life. He had a good understanding of the nature of authority, and a well developed capacity to empathise with the situation of the punter.

Section 4: Key Informant; Solar

Solar started work as a nursing assistant / student nurse in 1963. She became known to the researcher insofar as she came to work for the university as a lecturer, but during the few years preceding the interview she worked mainly at Lhangbyde, so on the 'pre interview' form there were no particular expectations or close working relationships recorded..

Beginnings, Expectations and Reactions.

Solar was unusual amongst the nursing staff, insofar as she had a pre existing interest in nursing as a career, and saw her application to work at Lhangbyde as a logical method of pursuing this goal. In her early career she worked mainly in wards which were termed 'high grade', so the patients that she dealt with were often fairly able. Her early memories relate to the experience of starting 'at the bottom of the ladder' and of having to go through a period of 'domestic' work before she was allowed to progress towards a more 'professional' role. During the process of learning the essential daily routines of life and work within the ward, she worked fairly closely with people who carried the label of 'patient', but who were also engaged in similar 'domestic' work. In contrast to Lochinvar, she came to the hospital with an expectation that she was taking the first steps upon a career ladder; but she also came face to face with the routines associated with the tasks of daily living. In her case it appeared as though she had to serve a 'domestic' apprenticeship before she was allowed to progress towards a professional role. It is interesting to speculate whether this difference in experience was related in any manner to her gender, but it was certainly true that in the early days of her career she shared the experience of performing domestic tasks in the company of people who carried the label of 'patient.'

> *Q "OK…right…So…Thinking about the first place you worked, you described it as a ward that had 50 women patients, what was a typical day at work for you."*
>
> *A. To begin with it was a 46-hour week. It was four-day 12-½ day shift. It dropped off from that .It was a case of going in, in the morning and emptying the huge milk churns of milk, that were left at the back door; from the farm, they still had the farm at that time at Lhangbyde. My first job was to get the milk from the big churn into smaller jugs, which were still quite big jugs*,(respondent laughs) *I don't know how many gallon that had been, that was my first job, then I had to make the tea, had to spoon out exactly 6 large spoons of tea into a muslin bag into two huge teapots to make for the 50 clients we had. Then it was just get the breakfast things ready. Never saw a face, unless there was someone else higher up the hierarchy of student nurses, probably had started the week before, someone senior to me; they were doing something else. It was* very (Emphasis in the text)

much domestic duties in the first instance, you know for the first few weeks".

Prompt *" OK…So that was the start of day?"*

A (Fast rejoinder) *"I had also at that point patients helping me. The ladies would already be there, and helping me to set out the tables".*

Q *"So the people who had the label of patients, did actually take part in the day to day running"*

A *"Very much so, the four domestics that were employed, they really did do the lot, they did all the work, we worked alongside them, to make sure they were safe, especially with boiling water. They were mostly very sensible ladies anyway."*

Q *"OK, Did any of them go to work in other wards?"*

A *"One or two did….yeah……, maybe more or one or two, some of them went and helped up in the sick ward, with bed making in particular, ehmmm.. working in the other kitchens if they were deemed able, they were employed as a kitchen assistant, maybe in another ward, if the ward they were in had sufficient workers for that area".*

There are two elements of discourse mentioned in Solar's account which made an appearance later in the previous chapter. The first is the notion of 'safety'. Although they were 'sensible ladies' those who were, or were to become, providers were differentiated on the basis of having a responsibility to ensure that those who carried the label of patients were 'safe'. The second element is the first mention of the 'sick' role. It is not clear which of the definitions of the sick role outlined by Lochinvar would apply. One would surmise that it would probably be that relating to very dependent patients.

Parole, Gender, Sexuality and Safety

In her account of her work, Solar first mentions the issue of gender in connection with the organisation of the 'parole' system. This related to the practice of allowing certain patients the privilege of freedom of movement within the grounds of the hospital, or, on particular days, the freedom to travel outwith the grounds of the hospital. Possibly because she worked in a female 'high grade' ward, the issue of safety, i.e. protecting patients from sexual exploitation loomed

large in her memory of the planning and organisation of the parole system; although it is true to say that the rules concerning geographical and temporal separation of the genders applied to the hospital as a whole. Solar goes on to describe how these issues of 'safety' applied not only to punters, but were extended to cover the behaviour of (especially female) providers.

Q "Did any of your patients go into town?"

A"Ahhm…..yes they did. There was ground parole for those who were deemed unable to go out of the grounds. They had ground parole they would go and wander round the hospital area itself, they were capable of that. There were others that had full (Emphasis in the text) *parole it was called where they could go to W or B on a Friday afternoon, after they got their pay…their money but it was every second Friday. They weren't allowed out the same time as the men were allowed out , it was consecutive days.. They weren't allowed out together. It was the same for the ground parole. It were the men who were out on a Monday on ground parole, it was Tuesday for the women. So men and women weren't allowed to wander freely in the grounds on the same day."*

Q" Ri…ght if men and women did manage to meet within the grounds, what happened, what was the significance of that?"

A"Ahmmm…well, they may have had sexual relations or whatever, they weren't trusted to be together, and they were in this place for their safety. It was not very safe for them, especially if they were women, if men had taken advantage of them. Molesting them or whatever terminology you wish. It was a safety *kind of ..; it was for their* safety. (Emphasis in the text)

Q"Were there any sanctions if they persisted in misbehaving?

A"There was sanctions I am afraid, they were, their full parole would be taken from them, maybe for a week or something like that . You are very naughty and won't do that again."

Q"I asked you about 1963. How long did this last really, those sorts of rules?"

A"The rules were mostly in place until I left in 1969. Things were easing up a fair bit by '69. There was quite a change in the philosophy of care, new consultants coming I think, and younger staff. Staff had more say in what they were trying to say. It was very very draconian for the first couple of years in particular."

Q"What about staff was there rules about what you could do and couldn't do as staff, what sorts of things were they about?"

A"Ehmm.. I think that actually… if you lived in the Nurses home, there was as many rules, you had to be in at 10.30 p.m. at night, lights out by 11.00, you were locked in, you weren't allowed out until the night sister came in the morning to unlock the door. We did have a metal hammer to break the glass, for they key if there was a fire. You had to get a late pass for Friday night, you were allowed out until 1.00 a.m. You were allowed out till 1.00 a.m. on a Friday night and 12.00 midnight on a Saturday. Those were the traditional times for the dances at the time. But you had to get up, you had to be up and down at Matron's office at 9.00 in the morning to ask for your late pass for that night.. If you didn't get up in time on the Friday morning to ask for a late pass that night……. if you were to be late you had to report to the night nurse when you came in. You had to report to her and if you were one minute late, your name was in red in the book that you were back late. / matron felt that she was your surrogate while you were a student nurse. It was her duty to protect you from the nasty things in life and making sure you were fit for your work in the morning as well. There was no a problem. If you smoked you could smoke in the nurse's home. We never had any drink, because we never had any money"

But no system of rules and expectations could remain the same forever: change was in the air

Q "So what sort of idea changed?"

A "Ideas, in the way that the patients were being allowed a bit more freedom:. being allowed to sit beside each other in the picture house. They were not allowed. There was men on one side and females in the other side when I started. But there was this slow (Emphasis in the text) *change, but it wasn't easy, but there were still people in senior positions trying to block these changes, saying It will all end in tears."*

Q "What might be the cause of the tears? What could go wrong?"

A "Well, those kind of thing were never actually put into words as such you know. This was the way it has been and this is way it has to be because it is safer this way, we cannot have males and females going off with each other. If you give them freedom their behaviour would deteriorate, but they didn't see it like that. If you gave them freedom, they would go back to do XY and Z. So it was very much contained as safe. It was all to keep them safe (Emphasis in the text)*; they don't allow them to do anything because something might happen."*

Q "Right.. And it was quite hard to specify?"

A "Yes. It didn't needing specified. It was Dr P says and Dr S says and Matron says ,and you don't argue."

Q So there wasn't any need to explain why for example, it was necessary to keep. particularly women safe from sexual encounters, it was simply a given , and it wasn't something where you asked the reasons for it."

A "No, and you would be questioned on it every day"

This was indeed a very powerful form of social control, so powerful that it did not need to be made explicit. It didn't need to be specified, and you don't argue. You would be questioned on it every day. The definition of the term 'safety' which Solar learned was widened to include a very general form of all encompassing responsibility which required that providers exercise the utmost vigilance at all times.

Q "Did you have any ideas in your own head, what was behind the idea of keeping people safe? What were they frightened about?"

A "I think one of the things was they were frightened in letting them out in the town in case they frightened other people, they were frightened to let them out in case you were run down, they were frightened to give them any freedom at all , it was a weird kind of thing that they had this responsibility for these kind of people, and they had to keep an eye on them; they had to be vigilant. That was the kind of terminology that was used. It was very much like a prison like atmosphere, but not punishing them .It was never done in my area, as a form of punishment. It was always meant to be some sort of a safety measure and we were responsible for these people."

Q "Right, OK, Do you think that there was any question around a concern that they might reproduce?"

A "Ehmm…Yeah that would have been…that was all the part that they were not allowed sexual relationships that would have been absolutely horrific if any of our female patients had conceived by a male patient in particular. That would have been just….. Heads would have rolled ..Ha Ha…. the Sister in my ward, her head would have rolled if any of her ladies had got themselves pregnant with a male patient."

The extracts reproduced above give a sense of the strength of the socialisation process undergone by Solar in becoming a provider. The use of the word

'horrific' to describe sexual activity which might result in conception; and the absolute injunction to prevent punters being 'interfered with'; this being the case even if the woman in question might be enjoying herself. It seems as though the responsibility to promote 'safety' constituted an absolute and unquestionable imperative.

Changing Times and a Changing Ethos.

Turning to the her experience of working at the hospital over a long period of time, and the forces that led to change, in answer to a question about turnover of patients, Solar made a distinction between movement of patients out of the hospital and movement of patients within the hospital which resulted from the provision of new buildings in the sixties and early seventies.

> *Q "And a kind of a last question about your experience of the patients, did people move on from Lhangbyde: was there a turnover?"*
>
> *A " At that time there wasn't much of a turnover. There was a lot of moving (Emphasis within the text) of patients because of the new buildings. In terms of moving out into the community; no"*
>
> *Q " And when you say moving, the sixties. This was the time when the hospital moved out of the main building and into the villas, , that went on until …….?"*
>
> *A "1974, the last buildings were opened in 1974. They were an addition; they were three within the ward. When I started there was the Eden and Boyd, Devon,* (Pseudonyms) *was just about to open, and that is where Jane went to, she was in the one next to me where she started. There was still a lot to be built up. The bit, the main building, the main hall, main kitchens, all the central training areas, there was a heap of buildings."*
>
> *Q "Was that seen as a great improvement on what had gone before?".*
>
> *A "Yes very much so, because it was light, huge modern buildings compared to what there was, . I think in terms of just the space and staff, new occupational therapy department there was lots of things going on with more entertainment. The whole place did come alive for a while there was lots of good ideas. In terms of giving them a fairly decent life within the confines."*

Q "So you were saying that it was quite a period of change not only in the buildings, along with the change in the buildings came some changes in Lhangbyde

A "Yes I think there was some changes in ideas, the place had grown so quickly, new blood came in, the surrounding area alone could not cope, staff came from a wider area, and the whole place was opening up to people who could see a career. So I think that opened up the whole scene. The whole ideas changed."

In summing up her experience of the strengths and weaknesses of Lhangbyde, Solar makes the link between the hospital regime and the norms of the wider society. In describing the advice that parents and relatives received she implies that there was little choice involved. The advice was a function of the moral outlook at the time, which valued protection and safety over and above choice and human rights. As a member of staff she accepted the fundamental outlook, but attempted to curb the excesses of the institution with the aid of some 'quiet advocacy'.

Q "Before I sort of ask my last questions, is there anything which you think is important that I haven't asked about? Something it would be important for others to understand if they were to understand what Lhangbyde was like? Which for you was the sign of the times, the fact of the atmosphere or whatever?"

A "The thing at the time was morality at the time was the thing that kept the men and women apart. Some of the women had come in there for the simple reason. Some of the women had come in at the time because they had an illegitimate baby. That was all in their case notes. ' Feeble Minded', 'Illegitimate birth'.. There was a lot of that. A lot of morality a lot of society's beliefs, they were safe at Lhangbyde. A lot of parents put their relatives into *Lhangbyde so they* would *be safe. They had been* advised *that this was the best place for them, and we had to make sure that it was the best place.* (Emphasis in the text)

Q "So for you, thinking back about your experience, what did you think was the best thing about working at Lhangbyde?

A (Nervous laughter) *"Ehmm ..I think you were allowed to care for people to a certain extent, I think it was good for me that I could be a very sort of quiet advocate for a lot of them gradually over a number of years. I stood up for them many times. I think that one of the worst things I found was the*

absolute lack of dignity afforded to them. I thought…. a lot of the times I thought I eased that: I ensured that they had privacy and toilets and the baths, and things like that. I did not know what I was going into, it was an utter absolute shock. When I saw it I was only seventeen. It took a long time for me to be able to make changes."

Q "What was it, that was a shock to you?"

A "I think the biggest shock was the lack of dignity, the lack of privacy, the lack of sorta basic human rights to go out the door and have a walk."

In summary, Solar came in from the outside world as a very young woman. She had to serve a 'domestic' apprenticeship before she could aspire to the professional role. She soon became very aware of the strength and ubiquity of the injunction to promote 'safety'. This was so universal that it applied to (particularly female) staff, but she was able to see the links between the rules of the institution and the norms of the wider society, and the expectations of the family and friends of the people who had been admitted. Her satisfactions derived from 'quiet advocacy' on the behalf of patients, and because of the length of her service she was able to experience the benefits to patients of changing times and a changing ethos.

Section 5: Key Informant; TopDoc

TopDoc had first worked at Lhangbyde in 1984 for a six month period as part of his training to be a psychiatrist. He took up a full time post at the beginning of the 1990's, and remained until its closure in 2003. On the pre-interview form, it is acknowledged that the researcher had acted as a facilitator to a person with learning difficulties who sat on a joint planning committee. TopDoc was a member of this committee, so the researcher knew something of his views on the transition from hospital based to community care. The wife of the researcher had worked more directly with the respondent on matters relating to the planning of services for individual punters.

His approach to the telling of the story of his work was fundamentally different to that of the nurses who tended to relate their reasons for going to work there to pressures in their wider life experience. TopDoc framed the story of going to work purely in terms of the training and education which he required in order to to follow the path of becoming a qualified and experienced psychiatrist. Similarly, when describing the nature of his professional career as it unfolded, his discourse was mostly confined to such matters as the diagnoses which applied to the patient groups he was describing, or the policy issues which arose at various periods of time. Perhaps because they were in constant face to face contact with punters throughout their working lives, nurses tended to focus more upon the dynamics of interaction with punters, and the effect that this had on their own concept of themselves.

Routine and Hierarchy

> *Q "OK, Can I first of all pick up some of the things you mentioned, because they were of interest to me. One of the things that you said there was that hierarchy was really quite important, and that it sort of made an impression on you that it was important in the hospital. What sort of hierarchy was it? Who was in it?"*
>
> *A "Well putting it in context, I had been in… I had worked in Queenstown as well as working in Wheatside,(*pseudonyms) *and you heard about how things used to be in the good old days if you like, from more senior colleagues: I suppose doctors and other staff were treated as being very important people; I hadn't actually[laughter] experienced it until I went to Lhangbyde where Dr Scott* (Pseudonym) *was the physician superintendent, did his weekly visit and it was eh… quite an event when Dr Scott, and I suppose I was part of his entourage, I was a doctor, arrived on a Tuesday, and there was a set sort timetable for what would happen, and ehh… going up for lunch in the dining room .There was a set table for doctors, there was a set table for other groups, there was a set table for other people; I had not come across that at all before.*
>
> Prompt *"Thank you"*
>
> A Respondent continues *"I had heard about it, but I had never come across it at all"*

Q Alright, "OK. You have mentioned kind of hierarchy in the medical side; was there a similar hierarchy in the nursing side?"

A "Yes….. absolutely you knew who the head nurse was, and what the different layers were…"

Clarification *"There were a number of layers were there?"*

A "*Yes, as I recall*"

Q "At that time was the head nurse called Matron, or had that changed by then?"

A " Yes it had changed by that time. It was a male nurse who was…..I can't remember the terminology ……. he wasn't called Matron, it was nurse manager or something along those lines.

Q " And also you painted a little word picture of Dr Scott's Tuesday visits and that you were part of the entourage. Ahmm…What sorts of routine? Would it be a sort of ward round type routine? Was that the best way to characterise it, or would there be a better way to characterise it?

A "Well ward round was part of the routine. I can remember very clearly that upon arrival coffee was served in one of the rooms, and whilst one's coffee was being served, that was when various informal discussions took place. More general chit chat more than anything else. Then it was off to the wards to start work, and then there was the lunchtime when everybody gathered and as I say there were set tables....

Q " Did you form any impression, either in your early days or later, about the nature of the routines; the daily routines in wards and so on. Did that make an impression on you or...../// was it not *something that you thought about?"* (Emphasis in the text.)

A " Well, since going to Lhangbyde in '92, I think there was a big *difference.* (Emphasis in the text) *I think there were set routines in 84.... that you had to get up at certain times, and do certain things, everything was very...time ruled.....everything had to be done at certain times. Whereas over the past ten years or so the regime if you like was much more flexible, and the system if you like was looking at what the individuals needs actually were, and how best to accommodate them. Numbers were less of course within the hospital in the last ten or eleven years compared with eighteen years ago; yes , there has been quite a drop.....Five to six hundred. 570 was the maximum number; but when I started it was probably down around 350, round about there. So there had been quite a drop, maybe not quite such a big drop as that .. but between 350 and 400; so there had been a big drop since from 8 years previously."*

Thus, on the part of this respondent, there was a memory of encountering when he first went there, a very formal pattern of work organisation. He describes the feeling that doctors were regarded as very important people, and that the structure of the organisation of work revolved around their professional needs. Such professional endeavour took place within a context where daily life for punters had been very much governed by a strict routine in the past, but subsequently the reduction in numbers had enabled the development of a more flexible approach.. One indication of the nature of working relationships within that hierarchy can be derived from the language used within day to day communication.

Q " Moving on now, you talked about formality before. When you first went to Lhangbyde, if you were addressing a patient, how would you address them, what would you call them //// would it be their first name, Mr or Mrs or…..?"

A " No it would always be by their first name, unless anybody specifically said, don't call me that, call me something else"

Q "Alright OK…since you have said that ehmm , amongst nursing staff certainly there were a lot of nicknames. Would those have been used in your contacts with them, with the patients, or would that not happen at all?"

A "No I did not use nicknames at all, again some of the patients for whom nicknames were being used were on the whole not in a position to say call me this or call me that but don't call me whatever [Interjection "Right"] its quite interesting though that even towards the closure of Lhangbyde, meeting with relatives, prior to patients being discharged, prior to IPP meetings or whatever, would call someone that we called Billy in the hospital William. That's not uncommon I suppose, but if that individual would rather called William then we should call him William I suppose. But these sorts of things just developed over the years, I suppose.

Q "In terms of relationships in the other direction, what would the patients call you, if they addressed you?"

A "They would call me Doctor A to my face, sometimes there was some other abusive terminology, but that was unusual"

Q "Thinking about staff to staff , in your relationships with staff, would you call them… well how would you address them.. how would you address a member of the nursing staff?"

A "It would depend on the circumstances of where we were meeting I suppose, and who else was involved but on the whole I think that I call most of the nursing staff by their first name"

Q "So you wouldn't call them nurse Smith or whatever"

A "No"

Q " And the other way round, how would they address you?"

A "Well that varied some .. they would one way or tother.. but some insisted on calling me Doctor A .. some would call me by my first name. Again that varied; it depended on the context of the meeting I suppose"

The respondent paints a picture of a world where relatively formal relationships were the norm. One gets a sense that although the medical staff may have functioned within a professionally defined context which was distinct from the everyday life of the ward, they retained an affinity with the community of the hospital as a whole, perhaps acting as a point of reference for that community which influenced the overall policies and direction of the hospital.

Definition of Learning Difficulty and the Sickness Role.

The respondent, in line with his commitment to the professional diagnostic responsibilities of a medical practitioner, in telling his story saw it as important to relate how a number of people who did not fall into the category of 'learning disability', had come to live at the hospital. In answer to a question that had not been asked, as an addition to an answer about the number of patients who lived at the hospital when TopDoc worked there, the respondent made the following observation:-

A "An awful lot of people who had been in hospital in '84 of course didn't have a learning disability at all. They had all sorts of social problems, nothing particularly current but they didn't actually have a learning disability"

Q Right.. OK since you brought that up, can I ask you ... I mean.. one of the processes that took place in Lhangbyde from when it was designated as a Mental Handicap Hospital .. the planning was done in about 1951, or at least the transition happened about 1954 / 55. Did you think that there was still some remainders of people who had perhaps a psychiatric disorder rather than a learning disability in your time.. or had that gone past.?"

A " By 92 ?"

Prompt *"Yes"*

A " I think that by 92 the vast majority of people without a learning disability….. but maybe not particularly bright, or with psychiatric problems or personality problems or social problems... I think that most of them had certainly ehh...left the service and had gone elsewhere. A lot of them still got support"

Clarification*: " So to summarise what you are saying, you think that from 84 to 92 you think that there was quite, if you like, a lot of work done on getting people who were not really appropriately placed in a learning disability hospital off to other provision, or out to the community?"*

A "Yes…Yes"

It looks as though this description of the sorting the 'wheat from the chaff' was a bit of a precursor to the later process of preparing people for the move to community based provision, inasmuch as it was seen by the respondent as important to be clear about the function of the hospital and the diagnostic categories which it was equipped to deal with, in order that the choice between accommodating and treating people within a hospital setting, or moving towards community care could be made on the basis of clear and unambiguous diagnoses. It is clear from Chapter 4 that Lhangbyde had always accommodated a mixture of people with a learning difficulty and people who had mental health problems. The respondent seems to be describing a determined effort to ensure that those who did not have a learning disability (using the terminology of the

respondent) were discharged from the hospital. The fact that he uses the phrase “Not too bright” would seem to indicate that his primary indicator of learning disability revolved around the measurement of IQ. Such an indicator would seem to provide a clear boundary between those who fall into the category and those who don’t.

Another important element of the story of the respondent’s work concerned the so called ‘forensic’ category of patients; i.e. those patients who had been sent to Lhangbyde by the courts. The admission, monitoring and regulating of the hospital careers of these patients, including the arrangements for their eventual transfer or discharge, was a major part of the consultant psychiatrists’ role.

> *“ I can also recall though my ehh.. I suppose dread would be the right word, going into what was termed the… eh was it the … S…?..... .STC or whatever it was …”*
>
> Prompt *“STU I think it was”*
>
> *A “Yes that’s what it was, yes, because that was an old block, upstairs and the atmosphere, environment eh.. I suppose the staff as well to some extent, the way the staff were dressed, it eh.. did not lend itself to being regarded as a particularly pleasant environment at all. Not for visiting”*
>
> .Prompt *“OK”*
>
> *A* (Respondent carries on) *“so if it was not a particularly pleasant for visiting, I am pretty sure it wasn’t particularly pleasant for working in or living in”*
>
> Prompt *“OK”*
>
> *A “ I can remember that ward very clearly indeed, some of the people who were in it too”*
>
> Clarification *“People who were patients?”*
>
> *A “People who were patients”*
>
> *Q “ Alright... to change tack totally …… when we talked earlier on about what you termed the forensic ward and the sick ward upstairs and downstairs, that brings up a notion about being sick (Emphasis from the*

questioner). One of the things that always interested me about Lhangbyde was that people in a place which was called a hospital , would differentiate between people who were sick, and people who were not yeah. Ahmmm… so /// who fell within the sick role; you talked about the downstairs sick ward.

A "The downstairs sick ward was really a // hospital in the most general terms I suppose in that it was a ward for people who lived in a hospital but obviously had some sort of physical ailment, whatever it might be that required some more intensive nursing or medical input, and they would go into that ward. I would say that the other folks in the hospital, certainly from '92 onwards, maybe a wee bit before that, were in hospital because number one they had a learning disability, and number two they had some sort of associated problem, be that psychiatric illness, or be that some sort of challenging behaviour that was presenting such difficult problems where they had been living, at home, or wherever they had been living before they came into hospital. That was why they were there. Prior to, or going back to 84, again there were certainly a large group of people who would not now be deemed to have a learning disability; who were social misfits, personality problems whatever it might be, that perhaps it was deemed appropriate in years gone by that they ended up in Lhangbyde hospital rather than in prison or in [local psychiatric hospital] *or wherever.*

Here the respondent seemed to be making a generalised point about the difficulty of drawing hard and fast borderlines: he recognises that the 'sick ward downstairs' constitutes that part of the institution which constitutes what would most generally recognised by the world at large as a 'hospital'; i.e. a place where illness would be treated. The admission criteria for entering 'the sick ward upstairs' should have presented an opportunity to delineate a firm borderline, based on forensic or legal considerations, but it is clear that he sees an important part of his professional role in terms of the provision of a gate keeping function which has an objective evidence base as its' foundation.

Sexuality and Reproduction: A Management Perspective

Q " Right... and were there any sanctions if particularly males were caught in female parts of the hospital.?"

A " It depends what they were doing I suppose, but if they shouldn't have been where they were then I daresay their would have been some sort of sanctions imposed" [interjection OK] and the chances are that, if there were males at that time, in places where they shouldn't have been, they

would have been the more able, and I daresay those who probably didn't have a learning disability who were getting up to those sorts of tricks"

This exchange followed after a section of the interview which examined the extent to which the genders were separated within the hospital. It became clear that TopDoc felt that one of his functions in relation to the governance of the hospital was to oversee a system of monitoring which ensured that patients, particularly the female patients, were not abused by other patients.

There are echoes here of Wolfensberger's (1972) notion of the person with learning difficulties as a 'Holy Innocent' insofar as if they were 'getting up to these tricks' then there was good chance they didn't have a learning disability in the first place as defined by the respondent.

.Q " OK, then that moves on a bit that ehmm…. that the question about gender sort of phases into a question about sexuality, and rules about that. You just said, just now that there were some ..... obviously…..male s..... presumably both males and females who had interests in that area as it were. How did the hospital deal with that as an issue..... early on ?"

A " Early on? You mean ... I can only really only speak about the last few years. I've been aware, again through looking at notes that there have been issues in the past where usually relatively able males have perhaps taken advantage of less able females, and that has led to the police being involved... approaches to the Mental Welfare Commission.... the usual sorts of procedures being gone through and looking at imposing some sort of regime that will prevent that particular male having access to more vulnerable females again. That being said though, there was obviously a group of both male and female patients who were in a position to give informed consent to having a sexual liaison, of some description; and I'm in no doubt at all that sexual relationships did take place between consenting adults if you like. Those deemed to be able to give informed consent. And as long as that was happening, and nobody was upset by it, and they weren't doing it in the wrong place; they were doing it in private, and everything seemed to be alright, and appropriate precautions were taken regarding the contraception and so on, then that, I suppose, was regarded as being acceptable within the hospital {Indistinguishable word}.

Q "Carrying on from that a little; were there any established couples amongst the patients in your memory?"

A " Before my time once again , but I think a couple did actually got married. There were established couples in that... it was a very small group

of females, I have to say who seemed to vie amongst themselves for the top male if you like, if it wasn't the top male it would be a group of males, young males, for whom the females would be vying for the affections of . That was some sort of ongoing competition that was certainly present throughout the time I was at Langbyde, up to the close almost. I am sure it was going on for a long time before I ever arrived.

Prompt *"OK"*

A " As long as nobody came to any harm, and they were deemed to be able to give consent to that sort of relationship, and they were doing whatever they were doing in private... nobody was coming to any harm.. fair enough. There were obviously courses for sex education and whatever, and certainly those who deemed able to benefit from that course would accordingly go through a sex education course"

The respondent in telling the story of the complexities of monitoring and regulating the expression of sexuality, seems to be adopting a fairly mainstream liberal position of freedom to act as long as there was informed consent, and no harm was being done to others. This goes against the stereotyped view of a hospital setting committed to the of regulation of contact between the genders almost for the sake of regulation, which would have the effect of ensuring that such contact did not take place. One can distinguish the existence of an almost biologically based metaphor of the females vying for the attention of the dominant males, but this was combined with a recognition that sexual feelings and relationships are an inevitable part of life, and that the key function of those who were monitoring and regulating that interaction was the avoidance of exploitation.

Overall Views and Changing Times

In asking TopDoc to look back upon his time at Lhangbyde it is important to understand his perspective and reiterate that he, in common with other providers who came from a medical or psychological professional background, described their starting point in fairly instrumental terms, i.e. not in terms of their personal life situation at that moment, but much more in terms of the development of their professional career.

Q "OK. Thinking about the earlier post first, what led you to work in Lhangbyde; what were your reasons for going there?"

A "Mental handicap at the time ….. that was the terminology….. was part of the psychiatry training programme, I had six months learning disability, mainly because, it was something I hadn't had much experience with, something I felt it would benefit my overall career"

When talking about their initial encounter with the reality of daily life at Lhangbyde, those providers who were nurses tended to talk about the overwhelming impact of the institution, or the experience of coming face to face with so many disabled people. Perhaps it is the case that doctors, who although they were closely involved in care planning, did not take an active part in the routines of day to day care, were able to adopt a more detached perspective, which focussed upon the structures and the organisation of the hospital, rather than the impact of individual patients, or collectivities of patients.

Q "Its hard to do, but thinking back to the first time you set foot in Lhangbyde were your expectations sort of challenged or changed by the experience of working there ?

A /// "What I can recall is the friendly atmosphere that there was there . I can also recall very vividly the ehh… /// the staffing hierarchies that were still very obvious there, but I can also recall certainly the patients with whom I was involved… the wards that I was involved with. They too appeared to be relatively happy with their lot, and the community spirit; I think those were the main recollections that I have of it"

The respondent also had quite distinct views about the nature and direction of change within the hospital

Q " OK while you have been talking you have been alluding quite a lot to change, if you could think about the biggest changes that have taken place since you first saw Lhangbyde in the eighties, what would they be do you think?"

A " // Well the biggest change would have to be the reduction in numbers over the years; I think with the reduction in numbers and perhaps.. more… money being found, certainly for a period of time, the quality of life for patients living at the hospital, I think did improve. Quite markedly"

Q "Right.. OK.. I'm trying to think about that process of change and the numbers coming down and so on ahmmm…When I've talked to other people they have characterised a change of emphasis in the institution, that in their early career the institution was interested not so much in throughput, it was interested in getting people into the system, and fitting them into the system. And then it was in later years that they became more interested in them being discharged from the other end. You distinguished just now that the forensic people tended to be in and out, but maybe others were……"

This question was more of an invitation to dialogue than a neutral question: it was building on what had gone before in the interview, and what had been derived from interviews with other respondents. Although it might have been thought to be leading the respondent towards a particular view, it is the belief of the researcher that the respondent was quite capable of putting his own interpretation upon it, and providing a unique insight into the nature and direction of change within the hospital ; in particular pointing to the fact that, despite the positive effects of falling numbers there might be a potentially deleterious effect of the process of change, in itself ,upon the day to day lives of punters and providers.

A "Yes but even in that area, the turnover wasn't there that great, but I would argue that I don't think there was … well has been a … latterly towards the rundown there was a rush (emphasis in the text) *with regard to discharge, but there have been maybe two or three phases of a lot of people being discharged and a lot of time in between where there has not been any sort of change at all. And I really do feel that quality of life did improve within the hospital in all sorts of ways for the patients maybe over the last 15 years as the numbers did begin to drop but as more money was made available , and I suppose that attitudes did change as well, with care in the community being proposed , an awful lot more work did go into people spending more time in the community, but I think it gave the patients a better quality of life in the hospital; there was more time .. we could always have done with even more time, but there was certainly more time to spend with patients…more OT* (Occupational Therapy)…*more physio.. more of the sort of PAMs* (Professions Allied to Medicine) *approach as well. Compared to, I would have thought going back 30 years or so the attitudes of staff had effectively changed as well, inasmuch as 30 years ago it would have been more of a custodial type set up, and those attitudes had changed over the past 15 years; it had been more of a .. on*

the whole.. more of a therapeutic type set up, looking at the needs of the patients and trying to meet them within the resources available"

Q " Ok.. I'm coming towards the end of the interview now, so if I am seeking to understand what it was like for you to work in Lhangbydee is there anything which I haven't asked about which is important?"

A "\\ Nothing that springs to mind"

Rejoinder *" OK"*

A " All I would say is that I did find it a very enjoyable experience, for most of the time. I have to say though that the manner in which the hospital closed or came to a close, and all the hassle around that. Other hospitals have closed elsewhere, and we did not seem to learn from others experiences; it is just the nature of closing hospitals; I do feel that patients, staff everybody, parents relatives , it could all have been done very much better, because we had plenty of time to think it through.. And I think over the last couple of years of its life it was not a particularly happy place to be working in, and I don't think a particularly happy place to be living in either, because there was still an awful lot of uncertainty hanging over staff and patients as to what their futures were going to be.

Q "You have answered a question I was going to ask about negatives; if you look back on your experience of working at Lhangbyde, what do you think has been the best thing about it what have you enjoyed most?"

A "I've enjoyed working with patients, I mean that's what I really *enjoy doing* (emphasis in the text)*; I have to say that more and more of my time was taken up with the politics and business side of things, with less and less time to see the patients. But I really did……do enjoy working with the patients and with the staff of the hospital too. All the staff, the nursing staff, .and everybody else overall….. on the whole I felt there was a…….. we've come back to the community spirit.... there was a good family type atmosphere there…. it helped everybody to live there and work there.*

Prompt *"OK"* {In an ending tone of voice}

A "Maybe I am looking through rose tinted spectacles, but it's not that *long ago .. that I really* did *feel that on the whole that it was a* very *nice environment…."* (emphasis in the text)

Prompt*; "Yes I think…."*

A "For an Institution",

In this section the respondent, in telling the story of the changes makes an important point about the varying pace of change. It seems that rather than there being a steady and progressive movement towards de-institutionalisation, the process took place in the form of a number of phases, varying from a high degree of change to none at all. In his view the declining population of the hospital made it possible, at first, to provide a much improved quality of life for the patients. He contrasts this with the final phase , where he describes the deleterious effects of the movement towards community based care upon those patients and staff who remained within the hospital towards the end of its working life.

In his final responses to a totally open ended question, the respondent is perceptive in identifying one of the key dilemmas underpinning hospital based provision, in that it is indeed possible to provide a place for living and working which promoted a 'community spirit' and a 'family type atmosphere', but that the cost of such provision is that it inevitably takes place within the context of an 'institution'. In a later chapter the nature of these costs, and the implications for the institutions which have replaced the hospital within the care system for people with a learning difficulty will be drawn out.

Section 6: A link to 'Recurring Themes'

In this chapter the emphasis has been upon providing extracts from the transcriptions of interviews with three key informants with the aim of providing a holistic account of their description and analysis of their working life at Lhangbyde. Although they covered a variety of content, with the aid of a variety of forms of discourse; and although the emphasis was upon the unity of the individual's experience, there were clear parallels with the recurring themes extracted from the totality of the provider interviews.

In figure 8, the common explanatory themes which have emerged from both chapters 5 and 6 have been drawn together and expressed in a diagrammatic form. Within this diagram there are explanatory themes which emerged from all

of the disciplines within the respondent group.. Although chapter 5 concentrates upon common explanatory themes and chapter 6 turns the spotlight on a limited number of key informants, the *content* of the findings which emerge is similar.

The diagram seeks to describe, in a concrete form, the processes involved in entering, remaining within and eventually leaving the institution. The berths within the harbour represent the spaces within which punters were accommodated or confined. In some cases these places were explicitly topographically defined, such as the boundaries between the male and female areas of the hospital, or the distinctive 'sick' wards (both 'Upstairs' and 'Downstairs') Sometimes the places that punters inhabited were conceptual for example whether they exhibited 'challenging behaviour', whether they participated in the hospital economy, or whether they were in need of special protection. Sometimes conceptual categories, such as 'grades', actually determined the naming of the spaces within which people lived; see for example the terminology describing high grade and low grade wards. Such distinctions led to disputes regarding assignment to alternative grades such as the wish to attend the high grade party.

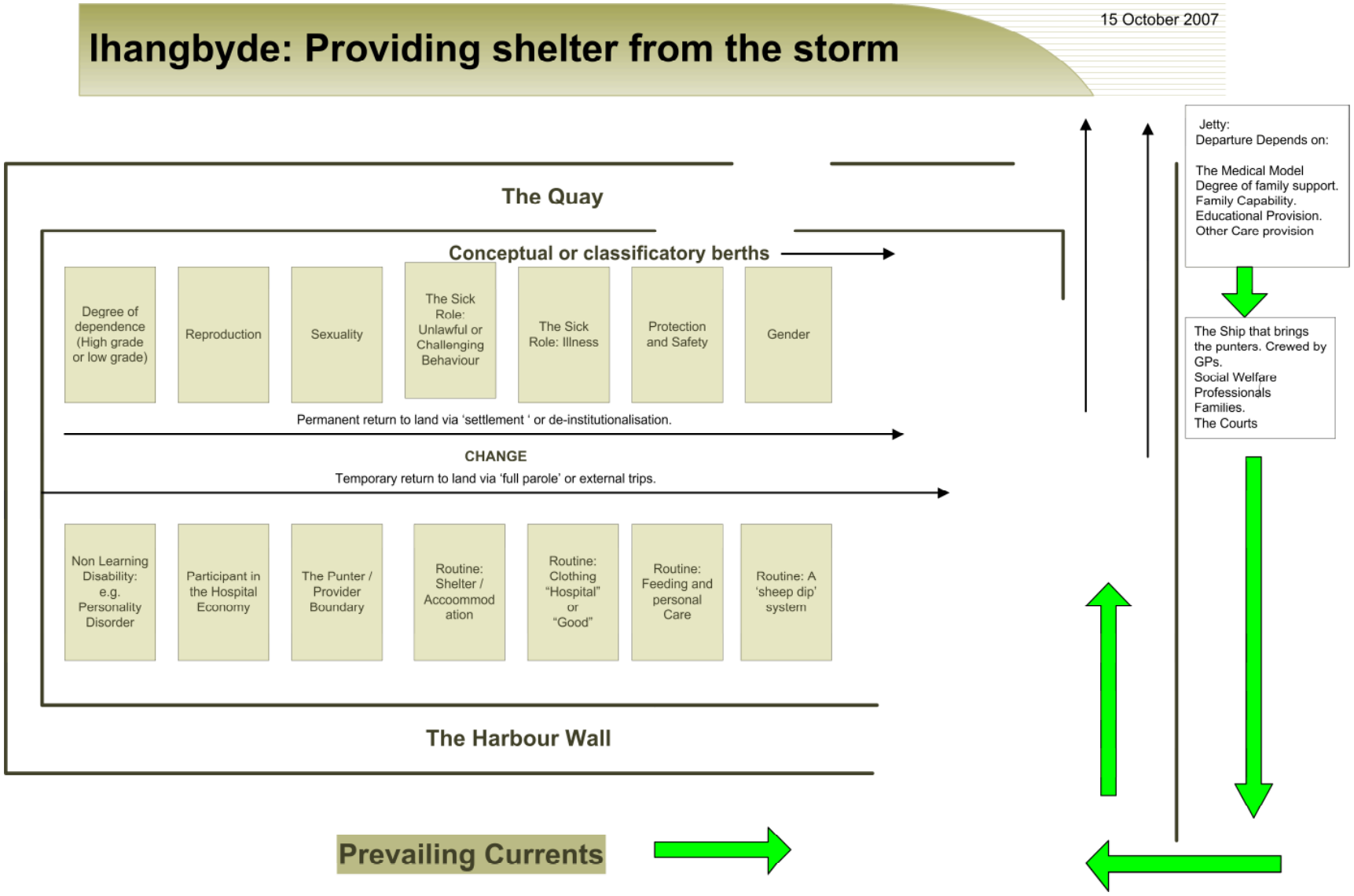
The dynamics of entering the institution are represented by the fact that the level of support from other institutions such as schools or families affected capacity to survive *outside* the institution, and the influence of certain professional groups on the decision to apply fro entrance to the hospital was crucial. There *was* scope for temporarily leaving the confines of the institution via the medium of 'ground' or 'full' parole. However final departure from the institution depended either on individual 'rehabilitation' or later at least upon the closure of the hospital.

The metaphor of the harbour as a provider of shelter fits in well with the cultural background of many of the respondents, both punters and providers. The diagram seeks convey both the separation and the connection of Lhangbyde as

an institution to the wider world. It also seeks to illustrate the fact that, for a long period, the inertia that derived from prevailing currents of orthodoxy, took it for granted that the hospital was the right site for both treatment and rehabilitative efforts. The prevailing currents on the sea of life tended to drive travellers back towards the mouth of the harbour. It shows finally that the movement for a return to the wider community via settlement and de-institutionalisation gathered speed, and led inevitably to the closure of the hospital, and exit of the punters via the landward side of the harbour.

There might be a case for saying that the metaphor of ‘refuge’ remains and a large harbour was simply replaced by many small ‘marinas’, but that may well be a suitable focus for future research.

Figure 8: Lhangbyde; Providing shelter from the storm.



Chapter Seven : Punters Tales

“I never said anything in hospital because there was no point. Nobody listened, so why speak? If you spoke they told you to shut up, so I stopped saying anything. I didn’t talk, it was a protest really rather than anything else. I only said two words
‘yes’ and ‘no’, and mostly I only said ‘no’.

Mabel Cooper
Brigham, Atkinson et al 2000 P22

“Although we are people with ‘learning difficulties’ we are no minors. We want to show out in the wide world. We do have an aim in our lives. We hope to be seen as equal freeman of the world”

Roets and Van de Perre.2004. p57

This chapter is structured in 12 sections.

Section 1: Introduction; finding the respondents.
Section 2: A profile of the punters.
Section 3: A profile of the group.
Section 4: Identifying themes from the group.
Section 5: Activity.
Section 6: Relating to others.
Section 7: Contact with Professionals.
Section 8: Sexuality and relationships
Section 9: Having a voice.
Section 10: Negativity and small mindedness.
Section 11: Overpowering.
Section 12: Emotional Impact.

Section 1: Introduction; finding the respondents.

The purpose of this chapter is to describe the effort which was made by the researcher to enable punters to tell their story, and to offer *their* description and explanation of their experience of being defined as a person who has a learning difficulty. It is well documented that Mabel's experience is not an isolated one, and is not confined to institutional settings: it is much safer to live up to the wider society's expectation of you, to fix the 'handicapped smile' upon your face, and present a passive image to the world (Sinason 1992). In chapter 2 the origins and aims of the self advocacy movement, which seeks to offer an alternative outlook, and to enable people with learning difficulties to speak out, has been set out (Williams and Shoultz 1982). This movement has been the progenitor of a critique of research carried out by non disabled people (Apsis 2000) and has led non disabled researchers to give thought to the manner in which they can facilitate inclusive research, which is driven by values including social justice and the redressing of past and present wrongs (Walmsley 2004). This activist stance will be considered later; however the aspiration of this chapter is to provide an accessible and transparent conduit for the expression of punter description and explanation of their experience. To this end the format of the discussion group, which commenced with a totally open question, and then followed through the themes which were raised, allowed respondents to bring in 'vignettes' (Hughes 2002) such as the story of the psychiatrist at the door. It enabled respondents to relate personal stories which were complex and highly emotional. The aim of the discussion group was not to answer pre-determined questions, or even follow an interview outline. The intention of the researcher was to start from as open a question as possible, and then to follow through the threads of issues which had been raised, thus enabling punters to use stories from their own experience (Fontana and Frey 2003; Wengraf 2001) The use of such a narrative approach also facilitates and reflects resistance on the part of the punter to the dominant metaphors which are present in professional discourse within health and social care. (Perez-Botella and Downe, 2006)

The researcher had worked as an honorary adviser with a self advocacy group over a ten year period. The primary purpose of the group had been to enable local people who had been defined as having a learning difficulty to have a voice in the planning and provision of services. They had sought, and had been given, a place on the group whose task it was to implement the national strategy (Scottish Executive 2000) for moving towards community based provision. The local authority had also developed a learning disability forum in order to inform the planning and delivery of services, and the group was actively involved in the administering and running of this forum. The members of the group mostly lived independently, or with their families of origin; and so the group developed over time, a social function. They ran their own social club in co-operation with a local ex-servicemen's organisation, and they also initiated their own social events for fund raising purposes.

The development of self advocacy skills took place over a long period of time. When the group first started, the members had not been accustomed to having much say in making decisions, both routine and strategic, about the direction of their own lives. (See 'Intimate Narratives' in Chapter 7, particularly the tale entitled '*Trouble in Store'*). It was only later in the development of the group that the members began to develop the confidence to seek a voice. (See the narrative entitled *Tactics*).

The researcher attended a committee meeting of the group, and sought their assistance in undertaking the research. The group were enthusiastic, and saw the research as an opportunity for people with learning difficulties to express directly their experience of living in the community.

Section 2: A Profile of the punters

In setting out the findings which are to follow, the researcher is conscious that they tend to focus upon the meanings that various punters have attached to the past and present experiences which they have undergone. The form of data gathering within the discussion group gave a sense of an unfolding narrative. At the time of listening to, and then transcribing the narrative, the researcher found himself wondering whether the people who were telling the story could be properly defined as having a learning difficulty. Perhaps this thought constituted the residue, in his own mind, of a definition of learning difficulty which is based upon Intelligence Quotient and contains an implicit assumption that a measured deficiency in cognitive intelligence carries with it a lack of facility within other areas This profile will concentrate upon a potted history of their life experience and how this led them towards the group. They had all been characterised by educational, health and social care professionals as being in need of specialised provision as a result of a perceived learning difficulty. In reporting the findings of 'Provider' interviews, for reasons of confidentiality, it was decided to give the respondents pseudonyms which were chosen by the researcher and related to his perception of their history and their roles at Lhangbyde hospital. With regard to the 'Punter' interviews with members of a self advocacy group it was decided to ask them to choose pseudonyms for themselves. The nature of these names may have significance for the individual respondents, but the researcher did not enquire as to the *nature* of that significance for the individuals concerned.

Bob is in his mid twenties, grew up in the area and went to the local academy, where he was placed within a specialist unit within the school. He acts as secretary for the group, and takes personal responsibility for such things as preparing minutes and agenda's for the committee meetings. He has a girlfriend who takes part in some of the activities of the group, but is not a member of the committee. He is a close friend of Spinner, and acts as a facilitator for him when

he travels out of the area. The responsibility of his work within the group is very important to him. He lives locally with his family of origin.

Spinner, who lives with Down Syndrome, is in his mid twenties and was born in London, but his father's family comes from the locality. He attended a mainstream primary school in London. He moved to the area at the beginning of his secondary education, and attended the same specialist unit within the academy as his best friend, Bob. His parents act as voluntary advisers to the group. He has been vice chair and is, at the time of writing, the treasurer of the group, and requires support in that role. He also attends the local community council, where he sees his role as speaking up for disabled people. He is the vice chair of a Scotland wide group which campaigns for integrated education, and attends their meetings which are held within the central belt. He needs support from his friend, Bob, in this role in order to facilitate travel to and from destinations which are a long distance from his home. When he was in primary school, one of his teachers said "That boy sure knows how to work a crowd!" and in the experience of the researcher this remains true up until the present. He lives alone in a rented house in the town with the aid of a care package from a commercial care services company, negotiated under the auspices of a local authority care manager.

Doddy was born in a town around 20 away where his mother still lives. He is in his early forties was educated at a local special school, and when he left home in his early twenties moved to the town to live in a hostel run by a not for profit charitable company. After living there for a few years he was allocated his own flat by the council and lives there whilst benefiting from five hours weekly of support from an assistant who is employed by the council. It was he, in 1994, who attended a conference in Edinburgh facilitated by People First (Scotland). At the time he attended a local authority run day centre, and had become interested in people with a learning difficulty developing their own voice, in the sense of having a say in the plans which are made for their lives. He came home and founded the local branch, and is still the chairman. An article in a local

newspaper described him as “a man of few words….. the powerhouse of the local People First branch” (Mansfield 1999) and this still remains the case. He gives a lot of his time to servicing the administrative tasks associated with the running of a ‘drop in’ centre, and is active in the development of new initiatives such as the use of drama as a means of promoting self advocacy, and innovation in the area of encouraging higher levels of employment for people with learning difficulties.

Annabel is in her early thirties, was born in the North East and has lived in locally all her life. She attended the same mainstream school as Bob and Spinner did. She lived with her parents until her early twenties, and then moved into her own apartment provided by a ‘not for profit’ housing association. She attended a local authority day centre for a short period of time. She does not regard herself as being in need of the help of an assistant. She has, in the past been very close to Jonathan, and they share a mutual interest in the use of drama as a method of promoting self advocacy for people who have been defined as having a disability. Annabel believes strongly that people who are stigmatised because of various forms of disability have to ‘make a stand for each other’ (Mansfield 1999) in the sense that they should recognise their common interests. She is particularly strong minded in espousing the right of people who have been defined as having a learning difficulty to have a loving relationship, and to become parents if that is what they wish to do.

Jonathan, who is in his mid thirties, was born in the South East of England, and came to live in a town 20 miles away when he was twelve years old. He was educated in a local special school and lived, with his mother in the family home. When she died he took over the tenancy of the family home. He has, in the past attended a day centre, but his widening interests have led to this playing a much smaller role in his life. He has participated in the learning disability forum, which is a local authority initiative aimed at encouraging service users to engage with the issues of planning and providing services for people with learning difficulties. He has also become involved with a community based support service for

people who have been identified as having mental health difficulties, and through this group has developed and interest in drama as a medium for promoting self advocacy. He is also very interested in gardening, and often acts as an advisor or facilitator for those in the community who find gardening difficult. He is easily bored, and likes to lead an active life within the community.

Tigger, who is in his late thirties, was born and raised in the North East countryside, and went first to the local village school. After undergoing mainstream education at a secondary level, he left the parental home, and lived for three years in a hostel provided by a not for profit company. He was later allocated an apartment in the same block as 'Doddy', where he also received support from an assistant for around five hours per week. . He attended a local authority day centre, and became, with Doddy, a founding member of the local People First branch. During this period, he was an active member of the St John's Ambulance society, providing voluntary first aid at local public events. Tigger has gone on to develop a strong interest in both the policy and provision of self advocacy services. He moved, with his partner, to the Edinburgh area, so that he could take an active role in the Scottish office of People First. He has recently married his partner. He is active in the group which guides the implementation of the policy changes set out in the review document 'The same as you?' (Scottish Executive 2000). He takes his time to formulate his ideas, and someone who seeks an opinion from him has to have the patience to give him time and space to do so. He is an abstract thinker, who, on the basis of his life experience draws parallels between the discrimination suffered by a range of stigmatised groups; but he combines this with an ability to work at a face to face level with people whose life experience has drawn them into such groups.

Section 3: A profile of the group and its' role within the research.

As well as providing a profile of the individual members of the group, it is important to acknowledge that the group is not static, and is more than the sum of its parts. It grew, changed and developed in the sense that the group at the time of writing is not the same as it was at the time of data gathering. New members have joined, and some members, such as Tigger have moved on to other activities. Such change brings with it stages of change in group process (Tuckman 1965) as it adapts to new challenges.

As well as stages of development within the group, it almost goes without saying that there are conflicts and alliances which ebb and flow within the group. Wolfensberger (1972) identifies the common stereotype of 'The Holy Innocent' which is often applied to people with learning difficulties. It is as if a perceived deficit with regard to levels of cognitive intelligence entails an *inability* to take part in power struggles, jockey for position within a group or join in with cliques or plots. The reality of this group is that it is no different from any other; to the extent that at one stage in its development the group members sought the aid of an external facilitator to aid them in identifying and working upon positive group processes and combating negative ones. Friendships (Bayley 1997) and partnerships form; some last, and some do not, and like any other, the group struggles with the process of concentrating upon the tasks it has set itself rather than the resolution of conflicts within the group. (Bion 1972).

As well as its campaigning role the group has a social function; the 'drop in' centre provides a place where people meet and share a conversation about the stresses and rewards of everyday life. The group runs fund raising dances around three times a year, and the membership very much values the fact that they are in charge of the location, format and musical content of the evening. One of the members, Spinner, runs a disco which provides the music on these occasions, and he is always assisted by other members of the group. This social

function of the group means that its members have a long shared social experience. There is a sense in which the manifest functions of the group revolve around campaigning and policy making, but the latent functions relate to the support it provides for people with learning difficulties who live with minimal support in the locality.

Finally it is important to be explicit about the adviser role which the researcher holds within the group. It is a central tenet of the People First ideology that decision making belongs to the members and not to the advisers or facilitators (Goodley 1997). There is a facilitator who is employed for nine hours each week, and the two advisers act in a voluntary capacity, attending the fortnightly committee meetings and working with the membership on individual projects such as employment promotion and fund raising. They offer advice on strategy and tactics and sometimes assist the facilitator and the membership with such tasks as drafting letters or responses to policy initiatives. The present researcher has fulfilled this adviser role for twelve years or more, so he is someone who is very familiar to members of the group, especially those who are on the committee. Crucially the facilitator and the advisers do not have a vote when decisions are taken by the committee and there is a recognition on the part of members that such non disabled people are likely to have different interests and perceptions to those who carry the label of learning difficulty. For these reasons, it is reasonable to say that although the researcher is trusted in his role as an adviser, his non disabled status means he cannot be regarded as a member of the group in the wider sense.

The self advocacy group were accustomed to taking decisions as a group. Their committee, which met fortnightly, was at the heart of their day to day activity; making decisions about everyday matters, such as the decision to order a new door for their office, and also acting as a forum for exploring more strategic matters, such as the decision to mark their 10th anniversary with a conference devoted to employment policies and practice. It was for this reason that the

decision was made to use a group interview or discussion as the data gathering method.

A great advantage of the group discussion was that it was possible to gather a lot of material over a limited period of time (Morgan 1997). It was not just the *quantity* of information which was important. One of the central questions to be addressed by the research concerned the manner in which punters, theorise about the nature of learning difficulty. The density and quality of the discussion which occurred within the group enabled the researcher to make links to wider questions of disability and difference, and it is the view of the researcher it was the interaction between the respective members of the group which provided a fruitful context for the development of such ideas.

In formulating interview questions for punters which sought to get access to their views regarding these ideas, the structuring of questions around the routines of daily living proved to be problematic. Potential respondents mainly lived independently, with some still living within their family of origin, and so the likelihood of their being common routines which could serve as a starting point for the group discussion seemed slight. The search began for a beginning question which would be as open ended as it was possible to get, and which could be used, in conjunction with probes and clarificatory questions to enable punters to identify what was important *for them.*
The first attempt to formulate such an open ended question floundered a little because, in the view of the researcher, it was phrased in an overly abstract manner.

> *Q"If I am to understand the lives of people who have the label, or have been given the label in the past, of having a learning difficulty, what do you think is the most important thing to ask them?"*
>
> Doddy *"Ask a person who has been labelled"*

Q *"Yeah, if I am going to write something which helps people understand your lives, what's the most important thing for you to write about; to ask* you *about, and then to write about"*

Jonathan*" Maybe, how do you feel about being given a label, do you think you would rather not have a label, just a name, be a person and not a label, which seems to be a bit insulting, be just a normal person with a name…..you know…., as they are…just like any other person"*

Looking back on this first attempt, by reading over the transcript, at getting the punters to tell their story, it is clear that there was a preliminary task to be accomplished, namely that of finding out what sort of questions were likely to be productive. With hindsight such a task might have necessitated a whole stage of the research process (Young & Chesson 2006) However, in the event, Jonathan's response to the original question had pointed the way to a form of question which facilitated a description of the ordinary experience of everyday living .

Q *" So picking up on that Jonathan , thinking about you as you would any other person, when you wake up in the morning ; what would make you think this is going to be a good day?"*

This question then formed the basis for the whole of the rest of the discussion, enabling the researcher to follow threads which emerged, and leading on to vignettes which concerned the everyday experience of punters. The first being the importance of activity in building self esteem, will be explored in the 'findings' section below.

Section 4: Identifying themes from the group

In order to abstract these themes, the responses from punters derived directly from the transcript of the discussion group have been examined, and selected themes, arising out of the stories that they told about their own experiences, have been identified, using the Nvivo term 'nodes' (Gibbs 2002). Some themes derived their names directly from the discourse employed by the punters, and

others did not. These nodes were then combined, with the aid of ‘coding trees’, in order to form wider concepts of meaning. To put this another way, in the terminology of Ritchie & Lewis (2003) there was a process of assigning stories to themes / concepts in order to portray meaning, and during the second stage they were assigned, by the researcher, to a wider category, often, but not always, derived directly from the categories employed by the punters themselves. Up until this point the coding strategies for the punters was broadly parallel to that employed during the processing of data derived from the provider interviews. However, because the manner of conducting the punter discussion group was much less structured, and because the findings were derived from a relatively small number of respondents, who had less time to make individual contributions, it was decided to add in some further stages of data gathering.

Punters who had been part of the group were interviewed individually, or in couples, and then, at a later stage the group discussion was staged once more. (Bob was not present at the second group meeting because of the illness of a relative). In both these individual interviews, and the second discussion group, the themes which had been abstracted from the first discussion group were reflected back to the punters. They were invited to comment on the abstractions that had been made by the researcher, and add to or amend the conclusions which had been drawn regarding the opinions that they had expressed. Also if other thoughts, which had not been expressed during the first discussion group occurred to them they were encouraged to express them. The findings which are set out below draw upon all three sources of data. These ‘amended second stage’ themes are presented here by outlining some of the ‘nodes’ which are included within them, and by providing some direct quotes from the transcript to illustrate these concepts.

Section 5: Activity

In answer to the initial open ended question about what made it worthwhile getting up in the morning Jonathan illustrated this theme in the following way :

> *"When I wake up and feel good; the sun is shining, and I have got something to look forward to that I can do that day , and maybe through the week, I have got different things happening; make you feel good about yourself, because there are lots of good things happening. You've got a lot to look forward to"*

Annabel characterised it as

> *"Being able to conquer everyday little…/////….conquests.....could be anything minor ...or// getting a tricky say bill sorted..... you know with a misunderstanding from one part to another, or getting something fixed "*

Spinner identified the issue in the following manner:

> *"Well I like to occupy my mind ….. it makes a right healthy attitude"*

And again from Doddy

> *" If I'm gan awa somewhere..like if I'm gan awa somewhere for a meeting ..if I've got a meeting and ken….if you think your input's. .important ….."*
>
> Jonathan "*like one thing leading to another, like the forum leading me to People First, I've got the Bridge, drama, gardening ; you make friends there and oh its …….. suddenly life becomes really exciting, and there's lots to look forward to …happening… You know what I mean, and you've got a partner as well…..*

Such activity included jobs that had to be done, interests such as coming to the drop in centre, attending a drama group, or taking part in a consultative meeting. Although other studies have emphasised the importance of independence through domestic endeavour (Booth, Simons and Booth 1990) the identification of this primary theme came as a surprise to the researcher, because people who

have been given the label of learning difficulty are often characterised by professionals in a somewhat passive role; waiting for things to be done for, to or with them by someone else. After carefully reading and re-reading the transcripts, the researcher was able to recognise the conceptual baggage that he brought with him from his 'professional' roles of 'helper' and 'researcher'. If the researcher had not been involved himself in some of this activity in his own right, albeit in a fairly peripheral manner, the punters might not have trusted him enough to share their opinion concerning the importance of activity in their everyday life. Belgian self advocates, or 'Musketeers,' expressed this emphasis on the importance of 'connection' much more poetically:-

> "Without our floating close co-operation our dream just could fall through. It was altogether sink or swim"
>
> Van de Perre & Roets 2002 P60

This category of 'activity' provides a very narrow avenue along which opportunity for insight into the everyday experience of punters might flow. The Belgian self advocates saw themselves much more explicitly as activists in the political sense of the word.

> 'A critical stance encourages us to acknowledge the (hidden) activism and resistance of people with 'learning difficulties'
>
> Roets G and Van de Perre 2004 P62.

The respondents within the discussion group were, in their own way, making a point which was just as radical: they were saying that people who had been assigned the label of having a learning difficulty were not passive or incapable, but, like others, valued activity in itself as a means of giving both content and meaning to their everyday lives.

Having made all these points about the centrality of 'activity', it is important to acknowledge that there was at least one dissenting voice. When asked what would make him think it was being to be a good day, Bob was not optimistic.

> "*Nothing really for me is a good day any way, I dinna wake up and think basically a good day anyway.....basically every day is a miserable day for me.....Yeah... I've lost baith my gran and my uncle"*
>
> Researcher: *OK, but thinking about day to day living in Seatown: is there anything that makes you think, this will be a good day in Seatown?"*
>
> Bob "*Nothing in this toon is a very good day.....it's a* boring *auld toon.*(Emphasis in the transcript)
>
> Tigger "*How about when you have got money....that's got to be a good feeling!"*
>
> Bob. *"Well I'm nae skint am I?"* (Laughter)

This response provides a timely reminder that although the group members are very capable of responding on an abstract level, events in their everyday life can make them think that life is less than fulfilling. Tigger makes a valiant attempt to look on the bright side, but Bob is adamant in asserting his right to be miserable!

In the 'follow up' group discussion, and in the individual 'follow up' interviews, when the theme of 'activity' was reflected back to the respondents, it was clarified and added to it in two ways.

> Spinner *"And it is about teamwork……. I work in Seatown recycling. All the jobs in there are not based on one person……. Everybody mixes in, and that is what I call teamwork"*

In other words 'activity' can, by definition, never be an individual activity; even in its' everyday manifestation at work, there has to be a collective dimension. In this quote, Spinner seems to be echoing the identification of the Belgian self advocates with other people who carry the label of learning difficulty, which is central to the discourse that they employ.

In a further response to the theme of 'activity' Doddy makes this even more explicit.

Doddy "*Actually activity is about the person having a voice……..not being led by members of staff….speaking up for each other…… the person who* has *got a learning difficulty speaking up for themselves"* (Emphasis in the original transcript)

In summary it is apparent that the theme of activity is an important one for the group, but it goes beyond mundane day to day concerns, and has implications for their collective identity with others who share the label of learning difficulty. It is a manifestation of a need to ensure that their voice is heard.

Section 6: Relating to Others

The issue of relating to others was identified as important; such relationships included the importance of having a partner in one's life.

Annabel: *"Not only have I got Jonathan in my life to make it even more interesting"*

Also the importance of peer support was emphasised.

Bob: *"Well I get on very well with…. Well first this lot here I suppose. If it wasn't for them I wouldn't be involved in a People First drop in, or I wouldn't be involved in Tigger's workshops and that, and so to really enjoy it."*

Although support from others was highly valued, this should not be taken to imply that personal autonomy was discounted altogether.

Tigger: *"Different scenarios require different…..different situations require, ken, different settings [*Interjection *"Right, OK"] like, for example if ///////// [*long pause for thought*] if yer nae feeling well, sometimes I think… I like to be, ken, myself and that .If I'm feeling a bit stressed oot I like to, ken.... be masel. Much as… it's fine that a'body shows ken, a caring side, but sometimes there's a fine line between caring and pity I always feel. It can*

be a fine line between actually being there for somebody, but also ken like…//////

Prompt *"Right…// OK"*

Tigger: *"That's just me"*

It might be that the fact that majority of respondents lived independently led them to rely more on peer support, than is the case for people with learning difficulties in general. Also the fact that they were all members of a campaigning group probably meant that they had all given some thought to the way in which they related to each other. In the follow up discussion group, and the individual 'follow up interviews, the theme of relating to others was reflected back to respondents and they agreed that it was an important element of everyday experience. Speaking in a similar vein as he did with regard to the theme of 'activity', Doddy emphasised the *collective* aspect of relating to others.

"When we wis at the Hillview (Pseudonym) *Hotel* (a self advocacy event) …..*what everybody thought….at the end of the day… what everybody said…..how things can change"*

It is not just the act of relating to others which is important, it is about learning from others about how things are, and how they can change. When asked whether there was anything that they wished to add Spinner further refined the theme.

"Actually yes… there was one thing there…….partnerships…partnership is not just based on one person….it is based on two people…like Doddy and myself"

Doddy added a rejoinder;

"And partnership is also how you get to know the person…..how you are getting on with them…..and people have feelings for one another……how they think about life. I would say it takes a bit of time to get to know"

Such partnership sometimes expands sufficiently to become a life partnership. In the individual follow up interview, Jonathon expresses it in the following manner:

> *"Having a partner, having things you can do together……it's great in life…….it makes such a difference"*

It seems from their responses regarding the process of relating to others that members of the group are, by implication, inclined to put an emphasis on the rewards of relating to other people who have been defined as having learning difficulties. One motif in recent social policy relating to this area is the view amongst service planners that people who carry this label further stigmatise themselves by preferring to be together. Wall (1998) quotes Wolfensberger's 'conservatism corollary' as an example of this where he urges us to:

> "train the handicapped not to commute and recreate in groups"
>
> Wolfensberger 1972 p54

Wall (1998) goes on to draw a parallel between the acceptance of self segregation on the part of self advocacy groups with the creation of women only spaces on the part of the feminist movement. In the past it may well have been the case that, living within segregated settings, with limited opportunity for employment and a lack of integration within leisure services (Bayley 1997) had the effect of *forcing* people with learning difficulties to accept isolation and segregation from the mainstream community. The findings presented below under the theme of 'disability and difference', show a recognition on the part of respondents that other disadvantaged groups may also react to widespread discriminatory behaviour by sticking together. However the fact that most of the respondents live independently, or with a small amount of focussed support, means that they have had to develop the face to face skills of co-existing with non disabled people; and indeed through their fund raising and social activities

People First has developed a visible profile in the area. It may thus be that their emphasis on support and partnership from other people with learning difficulties is a product of their campaigning commitment.

Section 7: Contact with Professionals

A particular instance of relating to others concerned the manner in which contact with professionals was perceived and managed. Tigger described an unexpected early morning visit from a doctor in the following way.

> *"Aye ..so I didna answer at first.. then again* [six hard knocks on the table] *and I'm still in ma bed, and then,* [six more knocks on the table] *and I said I'll get up, Oh bloody hell fa the hecks this at this time in the morning. And I opened my door, and here's [THE DOCTOR] at my door, saying that …..ehh…. I was referred to you by your GP. Ehh?? I says I think there's some misunderstanding here I said, that we would maybe look tult it in the future. I says I never agreed wi her….. ken. An he says Oh but I've got ken an appointment for you from your GP.*
> *I said Na, sorry yiv made a mistake; I was actually quite proud, because I kinda made a stand for myself, he wisna too happy wi me"*
>
> *"Aye and it wis efter that I lost the plot a bit……. The point I was makkin wis /.. professionals..// part of the point was professionals making the decisions for yi, rather than consulting wi you. I basically ask myself would she have done that wi somebody that had nae problems. I bet she widn't hae.....".*

Whatever the rights and wrongs of this misunderstanding, or difference of perception; there was a feeling that this respondent was not going to accept passively the plans that had been made on his behalf because of the implication that he did not need to be consulted about them. But relationships with the helping professions, or semi professions did not necessarily suffer from incongruent assumptions on the part of the respective parties to the transaction. Several of the respondents had assistants who helped them with the practicalities of daily living, and they valued the adaptability and flexibility of these helpers. .

Doddy.“ *I’ve got someone there, someone that’s there to help a person that’s* [hesitatingly] *less able and they need support, just say like the bill’s too expensive, there’s always someone there to support you.”*

*“She winna say ‘right we’re deeing this’.[*Interjection from Tigger *“No..No”]. she will probably say ‘Right Tigger fit de you fancy deeing?” That’s like fit Julie* [his assistant*] dis wi us, like ‘fit are we deeing?’*

“And if we cannae manage to see her ,ken, we can arrange to see her anither time, so…”

In the follow up group discussion, and in one of the individual interviews, the theme of the contrast between professionals on the one hand, and ‘Natural People’ on the other was reflected back to the respondents. The group had recently been involved been involved in using drama as a tool to promote self advocacy, and there was a lot of discussion about the characteristics of the people from a local theatre company who had helped to facilitate the planning and staging of the drama. They were described as ‘genuine’ and as being ‘in the same boat’. Some were recognised as having a disability, and others as able bodied people who had the capacity to be successful supporters. Spinner has had some experience of interviewing people who have applied to his service providers to become personal assistants, and was particularly thoughtful about the reasons for their positive abilities in the area of facilitation:

“*It all depends on their actual background……like every time I went to my interview….sometimes and that….when you hear about the history of what they have done in the past, and then they come…but not into that anymore, and if they should take a relapse, and it happens again, then they could get a bad reputation”*

The researcher struggled at first to understand exactly what Spinner was getting at; it seemed like he was describing people who had undergone bad experiences themselves, and were thus likely to be able to empathise with the day to day vicissitudes of living with a learning difficulty. He was also being realistic about the risk of them having a ‘relapse’.

Tigger came to the rescue:

> *"Fit I've found is that people who have maybe had personal hardships of their own…….have maybe encountered …ken abuse…..or ony ither personal things when they come to working with people with disabilities, I think…..it gives them a better sense of fit their life…..what people wi disabilities have to put up wi……..they dinna patronise you……which I've found good"*

But Spinner sounded a note of caution.

> *"You have to watch out because a person who used to work with me…be in charge of me and that…….I won't mention any names…..caused me a lot of trouble.....and that…….someone who is smart enough needs to come in and teach them at a certain level"*

Tigger was optimistic about the capacity of people who had experienced trouble in their life to empathise with others.

> *"You ken a'body speaks aboot ken, the worst disasters. There's aye something important that comes oot of it. I aye think back about September 11th….you ken there was sae much fowk killed injured and fit ever. I think that actually benefits people wi disabilities……I think it will be easier for fowk to be accepted, because so much happened at one time.*

There was thus a desire to retain control of the agenda in their relationships with professionals which was combined with an appreciation of flexibility in their relationships with personal assistants and with people from a wide and diverse background who had come into a helping role with them. Because the respondents in this group identified their support needs as being fairly practical in nature, it might be that their view of relationships with helping professionals is unrepresentative. It is notable that the views of these respondents contrast sharply with the reports in the 'providers tales' chapter of an overwhelming desire on the part of hospital residents to get close to members of staff rather than fellow residents. Respondents make a distinction between the one sided relationship with some professionals, and the fact that their relationship with

their day to day assistants and other facilitators include some of the elements such as their voluntary character, choice, intimacy, and equality (Wall 1998) which characterise friendship. To be sure these relationships are with people who are paid to care, but very often there are shared assumptions and understandings between punters and their assistants concerning kinship, social networks and local culture. This seems to be a clear positive which arises out of community based care.

In one of the individual 'follow up' interviews, Jonathan was at pains to emphasise the importance of continuity and some degree of reciprocity, in relationships with medical professionals.

> *"My doctor…….I get on fine ….I've known her for 14 years now. Being with her for so many years, she knows me quite well, and I've got to know her.* (Emphasis in transcript). *So if there are any problems, I can see her rather than a completely different person……. You feel more settled and happier."*

Section 8: Sexuality and Relationships

A particular area of concern with regard to relationships with others revolved around the issue of sexuality and relationships.

> Tigger *"Cos there's an issue ga'n on ay noo, which brings me… I was going to say this.. there is an issue ongoing the noo and its happening all over Scotland, /////// there's a sexual health review, for people with learning difficulties and that //////// and its Grampian and part of a national thing ..ken..people with learning difficulties ken…/////// are nae allowed to….ken…. are like prohibited fae…deeing certain things……"*
>
> Prompt: *" From having a sexual relationship?"*
>
> Tigger *"Aye"*
>
> Annabel *"Are not given the chance to have kids an a' that"*

Tigger *"And People First are ken.... against this because they feel that peoples sexuality and sexual feelings shouldna be taken awa, because it's an inbuilt…it's just something that's….."*

Annabel*" Wis there nae an issue a few years back that women wi severe learning difficulties and Down's syndrome were forced against there own will for getting a hysterectomy"*

Tigger *"Or sterilisation…Aye"*

Annabel *"Against their will"*

Tigger *"And ehh.....this is the worrying thing../// there's a working party right…..there's not one person with a disability on it. And the council's got a steering group on it, and me and M [*a facilitator*] raised that point, and we said that there should be disability representation, [*interjection *"Ok"] and we've raised it with People First Scotland, and exactly the same thing happened with a group in Glasgow a few months back"*

Thus the concern is that the policies of the caring authorities explicitly or implicitly fail to recognise the sexual feelings that respondents regarded as natural, and even when policies are being reviewed, it is not thought necessary to consult with them (Apsis 2002). The feelings which result from the discounting of their views by those who are in authority over them including social work staff, relatives and carers have been well described elsewhere.

> "At the same time this is known to be a vulnerable group of people for whom the prospect of enduring the sensibilities, needs and emotional pressures of others is appalling"
>
> . Oakes (2003). P456

When the theme of sexuality and relationships was reflected back to the group during the follow up group discussion, and the individual interviews, the emphasis moved towards the issue of reproduction, and the support, or lack of it, that parents who had learning difficulties could expect to receive. (Booth and Booth 2004) During an individual 'follow up' interview, Annabel spoke with some emotion about the rights of people with learning difficulties

"Because it is his and her body, and they can choose to do whatever they want"

The depth of her anger was illustrated when she spoke about a situation that she had read about.

"There was a recent story that this couple had three children, and that social services took them off them for no apparent reason, or warning. Now she is pregnant with a fourth, and she had to escape to Ireland. Now all the children are all adopted for no apparent reason for ever…….and this couple did not *have serious learning difficulties (*Emphasis in the transcript) *so whatever"*

Tigger tried to temper Annabel's anger to some degree by pointing out that she did not know the full facts, and by saying that under the terms of a recent review social workers had an obligation to act as an advocate for people who have learning difficulties. Annabel was still angry when she said

"To me it felt that social work felt that they had the right to take them"

Tigger introduced the thought that the action of the authorities might be related to wider forms of deprivation.

"Doon to the post-code lottery; a lot of things are doon to the area in which you live. Someone who has a disability is much more likely to have their kids taken off them…..to be living on an estate rather than in a nice suburban area.

Although there is evidence that parents with learning difficulties are often confined to the role of spectator within care proceedings (Booth and Booth 2006),there is a sense in which the truth or otherwise of Annabel's account of the particular case in question is a secondary issue for this particular group. What struck the researcher was the *emotion* behind the pronouncements on this issue, and a feeling that the authorities exercised their power over parents with learning difficulties simply because they had the power and felt justified in doing

so. On the one hand they are told that national policy guidelines require service providers to recognise that people with learning disabilities have sexual rights and needs (Scottish Executive 2000) but on the other, their experience in practice leads to an expectation that service providers will ignore their need for information and support; both with regard to questions around sexuality and relationships and also in relation to parenting skills.

Section 9: Having a Voice

The importance of having a voice is described in a number of ways by the respondents. The link with the theme of 'activity' outlined above is apparent, insofar as involvement with a self advocacy group is seen as presenting one of the few opportunities to express oneself. In the words of the punters; "It gies ye a voice"

> Q*: "OK so helping Doddy and spreading the burden was really quite important to you: but thinking a bit wider, what do you think People First gives you? What makes it rewarding for you?*
>
> Doddy *" It gies ye a voice"*
>
> Q: *"OK tell me more!"*
>
> Doddy *"It gives you a voice, and you've got the opportunity to speak up for yourself, instead of letting other people speak for yourself"*
>
> Prompt: *"OK"*
>
> Jonathan*" It gives you satisfaction"*
>
> Q *"Why does it give you satisfaction J?"*
>
> Bob. *"If you come down to the drop in and help out with different things, whether it be cleaning or advice or whatever, you can go away with a very satisfied feeling: you've contributed, you've done something to help or advise, or… in some sort of way"[*interjection *"OK"]" you get a good feeling inside that I've done some good…..it's a nice feeling; you know..... an achievement"*

Expressed another way:

> Tigger "*Helping shy young people get confident to speak up for themselves, and break down barriers that nae other folk can tear down*"

The experience of having a voice is contrasted with institutional living, where it does not seem possible to communicate one's concerns and choices, either with regard to routine, day to day choices or in relation to more strategic decisions.

> Doddy *" I used to stay at Limetree* (pseudonym) *House"*
>
> Researcher*: "Yeah..Ok"*
>
> Doddy *"It's like you dinnae hae a voice, they said it for you"*
>
> Tigger *"Can I say…..I was getting a little mixed up…. community is like … institution, that's the word you are looking for"*
>
> Prompt: *"Yes… but I didn't want to put words into your mouth….. I think that Doddy's point is still OK…from his point of view he is contrasting his experience at Limetree where you just said you didn't have a voice"*
>
> Doddy. *" I didna hae a voice… its like 'Fit time are yi coming hame and a' that , and be hame at a certain time; now since I have lived on my own I come hame ony time I want"*

During the 'follow up' group discussion, and during the individual interviews, the researcher reflected back this theme which had been named by Doddy as 'having a voice'; he asked whether it was still important. Jonathan stressed the importance of learning to speak up for yourself,. He said:

> "*It gives you a sense of importance..... I would think it could be very frustrating for them..... you know .....someone else speaking for them.....when they* know *what they want to say, but they don't but they don't find it easy to speak up for* themselves.*"* (Emphasis in the transcript)

Spinner's comments on this issue focuses attention on the behaviour of the able bodied carer or supporter.

> *"Well, when you are speaking to the person themselves..... well it must be to that actual person, not to the person who is with them. When they try to speak for themselves, another person jumps to speak for them"*

So, for Spinner, the issue of not having a voice is less to do with a lack of capacity on the part of the person who has a learning difficulty, and more to do with the propensity of others to speak for them. The researcher, in the role of devil's advocate, goes on to ask whether this is necessarily a bad thing.

> Spinner "*Well... because like that person will get very upset.....and very emotional"*
>
> Prompt "*How would that emotion show itself?"*
>
> Spinner "*By the expression on their faces*"
>
> Prompt**. "***Do people sometimes not notice how upset and emotional people are?"*
>
> Jonathan. *"They don't probably know what it is like unless they are in that situation themselves"*

By implication, Jonathan and Spinner are making subtle and far reaching observations It is *not only* the fact that other people speak for them, and in doing so undermine their capacity to learn to develop their own voice; it is the fact that having done so such people fail to recognise the signs of upset and emotional distress which result from this behaviour. Coming from a psychotherapeutic direction Sinason (1992) makes a distinction between the 'primary handicap' (the condition or impairment which is identified diagnostically as causative of a disability) and the 'secondary handicap' which is the adaptation which the person who has a disability employs in order to survive the reactions of others. She talks about the *shock* of intelligence revealed, and the fact that people with a learning difficulty often conceal such intelligence behind a 'handicapped smile' because experience has taught them that it can be dangerous to exhibit it. Goffman (1975) makes a similar point regarding the dynamics of the relationship between the virtual and attributed self. Spinner and Jonathan, in the above

extracts are providing evidence of a high level of emotional intelligence (Goleman 1996) regarding their capacity to recognise emotional upset by the expression on people's faces. They are pessimistic, concerning the ability of non disabled people to both recognise and acknowledge their capacity within this area. This, in itself is not surprising, because others have vividly described the frustration and confusion which results for experienced staff when residents of care home who had previously been assessed as having IQ's around the 20 mark, were shown to have a fully developed ability to write through the medium of an alphabet board. (Johnson 1989) It is interesting that Spinner and Jonathan felt able to display their ability within a discussion group. One comment on the care home experience pointed to the fact that:

> "The main change at House M which allowed the emergence of communication was the decision to locate meaning in the behaviour of the residents"
>
> Meek and Berki 1989 pp29

It has been acknowledged above that the respondents within the discussion group had long experience of wrestling with questions of meaning in the day to day discourse within the group. Others have wondered whether those who seek to help people with learning difficulties are motivated by questions of power or compassion (Brandon 1989). It may be that the support of their peers, and the fact that the researcher was known to them over a number of years, made it safe to be explicit about the central importance of having a voice, and to express the underpinning emotion.

Section 10: Negativity and small mindedness.

For the researcher, who was, after all, familiar with the members of the group and their capabilities, the emergent theme that was most surprising related to the identification of social processes which were characterised by Annabel in the following manner:

> Q: *"Annabel..... what is important for you about People First?"*
>
> Annabel. "*Helping shy young people get confident to speak up for themselves, and break down barriers that nae other folk can tear down"*
>
> Q: *"What sort of barriers do you mean?"*
>
> Annabel *"Other folks' negativity, small mindedness and prejudice.....the wie folk act towards you....body language they give oot.....the wie they spik to you; like you are a child, not a human adult*"

It was not the fact that the respondents went on to characterise their experiences in an abstract manner which was surprising; it was more the *level* of abstraction that they utilised, and the fact that they located that experience within a much wider social context. Other researchers have found that respondents who have been given the label of learning difficulty tended to have little difficulty answering factual questions, but needed support and assistance in the formulation of evaluative comments (McVilly 1995). This was patently not the case for respondents within the discussion group. It is without doubt the case that one of the major functions of the group was to take part in local, and in some cases, national planning and consultation processes, and it may be that they have picked up some of the forms of discourse employed by service providers and managers. It may be that the background of the researcher in the caring professions had led to an assumption that consultation was something of a one way process, with providers listening to the concerns of punters. One of the lessons of the research would seem to be that the educational and socialising process runs in both directions, and the respondents were perfectly capable of formulating their concerns in abstract terms. In the light of the fact

that the residents of a care home, who had no speech, were able to develop the ability to write and attribute their learning to the experience of watching television, (Johnson 1989) it is not surprising that people who lived with the label of learning difficulty should have the ability to learn from their surroundings.

As a preliminary to the interview, the researcher had asked about the important issues for someone to whom the label of learning difficulty had been applied.

> Bob *" Maybe, how do you feel about being given a label, do you think you would rather not have a label, just a name, be a person and not a label, which seems to be a bit insulting, be just a normal person with a name…..you know…., as they are…just like any other person"*

As a follow up to a question about what made for a good day, and what made for an empty day, the researcher tested the water to see if their opinions could form the basis for a wider perspective regarding disability and difference..

> Q*: "OK I wanted to clarify… I said at the beginning that I am talking to people who have in the past had that label ; do you think that empty day, that discouraging day that you talked about is just for the people, just happens to people who carry the label learning difficulties, or do you think it happens to everybody"*
>
> Tigger *" I think it is mair likely to happen to people with learning difficulties because …… na I think that….."*
>
> Annabel *" I think it's a wider issue than that "*
>
> Q: *"Alright"*
>
> Tigger *" I think that its mair people with learning difficulties are mair likely to be neglected… people just seem like…..social outcasts or like misfit social outcasts, and sometimes people with disabilities are often seen like social outcasts and misfits"*
>
> Q*: "OK that's interesting: Annabel; you were just saying that you think it is wider than that"*
>
> Annabel *"Nae just folk with learning difficulties, also with physical, and with mental health issues as well"*

Tigger *"Ok OK aye..aye…….. I agree with that.. the thing with disability goes roon the hale disability… stems from …which can go fae mental health …tae ken….*

Annabel *"From depression to schizophrenia….."*

Tigger. *" Aye.. mental health can cover a wide area …people that are nae fit …people that are nae in it….. but I widna even brak it…people who are probably mair likely tae*…

Another way of describing such social processes identified hinged around the area of segregation / inclusion of people with a disability

Researcher*: " OK.. I'd just like to follow up some of the ideas that you have brought up there; Annabel said a minute ago, that people in the outside world sometimes were….. small minded was the words that she used [*Interjection from Annabel *"Mmm"] What had you in mind when you thinking about people who were 'small minded'?*

Annabel *" Thinking that folks with learning disabilities should not be out in the community, … should be shut awa and forgotten about… should not be living in independent living"*

These social processes are seen to have an impact on everyday interaction

Jonathan [Speaking over the top of Tigger, who was taking some time to formulate the phrases of his sentence] *"It's almost, I suppose, as though people are biased, wanting people who have got learning difficulties segregated, or kept separate from people who haven't got learning difficulties. I suppose you don't have to actually know or hear people say that: its just a feeling that you might get…. Seeing people and body languages and things…you just get that impression"*

There was an understanding that sometimes living in the community could be challenging, but, in line with the findings of studies which evaluated the move from hospital to community (Wright, Haycox and Leedham 1994, Emerson and Hatton 1994. Booth, Simons and Booth 1990) none of the group members would prefer to live in an institutional setting, though they did not dispute the right of others to make that choice if they wished to

.

Q: So let's just take your example that you said earlier on, about the village, not the village, the community in Edinburgh with disabled people in it. Let's say a social worker, or a care manager came to you and said you had to live there in the future, what would be different about it, what would your reaction be?

Tigger*" Well I would say…I would rather stay where I am and tough it oot, than be … segregated"*

Q *"Ok… 'tough it out'… what would that mean?"*

Tigger *" It jist means… Ok it is probably hard…its probably mair o' a battle ye ken in the community, rather than living somewhere where yer protected fae a'thing [interjection "Right"] Whereas in these places you are protected fi a' thing… yer like sheltered like in // this nice little cosy like world."*

Living in the community was seen by Tigger to be somehow 'natural'

So as you first said, if I was told that in a few years time you have got to just live with so and so, with whatever disability that to me what feel a bit …. Not good [Interjection "Ok"] As said before, if things are happening naturally, as life goes on that's good…brilliant"

For Bob, the key issue was one of choice.

*"Well…../////….I don't think it is right for everyone to be cramped in one room. Ehmmm… but I remembered before I did went to…..I never lived …. I haven't been living in a hostel and that , but I've seen people in one and that, in one of them, but I think if they want to make the choice what they want, that's fine, and if other people don't like it , what they choose in their lives, that can be so patronising. So let me give one example [*interjection *"Ok"] Say I'm one of the people that works there, one day I came up to Tigger and I say 'Tigger I would like to put you in this place where you will meet people who is the same as you and that, that means I am choosing what he wants to do, not what he wants to do. [*Interjection*: "Right…so…"]..... I think anyone in the community has got a choice of their own"*

For Annabel the possibility of living in a segregated institutional setting was dismissed in a more peremptory fashion.

"I think if someone did that to me I would just tell them to stick it up their kilt"

In her individual follow up interview, Annabel summed up the power and pervasiveness of negative and small minded thinking in a a thoughtful and evocative manner.

"I've nae seen it, but I've kinda felt it…. The presence of illness……it's a mixture of ignorance and arrogance…… look at that peer thing ower there…..that person shouldna be here…..lets shut them awa; somewhere they are oot of sight….oot of mind"

Section 11: Overpowering

The researcher had attempted to summarise these issues under the heading of 'choice' but the group members wanted to go much further.

Tigger *" And overpowering"*

Spinner *"Yeah"*

Q *"Sorry?"*

Tigger *"And overpowering, overpowering"*

Q *"Say it…"*

Tigger *"Overpowering [louder] OVERPOWERING makkin decisions for somebody withoot……."*

Q *"So somebody who was doing that would be overpowering..... .Is that what you are saying?"*

Spinner *"Yeah"*

Tigger *"Aye overruling"*

Q *"Overruling?"*

Spinner *"Yeah"*

When the theme of negativity and small mindedness was reflected back to the group in the follow up discussion it was still thought to be important, but a further link was made to the issue of respect which should be rooted in the common humanity of everyone, including those who have been defined as having a learning difficulty.

> Jonathan: *"When they are talking to you they are talking down to you..... if you know what I mean they talk to you like you are down the scale"*

There remained a recognition that such stigmatising forces applied to groups apart from those who had learning difficulties.

> Annabel "*Same wi fowk we mental health issues as well.....it works for that people as well.....'aw their nae recht in the heid.....we dinna want them here.....get them oot o' here"*

Tigger went on to give some practical examples of this lack of respect in practice.

> *"They hid a'.....they went to a party.....and they hid to be back for 10 O'clock because of staff change over..... a lot of shite.....sorry but it's something that needs fucking changing..... sorry..... I shouldn't swear"*
> (Laughter all round)

For the group this negativity and small mindedness was all the more difficult to justify because normality was thought to be so difficult to define.

> Jonathan: *"I did see a poster at the Seatown Community centre with about, I don't know, twenty or thirty faces of people which said 'Who is normal; what do you call normal?' I mean...fair enough...I mean....."*
>
> Tigger: *"Every single person in the world has got a disability..... somebody walking slower than somebody else, walking slow might be a disability.....somebody else whose got.....being illiterate is deemed a disability..... Annabel supporting Celtic is a disability"* (laughter)

To summarise the issues touched upon by the group under the auspices of this theme, there was recognition that the experience of being 'an outcast or social misfit' was one that they all understood. It was also a commonplace that these social pressures had an impact on day to day interaction with others and that alternative strategies of institutionalisation / segregation or inclusion were available. The group described the manner in which these social processes put individual pressure on them as to whether it would be more comfortable to live in an institution or 'tough it out' in the community. These pressures have long been recognised in the literature relating to learning difficulty (Wolfensberger 1972, O'Brien and Tyne 1981, Race 1995) and more recently there has been evidence of the survival of institutional discrimination, even within the health service. (MENCAP 2007, Healthcare Commission 2006, Healthcare Commission 2007). What was distinctive in the responses of group members related to the fact that they could go beyond their own individual experience, and provide a generalised perspective on the process of stigmatisation, which might also apply to people with a physical disability or people who lived with mental health difficulties. In thinking about this, the researcher is reminded of disbelief encountered by others when they reported that people who had been assessed as having a low IQ had the capacity to write. (Johnson 1989) or the child psychotherapist who

> "became so used to having changes in her autistic patients ascribed to the fact that they could not have been really autistic in the first place that she took the decision to have each patient she took on assessed by a leading psychiatrist first"
>
> Sinason 1992.

It may well be that their capacity within this area results from the self advocacy work undertaken by the group which puts them in direct contact with other stigmatised groups; or it could be that they had a lot of experience of conceptualising their own experience of discrimination in order to present it to

service providers in particular and the public in general. If this *is* the case, it may be that other groups of punters, given appropriate support, could provide an articulate voice and a critical perspective from which to view the planning and provision of services.

Section 12: Emotional Impact

The final theme arose out of one aside by a group member, and has parallels with the 'Intimate Narrative' entitled *Different Strokes for different folks.* It concerns the emotional impact of the issues and experiences discussed above.

> Q *" Freedom…And that's important?"*
>
> Doddy *"Yes"*
>
> Jonathan *"Making you own decisions"*
>
> Tigger *"Braveheart"*
>
> Prompt:(laughing*) "You said 'Braveheart' just then!"*
>
> Tigger*" Sorry!"*
>
> Prompt. *" No... No if it makes you feel that way, I think it is quite reasonable to say that…."*

When the group was talking about the importance of freedom and independence, one of the members used the title of a film to express the emotion behind what was being said. The researcher's first reaction was to think it was a melodramatic appeal to emotion. But the group member clearly felt it was relevant, and fortunately the researcher was able to recover the situation by acknowledging its' importance. The exchange gives a flavour of how difficult it is for people with a professional background to acknowledge the emotional response that day to day experience can engender. In the follow up group discussion Jonathan and Annabel neatly summarised the reason for this emotion.

Jonathan "*All of us, we're all on this planet. We're all here for a purpose we've all got a voice that should be heard; do you know what I mean?"*

Annabel *"I think that folk with learning difficulties are getting tired of being patronised, pushed out of the way..... they* DO *want a normal existence.....to have their independence..... we're all bloody human after all"*

(Emphasis in the transcript)

In summary the punters' discussion grew out of *one* very open question. There were was no predetermined structure for the discussion; the direction of its development resulted from the following of threads which emerged from the original question. The themes which emerged from the initial group discussion were reflected back and checked out within the context of the second group and individual follow up interviews. These themes which have emerged from the stories contained within the initial and follow up discussion groups as well as the individual interviews are summarised in figure 9.

Once again the nautical metaphor is employed. Because punters had expressed an overall wish to live their lives in a 'natural' manner way, and to express the emotions that they *really* felt, the idea of a voyage upon the ship of life seems to convey the nature of the process in a succinct manner.

As is often the case what they wanted to *avoid* was sometimes more important than positives that they wished to achieve. It is significant that the naming of the processes of being 'overpowered' and being subject to 'negativity and small mindedness' was derived directly from the words of the punters themselves. The content of the other categories represented within the diagram is self explanatory.

However the key 'positive' category of meaning, and the one through which almost all of the others are mediated is that related to the importance of 'having a voice'. If one is truly to be the master of the ship of life, then to be the captain of one's own destiny and direction, it is crucial to both have a voice and to have it listened to.

Figure 9: Life's voyage.

Chapter 8: Intimate Narratives.

"Anything in any way beautiful derives its beauty from itself, and asks nothing beyond itself"

Marcus Aurelius.
Meditations (Book Four, 20)

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This chapter is structured in 9 sections.

Section 1: Introduction: Why include an 'intimate' dimension?
Section 2: Constructivism, reflection and the sharing of reflective knowledge.
Section 3: A Reflective framework which accommodates different ways of knowing.
Section 4: Autoethnography, narrative and reflexive thinking
Section 5: Some stories drawn from life.
Section 6: Spinner's Stories.
Section 7: Father's stories.
Section 8: Adviser / facilitators stories.
Section 9: A diversity of outcomes.

Section 1: Introduction: Why include an 'intimate' dimension?

In this chapter the use of language will be slightly different from that within the rest of the thesis. This chapter will focus upon a very personal account of my experiences primarily as a father, and also as an adviser to a local branch of People First and, by implication, as a researcher. Accordingly the convention of avoiding the use of the first person has been put into abeyance, because it would seem to be clumsy and inauthentic to use neutral 'academic' language to describe and analyse intensely personal experiences where I have been an actor which have informed my role as researcher (Ellis & Bochner 2003). Within both the introductory paragraphs and in the telling of the substance of the narratives the use of language will be expressive, and will be formulated in a manner which would be accessible to the people with learning difficulties who are the focus of the narrative.

In the chapter one of the thesis I have contextualised my interest in the experience of those who have been defined as having a learning difficulty, and my commitment to methodological eclecticism, by identifying a number of experiences in both my professional / occupational and personal / emotional life. These have been events which have constituted by far the greatest influence on my understanding of the nature of disability, and what it means to live alongside disability within the world. These revolved around being a parent of a son who has a disability and the opportunity that status gave me to observe the way in which people relate to a person with a disability. These events are 'intimate' in their nature, and the temptation has been to regard the telling of these tales as 'anecdotal' which would mean that they would have no place in a doctoral thesis which is evidence based. I have moved beyond this view for two major reasons.

Firstly, if this experience has facilitated an increase of understanding on the part of myself, then it should be included in order to promote understanding on the part of the reader of the research. This approach is activist and persuasive

insofar as the intention is not to encourage the reader of the research to view the world of disability from the same perspective, but to set up an internal dialogue with the reader which enables them to make explicit their own understanding of the nature of disability and difference.

Secondly, I aim to ground the explanatory categories which emerge in the later chapters of the thesis in the facts and evaluations which have been directly communicated by the punters and providers who were interviewed. This chapter both describes and analyses experiences which have profoundly influenced the formation of those explanatory categories. If the reader of the research has an understanding of the context within which this iterative process took place, then it should be possible to make an informed judgement about the verisimilitude and authenticity of the explanatory categories which emerge from the data.

Section 2: Constructivism, Reflection, and the sharing of Reflective Knowledge.

If the non disabled world is to benefit from the insights which are to be derived from an understanding of the experience of disabled people, researchers need to have access to an epistemological paradigm which is able to accommodate, and facilitate the transmission of their world view. Trends within a number of disciplines have converged to present a radical critique of staying within epistemological paradigms (Kuhn 1970). This process has been characterised in the following manner;

> "teaching continues as though nothing had happened, and the quest for immutable, objective truths were as promising as ever. For some of us, however, a different view of knowledge has emerged……..This view differs from the old one in that it deliberately discards the notion that knowledge could or should be a representation of an observer-independent world in itself and replaces it with the demand that the conceptual

> constructs that we call knowledge be viable in the experiential world of the knowing subject"
>
> von Glaserfield 1989 P1

Thus with regard to the experience of living with learning difficulty, the task of promoting understanding has two levels; the first is to illustrate how Spinner and myself consciously construct, through everyday creative activity the meaning of words, phrases sentences texts, and behaviours. The second is to indicate some of the influences which have acted upon that process of construction, and to frame these explanatory links within another set of epistemological perspectives (Lyon and West). It might be objected that the effect of this constructivist and rather pragmatic approach is to deny the possibility that objective knowledge can be identified and communicated. I would argue that within this study, the primary aim is not just to arrive at a representation of what exists, but to provide a map of what, in the light of the experience of a disabled person living in the world might constitute viable adaptations. The stories told later represent an attempt to outline some of the contours of that experience.

One effect of the framing of an alternative epistemological perspective within the caring professions (Burnard 2002, Schon 1983) has been the emergence of the 'reflective practitioner' within the caring professions, such as nursing and social work, who have traditionally been involved in the provision of services for people who have been defined as having learning difficulties. Theorists of reflective practice (Carper 1978) have addressed the issue of pre-paradigm conceptual structures; that is what it means to know about the practice of helping and caring. Carper distinguished four distinct patterns of knowing, which in my view can provide a framework within which to reflect upon the significance of the stories set out below.

The first of these was termed *empiric* which was defined as knowledge

"that is systematically organised to into general rules and theories for the purpose of describing , explaining and predicting phenomena of special concern"

Carper (1978) p14

An example of such a way of knowing might relate to the chromosomal basis of the definition of Down syndrome. With regard to the understanding of life experience such knowledge may constitute a necessary foundation of the social as well as the physiological definition of the syndrome, but for specific psycho-social, inferential and application purposes it does not have a great deal of predictive value.

The second pattern of knowing is described as *aesthetic* which is defined as being associated with the art of nursing in that it is expressive rather than formal or descriptive. It is concerned with the

"subjective expression of imagined possibilities or equivalent realities"

Carper (1978) P16.

An example my own clinical experience of the importance of this form of knowing relates to the experience of grief amongst people who have been defined as having a learning difficulty. In the past because of professional myths about the inability of people who fall within this category to feel grief, their participation in the social processes associated with mourning have sometimes been intentionally curtailed. The task for the helper is to try to put themselves in the shoes of a person who has suffered a loss, and imagine what they might be feeling.

A third pattern of knowing, *personal knowledge,* is defined as

“a standing in relation to another human being, and confronting that human being as a person”

Carper (1978) P18.

Whilst interviewing one of the providers he described his first week of working in a large mental handicap hospital. He described his encounter as being with twisted bodies, and people who could not speak but only make noises, sometimes loud noises. He went for a drink with his sister, who was also a nurse, and said to her that he didn’t think he could do this for much longer. He stayed, persisted and survived, and came to see the people who he worked with as individuals, with individual characteristics, individual needs and later individual talents for teaching him something about how to survive in the world. In the stories which are set out below, some of the pain and humour of the process of standing in relation to another human being are set out.

Finally the importance of the *ethical* or moral component of knowledge is set out in terms of a focus on matters of obligation, and normative judgement about what should be done. Thus, whilst acting as a helper, either professionally or less formally, with people defined as having a learning difficulty the question of independence is often present, either centrally or as a contextual factor, within the underpinning knowledge base. Whilst weighing up how to be helpful, a choice often has to be made between doing something *for* a fellow human being, which is fast and efficient in its’ execution, or doing something *with* another human being which puts them at risk of making an error, but in the longer run contributes to the growth of their capacity.

Section 3: A Reflective framework which accommodates different ways of knowing.

Having identified the diversity amongst ways of knowing, it seems imperative to take the next step in the reflective process and identify the questions which could be asked about the meaning and significance of narratives. A framework for learning through reflection (Johns 1995) will be adapted in order to provide a tool for evaluating the significance and impact of the stories outlined below.

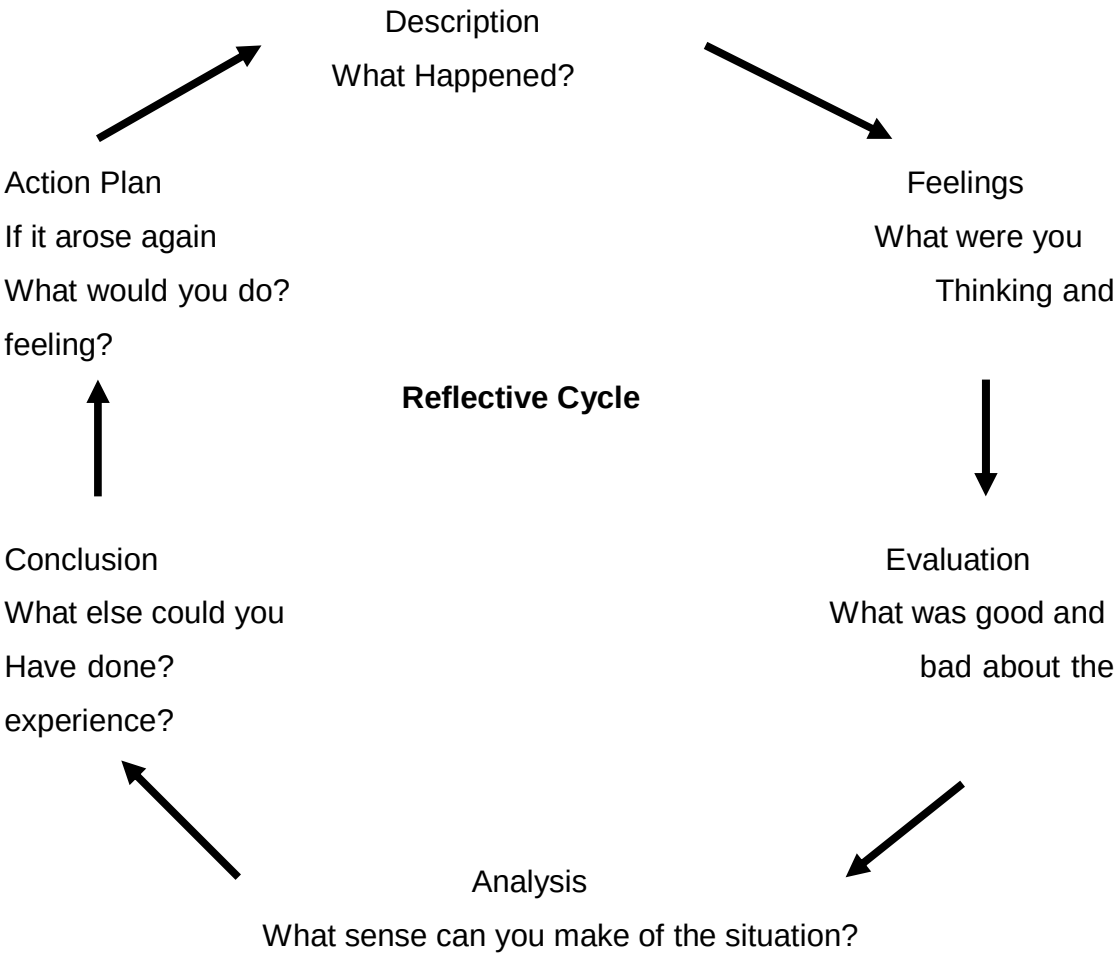
When thinking about the *aesthetic* or artistic knowledge perspective, intuitive questions may be asked concerned with the respective goals of the helper and the helped, the consequences of contact for both parties and for others who form part of the social context of the interaction. Also consideration should be given to accessing the feelings of the parties to the interaction. With regard to the example of aiding the grieving process discussed above, respecting silence, what people don't say, may be as important as what they do say.

Moving on to the *personal* way of knowing, the parties to the interaction would have to give some thought to the internal factors which might influence how the actors are feeling. A past personal experience of a family member with a disability might lead a helper to transfer feelings from that past person, consciously or unconsciously, to the present encounter. Turning to the *ethical* way of knowing a helper may need to reflect upon whether their actions were consistent with their ethical principles, and if they were incongruent what caused this. How often do helpers who profess to subscribe to a way of working which promotes independence and capacity make arbitrary decisions justified by a need for speed and efficiency or a pressing need to protect someone?

The *empiric* way of knowing, often drawn from the evidence base of a profession, addresses questions such as the meaning of symptoms, and the possible effects of medication.

Having considered the fundamental patterns of knowing, and the questions which may be derived from them, a final and key part of the reflective process is to set out a plan for the accomplishment of the reflective cycle. Gibbs (1988) expressed it diagrammatically in figure 10.

Figure 10: Gibbs Reflective Cycle.



Section 4: Autoethnography, narrative and reflexive thinking

The bulk of the work undertaken in this study has been survey based; that is to say punters and providers have been asked, in semi-structured interviews and in discussion groups about their experience of working and living, and their responses have been coded to draw out some key themes. In this chapter narratives derived from the experience of the researcher, and those around him have been utilised to pass on observations that have been made on the basis of life experience. It is reasonable to say that this amounts to a form of participant observation; some of the methods which derive from a biographic or ethnographic tradition of enquiry (Cresswell 1998) might be useful in the promoting of understanding of the significance of these stories.

Specifically, a potentially fruitful approach has been given the name of *Autoethnography* and is defined as.

"an autobiographical genre of writing and research that displays multiple layers of consciousness, connecting the personal to the cultural"

Ellis and Bochner (2003) P209

The method has its roots in constructivist, reflective and post modern currents of thought which confront the difficulty inherent is making an epistemological distinction between what is out there in the world and the categories of meaning which are resident in the human mind. The goal is to produce texts which promote dialogue rather than monologue, are evocative rather than definitive, utilise participants in their research rather than subjects in a manner which empowers rather than simply extracting knowledge.

In terms of attaching significance to the narratives outlined below, the method recognises that stories are always a representation of what has happened in the past; that is to say that they are mediated through the consciousness of the

story teller. Validity is defined in terms of verisimilitude, and the power to evoke experience in a manner which is lifelike and credible. The teller of the tale is encouraged to revisit the experience emotionally as well as cognitively. A concomitant of this type of engagement is vulnerability rather than detached sociological neutrality.

Section 5: Some stories drawn from life.

There is an important issue of ethics which needs to be discussed before telling the stories; it is concerned with the nature of ownership and consent. The first stories recounted belong to both myself and my son, Spinner; they are part of our shared experience. I am happy to relate them in order to promote understanding, but he might not be. In order to show respect for his wishes, I have told him that I would like to use the stories in my thesis and asked for his general consent to do so. In addition I have read over each story to him, in order to ascertain whether he thinks that I have conveyed it properly, and whether he is happy for it to be conveyed at all. It is the case that there are some stories which I think might be illuminating, but which Spinner regarded as private property. These will not be shared. I have also asked him to contribute stories of his own which, in his view, provide an insight into his experience.
There may be, in some circles, a wider concern relating to Spinner's ability to give consent at all. I have no doubt about his capacity in this regard. He has been involved both in conferences and part time teaching for nurses, where he talks about his experience. In an interview asking him about his life he said

> "I have four jobs. The first job is part time and I do this with my dad teaching nurses about special education. I teach them that we're not different. They always give me the best evaluations. It's a fun job"
>
> Mason 2004. P3

Some of the later stories relate to my experience as a father, and as a helper facilitator and later adviser to self advocacy groups. Other participants in the

narratives will not be identified, and so the decisions concerned with the exposure of material which might make me vulnerable are mine alone. (Ellis & Bochner 2003).

Section 6: Spinner's Stories

***Personhood**:* Spinner is around six years old, and we are walking down the road towards the playground. An elderly gentleman who we know by sight rather than by acquaintance meets us, and asks him "How are you today son?", whilst patting him on the head. He says "I am not a dog you know"

This story has an ethical dimension insofar it was the first time to my recollection that Spinner expressed a view about who he *was. It amounted to something of an epiphany with regard to my personal knowledge, because I realised that he had the ability to take the initiative in a self empowering manner. In terms of social construction, I am not sure that it had much to do with the disabled role; it was possible that this elderly man patted all children that he met.*

***A first step in a performing career**.* Spinner is seven years old. We live in London, but we are in the North-East to visit my parents. As part of a 'Gala Week' in a small fishing town, we attend a folk music concert in a local hotel. He is very interested in the order of the proceedings, and sits himself down next to the compere. There is a gap in the proceedings, and he makes his way to the centre of the stage and says "I am going to do a song now". My first reaction is to try to get him off the stage, but he stands firm. At the time the stars of 'The Young Ones' (A television comedy) have recorded a spoof version of 'Living Doll' and he is very fond of the song. I borrow a guitar from a musician, and provide an accompaniment for him. He is word perfect with regard to the lyrics,

and puts in a number of flourishes. The applause is deafening. A man who is acting as a stringer for the 'Northern Scot' newspaper is in the audience, and the story of his performance duly appears in the next days' paper. Every time we pass that particular hotel, he says "That is where my career started", and it is true that he does own a disco which plays at weddings and parties, and he does get invited up onto the stage to do a song with local bands. He did the same thing when he discovered a bar with an 'open mike' policy when he visited San Francisco.

In terms of my 'standing in relation to another human being, and confronting that human being as a person' , I was literally standing in front of a large audience working out the dynamics and limits of my relationship with Spinner. If I let him go on, was there a danger that, in the guise of an indulgent parent, I would be complicit in allowing him to make a fool of himself, and embarrass the large company of people who were present. In the last analysis I did not have to make the decision; he was adamant that he was going to perform. Perhaps if he had gone down like a lead balloon, he would have been discouraged from future performance. I doubt it somehow! His music, and his performances have become something of a defining characteristic of Spinner in later years.
Is his disability an integral part of his performance and the reaction to it? I can only say that when Spinner is performing with a local band, the lead singer often uses the same joke. "He is performing with a slight handicap tonight.....he is sober!"

Emotional Intelligence*.* Spinner is around twelve years old. We have a dog which has reached the age of fourteen years and is very sick, and I am beginning to think that keeping this dog alive may be meeting our needs, but is causing the dog increasing pain and misery. I come home early from work and decide that as I am 'the man of the house' and I should do something decisive. I take the dog to the vets to be put to sleep.

On the journey home, I am feeling grief stricken and miserable because this dog has been part of our family life for a long time. Turning in to our driveway I suddenly think “How am I going to explain this to him?” I wish that I had taken the time to do so. I walk into the kitchen with no dog, but with the lead in my hand. I haven’t had a chance to say a word. He looks at my face and says “Never mind Daddy, if you love somebody, then you have to let them go”

In Carper’s (1978) terms there is some empiric learning going on here for me. It is being brought home to me that emotional intelligence does not necessarily have to be founded on cognitive intelligence. In reflecting upon this incident, it is clear that emotion is flowing in a number of directions. My own grief forms a background, and my fear about telling him results from my concern about his likely grief. The tables are turned on me to the extent that he is clearly worried about my feelings, and gets in a pre-emptive quasi therapeutic strike. My reaction is “That was going to be my line”. I spent the next few weeks trying to get him to talk about his own feelings about losing the dog.

Protect and Survive*.* We are in the local pub a small North East fishing village; Spinner is aged about fifteen years, and is sitting at the bar, talking to the licensee, who is a very good friend of his. I am on the other side of the room, sitting down talking to friends. About two yards away from Spinner, also sitting at the bar, is a young man of around twenty having a very solitary drink.

The doors of the pub swing open, rather like the scene in a western movie where the baddy walks in and the pianist stops playing. The young man who has made the entrance walks up to the solitary drinker and says “I didn’t like your brother; I don’t like you; if you want to make something of it… outside…now”

I struggle to my feet with much scraping of chairs, in order to rush over to utilise my two degrees and counselling skills to protect Spinner from getting involved in this fracas, which is literally two feet away from him. Before I can get anywhere near to him, he looks over his Lucozade and says very loudly “Boys….*please*…. this is a pub, not a playground”.

There is loud laughter all round; it proves impossible to play the hard man when everybody around you is laughing.

This story starts with the emotion of fear which impending violence engenders. This fear is overwhelmed on my part by a protective instinct, which is partly to do with the parental role, but also to do with the perceived need to protect a disabled person. As it turned out his capacity to take control of this situation was in fact much more effective than any response I could have mustered. In Carper's (1978) terms there is a much wider 'aesthetic' question about Spinner's intuitive powers .How did he know that humour would be the best way to defuse this situation? Was he aware that the fact that he had a visible disability meant that he was fairly safe from an aggressive response from the two protagonists? I don't think so, I think this was an off the cuff response rather than anything considered .In terms of outcome, and future action, this incident led me to be much less fearful about his vulnerability.

Building Alliances. It is Saturday night in the local pub. A woman in her twenties is getting very drunk, and the more drunk she gets, the more affectionate she is, draping herself around several of the male patrons, including Spinner, who is aged around 17, and enjoying every minute of it.

The next lunchtime Spinner is sitting with his Welsh friend David (pseudonym), and the barman decides he is going to wind him up. He says to him, "Billy was in here looking for you this morning, you ken fit like, he gets very jealous and angry, and he has heard that you were snogging his woman. He asked me where you live, and I wisnae going to tell him, but he grabbed me by the throat….fit could I dee but tell him….sorry"

Spinner looks very thoughtful and says "Oh well, if he comes after me, he comes after me, but he will have to go through David to get to me"
David looks a bit shocked, as if he is wondering how he came to be involved in all this.

There is a cultural context to this story. It is the male North Eastern tradition of the 'wind up'. It is a ritual, a test you need to go through if you are to be accepted as an OK sort of a guy. In a sense there is a preliminary phase in that you have to be part of the (sub)culture if you are even going to get to the stage of being tested .My own feeling was that I was proud that Spinner, as someone who has a very visible disability, is admitted to this cultural playing field. It is interesting to me that the barman felt he was able to include Spinner in this ritual; some members of the culture exclude Spinner, but he seems to have the ability to reach into the culture and achieve membership. It is a very important social skill.

Not only did Spinner have the ability to play the game, but he played it creatively and came up with an adaptation that nobody had expected. I know where the adaptation came from; it is a survival skill (that of making alliances) which you need to learn as person with a disability attending a mainstream school. He needs to be able to make intuitive judgements about whether the threat implied in the wind up might turn out to be a real one. Since there are often parallels between the wind ups, and the trauma's and drama's of real life; within these judgements in themselves it is important to be able to locate the borderline between them.

Anticipating Mortality: Spinner is 21 years old; he has recently left home to live in his own house in a small town around five miles away. He is at home for the weekend when the woman who is acting as his assistant telephones. She is trying to persuade him to take part in an activity on a Friday night. He says "No thank you… Friday is the night I go out for a pint with my dad". She is clearly persisting in trying to persuade him but he is standing firm. He says "Look, I have told you; I need to spend some quality time with my dad before he pops his clogs"

A cold chill goes over my wife's heart.

There is a sense in which this story represents the process of coming to terms with the most obvious empirical fact, that of the fact of limited lifespan. Of course there is a large emotional component; most of us, particularly in out youth find it hard to come to terms with the fact that we are not immortal. One of the roles that Wolfensberger (1972) identified as being given to people with a learning difficulty was that of the eternal child. Children are usually protected from the hard facts of mortality, and some of those who care for people with learning difficulties adopt the same strategy. Although Spinner has been very upset by the loss of people close to him, he retains a matter of fact attitude to the possibility of loss. One side effect is that it brings my wife and I face to face with the fact of our own mortality.

Defining difference: We are going in to the vets to get the dog's injections done. A young man who he has never met before in his life comes up to him and says "My brother is like you" Spinner looks angry and says very testily "Like what?" The young man looks uncomfortable, mutters something and moves on.
Who is the carer? He and I are in a local pub where a friend of ours has a gig with his band. We are having a dance when a drunken lady asks me "Are you his carer?". Spinner replies " No....I am *his* carer."

One of the disadvantages of the disabled role is that it seems to give carte blanche to perfect strangers to tell you about their familiarity / expertise with regard to your disability. In terms of action, Spinner used to be very tolerant; but he is becoming less and less so. He sees approaches like this as being a diminution of his individuality and humanity. He expects people if they want to get to know the real him to make the effort to make his acquaintance properly. Personally, it puts me in a difficult position with regard to people who I don't know who have Down Syndrome; I long to say I know a lot about you; but I have to resist the impulse, because I can feel Spinner looking over my shoulder.

Three tales of sexuality.

(1). We are visiting a family member in Norway who is gay and has a long term partner. Spinner is very fond of both of them. A few days after he met him for the first time, He thinks it is important to make things as clear as he can. He tells his cousin; “I like you Bjorn (pseudonym).....but not like that.

(2). Spinner does a twice yearly class with me at the school of nursing where we do some role plays around the experience of disability and ask the students to comment on them. There are some attractive young women in the front row, and he is giving them his sunniest smile. Half joking, I say “when you are a teacher you have to have a bit of self discipline”. He replies “They were smiling at *me*; and anyway you are just jealous because you are old!”

(3). Spinner, myself, and my wife are doing the rounds of the tourist sites in Amsterdam. One of the ‘must sees’ is the red light district. In the UK and in other countries red light districts require a certain subtlety of approach in order to understand the nature of the ‘nods and winks’ which are on offer. Nothing could be further from the truth in Amsterdam; there is absolutely no confusion about what is on offer. He is a bit bemused by all the comings and goings. As we leave the area he announces in a very decisive tone; “I think sex is something you have with someone you love!”

When Spinner was smaller, there seemed to be a belief on the part of some of the professionals who worked with him that people with Down syndrome were asexual. It didn’t seem very likely at the time, but my wife and I thought that the professionals must know what they are talking about. As he has got older, I have not been able to see any difference between him and any other young man in this respect. It may be that people who live in an institutional setting have a limited opportunity to express their sexuality, but that is a different question.

Four tales of employment

(1) It is time for Spinner to leave the college of further education which he had attended for two years. He and I are talking to a local hotel owner; a man who has spent the majority of his life working in the building trade. We tell him that he is looking for his first job. His reply is “Oh aye..... he needs his dignity”. The thought goes through my head that I spend so much of my time as a professional and a trainer trying to draw the attention of other professionals to that simple truth.

(2) Spinner now works at a community recycling project, which started in a local authority day centre after one of the punters said he thought recycling was important. It has now ‘floated off’ and is part funded by an aluminium producing company. He does not regard the officer in charge as a therapist or helper; he calls him his boss.

(3) Spinner is visiting a distant relative in Hollywood who is a film producer. In conversation it comes up that this relative knows many famous actors. He says to him “I do a bit of acting back in Scotland”. He never lets a chance go by!

(4) Spinner runs a disco which plays at weddings, birthday parties etc. He has a well developed talent for looking at an audience, and modifying his ‘play list’ to suit their tastes. It does not make money, but he enjoys doing it, and it adds to his self esteem enormously.

These narratives, in my opinion, show that opportunities and innovation rely on activity at a number of levels. They rely on the attitudes as well as the abilities of the punter, but they also rely upon the capacity of service providers to take seriously the aspirations of those who use their services. They also show that there are many and varied forms of organisation which can be utilised in order to facilitate inclusion within the wider economy.

Section 7: Father's stories

Telling of the birth*.* My son was born a week ago, my wife is still in hospital; we have been told by the consultant that he has Down Syndrome. One of the functions of the father is to be the conduit of information to the outside world. I have to perform this function at a time when I am still in the stage of adjustment which some grief theorists call 'shock and disbelief'. Every so often I have the thought that it is all a mistake, and I will soon be told that he does not have Down Syndrome at all. My usual script is to say that "mother and baby are doing well, but unfortunately he has Down Syndrome" This usually produces a shocked but sympathetic silence, often accompanied by a reassuring touch.

I am passing by what I have always regarded as a feminist household in our street. It consists of grandmother, daughter and granddaughter; even the Dobermann dog is a bitch. I repeat my usual script, ending with "unfortunately he has Down Syndrome". The grandmother responds by saying "So what; he is a baby isn't he?"

This story is suffused with emotion. Birth is the culmination of the process of reproduction where the aim is to re-produce consciously or otherwise our own biology, personality, familial, social and cultural heritage. The ethic which permeates the process must be one of the only ways of behaving which remains acceptable even though it is totally egotistic .At birth the emphasis is on a future with no constraints, a new being who will make good the unaccomplished ambitions of the parents. When the fantasy dispels, all parents have to come to terms with limited possibilities for their offspring; the parent of a child with a disability faces this at birth if the disability is identified at that stage. The grief process is one way of looking at this experience. The grandmother's response was the first insight that I had into the personal being of my son. I had regarded him as a tragedy rather than a human being up until that point.

First Words: Spinner is about eighteen months old. He is very fond of our ginger cat, and has put a name to it. At that time we are being supported and advised by a peripatetic teacher from a special school. One day when she visits I tell her that he has said his first word. She adopts her counselling posture, and puts on her counselling face, and says that she is sure that I very much want him to speak, but that it is much too soon. He is sitting on the floor, and the ginger cat ambles in. I say to him "what's that?" He says "Cat".

This story puts in a narrative form the clash between the empirical knowledge base of a profession (teaching) which seeks to fix the minimum time at which children with Down Syndrome speak, and the day to day personal knowledge of the uniqueness of one disabled human being. I believe that professionals themselves get caught in the interface between these ways of knowing, and often institutionalise certain practices which are designed to provide clear borderlines between the forms of knowledge. The teacher concerned crossed that border, and later became a friend of the family.

Divine Intervention: It hasn't happened so much in recent years, but when Spinner was young it was not uncommon for little old ladies to come up to me or my wife and say "God has chosen you to care for one of these people". At first I was quite flattered to be chosen by God, but after a while it began to get a bit irritating.

This response is a subtle variation on the "What a tragedy!" reaction. It is still a tragedy, but God has chosen you because he knows you have the strength to cope. The reason for my irritation is that it is not a tragedy: Spinner is a wonderful son, who has talents which are all his own. It is a mistake to confine him to one particular all encompassing category of evaluation.

The moving plateau*:* We have been told by a professional that children with Down Syndrome often 'plateau' around the age of seven. In this story, he is now around fourteen years of age and is bright, humorous and very socially confident, and seems to continue to develop in leaps and bounds. Still, in the back of my mind, the plateau lurks. Will all this come to a sudden end? Is there a precipice at the end of the plateau? The professional *must* know what they are talking about.

We are on a visit to the Highlands, and we have taken to having an evening drink in a small rural pub, which has a pool table. Spinner has given some advice to a rather unconfident pool player. I think about the plateau; people with Down Syndrome have poor eye to hand co-ordination. In pool you need to get both the direction and the velocity of the cue ball right in order to become a competent player. Surely he could never be any good.

The unconfident player is left with the black ball at the other end of the table. He has to hit it at an acute angle in order to pot it. He says to Spinner "What should I do?" He says "Pot it" He says "I can't" Spinner says "I could". Everyone around the table is silent. If this were me taking this shot, I would almost certainly make a mess of it. He lines up the cue on the white ball, and slams the black ball into the corner pocket. Everyone in the pub cheers. I think that somebody up there must act as his guardian angel. Perhaps it is time to rethink the existence of the plateau.

For Spinner, this is a straightforward story of a triumph of his confidence and competence with regard to pool. For me it is a cautionary tale about the unreliability of empiric knowledge. I think I will give up predicting what he will or will not be able to do in the future. I will confine myself to describing what I think he is good at and not so good at currently. On the night I was proud of him, and a little envious of his confidence, and willingness to go for it, whatever the risks to his credibility.

New Parents.

(1) Whilst on a visit to the capital: we are walking across a London Park with Spinner, and there, sitting on a bench by the lake is a young woman in a Hijab and she is looking intently at him. She tells us that she is from Iran, and that she has run away to England, because her family wanted her to give up her baby who has Down Syndrome. We tell her she is right to trust her instincts about her baby, but she needs support. We give her the telephone number of the Downs Syndrome Association in London, and our telephone number at home in Scotland. We never hear from her again and I often wonder what happened to her and her baby.

(2)We are coming out of a swimming pool in rural Aberdeenshire, and there is a couple with a baby getting in to a car. As we are walking towards our car my wife remarks to me that the body language of the father is expressing how precious the baby is to him. When we get nearer, my wife smiles, and the man who is Asian in origin asks about Spinner. Does he work? Can he live independently? It becomes clear to us that their baby has Down Syndrome. We tell them that he is wonderful, which they can, in any event, see for themselves, and we answer some questions about education, work etc. I am optimistic about their baby's future.

These stories illustrate the trauma that parents face in the early stage of their children's lives, and how difficult it is to engage with them in order to help. In both cases we were trying to reach across a cultural gap. New parents are on the lookout for empiric knowledge and hard information, but it is only useful up to a point, because in practice children with Down syndrome are as different from one another as any others. In this situation I try to promote a positive attitude, and encourage parents to utilise their own strengths.

Concessions.

Every time we go to the local swimming pool and I buy our tickets, I say “Two with concessions and one without”. My wife has an ‘over sixty’ concession and Spinner has a disability concession. Each time we do this Spinner mutters.

Then comes the magic day; I reach the age of sixty, and I am entitled to a concession card all of my own! I say “three with concessions”. Spinner has a smirk on his face that reaches from one ear to the other.

I have not asked Spinner what this is all about. I think it has got something to do with a form of personal resistance to the process of having to publicly identify yourself as falling within a particular category. Worse still it has got to do with your parent taking responsibility for doing so; becoming a definer and thus colluding with the forces in the world which categorise you. The self satisfied smile was saying something along the lines of “see how the mighty have fallen”.

Someone to care.

At the end of our swimming session, my wife always gets out of the pool at the deep end, and Spinner and I get out at the shallow end. I am heading for the changing rooms and Spinner walks down towards the deep end where he holds his mother’s towel out for her as she gets out of the water. A young female swimming pool attendant says within my earshot; “I wish I had someone who would do that for me”.

This story speaks for itself; for me it is about the capacity to see the value in someone whether they are disabled or able bodied.

Section 8: Adviser / facilitators stories.

A Shakespearian Tale. I am involved in the planning of a conference about self advocacy. Sitting round the table are five people who have been given the label of learning difficulty and two non disabled facilitators, myself and one other. We are planning feedback from the workshops where people will be talking about their experience of attending special schools, hostels and day centres which cater for people with 'special needs'.

A man who has been a service user says, "What we need for the feedback to the main conference are issues not stories". Another service user says "What do you mean?" The first man says "Romeo and Juliet is a story; love, hatred and betrayal are issues"

I had been a teacher for around eight years at that time, and I could never have defined the difference so succinctly.

The shock that I felt probably resulted from an underpinning doubt about the cognitive and expressive abilities of people who carry the label 'Learning Difficulty'. My unspoken assumption was related to a lack of ability to abstract essences of a problem and then communicate them elegantly. This young man effectively torpedoed that particular stereotype, and produced a characterisation of the problem which, for all present, was evocative of their wider social experience and easily generalisable.

***Different strokes for different folks*.** At a self advocacy conference there is a 'roving mike', and service users are encouraged to say what is important to them about the day. Billy enthusiastically takes the microphone and says that he likes cornflakes for breakfast, and he enjoys washing the minibus with a power hose.

There is loud laughter from professionals and service users alike. The chair of the conference who is a woman who has been through the system of being defined as having a special need shouts angrily, “Show some respect!!!”

The chair was well aware of the ethical content of the knowledge that needed to be shared that day. For her, because of her own experiences, respect is a key ingredient of acceptable practice. For Billy his everyday likes were worthwhile conveying to the assembled company. For the professionals, and some of the more articulate punters present, only abstract concepts that referred to policies were worthwhile communicating.

Tactics We are at a committee meeting of a local self advocacy group. We have received a letter from the secretary of a local social club which has in it a phrase along the lines of “People like you should realise that…….” The members of the group are pretty angry, and the advisers ask for suggestions as to how we should respond, with an expectation that they will want to draft a strong letter. One of the group members says that there is a local group which wants to use drama to help people to express themselves. He suggests that we ask them to make a video within which all the members individually can say how his words made them feel. Then we could send a copy of the video to him.

In the reflective cycle that the group was going through, emotions arising out of the stereotyped views expressed in the letter were washing around. All agreed on the analysis, but the difference came in the activity proposed to deal with it. The particular experience of one of the members had made him aware that unmediated face to face feedback of emotion was most likely to lead to change, first personal, and then institutional. Intuition also played a large role in this understanding of the situation and the plan to deal with it. These qualities are clearly not confined to those who have a well trained cognitive faculty.

Trouble in Store: We have been holding a fundraising event at a local supermarket. The advisers had left, and a member of staff from the group home where Jimmy, one of the members, turns up. Jimmy had left the house without 'signing out' and the staff member shouts at him at the top of his voice to get his coat, because he is going home.

At the next committee meeting the members express their anger at the manner in which Jimmy was humiliated in a public place; treated like a child even though he is a grown man. The advisers suggest that we ask the area manager of the organisation which runs the group home to come to a committee meeting so that they can express how upset they had felt. The group are reluctant to do this, fearing that it will only cause trouble for Jimmy in the future. It is only after a lot of discussion that they come to the view that if they don't make their feelings known, there will never be any change. The area manager and group home manager do attend a meeting, and agree that the member of staff should not have behaved that way. They promise to work upon both his knowledge and his practice.

Leaving Early: The group has one of its fundraising dances, and at 9.30 it is in full swing. A group of residents from a group home get up to leave, because the shift is changing at their residence, and there are no hours available to support them after 10pm. When the management of the home is challenged at a later date they say that the people get tired, and suggest that the disco starts earlier. The members of the group ask who, in their right mind, would go to a disco at 6.30 in the evening!

These two stories illustrate the power of institutions to determine the manner in which people think and act. In the first story the whole experience of the members had told them that it can be dangerous to speak out, so it was best to keep quiet. It took a long while for their confidence to grow, and to some degree the second story shows that they have developed a capacity to take on the

management of institutions when they think that their life chances and choices are under threat.

Section 9 : A Diversity of Outcomes

What has been written in the early part of the chapter about the multiplicity of 'ways of knowing' must mean that each reader takes from these stories that which enhances their own understanding of the experience of that form of difference which is given the name 'learning difficulty'; perhaps utilising one of the frameworks that have been provided. Riessman (1993) emphasises the complexity inherent in the process of representing primary experience through the medium of research. She identifies five levels of representation (attending, telling, transcribing, analyzing and reading) and acknowledges that each level represents both an expansion but also a reduction. Holloway and Freshwater (2007) distinguish narrative enquiry from other qualitative approaches by emphasising its coherence and sequential form, and are of the view that participants in the research have more power to the extent that they control the form and content of the story.

I hope that the stories related above both give some direct insight into the day to day experience of myself and of those who are close to me, but also provide some understanding of the context within which research within the other 'sites of interest' took place.

Chapter 9: Interpersonal evidence and inferences.

Will your anchor hold in the storms of life,
When the clouds unfold their wings of strife?
When the strong tides lift, and the cables strain,
Will your anchor drift or firm remain?

Traditional Hymn popular in fishing communities.

This chapter is structured in 8 sections.

Section 1: Introduction
Section 2: Patterns of exclusion and difference.
Section 3: Routine and structure contrasted with activity and spontaneity.
Section 4: Personhood and the boundary between punters and providers.
Section 5: A place within the economy.
Section 6: Gender, sexuality and the spectre of reproduction.
Section 7: Having a voice.
Section 8: A comment upon the content of the synthesis.

Section 1: Introduction

Provision for people who have been assigned the diagnostic label of 'Learning Difficulty' has changed and developed dramatically in the north east of Scotland over the past decade. Two 'hospitals' which, in retrospect, were large scale residential units for people with learning difficulties have closed, and face to face care for people with learning difficulties is no longer provided by qualified social workers or registered nurses. The huge majority of people with learning difficulties, as ever, live in their communities with support from their family and others around them. Those who require more formalised support are linked to a variety of local authority, health service, commercial, and not for profit institutions, where if service providers have qualifications they are likely to be vocational rather than professional. (Appendix 6) In order to anchor ourselves amongst these 'strong tides' of change it is important to review the evidence in order to guide the planning and provision of services in a manner which takes cognizance of the views of those who have provided services in the past, and who are the recipients of services at present. Such evidence will be sought within four 'sites of interest'.

(1) The history of residential care within Lhangbyde hospital will be reviewed.
(2) The experience of those 'providers' who worked with those who were designated as 'patients', but have been given the appellation of 'punters' within the study.
(3) Key themes will be abstracted from the experiences of 'punters' which were explored within discussion groups and individual follow up interviews.
(4) The final source of evidence to be examined will be the 'Intimate Narratives' derived from the experience of the researcher as both a parent and a facilitator for a self advocacy group.

The prime objective of the chapter will be to synthesise the understandings gained from the four types of research activity outlined above, and to provide a theoretical foundation for the final chapter which will seek to set out the

implications for a form of practice which as well as reporting findings through the more formalised channels, will involve punters in the dissemination of those findings in such a manner as to empower them and facilitate their increasing influence on the process of planning and providing services. The process of synthesis will involve identifying strategic issues or themes and drawing out meanings from the four respective forms of research activity. Strauss and Corbin (1998) cited in Chapter 3, identified the efficacy of a coding device they gave the name of the 'Conditional Consequential Matrix'. They made use of the device during the process of analysis by pointing to a number of analytic points

> "(a) Macro conditions /consequences, as well as micro ones should be part of the analysis (when these emerge from the data as being significant).
> (b) That the macro conditions often intersect and interact with the micro ones.
> (c) Thereby, in direct or indirect ways become part of the situational context; and
> (d) That the paths taken by conditions, as well as subsequent actions / interactions and consequences that follow can be traced in the data (the paths of connectivity)"
>
> Strauss and Corbin 1998 p182

This formulation captures eloquently the manner in which, within the field of learning difficulty services, the history of past policy and practice, and the dynamics and routines of everyday service provision combine together to form a situational context. In this chapter, findings from the long past and more recent history, both within the hospital and within the community, will be drawn together in order to try to trace these 'paths of connectivity' and provide an understanding of the present in order to form the foundation of some comments upon future policy and practice.

Section 2: Patterns of Exclusion and Difference.

In his analysis of the experience of those who were classified under the heading of the disorder entitled ‘madness’ Foucault (1971) identified the central theme as centring upon social and moral order. Hunter (1987) made the point that within their search for ‘order, stability and permanence’ (See Chapter 4) our nineteenth century forbears set up patterns of care which became difficult to adapt.

In 1865 Lhangbyde hospital was set up as a county asylum charged with identifying and containing those who had been identified as ‘Pauper Lunatics’. In those early days there was little distinction made between those who were defined as mad and those who were identified as ‘defective’, and it was not until the early nineteen fifties with the coming of a regionalised health service that Lhangbyde was designated as an institution for adult mental defectives of both sexes. For at least a decade *after* it had been designated as such the hospital struggled to deal with the legacy of the asylum. In terms of the *physical environment* there was a movement away from prison like layout which was deemed appropriate for the perceived needs of the pauper lunatics and towards a campus environment which sought to promote the growth of a ‘community of souls’ where the governing metaphor was one of the ‘unsophisticated receptive eagerness’ of childhood with the more able promoting the progress of the less able. With regard to the classification of the patients, there were *always* those who had been admitted before Lhangbyde became a specialist institution, and had become an established patient for whom the precise diagnosis, and the reasons for remaining resident, had become somewhat hazy. There were those who presented challenging behaviour, and were designated as being ill and in need of psychiatric treatment in the ‘sick ward upstairs’. There was a sense in which the boundary between disability, sickness and other social problems *remained* an indistinct one. Medical and psychological practitioners saw it a major part of their role as late as the mid 1980’s to root out those who did not ‘really’ have a learning disability and to discharge them into other provision.

For those who had been unambiguously assigned to the category of mental handicap or learning disability, there was a further process of differentiation which took place. This was the separation into the categories of ‘High Grade’ and ‘Low grade’.

This *structural* differentiation between categories of disability or illness had powerful implications for the everyday interpersonal and wider social process within the hospital. If providers were assigned to a ward where patients were classified as ‘sick’ in the sense that they had been diagnosed as being mentally ill, or as exhibiting ‘challenging behaviour’ the atmosphere would be described as being institutionally difficult and personally not very fulfilling to work within. The ward would be locked, and the staff would be tasked to provide close observation as well as an ability to restrain patients both physically and through the use of medication. Those who worked in wards where people were ‘sick’ within the more usual definition of the term had to exercise a therapeutic role in relation to such conditions as diabetes or cancer. One provider said that if the two definitions of ‘sick’ were not sufficiently distinguished the result was ‘horrendous’ with nursing staff having to restrain disturbed patients at the same time as providing palliative care. Having made this distinction it was sometimes the case that patients who had been admitted with a ‘psychiatric’ label became ordinary ‘residents’ who fitted in unobtrusively within the day to day life of the hospital.

For those who had been ‘graded’ the experience filtered down into their self concept and into the discourse of everyday life. In chapter five under the sub heading of ‘Status and Hierarchy’ it was noted by providers that there was a clear ‘pecking order’ with punters using the term ‘low grade’ when they wished to insult a fellow punter. One provider told of the existence of separate ‘high’ and ‘low’ grade parties and the upset felt by a young man who felt that he had been assigned to the wrong grade. In later years the use of the terminology as a descriptor of individual people was frowned upon within the hospital, but the

classification of people with the aid of a measurement of their intelligence quotient still continued.

During the discussion group for punters one respondent took this definition of process of exclusion and differentiation one stage further. He used the term ‘misfit social outcasts’ to characterise the experience of people with learning difficulties. Another respondent widened this definition to include people with physical disabilities and those with mental health problems. Such excluding and differentiating behaviour was thought to be the result of ‘negativity and small mindedness’, and was contrasted with the ability of some of their supporters to be ‘natural’ in their relationships with people who carried the label of learning difficulty. Within the intimate narratives stories such as those entitled ‘Emotional Intelligence’ and ‘Protect and Survive’ convey the message that including people within a particular diagnostic category does not provide reliable information about their ability, or a reliable guide to the provision of appropriate support.

In summary, it appears that within all four ‘sites of interest’ the structures and processes of categorisation and classification have a profound effect upon the social milieu and the associated definition and self concept of people who carry the label of learning difficulty.

Section 3: Routine and structure contrasted with activity and spontaneity.

During the archival work it became clear that although the nominal / official models of care changed (for example from the provision of ‘attendants’ within the county asylum to ‘nurses’ within the mental handicap hospital) the routines of the institution were always thought to be of key importance. For example, in 1949 the “General Rules for management under the Mental Deficiency and Lunacy Act 1913” set out clearly defined roles and rules. The emphasis was on the responsibility of staff to care for people who are unable to care for

themselves rather than upon assessing and meeting the particular expressed need of individual patients.

In chapter five, evidence was presented which made clear the centrality of temporal routines within the hospital. Certain days were put aside for certain activities, and providers had a fairly clear idea of what should be happening at any particular time on a particular day. Activity revolved around the key activities of waking, washing feeding and clothing. There was evidence that whole cycle of routine was primarily influenced by the need of the kitchen. Another area where, routine seemed to be the only method of maintaining order, was that of clothing. Clothes were divided into 'hospital clothes' which were communal, and 'good clothes' which were personally owned.

Such an emphasis on routine can be contrasted with the replies of the punters when asked what made it worthwhile to get up in the morning.(Chapter 6) They emphasised activity; having 'different things happening', being able to 'conquer everyday little conquests'. In contrast to the value placed within the hospital upon being able to predict the course of any particular day one respondent emphasised the fact that one activity might act as a lead in to another unexpected activity. In the hospital, there is an unspoken assumption on the part of the patients, that they are expected to accept the routines of everyday living. The punters make a link with the social aspect of activity; the chance to work with others in a team, and the opportunity to 'have a voice' in determining their own life chances.

In the narrative entitled 'Leaving Early' (Chapter 8) the punters who run the dance get very angry. People who live within an institution, albeit a small institution, have to go home when the party has hardly started because the shift is changing at the place where they live, and the funding authority cannot afford the hours to enable them to stay out later. One of the most important things about going to a dance is spontaneity and novel experience. It loses its edge if you have to return home at 9.30.

In summarising this section and its concern with routine and the various forms in which it presents itself, the description by Foucault, quoted in Chapter 4 of an

> "Intermediary of an equally abstract reason which is order, physical and moral constraint, the anonymous pressure of the group, the requirements of conformity."
>
> Foucault 1971 pp xii."

This gives a sense of the all encompassing nature of the social control within a residential institution. In figure 2, in chapter 4 (Thompson 2003) the manner in which the cultural and social context determines the behaviour of actors within a given institution was set out. The temporal routines which governed the days and times when activities could and should take place, provided a rigorous and predictable form of social control. Undoubtedly these routines had a cost in terms of the freedom and choice of residents, although it could be argued that once they were internalised, they provided a safe and predictable social structure. It is interesting to note that the 'intimate narratives' make clear that there *continue* to be instances where it appears that the needs of the institution rather than those of the punters determine the manner in which services are organised. The most significant finding would seem to be that Punters value the opposite; it is part of what it is to be a good day if things *do not* turn out as predicted.

Section 4: Personhood and the Boundary between Punters and Providers.

> "One major development in persuading people to pay for things which were once given free is the multiplication of the 'caring professions'. The dominant approach to disability has led to many people being paid to 'fix us' or look after those of us who cannot be fixed"
>
> Mason 2000 p19

In chapter 4 Kendall and Wickham (1999) were cited to make the point that one purpose of analysis is to examine the statements which govern the relationship between subjects and the manner in which such statements go on to produce subject positions. In the past history of Lhangbyde the *dominant* discourse emphasised the importance of separating out people who had been defined as different in the light of their learning difficulty, and attempting to 'fix' them in a particular manner. Certainly at the time of the creation of the hospital as a specialist centre for the mentally defective in the early 1950's the governing discourse advocated the gathering together of people who were so defined within an 'adult deficiency colony for the region ' so that they could be 'educated and rehabilitated' rather than treated.

The implication of such a classificatory process for both punters and providers was that in order to evolve an unambiguous definition of what it meant to fall within either of these respective roles, firm boundaries had to be established. For the punter such definition often revolved around measured intelligence quotient, or the so called stigmata of degeneration such as physical deformity or vacancy of expression. The wearing of 'hospital clothes' referred to above further reinforced this definition. The cumulative effect of such process upon self concept was to persuade the punter to accept a subject position which was fundamentally different to that of the provider, and entailed the ascription of a lower status.

That is not to say that there was a total lack of resistance to such a definition. In chapter five it was made clear that punters would often try to interact with the nursing staff as providers rather than spend time in the company of their peers, as a means of symbolically breaching the boundary Within the dynamics of the grading process they would make strenuous efforts to ensure that other people viewed them as 'high grade'.

For providers such as Lochinvar in Chapter 6, the process of assuming the occupational / professional position of being a provider was a long and complex one. For nurses in particular it did not usually include a vocation to assume this type of role. Several respondents described a rather fatalistic attitude to drifting into the role of provider.

One particular task during the acculturation process was to personally manage their relationship with the punters. They describe the impact of coming face to face with so many people who were very dependent in terms of their support needs, who might be immobile, and sometimes had communication difficulties or made strange noises. The hospital instituted rules for the staff to follow which sustained boundaries between punters and providers, but there remained for providers a very personal task of adjusting to these boundaries.

In later years changes within the wider community including community placement and more integrated education meant that new providers brought with them into the hospital a more permeable set of boundaries, and in its turn the hospital became more person centred with regard to punters. This meant that the discontinuity between the social norms obtaining in the outside world and the regime within the hospital narrowed to some degree, although there were still pressures arising from institutional living.

For the punters who lived within the community, there was recognition that they were in need of facilitative assistance from people who were paid to fulfil that role, but they emphasised the necessity for ‘natural’ interpersonal relationships. They sought to resist a definition of them by professionals and para-professionals, which characterised them as the objects of therapeutic endeavour and ignored their humanity and individuality. However, those who had assistants providing practical support with the ‘conquests’ of everyday living valued them for their ‘naturalness’, adaptability and flexibility. In fact their criteria for identifying a helpful assistant came fairly close to the Rogerian requirements of

a therapist; congruence, empathy and respect. (Rogers 1961) They felt that someone who had bad experiences themselves were likely to be able to travel across the boundary between punter and provider and to put themselves ‘in the shoes’ of a person who had been defined as having a learning difficulty and were also less likely to patronise. One factor which might have contributed to this ability to work across boundaries, might be the shared assumptions between punters and their assistants concerning such matters as kinship, social networks and local culture. This, in its turn may mean that although punters who live within the community recognise the role of helper, they do not feel obliged to adopt a self concept which identifies themselves as being different in kind from the rest of humanity.

Within the intimate narratives, several of the stories address themselves to the dynamics of establishing personhood, and resisting the tendency of both institutions and professional practitioners to classify and objectify the experience of punters and those around them. The chapter seeks to show that punters are indeed ‘people first’.

Section 5: A Place within the Economy

From the time of its opening in 1865, Lhangbyde always had an intimate connection with the local economy. The District Lunacy Board which negotiated the financing and construction of the asylum was composed of men of substance from the local, agriculturally based, economy (Ferguson 1981). The land upon which the hospital stands was purchased from a member of the local landed gentry, and when the hospital became operational, local expertise was utilised to ensure that the annual rate of board for patients actually declined from twenty three pounds and ten shillings at the date of opening to eighteen pounds five shillings in 1900. Such low rates were possible because of the profits that were made by agricultural endeavour within the institution. Before the coming of the health service, at a time when the costs of boarding out patients were borne

by the Poor Law Guardians of the parish, it was not uncommon for the more able patients to be ‘boarded out’ with local farmers.

This wider social and economic context continued to have implications for the internal economy of the hospital. Although they were termed ‘patients’ there was no expectation that they were shielded from the obligation to contribute towards their own keep. As well as working on the farm, or in the laundry, the more able patients might be expected to undertake some employment which contributed to the care and maintenance of the building, or the care of less able patients. Such work was undertaken in the company of ‘providers’ who were commencing at the bottom of the occupational ladder within the hospital. In chapter six, Solar describes beginning her career as a nurse at the bottom of that ladder where she was expected to undertake domestic duties in company with four patients. It was thus certainly the case that the labour of punters always constituted a large component of the economy of the hospital.

For providers the existence of the hospital meant a source of steady employment if the key local industries of fishing and farming did not appeal, or were undergoing a downturn. The result of this was that there were many kinship ties within the hospital, with succeeding generations being drawn into its ambit of the hospital. In the late nineties, when active plans were being made for the closure of the hospital, much of the protest in the local press hinged upon the loss of such a large source of local employment, rather than a wish to retain hospital based care as a means of meeting the needs of patients.. Even after its’ formal closure the buildings remaining unused at Lhangbyde were marketed as a ‘development opportunity’ so it may be that it will retain a (different) role in the local economy.

The issue of economic activity was not raised directly within the punters discussion group except insofar as ‘activity’ was valued as a means of giving structure and meaning to everyday life. By definition, the members of the group

were involved in self advocacy activity and sometimes got paid an expense allowance for what they did. It was a source of some resentment that earnings limits which are applied to those who are on benefit are not applied progressively. It is usually 'all or nothing' and this means that members of the group have to be very careful about undertaking paid work. A related point is that it can be galling for people who have learning difficulties to be the 'star turn' at conferences etc, whilst their audience is made up of people who are paid to be there. Some members of the group are employed on 'therapeutic earnings' within community based enterprises, and all of the group members took part in planning and providing a conference for people with learning difficulties which was focussed on the need to promote 'real' employment. (People First 2003)

Within the 'intimate narratives' the stories of seeking and finding employment, and of the efficacy of innovative approaches to the promotion of employment on the part of local authorities and other service providers, show how important it is to the self esteem of punters to be seen to make an economic contribution, and to be valued for that contribution.

Section 6: Gender, Sexuality and the Spectre of reproduction.

Within the archival material the researcher came across very little discussion or justification of the process of gender separation. It was simply taken as a fact of life within Lhangbyde; the topography of the hospital and the rules governing access to particular locations said it all.

Day to day administrative and managerial practice reflected this assumption of gender separation as a natural order of things (Leslie et al 2003).

This historical legacy of a governing discourse which assumed a rigid separation of the genders survived until much later, and was reflected in the experience of providers. In practical terms there were indeed two hospitals within one. The 'full parole' days for men and women were different, in order to preclude the

possibility that they might meet outside the ward situation. In later years respondents who had responsibility for the overall management of the hospital recognised that any movement towards normalisation would have to accept that some contact between the genders was unavoidable, and even desirable. In the later years, patients were allowed to entertain friends of the opposite gender in their 'home' ward, and a few of these relationships culminated in marriage. It was acknowledged that some patients *were* in a position to give informed consent within a sexual relationship. The prime objective became to keep a balance between such normalisation and the responsibility of the hospital to protect the most vulnerable (usually women) patients from the more predatory (usually men).

It should be remembered that there was a sense in which the hospital also exercised similar controls over its' employees; especially the female staff. Thus the discourse of 'safety' was employed to cover both punters and providers, although it was most commonly applied to those of the female gender. For patients the rules relating to gender, sexuality and the possibility of reproduction shaded into one another. It is possible to trace the imprint of eugenic ideas and the influence of a populist version of Social Darwinism within this discourse. (Oakes 2003). In the latter years of the hospital's existence attitudes and policies were modified to some degree.

> "Relationships blossomed and ultimately the once unthinkable happened. We had residents who wished to marry. There were two marriages in the hospital, the parties concerned moved into a self contained flat, learned the required skills, and then moved out to make anew life for themselves in the community"
>
> Leslie, McHardy et al 2003 pp25

Within the punters discussion group the issue of gender did not, in itself, appear as being of particular importance. On the other hand there was a lot of

discussion focussing upon the relationships *between* the genders. There was a general emphasis on the importance of peer support and a specific opinion that having a partner made it easier to undertake the day to day tasks. All members of the group were adamant that it was part of what it is to be human to express emotions within the medium of intimate relationships and to have the opportunity to become parents if that was what they wished to do. There is some evidence from the literature that punters were right to be concerned about the lack of support provided for parents who have a learning difficulty (Booth and Booth 1998, Harris 1998) but what was noticeable was the degree of emotion attached to any pronouncements made about the issues of sexuality and reproduction, and the implication that punters felt that the responsible authorities exercised their power over parents with learning difficulties capriciously in a manner which did not take account of the views of punters.

Within the 'Intimate Narratives' it was made clear that the process of making *assumptions* about the sexuality of people with learning difficulties is fraught with danger. In fact all the evidence from the narratives would indicate that people with learning difficulties have to face up to the common dilemma's that *all* human beings encounter, and that the experience of carrying a certain label simply adds to the complexity of the issues around gender, sexuality and relationships.

Section 7: Having a voice

In tracing the 'paths of connectivity' within the sub headings outlined above the issue of differential power to both define and control practice and provision for people with learning difficulties has cast a shadow. Within the punter's discussion group the issue of having a voice seemed to be of prime importance in a number of areas of discourse. Consequently the researcher has made the decision to end this synthesising chapter by exploring this theme as it has manifested itself within the four major 'sites of interest'.

Within the archival material the notion of patients having a voice was noticeable almost entirely by its absence. The discourse within the early casebooks around admission of patients refers entirely to the process of identifying certain diagnostic characteristics such as intelligence level or visual stigmata, and using them as criteria for admission. There was no thought of recording the patient's opinion regarding their admission. The criteria for admission also required that certain paperwork such as a 'petition' by the public assistance officer was completed, and in chapter four a complaint on behalf of a patient who was refused admission was outlined. In the day to day running of the hospital, professional staff made all the decisions about what constituted desirable or acceptable behaviour. This found its most systematic form within a token economy system introduced in one of the wards in 1974.

> "We valued each resident's individual behaviour programme at 75 tokens per day with bonus points for extra duties which meant that approximately 80 tokens could be earned daily; 32 tokens could be exchanged for 32p and the remainder used towards reinforcers such as watching TV, playing music etc"
>
> Leslie, McHardy et al 2003 pp21

In the 1980's under the influence of such ideas as normalisation and person centred planning the governing discourse changed and patients began to be referred to as residents. They were allowed to take part in meetings called to plan for their future, and were give access to the services of an independent advocate if they wished to use one. Even later, residents groups were set up in order to promote personal choice both with regard to day to day living and in relation to the long term planning for their future.

For providers, their viewpoint concerning the process of punters gaining a voice was inevitably constrained by their position within an institution which assigned patients to a particular role. In the view of the researcher there were three

particular areas of discourse concerning this role which made it difficult for providers understand the importance which punters might attach to having a voice.

The first of these related to the complexity and ambiguity of definition which applied to the sick role within Lhangbyde. Within a hospital, people are normally defined as 'ill' and are exempted from normal social roles and responsibilities as a result of that definition (Parsons 1951, Cockerham 2001) but have the obligation to seek appropriate help from a technically competent person, normally a doctor. There is a secondary obligation to co-operate fully with that doctor in order to become 'well' and to resume a normal role in the wider society. Within Lhangbyde it is apparent that there were a large group of residents who could not be defined as being sick in these terms, for whom the hospital acted primarily as a residential resource, or even provided 'asylum' in the proper sense of the word. There were two, much smaller sub groups; those who are physically ill, and those whose entitlement to be included within the sick role rests upon forensic considerations. Doctors and other associated professionals saw it as their role to utilise their expertise to provide expert services for people who were defined as patients. In all of the interviews, no provider expressed the view that it was necessary for punters to have a voice in the planning and provision of such services.

The second area of discourse was that relating to protection, especially with regard to female patients and particularly within the area of sexuality. This discourse underpinned the system of 'full' and 'ground' parole. Punters needed to be protected from the outside world insofar as they had to prove themselves to be capable of operating with a degree of independence before they were allowed to explore it. There was also a sense in which the outside world had to be protected from the punters themselves. This discourse of protection meant that providers assumed a responsibility for decision making on behalf of punters,

and it was thus very difficult to concede any real power in such a manner which would enable punters to have a voice.

Thirdly, and finally, the discourse employed by providers to describe the process of change within Lhangbyde over the years led the researcher to the view that there was only a limited commitment to a form of empowerment which would give punters an authentic voice. One respondent talked in terms of 'quiet advocacy' on behalf of punters rather than the promotion of *self* advocacy. Specific examples included the covert management of pocket money on behalf of punters by holding back a proportion until later in the week, or, more subtly, seeking to protect a punter from the disappointment of being let down by relatives who do not live up to their promise to visit the patient. Such strategies were often employed with the very best of intentions, but did not give the punter the chance to deal themselves with the vicissitudes that life throws up. Even when they were given real choice, such as occurred with the end of communal clothing and the substitution of individual purchase and ownership; such choice was seen as being 'allowed' rather than as being a human right. Even at the time when punters were moving out into the community, there was pessimism on the part of the staff as to whether the level of acceptance within the community was sufficient to enable community placement to be successful. In such circumstances the researcher senses a strictly limited scope of commitment to the goal of giving punters a voice.

Within the punter discussion group the theme of 'Having a Voice' was identified and named by the respondents themselves. It first comes up in the discussion when 'activity' is defined in terms of the person with a learning difficulty having a voice and not being led by members of staff. The corollary of having a voice is to demonstrate to the wider world that people with a learning difficulty are not necessarily passive or incapable. The discussion moved on to consider the effect of having a voice or not on the life experience of the individual person with a learning difficulty. On the positive side doing something to help or advise was described as promoting a good feeling inside, being a source of satisfaction in

itself. Utilising their voice to express themselves did not just relate to matters of strategic importance. Having control of small, everyday decisions about such matters as when you eat and what time you get home was seen as a crucial determinant of self esteem. On the negative side being denied a voice was seen as being likely to result in the person concerned becoming upset and very emotional. Such upset was often missed by those providing services because it was expressed through the medium of non verbal communication; by the expression on their faces. For one respondent in particular the issue of not having a voice is less to do with a lack of capacity on the part of the person who has a learning difficulty and more to do with the propensity of others to speak for them.

The root cause of such a denial of a voice for people with learning difficulties is seen to lie within the practice of institutions rather than individuals. The punters produced their own term for this process; they called it being ‘overpowered’. They were not optimistic about the ability of professionals to break away from these patterns. They saw the antidote to this tendency as resting with the development of their ability of punters to speak up for themselves. They saw the support of their peers as being crucial to the capacity to speak up for themselves. They expressed the emotion behind this process with the aid of the expression ‘Braveheart’.

Insights derived from the intimate narratives added to what had been said by the punters about the importance of having a voice. On an individual level Spinner demonstrates that he has a voice of his own, in the way he talks about the way he regards his four jobs. Professionals and some able bodied people would probably define what he does as activities rather than jobs, but he is insistent on defining them on his own terms. In ‘Protect and Survive’ he shows himself to be perhaps more capable of adapting the manner in which he speaks up for himself than those around him, and the outcome was certainly positive, perhaps more positive than if a professional counsellor or mediator had been involved! The fact

that he has a visible disability may constrain the manner in which others react to him, but he has a well developed capacity to step outside conventional social roles. This ability to step outside conventional roles sometimes may provide him with the capacity to say things that other people may be thinking, but are too inhibited to express. The ‘Anticipating Mortality’ narrative demonstrates the positive contribution that such a capacity can make. It may well be that his long experience of self advocacy has provided him with the personal strength to be assertive as was demonstrated within ‘defining Difference’.

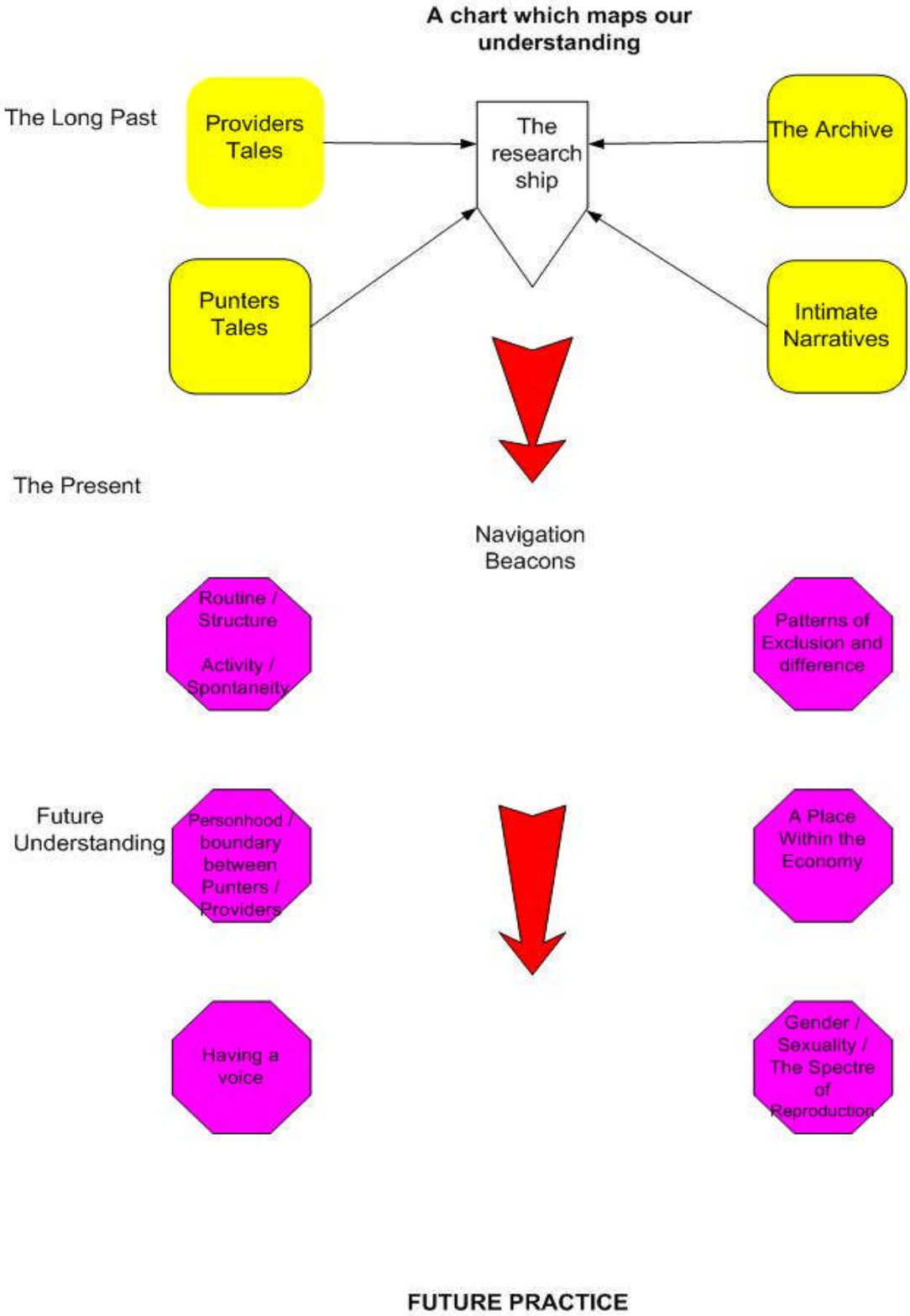
It was certainly true for the punters that the support of peers was essential if they were to develop the capacity to have a voice, and it is significant the narrative “Trouble in Store” was enacted many years ago. It is the feeling of the researcher that the punter who was the subject of the bullying behaviour would have been less passive in later years. Having said that some punters seem to have an inbuilt capacity to use their voice effectively; (A Shakespearian Tale) which may have more to do with their own individual life experience than external determinants.

The findings which seek to aid our understanding of the past and present as a foundation for future planning are set out in diagrammatic form in figure 11. Once again the nautical metaphor is employed, this time attempting to summarise the findings which have emerged from the whole of the research process. The chart has a temporal element in that it acknowledges the influence of past discourse and practice upon the present. It seeks to use the combined findings from all four sites of interest as ‘navigation beacons’, insofar as it is not thought possible to specify exactly what course to steer, only to map where the sandbanks and shoals are to be located. It is interesting to note that, although they emerged from separate and very different sites of interest, there is a degree of equivalence to be found in the findings.

The most important lesson from all of these is that those who seek to make their voice heard must be listened to with respect and this includes allowing them

both the time and space to speak. It is not enough for professionals to seek to 'empower' service users. In the punters' discussion group great emphasis was placed on the tendency of professionals and members of the wider community to *'overpower'* people with learning difficulties and to deny them a voice. Such a tendency is all the more pervasive because it is rooted in the dynamics of institutions rather than necessarily within the intentions of individual actors.

Figure 11


A chart which maps our understanding
The Long Past
Providers Tales
Punters Tales
The research ship
The Archive
Intimate Narratives
The Present
Navigation Beacons
Routine / Structure
Activity / Spontaneity
Patterns of Exclusion and difference
Future Understanding
Personhood / boundary between Punters / Providers
A Place Within the Economy
Having a voice
Gender / Sexuality / The Spectre of Reproduction
FUTURE PRACTICE

Section 8: A comment upon the content of the synthesis.

In figure 11, the nautical metaphor which has been employed to summarise the findings in the form of a chart has a progressive bias. The journey of the research ship towards greater understanding makes use of the research findings to plan practice which is informed by the experience of punters, providers and other participants in the world of learning difficulty. In section 7, it is acknowledged that the symmetrical topography of the chart is misleading insofar as the key importance of the explanatory theme entitled 'having a voice' means that it has an influential presence within all explanatory themes. That presence requires a close inspection of the relationships *between,* as well as *within* such explanatory themes.

Following Thompson's (2003) schema, the agency which emerges from the *personal* level both recreates and resists the demands of culture and structure. Throughout the archival work, and the provider interviews the researcher, who was an outsider in the hospital world, felt the pervasive influence of a particular matron upon the routines of the hospital, the extent to which staff and patients had sufficient space to be active and spontaneous, and particularly upon the politics of gender and sexuality within the hospital. At the next level, *cultural* imperatives meant that those providers who were nurses were faced with the process of abrupt transition from the role of fisherman or farmer to that of clinical practitioner. The researcher formed the view that the economic self sufficiency of the 'colony' that was Lhangbyde may well have had something to do with the availability of kinship relationships and agricultural skills. At the *structural* level, the coming of the health service and the associated change of function from county asylum to hospital changed the nature of the boundaries between punters and providers, constraining agency for providers in the sense that they developed a self concept that emphasised their therapeutic or facilitative skills rather thinking of themselves as attendants. The movement of patients towards community presence rather than institutional care caused some dissonance on

the part of medical and nursing staff who found it difficult to reconcile themselves to this change.

In the view of the researcher Bourdieu's (1992) scheme provides a further analytic perspective from which to view this summary of the findings. In Chapter 2, (Figure 3) speculation concerning the content of the 'Habitus' section of Bourdieu's scheme focused upon such issues as professional self concept, links to local culture and the organisational culture for providers. For punters there was a general interest in the dynamics of the service users' role and the extent to which they had a voice. One of the findings has been that within the hospital there was, to some extent, a common understanding of the culture relating to such things as 'pecking order' and routine. However within the punters' discussion group, there was a divergence, insofar as activity and spontaneity were highly valued, and this divergence was also reflected within the intimate narratives presented.

Similarly there has been a divergence in habitus as between punters and providers with regard to the categories which were employed to differentiate service users with punters perceiving such classificatory endeavours as being symptomatic of 'negativity and small mindedness'. There are several more examples of such divergence as between the habitus of punters and providers during the process of moving towards community based provision.
An advantage of Bourdieu's scheme is that it is possible to include the culture and tradition of the researcher within the habitus. Within semi structured interviews with providers, the group discussion with punters, but especially within the formation and storytelling within the intimate narratives, the influence of a commitment to facilitating a voice for punters is apparent.

The process of identifying influence of 'capital' is a more subtle one. Without doubt, the changing topography of the hospital, with the movement from the original building designed for the needs of pauper lunatics towards the 'campus' format changed the nature of the Lhangbyde experience for both punters and

providers. With the movement towards community based provision there was undoubtedly a movement away, with regard to face to face care, from the occupational capital represented by registered nurses and doctors. The punters present a very different face to face relationship with largely unqualified social carers. A crucial addition to the capital employed by punters could be said to be the knowledge, skills and attitudes which went along with the development of a voice. There was evidence from the punter discussion group and from the intimate narratives that such capital, in the form of confidence and articulacy, built up over a long period of time. It could be argued that the support that punters received from other punters and especially from partners represented a distinct capital gain.

In figure 3 the representation of possible parameters of the field to be known as difference was very crude indeed, with only two patterns of difference (segregation V Integration and Exclusion V Inclusion) identified. The punters and providers who were consulted have clearly added to the complexity with regard to difference. The providers, in several examples pointed to the requirement s of the institution itself for routine and structure; it seemed to the researcher that the kitchen exercised influence way out of proportion to its importance within the process of treatment and care. Individual providers recognised that any outsider would recognise the bizarre nature of many of the routines, and the strength of the socialisation processes which kept such routines in place. For punters, a key feature of the field known as difference was to be found in the concept of 'overpowerment'. If professionals and other providers who were paid to care were given too much power, they would use such power to unduly determine the life chances of punters. The only remedy to such overpowerment lay in the resistance by punters, rather than by policy and organisational changes.
For the researcher, the levels of analysis identified by Thompson and the threefold division contained with Bourdieu's system, represents a potential fruitful perspective from which to interrogate the detailed findings summarised in Figure 11.

Chapter 10. Conclusion, continuing problems and policy evaluations.

"*If we don't stand up for people with learning difficulties, who will stand up for the people who cannot speak for themselves?"*

Anna (A service user)

NHS Education Scotland (2004) Just Ordinary People: A Videotape .

This chapter is structured in 10 sections.

Section 1: Introduction and theoretical review.
Section 2: Gaining a voice.
Section 3: Combating exclusion.
Section 4: Promoting activity and spontaneity.
Section 5: The boundaries of care.
Section 6: Promoting economic activity.
Section 7: Gender and sexuality; the promotion of an ordinary experience.
Section 8: The Future contribution of research
Section 9: A brief and personal comment upon the application of post structuralist thinking.
Section 10: Summary of recommendations.

Section 1: Introduction and theoretical review.

This chapter draws out implications for future policy and practice from the findings summarised in the last chapter. In chapter 2 the literature relating to evaluative studies of services for people with a learning difficulty and self advocacy was reviewed, along with some relevant sociological perspectives and a tentative framework for the synthesis of empirical findings and theoretical frameworks. In chapter 3 a central research question was formulated which was

focussed upon the nature of that form of ‘difference’ which has been given the name of ‘learning difficulty’ within this research, and then in chapter 9, the findings of the research were contextualised with the aid of the frameworks derived from the work of Thompson (2003) and Bourdieu (1992). In the course or undertaking the research, the theoretical perspectives employed by the researcher have changed and developed, and it is important to be explicit about these changes, in order that implications for future policy and practice can be formulated in a manner which takes account of them.

The background of the researcher within the self advocacy movement inclined him towards an overall approach to the research which was detailed and faithfully descriptive in its selection and use of evidence Glaser and Strauss (1967). The original aspiration of the research was a broadly historical one, which aimed to examine the experience of both punters and providers within the hospital based care system. After the experience of the archival work and the provider interviews, this aspiration was modified in order to access the experience, both inside and outside institutional care, of punters through the medium of group discussion, and others through the medium of intimate narratives. For the researcher, this process of modification and expansion produced the thought that his personal experience should lead him to value what others have called “ontological expertise” (Tregaskis and Goodley 2004). That is to say, his experience of being a parent and an advisor, and his marginal position with regard to professional providers of service provided the opportunity of a research perspective which was reflexive, and to some degree ethnographic (Tedlock 2001). Although the majority of explanatory themes ‘emerged’ from the data within all four sites of interest, it has to be acknowledged that during the historical research, the transcription of interviews / group process and especially within the intimate narratives, the researcher and the informants took part in a constant process of dialogue which resulted in the abstraction of such themes. It is as though this expertise provides the pathways along which the structural

relationships outlined in Thompson's and Bourdieu's schema might flow. The researcher has thus some sympathy with a stance which makes

> "use of a collection of narratives that allow some insight into the specific and localised life worlds or discursive spaces and material conditions of a small number of people"
>
> Goodley , Lawthom et al 2004 p59

In chapter 9 a number of themes gathered from the experience of such a small number of punters, providers and other participants in the research were collected together. In this chapter the task is point to a practice which will enable Anna, and other self advocates, to do as she urges in the opening quotation. In pursuit of such an aim, some have advocated:-

> "the necessity to reconfigure epistemological configurations and to reinvent theoretical practice".
>
> Roets, Goodley and Van Hove (2007) P325

In order to achieve this, the same authors advocate the abandonment of grand narratives including the professionalisation which accompanies modernism and the notion of Intellectual disability as a grand narrative of deviance. They advocate instead the substitution of a theoretical framework which accommodates

(a) multiplicity and meaning (b) heterogeneity and rebellion and (c) a-signifying rupture and power takeovers. (Roets, Goodley and Van Hove (2007) p327.

With regard to the present research, this perspective would entail developing a critique of the manipulative power of discourses such as those associated with 'safety', 'protection' and the 'sick role'. In the light of such universalistic

discourses identified by punters as ‘Negativity and small mindedness’ people with learning difficulties are transformed into the ‘other’. Suspicion regarding some modernist values such as ‘empowerment’ is justified because of the ever present danger of transformation into ‘overpowerment’. The examination of the daily experience of punters, providers and others, calls into question the notion of a biologically or naturally determined human subject, and shows

> “how ‘subjects’ are fragmented, decentred and multiple’
>
> Goodley , Lawthom et al 2004 p100.

The research shows how the selves of punters, providers and other participants in the world of learning difficulty are forged within those grand narratives related to classification and diagnosis, such as grading and testing; and point to the power and knowledge which emanates from professional status.

This critique clearly has implications for the process of application of the findings contained within chapter 9. In the view of the researcher there has to be epistemological rethinking in order that institutional governance and policy formation can truly reflect the experience of punters, providers and others. The findings have shown how both punters *and* providers survive in the real world *despite* the efforts of the ‘caring’ organisations and professions rather than *because* of them. For providers, there is the struggle to reconcile the often bizarre routines of the caring institutions with the humanity of the punters whom they encounter. For punters, the *forms* of segregation and exclusion may have changed from ‘ground parole’ to ‘special needs’; but the fundamental experience of ‘othering’ has not. To put this in another way, evidence from the punters is unambiguous because it vividly outlines an experience of labelling which is negative because it defines and constructs deviance in damaging ways. The contemporary professionalizing / approving use of diagnostic and/ or managerial labelling is supposedly benign, but evidence from the provider interviews holds out the prospect that even *they* recognised the damage that such labelling

caused. It would be interesting to interview current providers in order to establish whether they too recognise this paradox.

In the discussion of the application of the identified themes relating to 'difference' which follows, both discourse and the power relations within which they subsist will be examined. At the end of this examination a short commentary will attempt to make a general point about present grand narratives and their links to those of the past and future.

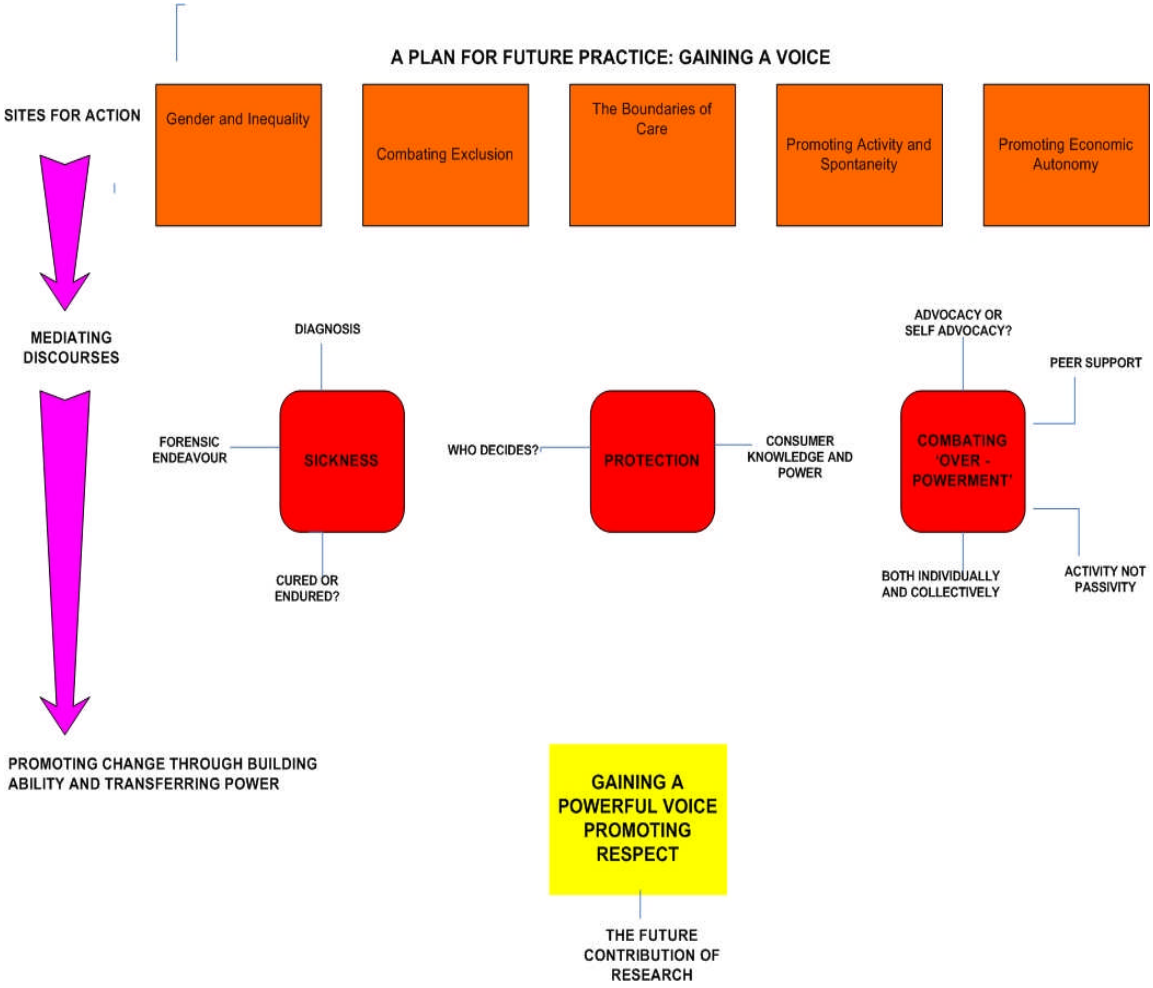
Section 2: Gaining a voice

In figure 12, the task of using the findings of the research as a means of planning future practice has been given a diagrammatic form. The diagram aims to outline the sites for action and the processes which are thought to be influential if our aim is to promote change through building ability and promoting power. It should be noted that it is not presented as a prescription for a direction of travel, but more as a map of the elements of a process which have been identified by the research. The topography of the diagram indicates one of the explanatory themes outlined in chapter 9 has been accorded a pre-eminent status within the process of thinking about future practice. If the task is 'to reconfigure epistemological configurations and to reinvent theoretical practice', then it must be recognised that the issue of gaining a voice is central. For punters, given their identification of the phenomenon of 'overpowerment', the importance of gaining a voice spilled over into their discussions of the other five 'navigation beacons'. This is probably because their voice has been routinely ignored or even actively suppressed in the past (Malacrida 2006, Ryan. and Thomas 1987). For providers it may be annoying or undermining if their voice is disregarded, but they have other sources of fulfilment outside their work. For punters, the imperative to gain a voice is central because their life chances are so often determined by those who are paid to provide services for them. To be sure the results from the punters discussion group and the intimate narratives have shown that people with learning difficulties, both individually and collectively, have the capacity for *resistance* by actively campaigning to change

and develop their life experiences; but they must be aided in this process by policies and practices which transfer power and enable them to gain an authentic voice in the determination of their own life chances.

This perspective emphasising the centrality of gaining a voice is consistent with an international current of opinion. The punters discussion group was formed with the aid of a local People First group, and that group is in turn part of a Scotland wide group which has, in turn, links with the People First movement in mainland Europe , Australia, New Zealand , Canada and the United States (People First Scotland 2003). It is acknowledged that there is something of a contradiction, because of the social and historical construction of disability in particular countries and cultures (Swain 2004), inherent in trying to conceptualise and equate the experience of people with a learning difficulty worldwide. But multi deprivation and common experiences of both material and experiential poverty would lead the researcher to believe there is a firm basis for international comparisons. Much of the theoretical thinking within the thesis draws upon the experience of Flemish self advocates, (Roets, and Van de Perre et al 2004), and the influence of the international People First Movement upon the formulation of the researcher's 'ontological expertise' is acknowledged (Dybwad and Bersani Jr. 2004; Williams and Shoultz 1982).

Figure 12. A plan for future practice; gaining a voice.



However the model illustrated also acknowledges that if this central goal of gaining a voice is to be accomplished, there are some 'mediating discourses', first identified within the hospital, but remaining influential in the present, which need to be both identified and confronted.

The first of these 'mediating discourses' revolves around the sick role and who has the right to speak for whom (Northway R. 1997; Barnes and Mercer 1996.) Within the hospital the psychiatrist and the psychologist saw it as an important part of their role to diagnose who 'really' had a learning disability, and those who fell within this category were accorded the privileges due to them. (Parsons 1951). With the closure of the hospitals and the movement of people with learning difficulties to small, community based units, the terminology

defining roles within the management of difference was gradually amended from ‘patients’ to ‘residents’ and then to ‘service users’. Doctors gradually lost the *inherent* power of leadership within a process of ‘treatment’ or ‘rehabilitation’ but retained their leadership in the community based multidisciplinary teams designed to support people with learning difficulties who needed health related services. Doctors in general and psychiatrists in particular, also retained a powerful role in the decision making role regarding capacity under the terms of the Adults with Incapacity (Scotland) Act, 2000. In summary, although discourse around the sick role was powerful in the past, it does not have now, and will not have in the future, the same level of influence on the day to day life chances of people with learning difficulty. In Chapter 6 Tigger described how difficult it was to assert his right to be consulted about decisions regarding his healthcare. Hopefully people with learning difficulties will in the future retain the right to utilise medical services without giving up the right to at least a nominal voice regarding decisions about the overall direction of their lives.

The second ‘mediating discourse’ which had its origins in the hospital system, but remains influential up until the present day is that of ‘protection’. Within the hospital it was as though those in positions of clinical leadership had an unspecified, but all encompassing right and responsibility to make decisions which they justified on the basis of protecting those who were in their charge. Within the small scale institutions which replaced the hospitals it is the view of the researcher that this generalised notion of a responsibility to protect the vulnerable remains, but there is uncertainty about the scope of such responsibility. (De Chesnay 2005; Spiers 2000) The best that can be said is that there is no residual right or rationale which enables service providers to simply assume responsibility for taking decision or actions which are justified on the basis of protecting adults who are deemed to be vulnerable. The principles governing the implementation of the Adults with Incapacity (Scotland) Act 2000 start from the premise that intervention must be necessary, benefit the adult and must be the minimum necessary to achieve the purpose (Scottish Executive,

2000). It is also thought most productive to intervene without using the act where possible. In both residential and community based care one way of giving a voice to people with learning difficulties would be to involve self advocacy groups in decisions regarding the task of protection. They might provide advice about their rights to people who have learning difficulties *and* contribute their experience relating to the difficult task of deciding what is an acceptable level of risk which might be entailed in facilitating a person with learning difficulties who wants to make their own decisions.

The third and final 'mediating discourse' which has an influence on the process of gaining a voice revolves around *power* and has been given the title 'Combating Over-Powerment'. There has been a good deal written about the desirability of empowering people with a learning difficulty (Ward 1998), but the punters discussion group was emphatic in saying that unless people with learning difficulties gained power over their life chances, there was an inherent danger that they would be 'overpowered' by service providers who may be well intentioned but have no real understanding of the world within which punters live. There may well be a role for many different forms of advocacy (Tufail and Lyon 2007), but the group took the view that it was important to develop the skills of self advocacy (Simons 1992). Positive support from their own peers was central to the growth of confidence and self esteem. It aided them in the process of 'conquering little conquests' and they would recommend that the benefits of self advocacy be extended to other people with learning difficulty. Although the group took part in the 'strategic' planning of services, they were aware that the everyday battles around being able to utilise community resources in the same manner as others were crucial enabled them to be active participants rather than passive receivers of services. (Richards 2007). Such individual conquests and wider campaigns, led them to identify a more profound effect upon both individual self esteem and collective self concept. Although the group see the process of gaining a voice through combating over-powerment, they acknowledge that people with learning difficulty may need to be aided in this

process by advisers, (People First Scotland 2006; Worrell 1988) in the same way that a hearing impaired person uses a hearing person as a signer. The point is that the decision making authority within People First lies with the people with learning difficulties and not the adviser. Their aspiration is that real power and influence in the planning and provision of services should pass to people with learning difficulties so that they can be truly empowered.

If the task of transferring rights plus the ability 'to reconfigure epistemological configurations and to reinvent theoretical practice' is to mean anything in practical terms the world of learning difficulties requires a transformation. It is acknowledged that people with learning difficulties, through the strategy of self advocacy, have gained an input into the planning and sometimes even the provision of services. However the research has found that in the North of Scotland, those who have power over the distribution of resources are still profoundly influenced by some of the discourses which have their roots in the hospital based system of care, and because of an a-historical managerialist grand narrative, seem unable to benefit from many of the gains in understanding which took place within the hospital system.

In the opinion of the researcher, the individual and collective resistance of punters through the medium of self advocacy provides more potential for change. The local People First group working in conjunction with a local drama group, has developed a series of role plays and small cameos which have been presented to groups of service users in day centres, within a college of further education and under the umbrella of service providing organisations. It has also used drama, within a project part funded by The Electoral Commission, as a means of encouraging people with learning difficulties to make use of their right to vote. Undoubtedly participating in drama can allow people with learning difficulties to determine both the form *and* the content of the stories that they wish to tell (Goodley and Moore 2002); but it needs to be facilitated in a manner which takes cognizance of the manner in which the life chances and self

concept of people with learning difficulties have been determined by past experiences within a range of institutions.

On an optimistic note, it is acknowledged that the local People First group is currently involved in a project to extend their use of drama, by taking their productions into 'mainstream' schools in order to pass on their experience to local pupils. In the view of the researcher this represents a real opportunity to 'reconfigure epistemological configurations' at a grass-roots level.

Section 3: Combating Exclusion.

It is a common misunderstanding of the principle of normalisation (Wolfensberger 1972) that its objective is to somehow make people 'normal' whatever that might mean. In truth, the objective is to seek to ensure that the manner in which services are organised does not, *in itself*, have the effect of excluding people from the experience of ordinary living. Although the archival material and the provider interviews showed that there was limited contact in both directions with the wider community, through the medium of family visits and 'full parole' for patients, the overwhelming effect of institutional living was to preclude people with learning difficulties from achieving real presence within the community. Segregation of their lives from that of others impeded enhancement of learning on both 'sides', because fuller participation was thus actively prevented.

During and after the process of closure of the hospitals, the first 'wave' of new provision concentrated upon the building of small units within a diversity of locations. These were usually small scale hostel type accommodation for between four and six residents. Although it was often difficult to establish links between individual residents and particular geographical areas, the small scale of these new institutions meant that they utilised local retail, community, health and social care resources, and that the community presence of people with

learning difficulties increased (O'Brien 1987). Although the new providers (Inspire 2007, Cornerstone Community Care 2007, Ark Housing 2007, Real Life Options 2007) initially concentrated upon the provision of 'bricks and mortar', there is evidence that they later turned, in company with local authorities, towards community support schemes within which people with learning difficulties are supported in their existing homes, rather than being relocated to specialist units. (Council / NHS 2003) From his self advocacy work, and his role in undertaking academic work with post registration students who were employed by the 'new' providers, the researcher came to the view that there was a great deal of variability in the extent to which punters were given a voice in the process of change. Some providers did extensive preparatory work which gave punters real choice with regard to the location of the place in which they were going to live and the people with whom they would share their home. In other cases the consultation was limited to such matters as the decor and furnishing of their rooms.

The evidence presented within Chapters six and seven relating to the opinions of punters and to the intimate narratives, would seem to suggest that this progress towards inclusion requires new attitudes and practices on the part of service providers. New definitions of the nature of learning difficulty or disability seek to avoid rigid classificatory systems which have the effect of excluding whole categories of people from ordinary living.

> "People with learning disabilities have a significant lifelong condition that started before adulthood, that affected their development, and which means that they need help to: understand information; learn skills; and cope independently".
>
> Scottish Executive (2000) 3:5

Such definitions leave scope to avoid the physical and social exclusion of people with learning difficulties, but they retain a naturalistic discourse which implies

that that the genesis of their 'otherness' can be located within something that happened before adulthood, and that the remedy is to be found in 'help'. In contrast to the situation where residential care was provided within a hospital, members of the community now have the opportunity to interact with people who have learning difficulties within their school (Rieser and Mason 1992)) or within other shared community resources. However, punters are pessimistic about the prospects for change insofar as people with learning difficulties continue, some time after the hospitals have closed, to be treated as 'misfit social outcasts'. This pessimism is justified by some findings (Stalker, Cadogan et al 1999) which suggest that physical proximity does not necessarily lead to social integration in the sense of developing friendships with people who are not paid to care. It seems that a discourse of essential difference has survived the transition from hospital to community; indeed many of the discourses relating to 'safety' and 'protection' which were so prevalent with the hospital remain and prosper.

The social model ideally requires that people are not categorised, and that rigid boundaries, which set them aside from fellow citizens are avoided (Bolderson and Mabbett 1991). The evidence from the punters discussion group would seem to suggest that their experience tells them that, in order to benefit from services, people with learning difficulties have to accept assignment to categories which do not reflect their self perception. In order to promote fundamental change in such discourse, and to give punters an authentic voice, power relations have to change so that service users themselves should be involved in setting the terms of the debate within the community in order that individual difference should not result in social exclusion (Roets and Van de Perre et al 2004; Inclusion Scotland 2007). This need not be an abstract debate; People First has played a role in the strategic planning of services for people with learning difficulties in the local area for a number of years. However, strict limits have been attached to the *power* exercised by people with learning difficulties; their input tends to stop short at consultation, with little power to determine the future direction of policy change conceded to them. It is as though

the power that has been taken away from people with learning difficulties by professional discourse is given back to them in small measure.

On a group level, involvement in such activities as being stewards at a fundraising event for cancer research and such initiatives as the 'Make a Difference Day' where they have organised a social event for residents of a sheltered housing complex for the elderly, constitutes resistance on the part of the group to predominant discourse, and could be said, by implication, to constitute the development of a new voice. The effect of such activity is to change the perception of people with a learning difficulty from that of being passive receivers of service to becoming active participants in community life (People First, 2006). The experience of taking part in self advocacy activity could be seen to constitute a training course in acquiring the knowledge and skills which are necessary to achieve this transition from exclusion towards active inclusion. In Bourdieu's (1992) terms it constitutes an accumulation of forms of psychological and social capital.

One of the group members runs a disco which plays at birthday parties, weddings etc and the researcher has come to realise that this is very much his way of demonstrating a voice. The numerous local people who attend one of these disco's are presented with the fact that he makes thoughtful choices about the music he plays, depending on the composition of the audience; and they have to reconcile this ability with the 'otherness' emanating from a visible disability. It may be that the musical form of communication is not so vulnerable to the wider social currents. The discourses emanating from the sick role or the need to protect him do not seem to apply, and the audiences seem happy to complain if he is not living up to their musical or entertainment expectations!

On an individual level such participation in the business of everyday life produces a dissonance which, in the view of the researcher, throws up an epistemological paradox associated with consumer involvement in the planning and provision of services. If a punter is *too* articulate and successful during their

involvement with a planning group or a public discussion, it has been the experience of the researcher, when he has acted as a facilitator / supporter in this situation, that the professionals around the table start to express doubts as to whether this person *truly* falls within the category of learning difficulty. Conversely, punters involved in these processes often point out the unfairness of professionals being paid well to attend conferences, when service users who might be the 'stars' of the proceedings are on expenses or 'therapeutic earnings'.

Section 4: Promoting Activity and Spontaneity.

It appears from the evidence provided within all four areas that institutional living is antithetical to the promotion of an active and spontaneous style of life. In preparation for hospital closure 'supported living services' which emphasised small scale provision were developed. The guiding policy goal for providers was that this reduction in scale of the services would, *in itself*, lead to more community presence, and an increased ability on the part of the service providers to take account of individuality and diversity.

This has happened to a limited extent. The physical presence of people with learning difficulties in the community has meant that local people have become used to seeing them in the supermarket or at social events. However, the evidence from the punters discussion group points to a much wider aspiration and indeed, expectation, on the part of service users. They see the ability to 'conquer everyday little conquests' (Chapter 7) as being fundamental to the development of their ability to put into practice the principles of ordinary living. (Brandon 1988) They are realistic about their need for support, and are complimentary about the assistants who provide such support in a 'natural' and respectful manner.

There are, however, two sorts of constraints upon the ability to develop services which promote activity and spontaneity. The first is the survival of some of the

institutional practices within small scale institutions which were seen in hospital based care: especially those relating to the management of time with the aid of shifts and schedules. One example being the 'Going home early' narrative outlined in Chapter 8, and another being the complaint voiced by Doddy in chapter 7 about the effect of being without a voice in the place where you live. If punters truly had a voice in the 'new' institutions they could make real choices concerning the time that they went out and came home again. Service providers would argue that such restrictions are a function of a limited budget, but this is simply a way of stating that practice is led by service needs rather than punters requirements.

This is closely related to the second constraint which derives from both the amount and the manner of organisation of the funding for support services. Local authorities have largely absented themselves from the *direct* provision of accommodation and community support services, with the result that face to face care of people with learning difficulties is rarely provided by professionally qualified nurses or social workers. Such care is now largely contracted out to private and / or voluntary organisations, some commercial and some which operate on a 'not for profit' basis (Appendix 6). There is a downward pressure on the costs of caring which results in an inability on the part of service providers to be flexible and responsive (Cornerstone Community Care 2006). Another example of the effects of such restricted funding relates to another aspect of ordinary living, namely holidays. Funding for the care of people with learning difficulties ceases after 36 hours absence from their home institution. It would not thus be possible for them to take independent holidays.

It might be thought that the duty laid upon all local authorities in Scotland to offer direct payments to all disabled people by the Community Care and Health (Scotland) Act 2002, might provide an avenue for people with learning difficulties to both access and control day to day services which in the terminology of the punters discussion group might aspire to be 'natural'. However eligibility and

capacity to benefit from direct payments is still decided by the local authority, and the advice and support is provided by a contracted company. At the time of writing the basic ceiling limit for cost calculation in the employment of personal assistants is £6.30. per hour. (Direct Payments Caledonia. 2007) It is difficult to imagine that a consistent and stable system of facilitative care could be financed on such a cost basis.

In the view of the researcher this survival of institutional practices focused around time management, and the tendency towards the retention of centralised budgetary control are symptomatic of a fundamentally unchanged epistemology. The grand narratives which were constructed around diagnosis / treatment and / or rehabilitation within a self sufficient colony (the 'harbour' metaphor) can be acknowledged to be sometimes still present but relegated in importance or marginalised. It appears that the ascendant grand narrative can be said to be that of 'managerialism' (Protherough and Pick 2002): people with learning difficulties *still* need to be identified and characterised as such, and having been so, are consigned to the care not of professional nurses and social workers, but more often to quasi-contractual relationships with a variety of providers organised on the basis of a market system. (Pollock 2004)

It seems likely that if service users truly aspire to services which encourage both activity and spontaneity, they will need to gain not just a voice, but some real *power,* within the process which controls the organisation of support services. It may be that punters have built up some capital as a result of self advocacy activity, but it may be that such capital needs to be invested in the creation of service provision which is controlled by people with learning difficulties. Such control could be promoted *individually* through people with learning difficulties being facilitated to become an authentic party to a service provision contract; rather than being a party whose interests are mediated through the medium of care management. Collectively, self advocacy organisations could be given real

power within the commissioning process to determine which providers are most likely to meet their members' needs.

The ideology of the contractual / managerial grand narrative would posit that service users gain a voice by making choices in the form of the contracts which they enter into. If punters value activity and spontaneity they would make choices which further these objectives. At present they have no authentic voice in the commissioning and contracting process which is undertaken on their behalf by others. If spontaneity and activity regarding *everyday* choices is to be promoted, then punters need to be facilitated to develop the skills which would enable them to exercise real power within the *strategic* commissioning and contracting process.

Section 5: The Boundaries of Care

In chapter 9, the nature and the genesis of some of the boundaries between punters, providers and other groups within the wider society were outlined. The key problem for the future is to use the understanding to design systems of care and support which are inclusive, and enable the punters to retain a modicum of autonomy and self esteem. The lessons from the research are both negative and positive. On the negative side of the equation, rigidly drawn barriers between punters and providers had the effect of construing punters differentially in terms of diagnostic and classificatory categories. Despite such constructions, evidence from the provider interviews made clear that Lhangbyde hospital encompassed a deep pool of both personal and professional experience and understanding relating to the day to day tasks of caring for people who had been defined as having a learning difficulty.

From within the archive, evidence was produced relating to the dynamics of the organisation of services within an institutional setting. With the coming of the health service, and the movement towards specialist regional provision for those designated as mentally handicapped, the governing discourse moved towards a

model which combined medical care with the construction of a self sufficient ‘colony’. There was evidence of conscientious care from committed staff, but the cost to punters in terms of the loss of autonomy and self esteem was high indeed. In terms of future provision, although there are still residential communities for people with learning difficulties (Camphill 2007) whose mission seems to be to provide a refuge or ‘harbour’ protecting them from the vagaries of the world (Rayner 1996), the dominant models of provision require that the objective should be that people with learning difficulties should be integrated with the wider world rather than segregated. For both hospital and then community based providers, it became progressively more difficult to construct firm boundaries around their day to day interaction with punters. There was a sense in which the close geographical and cultural proximity emphasised that which the punters and providers had in common. In the opinion of the researcher all these elements survive to some degree in both present and future planned services.

For punters, especially those whose stories were told within the intimate narratives recounted in chapter 8, despite the fact that they have in the past been treated in a manner which is less than respectful, there was a degree of optimism that it is possible for them to receive that care and support that they need in a ‘natural’ manner without the necessity of being ‘overpowered’. Assistants were not, on the whole, recruited from the ranks of qualified nurses and social workers. If they have a qualification at all (Appendix 6) it is likely to be at a vocational level (College 2007). On the face of it, the relationship between punters and providers has changed from one where professional providers were employed by health and social care agencies, which were publicly accountable; to one which is governed by the law of contract and is answerable only to regulatory bodies (Talbot-Smith and Pollock 2006). But if the contract exists it is a proxy one, with the punter more likely to be a spectator to a contract between commissioners of health and / or social care on the one hand and a commercial or not for profit provider on the other. It will be interesting to see if these ‘new

providers' develop any professional aspirations of their own, and whether such aspirations will be modelled on the traditional professions such as the law or medicine; where practice is based on a systematic body of theory which leads to authority recognised by their clientele, and the wider society endorses broader sanction and approval of this authority. It seems more likely that such providers will define their professionalism in a different manner, and see themselves as a reflective practitioner whose mission is facilitative within a context of a fragile and uncertain knowledge base (Jones and Joss 1995). If this is the case then the boundaries between punters and providers are likely to become more fluid, in response to the variety of helping relationships on offer.

If the boundaries of the caring and supportive relationship are to drawn in such a manner as to provide a service which meets the needs of people with a learning difficulty in a manner which combines both inclusiveness and competence, then the new providers and the traditional caring professions must learn from one another. Registered nurses and social workers can contribute their understanding, built up over a long period of time, of both evidence based methods of helping and the 'ontological expertise' arising out of long experience of face to face contact with people who have learning difficulties. These 'new carers' and local providers tend to be close to the communities within which they work, and have not been subjected to the sort of institutional pressures which lead them to develop rigid and stigmatising concepts relating to people who have a learning difficulty. Future success or failure is likely to depend on whether modern frameworks of funding and governance will provide enough resources for both education and training of the new providers. There is an opportunity for such training to undermine the diagnostic and classificatory grand narratives by including an input from people with learning difficulties, either individually or through the medium of punter controlled organisations. In this way the voice of the punters could confront that epistemology which regards the 'otherness' which attaches to them as a somehow 'natural' result of a diagnosis or classification. One method of increasing the likelihood of cultural

transformation would be to move away from the 'proxy' contractual system, towards one in which people with learning difficulties had real *power* to determine the goals and methods pursued by the services they use, and the evidence base which underpins them.

Finally, one boundary which is of paramount interest to the researcher, for obvious reasons, is that between the punter and parent or other non professional carer. In the provider interviews there was an implication that contact between Lhangbyde patients and their families was to say the least variable. The dominance of professional 'diagnosis' and the discourse of 'safety' may have led to the belief that it was constructive to leave decision making and care to the professionals; leading to an effective severing of the relationship with families.

Within the intimate narratives, and despite the fact that young people with learning difficulties lived with their family of origin and made lifelong use of community based resources; the stories illustrated how difficult it was to break away from professionally derived discourses relating to such matters as 'plateaus' or 'asexuality': for family members to cross over the epistemological boundaries which had been created by their own life experience. Contact with professionals who are paid to care, and the dominance of the 'sickness' and 'safety' discourses in the wider society can overwhelm the intuition which flows within families. Even within these intimate relationships the notion of 'otherness' can be overpowering. It was only the voice of the punter, the resistance of people with learning difficulties themselves, either individually, or collectively, to being defined in this restrictive manner which effectively challenged such discourses. It has led the researcher, in his parental role, to abandon the attempt to employ diagnostic or classificatory schemes to predict which achievements may be possible or not. It is safer to develop the skill of listening to the voice of the punter and the aspirations being expressed, and to utilise that

which they draw from their own life experience to facilitate self development on the part of the punter.

Collectively, it may be that pilot schemes to enable the punter voice to be heard, to utilise the expertise of self advocacy organisations to inform the wider community; perhaps through the medium of presentations within 'mainstream' schools, would promote an understanding on the part of the wider community of the needs and aspirations of people with learning difficulties. The local People First group is currently working with the local education authority to develop such a scheme.

Also the everyday living activity of punters exercising their right to have a voice in deciding what they do has a very direct impact on the preconceptions of at least some members of the wider community. Spinner expressed the view in chapter seven that people who have had distress in their own life have an increased capacity to empathise with punters and cross the boundaries which separate them from others. It would be very interesting to test this hypothesis in later research.

Section 6: Promoting Economic Autonomy.

Evidence from the archive showed that it has *never* been the case that all people who have been defined as having learning difficulties are economically inactive. Within the hospital, patients worked as auxiliary carers and cleaners, laboured on the farm and in the laundry, and later engaged upon small scale manufacturing activity. This was acknowledged by the providers, but it did not lead on to punters being properly remunerated for their labours. The punters themselves and those who featured in the 'Intimate Narratives', were well aware of the close connection between rewarding employment, dignity and self esteem. Such evidence points to a need to encourage real employment for people with learning difficulties.

Within the punters discussion group the importance of activity was emphasised, and real employment was seen to be a fulfilling and empowering form of activity. Members of the group had taken part in a conference aimed at promoting the

employment of people who had learning difficulties. (People First 2003). The issues which had emerged from the conference included:-

- Proper wages for 'supported employment'.
- Changes in the benefit system to encourage people to take opportunities without being unduly penalised.
- Financial support and disability awareness training for potential employers.
- Support for people with learning difficulties so that they could try different sorts of work.

Members of the Punters discussion group had also involved themselves in Scotland wide activity aimed at promoting the employment of people with learning difficulties. (Out of the Box 2006) People who contributed to the report from this project told how they had been taught to have very low expectations of ever getting a job.

> "My aunties used to ask my brother and sisters what they wanted to do when they grew up, but they never asked me"
>
> Out of the box 2006 pp 4

The report also provides details regarding the experience of punters of the support they needed to make good choices when it came to seeking employment, and the practicalities involved in actually being an employed person, such as transport to work and what staff could do to facilitate their continued employment. The issues which arise out of these two reports are consistent with the emphasis within the punters discussion group upon the need for people with a learning difficulty to have a voice in the planning of services, and the need for sensitive facilitative help to enable them to achieve this. Once again, it appears as though the professional / diagnostic discourse, where people with learning difficulties are categorised, and then specialist systems of

support are put in place remains dominant. Evidence from the punters discussion groups indicates that punters would prefer a system, which enabled them to receive that support which they need to access ordinary employment.

As well as the direct promotion of economic autonomy for service users, evidence from this study has made it clear, from the archival material onwards, that the care of people with a learning difficulty has provided employment in the area for a very long time. The evidence from the providers' tales in particular showed how many of the nursing staff came into employment within this sector, not from any great sense of professional vocation, but more out of economic necessity. With the passage of time, and the movement away from attendants working within an asylum towards nurses working within a hospital, the education and training of staff became more formalised, resulting in a staff group who came to think of themselves as professionals. The coming of the 'contract culture', as exemplified in appendix 6, has to some degree reversed this process. Face to face carers, if they have any qualification at all, are likely to have undergone vocational training, rather than education at a diploma or degree level.

Also at the time when the closure of the hospitals was being planned, the dominant form of replacement provision was the 'not for profit' or charitable company. There is now good evidence of a process of 'cartelisation' within residential care in the provision of care for the elderly, (Scourfield 2007) and this is beginning to manifest itself in relation to the care of people with learning difficulties. Small localised companies are being replaced by large, often multi national, providers who have a limited interest in employing professionally qualified staff at a face to face level. At the time of writing they tend to pay at levels (Appendix 6) which are more in line with the mass retail trade (Around £6 to £7 per hour). Such macro economic change makes It difficult to see how they will attract and retain staff with the capacity and the motivation to provide the

often subtle and facilitative support which the evidence from the punters tales would suggest is desirable.

Thus, for both punters and providers, with regard to the organisation of their employment, there is some evidence that the discourse of the market, modified for punters by limitations concerned with access to benefits, is replacing a discourse informed by professionalised forms of support.
For punters gaining a real voice would have a positive effect. Some local authorities have already set up semi-industrial projects, often in partnership with commercial companies, which are active in the area of recycling. There is anecdotal evidence that such projects were often inaugurated after ideas which came from punters were developed by local authority workers. Also they have often moved away from their day centre origins, and set up as semi independent industrial units. This has enabled punters to think of themselves as 'going to work' rather than being cared for.

Section 7; Gender and Sexuality: The Promotion of an Ordinary Experience.

Evidence from the archive and from the providers' tales showed that over the years there was gradual change in policy and practice in this area within the hospital, and later within the community, which reflected changing norms in the wider society. To be sure the discourse of 'safety' remains influential, with a concentration upon the linked issues of protection from exploitation and the determination of capacity to give informed consent to sexual activity. The predisposition to attempt to control the expression of sexuality thus remains, but there is a developing acknowledgement of the right of patients to engage in consensual sexual activity if they wished to.

The evidence from the Punters discussion group showed how passionately the informants felt about their rights in the area of sexuality and reproduction. It is

not over dramatic to say that they equated the right to have a loving relationship as being a defining characteristic of what it is to be human. Within the 'Intimate Narratives' it is clear that although parents and other carers may still be influenced by proto-eugenicist patterns of thinking, people with learning difficulties consider engaging in loving relationships to be a normal aspect of everyday ordinary living.

There is evidence to suggest that, at a policy level at least, service providers are beginning to engage with the reality of such an aspiration for an ordinary life. The local council, in company with others in the Scotland, is engaged upon consultation regarding the production of guidelines and training for both commissioners and providers of services for people with learning difficulties. The consultation will focus upon guidelines produced and developed by a multi-agency group within the Lothian area of Scotland as a template for policy and practice and staff training. (Edinburgh City Council 2006). The report entitled 'Making Choices Keeping Safe' is clear in setting out its policy values.

> "This policy and its associated guidelines adheres (sic) to the values that are firmly rooted within the United Nations Declaration on Human Rights and the philosophy underpinning Harm Reduction. It supports the rights of all people with learning disabilities to access health information and services in a safe and supportive manner"
>
> Edinburgh City Council 2006 pp6

In the light of the findings from the research, it is clear that the simplistic proto-eugenicist thinking remains a powerful current and may be influential upon parents, other face to face carers, service providers and upon the wider community. The ubiquity of such currents within the habitus of so many parties may well make the process of implementing new policy guidelines a complex process (Craft 1994). The policy guidelines from Edinburgh City Council include

a training guide aimed firstly at managers and then at other care staff. In the light of the findings of the research, especially those emerging from the punter discussion group; it is imperative that people with learning difficulties who have expertise in self advocacy should be directly involved in the planning and provision of such training.

It is hard to be optimistic that an 'a-signifying rupture and power takeover' conceding the right of punters to engage in a loving relationship, which may result in reproduction, can take place within this area. The power to administer the 'panopticon' first identified by Foucault (Danaher, Schirato and Webb 2000) is omnipresent within the child protection system (Booth and Booth 1998, 2004, 2006). The deficit thinking underpinning much professional practice (Goodley, Lawthom et al 2004) , and the implied conflict between facilitative national / local policies in this area, and the reality of child protection policy based very much upon an overriding discourse of safety, makes it likely that people with learning difficulties will have to fight hard to have their aspirations recognised. In Chapter 7 Tigger expressed his dismay that a steering group set up to evolve guidelines within this area of policy and practice did not include one person with a disability. If there is to be significant change within this area it is essential that the voice of people with learning difficulties, which was so vehemently expressed within the punter discussion group is both heard and acted upon.

Section 8: The Future Contribution of Research.

Throughout this chapter the theme which has been given the title 'Gaining a voice' has been, in various guises, omnipresent. In the light of the findings of the research, it is the view of the researcher that the primary task of research within the field of learning difficulty should be to further facilitate this process in the

future; but this does not necessarily imply that the research effort should focus *exclusively* upon the punters. The present research project through the medium of archival work and with the aid of interviews has focussed on the hidden history of *both* the providers and the punters. In the early stages and particularly within the archival work and the provider interviews the methodology was not explicitly informed by the punter perspective. The shape of the semi structured provider interviews was determined by a predetermined 'checklist' of life experiences (Ager 1998). In the event, the process of describing these 'routines of daily living' gave providers a voice, insofar as they were able to present their view of the explanatory themes which helped them to make sense of such routines.

In the punter discussion group and through the medium of intimate narratives the perspective shifted towards the service user. Also, the background of the researcher in the facilitation of self advocacy meant that he had been exposed to the concerns of punters over a long period. In looking to the future role of research in this area the key task has been eloquently expressed in the following manner:

> "How do we as researchers avoid the continuation of the 'othering' experienced by many people with learning disabilities in research?"
>
> Walmsley and Johnson 2003 pp19

In order to promote inclusiveness within the area of learning difficulty it is the view of the researcher that research activity needs to take place at a number of levels. The findings of the present research would be disseminated with the aid of the people who took part in it, both to an 'academic / policy making' audience through the medium of journal articles and conferences: *and* to people with learning difficulties through the medium of drama within self advocacy groups. First level meanings were reflected back to the punters group through the medium of a follow up group discussion and individual interviews, but the

medium of drama would allow an extension of the dialogue between researcher and punter so that the understanding of both could be developed.

At the more abstract level the ‘navigation beacons’ which have emerged from this historical study such as ‘patterns of exclusion and difference’ and ‘gender/ sexuality / the spectre of reproduction’ could be converted into hypotheses which would be utilised to evaluate the services being made available by the ‘new providers’. At a ‘coal face’ level, the type of research skills which have been utilised in the present research could be used as a support for the process of self advocacy (Chapman and McNulty 2004) in order that a wider range of people with learning difficulties can gain the opportunity to gain a voice in determining what is important to people who utilise services.

One very important aspect of this process concerns the role to be played by non disabled researchers. It is part of modern definitions of what it is to be a person with learning difficulties that they require support in order to live fulfilling lives, (Walmsley 2004; Scottish Executive 2000) and this might include participation in research. Such support in the research process requires knowledge of research processes and techniques, and an ability to provide such support in a manner which is facilitative rather than undermining. Experienced researchers have an understanding of the processes of posing research questions, choosing a population to study and the research method to be employed, processing the data which is derived and disseminating it in an understandable form. It is possible to involve people with learning difficulties in all the stages of research and to facilitate an experience which enables them to learn about research skills (Townson, Macauley et al 2004). However, it is often the case that the phrase ‘Nothing about us without us’ rings in the ears of non disabled researchers and that there is a form of guilt which results in the nature of the respective contribution of punters and professional researchers being blurred within the reporting of the research (Walmsley and Johnson 2003). There is an implication

that the collaboration of people with learning difficulties is an essential ingredient of useful research often characterised by

> "The view that people with learning difficulties have unmitigated access to the experience of disability denied to the 'non disabled' individual. It is the knowledge constructed from this position of privileged ontology that allows the construction of perspectival epistemology"
>
> McClimens 2004 pp 72

For the present researcher such absolutism has a similar ring to it as the conceptualisation of people with learning difficulties given the name by Wolfensberger (1972) of 'Holy Innocent'. It is almost as though their experience is different in kind. An antidote to this absolutism is to show respect for the ontology of *all* the participants in the research.

A more productive approach is to acknowledge and make explicit the contribution of all the respective parties to the research, including such things as the recording of narratives, the location and sharing of records, and the editing process which takes place when the data is coded and written up (Atkinson 2004). Atkinson reports that the actual process of taking part in an oral history project was reported as having an empowering effect by the subjects of the research, and the experience of facilitating the punters' discussion group would lead the researcher to concur with that view.

Having argued against a 'privileged' ontology it is important to acknowledge the reality of differential power relations. (McClimens 2004) It is undoubtedly the case a huge percentage of research in the area of learning difficulties is done 'to' people rather than 'with' them. The same arguments which have been rehearsed above for giving people with learning difficulties a voice and the right to control their services apply also to the research process. Give the location of modern support services within the community, it is important that consumers of

such service have an input into the commissioning of relevant research, and influence in the planning and execution of such research. In the view of the researcher the most productive site for such a reconfiguration of the research process is likely to lie within an organisation where people with learning difficulties have already developed the knowledge, skills and attitudes which will enable them to be assertive about the goals and methods of research. It is possible for experienced researchers to be allies in this process, but it may be competing demands of audience, ownership and authority within the world of academic publication will place a number of strains on such an alliance. (McClimens 2004)

Section 9: A brief and personal comment upon the application of post structuralist thinking

This concluding chapter commenced with a theoretical review which aspired to moving beyond the analytic schema derived from Thompson (2003) and Bourdieu (1992). In chapter 2, a wide ranging definition of discourse which identified it as being 'made up of statements that set up relationships with other statements: they share a space and establish contexts; they may also disappear and be replaced by other statements' (Danaher, Schirato and Webb. 2000) was presented. This definition was utilised in chapter 4, which reported the results of archival work.

Then, at the beginning of the present chapter, dissatisfaction with the twin grand narratives of modernism with its commitment to diagnosis and classification on the one hand and 'Intellectual disability as a grand narrative of deviance' (Roets, Goodley and Van Hove 2007) was acknowledged.

In the researcher's view, pointers which facilitated multiplicity and meaning are attractive, but make it difficult to acknowledge that further grand narratives may be emerging to take the place of previous ones. Within the findings which relate to the transition from a hospital to community based system of care, a grand

narrative of ‘managerialism’ appears to be omnipresent within both health and social care organisations, as it is within the education system. It could be argued that that this is a discourse, as defined above, which is confined to some particular social institutions. However, in making the attempt to apply the findings of the research to the future development of services for people with learning difficulties this emphasis on the central importance of management, rather than asylum, treatment, rehabilitation or even empowerment appears to the researcher to be almost universal.

The researcher would argue that this ubiquity with regard to that which is sayable (and by extension what is not sayable) is connected to a much wider movement towards a service based rather than a manufacturing economy, and is a product of pressures arising out of financial and global trends (Glyn 2006). The politics of welfare provision require that if people with learning difficulties and their allies are to understand the pressures which are being placed upon them, they must be made aware of these wider understandings. However such understandings may not preclude future ‘post structuralist pointers’ identifying new movements and trends within the world of learning difficulty.

Section 10: Summary of Recommendations.

In order to make a start on the process of letting the people who took part in the research know about the results which came out of it, some of the Recommendations are set out here in plain language.

(1)Including people with learning difficulties means that their lives have to be described in ways which take account of what they want to get out of life, and the help they need to achieve this. If people with learning difficulties are

going to lead a full life, then they need to be helped to take part; things need to be done *with* them rather than *to* them.

(2)People who took part in the research said they liked to lead an active life, where they can do what they want to do at the time they want to do it. This won't happen if they are forced to live in places where there are too many rules and regulations. This means that the people who help them have to be properly paid, and have to be educated and trained in order that they can understand what services people with learning difficulties both need and want. They need to understand that services should be provided in a way which does not take over the lives of people with learning difficulties.

(3) It is understood that helpers, whether they be nurses, social workers or other sorts of carers have a job to do, and need to be given the respect that allows them to do it. People who took part in the research appreciated those helpers who talked to them in a natural and friendly way. They also appreciated helpers who had enough knowledge and understanding of the problems which they might face to work in partnership with them to come up with a good solution.

(4)People with learning difficulties, like anyone, else like to have a *real* job so that they can think of themselves as doing something which is useful. People with learning difficulties know enough about life to help other people who have difficulties to make changes which would enable them to have a good life. If they do work, they should be properly paid for it.

(5)The research showed that when people lived in institutions, and sometimes when they live in the community, they are not allowed to have a loving relationship with a partner that they have met. People who took part in the research said that it was wrong to prevent people with learning difficulties having a partner. They knew that sometimes people have to be protected from others who might want to take advantage of them; but this should be done in a way which helps them to make grown up choices. Staff in the hospitals sometimes had a good understanding of this need, and this understanding should be taught to helpers who work within the community.

(6) If all the things which have been identified as important are to happen, then people with learning difficulties *must* be allowed to have a voice when changes are being planned. They also need the *power* to insist that changes take place. Just because they are sometimes ill, and sometimes in need of protection does not stop them wanting a say in planning their future. People who took part in the research said that in the past they had often felt *overpowered* by the people who were paid to care for them.

(7) People who took part in the research enjoyed giving their views to the researcher about what had happened to them in the past, but in the future they would prefer to have more say about the kinds of questions that are asked. They would also like to take part in telling people who plan and provide services, and other service users. This might help them to do their own research projects in the future.

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Appendices.

Appendix 1: A Doric Glossary.

A’: All

A’ body: Everybody

Aboot: About

Ain: Own

Aye: Yes or Always (Depends on context)

Ay noo: Now

Cannae: Can’t

Couldna: Couldn’t

Dee: Do

Deeing: Doing

Didnae: Didn’t

Dinna: Don’t

Disnae: Doesn’t

Doon: Down

Fae: From

Fit: What (depends on context)

Fowk: Folk / People

Gie: Give

Gies: Gives

Hae: Have

Hame: Home

Hale: Whole

Hid: Had (Depending on context)

Hidna: Hadn't.

Ither: Other

Haen: Having had.

Himsel: Himself

Hoose: House Intae:

Intae: In to

Jist: Just

Ken: Know / You know (Depends on context)

Ken't: Knew

Ma: My

Maist: Most

Makkin: Making

Masel: Myself

Nae: No

O': Of

On't: On it

Oot: Out

Peer: Poor

Shouldna: Shouldn't

Si: So

Spik: Speak

Spikkin: Speaking

Stappit: Stopped

Til: To

T'ult: To it.

Yi: You

We: With (Depending on context)

Wernae: Weren't

Wi: With

Wid: Would

Wis: Was

Wisna: Wasn't

Withoot: Without

Transcription Convention: / = a pause ////= a long pause./

Appendix 2: Information for punters and associated providers. (Replaced by punter information / permission sheets)

RESEARCH INTO THE LIVES OF PEOPLE WITH LEARNING DIFFICULTIES INFORMATION SHEET.

My name is : Barry Gault.

I am a teacher at a School of Nursing.

I am interested in talking to people with learning difficulties who live in a hospital. I want to know about your life, and your views about what it is like to live in a hospital.

I have asked ....., who I think you know very well to talk to you to make sure that you are happy to talk to me.

Nothing you say to me will be heard by anyone apart from myself and one other person at the school of nursing.

Nothing will be written which will identify you by name.

Appendix 3: Punter information / permission sheet.

The Robert Gordon University: School of Nursing & Midwifery

Learning Difficulty Research Project.

Permission to be interviewed.

As you are aware from the group interview that you were kind enough to take part in on the 30th September last, I am interested in interviewing the people who took part as individuals or couples. The purpose of doing this is to ensure that I understand correctly the answers given by group members, and to give you the chance to comment on the issues that were brought up during that interview.
If you agree to be interviewed, I, as the researcher will be bound by the following rules.

- The tape of the interview will only be listened to by myself for the purpose of making a written record of what was said.
- The written record will not contain anything which will identify you individually.
- The written record will be confidential, and will only be seen by myself, by my two supervisors at the university, and perhaps by academic staff engaged in assessing my final thesis.
- The taped and written records will be stored in a secure place where only myself will have access to them.
- Any quotes from you which appear in the thesis will not be able to be identified as being spoken by you.
- You are free, at any time to withdraw your agreement to take part in the project.

I agree to take part in the individual interview, and to a written record being kept of the content of that interview.

Name.....

Date.....

Name.....
Date.....

Appendix 4: Script outline for semis structured provider interview.

WHEN: When and for how long they worked at Lhangbyde ?

WHY: Their reasons for seeking employment at Lhangbyde.?
Expectations: Were these changed by the experience of working at L?

WHAT: What typical daily routines did they engage upon in their work with punters?
Some examples Sleeping, waking, eating, working, leisure activity, work, clothing.Domestic Work

WHERE: What was the physical layout of their workplace?

HOW.
Relationships: Staff/Staff; Formal Nurses, Medics, Management, Other Staff.
Staff / Staff: Informal, Friendship, Kinship
Patient /Patient.
Patient /Staff :What terminology was used High Grade / Low Grade?: How were punters addressed? First names? Second Names? What about from Punters to providers?

The Outside World. Staff, their place of origin and residence.
Patients: Contact with the outside world: With Friends / Relations .Outings. The outside world coming in.

Rules.
For staff
For patients.
Rules about gender.
Rules about sexuality.

The Sick Role: Who fell within it.

Change: How did L change during their time there?

Evaluation: The best thing and the worst thing about working at L.

Barry Gault 2002-11-12

Appendix 5: 'Pre interview' Form for Providers

PRE-INTERVIEW / BACKGROUND FACTORS.

Name of Interviewee:

Date of Interview:

Previous Relevant Knowledge /Experience of Interviewer.

Previous Relevant Knowledge / Experience of Interviewee

Any obvious inequalities of power and vulnerability ?

Any 'potential interview identities' immediately apparent?

Place of Interview.

Other Factors affecting atmosphere of Interview..

Feelings of the Interviewer about the overall experience of the interview.

After the tape went off.

Appendix 6: Examples of advertisements for care staff.

Press + Journal 08.06.07

10 Press + Journal 08.06.07

inspire
partnership through life

Inspire aims to offer opportunities for an excellent quality of life to people with learning disabilities in North East Scotland. As a not-for-profit organisation, we support over 600 individuals, and have a workforce of over 600.

Payroll Administrator

ABERDEEN - REF 46. 38 hrs per week Salary £15,820 - £17,163.

We are seeking an experienced person to handle all aspects of payroll and related communications and correspondence. The successful candidate will be able to communicate confidently with colleagues at all levels to provide advice, guidance and information. Consideration would be given to applicants with no payroll experience, but who possess a high level of communication skills and numerical literacy

This post will be subject to a Standard Disclosure check.

For informal enquiries about this post only please contact Carol Benzie on 01224 715544.

Support Workers

Salary: £14,373 - £17,663 per annum pro rata (Qualification bar £15,820) plus benefits.

RESPITE SERVICES ELLON - REF: 44. INVERURIE - REF: 45. Various part-time hours.

We are offering an exciting opportunity for people who are keen to join a team of staff either at our respite service supporting adults with learning disabilities in Inverurie, or at our respite service supporting both adults and children with learning disabilities in Ellon.

The work at our Ellon respite services is particularly exciting and diverse as you will work with both adults and children. The respite users at both locations have a variety of needs and come to respite to learn independence skills, to socialise, relax or just have a break. You should be able to demonstrate a skilled and positive approach to service users with complex support needs and be able to model good practice.

RESIDENTIAL INVERURIE - REF: 47. Various part-time hours.

You will join a dedicated and hard working team in Inverurie, supporting individuals with learning disabilities, undertaking a range of day to day activities, including supporting service users with social and leisure activities and personal care.

COMMUNITY LIVING PROJECT INVERURIE - REF: 48. Various part-time hours.

Our community living projects support individuals in their own homes or in the community. Posts here will not involve sleep-ins but may involve some weekend and evening work.

Working at our respite and residential services entails shift work, weekend working and sleepovers. A flat rate payment is made for sleep-in duties worked in addition to normal hours.

Relief Workers

ELLON, INVERURIE. Hourly rate £6.75

We would also welcome applications at this time for relief work in the above areas. Relief Workers are retained on an "as and when required basis" covering staff for holidays and absence, undertaking a range of day to day activities, such as supporting service users with social and leisure activities and personal care.

For our support and relief worker positions, we are more interested in your energy, character and values than in any previous experience or qualifications, although a background in similar work would be an advantage.

These posts will be subject to an Enhanced Disclosure Check.

For an application pack, please contact us at Old Stoneywood Church, Bankhead Road, Bucksburn, Aberdeen, AB21 9HQ Telephone (01224) 715544, quoting the post reference number.

Closing date for completed applications for all posts: Friday 22 June 2007. Interviews will be held on 3 July (refs 44 & 45) and 4 July (ref 46) . Others to be advised.

We aim to be an equal opportunities organisation and welcome applications from all sections of the community. All applicants who have a disability and meet the minimum requirements for the job will be interviewed.

www.inspireonline.org.uk
Inspire - formerly known as Partnership Scottish Charity No. SC000038

Cornerstone Community Care

Leading the way in providing services for people with learning disabilities in Scotland.

Cornerstone's Aim is "to enable people who require our support to enjoy a valued life".

Aberdeen

Support Assistants

Ref: V07 – 1175.
Salary Scale: £13,250 - £14,243 per annum (part time pro rata).
Various part time hours available.

Would you like to be a **Support Assistant** working with adults with learning disabilities in their own homes and the community?

We have several vacancies across Aberdeen City.

Enthusiasm, a caring nature and a commitment to person centred care are a must as you'll be supporting service user's in attending to their personal care needs and with the day to day running of their homes.

We'll pay you from £6.53 to £7.02 per hour and offer an excellent benefits package including a pension scheme. You'll have between 32 and 37 days leave per year, and opportunities for further training and SVQ's.

All successful candidates will be required to undertake a Disclosure Scotland check at an enhanced level.

For an informal chat please contact Aileen Hossack on 01224 256016.

Interested? Telephone 01224 256056 or e-mail: vacancies@cornerstone.org.uk quoting the reference code and we'll send you an application pack.

Closing date for applications is Friday 22nd of June 2007, 12 noon.

Cornerstone welcomes applications from all sections of the community and actively seeks to increase the diversity of our workforce. Scottish Charity No: SC004780.

www.cornerstone.org.uk

CLEANERS

Aviemore & Grantown on Spey
Up to £6.21 per hour

We currently have vacancies at the following Sheltered Housing Developments to undertake cleaning duties within communal areas.

Part-time Support Workers

Peterhead • From £6.59 per hour

Support Workers are required to help support service users with varied needs in their own tenancies.

Experience is not essential, as full training and support will be provided. What you will need is a positive attitude towards people with learning difficulties, and a committed approach to supporting people within their own homes. In this highly rewarding role, you will enable people to participate in a range of daily living and social activities that most of us take for granted.

You must be able to work within a varying shift rota to cover 24 hours per week. This will include some weekends and sleepovers.

Application forms and job descriptions are available from CIC, 16 Crown Terrace, Aberdeen AB11 6HD. Tel: 01224 577150 or 01467 670879.

Please quote ref: 088/A

Closing date: 19 June 2007.

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putting individuals first ...

Press + Journal 08.06.07