

**POWER AND DISABLED PEOPLE:  
A COMPARATIVE CASE STUDY OF THREE  
COMMUNITY CARE SERVICES IN LONDON**

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Thesis submitted in partial fulfillment of the requirements of The  
University of London for the degree of Doctor of Philosophy.

Department of Social Policy and Administration.  
The London School of Economics and Political Science.

June 1999



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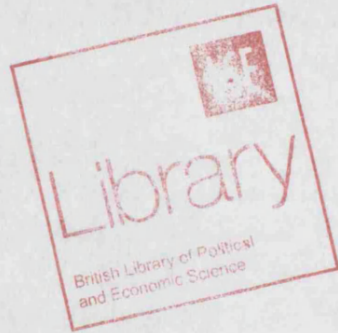


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## ABSTRACT

The main research question addressed is how the perceptions and experiences of people with disabilities around what is termed 'quality of life' are enhanced or modified by differing service delivery systems. This approach is based on the assumption that people with disabilities have unique knowledge about services, providing a core understanding of the power around decision making and its effects on their lives.

The perspectives and methodology used are underlined by concepts of user autonomy, social control, independence, interdependence, advocacy, respect and citizenship. The case study methodology provides an in-depth focus on both 'positive' and 'negative' ethics in social science.

The research area was examined within a multi-professional framework and aimed at a triangulation of perspectives from participant observation, user and professional interviews, tailored vignettes and organisational documentation from services formally designed to empower their users following the latest government policy. The research, following the principles of grounded theory, examined to what extent care management and advocacy, residential support and service brokerage and a more traditional day centre system were achieving these primary aims.

The qualitative data generated by the research gives rise to a socio-organisational power analysis of 'service forums'. The service forums are constructed from 'service postures' and 'service cultures'. Service posture refers to the set of formal values and beliefs owned by an organisation. The service posture for the residential consortium is summarised as 'normality', the day centre's as 'respect' and the care management organisation's as 'advocacy'. The organisations' service cultures are the unofficial presentation of the service, shown to come from the service posture, either being complementary, its antitheses, or quite separate.

It is clear that the behaviour of the workers and the structure of the three organisations studied have both distinct and profound effects on their users' senses and experiences of power. The conclusion explores the elements of disability, choice and decision making which make up the socio-organisational power structures with respect to each organisation. Finally ways in which a participatory service delivery system could be constructed are considered in the context of training, policy and organisational structure.

## ACKNOWLEDGMENTS

Foremost I wish to thank Professor Shula Ramon for her excellent supervision and support. I would also like to pay tribute to both my mother Althea and brother Stewart who proved invaluable proof readers.

At the London School of Economics I would like to thank all the staff and students in the department of Social Policy and Administration singling out Professor Howard Glennerster. As for my friends the now Dr. Nicola Morant and Dr. Kalwant Bhopal offered much encouragement and support. I would also like to thank the E.S.R.C for funding me and for having an effective approach to administration.

Both the staff and users of the three organisations studied gave first class commitment and input in to this venture and I would like to thank them for their patience.

The postgraduate group at the University of Durham Department of Sociology along with Professor Tim May, has also proved an inspiring forum for the final stages of the work.

On a personal note I wish to thank Professor John Carpenter for being an understanding boss, Alison Dannell for living with me through most of this and Tricia Webb, Jo Lancaster, Marilyn Kendal and Dr. Richard Thompson for their sterling last minute support. Finally I wish to thank my father David for agreeing not to read the thesis so I can present it to him.

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## **1 INTRODUCTION**

'If by integration you understand a breakthrough into able-bodied society by disabled people, an assimilation and acceptance of disabled people into an already established set of norms and codes of behaviour set up by the able-bodied, then YES I am against it....If on the other hand by integration you mean there shall be participation by all members of a society, catering for the full expression of the self in a freely changing society as determined by people, then I am with you.' (Oliver, 1996, p. 92)

In this quote Oliver (1996) changes the words of Steve Biko, the murdered South African activist to illustrate the social struggle felt by disabled people to gain power on their own terms.

Discussion around de-institutionalisation in England has been centre stage in social policy since the 1950s. Enoch Powell's (1961) famous water tower speech marked the watershed for people with mental health needs, the Jay Report (1979) marked the move to ordinary living for people with learning disabilities. The move to the community for people with physical disabilities has always been more diverse depending on the different types of disability concerned. In recent years the emphasis has been on empowerment, choice and decision making for all the groups concerned. The research asks the question; what measures in terms of policy and practice have been formed in response to the paradigm shift to the new empowerment ethos in service design?

Can the community internally as a collection of individuals and groups be expected to care for people with disabilities and in doing so provide the appropriate levels of support? In the main the answer appears to be no. Community services have needed to be developed externally to provide a realistic alternative to the all encompassing hospital based system. The users of these community services are supposed to be empowered and involved in the decision making processes that affect the quality of their lives. However in practice choices such as who people share their houses with and what they do on a day to day basis are often not their own. The move to the community can be seen as an attempt to place people in as near 'normal' or 'ordinary' surroundings as possible. This one dimensional approach is now considered to be inadequate if true integration and participation are to take place. Service systems are now looking to employment and leisure opportunities to enhance people's community profiles.

It is my intention to develop a critical and conceptual analysis of the components of power which contribute to the decision making processes that people with disabilities experience within three London based service delivery systems. This includes both broad notions of value, social control, need, care and disability as well as more precise issues of personal identity, deviance, interdependence, advocacy, respect, citizenship, autonomy and the stigma potentially experienced by a disabled person. These structures and concepts can be incorporated into models of connecting disabled people with services. These include the comparative service design aspects of care management and advocacy, residential support and service brokerage and the more traditional elements of a day centre.

The main research questions are as follows:

- 1) How do the working styles of different organisations affect users' experiences and feelings of power?
- 2) How are service users blocked or incorporated in decision making and how do they develop a sense of power within the organisations studied?
- 3) How might a participatory service delivery system be constructed?

The thesis is divided up into ten chapters. The second chapter on empowerment explores the core theme behind the study, this leads into the third chapter on social control which in many senses is the antithesis of empowerment. The fourth chapter explores the consequences of empowerment and social control by examining needs and quality of life. Questions are asked around disabled people's need for empowerment in relation to quality of life in both practical and theoretical senses. The fifth chapter looks at the community care policy in England that has led up to de-institutionalisation and the setting up of services in the community. The sixth chapter examines the design of these services paying particular attention to the types of services chosen for the study. The seventh chapter provides a detailed description of both the theory and practice behind the methodology chosen, with particular regard to the construction of ethical research designs. Chapters eight and nine present the analysis of the data around the following themes; 'disability', 'respect' and 'power'.

Chapter ten presents the original theory of service forums as a model of socio-organisational analysis. In chapter eleven this theory provides an explanation of the critical and conceptual components of power in the three London based service delivery systems studied.

In each chapter the terms and language used may appear inconsistent at times, as case management has changed to care management and some groups and individuals prefer to be referred to as 'disabled people' while others write and speak of 'people with disabilities'. All the terms are used as true to their original text. 'User' is the preferred term for this researcher, but it is recognised that some people object to this term as it can be associated with 'drug use'.

## **2 EMPOWERMENT**

'Of the best rulers  
The people only know they exist  
The next best, they love and praise  
The next, they fear  
And the next, they resist

...

But of the best when their task  
    accomplished, their work done,  
The people all remark,  
"We have done it ourselves."  
(Lao Tzu, 1958, p. 36)

### **2.1 Definition of Empowerment**

To define empowerment it is first necessary to examine power.

'Bertrand Russell has observed that the concept of power is fundamental in the social sciences in the same way that energy is fundamental to physics.'

(Soloman, 1976, p. 15)

'Power determines who defines need, power determines how need is defined, and power determines whose need is met and equally whose need is not met.'

(Oliver, 1994, p. 12)

Power is the capacity not only to impose will (interpersonal superiority) but also to set the terms of an argument or to prevent an action. The Oxford English Dictionary states that power is 'the ability to act out a faculty of body or mind on a government, social situation or person'.

The prefix 'em' is attached to the noun 'power' to create a verb; 'to make or cause'. Therefore to empower is to cause power not actually to give it. 'Empowerment' has its origins in the Latin word 'potere' which means 'to be able'. This gives it a proactive nature focusing on what people can do not what they can't. Empowerment can also be viewed as attempting to remove or challenge oppression whether it is physical, verbal or mental. Empowerment therefore is the authorization of power; the force that makes it happen.



Empowerment is an emotive term which is often left unspecified in regard to both process and outcome. Ward and Mullender (1991) point out that 'empowerment' in the 1980s and 1990s had become a bandwagon term having a similar impact to the use of 'community' in the 1970s. They have both been used as 'social aerosols' sprayed on troubled areas to make things seem better, but being disconnected from their strong ideological and political base in equality and social justice. Definitions have therefore become vague and fuzzy. Rees (1991) suggests that empowerment has been bastardised by right wing politicians using it to describe the merits of economic independence. This follows the social policy scenario of 'fending for yourself at all costs', a kind of Darwinistic survival of the most powerful within a rationed welfare system.

A number of citations in Staples (1990, p. 30) define the elements of empowerment: Swift (1984) writes that empowerment is the 'antithesis of paternalism'. Rappaport (1984) states it is connected to 'one's own participation', Kahn and Benders (1985) describe it as the 'recognition of your own competence' and finally Pinderhughes (1983) sees it as the 'building of individual/collective strength.' From this we can construct a frame of empowerment as self knowledge and strength to act effectively. We can consider empowerment as both a goal and a process. It involves the right to access information and the choice whether to act upon it. Luckenbill (1979) defines power from a social interactionist standpoint. He states that power is a distinctive asymmetrical collective transaction, it is a property born out of the relationship of two or more people. Power can be considered in terms of both a macrosystem (general issue) and/or microsystems (personal). Soloman (1976, p. 16) looks at both the direct and indirect blocks to power that exist within systems:

<b>Indirect Power Blocks</b>	<i>Primary Level</i>	<b>Direct Power Blocks</b>
Family process prevent optimum development of personal resources		Inadequate health care
	<i>Secondary Level</i>	
Limit the development of interpersonal and technical skills		Denied an opportunity to develop interpersonal or technical skills (Education)
	<i>Tertiary Level</i>	
Limited personal resources and reduced interpersonal and technical skills. Reduced valued social roles.		Devalued social roles (eg Income)

Empowerment is a combination of both the believed and actual ability to affect the course of your life and others around you. As Gruber and Trickett (1987) suggest there is a difference between people who think they are powerless to act and those that actually are powerless.

For a simple but broad 'working definition' of empowerment which allows for individual, organisational, social, cultural and political levels of analysis I have chosen Wolff (1985): 'The mechanism by which people, organizations, and communities gain mastery over their lives.....the aim should be to enhance the possibilities for people to control their own lives'. (p. 153)

## **2.2 Context of Empowerment**

The conflicts inherent in any discussion around empowerment and its relationship to wider issues of welfare are illustrated by the following points:

- 'Two major challenges face social care professionals. One revolves around determining who or what controls the provision and quality of services: peoples needs, their rights to resource availability.....The second challenge lies in determining who makes which decisions about people's lives, the individual or the state, and by reference to what values.'  
(Braye and Preston-Shoot, 1995, p. 79)
- The issue of rights itself is problematic. Tensions and infringements can exist between the personal autonomy, protection and well-being of any individual.
- There may be conflicts over the interests of different groups e.g the relative interests of the family of a user, the professional, user and perspectives such as feminism. There can also be conflicts created by community empowerment. Cheung (1990) writes about the 'public panic' caused by the proposed introduction of a unit for people with mental health needs into a Hong Kong community.
- Oliver (1994) suggests that welfare systems are based firmly in paternalism.
- Policy documents attempt to provide a clear and seamless guide to how welfare can be provided to disabled people. However the history of social policy is littered with the problems caused by the conflict of on the one hand the needs and choice for welfare recipients and on the other issues of economy and efficiency around expenditure of public money.

The tensions highlighted above have been added to recently by the intensification of the debate over individualism versus collectivism within western welfare systems. Is disability seen as a human rights issue or one concerned with the appropriate levels of welfare provision? If the answer is the latter, should services be looking beyond anti-discriminatory practice to anti-oppression work? Connected to this is the issue of the professional role, how can a worker gate keep resources of services as well as aid the empowerment of users of those same services? The role of advocates and service brokers will be drawn out later in section 2.6 and 6.2 respectively.

Within recent community care policy a potential conflict exists as to whether it aims to fit people into society or fit society into people's lives. The following quote illustrates this point 'Services continue to cater for dominant social groups and to be primarily functionalist, using a 'fix it' model of care or care for individual symptoms and problems, rather than enabling service users to tackle the structures which oppress them and limit their opportunities.' (Braye and Preston-Shoot, 1995, p. 2)

Wolff (1985) categories the realms of empowerment as:

- 1) Individual (personal).
- 2) Family/advocates.
- 3) Associated groups (small charities and organisations, self help groups).
- 4) Institutions/communities.

Zimmerman (1990a) points out that the individual orientation of empowerment often referred to in literature may ignore the psychological and sociological context of the person in relationship to their environment. Psychological empowerment as presented by Zimmerman (1990b) encapsulates theories of learned helplessness and differs from perceived control ideas because it is multidimensional and includes a theoretical link with community involvement. Learned helplessness is an avoidance theory formulated by Mair and Seligman (Rachlin, 1976) from classical behaviourist roots. They interpreted the results of various experiments with animals which indicated that there was a zero correlation between responding (to a shock) and events in the environment. That is to say that the animals had learnt that they were 'helpless'. From these animal experiments a model of learning was applied to people with clinical depression. It was suggested that this group as with the animals had learnt to be helpless, they also considered it futile to help themselves.

Disempowered groups are devalued by society, in some way they can also learn to be helpless. Groups bound by gender, sexuality, ethnicity, religion and disability have been historically oppressed by a society whose ruling government, led predominantly by white, middle class, able bodied males, wished for homogeneity. We learn something about what it is to be disempowered as children; from being told not to do something, to being actively bullied. Laws have to restrict our free will, within some well thought out parameters. Social justice is born out of the constrictions and pressures of society's attempts to be fair about free will and the representation of the needs of all groups.

Rees (1991) adds to this expanding context of empowerment by discussing the acquisition of a political identity for the disempowered person. This is a move from a passive political role of receiving goods and services to one of active creativity and self expression within a service. The tangible side of a political identity is the right to vote, organisations such as 'The National Association of Mental Health' (MIND) have been campaigning to facilitate voting by patients in long term hospitals for many years.

Unlike other groups, people with disabilities can be medicalised by powerful others into labelled groups to be herded into a dependent system of care and benefits. They are not viewed as producers contributing to the community, instead they are viewed as takers. They are not commodities or commodity suppliers, being encouraged to be grateful for any service they receive (Oliver, 1994). As Stainton (1990) points out most devalued minorities would argue a case against their oppression but they would not want to change their colour or sex. However, many people with physical disabilities would want to alter themselves physically (be able bodied). On the other hand, people with disabilities don't always perceive themselves as having a disability. Many deaf people see the hearing world as alien to their own. We must also remember that few disabilities are visible and many are episodic in nature. People with psychiatric illness don't necessarily stand out in the crowd. Many disabilities are transient or progressive, not being present in childhood or coming and going with age. The relationship between disability and empowerment is not a simple one, it is a complex interaction of many of these elements.

Self expression as argued by Soyer (1975) may include the 'right to fail'. This presents serious difficulties for the roles of various professionals who often see themselves in loco parentis and therefore are there to prevent failure at any cost. There are no fixed rules on how people with disabilities are supposed to interpret their own

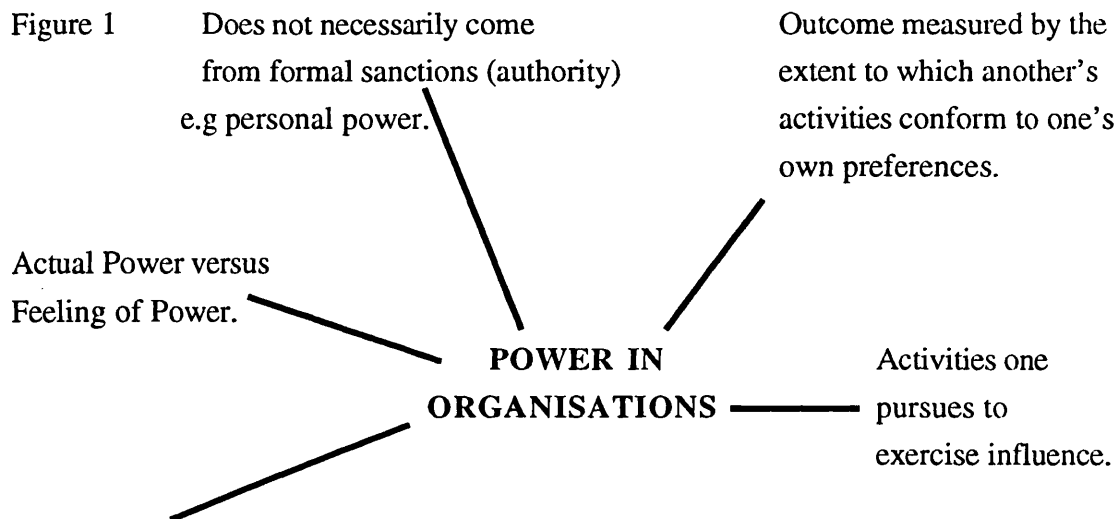
disabilities. People may present their disability as a positive aspect of their lives, heightening awareness or driving them through work or leisure (see section 3.5 on positive deviance).

The question here is does the creation of caring or helping someone add to or negate their sense of empowerment? In enabling others do you necessarily increase dependency? Gruber and Trickett (1987) refer to this as the 'paradox of empowerment.'

Power needs to be seen within a framework of policy and practice and thus moving away from its use as empty rhetoric. Empowerment as presented in staff training policy appears to expand the repertoire of skills but is not used to deepen the self-awareness of staff. The notion of disempowering institutional structures in a radical examination can be expanded to the government itself. Russel-Erich and Rivera (1986) put this in terms of the class conflict and state that community empowerment is against the interests of social work. Oppression in our culture as Ward and Mullender (1991) show is largely a force in favour of white middle class able bodied men. The process of oppression is supported and perpetuated by social institutions. People who have power, internalise it and are less likely in their strength to be oppressed by powerful others. We should all have the right to social justice; that is basic liberties, equality, the opportunity for advancement and positive discrimination.

Empowerment is a tool of social justice aiding a more equitable distribution of resources and developing non-exploitative relationships between people, encouraging self respect, confidence and skills. These skills may be self sufficiency, competence, critical analysis, commitment to a position and the motivation and sense of control to act upon it. In the issues around disability these qualities are often denied to vulnerable and oppressed groups.

Figure 1 is adapted from Mondros and Wilson's (1994) work on organisational power. It indicates that power within organisations does not necessarily come from formal hierarchies and it is not synonymous with authority. This fits in well with Lipsky's (1980) work on street level bureaucracy (see section 5.5). Mondros and Wilson go to describe three useful models of regaining power or empowerment.



**Models of Gaining Power:**

- 1) Grassroots Model: induce power holders to give up power by the use of conflict and confrontation (work of the Disability Action Network - DAN).
- 2) Lobbying Model: work on specific laws and regulations around an issue, involves public education (work of the National Association of Mental Health - MIND).
- 3) Mobilising Model: mass education, use of dissent and protests to effect change (Freire, 1972).

Similarly Rappaport (1984) states that it is easier to define disempowerment in terms of alienation and helplessness, but it is difficult to define empowerment as it exists in 'different forms in different people and contexts'. (p. 34 )

Social scientists often use terms that are more commonly understood by their negative connotations; people can define mental illness more easily with examples from so called abnormal behaviour but find it much more difficult to characterise the elements of good mental health. Hence services have a tendency to push for crisis intervention rather than proactive measures of good mental health and self advocacy. Freire (1972) writes that 'In order for the oppressed to be able to wage the struggle for their liberation they must perceive the reality of oppression, not as a closed world from which there is no exit, but as a limited situation which they can transform.' (p. 39)

It is important to unpack this statement by Freire. This 'reality' can only be 'perceived' given the democratic right to accurate and relevant information. The situation is 'limited' in the sense that we are all capable in some way, of choice. Freire illuminates the clear relationship between self power and education. Education allows the person to place themselves in a historical personal reality. It allows them to lay claim to the on

going history of disability they are part of. Freire writes 'In fact, those who, in learning to read and write, come to a new awareness of selfhood and begin to look critically at the social situation in which they find themselves, often take the initiative in acting to transform the society that has denied them this opportunity of participation. Education is once again a subversive force.' (ibid, p. 9)

Gentle Teaching as described by McGee (1987) is a non-aversive method for allowing people with learning disabilities to express themselves in other ways than so called 'challenging behaviours'. Teaching in these terms is seen as a process of mutual change as both parties teach and learn. Education has historically been viewed as sacrosanct to power. Empowerment is portrayed not only as answers to questions but the construction of the questions themselves. It has been written of Freire's approach (Levy Simon, 1990) that 'historically disempowerment requires an approach based on questioning, a set of interventions that encourages clients to find their own answers, and, indeed, to shape their own central questions needed in making their own way in a difficult world.' (p. 35)

Ivan Illich (1976) in his book *Medical Nemesis* writes of what he calls social iatrogenesis, that is 'medical bureaucracy creates ill-health by increasing stress, by multiplying disabling dependence, by generating new painful needs, by lowering the levels of tolerance for discomfort of pain...' (p. 41)

He goes on to stress that the medical world destroys the person's will to solve their own weakness and thus creates a 'morbid society' that encourages people to become consumers of an industry of medicine. He sees people disempowered to deal with the pain they receive. 'People unlearn the acceptance of suffering as an inevitable part of their conscious coping with reality....' (ibid, p. 133).

Gibson (1991) notes the inability or avoidance of workers to empower clients in the health field. 'The health care professional needs a commitment to serve, rather than accumulate power for personal use.' (p. 358)

Mcknight (1985) writes that his research 'indicates that it is impossible to produce health among the powerless. It is possible to allow health by transferring tools, authority, budgets and income to those with the malady of powerlessness.' (p. 38)

Anderson (1986, p. 19) supports this by reinforcing the notion that ‘poverty and inequality are causes of ill-health’. Saltman (1994) describes a number of different forms of patient control:

- 1) Logistical versus clinical.
- 2) Content democracy versus process democracy.
- 3) Commercial versus democratic.
- 4) Economic versus political.
- 5) Individual versus communitarian.

Some of the conditions required for empowerment are shown in figure 2. This illustrates that resources without the competence to use them does not lead to empowerment nor does choice without the information to make judgments.

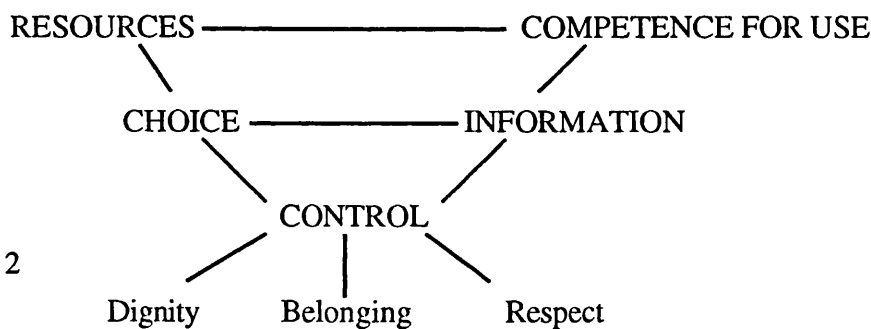


Figure 2

Breton (1994) argues that the necessary components of empowerment are born out of social action, political awareness (‘self as a political being... a consciousness raising process of politicization’ p. 26), the right to have a say, recognise oneself as competent, and to use power to take a valued role in life. She goes on to say empowerment - orientated practice involves the principle of collegiality (abandon the expert role) and stresses the importance of group work in pursuit of social justice. In terms of practice Skelcher (1993) describes the disempowering actions of a service delivery system as:

- ‘Being told, rather than asked, what they want.
- Being asked what they want, but then being given something different.
- Not being given what they are entitled to, or being treated less favourably than others in a similar situation.
- Not being given any choice.
- Having to keep repeating their story to different officials without anything appearing to happen.



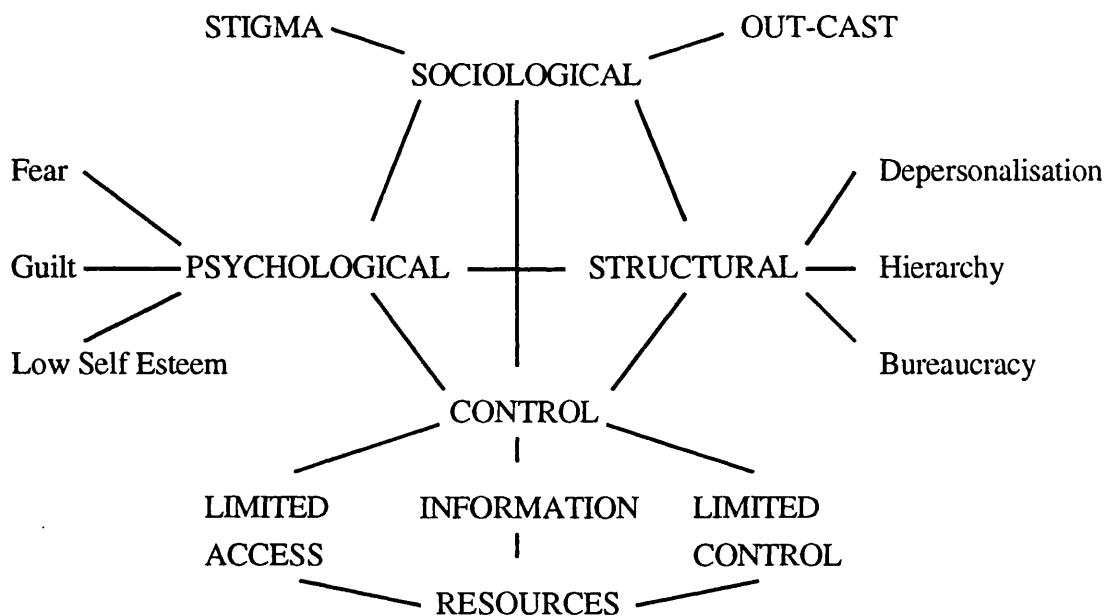
- Being promised that something they have requested or struggled for will happen, and then at the last minute being told (or discovering at second hand) that it will not.
- Being kept waiting and/or knowing that decisions affecting them are being made, but without being told what is happening.’ (p. 16)

Abberley (1987) describes a theory of disability as oppression stating that it:

- 1) recognises and, in the present context, emphasises the social origins of impairment;
- 2) recognises and opposes the social, financial, environmental and psychological disadvantage inflicted on impaired people;
- 3) sees both 1) and 2) as historical products, not as the result of nature, human or otherwise;
- 4) asserts the value of disabled modes of living, at the same time as it condemns the social production of impairment;
- 5) is inevitably a political perspective, in that it involves the defence and transformation, both material and ideological, of state health and welfare provision as an essential condition of transforming the lives of the vast majority of disabled people.’ (p. 17)

From the collated research some of the conditions to create oppression and thus deny empowerment are shown in figure 3. It can be seen that oppression as with empowerment can occur at numerous structural levels, encompassing both psychological and sociological factors.

Figure 3



As a practical example Sayce (1991) criticises the creation of 'at risk' registers for people with mental health needs. She fears this could be disempowering by facilitating the abuse of confidential information within a bureaucracy. It is important to stress the free access to information that people need to construct their own choices. A nation wide network of computer terminals were developed from Calgary in Canada in the late 1980s. This system was used with great effect by people with disabilities exchanging information on a wide range of subjects. However it only worked if no outside censors or controls were placed on it. Information is power but it can only empower if the person receives adequate and accurate supplies of it. Dawson (1992) writes that information increases satisfaction with health care, reduces stress, aids recovery from illness and operations and increases compliance with medication and other treatments. Dawson advocates the need for special information services. 'Disabled people have specific and general information needs which cannot always be met through general information services such as libraries and Citizen Advice Bureaux.' (p. 6)

Staples (1990) states that due to the structure of society, power is not likely just to be handed over to the 'have-not's'. Power is one of those intangible ingredients like freedom which is not bestowed but taken by people. Staples (1990) says 'While one can foster and facilitate the empowerment of another, it cannot be done for another'. (p. 32)

The person themselves must redefine their own self and evaluate the change they experience. Many professionals have now been on training courses entitled 'Befriending' or 'Client Empowerment'. It is possible to question whether it is possible to become experts in these areas. We can become more aware of the issues involved in friendship but we cannot make a science out of it. Friendship like power is not a bestowable designer product. If used as such it may either become patronising or a token gesture.

Levy Simon (1990) writes 'I suggest, the one function that social workers, or, for that matter anyone else cannot perform for another person is that of empowerment. Empowerment is a reflexive activity, a process capable of being initiated and sustained only by the agent or subject who seeks power of self-determination.' (p. 32)

Barker (1987) writes that 'Users did not develop these phrases (user involvement, consumerism, advocacy, legal representation, patients rights) to name their own activities. Professionals often interchange them without discrimination.' (p. 1)

Brandon (1991) illustrates this point further ‘Do terms like empowerment and befriending amount to full friendship and full power? If they do, then why not just call it friendship and taking power and control.’ (p. 3)

To finish two further writers show the powerful impact of terminology used:

‘To be free, you must first assume your right to freedom’ (Rushdie, 1990).

‘Only power that springs from the weakness of the oppressed will be strong enough to free both (that is the oppressed and the oppressor).’ (Freire, 1972, p. 28)

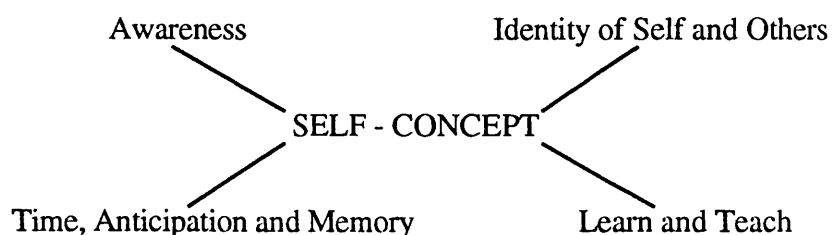
### **2.3 Self Concept and Empowerment**

Evans (1992) writes about empowerment not being concerned with the adaption of the disempowered individual to the world but increasing the individual’s capacity to ameliorate problems. As has been shown, definitions of empowerment are difficult, as they are often inextricably linked with self concept, self-awareness and self-consciousness.

The concepts surrounding self are often defined in terms of each other, seeming tautological. Scott (1969) suggests that inherent in self-concept is the ability to take the self as an object of its own perception, he goes on to say that to do this a person must learn to view themselves from the point of view of other people.

Bateson (1973) describes consciousness as best compared to a television screen, on to which limited, highly selected information is transmitted. We can draw a distinction between self-consciousness and self-awareness. Self-awareness is the ability to observe the television screen. Self-consciousness is the interpretation that there are many other levels of consciousness or television stations which may or may not be operating at one time. Self-concept can also be viewed as the configuration of the abilities in figure 4. It being placed in the context of time by memory along with learning, identity and awareness.

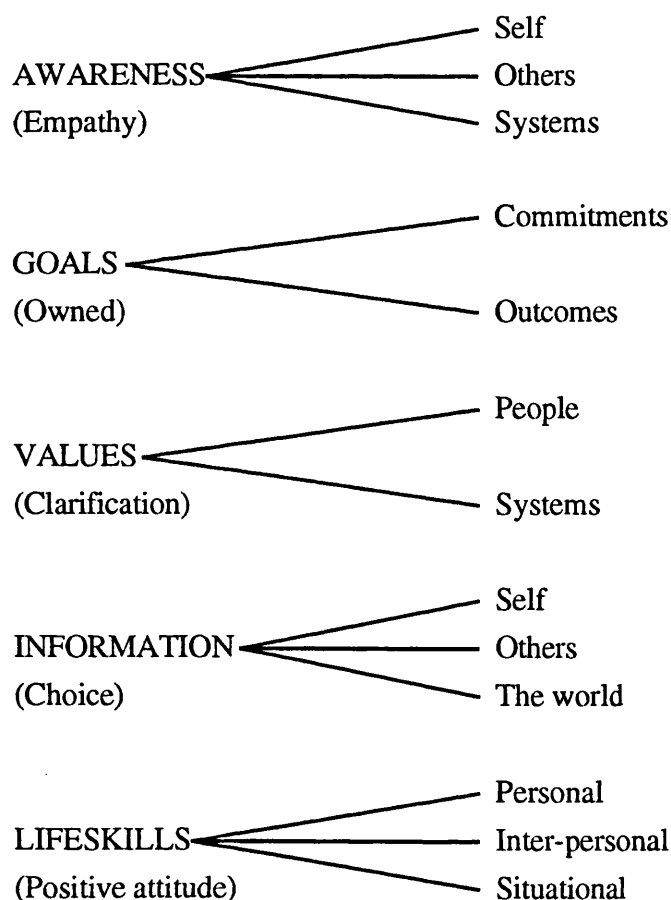
Figure 4



In theory, a faulty self-concept is manifested as a poor self-recognition system in people with disabilities. This is due to a disrupted process of symbolic thought. Robinson (1978) saw lack of self recognition as a diagnostic aid to Alzheimer's Syndrome. Manns stated that self-recognition in children with Downs Syndrome measured through using mirrors was delayed in accordance with Piagetian stages of child development. Baron-Cohen (1986) pointed to autism being a unique blend of specific cognitive deficits such as an inability to pretend play, added to a reduced desire for social interactions within the philosophical framework of the self. The development of language is seen by many child psychologists as the catalyst in breaking the child's egocentric self allowing the formation of a mature concept of self. In terms of empowerment are we creating, mending or increasing self-concepts? Therapy can be criticised as a means to impose external ideas of self on to people.

Bateson (1973) suggests that people are governed by a desire to fit in, conforming to a balancing system of social and private norms. Figure 5 is adapted from Anderson (1986, p. 20) and shows some of the elements of self empowerment.

Figure 5



Self concept in relation to empowerment must combine elements of consciousness raising, self awareness and realising the self as a political entity. Self concept has both an internal and external element in empowerment. Externally the self is presented to others for evaluation and this itself can be an expression of power or potential power (Goffman, 1958). Stigma which is possibly felt can be internalised, it therefore can be seen that people need to feel powerful as well as be powerful.

#### **2.4 Identity, Stigma and Empowerment**

Stigma is best viewed in terms of the negative interaction that takes place between individuals, groups and services. It is characterised by a loss of dignity, ill treatment, shame, denial of citizenship, labelling, embarrassment and disadvantage. Hence these processes can give loss of rights and degrading treatment.

Kieffer (1984) writes 'A man doesn't know his rights, ain't got no rights...' Jim, Appalachian Storekeeper.' (p. 9)

It is important to note that stigma is not a necessary consequence of the above. As Spicker (1984) points out it does not apply to all people using a low status service. We must consider stigma primarily in terms of the personal perspective that an individual has and not a passive response. When a service is used it does not form part of a equitable transaction with a passive recipient. The service is a vehicle for a personal interpretation of value. If that value is negative, stigma may occur. Stigma is not always an unwanted by-product of a badly presented service, it can be part of a calculated consequence. In the early nineteenth century, stigma became essential as a means of preserving the distinction between paupers and labourers and a method of deterring the poor from dependency. Titmuss (1958) discusses stigma not primarily in terms of a loss of money or reputation but through the secondary influx of humiliation. Titmuss in arguing against the Poor Laws states: 'The problem of poverty is not a problem of individual character and its waywardness, but a problem of economic and industrial organisation'.

The stigma then should not be placed at the door of the poor but at the large organisations which perpetuate it. Clifford (1975) studied people's attitudes to claiming benefits. Two thirds thought they would lose self respect if they claimed benefits. This is equivalent to saying that they disrespect people who claimed them. Claiming benefits would spoil their social role by putting a distance between them and others. With regards to services this social distance exists for people using Social

Security but not Education or Health services. Goffman (1963) describes stigma as an attitude that is deeply discrediting, making one feel (negatively) different from others.

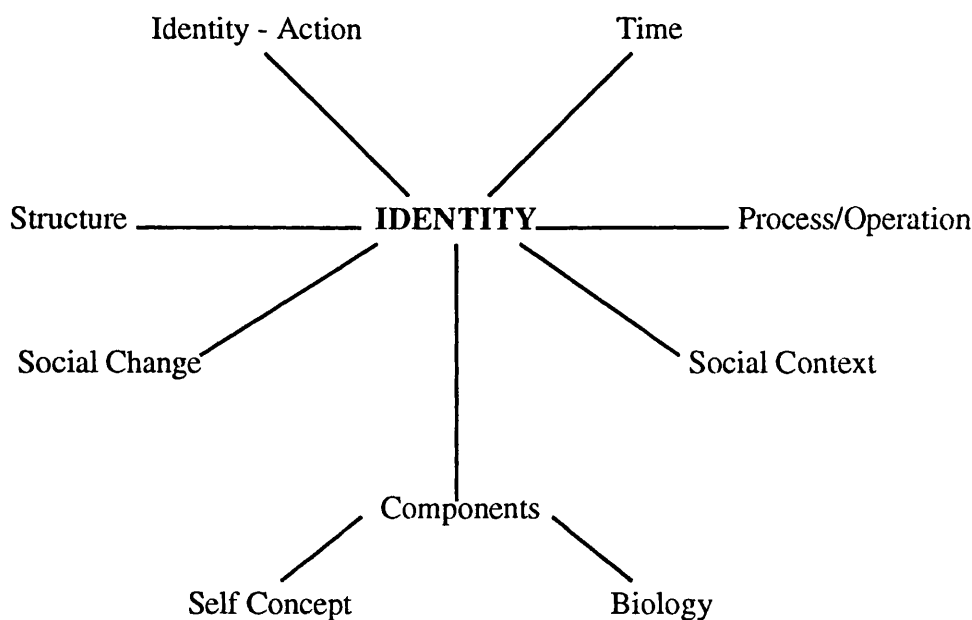
It is important to look not only at how a stigmatised person views themselves but also how they feel other people view them. The value judgments that constitute stigmas are communicated from the person's reference group. Goffman (1963) talks of 'spoiled identity' as the discrepancy between what we would be and our true social identity. People can often be seen to make allowances but not treat someone on an equal basis.

Goffman (1963) describes a number of useful criteria around stigma:

- 1) 'visibility'
- 2) 'know aboutness'
- 3) 'obtrusiveness'
- 4) 'perceived focus'

Stigma here is enhanced by its degree of visibility, how many people know about it, how obtrusive it is and the focus upon it. Identity is a dynamic social product residing in psychological processes which can only be understood in terms of the social context and its historical significance. Figure 6 is adapted from the work of Breakwell (1986) and shows the dynamic interrelationship that forms identity.

Figure 6



Breakwell's (1986) notion of social identity is that it is 'that part of the self concept derived from group membership, interpersonal relationship, social position and status. This is obtained through a process of assimilation, accommodation and reevaluation. Someone's identity, containing their self-concept, can be damaged in a number of ways. Stigma can inflict changes upon the person's view of themselves directly or by their perceived social image. The process of social influence can rapidly destroy self-esteem.' (p. 23)

Breakwell (1986) describes a number of coping strategies which people experiencing stigma use:

Intrapsychic Strategies:

- 1) Modification to the process of assimilation and accommodation.
  - a) Acceptance.
  - b) Deflection.
- 2) Modification to the process of self evaluation.
  - a) Re-evaluate current identity contents.
  - b) Re-evaluate prospective identity contents.

Interpersonal Strategies:

- 1) Isolation.
- 2) Negativism.
- 3) Compliance.

Group and Intergroup Strategies:

- 1) Group Support.
- 2) Group Action.
- 3) Social Support.

In the face of disempowering threats, as described by Hasenfeld and Chesler (1989) parents and families of people with disabilities cope in a wide variety of ways. Almost all of the families they studied could not manage alone and reached out for some sort of networking support from friends, neighbours and family members. Disempowerment can have a far reaching, ripple affect. Social support networks among 'ordinary people' are important for all people. For people with disabilities they can be vital. The experience of stigma makes social support more difficult as well as crucial. Reiss and Benson (1985) studied the psychosocial correlates of depression related to people with

learning difficulties. They concluded that low levels of social support were linked with depression. Loneliness was a major contributing factor in their depression. Friendship provided an empowering emotional integration and a degree of self stability. Empowerment, like social support, cannot be tailored to fit the individual, it has to be slowly and personally built by trial and error. The principle of Normalisation (now referred to as Social Role Valorisation) as developed by Wolfensberger (1972) preaches the value of integration. Those concerned with giving the best possible care to a person with disabilities can only provide opportunities, advice, awareness and support to the people who want them. It is a very practical part of the empowering process for the person to take these opportunities or not.

Mest (1988) researched the social support systems of people with learning difficulties. Participants in the study emerged not just as a 'collection of people who are retarded' but having affiliated 'in groups'. These groups shared intimate experiences relying upon each other for a variety of needs. This is the same for non-disabled people. Social networks can be identified in terms of the empowering social exchanges of costs and benefits involved within them. Social support can be observed as both quantitative (number of attachments or 'company') and qualitative (nature and strength of attachments or 'intimacy') in nature.

Maguire (1983) indicates that friendship as part of social support networks has two categories:

- 1) Convenience - people met at work.
- 2) Committed - true friends chosen and held on to in various situations.

Brandon (1989) demonstrates that most people with disabilities in institutional care have many of the first type of friends but few of the second. The attachments they have are numerous but the strong ones are with members of staff and are often unreciprocated. Committed friendship offers a primary means of self evaluation and self concept development which if missing fails to dispel stigma. People require friends to affirm their decisions in life. Atkinson (1986) in discussing community social networks for people with learning difficulties indicated key friendships formed between clients and social workers. She states that there seem few better ways of measuring the quality of someone's life than looking at the strength and numbers of their friendships. Brandon and Beail (1991) asked whether professional relationships can be friendship. If so what does this mean and if not what replaces it? Friends and other positive social relationships can be empowering for people offering them verification of self and the opportunity for social acceptance. Friendships can happen



between any people, but within the professional/caring world self awareness of the power dimensions involved need to be considered.

## **2.5 Process and Outcomes in Empowerment**

Rees (1991) sees the process of empowerment as having strong ties with the values and structure of the normalisation (Social Role Valorisation) movement. He suggests that empowerment as a process contains the following components:

- Understanding the themes involved.
- Evaluation of self image.
- Specifying the problem.
- Awareness of policy.
- Choice - control access to resources and information.
- Solidarity.
- Use of language.
- Evaluation and assessment - continuing process.

Kieffer (1984) presents a developmental theory of empowerment as 'a dynamic of long-term development from socio-political illiteracy or 'infancy' to socio-political 'adulthood.' These stages parallel others identified in child development.

1) The 'Era of Entry' - 'shared sense of integrity in their sense of self identity and daily lives.'

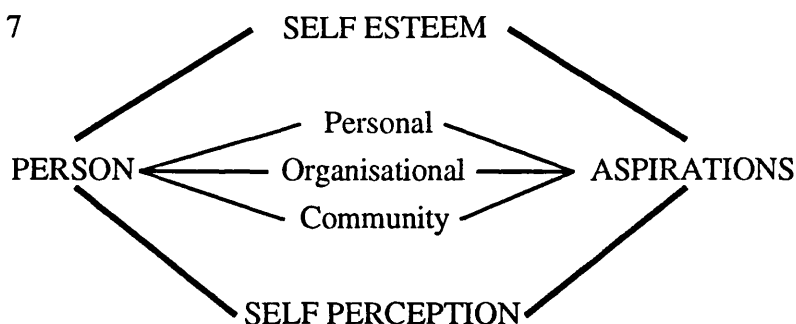
2) The 'Era of Advancement' - 'mentoring relationship, the enabling impact of supportive peer relationships within a collective organisational structure and the cultivation of a more critical understanding of social and political relations.'

3) The 'Era of Incorporation' - 'self concept, strategic ability, and critical comprehension substantially mature.'

4) The 'Era of Commitment' - 'reconstructing their sense of mastery and awareness of self in relation to the political world.' (p. 18)

We can break empowerment down into a number of interactional spheres. Hasenfeld (1987) talks of the process of empowerment, through which clients obtain resources which may be personal, organisational and community based. Figure 7 demonstrates the relationship between the elements in this process.

Figure 7



### Personal

The personal process of empowerment involves the re-evaluation of the self-esteem of the person using their own awareness. For this to develop, the information a person receives concerning themselves must be accurate and extensive.

### Organisational

Hasenfeld and Chesler (1989) see the process of power transformation occurring on three levels :

- 1) Client-worker level - more information, training to assist themselves and linking with social support.
- 2) Organisational level - institutional accountability to the client.
- 3) Inter-organisational or policy level - greater control over agency resources, the increased participation of advocacy groups. Moves to break the monopoly over services, allowing choice. Perrow (1978) writes of this 'Organisations and programmes acquire considerable power over clients and this power is an insurance for the survival of the system.'

### Community

Riessman (1984) focuses on self help groups which appear to begin with everyday, community rooted concerns. From these they move by means of popular democracy and common sense to larger structures allowing criticism and further demands for institutional change. Empowerment is fundamentally egalitarian and concerned with both 'bottom up' and 'top down' change. However people do not live in an egalitarian world, so change occurs in fits and starts while people attempt to follow the principles around these rights. Riessman goes on to describes a system for such change:

- 1) Development of a system whereby professionals have to be formally qualified regarding skills, training and their own limitations.
- 2) Making available a handbook for consumers showing how to select and get the best service. This is the key to information access and processing.

- 3) Development of a people's medical library with self educational material.
- 4) Forms which can be easily used after professional consultations to evaluate service.

The goals of empowerment are described by Hasenfeld and Chesler (1989) in terms of a number of distinct levels:

- 1) Intrapsychic levels - educated and raised consciousness.
- 2) Interpersonal - having greater social influence.
- 3) Sociopolitical - organisations retrained.

Rees (1991) sees the goal of empowerment in terms of positive discrimination increasing liberty, equality and non-exploitative relationships. Defining a non-exploitative relationship is in itself not easy but it must be one with a positive interactional posture, based in respect, safety, mutual trust and learning.

## **2.6 Advocacy and Empowerment**

Power may be denied to many people who are devalued in society. These people may have had few educational experiences, they may have had little experience of social interactions or have greater needs in terms of communication. They may need some help in speaking up for themselves, self advocacy and in accessing power. Advocacy provides a possible answer to how these people regain or gain power for the first time. Advocacy in its broadest and simplest sense is *the representation of a person's or group of people's interests as if they were your own., or the support of someone to represent themselves*. This encompasses both self and others acting as advocates, paid and non paid roles and formal and informal structures. What follows is a list of formal (professional) advocates and informal advocates (lay):

### **Formal Advocate Roles**

- Lawyer.
- Barrister.
- Trade Union Officer.
- Accountant.
- Priest.
- Ombudsman.
- Mental Health Act Commissioner.
- Guardian ad Litem.

## Informal Advocate's Roles

- Spokesperson.
- Guide (problem solver).
- Information aide.
- Mentor.
- Neighbour.
- Enabler.
- Defender of cultural and ethnic identity.
- Supporter of role challenging.
- Companion.
- Friend.

If a person using services has enough personal power, they may only need an advocate for special purposes such as in a court of law. Therefore with reference to empowerment advocates must be optional not compulsory. More specifically advocates are used by the caring services to provide a means of support for service users to voice their needs, complaints and acquire/monitor better services. This process often includes social dimensions as well as more technical service design elements. For example Advocacy Partners is a Citizen Advocacy organisation based in Twickenham which has 30 advocacy matches in the Richmond area. Its roots lie with the Advocacy Alliance which in turn is connected to a national advocacy organisation. The project describes its purpose as building one-to-one relationships between volunteers and people with learning disabilities in the community. It is managed by a voluntary management committee, is a registered charity and a company limited by guarantee. This organisation states its role is to help advocate for: 'Anyone who, because of a disability, finds it hard to express a personal opinion, and who may not be listened to anyway. Also some people with disabilities have very little contact with friends or family, and indeed, their only contact may be with paid workers. An advocate can help to prevent this social isolation.' (Taken from the 'Advocacy Partners' flyer)

Nursing is often seen as a 'task orientated' rather than 'person orientated' discipline. There has been a lot of debate in the Nursing Times (Morrison 1991) about the role of advocacy in nursing, some say that nurses just do it anyway, others say they cannot. The U.K Nursing Council states that advocacy is contained in their nursing remit, however no formal skills training exists for nurses in this area. The cost of being a professional and acting as an advocate can be high if the individual 'blows the whistle'

on the poor quality services they work for. As Brandon, Brandon and Brandon (1995) and Tattam (1989) describe this can lead to the whistle blower losing their job, being ostracised, suffering personal hardship and even having a nervous breakdown. The impact of whistle blowing in the 1960s helped speed deinstitutionalisation in Britain.

What follows is an examination of the main forms of advocacy which exist within services for disabled people.

### Self Advocacy:

'Self advocacy is about power - about people regaining power over their own lives. The psychiatric system in this country seems peculiarly designed to deny power to those who enter it (or are sent into it) for help. Such powerlessness is then reinforced by the practices and attitudes of the wider society into which the recipients of services eventually emerge. Through self-advocacy, through taking positive action for ourselves, we challenge this process, both by working to change the psychiatric system and by challenging our devalued status in the eyes of the majority of society.' (Survivors Speak Out, 1988).

The development of assertion and listening skills for users is also often involved to ensure staff become receptive to complaints and praise. What follows is a list of the needs/wants in self advocacy:

- Inner freedom.
- Self-confidence.
- Sense of belonging.
- Chance to contribute.
- Happiness.
- Be heard.
- Get a response to demands.

Self advocacy is the individual speaking up for themselves. When a group of individuals get together they are often called a self advocacy group. However this type of advocacy really comes under the umbrella of collective advocacy.

### Collective Advocacy:

A group of marginalised people come together to demand their rights. They meet to learn relevant skills and develop power. They lobby for change in their status and in

the services they receive. Self advocacy may lead onto collective advocacy. Collective advocacy also includes pressure groups and organisations which may not be wholly composed of people with disabilities e.g MIND and MENCAP.

#### Citizen Advocacy:

Citizen Advocacy is best defined by the work of O'Brien (1981): 'a valued citizen who is unpaid and independent of human services creates a relationship with a person who is at risk of social exclusion and chooses one or several of many ways to understand, respond to and represent that person's interests as if they were the advocate's own thus bringing their partner's gifts and concerns into the circles of ordinary community life.' (p. 1)

The recruitment of advocates for identified devalued people would be made by a paid co-ordinator of the citizen advocacy project. Brandon and Brandon (1988) outline the principles of citizen advocacy:

- One to one relationship or match.
- Independence of advocate.
- Loyalty to partners.
- Non payment.
- Long term relationship.
- Diversity of functional contacts.

The roles of citizen advocates are governed by various kinds of relationship:

Content: Degree of the need for involvement of partnership e.g emotional input and/or functional input.

Legal: Status of the person they are partners with.

Demand: Frequency and intensity of contact.

#### Peer Advocacy:

John Perceval in 1847 founded the Alleged Lunatics Society as the first peer advocacy organisation. The main aims of Peer Advocates are: providing support, guidance, advice, counselling and advocacy for other people with disabilities. Peer advocates mainly work as volunteers at a one to one level using their direct experience of services. This allows them to act as positive role models.

### Crisis Advocacy:

Crisis advocacy occurs when someone speaks out on behalf of anyone who is in danger. The person is called on for help when and if problems arise. Many citizen advocacy groups feel that a small pool of crisis advocates is necessary, but they are hard to recruit.

It is important to note that many advocates are not 'valued' citizens but may be unemployed, some perhaps being disabled themselves. Clearly the experience of people with disabilities can make them excellent advocates. Effective advocacy depends on the personal qualities of the working advocates. Rose and Black (1985) discuss the co-dependent relationship between empowerment and advocacy, advocacy being seen as a set of activities practically focused by empowerment. They see the advocate working to put themselves out of a job, allowing the person to speak on their own. Advocacy is not valid without empowerment and empowerment is impotent without advocacy.

A group of people with disabilities who have been traditionally devalued by a service will often, after the introduction of an advocacy scheme, put increasing pressure on the advocate as they realise the extent of their own demands, needs, wants and the power they have been denied or were unaware they had. As an advocate it appears to be paramount to trust your partner by following their perception of reality. This helps produce the freedom they seek, even if their perception is overwhelmingly 'distorted' by conditions which have shaped their lives. The partnership moves towards a dialogue which is open and a continuing bond between the partners. This allows the person to argue with passion and vigour, not just with token representation. Effective advocacy allows the spread of power to the person where it becomes secured, grounded and used.

A number of problems may occur around the development of advocacy services. There may be a conflict between the professional advocate and the user given a potential lack of independence the professional may have in the role. The relationship is a difficult one; is it befriending or more professional, expressions versus instrumentalism and empathy versus action? Will the advocate get paid? Money gives value but with it come concerns about accountability. If we follow the road of individual advocacy, does it clash with disability rights in the form of acts or should we concentrate on group action or individual cases? Should advocacy groups be small, scruffy and amateur or big, glossy and professional? Less respectable amateur groups have less to lose in

terms of structure and status if they challenge the system. Finally how should we measure the success of advocacy, by the user getting what they want or some other dimensions? True advocacy may be giving people what they want but it may be against professional interests. Sensitive and empowering outcome research has to be performed.

The move towards user involvement is driven by both advocacy and consumerism. Lupton and Hall (1993) make an important distinction between new user involvement projects driven by policy makers' attempts to be more efficient and users wanting more hands on control of services.

## **2.7 Consumerism and Empowerment**

In line with an approach that gives users more control Griffith (1988) made two suggestions which represent one view of the role of consumerism in welfare:

- 1) Public sectors managers must introduce the interest and value of the consumer.
- 2) Providers should enlarge and compete.

The other side is represented by the comments of a member of a campaign against psychiatric oppression (Barker and Peck 1987): 'Survivors of the mental health system are no more consumers of mental health services than cockroaches are consumers of Rentokil.' (p. 1)

This powerful statement gives a flavour of the discontent which some service users feel, and the distrust they can have of the new consumer ideology within welfare systems. For example consumers in mental health services may not want a services, do you call a person about to be sectioned under the mental health act a consumer of the service? As The Local Government Management Board (1993) pointed out, users of services or consumers of services can be direct like a patient or indirect like the family/carers of a patient. In other words it is not always obvious who the consumers of a service are.

Welfare needs to be discussed within the context of economics. It can be suggested that efficiency and effectiveness in human services has empowered managers and administrators when it would have been better enhancing equity and democracy for users. Recently we have seen service providers wanting their clients to become more adept consumers of services, but consuming is quite different from producing. Riessman (1984) values the role of the consumer as scrutinising, questioning,



evaluating, checking, testing and shopping. However Rees (1991) argues that the process and outcome of empowerment has little to do with the experience of being a consumer, which consists of nothing but choosing from a range of objects determined by others. This process does not ensure that people's interests are paramount. A person's political identity can be in direct opposition to their consumerism. In human services, if professionals maintain control, clients as consumers can only at best express gratitude. Ward and Mullender (1991) split empowerment into consumerism and user control.

Braye and Preston-Shoot (1995, p. 26) discuss the problems of a welfare system built on consumerism by referring to the work of Hambleton and Hoggett (1990):

- 1) 'Public welfare deals in need, not want.....Consumerism and customer care ideologies in welfare do little to promote rights of citizenship or to respond to collective need.'
- 2) Accessibility criteria.
- 3) Choice is still based on a limited availability of resources even when budgets are devolved to care managers.
- 4) New consumers may not have the power to represent themselves.
- 5) It is unclear too about the redress that consumers would have against professionals.
- 6) How is information regulated in terms of its quantity, quality and dissemination within and between services.

Barker and Peck (1987) write 'Simple consumerism envisage consumers expressing their preference and power through purchases. Nader considers this approach naive. The public has never been supplied with the information nor offered the quality of competition to enable it to make effective demands through the market place.' (p. 1)

Real empowerment might be considered as coming through the consumerist ability to hire and fire your own care employees. This would be a very clear measure of a service's empowerment of users since at least some involvement in this process would indicate empowerment at work. Deakin and Wright (1990) state strongly that 'the choice for the left is clear: either to take seriously the task of addressing issues of quality, responses and accountability in relation to the whole range of public services or to watch the steady erosion of these services at the hands of people who equate the value of services with cost and have no commitment to the principle of equity.' (p. 34)

Consumer has two meanings in the Oxford English Dictionary:

- 1) Purchaser of goods or services.
- 2) User of an article.

Rees (1991) refers solely to the second of these two. The user of an article may have no choice or power over what the article is. However that is not always the case, it appears to be contingent on the users' ability and/or opportunity to exercise a veto or choice over an article. Economic power, information and choice are the governing elements here. It is argued that choice itself can be disempowering.

Choice has been defined in terms of 'judgment' not just the 'picking' between things but 'a deliberate action deriving from an awareness of a need or preference.' (Barnes and Proir, 1995, p. 54)

The use of 'judgement' is problematic when considering the potential oppression of people with disabilities, particularly learning disabilities. Judgment for this group is traditionally characterised as limited or absent. Is choice a simple yes or no decision between options or a weighing up or gradations, a sophisticated analysis of subtle difference or is it both? Barnes and Prior argue that more choice is not synonymous with more value, that in fact choice is so prolific in our society that more choice can be daunting, unhelpful and sometimes very irrelevant. They even say that choice can be experienced by some as 'risk'. Barnes and Prior put forward other ways of analysing public services based around coercion, predictability, frequency of use, significance and participation. The role of choice therefore needs to be considered within this wider framework.

Consumerism is certainly connected to economic power and has a strong connection with materialism which in itself produces political power. However in the world of economics just being a consumer is not enough. Sellers may have a desire to keep you only partially informed. It is important to take note that the cost and effort involved in collecting information on a product is proportional to the detail required. People give up, get out the credit cards and trust that they are not being violated. Consumerism is an evolving concept born out of the last decade's information explosion. The question arises whether the right to information goes beyond not being lied to (economical with the truth concerning choice), to information on comparative performance of products and services. Should we look towards more in-depth information on services and products that might be available in an 'ideal world.'

Clarke and Stewart (1992) state that 'Entry into the market of new suppliers may be difficult, preventing new firms developing to meet customers' needs; start up costs can be high or the supplier may be in a monopoly position. Private firms can deploy great resources against which the power of the individual customer can be limited.' (p. 4)

Aspects of good consumerism are:

- 1) Partnership in practice.
- 2) Interpretation of information.
- 3) Research.
- 4) Trial pilots of products.
- 5) User oriented service.
- 6) Accountability.
- 7) Redress.

Newman (1990) argues that only poor people are offered partnership, the rest of us get control of the services we receive, or we pay others to do the job for us. If we consider the consumer as a purchaser of services backed up by the power which money brings to a choice, then this service may ensure the consumer interests are not consumed. I disagree with Rose and Black (1985) when they say that there is a striking parallel between consumers of services and consumers of commodities and that both are out of the control of the consumer. Consumers of commodities do have some control, they have a veto to remove financial support, but this is dependent on quality alternatives and information. Our society is one under stress from many economic and social competitions. The result is little tolerance for the oppressed and deviance becomes polarised. Medical labelling has increased the number of people with exceptional consumer status to the point where people free of therapy-oriented labels are exceptions. However long-neglected psychiatric patients have suddenly been magically transformed into service consumers, presumably as active participants in service development. The formidable American consumer movement grew from concerns about service quality and the scarcity of accurate and impartial information. As Aaker and Day (1971) indicate in the world of industry most real innovations come from the users' view point. Ralph Nader quoted in Brandon (1991) gives a clear picture of the consumer movement: 'the public has not been supplied with the information, not offered the quality of competition, to enable it to make effective demands through the market place.....The task of the consumer movement now is to gather and analyse and disseminate information by demanding it and by mounting private actions by consumer groups to publicise it.' (p. 79)

Consumer choice within services can go one of two ways:

- 1) Quality control assuring privacy, respect and individual service plans.
- 2) Genuine extensions of the democratic process.

The Skeffington report on participation planning in 1969 stated that people should be kept informed about the preparation of a local plan for their area. The Griffith report (1988) highlighted the lack of understanding and information the National Health Service management shows towards users. Henry (1988) working in a psychiatric hospital in Turin with the largest co-operative of ex-patients in Italy stressed the importance of a move towards autonomy and non-professional intervention. He goes on to stress the importance of common sense psychology replacing the existing ethos of reducing people's difficulties to symptoms.

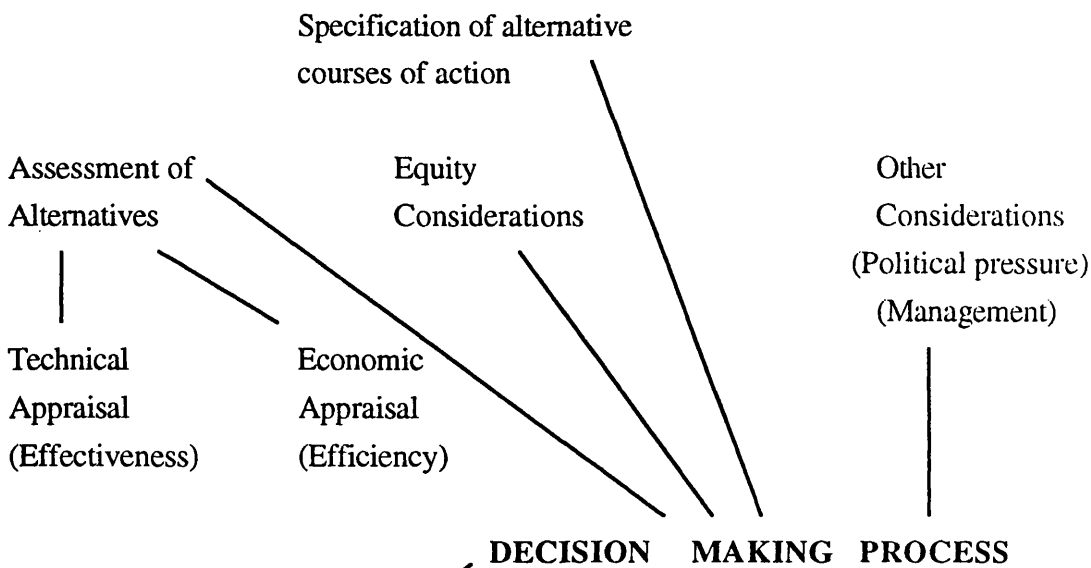
Henry (1988) sets out a scheme within the walls of a psychiatric hospital whereby patients developed practical skill in handling money supported by a real working bank. This active consumerism upgraded the status of the patients in a practical manner which was not tokenistic.

There have been a number of criticisms of consumerism mentioned already. In addition, it has been suggested that consumerism has made no difference to the system, because the culture of free enterprise was already in existence and the change would have happened anyway. Furthermore the benefits gained by the movement i.e improved product quality and choice have been outweighed by increased prices and taxation. Finally the language of consumerism with its focus on the position of the individual in a market place of goods has obvious limitations to a congregated mass service. It is a process based in a highly individualistic nature. One question is whether the ideology of power in the consumer movement bears any resemblance to what goes on in the service market place? Participation in community care clearly contains elements of control, delegation, manipulation and power. Participation is the method of expressing views to those in government, and to those with decision-making powers. This can be direct through lobbying or indirect through voting. Citizens can have direct influence on policies via interest groups and informal contacts with governments. The problem is that public participation may not be encouraged unless it is perceived to support professional aims.

The National Health Service did introduce consumer representatives in the form of independent community health councils, whose role is to assist in putting forward complaints. McGrath (1988) presents the case for consumer participation in the 'All Wales Experience'. The participation of carers was encouraged throughout the planning and management of this project for people with learning difficulties. It was discovered that consumers needed support in gaining skills to evaluate the processes they experienced. Problems arose with the time taken to implement decisions and with conflicts in service priorities.

What are the elements of our economic system which can reinforce or hinder the movement towards consumer participation? What lessons can we learn from such appraisals that aid the setting up of a realistic and practical consumer participation service? We need systematic thinking, a recognition of the scarcity of resources and an explicit framework for value judgments. What we are particularly concerned with is that individual service users are not seen as the most effective judges of their welfare, the most important unit of reference. Drummond (1986) presents the view that the economic appraisal of service provision needs to go hand in hand with a technical appraisal, this is adapted and illustrated in figure 8.

Figure 8



Assessment of costs and benefits of the alternatives:

- 1) Enumeration of the relevant costs and benefits.
- 2) Measurement of costs and benefits.
- 3) Explicit valuation of costs and benefits.

Community projects for the care of ex-psychiatric patients and people with learning difficulties are often set up with a broad range of people's abilities in mind and thus economic appraisal becomes more vague and less viable and less relevant. The money often is being headed off to deal with more 'challenging' clients or forms of crisis intervention. Economic appraisal, like empowerment, is concerned with assisting choices:

- Between objectives?
- Ways of achieving objectives?
- Who receives the service?
- When?
- How?
- Where?
- How much?

It is important to state exactly what is the cost of a unit of resource. Are there benefits to be derived from using alternatives? Financial cost is the cash outlay for a unit of resource. Adoption of the criterion of economic efficiency implies that choice in care should be made so as to derive the maximum total benefit from the resources at the community's disposal. This teleological approach has its pitfalls in terms of the technologies it generates in measuring the qualities of people's lives (see section 4.4).

## **2.8 Summary**

The difference between having a feeling of power and actually having power has been mentioned and it is often easier to define empowerment by its absence rather than by its presence. The working definition of empowerment by Wolff (1985, p. 153) to be used in this research 'The mechanisms by which people, organisations, and communities gain mastery over their lives' allows for the infusion of the following elements: competence, information, participation, needs, transactual relationships and political actualisation for disabled people. A precise definition is too constricting not allowing for the accommodation of the very personal agendas that constitutes empowerment. This personal agenda is wrapped within self-esteem, personal care and the exploration of power. At a social level, networks of support aid the eradication of learned helplessness, offering a means to affirmation of self identity and the avoidance of stigma.

The empowerment of communities involves education and/or reeducation and the subsequent development of community identity and objectives. Community empowerment is concerned with the potential for disabled people to become 'full citizens'. This may involve on a local level a challenge to organisations and systems, where power can be blocked around education and access to quality information.

At a political level empowerment involves the potential to join forces with other organisations communities and lobby at a national and global level. The historical dimension of disability is owned mainly by the non-disabled, but there is an empowering move to take this 'disability mythology' from the hands of professionals and the media and by doing so create a new historical discourse of disability.

It is clear that the role of the advocate is not an easy one. There are many conflicts of interests and the challenges in being both a professional providing a service and an advocate for people using that service can result in a conflict of interest. This chapter began with a quote from Lao Tzu (1958), the 'best ruler' described could be considered as an advocate; empowering people and subsequently putting themselves out of a job. A person advocating for themselves needs self-esteem and confidence, leading to assertiveness and practical knowledge. Advocacy is in the long term moving from advocacy 'with' users to advocacy 'by' users. Pinderhughes (1983) writes positively on the reciprocal nature of power sharing for professionals 'For sharing our power means empowerment for our clients and empowerment for clients means empowerment for ourselves.' (p. 338)

The practical issues around for example a disabled person attending a management committee meeting are numerous and complex. They include transportation to the meeting, the ease of access the person has to the building where the meeting is held and financial remuneration for attending the meeting. In the meeting will the person be listened to and will their suggestions be acted upon in a non-tokenistic way? In addition who actually owns the meeting and resulting action? Empowerment here is the belief that the person will be listened to and action will be taken. This is summed up as the move from lip service to real participation.

The question of whether consumerism encourages increased monitoring, innovation and participation within services by their users was also explored. Having consumer status is no guarantee of empowerment as there are both weak and strong consumers. In the next chapter on social control the role of professionals and institutions will be examined in detail.



### **3 SOCIAL CONTROL**

‘Nathaniel Lee, protesting against his consignment to Bethlem, .....(said) They called me mad, and I called them mad, and damn them, they outranked me?’

(Porter, 1987, p. 3)

In this chapter I intend to discuss how societies construct systems of social control based on norms and concepts of deviance. I will therefore draw on the elements of power and stigma that run through the thesis. I illustrate and punctuate this theoretical work with the personal accounts of people with disabilities. I do this for two reasons, firstly it brings the subject to life since the consequences of social control are often very powerful and need to be expressed in the words of the people experiencing them, secondly because my own research design is concerned with the personal accounts of people with disabilities. As Bogdan and Taylor (1976) write ‘Devaluing an individual’s perspective by viewing it as naive, unsophisticated, immature, or a symptom of some underlying pathology can make research one-sided and service organizations places where rituals are performed in the name of science.’ (p. 51)

#### **3.1 Definition of Social Control**

The following definitions of social control were selected from Gibbs (1981): Berndt (1962) sees that social control covers all the processes and procedures which regulate behaviour and push people to conform to the norms. Cohen (1966) writes that social control prevents or reduces deviance. Hollingshead (1941) states that social control is concerned with how society makes its members susceptible to its regulative systems. Finally Wood (1974) suggests that it is the use of power with the intention of influencing the behaviour of others. Social control can be viewed as the exercising of power by direct or indirect means. It encompasses behavioural, personal, group and wider societal dynamics. It appears to be part of an attempt to reduce deviance to routines and norms which the society itself projects.

#### **3.2 Context of Social Control**

The following questions illustrate a number of key issues surrounding social control:

Who is using it?

Whom is it used upon?

Is it intentional in nature?

How is it achieved?

What is the aim of using it?

What recourse do people have to it?

As citizens of a society we are all under continual social control. Therefore social control might be in danger of becoming a term that means everything, but in turn loses its explanatory value. The obvious signs of social control are the threat of punishment; imprisonment and fines if we deviate from norms and the reward of recognition if we fulfil socially valued expectations, for example reaching educational heights and financial success. If we belong to a minority group we contend with the social stereotypes and stigma that may be attached to it. However it is misleading to consider social control only in Orwellian terms; an oppressive image of an evil dictatorship. The influence of social control can be far more subtle and is neither defined by positive or negative qualities. Our decisions, choices and aims are shaped by the norms and social controls that society, others and ourselves create.

### Intentionality of Social Control

Social control is more likely to be framed with intentionality to make it distinct from everyday accidental interactions and behaviours. However it is possible to socially control by inadvertent actions.

### Subject of Social Control

People and people's behaviour must be seen as the subjects of social control. Horwitz (1982) uses psychotherapy as an example of social control, in its attempts to alter people's personalities. Cohen (1966) sees deviance as the subject matter of social control. To state what is deviant or not deviant is questionable in itself. Deviant to whom and defined by whom? It is too confined to only consider social control as a response to deviance, whereas its original sociological conception was set more widely in notions of conformity, organisational work and the promotion of harmony, not just normative rule - breaking.

In the 1950s and 60s with the work of Goffman (1961) and Scott (1969) the concept of social control grew from a benevolent beginning to the point when it became almost synonymous with the intent of 'society'. More recently there has been a move back to a more benign notion of social control in the work of Rothman (1971). If we view social control as the promotion of harmony and cooperation to benefit members of a group, then we must ask what has gone wrong in our recent history, as the asylums do not seem to have benefitted many living or working in them. This notion of the changing face of social control in the area of mental illness described by scholars such as Horwitz is an interesting one. In contemporary terms we can see that social control is not only deviant coercion or isolation in hospitals but potentially more constructive

aspects such as rehabilitation and ‘therapy’. Horwitz’s book on *The Social Control of Mental Illness* (1982) investigates the relationship between a social control theory of mental illness and factors such as sex, race, and differing cultures. He describes how these factors potentially lead to conflict and thus to social control systems.

### Initiators of Social Control

The state is the most obvious exponent of social control. Any society requires legal, educational, religious, health and other social control systems. ‘Powerful Others’ are prime users of social control systems, for example the media and big businesses. However more generally we all use social control techniques to order our lives, to gain what we want, when we want it.

### Process of Social Control

We can appreciate the quantity and diversity of the means of social control by adapting a list by Gibbs (1981):

- |                            |                       |
|----------------------------|-----------------------|
| * Corporal Punishment      | * Executions          |
| * Incarceration            | * Pleas               |
| * Blackmail                | * Contracts           |
| * Gifts                    | * Segregation         |
| * Promises                 | * Rehabilitation      |
| * Flattery                 | * Media               |
| * Psychosurgery            | * Justice             |
| * Fines                    | * Lying               |
| * Socialisation            | * Education           |
| * Rewards                  | * Conformity Pressure |
| * Religious Indoctrination | * Therapy             |

These are all forms of social control, but this does not necessarily mean that they are all exploitative. In other words it is possible to care, be altruistic and socially control at the same time. It therefore appears that social control can be done in a spirit of mutual respect and dignity without inducing a contradiction. It is fair to say that it is near impossible to do anything in the realms of society without infringing on some kind of social control or perhaps more broadly speaking inferring ‘social guidance’. For our purposes we need to narrow the field to look at more formalised ways that organisations and social trends have effected a particular approach to ‘deviance’, and more specifically disability.

Davis and Anderson (1983) do this by looking towards external public/social control modes such as:

- Custodial - prisons and hospitals (see section 3.7 on total institutions).
- Educational Establishments.
- Community Care.
- Self help organisations which can be viewed as allowing the deviant to take more social control, or what is better described as personal control, over their own lives.

There has been an ongoing debate around the selective use of rewards as opposed to punishments as a means of social control. Group self-regulation exists in all cultures involving persuasion, rhetoric or symbolism without the use of force. People often comply with norms because they believe them to be either right (legitimate) or they fear negative sanctions and desire positive ones, even when they do not agree with the norm. Table 1 is adapted from Davis and Anderson (1983) and demonstrates the external and internal dimensions of social control in relation to pervasiveness:

<b>Table 1 Social control and pervasiveness</b>		
<b>Mode of control</b>	<b>High pervasiveness</b>	<b>Low pervasiveness</b>
<u>External</u> Control	Asylum/Prison	Bureaucracies/Business
<u>Internalised</u> Norms and Values	Alcoholics Anonymous Feminist Movement	Self Help
<u>Externalised</u> Control and <u>Internalised</u> Norms and Values	Families	Professions

Coercion can be considered the most external form of social control. It is possible when considering people like Brian Keenan (1992) as a hostage in Beirut, to say that they may well be governed in body by the power of others but it is not valid to conclude that they have given up on their own internal control. To be labelled deviant does not always mean that you have to act deviantly. In terms of interpersonal power we can consider the range of control and place this in table 2 over the issues surrounding the treatment and care of people with the label of 'challenging behaviour'.

Table 2 Social control and challenging behaviour	
INTERNAL Medication	EXTERNAL Psychotherapy
COERCION Restraint	NON-COERCION Non-Directive Therapy
INTRUSIVE Behaviour Modification	NON-INTRUSIVE Non-Directive Therapy

What this demonstrates is the broad spectrum and nature of social control for one small group of people with a particular deviant label. Of course there is no reason why care givers can not use a combination of any of these means to handle the so called 'challenging behaviour' of an individual. Above all it appears that people need self-awareness of their own value systems when working with the tools of social control.

Rock and Downes (1988) describe social reality in a way which can be applied to the process of social control. To them social reality appears when people build a world for themselves by deciphering their environments.

Garfinkel (1967) encouraged his students to cause trouble in their social environments by giving literal answers to questions or taking up conflicting social roles against the agreed norms to shake out the hidden processes of social life, thus 'flouting normal expectations'. In doing so they uncovered the mosaic of complex process that govern what is known as acceptable social behaviour. We therefore have to dig into the reality around us to gain insight into the depth and nature of social control.

#### Outcomes of Social Control

Societies have to be ordered. Social controls are therefore required to regulate the wishes and behaviour of different individuals; Andeneus (1974) noted that crime went up in Copenhagen and Montreal when the police went on strike. Social controls can tell us about the normal mode of working in a society not just its response to deviance. Justice for the powerful is well advocated by the powerful. This is not true of the weak. Morality, ethics and justice can be operationalised by social controls. It can also be suggested that social control allows democracy to take place. Is social control concerned with the removal of deviance and the reinstatement of conformity, or is its aim to achieve a less sinister manipulation, like organising the interdependent elements

of society? Theoretically it has been suggested that social control is neither good nor bad but just contains the 'potential for action'. It can be used to intervene where someone's actions may be damaging to others or it may have an informative role.

Gibbs (1981) comes to a final definition which can be simplified into:

'Social control being an attempt by one or more individuals to manipulate the behaviour of another individual or individuals by or through the following:

- 1) Communicating about another party.
- 2) Manipulation by punishment, rewarding or rectifying another parties behaviour.
- 3) Communicating allegation about another party.
- 4) Presumed influence of other parties.
- 5) Using a party to gain information on another party.'

The five categories above all involve some degree of power expressed by one person over another, social control therefore is framed as a 'relationship of power'. (p. 21)

### **3.3 Power and Social Control**

Power goes hand in hand with social control. Powerful people use social control to gain power and subsequently more control. Control is the 'actual action' of power, power is the intent and/or capacity to act. Gibbs (1981) defines power in relation to social control as: 'the perceived capacity of an individual (or more than one individual and acting in concert) to control some behaviours of another individual or other individuals and remain free of control by others as a consequence, with such capacity perceived by at least one member of the social unit in question'. (p. 34)

Duke (1976) writing on Max Weber sees power in terms of probable outcomes; 'Power is the probability that one actor within a social relationship will be in a position to carry out his own will despite resistance, regardless of the basis on which this probability rests'. (p. 45)

Weber uses 'imperative control' to describe how a command with a specific content will be obeyed by certain persons. Discipline is therefore the probability that by virtue of habituation a stated command will receive prompt obedience from a given person. There are however a series of problems in defining power:

- 1) It is still confusing that power appears to be both a potential to act and or an action itself.
- 2) It is not always easy to distinguish it from coercion, control, persuasion and influence.

- 3) Do we consider it to be mono or multidirectional in nature?
- 4) Do we frame it in or out of legitimacy?
- 5) Is there a finite amount of power about?
- 6) Do we consider it a resource?
- 7) Is it situationally specific?

The work of Weber as characterised by Duke (1976) indicates that power is the:

- 1) Physical Acquisition of Strength.
- 2) Superior Social Organisation.
- 3) Legitimized Authority based in
  - Tradition (history).
  - Charisma (personal).
  - Law (structure).
- 4) Social Prestige.

Cohen (1985) writes that humanistic civilizations are defined by their 'good' use of power. In other words you can judge the value of a society by the way it treats the most de-valued of its citizens. This is clearly seen for people with disabilities since they are and have been one of the easiest groups to exert power over and often are the most in need of support. Fiarrison (1995) argues that in 'the process of obtaining access to welfare, marginalised groups tend to have less opportunity for 'empowerment' than do better placed ones, and that support for the marginalised often carries implications of stigma or social control more strongly than does 'mainstream' welfare provision.' (p. 12)

These inequalities are not born out of people just being different, or what some see as the innate selfish nature of human beings, or the natural laws of economics and markets. Fiarrison (1995) sees it as being 'tied in with the social division of welfare and with the operation and structuring of institutions.' (ibid, p. 25)

It can be suggested that a reactive more punitive approach developed (Cohen, 1985) to social control. Social control has intensified in the twentieth century, but it has also dispersed from a closed system of incarceration to a more extensive covert one.

I will discuss the changes around the treatment of deviants in asylums, focusing on the mind as the centre for punishment, not the body. The post 1960s brought decentralisation and deinstitutionalisation. This is seen in the move to community control of psychiatric patients, people with learning difficulties, the elderly infirm and

offenders. This post-industrial shift became part of a new 'empire building' era, that is innovation, scientific knowledge, screening devices, use of drugs and behaviour modification became the in vogue social control systems. With each invention and redefinition of deviant groups for treatment the social control system creates the market (deviant population) and the product (community specialty). It is clear that control systems are required for groups that may pose a threat to themselves or others. However this can be part of a seductive move towards more easily coercive systems of social control. In terms of psychiatric care, the move away from restraining straight jackets to drug use is not a reduction in social control, rather a shift in convenience.

Power as described by Ingleby (1983) is the 'stock-in-trade' of historians, and if the work of sociologists and psychologists has failed to give us a deep insight into power we must turn to history for more insight. Michel Foucault, the French historical philosopher pivots his work on the conception of power. Foucault in his book *Discipline and Punish* (1977) writes on the subject of power, 'We should admit that power produces knowledge (and not simply by encouraging it because it serves power or by applying it because it is useful); that power and knowledge directly imply one another, that there is no power relation of a field of knowledge, nor any knowledge that does not presuppose and constitute at the same time power.' (p. 23)

He sees that social control, particularly of crime has become more finely tuned to people as social beings as opposed to bodies for physical punishment. According to Foucault the reform movement was not established to define a new right to punish based on an improved system of value, but to set up a new 'economy of power'. This would bring about its better distribution so that it should be neither too concentrated at certain privileged points, nor too divided between privileged authorities. To put it another way it would 'punish better not more'.

Foucault (1977) describes in a similar way to Goffman, an analysis of the army, with discipline as the art of rank. Cadets are socially controlled in a number of ways:

- Time-table (e.g role - call)
- Temporal elaboration of the act (e.g marching to drums)
- Correction of the body and the gesture (e.g salute)
- Body-object articulation (e.g use of a weapon)
- Exhaustive use (e.g not to be idle)



Foucault goes on to define the mechanics of working discipline further:

1) Hierarchical observation. 'an apparatus in which the techniques make it possible to see the effects of power, and in which, conversely, the means of coercion makes those on whom they are applied clearly visible.'

2) Normalising judgments (Normalising here is seen as imposing homogeneity on subjects);  
Corrective.  
Reducing Gaps.  
Programme.  
Set Regulations.

One of Foucault's main themes is that the modern state exercises its power in different ways through time. It aims now to discipline the mind, rather than to subjugate the body; norms are more internalised. Foucault talks of the new 'power of life'. A person's most private life becomes group owned; documented and discussed by a host of agencies. We can see this most clearly in terms of a ward round where a patient's private problems may be discussed by a doctor, five medical students and a group of nurses. Foucault also provides us with a valuable understanding of the importance of discourse. Davis and Anderson (1983) point out that we take much of the discourse around us for granted; ways of thinking, speaking and general habits. The industrial revolution cut off our discourse with the mentally ill and others who became segregated. Foucault describes institutions as packages of power techniques or, as Cohen (1985) might describe them, deposits of power to be left behind or drawn upon when required. One major contribution that Foucault gives to our understanding of the process of power is not that professionals may use it, but that their job descriptions by definition (e.g a psychiatrist) mean that they can do nothing except use power. I will discuss the role of the professional in social control in section 3.8.

### **3.4 Conflict and Social Control**

Conflict is seen very much as a natural and vital dynamic in everyday existence. The classical conflict theorists are Marx and Engels who used the idea of the dialectic to assert as Duke (1976) explains 'that any aspect of social life, which we may initially label as the thesis, always produces or engender its opposite, which is called the antithesis. These are by definition and in actual reality in conflict with each other, and there is a natural tendency for this conflict to grow and increase, to multiply and to affect many connecting areas. This conflict is resolved into a synthesis; containing contrary elements of both but not necessarily in equal proportions'.

Figure 9

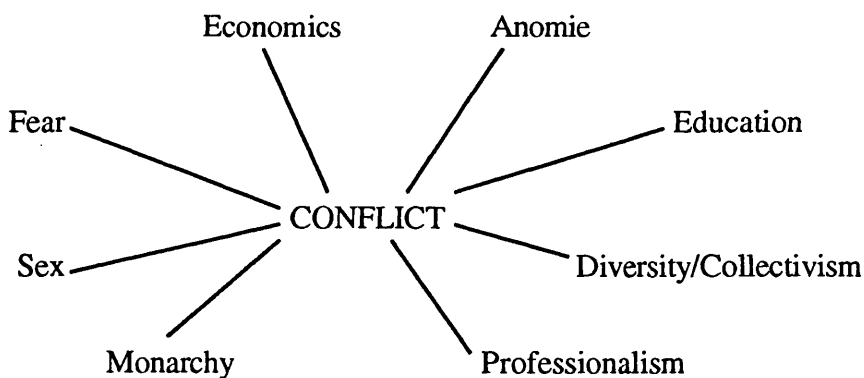


Figure 9 illustrates some of the potential vehicles of conflict and social control, which are discussed below. Marx and Engels applied the dialectic to economic production, its structure in relation to society and the roles of the conflicting classes. They asserted that the power of social control is fostered and used to protect the economic interests of the upper classes over the lower classes.

It is important to note that there are other power bases apart from economics, for example the monarchy and professionalism. Max Weber (1947) put forward a conflict theory which could almost be called an order theory. He studied and theorised on power and how it can be used to create social order. Weber, like Marx, constructs his theory around gaining power through economics mainly but also sex, religion, education, or any other means. Conflict occurs as the above resources become scarce and one individual gains at the expense of another. So power is the ability to achieve or demonstrate your own will over others in gaining a key resource.

Weber suggests that people obey others because they perceive their power as legitimate and thus are bound to them. Weber, unlike Machiavelli, believed that fear was not a prime motivator of social control and was unpredictable and often ineffective. Obedience to social control systems in any society is best based, according to Weber, on a combination of motives and reasons, which could include material and emotional interests framed in legitimacy. Farrell and Swigert (1982) go on to discuss conflict theory in an attempt to explain deviance. This theory states that deviance is the result of the high degree of cultural diversity that exists in modern society. The unsatisfactory nature of extensive collectivism induces behaviour that is against the norm presented by a dominant power: this dominant power being the wealthy and prestigious one, the one with the 'status'.

The main force behind Anomie theory was Durkheim's (1951) effort to account for the frequent tendency of an increasing division of labour to be accompanied by the imperfect coordination of the parts of the system, the decline of social solidarity, and conflict among the social classes. Durkheim explained this by saying that those who performed special interest tasks had not developed, through continuous and intimate interactions, a system of common rules and understanding. The body of common rules, which is the principle mechanism for the regulation of the relationships among the elements of the social system, had broken down. The consequence was a sense of normlessness and deregulation or, as Durkheim described it, 'Anomie'. He used this to explain the pathological state of the economy in countries such as America where people compete with each other for resources and goals, pushed by a common belief in the 'American dream'. Durkheim also used this theory to explain suicide as the ultimate consequence of people's 'malady of infinite aspirations'.

Merton (1957) extended and refined Durkheim's theory. He proposed that the interplay of institutionalised means define the objective conditions of action in 'social structure' along the following dimensions.

- 1) Culture goals - wants and aspirations.
- 2) Norms - legitimate pursuits of goals.
- 3) Distribution - opportunities for achievement.

Feelings of suicide and other actions depend on the interplay of the above and whether people accept, reject or substitute them. Merton saw Western societies, with their uniformly high goals, as one exceptionally productive on one hand with much effort and accomplishment, and on the other frustrating and a great strain, especially on the lower classes with less access to institutionally permitted means to gain objects of desire. The lower classes may resort to deviant ways of gaining these goals and hence there is a concentration of deviance in the lower classes (I will discuss the conceptualisation of the 'underclass' later in more detail). This disfunction between goals and means and the consequent strain leads to a weakening of personal commitment to the culturally prescribed goals or institutionalised means leading to an anomic state.

People have a number of coping strategies under this strain, which Merton (1957) characterised in the following ways:

Adaptation to Disfunction - Acceptance.  
- Rejection.  
- Substitution.

This leads us to the following models of adaptation:

- Conformity is bowing to social stability, that is the acceptance of culturally prescribed and institutionally accepted means.
- Innovation is finding legitimate means to gain goal acceptance of culturally valued means but reject institutional means.
- Ritualism is the elimination of the goal and an obsessive attachment to the institutional means.
- Retreatism is the rejection of both the goals and means.
- Rebellion is the replacement of both goals and means.

Durkheim (1951) argues that nonconformity is a vital part of any organised society. Therefore deviance can only be seen as 'normal'. He goes on to say that ordinary people are not trained in what is legal or not, but acquire a profound understanding of illegality, and what is wrong and right from various sources; gossip, media accounts and public prosecutions. These methods instil in the person a role model of what a citizen should or should not be. The group itself coheres by accounts of non-conformity. Deviance, including criminal behaviour, reinforces a community spirit/identity by the expulsion of wrong doers. This must also include the segregation of deviants with disabilities to hospitals and other situations. Therefore deviant recognition and segregation heightens public awareness but not necessarily tolerance.

Farrell and Swigert (1982) state that a larger society is not characterised by its social and cultural diversity but by the official standards of those best able to institutionalise their morality as the dominant one.

Some disabled people are defined by the 'able-bodied' as being not only in wheelchairs but in easily definable environments such as hospitals. People/minority groups therefore become conveniently typecast; similarly this dynamic has been applied to attempts to confine the black working classes in ghettos. This allows others to define themselves as the dominant white middle class. This way of socially controlling deviance perpetuates some groups as devalued and stigmatised and others as valued. The giant institutions for people with mental illness and learning difficulties were often

open to public visits that had the purpose of demonstrating not only the encapsulated virtues of a society run on order and routine but of reassuring people of their own 'higher status'. We therefore need a bottom to see that we are at the top.

### **3.5 Social Control and Deviance**

What follows is a more detailed examination of deviance and norm structure. Farrell and Swigert (1982) suggest that if individuals are defined as deviant they may be excluded from opportunities for adopting legitimate roles. Rock and Downes (1988) define deviance as banned or controlled behaviour which is likely to attract punishment or disapproval.

So what makes someone have the label of deviant and others to exert social control over them? The category of deviance in sociological literature attempts to be impartial to value judgments by including a scatter of issues ranging from convicted murderers through homosexuals to jazz musicians. 'Deviance' as a word in common usage however has a negative connotation. To include issues of homosexuality and abortion in lists of deviance along with serious crimes is unacceptable. Deviance can be considered the cornerstone to ideas of morality in society.

Farrell and Swigert (1982) present a two level theory of deviance:

Primary Deviations - are those which are original and specific to the person. They can be transient incidents of rule breaking and may have been caused by an accident, experimentation or group pressure. They remain primary as long as they are seen as incidental to the individuals total situation, for example a temporary physical disability.

Secondary Deviations - A deviant role is defined by the public norm and its stereotypes. Stigmatised people may develop a heightened sensitivity to others. They are perceived as norm violators, and as a result they feel they have no choice but to redefine their own self-concept in terms of the presented stereotype. For example the 'handicap' role model expected of people using wheelchairs.

Traditionally sociologists construct theories of deviance around the activities of negatively labelled groups such as juvenile delinquents or burglars. However not only does deviant behaviour extend beyond criminal activity but we can consider it as 'deviating' from agreed societal norms in two directions. In statistical terms the 'norm' is the peak of the normal distribution curve. This curve has a positive tail as well as a negative one. A neglected area of work therefore is that of positive deviance. When discussing the term positive deviance it is useful to consider who it is positive for, the



society or community that witnesses the individual's actions or the person themselves. The individual may well view their so called deviant behaviour as positive.

### Personal Perception of Positive Deviance

- 1) Prostitutes: may view themselves as providing a needed social service.
- 2) Graffiti Artists: may believe their work is an unappreciated skilful art form, contributing to a city's modern colourful image.
- 3) Gay Activists: organisations like Stonewall working to reclaim words like queer.
- 4) Road/conservation protestors see their actions as legitimate and vital civil protests.

### Societies' Perception of Positive Deviance

- 1) 'Idiot Savant': Rainman is a film about a man with the label of autistic who shifts in deviance through the eyes of his brother. Stephen Wiltshire's book Floating Cities (1991) demonstrates the immense value that someone can obtain from their deviance. He is labelled Autistic and has a truly remarkable gift for drawing.
- 2) The Great British Eccentric: is a deviant label applied with nationalistic pride to characters with 'abnormal' attitudes to life. Louis Kronenberger in Company Manners (1954) states that 'we might define an eccentric as a man who is a law unto himself, and a crank as one who, having determined what the law is, insists on laying it down to others.' (p. 6)  
Eccentrics are seen as 'odd' but are valued for their entertainment value and image as the underdog fighting the system. It may help that they are also often very rich.
- 3) Shamans: some societies value the wisdom of those who are seen as wounded healers. Shamans may be viewed in Western cultures as having some kind of psychiatric illness but this is perceived in their own culture as a form of enlightenment or second sight.

Other positive deviants could be Jesus Christ, Joan of Arc and many artists including Van Gogh who are valued for their artistic genius but also viewed as having a mental illness. Porter (1987) frames the social history of madness as a subculture, 'what people had on their minds at the time.....Their testimonies are eloquent of their hopes and fears, the injustices they suffered, above all what it was like to be mad or to be thought to be mad.' (p. 1)

Porter also writes on the madness of society, for example the effects of civil wars, as a kind of positive deviance, 'Often such madness was seen to be positively therapeutic through producing a cathartic effect.' (p. 40)

The process for a society was similar to the loss of reason leading to wisdom, seen for example with King Lear. The relationship between madness and genius is also explored by Porter using the work and private life of Virginia Woolf; he writes 'Certainly she feared that psychiatric treatment would rob her creative well-springs of their powers.' (ibid, p. 60)

Woolf wrote to Ethel Smyth in 1930 'As an experience, madness is terrific I can assure you, and not to be sniffed at; and in its lava I still find most of the things I write about. It shoots out of one everything shaped, final not in mere dribblets, as sanity does.'

This is similar to Plato's ideas of divine madness and William Blake's 'rejoice in madness'. The role of the fool in the history of positive deviance is another fascinating one. 'The fool-indeed, comedy in general-challenged order, but it dissolved its own rebellion in laughter.' (ibid, p. 125)

Porter's most important message was that madness is not synonymous with meaningless. The actions of a person with a learning disability or mental illness may appear bizarre to an observer but often makes perfect sense to the person themselves. Brown's (1995) work entitled 'I was born (in a hospital bed) - when I was 31 years old' is the story of a disabled man's awakening to the positive role potential of being disabled. 'I decided right then and there to be nice to my body. In essence I made a life-affirming decision. I recognized myself for who I was, my disability and its limitations-and with my disability and its affirmations.' (p. 104)

'A few years ago a friend commented to me that losing his leg was the best thing that had ever happened to him. I looked at him in amazement and wondered what he could possibly be thinking. He attributed to his disability a desire to be more focused, to settle down (though his idea of settling down would put many another person in situations of peril) and to pave a smoother road for his life to follow.' (ibid, p. 104)

Brown (1995) sees his role in promoting what he calls a 'positive disability mythology', stories of worth about disabled people, the making of heroes and heroines. This shows a reclaiming of not only history but of shared mythology for disabled people.

In studying the 'postures' (posture refers to the set of attitudes, beliefs and values that people carry around with them) of people making a positive shift in deviance we need to understand the process and points of personal and social reference that encourage a shift or re-interpretation of the negative aspects of their deviance, thus used as a springboard to personal growth, around a conception of positive deviance.

Cumberbatch and Negrine (1992) in discussing images suggest: 'the courageous disabled person (on television) facing up to adversity, does not give adequate account of the everyday experience of the majority of people with disabilities and those close to them.....rather it plays upon the courage and determination of the individual in question who appears as a shining example to the rest of us'. (p. 34)

### Norms

Gibbs (1981) selects two definitions of norms; Bierstedt (1963) sees a norm as a rule or a standard that governs our conduct in the social situations in which we participate. It is therefore a societal expectation. Birenbaum and Sagarin (1976) see norms as legitimate socially shared guidelines to the accepted and expected pattern of conduct.

The Functionalist theory of deviance is not concerned with it as a problem or an example of a system gone wrong, but as an essential part of the make up of society, deviance as a need. Deviance clarifies and maintains the boundaries of social norms which hold societies together.

We can see how social reality is constructed especially when we consider the evidence that supports the concept of the self-fulfilling prophecy. That is if you place someone in a particular role they are likely to sooner or later fulfil it. People's self-concepts can become receptive to other's norm interpretations, and it follows that they tend to think that if they do things which are deviant they themselves are 'deviant'. The morality of a person's actions can be separated from the label attached to that person. Good (right) people sometimes do bad (wrong) things.

In summary; once deviance becomes the dominant definition in someone's life, the self fulfilling prophecy of stigma can arise and cut down ways for the person to project anything but the stereotyped label assigned to them by existing social conventions. This process may be internalised or rejected by the person experiencing it.



### **3.6 Social Control, Stigma and Stereotypes**

A stereotype is a defined role or image in terms of a popular conception of how someone 'should' be, not necessarily what they are. Behaviour adhering to the norms of the day can be reinterpreted in terms of a stereotyped label. It may be difficult to shake off a stereotyped label once it is applied. This is characterised by the work of Rosenhan (1973). He sent members of his research team to various psychiatric hospitals in America and instructed them to say that they had 'heard voices' and display no other symptoms. All concerned were diagnosed as having schizophrenia. Rosenhan described how the behaviour of these pseudo-patients was interpreted and reframed as continuing evidence of their 'abnormality'.

Bogdan and Taylor's (1976) work contains a dialogue from 'Ed' a person with a learning disability. They write that 'to be labelled retard is to have a wide range of imperfections imputed to you. One imperfection is the inability to analyze your own life and your current situation. Another is the inability to express yourself-to know and say who you are and what you wish to become.' (p. 47)

In terms of the stigma attached to a disability, a person may acquire, in terms of their self-concept, a certain degree of shared devalued group characteristics. This was pointed out by Farrell and Swigert (1982) in terms of:

- identification
- integration
- consistency
- membership
- reputation

Scott (1969) describes the acquisition of roles taken by partially sighted people under the guidance of what he sees as a multi-million pound disability business, writing that: 'the behaviour of at least some subgroups of the blind conforms to the stereotypes in spite of the fact that there is nothing about the condition of blindness that makes such behaviour necessary.'

1) 'Many of the attitudes, behaviour patterns, and qualities of character that have long assumed to be given to blind people by their conditions are, in fact, the result of ordinary processes of socialisation.

2) Organised intervention programs for the blind play a major role in determining the nature of this socialisation.'

As human beings we are cognitive problem solvers. That is to say we continually attempt to make sense of our environments. One of the most unpredictable aspects of our existence is the attempt to understand and predict other humans' behaviour. Therefore it follows that we process information as simply as possible through categories. Stigmas and stereotyping allow us to process and predict peoples behaviours quickly. As mentioned this however can result in a self-fulfilling prophecy. Scott (1969) suggests that: 'some blind men might be termed "true believers". They have become what others, with whom they interact assume they must become because they are blind.....Occasionally, a few highly gifted blind people through great personal effort, are able to achieve independence. Such persons are regarded as "amazing", as rare utopian models of the highest ideals of workers for the blind.'

(p. 34)

Scott discusses how some non-true believers manage to 'insulate' themselves against the expected blind role. Given the opportunity, these people drop their acting role and become 'normal' people with a sight problem. Scott however goes on to describe 'blind beggars' who deliberately flout their expected blind role using their disability to gain money from people. Here we can see how the negative deviant role can be used to benefit the individual (a positive deviant shift). There is much to be learned about our own prejudices and value system if we consider why we value some forms of deviance and not others.

Jahoda, Markova and Cattermole (1988) interviewed twelve people with mild learning disabilities along with their mothers and members of staff working at the Adult Training Centre they attended. They discovered that although the participants were aware of the stigma attached to them, the majority saw themselves as essentially the same as other people. This challenges the idea that people with learning disabilities self-concepts are formed through the influence of significant others. It also goes against the classic work of Edgerton (1967) stating that people with learning disabilities denied their disability 'passing over' in an attempt to appear normal. Cheston (1994) describes people using the special education services in the following way 'Many of the leavers in this study were powerless to explain their presence within special education while others accounted for difference between themselves and their peers in terms of a sensory or physical disability.' (p. 68)

### **3.7 Social Control and Institutions**

#### **Emergence of the Asylum**

A closer examination of the rise and fall of the total institutions known as asylums provides an insight into the historical significance of social control. The industrial revolution created new victims (sub labels of deviance). Up until the eighteenth century English society treated people with psychiatric illness and learning difficulties as part of a larger group of deviants called the poor, which also included minor criminals, vagrants and the physically disabled. Potts and Fido (1991) describe how in the 1830s there were early humanitarian approaches but by the 1850s having a learning disability had become a cultural and social evil. Around the 1820s Samuel Tuke, Conolly, Mitchell, Pinel and the work of the York Retreat represented the original embodiment of asylum: sanctuary, a place of refuge and safety. Some of their ideas were progressive even by today's standards in promoting family values, respect, small units, treating people with kindness, dignity and respect along with continuous checkups on staff performance. John Conolly (1830) criticised the new asylum managers of his era by saying 'they may point to the spaciousness of their grounds, to the variety of occupations and amusements prepared for their patients; to the excellence of their food and the convenience of their lodging: and urge that as little restraint is employed as is compatible with their safety; but the fault of the association of lunatics with each other, and the infrequency of any communication between the patient and persons of sound mind mars the whole design.' (p. 20-21)

This represents an early appreciation of issues that we would describe today as social role valorisation. Rabinow (1984) discusses the work of Foucault stating that Tuke looked at mental illness in relation to the labour market, socio-economic issues and the industrial age with a commitment to order, control and discipline. Segregation was based on religious belief, the sight of evil causing suffering. Religion being the concrete form of what 'cannot go mad'. The asylum did not remove guilt from the madman but reorganised it, so they were vulnerable to themselves. Pinel advocated medical segregation for the care of alienated minds. Religious conflict was seen as increasing madness. He looked to silence, 'recognition of mirror', perpetual judgement and medical personage for treatment.

Scull (1977) attributes the move to the asylums as part of the English reform movement which came about as a result of the new urbanisation and industrialisation of the country. He states that more important than this move to the cities was the move to a capitalist system. The market economy could no longer afford to support these deviant

non-consumers who appeared to have no ability or motivation to work. As a result of this attitude the living conditions in the workhouses were made sufficiently unattractive so all save the very needy were deterred from seeking relief. Special asylums were built to handle the people that the workhouses failed in their efforts to teach the value of an ordered capitalistic system.

In addition the development of the market economy destroyed the traditional ties between the classes and with them went any notion of benevolent paternalism. New bureaucratically organised regimes could act as a buffer between the upper classes and the developing deviant groups. New deviant labels were created, and people subsequently became a 'problem'. Shutting away devalued people meant and still means that the general public do not have to come to terms with their own prejudices and fears. The deviant madman could be seen in the eyes of the evolving natural sciences movement as a defective machine which required reconditioning under a strict system of social control. This process was accelerated by the 1913 Mental Deficiency Act as Potts and Fido (1991) describe 'The act permitted the certification and detention of people on the grounds of their level of handicap, defined as idiocy (severe), imbecility (moderate), feeble-mindedness (mild) or on the ground of moral defectiveness.' (p. 10)

The major aim here was to stop these labelled groups reproducing (eugenics). The outcome of this process was that between the 1840s and 1920s the number of mental deficiency hospitals increased ten fold.

### Total Institutions

Goffman (1961) defines total institutions in terms of the following:

- place of residence and work
- large number of like situated individuals
- cut off from the wider society for an appreciable period of time
- lead an enclosed formally administered round of life

Goffman was concerned with a sociological structure of the self and how it was put under pressure, altered and adapted by the workings of an institution. There are of course many types of institutions, they included anything from a room to a prison or hospital. Each place having in common a set of unique informal and formal rules. These rules may be obvious or subtle in expression but provide the bases of selecting

people entering into the institution or being barred from it. An institution in Goffman's terms presents a whole world for its inhabitants which is often self contained. Goffman (1959) uses the analogy of actors on a stage for the inmates in the institution, acting out well defined roles. The institutional roles themselves may vary considerably but are directly responsible for the adaptation of the inmates' self. Most institutions have some kind of barriers of a physical or social nature. These may be brick walls, fences or vows of silence: Institutions fall into one of the following roles:

- Care for people felt to be both incapable and harmless (e.g non-secure hospital for people with learning difficulties).
- Care for people felt to be both incapable of looking after themselves and a threat to the community (e.g secure-hospital for people with learning difficulties).
- Containment of intentionally dangerous people. Prisons are both an institution of social control and a symbol of legitimate coercion on the part of the state.
- Work objectives (e.g oil rig).
- Retreats (e.g monastery).

Goffman describes the distinctive, common characteristics of a 'total institution'. An institution may not have all of these characteristics but it must have some of them:

- Breakdown of the barriers ordinarily separating places of sleep, work and play.
- All of the above done in the same place under the same authority.
- Congregation of people for activities.
- Phases of day tightly scheduled.
- Some kind of total plan.
- Bureaucratic organisational treatment of whole blocks of people.
- Surveillance.
- Compliance.
- Maintenance of antagonistic stereotypes.
- Large management group and a small supervisory staff.
- Social mobility between staff and inmates is kept to a formal minimum incorporating a social distance.
- Information is not readily available for inmates.

These last two elements add particularly to the stigma of an institution. As I have discussed before, access to information is power. Hospitals keep extensive records on patients 'behaviour' and actions and up until recently patients were not allowed access

to these records and even now access can be very limited and certainly not encouraged. Employment for inmates within these institutions is usually minimal as is the payment for any work done. Hospitals may use a system of token economies where as part of a treatment regime patients are given a minimal reward for complying with certain rules. The classic text by Potts and Fidos (1991) is a collection of personal accounts of life in a 'mental deficiency institution'. It involved interviewing patients from The Park (colony) which opened in June 1920. They write that 'These memories are a valuable source of historical information which may prevent society from repeating the mistakes of previous care systems.' (p. 11-12)

'Then when it were me last day (of work), he came and said I were going home, instead of taking me home, he took me to another hospital and I never saw me mother and father.' (ibid, Elizabeth, p. 13)

The book chronicles the lives of people with learning disabilities (8 men and 9 women with an average of 47 years of institutional life each) illustrating how they dealt with:

- Removal of their children.
- Teaching themselves to read and write.
- The Park was used as a kind of Bogeyman (threat) by some parents in attempts to restrict their children's behaviour.

The reasons for people being there were mixed:

- 'I was brought there 'cos I wouldn't get up for' mill.'
- Becoming a parent without a husband.
- Death of parents.
- Poverty.

'In assessing defectiveness, no account is taken of age, personal circumstances, individual experiences or reactions to the trauma of being 'examined.' (ibid, p. 18)

The image of the institution is a bleak one being cynically altered for the annual board of control visits: 'And they used to put soap in the sinks. We never saw soap.' (ibid, p. 23)

Goffman (1961) states that inmates come to an institution with a 'Presenting Culture' derived from their 'Home World'. The entrance process includes 'The Welcome'. This may involve removing the person's (prisoners or patients) social status by taking away their life history, making them wear a uniform, forced bathing and a haircut or loss of their name. Goffman summed this up as an attack on, or contamination of the persons sense of the self. Potts and Fido report the characteristics of the institution in the following ways:

- Money was taken from people and they had to wear uniforms. 'White aprons and hats all the same and black stockings and boots.' (ibid, Doris, p. 38)
- Name tags, standard haircuts, work duties and a lack of privacy.
- Punishments 'One of them, the nurses, put a person in a bath of cold water. That weren't any good for them!' (ibid, Joe, p. 43)
- If you were bursting to go somewhere and you wet yourself, you know like with me, you got punished.' (ibid, Margaret, p. 59)
- A kind of pecking order: 'The high-grade patients are the skilled workmen of the colony...the medium-grade are labourers...the best of the lower-grade patients fetch and carry or do very simple work.' (ibid, p. 71)
- Leisure: 'Personal celebrations such as birthdays are, however, remembered by very few people. You didn't do owt. I didn't bother.' (ibid, Henry, p. 94)
- Relationships were mixed, one woman reports ' I hadn't any (friends) really. I just sat on my own doing me fancy work and me knitting.' (ibid, Margaret p. 106)
- Sexuality: Homosexuality seemed to be preferable to heterosexuality. Probably it avoided embarrassing pregnancies on the wards.
- Rules and routines are needed but more are required when it was overcrowded and understaffed.

Cohen and Taylor (1981) characterise institutionalisation as an inability to survive outside the institution, a sense of regression, apathy and disillusion. Goffman appears too concerned with the victimology of people in institutions. People with disabilities are capable of fighting back by using a number of means from making 'songs of protest' (Brandon, Brandon and Brandon 1995) to taking up strategies to exploit the situations they are faced with. Sometimes they may even escape. Goffman also implies that stigma is inevitable. This is assumption without solid grounding. Stigma is a personal interpretation. People who we think should suffer from it don't and those who we don't think suffer from it do. Staff like inmates also suffer institutionalisation,

they are subject to the constraints of the institution, they also have to adapt to the demands of an often brutalising system. Milgram's (1974) classic experiment and discourse on obedience to authority dramatically illustrate that so called rational people will act under authority often against their moral conception of what is right. From a thousand subjects two thirds obeyed a direction to give a life threatening electric shock to the experimental stooge. Milgram suggests that it is not the type of person you are, it's the situation you find yourself in that has the greatest influence on your behaviour. Milgram discusses the 'agenetic state'; when a person will carry out instructions without question. It is unclear how much damage if any this agenetic state might cause to the person. Milgrams work sparked off a heated debate around ethics and research.

We must look towards the environment around them for answers. Potts and Fido (1991) note that 'Health services spend less on food in mental handicap hospitals than in general or psychiatric hospitals.' (p. 47)

They go on to indicate that the institutions were supposed to be designed for improved health care but the National Development Team indicates that the standard of care was worse than anywhere else. Hospitals, it appears, are not always good places for your health. Joey Deacon book *Tongue Tied* (1974) gives a more positive picture of institutional life and in particular the friendship between a group of men with the label of 'mental subnormality'. This group wrote the book as a team at a rate of about 6 lines a day. Deacon has a great eye and memory for detail and the others typed or could write or read. Deacon records 'When I left school I stopped at home, and every morning my Mum used to put me outside the front door. She used to ask me how many motors had passed and I used to answer by blinking my eyes. I blinked once for every motor that passed. My Mum understood this.' (p. 1)

He goes on to describe the high degree of support he got from staff, friends and visiting family. He also took on an advocacy role for the group. 'I asked to tell Dr. Engler that I wrote a letter (about getting a T.V) for all the spastics boys in my ward.' (ibid, p. 23)

He talks also about arranging 'town parole' i.e the luxury of being able to leave the hospital and go to the town. In contrast to Deacon's personal accounts, Goffman's moral career of the mental patient stated that the problems of the patients and their elicited behaviour was not due to the organic nature of the condition but the processes of the institution. I have used personal accounts of institutional life to illustrate some



of the issues around having a learning disability or other disability. There are however other accounts which are equally as important. Brock (1975) writes a personal account of the life of her disabled child Christopher Goodey (1991) edits 32 parent stories about their disabled children. Williams' (1992) book 'Nobody Nowhere' is an autobiography of a woman with autism, but also it is an act of self advocacy, a projection of her self in the valued world of publishing. It provides a fascinating insight into autism 'I learned eventually to lose myself in anything I desired - the pattern on the wallpaper or the carpet, the sound of something over and over again, the repetitive hollow sound I'd get from tapping my chin. Even people became no problem. Their words became a mumbling jumble, their voices a pattern of sounds.' (p. 3)

Williams (1992) again brings us back to the issue of labeling and its attached value by stating, 'I do not believe that being sane or intelligent is any more superior than being insane or retarded.' (p. 179)

### Decline of the Asylums

It has already been stated that from 1850 to 1950 there was an immense increase in the number and capacity of asylums. The peak in 1954 when the mental hospital population was 148,000. After 1954 a decrease every year occurred. The move to the community had begun. Scull (1977) stated 'Hospital Services for the Mentally Ill anticipated the complete abolition of the mental hospital system within 15 to 20 years.....all provision being in District General Hospital'.

We are still waiting for the final stages of this new paradigm shift. Scull also puts forward as a reason for the demise of hospital treatment the revolution of the psychoactive drugs such as Thorazine (French name) and Largactil (English name). The rationale is not as simple as this, Scull (1977) points out that there were new patterns of management for patients before drug introduction suggesting that psychotropic drugs may have facilitated the policy of early discharge but they can not be held primarily responsible for the massive change. A major factor in closing the existing hospital service was the total institution framework put forward by Goffman and others. So a move to the community could be characterised by:

- 1) Development of new patient management drugs.
- 2) Emergence of a concern for the social well being and rights of the patients.
- 3) The promise of rehabilitation from living in the community.
- 4) Increased tolerance by the community at large due to:

- Two world wars, with the realisation of shell-shock and the writings of Wilfred Owen and other poets, showed the general public that mental illness could happen to anyone.
- In the 1920s the theories of Freud on the psyche lead to a better understanding and acceptance of the mental health issues.

5) Ramon (1985) stresses the role of the developing power structure of psychiatrists making careers in the new field of community care.

6) Hospitals had been continually attacked for overcrowding and those in positions of power were aware of this. Social acceptance of mental illness within a psychological framework led to the open-door policy, psychiatric wards in general hospitals and therapeutic communities and eventually to community care policy.

### **3.8 Professional Social Control**

To understand social control within the context of services provided for disabled people it is important to consider the role and status of the professional. Table 3 gives examples of different roles and their defining characteristics:

<b>Table 3 Social control and services</b>	
<b>Role</b>	<b>Characteristic</b>
Amateur	Non payment
Expert	High level of knowledge
Lay Person	Personal commitment

The professional is seen as an expert, with a high degree of knowledge and is one who is paid for their input. They are also perceived to have personal commitment in their subject area.

Reiss (1971) writes 'A profession is commonly regarded as a special kind of occupation where technical knowledge is gained through long, prescribed training..... Knowledge itself is regarded as a systematic body of theory and practice. Adherers to sets of professional norms that stipulate the practitioners should do technically competent work in the clients interest.' (p. 34)

This quote illustrates a number of issues around the conception and practice of professionalism. I have already mentioned how the well-ordered almost neo-military running of the asylums in the eighteenth century aided the development of new professional groups. The institution is typically isolated from the community, allowing the professional to develop methods of working insulated from any external 'lay' or other interference. The developing medical model of deviance delineated specific labelling of people with mental illness and learning difficulties. Medicalisation also promoted the growth of experts. Hospitals required an enormous administration and managerial organisation. This all helped to design a hierarchy and create new breeds of nurse/managers. Ramon (1985) discusses the professionalisation process in the 1950s. The split between physical and mental illness came as psychiatrists inferred that mentally ill people were unable to have insight into their own condition.

Labelling theory as expounded by Schur (1971), Gove (1975) and Scheff (1966) has had an important influence. Scheff states that most psychiatric symptoms can be labelled as rule breaking or deviance.

Labelling is the domain of the professional, a tool which often alone gives the 'lay' person a sense of reassurance in authority. Organisations like Alcoholics Anonymous (AA) have encouraged a medical view of alcoholism which appears to remove some perceived stigma. However there are many types of medical disorder (eg AIDS) that people may not be responsible for, but they have an attached stigma.

The professional domain of the psychiatrist is built in the following ways:

- 1) Psychiatrists are more sensitive to signs of mental illness than the general public.
- 2) Medical ideology suggests that it is 'safer' to treat someone who may not be ill than it is to release someone who may be ill.
- 3) There is a great difficulty in reversing the committal process of putting someone in a hospital (eg. routines etc).
- 4) As Goffman pointed out the institution is not a healthy place to be in under any conditions.
- 5) After you have been in a institution it may be difficult to shake off a deviant potentially stigmatising label.

Labels placed upon people with learning difficulties act to try and consolidate the persons role as a 'mentally handicapped' individual. Gove (1975) suggests that without the label which is often connected to measures of IQ the problems for the person would be reduced. Becker (1967) writing on labelling sees deviance as created

by society in that it is a response to the application of rules and sanctions by others. In other words learning difficulties is not a universal absolute concept it has to be considered away from the professional convenience of a labelling system. Labelling by its very nature is relative to context, schooling, expectations and society as a whole. People First, the pressure group for people with learning disabilities, proclaim 'Label jars not people.'

People need to consider and respect individual difference. Disability should be perceived in terms of a continuum. Schur (1971) stressed that a consideration of values is essential to any study of deviance are people good, bad or just different. As Shakespeare wrote for Hamlet 'there is nothing either good nor bad just thinking makes it so'

Jones et al (1978) wrote about the two faces of professionalism; one traditionally benevolent, the other greatly self interested and motivated. The third is as a social agent. The work of Jones et al (1978) and Wilensky (1964) characterise the professional world in the following ways:

- 1) Skills based on theoretical knowledge.
- 2) Provision of training and higher education.
- 3) Tests the competence of its members.
- 4) Adherence to a professional code of conduct.
- 5) Longer established professions have a uniform and common public image.
- 6) Involves a socialisation into an institutional context.
- 7) A high degree of personal commitment.
- 8) Full time activities at the task.
- 9) The establishment of training at university level.
- 10) Formation of a national professional organisation.
- 11) Political pressure to gain legal protection (lobbying).
- 12) Construction of a code of ethics.

Illich (1977) suggests that we should call the 'mid-twentieth century 'The Age of Disabling Professions', an age when people had 'problems', experts had 'solutions' and scientists measured imponderables such as 'abilities' and 'needs'. (p. 11)

He goes on to refer to professionalism in terms of the rise of techno-fascism, impoverishing greed and the monopolies created by 'organised specialist cartels'. The two quotes that follow show how Illich sees professionals creating and defining new

needs that they alone can satiate. 'To be ignorant or unconvinced of one's own needs has become the unforgivable anti-social act.' (ibid p. 2).

'the progressive fragmentation of needs into ever smaller and unconnected parts made the client dependent on professional judgment for the blending of his needs into a meaningful whole.' (ibid p. 25).

The positive aspirations of professionals may have negative outcomes. Guggenbühl-Craig (1971) says that the "ministering professions" can also do the greatest damage - harm caused directly by their very desire to help.' (In the preface).

He makes an emotive comparison between social work and the inquisition. Stating that there are similarities in the attempts of both to alter maladjusted beliefs, saying that what is of concern is not the welfare of the protected but the power of the protector. What the professional believes is right. 'People are the most cruel when they can use cruelty to enforce the "good".' (ibid, p. 10)

Guggenbühl-Craig also questions the motives for joining the caring professions, citing voyeurism or fascination with the disturbed side of life fueling a polarity between the idea of a disturbed weak, childish client/patient and the superior proud worker/physician. Professionals are seen as social agents of change and therefore are given a mandate to care. This caring itself can involve a degree of control, labelling for professionals is part of a 'short cut' or 'short hand' in diagnosis and assessment. Social control for many professionals is therefore a soft control (e.g therapy) particularly for those working in the public sector. The duality of care and control is a fascinating one. When does caring through control become just control?

### **3.9 Further Guises of Social Control**

#### **Social Control, the Media and Images of Disability**

Sanders (1992) suggests that the general image of deviance in the media is simplistic, amoral and stereotypic. Cumberbatch and Negrine (1992) suggest that television rarely deals with issues sensitively failing with its portrayal of people with disabilities to show their "ordinariness" and humanity. Longmore (1987, p. 65-79) lists these stereotyped images of disabled people in the media:

- Disability or physical handicaps as an emblem of evil.
- The disabled as monsters.

- Disability as a loss of humanity.
- Disability as total dependency and a lack of self-determination.
- The image of the disabled as maladjusted.
- Disability as compensation or substitute gift (for example, the blind having “other” [unnamed] gifts)
- Disability leading to courageousness or achievement.
- Disability as a sexual menace, a danger stemming from a loss of control.

The media edits the reality surrounding a person with disabilities to promote and create clear, easily digestible stereotypes. The actors role in portraying a person with a disability is usually one of the ones listed above not a person who happens to be disabled. As Ramon (1993) points out the influence of the media is bi-directional, reflecting public opinion as well as guiding it.

The media make social issues palatable for a extremely varied audience in doing so it makes perfect sense to construct or go along with existing stereotypes. The employment of truly disabled actors is a contentious issue in television. The number of disabled people presented on television is not representative of the general population. The recent pressure on newspapers to reveal private sources of information (photographs and letters) on delicate political and criminal matters has added another twist to the social control role of a government over newspapers and therefore in turn over the general public. The information received about the Falklands and Gulf wars being heavily censored to not only make sure information was not passed on to the enemy but so that the public back home got the ‘right idea’ about the way the war was proceeding. It is interestingly that the media has a problem of conflicting stereotypes with disabled war heros. On one side they are deviant, disabled wheelchair users and should fulfil the stigma/stereotypes that goes with this. On the other side they are heros of a war, but do not fit the idealised image of a well dressed tall, handsome, physically athletic movie hero.

The role of charity advertisements is another area plagued with contradictions. Does a charity go for a sympathetic but patronising line to gain understanding and aid or does it go for a more positive role model for the disabled people they represent. Charities like MENCAP and The Spastic Society, now known as SCOPE, are changing their images in the media, slowly guiding people away from giving money to these ‘poor folk’ to a more positive image of real understanding.

Sanders (1992) states that media messages are ideological constructs used by audiences to identify, interpret, and devise solutions for deviance. There has always been a heated debate about the media's presentation of deviance, such as between the Mary Whitehouse versus the freedom of expression groups. If we take the example of the American coverage of the AIDS epidemic, in the first two years no television network covered it up until the death of Rock Hudson in 1985. From then on television shows such as St. Elsewhere attempted to promote an image of control over one's 'passions', implying if one did not the consequences can be terminal. The media use of language can be selective and infer social control. Police on news reports may say that crowds 'were' a certain size but demonstrators 'claim' they were bigger. The role of the expert or professional in the media is a powerful one.

The media is a very powerful group of organisations with a vital role in social control. Political parties require increasingly more sophisticated media campaigns to win. That is not to say that the media is in the hands of the government or anyone else but its persuasive power in social control is undeniable.

#### Social Control in Architecture

Foucault (1977) takes Bentham's construction of the Panopticon and discusses its homogeneous power, its controlling influence on relationships and its subjugation to enforce pacificity. The Panopticon is a construction that has a central tower which looks out on every cell in a complex. These cells are all back-lit, thus a visibility trap is set up that permanently induces inmates to assume they are being watched. Foucault (1977) states that this 'architectural apparatus is a machine for creating and sustaining power relations independent of the person who exercises it; in short, that the inmates should be caught up in a power situation of which they are themselves the bearers.'

(p. 38)

This internal aspect makes the Panopticon distinct from the more external control of the asylum. Newman (1972) pointed out that crime rates increase with the height of a building from an average felony rate per annum of 8.3 per 10000 people in three story buildings to 20.2 per 10000 people in buildings of sixteen stores or over. Whereas 17% of all crimes in low-rise buildings occur in communal areas, the comparable figure for high-rise buildings is 55%. He goes on to discuss:

- 1) The capacity of the physical environment to create perceived zones of territorial influence.

- 2) The capacity of physical design to provide surveillance opportunities for residents and their agents.
- 3) The capacity of design to influence the perception of a project's uniqueness, isolation and stigma.
- 4) The influence of geographical juxtaposition with safe zones on the security of adjacent areas.

Newman in his book *Defensible Space* (1972) is advocating that we look at the way physical environments can act as controlling agents in our lives and thus effect crime rates. The architecture of wards, hospitals, cities and other developments around us does not happen overnight, by chance, it is part of an on going evolution of people interacting with the environment. Architecture is therefore a perfect vehicle for social control.

### The Community

The 'community' can be a harsh reality for urban survival. Cohen (1985) points out that community care has not always been arranged for the best reasons. Social control factors such as financial pressures and entrenched welfare policies often have a great influence. Clients are selected and grouped on poor principles and subsequent community services can be narrow and limiting. The traditional rural community with its sense of belonging, shared support, values and an open door policy is misleading in its romantic image. The community was seen in the nineteenth century as the utopia of self-help. The notion of the community developed with a strong positive connotation but also with a lack of understanding of its negative potential for forms of oppressive social control. Barbaric acts have been taken in the name of the 'community' such as ethnic cleansing and it can appear to justify many forms of treatment which might be dammed in the old institutions but as long as they are performed under the auspices of the 'community' are justified (see chapter 5 on English Community Care Policy).

The irony of social control in the community is that the community is the place which defined the deviance that sent people to the institutions in the first place. It is also important that the community is seen as the place to reverse the process as Cohen (1985) points out it is the failing of many anti-institution lobbies, including the normalisation approach, that they do not address the reason why the person was labelled deviant in the first place. He believes that the main cause of deviance lies in the community in families, schools, religious organisations and other institutions.



## The State

Contact with the state can be viewed in a number of ways, as suggested by Cohen (1985):

- 1) Sense of value to care for the 'needy'.
- 2) Sense of obligation - clinical/social accountability.
- 3) Sense of control over a potentially unpredictable deviant population.

The reasons the state selects issues to socially control are sometimes perplexing and difficult to unpack. Alcohol is an acceptable drug but marijuana is not. Violence also is acceptable if popularised in the media or sport. Abortion floats between a crime and a right within the realms of social control. Recently we have seen the extension of the concept of an 'underclass'. Articles on its growth description and threat have been multiplying, see Dalrymple (1990) and MacNicol (1985). This so called deviant subgroup is defined as permanently unemployed and largely unemployable, having come from 'difficult' family backgrounds.

Sir Keith Joseph described the plight of the underclass as the existence of a 'cycle of deprivation'. The deviance (social deprivation/disadvantage) is thus seen as being passed on from generation to generation, by nurture or nature or a combination of both. In a speech in Birmingham in 1974 Joseph was heard to be on the verge of advocating the compulsory sterilisation of the poor. This is potentially the strongest form of state social control to halt the transmission of undesirable characteristics. This is a deliberate attempt to ignore the effects of structural inequalities. The underclass as a concept is a cocktail of factors: income, skill levels and value systems. As an area of study it needs to be unpacked or thrown out as an over emotive construct. This illustrates some of the issues around the social control role of the state. There is a throw back to viewing the lower class (underclass) as a dangerous entity. It is in the interests of private property owners to protect their capital, maintaining public order.

The behaviour to be encouraged was to be more industrious, punctual, thrifty and to have an increased morality. However there are a number of unanswered questions in this simplistic approach. The exact reason or reasons for this social control pressure are not agreed upon in the field, suggestions are:

- 1) A sense of nostalgia.
- 2) Industrialism and the right to ownership of the means of production.
- 3) Rising professional middle class - status, power and security.

Mohl and Bretton illustrate two sides of the argument by saying that you can consider the reforms of the nineteenth century as either an attempt to aid the poor by indoctrinating them into religious social orders and morality, or more simply a class effort to dominate. As I have mentioned, the original use of the term social control was positive, as a way of uplifting workers. The overshadowing of deviance as a dominant paradigm in the field led to social control gaining more of a big brother/Orwellian theme. Words like enforcement and impositions became more prevalent in describing the pressure placed upon people in social situations. Little time has been spent looking at the concept of social control as a voluntary perhaps even ‘helpful’ process.

The Society

Gibbs (1981) states that social control contains a spectrum of public opinions, laws, belief systems, education, persuasion and religious systems which all contribute to the structure of social order. I am now going to look at the theories of social control which contribute to an understanding of societies.

To begin with, punishment and rewards systems play a vital role in people’s lives on a personal and societal level. Gibbs (1981) theorises that punishment follows relative rates of employment. When employment is high; punishment tends to take the form of imprisonment and when employment levels are low, punishment takes the form of increased use of fines. This notion has not been supported by statistical data, for instance relative rates of employment in the USA go against this trend.

Gibbs (1981) states that the use of penalties is a strategy to maintain dominance and increase ‘cultural distinction’, that is the character of a punishment is a reflection of the cultural values of that society. Table 4 demonstrates the social value systems of societies:

<b>Table 4 Social value systems in societies</b>	
<b>Important aspect of society</b>	<b>Giving rise to social control</b>
Death is a common occurrence	Death penalty is in common use
Liberty is important	Imprisonment is common
Financial gain is a priority	Fines are common
Performance is a priority	Devalue lack of ability to perform
Competence is a priority	Devalue lack of competence in people

It is possible to construct a long list of socially valued or potentially socially valued aspects of a society, but we can see from the latter two examples that a person with disabilities is likely to come under greater stigmatised pressure from a society that values the area that the person has a deficit in. In particular, Western societies are constructed on systems of competence and compliance. People are expected to reach certain levels of education and behave in socially valued ways.

### Social Control and Therapy

We can illustrate some of the issues involved in the process of soft social control by taking mental illness as an example. The two prevalent approaches to mental illness are the psychiatric approach and the labelling perspective, Scheff's (1966). The psychiatric approach focusses on 'illness' as a set of symptoms and a disease. The labelling perspective is unconcerned about why people develop mental illness, suggesting that its occurrence is so widespread that the possible reasons are too numerous for investigation. Instead it is important to look at why certain individuals, but not others, are selected to take on the social role of the mental patient.

Horwitz (1982) points out that the commitment of some people with a mental illness to hospitals often gets processed quickly without an appropriate examination of the person's mental condition. Rosenhans' (1973) graphic account of how easy it is to be diagnosed 'insane' when you are in fact 'sane', has been discussed earlier. There is a continuing argument about the usefulness or harm caused by the label of mental illness. Psychotherapy is defined by Horwitz as the attempt to change the personality of people intentionally and voluntarily, and is therefore therapeutic social control. Horwitz (1982) lays down certain conditions that have to be met if this process of psychotherapy is to be successful:

- 1) Use of mutually shared cultural symbols.
- 2) Relationship of trust.
- 3) Voluntary and a desire to change.

He goes on to state a number of principles:

- 1) 'The application of psychotherapy varies with the cultural distance between therapists and patients.'
- 2) 'The application of psychotherapy varies inversely with the social class of the patient.'

3) 'The application of psychotherapy is inversely related to the perceived severity of the mental illness.'

So the picture we can create of the ideal psychotherapy patient is someone of higher social class and education, suffering from a mild disturbance. Psychotherapy can be viewed as a process whereby the quality of someone's emotional life is improved. Like everyone else people with lower intelligence and learning difficulties have an inner world as well as an outer one, an unconscious as well as a conscious world. Therefore they need access to psychotherapy, particularly as people with learning difficulties often feel powerless. They learn to understand loss in the way that few people do. Horwitz has a reductionist and separatist view of psychotherapy neglecting the importance of issues like counter-transference and the differing training and social background of therapists.

It can be suggested that the boundaries set up by professionals to distance themselves from clients and sometimes other professional can cause harm. Does the professional act to 'fit' the client or does the client bend to 'fit' the workings of the professional? Our original definition of professional referred to acting in the best interest of the client. In terms of empowerment the security of the professional can be enhanced by the disempowering of the client to a point of subservience. Keeping the client on the outside of the profession can be achieved in a number of different ways with private jargon, complex administration, intensive routines, overprotective reception staff, unfriendly physical environments and over use of drugs. The professional therapist can be seen as perceiving that the client is incapable of making informed choices, hence needing directive, invasive treatment.

### Social Control and the Family

The family provides a framework for social control, around maintaining and reproducing successive generations. The high interest, bordering on moral panic in divorce rates, lone parenting, illegitimacy, abortion and child/elderly neglect and abuse bring into question not only the role of family but whether it is falling apart as a social structure. If it is accepted that the family is in decline then whose responsibility is it to protect it; the state, the church or academics? Sociology and social policy have long been concerned with the family as an object of social control, analysing its role and occasionally encouraging the development of new health care professions to work with it. Rodger (1996) writes on the politics of families and social control 'In Britain a battle has been joined between those on the right who are struggling to set a policy and

political agenda on family issues around the motif of 'back to basics' and those on the left who wish to ground a concept of 'ethical socialism' in notions of community service, personal responsibility and family obligation.' (p. 2)

The main theories of family and social control are Post-structuralism (Nietzsche, 1974), systems theory (Hill, 1971) and feminist theory (Oakley, 1974). The modern family can be seen as 'founded on the domestic slavery of women', Phillips (1988) sees the capitalist class gaining a free service from this stabilising process and thus state policy is designed to encourage marriage and propagation. He goes on to describe this stabilising effect on society by 'fragmenting potential resistance to the system'.

The increasing state intervention in these areas along with a focus on family values or 'back to basics', has led many people to question the role of state social control. Should we have more freedom of speech and expression and does more social control inevitability lead to even more social control?

### **3.10 Summary**

This chapter has examined social control, its relationship to power and the expectations surrounding disabled people and the nature of professionalism. Social control is both an intention and action which occurs at all levels and in all aspects of society. It is an expression of power often as a reaction to some form of conflict. It aims to influence, limit or eradicate deviance in contrast to the norms and values that exist within society. The classic example of social control is that embodied in institutions but, families, architecture and therapy present clear elements of softer but active forms of social control.

Social control therefore derives from society, which in itself is no answer. Society forms and is formed by a myriad of factors, influences include the media, family, government and professional opinions.

I began this chapter with a quote from Porter (1987) which illustrates the importance of labelling attached to disability and the subsequent discrimination that can be experienced by people with such a label. Nathaniel Lee's attempts to control this process and his feelings of disempowerment caused by the inferred status of the professionals around him demonstrate the key role of the professional in social control. It is not implied here that professionals are involved in some global conspiracy to oppress users of services. Individuals within the professions may vary in the types of control they

prefer to use. Some may take invasive lines in treatment and care, others may use more gentle and nurturing approaches. However in the assessment and response to need (which I will discuss in chapter 4) professionals use social controls explicitly and implicitly to create an environment that attempts to improve the quality of life for disabled people.

## **4 NEED AND QUALITY OF LIFE**

‘Quality of life represents the degree to which an individual has met his/her need to create their own meaning so they can establish and sustain a viable self in the social world.’ (Brown, 1988, p. 15)

Need is the drive for all welfare responses. Examining it along with quality of life provides both a theoretical and practical foundation to the chapters that follow on community care policy and more specifically service design. A series of questions are addressed around each topic; who defines need and how it is met or not? Do the needs of the individual clash with those of the group and how are such conflicts resolved? Does having your fundamental needs satisfied guarantee a high quality of life? What is the role of the professional in assessing need and providing services? What is a service and are services always the best structures to meet needs? Is it possible to measure quality of life with any accuracy?

### **4.1 Need**

Need is obviously an emotive term. It conjures up debate in many areas including the structure of welfare, the rationing of resources, the basic survival of people and their potential for happiness. In the Oxford English Dictionary ‘need’ is characterised in terms of a ‘necessity or obligation to or to do...(in terms of)...circumstances that require some course of action.’ This definition shows the obligatory nature of need in reaction to a given situation. The question here is who is obliged to meet this need? Bradshaw (1972) in a ‘Taxonomy of Social Need’ distills four types of need:

- Normative Need: Defined by experts.
- Felt Need: Wants.
- Expressed Need: Demands.
- Comparative Needs: Territorial justice (needs compared to other people).

Bradshaw (1972) offers a definition of need based both in internal and external judgment. Needs here may stem from a rational choice or a motivating feeling. Needs are not wants, wants are subjective. It is commonly thought that people make choices based on their own wants, but this may not always be the case. Needs here are usually matched with the concept of wants. “I may want a cigarette but I need to stop smoking”. But you can, of course, want what you need.

Thayer (1977) gives a good working example of Bradshaw's need typology: 'Normative need is what the expert or professional perceives to be need in a given situation; felt need is need perceived by the subject themselves; expressed need, or demand, is felt need turned into action in the form of a request for services; and comparative need is need deduced by the outside observer in circumstances where the individual not in receipt of a particular service has similar characteristics to others who do receive it.' (p. 54)

Need is a drive, a motivational force caused by an imbalance or lack, but it is still unclear for exactly what types of things we are driven to need. A contrast also exists between need and potential ways of satisfying it. We could consider a drive to take drugs as understandable but not in terms of it as a need, but a physiological and psychological addiction. It appears that for a 'need' to be recognised it means that if it is ignored then serious harm will occur. Serious harm can be defined in terms of a disruption to the pursuit of individually valued goals. The question here is who defines these goals? This encapsulates Doyal and Gough's (1991) universal principle for a theory of human need. They go on to present an argument using a similar conceptual base to the interactionist one of Goffman (1961). Poor need satisfaction leads to impaired social participation and a threatened sense of self (see section 2.3). In other words we construct our sense of self by presenting it to others for evaluation and to do this we need certain things. The problem here is how you coordinate need satisfaction to actualise someone's self concept.

In work on the 'hierarchy of prepotency' Maslow (1943) presents a list of human needs which encompass both relative and absolute terms:

- Physiological.
- Safety.
- Belongingness and love.
- Esteem.
- Self actualisation.

The last three fit neatly into the work of Doyal and Gough (1991). Ware and Goodin (1990) in turn present a clear description of absolute and relative need formulation. There are certain physical resources that we all need such as water and food. We can consider these absolute needs. Doyal and Gough (1991) try to demonstrate with some success that we all have the same absolute needs in the physical and autonomy realms.



Some conservative writers have argued that we should only consider needs within these parameters. It follows that we live in a Western culture which provides such needs and thus any further consideration of need is not required. There are a number of problems with such a proposition. Firstly it is obvious that the physical conditions (needs) of people living rough on the streets are not being adequately met. More importantly physical survival is a necessary but insufficient criteria to define needs. This opens the way for a debate around relative need construction.

Townsend, a true relativist, would relativise the physical shelter category into the following; privacy, space to cook, play, warmth and segregation for a family to sleep. Harrey (1966) would add to this list: social and environmental services, consumer goods, recreational opportunities, neighbourhood amenities and transport facilities. Doyal and Gough (1991) would construct further intermediate needs to include; a non-hazardous work environment, security in childhood and significant primary relationships. The only reason for inclusion in this later list is whether it satisfies a positive contribution to the basic need of personal physical health and autonomy. We have to ask the question of whether these needs are common or universal to all humans?

#### **4.2 Demand**

A demand is a request for a need to be met. Demands are often connected to economic theories. Jones et al (1978) describe demand as a need that is backed by the money to pay for it. Nevitt (1977) stresses how demand theory has not been taken seriously by social policy makers. Social demands are those which have been prioritised according to the social issues of the day. The main issues to social policy makers are regulation, law and customs as driven and given reality by their economic base. Economics (being the study of human behaviour and actions around scarce resources) can give insight in to the process of making decisions. Nevitt (1977) defines demand as a function which is determined by the incomes and tastes of the consumer. She goes on to describe a rights based approach to demands and suggests that the modern conceptualisation of need is one far removed from survival and has more to do with the acquisition of goods.

Nevitt (1977) highlights five assumptions of human behaviour which are necessary to promote a continuous curve of demand:

- 1) Ability to make a choice.
- 2) Consistency in selection.
- 3) Desire for more than one thing.
- 4) More of a commodity is better than less of it.
- 5) The more you have of one thing the less you want of it.

We can therefore conclude from this last point that there is a level at which need is satisfied and demand is met. Nevitt (1977) suggests the use of a matrix of need related to agreed standards of goods formulated by an independent group of consumers. She also states that we should remove the notion of 'needology' as a unnecessary expression of relativism. This is seen as a 'heavily value-laden' statement of need created by people with a great fear of the market economy.

#### **4.3 Need, Empowerment and Values**

It can be suggested that needs can be chosen for you by another party who might be in a better position to select (normative need and the expert role). For example you may be unaware due to an illness that you need certain medical support a Doctor may choose an appropriate course of action. In terms of consumer empowerment this could be a strongly negative statement, giving the word 'need' a potentially paternalistic edge. It is important to define what we mean by informed choice; Doyal and Gough (1991) suggest that this is being able to formulate aims and beliefs about how to achieve them, along with the ability to evaluate the success of these beliefs in the light of empirical evidence. This suggests that people have a right to fail and take some responsibility for the positive and negative aspects of their lives. Autonomy here is a kind of self empowerment, acting as an agent for yourself. Doyal and Gough (1991) give a useful description of the empowering process of need satisfaction based in autonomy:

- Actors have enough intellectual capacity to formulate aims and beliefs.
- Actors have enough confidence to want to act and to participate.
- Actors communicate in some way their aims.
- Actors perceive their actions as being done by themselves.
- Actors understand the empirical constraints on the success of their actions.
- Actors are capable of taking responsibly for what they do.

These issues are salient to people with learning disabilities who are often seen as not only intellectually inferior but having little confidence, limited communication and lacking in competence and the capacity for responsibility. Therefore need satisfaction is a kind of positive freedom, as Doyal and Gough (1991) call it; an opportunity to attain materials, education and a style of living. This is similar to the work of Freire's (1972) on the relationship between self power and education (see section 2.2). Stainton (1994) builds a rights/autonomy based approach to empowering people with disabilities through changes in social policy. He sees autonomy as the way of organising and balancing the constructs of freedom, equality and democracy and putting them into practice. He also interestingly uses Berlin's (1969) work to distinguish positive and negative freedom:

- Negative Freedom - freedom from (external concept).
- Positive Freedom - freedom to do or be (self concept).

Stainton's evolving argument takes in some important issues around the role of rationality and emotion in choice, freedom and autonomy. He sees freedom in terms of the ability to exercise rights Stainton (1994): 'Someone who merely reacts to external stimuli or by brute instinct cannot be said to have made a choice. In other words choice implies some degree of rationality.' (p. 11)

This implies that there is a value base around choice; that is the more rational a choice is, the more of value it becomes. Thus people who have more rationality have more right to make choices. Stainton defines autonomy as 'the agent's freedom from both internal and external constraints to formulate and pursue self-determined plans and purposes.' (ibid, p. 22)

Hume unlike Kant sees passion and not rationality as the basis for morality. People with learning disabilities may be considered to sometimes have limited rationality based in intellect but their emotional world is the same as the general population. Stainton's (1994) argument finishes with the construction of rights born from autonomy in compensation for people with disabilities history of disadvantage. He stresses their rights must have full support and be subsequently exercised for them to be meaningful.

Moody (1992) provides a critic of autonomy as the soul means to empowerment by stating: 'insisting upon the ideal of autonomy contradicts disturbing facts about the conditions of frail elderly men and women - above all, with the erosion of their power to choose and of the ability to carry out their choices. The irony is that we want to uphold autonomy for the elderly at just the time when their conditions make autonomy least attainable and at a time in life when other human needs - for care, for respect, for meaning - are more pressing'.

Moody (1992) is not saying there is anything intrinsically wrong with autonomy except in its overuse. To him autonomy is not synonymous with respect. The emphasis here is to consider respect for a person within the context of their personal life histories.

Jones et al (1978) suggests that 'equality' (equal shares) and 'equity' (fair shares) are key to any notion of personal and public empowerment around needs. It is very difficult to produce a policy which is both based in equality and equity as people's needs are rarely the same and resources are always limited in some way. As some people seem unconcerned about the inequality in their own lives seeing it as somehow part of the natural order of things, is it therefore desirable and empowering to do anything about this? Many people, particularly on the new right believe that equality would only produce an undesirable uniformity.

The notion of values chosen for social acceptability are closer to some groups of people than others. People born into a low socio-economic group have a lower chance of attaining some socially desirable goals. In empowerment terms inequality denies not only physical gain but the ability to take responsibility for one's actions. Rights are perceived in a number of different ways: they can be set in law, they can be what is expected and also what is wanted. When rights are referred to responsibility is often overlooked, responsibility is the obligation to uphold rights. Tawney (1930) states that equality is impossible to gain but should be viewed as a goal. He states that we do not use the impossibility of absolute cleanliness as an excuse for rolling on a heap of manure.

Britain like many other Western nations has over the last fifty years created legislation to protect basic human rights; eg Civil and Political Rights. One major aim for social policy is the pursuit of social justice. Justice is concerned with fairness, thus it is relative to cultural norms and social stereotypes.

Social justice might be said to be a 'right' action, of general interest to all. Rawls (1971) theory of justice is highly influential in this area. It can be characterised as two principles:

- 1) Each person is to have an equal right to the most extensive total system of equal basic liberties compatible with a similar system of liberty for all.
- 2) Social and economic inequalities are arranged so that they are both of:
  - a) Greatest benefit to the least advantaged, consistent with the just savings principle.
  - b) Attached to offices and positions open to all under conditions of equality of opportunities. A chance for advancement (i.e positive discrimination).

Runciman argues that there are three basic criteria for the distribution of social goods and resources: need, merit and a contribution to a common good.

Therefore a just society will not be egalitarian as some people will have special needs and will quite rightly need more than others. In a hypothetical society under these principles unless people have a special claim based within this framework there will be a steady move of money from the rich to the poor. Having a right is one thing, knowing you have it is another, acting upon it is yet another.

The conception of need which allows for personal presentation of autonomy to others is compatible with the notion of empowering the individual's presentation of self. Need is the stamping ground between the resources which are usually limited and the right to control one's life. One major theme that comes out of this relationship is that power is inherent in information. Professionals may gate-keep resources, this has always been a primary aim of policy. Sometimes it occurs for good reasons but gate-keeping information on acquisition of goods/services is clearly disempowering. A move is required from much of the language of need which is passive, to an active users' understanding and participation within the process. Instead of seeing the views of people with disabilities as troublesome, they can be seen as a 'commodity'; information to shape and evaluate a new consumer service (see section 2.7).

#### **4.4 Quality of Life**

Quality of life in recent years has become a contentious issue, with the increased cost of specialised medical intensive care and pressure for improved social conditions for users of services. The new technology and ethical dilemma of sustaining life at any cost makes for a difficult balance. Research by Baldwin, Godfrey and Propper (1990) indicates the interested parties in the quality of life debate to be economists and social policy makers.

Economists are concerned with the cost of welfare systems and social policy makers the value of government intervention. There are many questions in this area which remain unanswered: how can we find, analyse and measure quality of life? Is it a task worth doing in terms of understanding human nature or the proposed responses to need in welfare objectives? In meeting needs is quality of life necessarily increased? Is quality of life different (qualitatively and quantitatively) for people with and without disabilities? Should we do everything possible to prolong life ignoring the subsequent quality of the person's life? Is quality of life universal to all cultures and societies? Can a person be their own judge of quality of life?

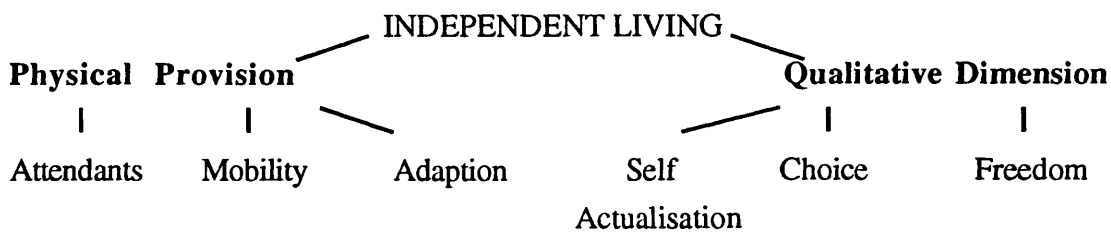
What follows is a selective examination of the literature and thought in this area. Issues are highlighted that are salient to any consideration of people's personal and collective accounts of their power in making decisions and choices around happiness and an increase in their quality of life. Aggernaes (1989) presents a needs analysis of quality of life related to health and states that: 'Specified objective quality of life is the degree to which the individual has satisfied his or her needs. Specified subjective quality of life is the degree of satisfaction that the individual feels in connection with the satisfaction of needs. General subjective quality of life is the degree of satisfaction that the individual feels with life as a whole.' (p. 140-141)

Aggernaes also draws a useful distinction between resources for quality of life and quality of life itself. Chamberlain, Rogers and Samuel (1990) used four different techniques to measure the quality of life of clients with learning disabilities:

- 1) Assessment of needs.
- 2) Engagement in a meaningful activity schedule.
- 3) Consumer satisfaction (including a parent views questionnaire).
- 4) Programme analysis of service systems (PASS) on service atmosphere and values.

This is a symbolic interactionist interpretation of quality of life. Brown (1988) moves on from this approach to consider quality of life in terms of two dimensions of independent living as illustrated in figure 10. Physical provision refers to the external aspects of independent living and the qualitative dimension refers to those more internal aspects of the independent self. This approach includes elements of normalisation, social integration, consumerism, self-help and civil rights. Finally Brown looks at outcome measures in terms of community adjustment around: occupation, residential environment, social support and personal satisfaction.

Figure 10



Well-being

Empowerment can be seen as the tool of social justice in creating a world which contains more of the following: positive discrimination, access to information, equality and equity. These are all elements of empowerment that push a person towards a sense of well-being. Well-being can include the categories of need which also are required to construct empowerment: dignity, respect and a sense of belonging. Griffin (1986) analysed well-being from a utilitarian perspective, framing it as two types of utility (utility being the presence of pleasure and the absence of pain): mental states and desires.

The philosophical problem with this is that if a machine could be designed that we could be plugged into, which fulfills all our mental desires we still might not want to give ourselves up to it. Secondly the proposition concerning desire suffers from the problem that we do not always desire what is good for us. We may have to consider this notion within the parameters of informed choice and rational desire. It is also important to understand the distinction between praise and respect in terms of people’s sense of well-being and value. We can praise anyone for a job well done but we reserve our respect quite often for people around some other notion of status. We must look for a means of equality in respect related to disability and the role of the professional. The role of the professional is discussed in section 3.8. Mayers (1995) writes ‘a sense of well-being suggests that the person has come to terms with his/her condition and is at peace with himself/herself.’ (p. 147)

This represents an example of positive deviance (see section 3.5). Mayers (1995) goes for a holistic definition of quality of life; ‘quality of life refers to a person’s subjective well-being and life satisfaction in that it includes mental and physical health, material well-being, interpersonal relationships within and without the family, work and other activities within the community personal development and fulfillment, and active recreation.’ (p. 147)

Evans et al (1985) designed a quality of life questionnaire around five major factors of well being:

- Occupational well-being
- Social well-being
- Family well-being
- Personal well-being
- Physical well-being

Bergsma and Engles (1988) try to operationalise quality of life into four levels:

- 1) Macro: Meaning of life in society
- 2) Meso: Person's social environment
- 3) Personal: Person's pain and hopes
- 4) Physical: Measurable behaviour

No mention of spiritual satisfaction appears in the above, Aristotle would place this as the most important aspect.

Sen (1993) puts forward an interesting discussion around advantage in relation to capabilities, functioning, well-being and freedom. The capability of someone is seen as their ability to achieve various valuable functions. Quality of life according to Sen is therefore a selection of these capabilities. Examples of functions can be as simple as being able to feed yourself or as complicated as achieving self-respect. Sen states that freedom is a difficult concept to work with. Freedom it is argued tends to be considered as a choice separately from the context of an actual choice. The conflict here is that it is wrong to consider that range of choices without the nature of what the choices actually are. In other words more choice does not on its own constitute more freedom. Sen finally makes a distinction around the value base of well-being, freedom and achievement: promotion of a person's well-being and the pursuit of other goals against achievement and the freedom to achieve.

### Happiness

Any discussion about the nature of happiness has to consider a number of questions. Does happiness result from the satisfaction of needs or demands? If we arrange wants and needs into a hierarchy are they distinct or are they interdependent? A person may insist on virtually any personal goal to be happy. The problem with defining quality of life in terms of need satisfaction is that a person may have all his/her needs fulfilled but



still be unhappy, for example issues around not having enough time to do certain things or having lost a partner.

Nordenfelt (1993) presents a theory of quality of life based on happiness, as part of a want-equilibrium; 'Human beings have more goals than what can be sensibly called needs. Human happiness is, I would claim, is dependent on satisfaction of all kinds of goals, not only on the satisfaction of the basic needs described in current psychological theory.' (p. 9)

Nordenfelt argues that we need to assess quality of life in detail and this must include aspects of the personal, social, intellectual and spiritual. The satisfaction of needs is not enough to understand the multifaceted nature of happiness for the individual.

Aristotle based his theory of quality of life (eudainsonia - ultimate good in life) within a hierarchy of virtues, happiness being a certain type of active living. This for humans is the fulfillment of their essence, essence being the purpose of everything to exercise its function. The function of human beings as opposed to other animals as defined by Aristotle is to act in accordance with the rational principles of virtue, that is to act rationally. Nordenfelt (1993) writes of Aristotle: '(he) in fact proposes a hierarchy of virtues in the following way: those virtues which are predominantly of a spiritual character, or those which are mainly performed by the soul, have a higher position in the hierarchy than those which are mainly of a bodily kind.' (p. 19)

One of the essential characteristics of humans is that of their intellectual capability. This puts people with learning disabilities in a devalued position if we follow Aristotles' argument. Bentham based his theory of quality of life (utilitarianism - principle of utility) within psychological hedonism. Quality of life and happiness can be related to pain and pleasure. Bentham provides an examination of both pleasure and pain categories:

- Intensity
- Duration
- Certainty or uncertainty
- Remoteness
- Fecundity (ability to generate new sensations of the same kind)
- Purity
- Extension

The aim of any welfare system therefore is to provide the greatest care to the greatest number of people over the longest length of time. However quality of life belongs to the person's inner well-being as well as the external welfare they experience. For utilitarianism to work relative utility must be measured, ranked and made applicable to the individual and group.

### Quality Adjusted Life Years

Quality adjusted life years (QALYs) are an attempt to quantify and qualify quality of life out of the union of utilitarianism, and health economics. Nordenfelt (1993) along with others asks the question 'By what measures do we create the optimal quality of life in the population?' The answer must address issues such as the future states of people and how you could evaluate outcomes and cost benefit analysis. The work at York University attempted to answer these questions with the development of the QALY. This was a matrix constructed from distress and disability ratings assigned and prioritised by 70 health professionals. It formed a mathematical linear transformation where complete health is represented by a score of 1 and 0 stands for death. One QALY equals one year of complete health. Baldwin, Godfrey and Propper (1990) state that 'The QALY is the arithmetic product of life expectancy and an adjustment for quality of the remaining life years gained.' (p. 57)

Nordenfelt (1993) writes that 'One remarkable result of the investigation is that the test-person considered two states - in bed with serious suffering and unconsciousness to be worse than death.' (p. 151)

The QALY is therefore both a description and a valuation. There are a number of arguments against the use of QALYs, summarised as follows:

- 1) The QALY is a measure of health over a time period not quality of life.
- 2) QALYs are based upon the systems of psychometric testing. How much sicker are you in state x than in state y? How should a person interpret this question unless there is a detailed explanation? The only way of truly judging is on an individual face to face level.
- 3) How can we compare say 7 years of healthy life to be equal to 10 years of unhealthy life?
- 4) Ethically how do we distribute QALYs through the population, how will older people and people with disabilities fare in these calculations?
- 5) Who makes the final decision around quality of life measures and distribution of available resources?

Quality of life is concerned with satisfaction about life in a total way, not just health or welfare. These contribute to it but do not give the whole picture. Some writers argue that the individual is the ultimate judge of their own quality of life. Mayers (1995) suggests that 'discussion with a client about his/her individual quality of life and what this means to him/her is probably more realistic than trying to measure aspects of it.' (p. 146)

Some suggestions have been made that the term 'quality of life' should be replaced with 'quality of experience' in an attempt to move the focus on to people's own interpretation of their lives rather than the scaled external judgments made by professionals. 'Quality' here is associated with the significance that people place on their own needs and life events not others' projected value measures and judgements.

#### **4.5 Need and Service Provision**

The New Right based its policies on nineteenth century liberalism where the state only provided aid to those people whose needs cannot be met by any informal networks such as families and friends, the market or voluntary services. Ware and Goodin (1990) discuss the social justification of state provided welfare in terms of the idea of social citizenship. A person living in a society and attempting to act as a full citizen is justified in demanding certain rights which are absolute and relative in formulation, for example economic and social welfare. The heterogenous nature of a society provides us with a degree of relativity of need.

Culpitt (1992) suggests that the Welfare State has been under attack by the rejection of social ideals of citizenship rights and obligations, the main concern for the Welfare State being its feasibility not legitimacy. It is suggested that as a result of this, collective responsibility and obligation have become somehow unjustifiable in government circles. We have seen a move to a belief that we should be individualistic in nature, not sharing the skills we have or the benefits we gain from them. This attitude has been reinforced by the continuing capitalization of Eastern Europe. Culpitt (1992) puts forward the extreme argument for the total withdrawal from social service provision by the government as the government can never respond completely to complex social uncertainties. Since the only 'true' social reality being the "morality of the market". However the use of the market allows for satisfaction of mutual need. The consumer becomes aware of the problems if there is not an adequate service. The provider is obligated to respond to this situation by providing better services.

Some problems with the market economy of service are pointed out by Lowe (1992):

- 1) Politicians and civil servants who constitute “the state” may not be neutral arbiters but interested parties in their own right.
- 2) Certain groups with special contacts, expertise and knowledge may command unequal access to governments and thereby command an unequal share of power which they can turn to their own selfish advantage eg medical profession dominating the NHS.

Table 5 shows the various models of social services based on the social provision work of Ware and Goodin (1990):

<b>Table 5 Needs theory and models of social services</b>			
<b>Model Impact</b>	<b>Who is Covered</b>	<b>Level of Cover</b>	<b>Redistributive</b>
<b>Residualist.</b> (needs-based)	Universal Means Tested	Limited. Not well advertised	Not effected. No back payments
<b>Insurance.</b> (contributions)	Requires contributions Individual/employer	Depends on contributions	None
<b>Social Citizenship.</b> (rights - based)	Universal/need to be a resident	Fully socially relative	Bias to middle class

Ware and Goodin (1990) coin the phrase ‘conventional wisdom’ that it is indisputably better for people to be provided with more of what they need up to the point that they need no more of it.

In relative terms we could consider the alternative to giving more to an individual to equalise the level of relative need, to be taking away from the majority to gain the same end. Ware and Goodin (1990) go on to say ‘it is important to distil socially relative needs.....people’s felt deprivation is relative in terms of their aspiration and expectations, which are relative in terms of their reference group and average accomplishments within it’. (p. 34)

This is Ware and Goodin’s (1990) concept of ‘strong relative need’.

Table 6 is based on Ware and Goodin's (1990) analysis of absolute and relative need in policy specific areas.

<b>Table 6 Absolute and relative needs in policy</b>			
<b>Area</b>	<b>Absolute Need</b>	<b>Relative Need</b>	<b>Notes</b>
<b>Housing</b>	Shelter	Standards of Health and Hygiene	Equality of housing
<b>Food and Clothing</b>	Sufficient to survive	Level of comfort	Illuminate competition
<b>Education</b>	More is better	Culture	Equalise relative need
<b>Legal Aid</b>	Justice is a virtue	Level of aid in courtroom competition	Reduce grandeur of court rooms.

Satisfaction however is not a comprehensive measure of quality, as you have to look toward what people really need (perhaps even want) not just what professionals can get away with giving them, without a complaint. Assessments in these terms often work to manage users' of services expectations since there may be a fear that unobtainable goals will disturb the user.

Why do some professionals doubt the ideas of users of services? They appear to think that what users say is self-interested, biased and lacks understanding of the real issues. Doyal and Gough (1991) state that we do have a problem in allowing people to make their own choices concerning needs if they are limited by a lack of knowledge. The choice they make is seen as 'epistemically irrational'. McKnight (1977) describes the following two sets of assumptions around need:

Professional assumptions around the conception of need:

- 1) Translation of need into deficiency - therefore the person is in an unfortunate situation.
- 2) Placing the deficiency in the client - isolation of the individual from the context.
- 3) Specialisation - using technique and technology as the main goal.

Professional assumptions around the remedy to need:

- 1) The client is the problem, the professional has the solution 'a basic definition of "unprofessional conduct" is becoming involved with the client. To be professional is to distance - to ensure that the relationship is defined in terms that allow the client to understand who is really being serviced.' (p. 83)

- 2) The remedy must define the need. Therefore you can create new needs from new remedies.
- 3) Coding the problem into a solution using language which is incomprehensible to lay people.
- 4) 'It is the capacity of services to define the output of their service in accordance with their own satisfaction with the result.' (ibid, p. 87)

There are a number of problems with this view, firstly that people in authority are not immune to irrational choices themselves, and lack of knowledge from users should be met with increased education not diminished choice. This would allow awareness of the consequences of the resource they are receiving i.e. taking responsibility, which is a core issue. If the needs are constructed and distributed by a particular authority, how can any independent evaluation take place? In Marxist terms those at the bottom of the 'social value ladder' have been handed down what authority judges as needs (often a reflection of current professional ideology) but they may be quite different from their 'real' needs.

The New Right writers such as McInnes (1977) stress the only way of handling need is to divorce the welfare state and focus on labelling need within the consumer framework in the market. This process however would make constructing and enforcing justice very difficult.

#### Exclusivity of Service Paradigms

Figure 11

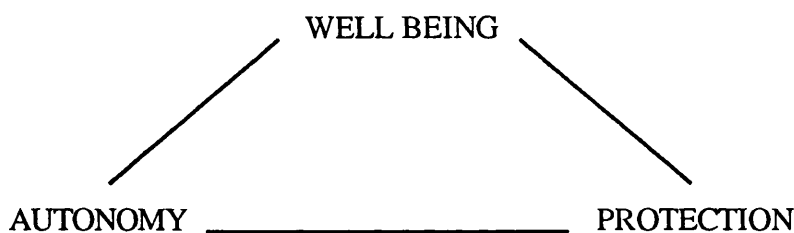


Figure 11 represents three possible service paradigms for working with people with learning disabilities. A problem arises when any one of these is exclusively followed, as tension is set up with the others. For example if as a worker you allow a user to take increased risks following 'autonomy' this may threaten their 'well-being' or 'protection' by putting them in personal danger. Doyal and Gough's (1991) theory of need develops around the avoidance of harm to personal autonomy and physical health so that a person can participate fully within the community.

There is a question here about what services do with needs. Do they train users to desire certain available services? Do they gatekeep the scarce resources? Do they through direct and indirect means, manage need expectation? In practical terms Jones (1978) writes on the structure of services:

- Universal Social Service - is one where all citizens contribute and from which all are entitled to draw equal benefits, e.g NHS.
- Selective Social Service - is one where benefits are only available to certain applicants under certain conditions, e.g social services.

Brown (1988) writes that 'Concepts such as normalisation, independent living, deinstitutionalisation and least restrictive environments have had a dramatic effect in recent years upon the delivery of services to people with disability. What is not clear is the secondary impact these concepts have had upon the people themselves.' (p. 7)

Services tend to view increasing quality of life with increasing independence but this may not be the most important goal for clients. Doyal and Gough (1991) state that orthodox economics presents need as a series of preferences and there are two fundamental principles at work. Firstly, individuals are the only authorities on their interest or wants. Secondly we must consider 'private sovereignty' over needs, that is to say what is to be produced, how it is to be produced and how is it to be distributed should be determined by the private consumption and work preferences of the individuals. There is an assumption here that satisfaction can be measured. This gives strong support to empower people. Instead of treating people's attitudes and wants as symptoms of damaged minds, people get the opportunity to make choices and their degree of satisfaction goes towards the next policy decisions. A consideration of the basic level of need satisfaction within the framework of autonomy and physical health is salient. Again there are problems here with this cost benefits utilitarian analysis of needs.

How do professionals record need and in doing so do they give space and credence to wants? On the list of options open to people are there things which cannot be offered yet, or does this raise users' and carers' expectations unnecessarily? The Richmond Upon Thames Mental Health Needs Review (1995) illustrates that users' self assessment during the study were extremely close to the nominated professional profiles of users' needs.

## **4.6 Summary**

This chapter has examined needs, wants, demands and what is loosely termed quality of life in detail. Questions have been asked about the purpose of a service in welfare, namely is it to meet the needs of users and improve their quality of life or more cynically is it to meet the needs of professionals?

Expressing a need is an expression of power, removing a need is a powerful action, having no needs is either a realisation of complete power or complete lack of power. Sometimes people are not aware of their needs and wants, and we all choose differently at different times. Support may be needed for people to explore hidden dreams, and flexibility required for timing of need reduction. In other words needs are inherently personal things. The power of professionals versus people's needs lies in the following:

- 1) Interpreting power of what people say.
- 2) Acting as intermediaries between people and ruling groups.
- 3) Acting as gate-keepers to services or the resources to acquire services.

Professionals are given the social mandate to negotiate on behalf of people and societies to redefine the meaning and ways of satisfying needs.

The discussion around the definition of need has shown the importance of conflict in needs analysis and the confusion over demands and the consumerism that can follow it. What we refer to as services in welfare are often steeped in professional assumptions of need and the fitting of users into specialised services. The significance of ideas around social justice such as equity and equality have been discussed along with well-being and capabilities. From the work presented it is useful to take Aristotle's idea of high quality of life stemming from fulfillment of self by engaging in things that people are good at. Utilitarianism offers a means to compare different approaches using a cost benefit analysis within the parameters of health economics. 'Happiness' as a construct is of increasing interest, breaking the argument away from the confines of pure needs analysis. We may have all we need but still be extremely unhappy. Happiness proves illusive by its personal nature, being resistant to rational arguments based in health economics and utilitarianism.

Historically professionals have had a tendency not to trust users of services own words and their 'right' to make decisions about their own service provision, stating they will choose an inappropriate package of care. 'Informed choice' is in vogue in services but still cases of 'enforced choice' occur. If professionals seriously intend to empower the



users of services by giving them choices around their needs and wants, then they may have to do more than lip service. They must respect users' subsequent decisions even if they are in direct disagreement with their professional opinions. It has been presented that it would be more empowering when designing, writing and implementing care packages to consult people on their wants not just needs. In doing so users could put themselves within a framework of positive value and also educate themselves about the potential outcomes of provision not bear the stigma of benevolence. The use of the word 'need' is far nearer to the notion of stigma than say 'wants' or 'desires'. When 'ordinary valued' people discuss their aims in life do they construct a framework of 'need'? They talk of wants, wishes and desires. 'Needs' tend to focus on people's weaknesses and short comings rather than their hopes and what they wish to attain.

Quality of life must by its very nature be ultimately personal. Some absolute needs should be met in a universal sense to ensure quality of life; physiological, health, education, shelter, warmth, food and water. The debate gets difficult around relative needs, for example Atkinson (1985) suggests that friendship is as important as vitamins in people's lives, this being no different for people with learning disabilities. Organisations involved in the assessments process may need to consider un-met need and the perfect satisfaction of needs and wants initially without reference to resource issues. This allows for true understanding of the users' world before cost issues are incorporated. We all have limits on our choice since social control systems reduce our choices often for very good reasons. Freedom must go hand in hand with limitations on choice and responsibility.

Any single minded pursuit of one ethical principle in support of quality of life is problematic due to its narrowness and subsequent tension with other approaches. For example autonomy as a construct is not synonymous with empowerment and more of it does not ensure increased quality of life, particularly for the elderly. We must also answer the question as to whether people with disabilities really want services to satisfy their needs? Some people may require help and support that is perhaps best not defined within the parameters of a service, but in terms of funding and structured provision in the form of non-specific-services.

## **5 ENGLISH COMMUNITY CARE POLICY**

‘The key question concerns the extent to which different people in need of support are accepted as legitimate members of the community and adequately integrated into routine life.’ (Crow and Allen, 1994, p. 173).

It is difficult to totally separate out the values supporting community care policy from its formation, interpretation and implementation. However, in this chapter I have attempted to segregate the main values and issues to make them more easily accessible to analysis. The historical and power contexts of community care are vital to understanding the current position of the government, carers, users and professionals. Recent community care policy does not represent a revolution in philosophy for the majority of disabled people as they have always been cared for at home by members of their families or significant others. However, the attempts to integrate those people who have been in long stay institutions into the community does represent a radical change in philosophy towards integration. In the introduction of Skidmore’s (1994) book on the ideology of community care he asks the key question: ‘Is it care by the community or care in the community?’ Whichever option is taken it includes the following assumptions:

- that there is a community
- that the community cares
- that formal structures (such as hospitals) can be separated from the community
- that communities are safe and friendly places
- that communities are static

Further to this can the community be considered organic or mechanistic, artificial or natural?

### **5.1 Definition of Terms**

#### **Community**

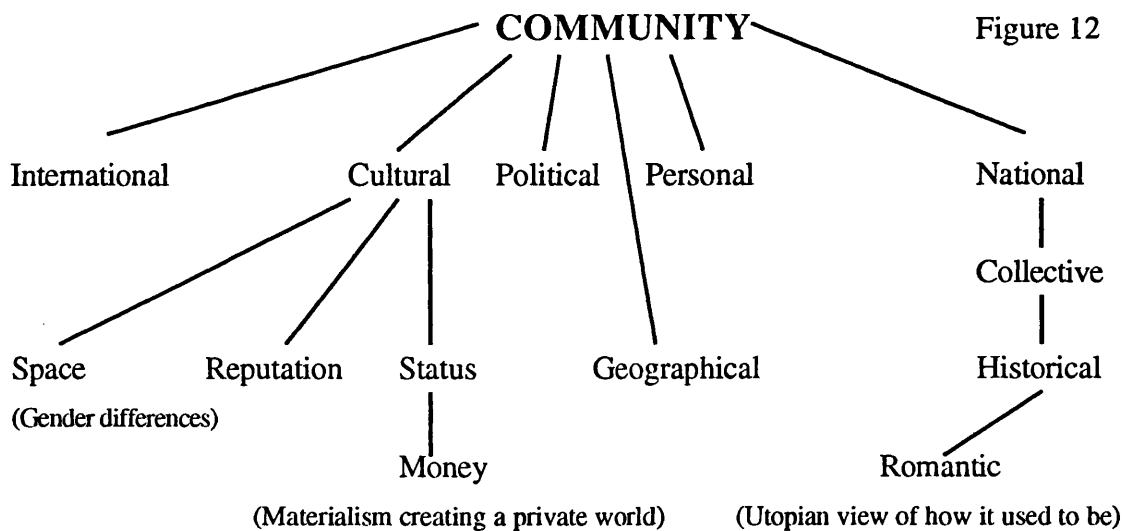
There are many definitions of community. Bulmer (1987) points out that it carries an aura or sense of goodness, Cochrane (1986) writes ‘Today governments seem to use ‘community’ as if it were an aerosol can, to be sprayed on to any social programme, giving it a more progressive and sympathetic cachet; thus we have community policing, community care.....’ (p. 51)

These statements highlight the problem of dealing with a concept such as community which appears to carry no negative connotation.

In the main there appears to be very few references to the negative aspects of communities in the research and writings covered. Skidmore (1994) does however refer to communities being insistent on retaining some members as well as rejecting others, the implication being that community support can come with a price. It was written of the 1950s that in working class neighbourhoods: 'communities were held together by the application of social sanctions against those who flouted the norms of local social life.' (p. 25)

Crow and Allan (1994) also point out that 'one frequently finds a tension between, on the one hand, the benefits for social order of community integration and, on the other, the high value placed on individual freedom and choice.' (p. 154)

Communities need and benefit from systems of social control (see chapter 3) but they are bound to infringe on some aspects of personal liberty for individuals within the community. Figure 12 is developed from the work of Bornat, Pereira, Pilgrim and Williams (1993). It summarises the origins and issues in the construction of communities:



It is more likely, but not inevitable, that if you live geographically near someone you will have a relationship with them. A consideration of people's wider social networks is perhaps a more helpful way of looking at communities than friendships as they are

not necessarily based on locality. Other factors such as family relations, where people work, religious beliefs, ethnic background and shared feelings of adversity (Durkheim, 1952), are some of the many factors which affect the probability of structures called communities forming. Community can therefore be defined in terms of a social experience which may or may not be connected to a geographical location, this is perhaps better considered as a shared experience of common interests. Willmott (1982) defines community in a similar way to Bornat et al (1993) except with the addition of the notion of the 'spirit of a community'. Spirit is not easy to define but seems to refer to the energy or animated quality of a community. In romantic terms 'spirit' could be viewed as the smoke that rises above the workings of the machinery of the community, the fusion of issues in figure 12. The 'rites of passage' for younger people moving into adulthood also indicate the spiritual binding of communities.

Lynch and Perry (1992) discuss the nature of 'community' in a useful way suggesting that it:

- infers some kind of pattern of relationships between individuals or groups of individuals,
- may also imply a high degree of intimacy, personal interaction between people, with the quality and substance of the relationship being characterised by commitment and a sense of common purpose sustained over a period of time,
- may be a convenient way of identifying a particular geographical location,
- implies shared interest and origins (could be of cultural and ethnic importance).

Skidmore (1994) characterises community by referring to a series of anthropological descriptions, three of which follow:

1) The geography of being: 'If a person feels that he belongs in a particular location then that is his community.' (p. 3)

2) The atlas of existence: 'Those 'ideals' (e.g family structure) that help construct reality become symbols of normality.' (ibid, p. 17)

3) Natives, exiles and refugees: natives have entry into a community by birthright.

'Outsiders can join peripheral activities but one is elected to membership once commitment has been proved.' (ibid, p. 30)

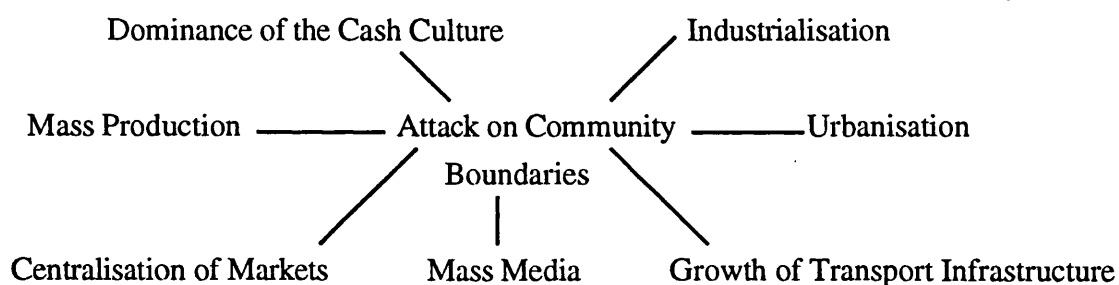
Skidmore describes community 'refugees' as people decanted out of their communities. The institutionalisation of people with learning disabilities fits this description well. Self-help groups as well as mutual aid organisations, advocacy groups and scientific

groups can also be considered communities due to their shared goals and ideals. There seems to be more room for hope in the community than institutions by their more open and permeable nature. However when 'communities of like minded people' do live within institutions. Strong friendships, bonds and a sense of camaraderie within networks of patients grow (Deacon 1974) and are often broken up during the course of deinstitutionalisation. The value of a community, wherever it may be based, depends on the personal significance people place upon their ties. A positive community appears as a reflection of its personal network of valued people. O'Brien (1987) refers to a study of social relationships for people with learning disabilities. In this it was reported that approximately 90% of people with a learning disability living in residential accommodation had no contact with non-disabled peers. Approximately 50% of the group had no, what was termed, 'special relationships'. O'Brien makes the point that community programmes do not make communities but influence their emergence by reducing segregation and promoting personal relationships. He stresses the importance of conflict resolution in the community as a key to its' development.

### Community in Crisis

It has been suggested that the increased breakdown of marriages (see section 3.9) has occurred as people have been encouraged to lead more private lives. Communities therefore perhaps become less family centred. This may have developed due to the emphasis on individualism and hypermobility during the last few decades. One potential distinction between a community and a institution is that an institution can have all its members removed and replaced with a new set without affecting its function. However if the same occurs in a community it no longer functions. Figure 13 below (adapted from the work of Crow and Allen, 1994) maps out community's boundaries and how they might be considered to be under attack. It is clear that post industrial development is a major force in this attrition. Community boundaries are marked out by rituals, events and attitudes. Boundaries here are fluid and in constant flux so that the process best fits the analogy of a permeable tea bag rather than a rigid balloon.

Figure 13



Policy makers appear to hold two conflicting views of community; one an altruistic model of benevolent individuals caring for each other, the other a breakdown of care leading to increased societal control. Etzioni's (1995) work on what he terms 'Communitariansim' projects new forms of social relations that can be used to challenge the state. McKnight and Kretzmann (1985) argue that traditionally social policy makers have either looked to the individual (consumerism) or the institution (mental handicap hospital) to provide answers to social issues. McKnight suggests that as a result of this polarity community regeneration has been ignored. He sees institutions as controlling forces and communities as networks of consent. There is however hope through community regeneration, he believes communities to be realistic, flexible, creative and independent associations of individuals where their citizenship can be expressed. McKnight may be guilty here of ignoring the negative potential of communities to control people and groups.

McKnight goes on to present three conflicting visions of society; firstly the therapeutic vision, where the role of the professional is to meet the needs of the client and fit them into the community. Secondly the advocacy vision where disabled people are protected by a team of advocates and self help groups from the woos of the community. A third vision is of the person being incorporated into a problem solving community, a place that accommodates fallibility, the disabled person being 'recommunalized'. McKnight's vision of advocacy could be considered rather limiting. Many advocacy organisations use self advocacy to aid the person to more interdependent living as to portray advocacy as only protection is rather simplistic (see section 2.6). There is no doubt that the romantic 'pop round through the open back door for a cup off sugar' image of community is harder to find in England today, if it every existed. This is not necessarily a decline but an evolution towards more multi-cultural, mobile communities. Now with the explosion of home personal computer use communities of internet users are expanding and perhaps in the future whole 'virtual communities' will develop. These communities may allow a certain amount of self control over the presentation of the disabled persons identity.

### Engineering the Community

The vision of community held by planners in social policy is influenced by notions of intervention and the social engineering. In an empirical sense, communities are a response to a combination of specific social conditions: physical proximity, density of networks, degree of openness, longevity of settlement and levels of resources. These can be studied and arranged into sociograms (Parten, 1932) of interconnecting

relationships. Often these are being orchestrated by developers, builders and other artificial organisations. Crow and Allen (1994) refer to this engineering of the community as a process where you: 'keep the good bits, modify those that are not working well; re-evaluate the whole and continue'. (p. 157)

They point to two problems with this approach:

- 1) This presents a false mechanical view of community, which is in fact organic in nature.
- 2) What should the community be changed to? The ideologies behind communities may be unclear.

Western culture tends to place value on employment and physical attractiveness. It is illegal to discriminate in terms of people's inherited physical characteristics, however there is evidence that so called 'ugly' people are discriminated against. This is termed 'lookisms' (Goodwin, 1996). Our economy is more and more being based in services where employers are increasingly becoming concerned with the attractiveness of their staff. What effects does this 'body fascism' and employment prejudice have on the population of disabled people? Disabled people are not traditionally portrayed as attractive and have reduced opportunities to work within communities. Cohen (1987) does however write that 'Community is as much about difference as it is about similarity and identity.' (p. 8)

Workers in the disability field often place importance on the phrase to 'celebrate difference.' This refers to a shift away from perceiving difference of physical or mental states as negative, a problem to be solved, to viewing it as an opportunity for a positive contribution to the community.

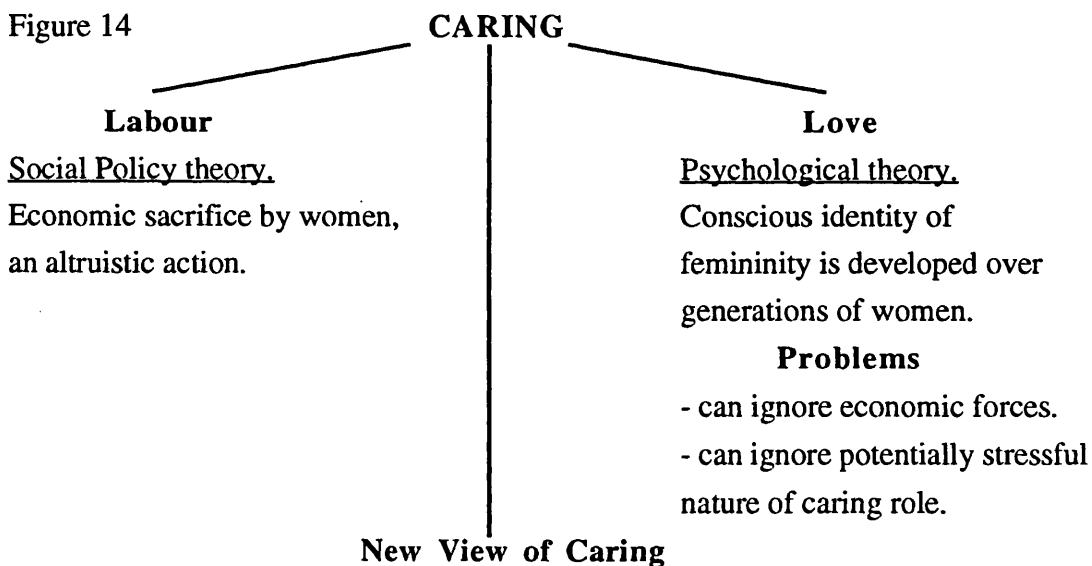
### Care

Care or caring includes the notions of physical and material assistance as well as a general regard for welfare along with affection and love. Caring can be broken down into 'tending' which is comprised of duration, intensity, complexity and prognosis. In 'caring for' or 'tending for' someone issues of respect, concern and love are evoked. Traditionally these values are associated with the roles taken on by women. Feminist theorists argue that community care is primarily family care and this in turn is care by women. Lewis and Meredith (1988) point out that the Equal Opportunities Commission estimated that in 1982 55% of all carers were female, 35% were male and 10% were unknown. These figures do show that caring is significantly higher in

women but not exclusive to them. The role of men as carers needs further research.

Graham (1993) puts forward caring as a 'labour of love' and this is framed in emotional terms, these are the bonds that tie us together socially. Caring is therefore caught up with concepts such as duty and loyalty within social networks. Graham goes on to explore caring by saying that it is not only based on symbolic emotional bonds (love) but the transaction of materials (labour). Bornat, Pereira, Pilgrim and Williams (1993) make the point that gender can not be considered in isolation without reference to ethnicity, disability and other factors. They go on to stress that women should not be seen as the passive victims of oppression within patriarchy, they should be seen as actively struggling to care. The independent living movement similarly stresses that people with disabilities should not be seen as victims, they would however object to the inference and image of a carer necessarily 'struggling' to care for someone. Figure 14 summarises Graham's argument (1993).

Figure 14



- Caring is not just a way of women gaining femininity but it acts to keep others alive and improve the quality of their lives.
- Caring is not just within a natural family unit but can include, for example women, older people and disabled people.
- Caring is a practical application of many actions and roles that cannot be defined in abstract.
- Caring often isolates women.
- Caring can also be highly rewarding and satisfying.



Morris (1993a) adds to this criticism of some feminist writers by stating they have focused on women as carers and not as disabled individuals. 'There is no consideration of economic independence being an issue for those who need help with the task of daily living, of the way that such economic independence would enable people to influence the quality of their lives, or of the way that it would diminish the vulnerability to abuse.' (p. 48)

In other words, some feminists writers have taken the 'need' of disabled people for granted and therefore reinforced their dependency. Care is encapsulated within the relationship that two people have; the carer and the cared for. A second way of framing caring negatively is within paternalism, in which caring involves labelling someone as weaker than oneself. From this position a measure of 'need' can be made (see section 4.1). This may lead to a value judgement of whether a person is 'worthy' or not of care. Care therefore can have a patronising interpretation, users may even be under pressure to be grateful for what services they receive. As stated earlier caring is not necessarily framed within stressful, burdensome and difficult obligations, it can provide people with power, satisfaction and a sense of purpose. In many policy documents in this area what is meant by caring and in what context it is framed is not defined or discussed.

### Community Care

The fundamental questions here are what in terms of care do we expect to get out of the community and provide within our communities? A sense of belonging? Shared taxes for agreed motives? Someone to drop in from next door to see if we need a pint of milk? Someone to help us get dressed in the morning? This leads on to the question of what policies can be created to guide ordinary people and services to address this kind of caring in the community? Bulmer (1987) and later Lynch and Perry (1992) distinguish between care 'within' the community and care 'by' the community. The former involves the provision of services which help and support people with disabilities in their own homes. Care by the community suggests that the local community itself will recognise need and as a consequence provide care. Such services would be locally led by users and their advocates, this having resource implications. Bulmer suggests that a useful distinction could be made between resources fed into the locality from outside and those mobilised from within.

Bulmer (1987) believes that the term community care was initially used in reference to the mentally ill in a chapter in the report "The Development of Community Care" by the Royal Commission on Mental illness and Mental Deficiency (1957). It is clear from the following work that community care does not exist as a clearly operationalised set of definitions. In contrast Bennison (1988) suggests that community care as a term has been around since the turn of the century with respect to the guardianship of people with learning difficulties.

### Community as Normal, Ordinary and Homely

The notions of what is "homely" or "normally" are difficult ones. Wolfensberger's (1972) construction of Normalisation and his later work on Social Role Valorisation (SRV) provides a practical framework for the application of what can be called ordinary living principles. SRV and Normalisation influenced policy all through the 1980s and 1990s by promoting integration for people with disabilities (particularly learning disabilities) and their increased social valuing within mainstream society.

Skidmore (1994) suggests that subgroups such as disabled people can be marginalised by being 'normalised' into the community. The subgroup no longer exists in the community as it has been swallowed up by the normal majority with the highest profile. This is the price paid by disabled people if they want to belong. He goes on to discuss the personal psychology of people carrying the norms of the community with them as they enter the world at large. He refers to this as the Lippman syndrome, that is to define something and then only see confirming instances. The issue is made more complicated by the ability of people to be members of more than one community at the same time, this can be viewed in terms of ethnicity, gender and class.

Skidmore uses this argument to support the segregated approach to special education. This was founded on one piece of research, ignoring the mass of rights based literature and work done by disabled people themselves, such as the social construct theory of disability presented by Oliver (1990). Skidmore also suggests that some sorts of caring are negative; the person receiving care is in a sense deviant by virtue of disturbing the connections of the community. The value base of community care is to be founded in what is termed 'ordinary life' objectives. That is the size and type of accommodation, day services and support offered to people with disabilities. Wright et al (1994) refers to five basic questions that the person with a disability should ask themselves in relation to their 'ordinary life':

- 1) Who am I?
- 2) Whom do I know?
- 3) How do I live?
- 4) What can I do?
- 5) How can I influence and control my life?

Community care policy could be considered not to be based in buildings but in a diffused relationship between a set of ideals as shown above and disabled people. In practice this means disabled people living in 'ordinary homes', using local schools, colleges, social clubs, pubs, shops and other facilities (perhaps viewed/defined differently than services) that the wider public use. These approaches are aimed at disabled people gaining employment and forming ordinary family ties and valued social roles.

Community care can be considered in two conflicting realms; the independent individual living within the physical construct of the community opposed to the person being a part of a caring network supported by others. It is the policy maker's task to ascertain need in the community and plan services accordingly. The systems of value that I have described have had an impact on the development of community care policy.

## **5.2 Context of Community Care Policy**

For the purposes of this analysis a crude distinction is employed in that pre Griffiths (1988) is seen as the background to contemporary community care policy and post Griffiths is seen as contemporary community care policy. Firstly this background or context is explored. Community care is not a single set of policies put forward by one pressure group or academic body, just as it did not come about due to a single push from statutory organisations. It is the evolving product of statutory organisations, the voluntary and private sectors. The Department of Health and Social Security in 1977 recognised the multi-faceted nature of community care not only from the professional realm of providers, but the role of the family and carers. The policy documents that followed from this emphasised the part played by the informal and voluntary services. Bulmer (1987) highlights the first moves towards community care as revolving around the principle aim of the 1959 Mental Health Act, to reorientate mental health away from institutional care towards care in the community. It is however contentious and practically impossible to legislate everybody into undertaking care.

## The Political Spectrum

Glennerster (1985) writes of the workhouses accommodating growing numbers of sick, elderly and infirm paupers. The Metropolitan Poor Act of 1867 and a Poor law Amendment Act of the following year meant separate infirmaries were created known as pauper hospitals. The stigma of this poor relief remained in the form of the 'undeserving poor', in other words why should we care for some people? For example, how do we take rationing decisions around giving kidney dialysis to chronic alcohol and drug abusers? Do we provide funding for cosmetic surgery? What support do we provide for sex offenders in the community, or should they be 'outed'?

Glennerster (1985) writes on the interpretation of welfare that in terms of the Americans it means cash handouts to hoodlums, whereas to the economist it is a collective term meaning anything from happiness to utility. This example illustrates that the definition and distribution of welfare in policy is ideologically laden with stigma, politically it means very different things to different groups. Bosanquet (1983) in discussing the politics of welfare says that the Old Right was established in ideas of traditions and hierarchy. However monetarism and the macroeconomics surrounding it form the New Rights policy of self interest for citizens, the entrepreneurial individual representing the ideal. The new right sees the scarcity of resources being caused by what Bosanquet calls 'big government' waste.

Social security is seen as interfering with peoples' freedom, the individual should be empowered to make choices around contributions to any system they choose. Waine (1991) states that since 1979 the British conservative government has attempted to distinguish itself from previous governments in a number of ways, one of which is a move to champion the cause of independence. The world economic crisis in the early 1970s pushed the government in the late 1970s and early 1980s to remove the protection surrounding personal social service welfare. A discussion taken from Waine (1991) on the nature of independence is a helpful summary:

- 1) The conception of the New Right is that the state has operated to pre-empt decisions which individuals ought to take for themselves.
- 2) The post-war welfare state has created a central role for the state as a provider.

Waine (1991) goes on to suggest that the concept of independence has not become a guide for policy decisions but a rhetorical justification after policies have been formed. The removal of State Earnings Related Pensions Schemes (SERPs) being an example of the state taking on a new role in intervention, but not actually removing its involvement

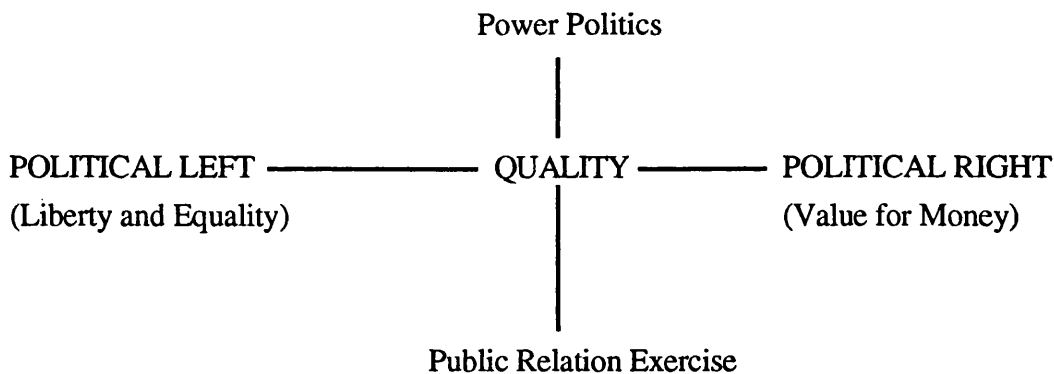
altogether. This relatively new approach is a challenge to social policy in that it reduces the state role in using national income for welfare. Policy objectives have moved to the individual ownership of houses and individual choice in welfare in both social services and health care. The voluntary sector has begun to represent a decentralised alternative, the formation of contracts for such organisations being the new government role. The latter continues to fund the voluntary sector. In turn benefits for people are being increasingly related to their own contributions. So the New Right politics fed into community care by encouraging the care of people at home and in the private, or voluntary sector moving them away from statutory provision.

### The Issue of Quality in Policy Terms

Papers in the area of primary health care and the National Health Service leading up to the White paper 'Caring for People' increasingly focused on the quality of services people with disabilities were receiving. Wistow (1991) points out five origins of this interest in quality, firstly the poor performance of caring services, highlighted by the scandals of institutional care. Services began to be seen as having the potential to cause harm as well as help people. Secondly that it was seen as untenable to increase spending on services without stricter controls on efficiency and accountability, therefore policy developed to squeeze more from current spending practices. The question here is does quality therefore replace quantity? Thirdly user pressure groups and self help groups began to have a louder voice and also to be heard. They asked for more power and control over the services they received. These movements were not necessarily asking for high tech interventions but improvements to the everyday quality of their lives. The work of Oliver (1990) around the social construction theory of disability illustrates this point. Therefore a move towards enabling, participation and empowerment gathered ground. Fourthly customer consciousness and quality awareness emerged, comparing the NHS and other organisations with commercial ventures. This was encapsulated by new ideas on management and the construction of market ideals. Finally a push towards care around the quality of life for people also came from a professional view. The influence of training movements such as Normalisation and Social Role Valorisation were important, in changing the attitudes and objectives of some professionals.

Figure 15 is adapted from the work of Pfeffer and Coate (1992) and shows the differing agendas for the political parties around the concept of quality.

Figure 15



### The Move into the Community

The 1962 Department of Health and Social Security Hospital Plan anticipated a decline in beds used by mental health patients from 3.3 per 1000 in 1961 to 1.8 per 1000 in 1975. Psychiatric Hospital beds being replaced by District General Hospital beds. This move was reinforced by the 1971 Government White Paper Hospital 'Services for the Mentally Ill'. The key Department of Health and Social Security Hospital 1975 planning document; 'Better Service for the Mentally Ill' continued the deinstitutionalised push, but it provided no guarantee of numbers or distribution of this change. The split between health authorities and social services was a strain on administration and management resources, which today is still being felt. The MIND campaign in the early 1970s contributed substantially to the lobby for more and better services in the community for people with mental health problems. MIND's manifesto 'Common Concern' (1983) influenced the area with a number of statements:

- The need to value clients as full citizens.
- A move to minimise client dependency on professionals.
- Increased self-determination for users.
- Provide an adequate programme of treatment.
- Using as near as possible usual environment for treatment.
- Local accessibility for users of services.
- As far as possible to alleviate distress.
- Move towards reintegrating people into the community.

This section has given the context to contemporary community care policy. The changing political spectrum and philosophy along with a desire for quality and extending new professional power bases in the community led to the start of hospital closures. The influence of personal empowerment, a new rights philosophy, feeds into

the devolving nature of individualised service design. The next section explores the objectives of the newly involving policy.

### **5.3 Key Elements of Contemporary Community Care Policy**

#### **Objectives for Community Care Policy**

The 1988 document Community Care ‘Agenda for Action’ put forward by Sir Roy Griffiths had the remit: ‘To review the way in which public funds are used to support community care policy and to advise on the options for action that would improve the use of these funds as a contribution to more effective community care’. (Preface)

Griffiths stressed that his remit was ‘not to deal with the level of funding but rather to suggest how resources, whatever the level, may better be directed.’ (Preface)

This work was primarily a response to the Audit Commission report (1986). Griffiths was the managing director of a large retailer and was asked to apply the principles of the internal market to welfare. This was a clear adoption of a business approach to welfare provision, he pushed towards a purchaser/provider split and increased use of the markets. A neat retail philosophy was reflected in the government’s vision, what might be called ‘Marks and Spencerism’. It began in the 1980s with the increased use of management principles in the running of welfare services. The next logical step in this increasingly consumerist approach was the creation of a large market for services. Griffiths also saw the key elements contributing to a revised notion of community care as the collaboration between all the organisations and people (including family and carers) involved around the discharge of a person from institutional care.

Griffiths’ (1988) proposals for action can be summed up as follows:

1) Appointment of a Minister of State in the Department of Health and Social Security clearly responsible in the eyes of the public for community care. This minister would lay down standards of service and assess the quality of existing service delivery systems, arranging grants based on recommendations.

2) Local Social Service Authorities should (within available resources):

- Prioritise, plan and develop service objectives at a local level.
- Identify and assess individual needs driven by personal user preference.
- Deliver packages of care around informal carers and their neighbourhoods.
- Take up a role not only as a prime provider of care, but use the voluntary services to widen consumer choice.

3) Social service authorities should be made responsible for:

- Assessing people's needs for residential care, meeting these costs if the person is unable to do so.
- Continued funding of community care projects under the provision of 'joint finance'.
- Spending the money allocated to the social fund for community care.

4) To facilitate the above, local social service authorities need confidence that their resources match their responsibilities:

- Appropriate transfer of funds by central government to local government to cover the costs of the implementation.
- Ensure that these funds are used in accordance with their original aims.
- Payment of enabling grants are only made when central government is satisfied with the local objectives.

Griffiths saw the function of a 'community carer' to be developed into a new occupation, with appropriate training and support. He saw the need for the development of care management and a need for a greater investment in training both at a local and national level. This included a transfer of skills from the professional realm to more informal care systems (e.g voluntary sector work). This could be seen as a challenge to the power of professional organisations, or a positive power sharing exercise. Griffiths (1988) goes on to write: 'The proposal will diminish the responsibility of social services for supporting residential and nursing home care, but to the advantage of community care services as a whole. Our social service system is essentially designed to provide a standard range of benefits for large numbers of people against objective tests of entitlement. It is not an appropriate system for the direct provision of individually tailored packages of support, within a finite community care programme.'

So this represents a move away from block funding and congregation to more individualised service design. The White Paper 'Caring for People': Community Care in the Next Decade and Beyond (1990), supported the majority of Griffiths' recommendations, except the use of specific grants for funding community care (with the exception of those for people with mental illness).



It stated that community care is designed to promote domiciliary, day and respite services to enable people to live in their own homes wherever 'feasible and sensible'. The definition of what is 'feasible and sensible' is a problematic one. No special Ministry for community care was developed. Professional discretion in these areas still plays a dominant role. The National Health Service and Community Care Act in 1990 gave legislative weight to these proposals. Therefore it promoted the development of domiciliary, day, and respite care to support people in or as near as possible to their own homes. In doing so, more support for carers was made a priority, this being taken into consideration when working on the user's assessment of need. Care management as a form of co-ordination of care along with the developing independent sector became the cornerstones of developing community care policy (see the section 6.1).

The government therefore devolved power to the local authorities, giving them responsibility to provide and/or organise social care provision. This included a major consultation procedure between health, housing authorities and voluntary organisations. Therefore a move from the Health Service to Local Authorities took place, a marginalisation of the service system. Overall the emphasis was on local authorities as purchasing organisations rather than directly providing services. This proposed purchaser, provider split was not contained within the 1989 White Paper but its future development was encouraged. What follows is a timetable of the changes in community care between 1991 and 1993 adapted from the work of Rao (1991).

By April 1991:

- the establishment of inspection units.
- introduction of a targeted grant on mental health to accelerate services.
- revised complaints systems to monitor the standards of community care.

By April 1992:

- the publication of a community care plan.
- the introduction of an assessment system to which all of those likely to need community care will be entitled.
- preparatory work on the case management systems.

By April 1993:

- a unified assessment system.
- fully working case management systems.
- transfer of funding away from social services to local authorities.

The principles and objectives of Community Care policy at this point were to enable the person to remain in their own home whenever possible rather than being cared for in a hospital or residential home. To give support and relief to informal carers (family, friends and neighbours) coping with the stress of caring for a dependent person. To deliver appropriate help, by the means which cause the least possible disruption to peoples ordinary living. To relieve the stresses and strains contributing to and/or arising from any physical or emotional disorder. To provide the most cost-effective packages of services to meet the needs and wishes of those being helped and finally to integrate all the resources of a geographical area (community) in order to support the person within it. These measures push to develop choice and some kind of partnership between those concerned. The resources mentioned might include informal carers, the NHS, personal social services and an organised voluntary effort, but also sheltered housing, the local social security office, the church, the local clubs and so on. The Audit Commission stated in 1986 that community care was not about imposing a community solution as the only option, in the way that institutional care has been the only option for many people in the past.

#### The Purchaser and Provider roles

The 1990 NHS and Community Care Act stated that 85% of all provision in the community will be provided by the private sector. In the policy move towards consistency and equality of service within the mixed economy of care, local authorities are supposed to treat their own service units no differently from others with whom they contract. This requires significant changes in the traditional approach of these authorities, social services playing an increased role in facilitating the mixed market of service delivery in competitive tendering and contracting. In this split the combined measurement of relative performance of both parts is encouraged. The question also exists concerning the extent to which the market will provide a varied and competitive environment for the purchaser to buy services. The purchaser/provider split comes from the governments' ideology of the construction of a regulated market of welfare. It is unclear how the government aims to increase private sector competition for service delivery (see section 2.7).

### Information Systems

The availability, accuracy and quality of information is often an issue. With the increased use of computers, devolved budget and tailored packages of care, information systems have become more powerful tools for services to use. Steele, Hickley, Rowlands and Moore (1993) describe the Policy Studies Institutes guidance for services in 'Meeting the Need for Information'. The purpose of the information policy was described in the following ways:

- 1) To enable social service departments to fulfil efficiently their responsibilities to provide information.
- 2) To enable social service departments to meet service user's information needs effectively.
- 3) To establish a framework for planning user information services and to set priorities for future developments.
- 4) To ensure that users receive a consistent quality of information about services throughout all the departments.

### Service-led, Needs-led and Assessment-led Community Care

Jowell (1991) discusses the NHS Management Executive definition of need as 'the ability to benefit and it's outcome as "achieved benefit'. She goes on to say that to judge community care it is necessary to assess both planning and assessment of need with the satisfaction of service-users. Rao (1991) sees these issues, and I agree, as more to do with how Social Service organisations should function rather than about putting in place user's rights around their needs and access to power and information.

### Care Management

Care management is based in user-led services which have two main elements in Community Care in the Next Decade and Beyond (1990):

- 1) A progressive separation of the tasks of assessments from those of service provision in order to focus on needs, where possible having the tasks carried out by a different member of staff.
- 2) A shift of influence from those providing to those purchasing services.

It may be more accurate to say that a move from service-led to assessment-led, rather than needs-led working practice is taking place.

The recording of un-met need by care managers is a continuing concern. It is unclear whether the system of assessment available encourages such a process. The use of the phrase 'met un-need' has also been coined. That is to say the giving of a service to

people when it is not required. The benefits being the continued existence of that service and the need to appear as if the person is having their needs met by placing them in a (any) service. For a detailed discussion of care management see section 6.1.

Participation in Community Care

The participation of users and carers in community care is another key element in contemporary community care policy. Shemmings (1991) writes ‘Participation must surely involve more than being present, if it does not then we each participate in our own funeral.’ (p. 18)

Philpot (1994) sees the Seebohm report as the first step in advocating for citizen participation in personal social services. He goes on to describe the role that managers within the services will have to play in order to put this policy into practice and set the ‘tone’ of any organisation. They should nurture independent user groups, recognising and encouraging flexible networks of user self help groups and other structures. They should set the boundaries very clearly for user involvement, not confusing involvement with consultation. With confusion over the terms used in this area it is helpful to look at Arnstein (1969) classic ‘ladder of participation’ which provides an overall typology of citizen power. It gives a clear and useful illustration of some of the key issues of user participation within services.

<u>Degree of Power</u>	<u>Name of Level</u>	<u>Level</u>
Degrees of citizen power:	Citizen Control	8
	Delegated Power	7
	Partnership	6
Degrees of tokenism:	Placation	5
	Consultation	4
	Informing	3
Nonparticipation:	Therapy	2
	Manipulation	1

Arnstein (1969) astutely comments ‘participation without redistribution of power is an empty and frustrating process for the powerless.’ (p. 216)

He describes the nonparticipation rungs of the ladder as the attempts of power holders to educate or re-educate users into a particular role. This role may be for them to be grateful recipients of a second rate service. Therapy is perhaps misplaced; Arnstein

sees mental illness as synonymous with being powerless. This is a rather unjust and simplistic judgement of therapists as some kind of 'mind police' ignoring the injustices of society while molding patients to fit into it. However the power relationship of therapists to clients is one that stimulates strong debate (see section 3.9 for an examination of social control and therapy). Tokenism refers to the powerless having a voice but with no guarantee that any notice will be taken of them, consultation is seen as advising but not deciding for the person. Arnstein writes that information tends to be one way; down from professionals at this level. Placation is a strategy used by the powerful to place a hand picked 'worthy few' in a position of influence to add credibility to a professional agenda. Citizen control means people are demanding control over the issues that they are concerned with, they negotiate real and lasting solutions. Arnstein does point out that the ladder can not be considered anything but a helpful simplification of the interconnecting issues around power.

Berry (1988) similarly views consultation as limited in her analysis of consumerism. It can be suggested that 'clients' views are sought in order to provide appropriate services, and to allocate scarce resources equitably. This approach requires the public to participate only in so far as it can provide information.....The power relationship between the department and the client is not changed in any way.' (p. 14)

Berry sees the next step up in consumerism as involving market forces in the process. Berry's final level is that of empowerment or consumer rights, a step as she sees it, towards local control. Marsh and Fisher (1992) describe the principles of partnership in social work practice as:

- '1) Investigation of problems must be with the explicit consent of the potential user(s) and client(s).
- 2) User agreement or a clear statutory mandate are the only bases of partnership intervention.
- 3) Intervention must be based upon the views of all relevant family members and carers.
- 4) Services must be based on negotiated agreement, rather than assumptions and/or prejudices concerning the behaviour and wishes of users.
- 5) Users must have the greatest possible degree of choice in the services that they are offered.' (p. 13)

To add to this it can be said that users, when interviewed, tend not to answer in terms of a global statement about the 'service', rather they answer in terms of the named care

worker, the person they have the most contact with. The important issues to them are more likely to be around being poor than about complaints of official policies. In other words satisfaction research tends to start from a service perspective which users do not frame themselves within.

Wilson (1993) describes the different ways satisfaction questions can be interpreted by users.

- 'Are you satisfied, given that you know it is the best you can get?' or
  - 'Are you grateful for what you have been given?' or even
  - 'Are you going to be impolite enough to say what you think about the service?'
- (p. 510)

Criticisms of satisfaction surveys are offered by some researchers. For example Beresford and Croft (1993) state that satisfaction surveys are tied to existing expectations and knowledge, were as they should be exploring new areas. Wilson (1993) concludes that clients are capable of assessing a service they receive, but not necessarily the potentially complex management structure behind it. Many groups however do have low expectations of the service they receive and this needs to be challenged to get a clear and fair picture concerning quality.

### Partnership in Community Care

There is a push in community care policy towards collaboration, partnership, joint funding and multi-disciplinary team work. Rao (1991) discusses the development of professional collaboration at two levels of partnership:

- 1) Inter-professional production of community care plans.
- 2) Inter-professional production of individual care packages.

This push towards more collaboration increased in the mid 1970s when joint finance came into practice. Partnership needed to be fostered, not only between the public, commercial and voluntary sectors but also between the providers and consumers.

The elements of partnerships adapted from The Community Revolution (1992) are:

1) Seamless services:

- Interpret 'consultation' with the NHS as 'involvement'.
- Develop closer liaison with housing agencies with joint reviews of dependencies and agreement on support in sheltered housing.

- Involve independent organisations in the planning process. Understand and make an appropriate response to the varied nature of the voluntary sector.
- Consult users and carers directly.

## 2) Working together:

- Joint local budgets for purchase of social and health care.
- Agree and implement arrangements for discharge patients from acute hospitals and for providing them with care in the community.

These points reinforce the policy move towards multi-disciplinary working practices based in joint funding.

### The Enabling Role

Taylor, Hoyes, Lant and Means (1992) define the enabling state in three parts:

- 1) A minimal definition giving only a role of assigning and regulating contracts.
- 2) A broader definition stresses the 'enabling' authority has the task of guaranteeing procedural and sometimes substantive rights - developing a range of procedures designed to ensure equality in assessment and delivery of care.
- 3) A further strand of the argument focuses on the need to develop consultative and participant mechanisms to reinforce the democratic system.

Wistow, Knapp, Hardy and Allen (1992) provide three different interpretations of the enabling role:

- 1) enabling personal development.
- 2) enabling community development.
- 3) enabling market development.

The significance here is that they can be considered separately, the third role regarded as not being compatible with social care. In summary there is a polarity between the market forces leading to consumerism of the political right as opposed to the democratic citizenship proposed within communities of the political left.

### Contracting

Contracting is seen along with the purchaser/provider split as the framework for involving clients and taking account of their preferences, although there will continue to be practical limitations on choice. The types of contracts as defined and developed

from Implementing Community Care (1992) are:

1) Block Contracts: are effective in providing security and continuity of supply, and are likely to give rise to lower unit prices. But this may be a route to return to a service-led focus.

2) Per Place Contracts: provide less security for providers, and therefore of supply. They are also likely to lead to higher unit prices. On the other hand, such contracts do more to preserve flexibility to meet client choice, and maintain more budget freedom for the social service departments.

3) Client/Carer Contracts: involvement of users and carers in detailed individual contracts.

Recent government policy is suppose to be advocating the move through 1) to 3).

We should ask the question who will benefit from the use of these contract systems, and to what degree, if any will users of services be able to get redress if contracts are broken? Will there be an increase in malpractice suits and recourse as in some other market-style consumer protection systems? There is no evidence that service users will have a legally binding document with recourse on issues of un-met need.

#### **5.4 Community Care Policy Implementation**

Stevenson and Parsloe (1993) suggest that the government is faced with an ideological dilemma. On the one hand how does it establish an enterprise society which rewards individual initiative and self-advancement and, on the other how does it ensure adequate care for those who fall short of the mark? Furthermore the Conservative Prime Minister between 1979 and 1990 made it plain that for her communities did not exist, only individuals and families. The next section discusses the implementation of community care focusing on the construction of welfare markets and the underlying funding behind them.

#### **Markets**

In the last fifty years a paradigm shift in welfare has occurred. In the 1940s welfare was non-competitive, with equal access to all and was organised by an elected representative performing financial and administration tasks. The system is now moving towards a competitive market. There are a number of problems associated with this change. Can a market welfare system gain support from its users? Can it provide consumers with a truly empowering and accountable system? Is it possible to mix the benefits of markets and social welfare provision? Are customers going to compete with each other for the best services on the market?



Shopping can be considered a political action, Pfeffer and Coate (1992) see this as 'ethical purchase behaviour'. They offer an important critical account of the market structure seeing little social justice in the market. 'If you are poor, you have less choice than if you are rich. If you live in one area (poor, depressed or rural) rather than among the urban middle classes, you may have to buy from inferior shops offering fewer choices, and you may have to pay more for the goods you require. Producers and retailers have no interests in your well-being; they will satisfy your wants if it serves their own ends; they are not interested in your needs.' (p. 37)

It is also important to note that some people in welfare systems may be reluctant customers, not wishing to use any service let alone the best one in the market (e.g those under section with specific mental health needs).

If service delivery becomes 'customer orientated' it will still be fundamentally management-led. It may just assume many of the tools of the market such as customer surveys, complaints procedures, standards setting, customer panels and public attitudes testing. Taylor, Hoyes, Lant and Means (1992) state that the market approach seeks to empower consumers by giving them the right to 'exit' from a service if they are dissatisfied. Researchers (Le Grand, 1990) have commented on the state being the prime funder of services and not the provider, envisaging the new mixed economy of care coming from a 'quasi-market' setup. Taylor, Hoyes, Lant and Means (1992) point out that quasi-markets differ from conventional markets in the following ways:

- Supply in quasi-markets - the objectives and ownership structure is often unclear, providers are not necessarily privately owned or profit maximising organisations (eg voluntary sector residential homes).
- Demand in quasi-markets - purchasing power may not be expressed in the form of 'cash' but as a budget 'voucher' to be spent on specific services. Moreover, the consumer may not make the purchasing decisions; such choices may be exercised by agents such as G.Ps (fund holders) or care managers.

They go on to point out that the NHS and Community Care Act (1990) can be perceived as a quasi-market reform encouraging alternative supplies and seeking to avoid monopoly situations. Within the welfare state users express influence through a system of democracy which includes some in-built participation mechanisms. A pure market involves the consumer directly purchasing care. The consumer would hold a contract with the provider. Quasi-markets can still be seen as the state purchasing care,

developing a market of alternative providers of care. Saltman and Casten von Otter (1992) state in a paper on the emergence of planned markets that 'Patients have become increasingly vocal in their opposition to continued rationing by queuing.....Similarly, patients have become less tolerant of health system practice that steer treatment patterns in directions that reflects the health provider's, rather than the individual patient's, treatment preferences. Finally, patients are less willing to accept passively the costs imposed upon them by a variety of logistical factors, such as long waiting times...'  
(p. 5)

The question of whether the mix of benefits and competition in the market can be balanced with social welfare provision remains to be seen. Two ideal-type models of markets for users of services follow. In the Public Competition Model patients are the central agents of change. Providers strive to attract a larger number of patients and use a higher proportion of the pre-established public budget. The Swedish health system is an example of such a market. The Mixed Market model mixes private and public markets in which existing and new privately capitalised providers can bid for contracts against present publicly capitalised providers. The manager is seen as the main agent of change, for example in the White Paper Working for Patients (1989).

These moves in policy may well have a levelling effect on the public providers of services as pressure from the mixed market forces them to strip out needed services for profitable ones. There is a bias in the public based systems reflected in the unequal ability of educated, middle class and better-off patients to 'work the system' in their favour. Private based systems are of course biased to those who have the largest disposable incomes. Contracts granted to privately capitalised providers may, under cost pressure, generate below-average quality of care, particularly in service areas where professional medical interest is lower (Schlesinger et al, 1987). This may be so extreme as to require legal action on exploitation and negligence. There may also be problems in the role of the manager within mixed markets. Where will their allegiances lie? They may become gatekeepers of services as they act both as patient advocates and providers of the services.

The fundamental question is do markets empower or disempower people? This depends on the extent of market choice and the power of the consumers to make choices within them. This in turn relies on the quality and quantity of information on the market made available, which has an influence on the quality of products available. Markets are primarily driven by profits not necessarily quality. Quality information in

the right environment may lead to quality purchasing and in turn profits but this is not always the case. Trevillion (1992) supports this position by making a series of negative points about the potential role of the market:

- 1) The market leads to 'enlightened self-interest' which in turn pushes for projects with wide profit margins and little financial risk.
- 2) Reduced choice may also be an effect in commercial style contracts.
- 3) Power for the user may reduce as the care manager may be the only person who understands the whole picture of care.

Trevillion (1992) makes the important distinction that markets generate competition whereas networks generate cooperation. This however is not as simple as it sounds, markets may encourage cooperation, but it only makes sense for them to do so if the individual contributors to the market benefit. To empower users of services it would appear to make sense to break up the purchaser side of service delivery along with provider monopolies. This would mean budgets and power would be devolved to the user (see section 6.2).

### The Costing of Community Care

Schorr (1992) discusses the cost effectiveness and assessment of community care. He suggests that to care for the elderly at home may well be less expensive but to care for the mentally ill and people with learning difficulties in the move away from institutions is notably more expensive than institutional care systems. He offers five reasons for this:

- 1) If given the choice disabled people opt out of residential care.
- 2) Individual professional assessments are not cheap.
- 3) Due to decentralisation to local authorities the levels of community care across the country is 'patchy'. This depends on a number of different factors around available resources and the history of service provision.
- 4) Potential costs have to take consideration of the so-called 'Pandora effect'. The more home based services are on offer, the more the demand for such services will increase.
- 5) There is a need for backup services, e.g respite for carers.

The move towards bottom-up processing the needs-led distribution of individual packages of care requires an imaginative and far sighted use of finance within affordable limits. There needs to be more and better alternatives on offer to the user of services. The potential for care managers to control client's tailored budgets and

subsequently purchase services, points to a need for the information, finance and quality appraisal to be easily recognised, accessible and rigorous. The mixed market of providing services also needs to have information to price and evaluate its service relative to other services, care managers, families and users. This gives a measure of cost effectiveness. Any consideration of costing must take account of less direct or obvious forms of costing. Knapp (1993) usefully defines opportunity costs in reference not to price, but in terms of what is given up to gain something. The role of the carer is an important example of this, in terms of missed employment through caring.

There are four situations where the market price differs from this opportunity cost as markets are never perfect:

1) Items that cannot have a market price such as human capital, for example not being able to return to work when placed in a caring role.

- Direct Costs - compensation.
- Indirect Costs - forgoing work.
- Non-economic Costs - stress.

2) Market prices are not stable. Analysis must be viewed over time.

3) Distorted by market imperfections for example the monopoly of a service, indirect taxation and unemployment.

4) Inputs are shared for example between users.

It is also important to take note that the pricing of any service is not an exercise in accounting but a practical expression of the value systems present in an organisation. Netton (1993) writes on the subject that customer charges have the purpose:

- 1) To act as symbols of change within a system.
- 2) To prevent waste or abuse.
- 3) To reduce total cost.
- 4) To shift priorities.
- 5) To influence the social care market.

Care managers and users holding the money to buy services supposedly became more intent on gaining quality services, to exercise their 'voice'. This may be in practice the only comeback a user has on a service because they may be denied exit from it. Judge and Matthews (1980) report how an increase in charge for meals-on-wheels resulted in

an increase in consumer criticism of the quality of the meal served. Charges started to approach a level where consumers felt more able to complain or reject the services. Policy makers tend to believe that making professionals aware of the prices of services has the effect of reducing wastage. Many professionals are however afraid of dealing with money and budgets, preferring to avoid more paperwork and not take responsibility for mistakes with finance.

### **5.5 The Value Base of Current Community Care Policy**

At the beginning of this chapter the value base behind the original conception of community care was laid out. What follows is an in-depth analysis of the value base behind contemporary community care policy.

#### **Empowerment and Community Care Policy**

Table 7 is adapted from the work of Taylor, Hoyes, Lant, Means (1992) see also Burns (1992):

<b>Table 7 User terms in different situations</b>		
	<b>Clear Bargaining Power</b>	<b>Limited Bargaining Power</b>
<b>Product:</b>	Consumer	Recipient
<b>Services:</b>	Client	User
<b>Organisation:</b>	Customer	Survivor
<b>State:</b>	Citizen	Subject
Move Towards Empowerment ←		

Shearer (1991) points out that the document *Caring for People* mentions consumers, users, customers, clients, patients, sufferers, people who are in need, dependent and vulnerable. The point being that these terms give two conflicting images, one of the strong and independent individual and the other of a person who desperately needs the community's care.

One thing is clear, that the terminology around peoples' expected roles is confused. The creation of the mixed economy of care market is seen as the main move towards empowerment in policy structure. Empowerment here is seen as an increase in citizenship. Trevillion (1992) goes on to describe partnership as part of citizenship:

- It involves working with all those concerned in a particular situation.
- May serve the interests of more than one person. The process of collaboration is likely to have an impact on all members of the partnership.
- Professionals have to be prepared to share power both with one another and with the communities they serve.

The Discrimination Act (1995) has failed twelve times before it was passed through parliament. The Act presents anti-discriminatory legislation around rights such as equal access and employment. The Audit Commission report in 1986 looked more at the financial and managerial implications of community care rather than user empowerment and the consequences of change in terms of individual welfare rights.

The potential compromise of advocacy and other support services is a continuing dilemma for organisations working within this sector. There may be a problem with the local authority becoming more involved in these organisations, that is they lose one of their major attractions to users; their independence. Allegiance to the authorities implies a degree of accountability that affects their potential to support user advocacy and lobbying. The degree to which this occurs may depend on how much the authority is involved in financing the organisation and what checks it places on money spent. Therefore there is a need to recognise that the value of voluntary organisations lie with their autonomous flexibility around the communities they represent.

Presently all authorities have complaints procedures, but users do not have the right of 'exit' from services if they do not value the service. At a more collective level the White Paper gives equal rating to consultation between service providers from the voluntary and private sectors and users and their advocates. The idea of users as their own care managers has been hinted at in policy documents but never formalised. Giving users and carers access to information in forms they can understand is mentioned along with the importance of integrating literature on different levels to different ethnic groups. There is still a long way to go before 'unmet' is accurately recorded and power sharing between professionals and users of services takes place. This is the move from lip service to an everyday reality. The role of the users seems to have been pushed to a kind of 'voiced quality control' and away from a capacity for absolute decision making. In summary, we see a stress on 'voice' supported by advocacy rather than 'exit' supported by rights. The Audit Commission in its Community Revolution document (1992) touches upon these issues: 'Community care delivery involves power sharing - often difficult for someone who already has power or

a vested interest in the status quo. Planners, care managers and service providers must share their power with service users, but for them to be in a position to do so, colleagues, council members and trade unions must be prepared to relinquish and share power with them.’ (p. 34)

A dynamic approach to power sharing is shown in Figure 16. The interrelationship of professional structures and working practices clearly demonstrates the complexities involved in this process.

Figure 16



Jowell (1991) states we need to consider the following issues when working on user empowerment:

- Policy guidance for users.
- Public debate forums.
- Systems to inform service users.
- Common language (no jargon).
- User right entitlements (following the Disabled Persons Act 1986).
- Counter-balance the power of the purchaser.
- Providers must take their cues from users and carers.

With the failure to date of the Disability Bill of Rights, the above values have not yet been addressed by policy makers. People with disabilities need their rights to be put into the same structure as those of women, ethnic minorities and children which have

recently been fought for and won, although these rights have not always been upheld (see chapter 2 on empowerment).

### Service Culture and Community Care

Figure 17

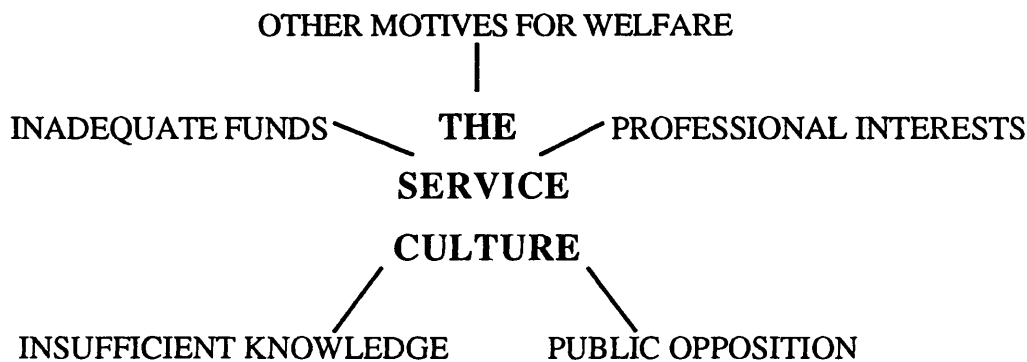


Figure 17 shows the composition of service culture; that is the sets of values beliefs and attitudes that form a service. Service culture provides a framework for understanding the practical structure that policy gives service systems as they evolve and are interpreted by workers and users. Dowson (1991) is very critical of the service development since the 1970s. He suggests that the welfare state can be described as a system of social control, and states: 'People who are unable to conform to social norms, or who refuse to conform, are oppressed or excluded so that they do not threaten the social system. Social services represent one of the mechanisms by which this function is achieved, at the minimum cost.' (p. 43)

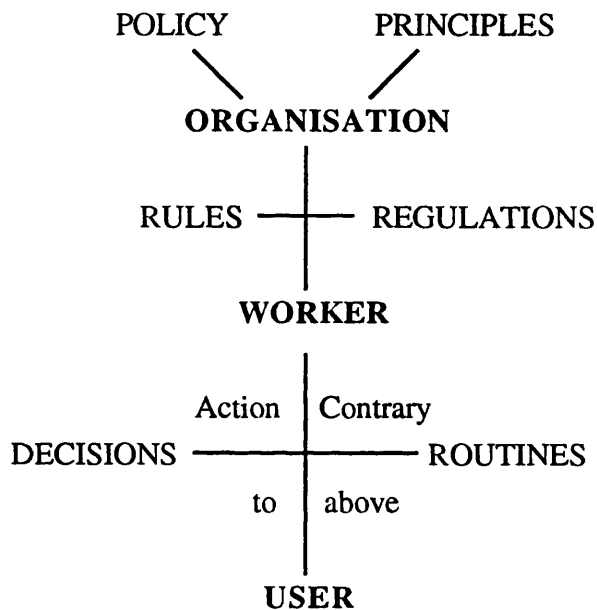
Dowson goes on to describe the main purpose of the policy document 'Caring for People' as to control the flow of funds into welfare services, not to have a beneficial impact on the lives of people who need services.

Dowson talks of 'Social Devaluation' being the process affecting devalued groups of people. It is a culture that adds to their disadvantage by removing their valued roles and status, segregating them and congregating them together. Lipsky (1980) and later Hudson (1994) gives an excellent analysis of the theory and practice of what he terms 'Street-level Bureaucracies' role in public services. This is a vital part of the service culture in explaining policy structuring by everyday workers. Lipsky sees a need to analysis the systemic bias that welfare workers employ when dealing with certain clients.



Clarke (1993) writes that a feature of the professional bureaucracy is that it tends to develop two types of hierarchies: one among the professionals working 'hands on' and the other among the administrators who organise the service. Figure 18 is adapted from Lipsky (1980) to show the elements of street-level bureaucracies. Policies and principle feed down from above into an organisation. These provide the rules and regulations for workers, however these rules and regulations are in turn under the influence of individual and group working styles.

Figure 18



Lipsky avoids developing what might be called a conspiracy theory with professionals at the centre, but states that workers make these decisions and create routines to cope with the pressures of their work. Workers need to make life easier for themselves, particularly given high burn out rates. Pressure may come from too high a case load, sharing peoples suffering, inadequate resources, limited support and lack of training. Lipsky goes on to argue 'that public policy is not best understood as made in legislatures or top-floor suites of high-ranking administrators, because in important ways it is actually made in the crowded offices and daily encounters of street-level workers.' (p. 24)

In practice stereotyped worker responses, distancing users of services with terms such as 'prioritising' and 'crisis intervention' set the tone of street-level bureaucracy. These systems place the user in a service culture dilemma; wait your turn for the service, or speak out against the service and risk losing benefits and favour. This adds to the ethos of people not being sure of the degree to which they deserve services. Lipsky speaks

with almost reverence in describing street-level bureaucracy, as being the nearest that everyday people get to government. Street-level bureaucrats are torn between the demands of service users to be responsive and the demands of policy makers to be effective and efficient with public money. Hence the role of an advocate may be in conflict with working within an organisation. The advocate's work is often on an individual basis to free up resources, where as the organisation works with groups in a rationing way. Street-level bureaucrats can be seen as agents of social control. They develop and perpetuate the idea of service user's relative worthiness, in terms of meeting particular needs in the redistribution of service finance. Lipsky describes street-level bureaucrats as policy makers for three reasons:

- 1) The degree of discretion they can exercise when interacting with users.
- 2) Their (workers) actions taken as a group add up to what is known as 'agency behaviour'.
- 3) They have relative autonomy from the organisations that employ them.

Street-level bureaucrats like other bureaucratic approaches manage the users of services by teaching them to adhere to appropriate ways of behaving. Deviance from these norms may mean punishment or some kind of punitive reprisal.

Billis (1984) states 'What I found striking - and the reason for the biographical aside - was the void that existed in many settings between the grand statement of general intent (ideologies, theories, and the like) and life at the institutional grassroots.' (p. 1)

In common with Lipsky, Billis sees that the policy is rarely administered directly and is rather mediated through institutions, professionals and administrators. What follows is a policy/service empowerment measure developed from the work of Taylor (1992):

1) What choice are users given?

- Range of options
- Access
- Rationing
- Information: Language used  
Partial sighted  
Hard of hearing
- General circulation in locality
- Advocacy

## 2) What decisions can users make?

- Authority to take decisions
- Opportunity to influence decisions
- Views sought before implementation

## 3) What voice are users given?

- In the care management process
- assessment of needs
- in choices made
- In the service delivery
- they have a contract
- is there a user committee
- (with what powers)
- Individual/Collective

## 4) What redress are users offered?

- Complaints
- Review
- Exit
- Access
- Information
- Advocacy

## 5) In the Community Care Planning and Purchasing process:

- in the range of options available
- in the framing of contracts
- in the ground rules and principles
- in standards setting and monitoring
- in the development of future services
- in distribution and rationing
- in the provision of back-up and advice

6) In the Local Health authorities as a whole:

- Access
- Information
- Resources and Facilities

7) What support is available to users?

- Advice and Information
- Advocacy
- Development of advocacy
- Development of user-led services

It is important to remember that the majority of people with disabilities have always been cared for at home by relatives (mostly women). Until recently the role and power of carers has not been explained or explored to any great extent in policy. The Carers Recognition and Services Act (1995) sets out a separate assessment system for carers who provide 'regular and substantial' care. However this term is not defined adequately. It is important to note that if the carer is under 18 then they can become a 'child in need' under section 17 of The Children Act and subsequently gain extensive service support.

### **5.6 Summary**

This chapter began with a quote from Crow and Allen (1994) on the nature of community care policy, a policy that has certainly aided the move for people from institutional care into houses in towns and cities across the country. The extent to which these people have become full members of their local communities is however in doubt. Subsequent citizenship involves the political dimension of participation and power sharing. Integration into routine life for people with disabilities again is a troubled area. What constitutes a 'normal', 'ordinary' or 'homely' living arrangement is difficult to quantify and qualify. Work on the empowerment of users within these areas is under researched, and the recent work (Lewis and Glennerster 1996) on implementing the new community care provision does little to change this. Research has focussed more on the multi-disciplinary, multi-sector and the cost outcomes of community care policy.

Policy making around community care has occupied centre stage in Britain since 1985, governments cannot legislate people into 'caring' or 'feeling responsible' for members of a community, policy can only act to educate, encourage and direct public thinking. The problem for any service design system is the trade off between quality, price and choice. Community care policy has developed from a number of sources; user pressure groups, scandals of abuse in hospitals, the changes in thinking in the sociology of deviance, psychology and social policy as well as ideas of the market and consumerism. The political struggle between the left and right; both attempting to define and own the concept of 'empowerment' has shaken up the whole debate.

The problems around defining both community and care have been demonstrated, however the most difficult question to answer is does the community care? The power of street-level bureaucrats to make and shape policy within a service culture is enormous. The challenge to these professionals and the structure of the delivery of community care is whether they will be prepared to share or give up power to both carers and users of services.

There has now been several years of the new community care policy and its practice. This period has not been an easy one for workers, users of the services or their carers. Problems around the market sectors, financial costing, needs led assessments, red tape, organisational change training and the purchaser provider split have all been evident. The role of the market, 'quasi' or not is unclear with field workers being uneasy about a business-like association with welfare. This can be summed up by the conflict between meeting needs and profitability. Social workers appear to be becoming market managers rather than the 'hands on' counsellors they may well once have thought they were. Greater interdisciplinary collaboration is occurring but whether care managers are truly working from a needs-led rather than assessment/resource-led perspective is uncertain. This process has also taken a lot of energy and effort to coordinate.

The work carried out by Hoyes, Lant, Means and Taylor (1994) for the Joseph Rowntree Foundation provides a critique of Community Care policy in England, and is summarised as follows:

- Local authorities are at risk of putting users choices secondary to resource constraints.
- The mixed economy of care is unlikely to provide a viable alternative to the 'set list' on offer to most users and carers.

- Users have more control and choice when they pay the service providers directly.
- Users sometimes require less robust, quantifiable services (voluntary-specialised) these are in danger of being squeezed out.
- Communication problems are evident in care management systems.
- Professionals tend to put the wishes of carers over those of service users.
- Professionals need more training to cope with changes.
- Local authorities are often protective of their in house services so are reluctant to open up a 'true' market of care provision.

There also appears to be a shortage of advocates and a bias towards the more vocal users of services in getting their needs met. It is quite possible that in the construction and forcible application of policy, opportunities for the development of innovative welfare projects are being stifled. Achievements have been made by community care policy; many people have moved away from the total institutions to live in the community. Rehabilitation programmes have been used to play an important role in the integration or reintegration of people into those communities.

## **6 ENGLISH COMMUNITY CARE SERVICES**

'The institutions themselves may now be discredited, but the interdependence of housing and support which they pioneered retains a powerful influence, not least in terms of perceived security and efficiency.' (Collins, 1996, p. 3)

This chapter examines community care services, paying particular attention to the types of services chosen for the study. Care management was researched in the late 1980s but it was the early 1990s policies that brought it into practice at a national level. Care planning has always been a loose term synonymous with assessments and co-ordination but over the past five years it has become more central to service provision. It can be argued that individualised funding has been around for a long time in one form or another. Begging for money and early philanthropic work are kinds of direct funding. Day services, originally developed as a form of respite for carers, have in the last ten to twenty years taken on a new educational role. As all these areas are potentially interlinked, it is quite possible for a care manager to put together a care plan for someone with a disability which is individually funded and includes elements of a both day services and residential support.

### **6.1 Care Management**

#### **Definitions**

All the terms used here are true to their original context, it is however important to note that 'care' has taken over from 'case' as the less stigmatizing term. CHOICE, one of the first case management projects in North London, (Banks 1988) recently decided to drop the term 'management' and refer only to users of the service, as they objected to users being seen as in need of management. Users of the service also objected to being called cases not people with needs. The following definitions illustrate the stigma attached to the term. 'Case' as defined by the Oxford English Dictionary is 'matter being investigated by the police, social worker.....diseased condition of a person, instance of any disease'. In turn 'Management' is defined as 'administration of business concerns or public undertakings'.

This use of medical and business terms to describe the needs and services of disabled people is in stark contrast to the social model of disability characterised by Oliver (1994), see section 7.3 on the definition of disability. Challis (1990) describes case management as the coordination of care through an identified 'responsible' individual perhaps a key worker. It is more broadly viewed by O'Connor (1988) as a complex

system of interrelated functions performed by personnel at various occupational levels in the service-delivery system. Case management focuses on helping clients identify and resolve concrete problems in their lives, a therapeutic emphasis on changing the social system, clients being viewed as agents of change, not as victims. Holloway (1992) states its purpose as 'to enhance the continuity of care and its accessibility and efficiency'.

The question of whether care management is a relatively new concept is worthy of debate. Banks (1988) sees it as a general and well used tool to connect a client from a particular group with the service he/she requires in a situation where service provision is complex. There is a lack of operational clarity, it is unclear whether care management belongs within social work or to a variety of different professions. O'Connor (1988) and Payne (1995) view it as a core social work technology. Johnson and Rubin (1983) see case management often interpreted as an assortment of activities requiring substantial commitment from all organisational levels for successful implementation. Osborne (1991) describes it as an odd combination of roles, including needs assessment, advocacy and gate-keeping. This conservative view of care management is balanced by Brandon (1991) who states that the purpose of case management is to change the nature of the delivery service allowing the devolution of power to people with disabilities. Austin (1990) and Biggs describe the construction of care management in terms of; planning, coordinating, providing care, identifying long term clients, rationalising the provision of services, monitoring, screening and assessment. Callahan (1988) goes on to say care management concerns:

- Direct services to clients, caregivers and family, the stated goals of which are to improve access, coordination, quality and efficiency.
- System development, the goals of which are to access delivery systems, develop services and identify emerging needs and problems.
- Cost containment, gate-keeping, resource allocation and service rationalisation.
- To promote a philosophy of providing conceptual unity to problem solving, regardless of the nature of the target system.

Roberts-DeGennaro (1987) describes good care management as the continuity of services in 'planfulness', e.g rational decision-making, designing and executing a treatment package, coordination among all providers of services, effective involvement of the client, timeliness in moving clients through the process and maintenance of useful information recording systems.



### Care Management in The United States

Case management originated in America, the transformation of health services having began there in the 1950s. In the 1960s social legislation began to form a policy of integration, with the 1963 Community Health Centre Act. 1966 saw Medicare take over from a two tier health system but not until 1975 did full deinstitutionalisation occur, with health centres taking responsibility for patient discharge. Berkowitz (1992) writes that in the mid 1970s the US community care system became decentralised, allowing pervasive fragmentation in public funding which favoured targeted aid to defined client groups.

Worley (1991) indicates that the growing realisation that the service had to be coordinated in an efficient and effective fashion for individual patients eventually led to the development of the care management approach. An economic recession triggered capping of federal monies in the early 1980s, as a result of which twenty funded care management demonstration projects were set up. Their aim was to (Berkowitz 1992):

- Improve coordination of services at all levels, without major structural system changes.
- Encourage comprehensive planning and management.
- Manage the risk involved in moving to a managed care system.
- Facilitate the effective and efficient use of expanding community services.
- Facilitate system development, the goals of which are to assess delivery systems, develop services and identify emerging needs and problems.
- Encourage cost containment; the goals of which being gatekeeping, resource allocation and service authorisation.

Rapp and Wintersteen (1989) describe the US 'strength model' of case management which contains strong elements of advocacy, service brokerage and empowerment. In the United States care management evolved as a term to describe a number of different approaches to the assessment, design and implementation of packages of care for long term client groups.

### Care Management in England

The term care management does not appear in English community care literature until the mid 1970s, when it was used in particular relevance to the key worker system and Individual Program Planning (IPP). North American care management intended to integrate a diffused and fragmented service delivery system this was also true in

England where the need to move from a service dominated provision, to one led by client's needs was emphasised. Medin et al (1990) point out the similarity between the Australian and the English systems, where over the last decade there has been a noticeable growth in concern from both health care consumers and providers. Both the consumer and the provider elements of the health system were demanding change to ensure that the system became more responsive to needs.

The Personal Social Service Research Unit (PSSRU) piloted care management projects in Kent and Gateshead in the early 1980s. Challis and Davies at the PSSRU (1986) used an intensive case management model to work with a elderly client group. The approach was characterised by giving workers a reduced case load of thirty, independency from services to which they were normally attached, a strenuous attempt to avoid the use of nursing homes in care plans for the subject group, and a high degree of autonomy and flexibility. Lewis and Glennerster (1996) point out the important elements of the PSSRU study, which meshed with the government community care policy aims, as:

- Gains in quality of life for both users and carers with no extra cost.
- Increasing the possibility of a move from institutional to domiciliary care.

The PSSRU worked with a particular 'intensive' based model of care management, being 'intensive' made it difficult to generalise the findings across other models of care management. The evaluation was based around issues of cost effectiveness, rather than on the content of or quality of care.

The different boroughs studied by Lewis and Glennerster (1996) had very different views of what care management should be like, from a mechanistic approach to very flexible systems, with care managers being directly perceived as valued workers to failed specialist social workers. Payne (1995) highlights the tension between the attempts of the care managers to control resources and the principles of user involvement. The conflict seems to lie between a gatekeeping and a facilitating role and professional interests and advocacy. What follows is an outline of the key points of this policy as it affects care management.

Ramon (1992) describes the impact of the 1988 Griffiths Report as the mixing of the supply economy of care with social services departments as enablers. She stresses the managerial principles, that those who make resources-committing practice decisions

should also be accountable for those resources. Care management is partly about the concentration of responsibility, authority, accountability and the reduction of the conflict of interest felt by front-line allocations between the interests of consumers and the interests of suppliers. The policy created by Griffiths points towards the reduction of inappropriate and unwanted admissions to institutions for long term care through devolving of budgets to care managers.

There has been no policy requirement that care managers should hold budgets. However since 1988 other policy aspects have evolved:

- 1) Aims to care for higher proportion of users in their own home.
- 2) Community care brought up to international standards.
- 3) No bonanza of resources.
- 4) The White Paper 'Caring for People' (1990) gave the green light to the development of care management in the provision of community care for adults. It was however far from prescriptive in how professionals should implement changes.

The Community Care Act (1990) provided the legal base for care management in Great Britain. The importance of care management is stressed: 'Care Management will play a key part in achieving the governments objectives for community care by:

- ensuring that the resources available (including resources transferred in due course from social security) are used in the most effective way to meet individual care needs.
- restoring and maintaining independence by enabling people to live in the community wherever possible.
- working to prevent or to minimise the effects of disability and illness in people of all ages.
- treating those who need services with respect and providing equal opportunities for all.
- promoting individual choice and self-determination, and building on existing strengths and care resources.
- promoting partnership between users, carers and service providers in all sectors, together with organisations of and for each group.' (para. 3.3)

### Models of Care Management

There are many models of care management which tend have a number of elements in common, that is; assessment, planning and monitoring of services. Some have

additional features that emphasise particular approaches such as individualised funding (Brandon 1991), advocacy and counselling (Banks 1988).

When considering any model of care management a series of questions can be asked:

- 1) Which population is to be served and what is their health status?
- 2) What is the relationship between the care manager and client?
- 4) Is the care manager going to deal directly with money?
- 5) Who is the care manager primarily accountable to (i.e to the client or to the service)?
- 6) Is the care manager directly involved in service delivery?
- 7) Is the care manager going to provide some kind of counselling function?
- 8) How empowered is the client?
- 9) Is a single worker or agency system being used?
- 10) Are shared core tasks being used?
- 11) Is it a joint agency model?
- 12) Is it an independent agency model?

Zawadski and Eng (1990) identify three models of care management;

- 1) Prior Authorisation Screening Model, focussing on an assessment leading to an institutional placement.
- 2) Brokerage Model. Whether that means a non-profit or profit system, an advocacy based project with a board of directors.
- 3) Consolidated Model, based on a multidisciplinary team assessment system.

The PSSRU model of care management as already mentioned focusses on devolved budgets of two thirds of the cost of residential care to the care manager, giving responsibility for assessment of needs and subsequent purchasing power, whether that may be a traditional service entry or an individual buying of services. This is an example of a more pluralistic form of social care provision, advocating with the client in an increasingly holistic way. Benjamin (1992) describes the structure and effects of the American Primary Health Care Management Models as follows:

- 1) Expands the scope of care coordination by focusing attention not only on the hospital but on the community and informal networks.
- 2) It utilises multidisciplinary teams.
- 3) It enhances the process of assessment, resources and monitoring.
- 4) It uses a holistic focus with consumers.
- 5) Utilises risk appraisal mechanisms.
- 6) Provides access to patient education, health education and information and prevention-orientation services.

This model has a higher proportion of professional staff and lower caseloads than other models, so is more expensive to run. Table 8 is adapted from Renshaw (1987) and highlights some of the issues involved in the construction of care management systems:

<b>Table 8 Care management systems advantages and disadvantages</b>		
<b>Feature</b>	<b>Advantage</b>	<b>Disadvantage</b>
Single worker for all	Continuity	Lack of delegation to case management special worker
Direct worker with client	Simplicity, continuity	Conflicting tasks to be undertaken
Specialist case management workers	Clarity of responsibilities	More of a major reform for service and staff.
Tasks shared with other workers	Makes use of specialist skills	Lack of worker continuity
Restricted caseload	More time to plan and carry out tasks effectively	Resource/cost implications
Peer group review	Group support exchange good ideas	Time factor
Workers are qualified (professional)	Social work skills	Unwilling to do mundane/manual tasks (non-professional)
Written recording format	Improved clarity of aims and task consistency	Over bureaucratic and over formalised
Worker has control of resource	More cost-effective	Potential clash of interests
Authority over service	Ability to obtain service	Loss of credibility at local level
Advocacy - independent	No vested interest in service	Lack of authority

Under the US chronic mental illness model of care management the stable and continuous relationship between the care manager and client is stressed. There also appears to be a split between following a psychotherapeutic or a socio-therapeutic role by the care manager.

Care management models can be considered to fall along a range, with system analysis at one end and service analysis at the other. Care management programmes with a dominant service orientation focus on the needs of individual clients. These emphasise traditional advocacy skills, broker skills, designing, implementing and negotiating care plans for clients. At the other end care managers have the authority to purchase and terminate services and are more responsible for gate-keeping of resources.

### The Role of the Care Manager

Berkowitz (1992) defines a number of core skills required by a care manager:

- 1) High degree of cognitive flexibility to define situations and problems in a variety of ways so that new strategies can be created and new ways of maximising resources might be discovered.
- 2) Negotiating and conflict resolution.
- 3) Computer literacy and knowledge of management information systems.
- 4) Multidisciplinary working knowledge.
- 5) Financial planning.
- 6) Consumer oriented working practices.
- 7) Awareness of ethical needs.
- 8) Accountability knowledge.

Roberts-DeGennaro (1987) wrote that to meet care management responsibilities workers must have extensive training and continuing education in various areas such as; assessment, clinical skills, management, planning, advocacy, networking and human relations. Goldberg and Connelly (1982) add to this list with coordinating community work, consultancy skills and to act as a general buffer to anxiety. Moore (1990) discusses the assessment abilities of care management in the following ways:

- Assess individuals ability to meet environmental challenges.
- Assess the caring capability of the individuals family and peer group.
- Assess the resources within the formal system of care.
- Assess the ongoing needs of the individual.

Some writers focus on the clinical/therapeutic aspect of care management. Roberts-DeGennaro (1987) takes up an extreme stance by stating that only through therapeutic involvement can a care manager achieve a good understanding and assessment of the clients needs.

Johnson and Rubin (1983) suggest that a direct clinical function is required by the care

manager for another reason; that mental health workers may feel themselves vulnerable to being perceived as less than professional. They go on to describe a diagnostic and therapeutic function for care managers:

- 1) Recognise early signs of decomposition or unmanageable stress and understand various environmental circumstances in terms of their likely effects on psychological facets of the clients illness.
- 2) Care managers can motivate and secure clients compliance with a discharge around a plan of service utilisation.
- 3) Care managers can provide one stable relationship for clients to rely on as they move across institutional, community and aging boundaries.

Renshaw (1987) also stresses the importance of this single guide through service provision. She also mentions the importance of this person being a qualified professional with 'greater authority'. O'Connor (1988) suggests that there is a distinction between social service workers and caseworkers, where the tasks carried out by the former involve more autonomy and complexity. Case workers lacking the knowledge, skill, experience and autonomy required for supervision in planning and implementing work. Austin (1990) states that the foundations of social work are located in person-in-environment theory making it particularly well suited to performing care management. However not only social workers are care managers, occupational therapists, nurses and other disciplines fill the posts.

#### The Process of Care Management

O'Connor (1988) clarifies the care management process in terms of practice and systems. The practice being the tasks in the process that involve direct and immediate implementation of a care plan. The system refers to the administration supports, systematic arrangements, informal/formal community resources necessary for implementation of care management practices. He goes on to lay down five levels of personnel in the system:

- 1) Case aides.
- 2) Volunteers.
- 3) Social services workers.
- 4) Social case workers.
- 5) Supervision and administrations.

The practice of care management can be based on two assumptions about human behaviour:

- 1) People who are successful in everyday life are those who use and develop their own potential and who have access to the resources needed to do this.
- 2) It is largely a function of the resources available to the individuals and that a pluralistic society values equal access to these resources.

Austin (1990) describes the funding patterns that exist within systems as:

- Fragmented/pooled.
- Prospective/retrospective.
- Capped/open-ended.

Challis and Davies (1986) point out the importance of improved accountability to allow appropriate budget limitations. Roberts-DeGennaro (1987) describes care management as a step by step process involving the following:

- Network formal resources.
- Target population.
- Assess client strength.
- Develop care plans.
- Design individual service plans.
- Client agency contract.
- Implementation of care plans.
- Monitoring of delivery of services.
- Evaluation with the client within an environment of self determination.
- Termination of care.
- Follow up of termination.

In summary, care coordination should entail a holistic view of the care, an understanding of the number and sequence of steps that comprise the process and integration of good care practice. Any evaluation must also involve the management of information, its collection, reporting and presentation.



### Outcomes in Care Management

Renshaw (1987) discusses the term 'input mix efficiency' which is the theory that care management will match resources to needs. Rubin (1986) and Moore (1990) state that the goal is to integrate formal support with the family and other groups for the user. Renshaw (1987) states that the aim of care management is to recognise that the client is autonomous and accountable. Challis and Davies (1986) suggest that 'The outcome of care for elderly clients is determined by the level and type of care services received, the elderly persons individual characteristics and circumstances (Quasar inputs) and the way in which services combine with clients circumstances and characteristics'.

- Output - Morale scale and quality of care.
- Quasar inputs - Social supports, dependency, health, personality, attitudes to help, physical environment and other functions.

Allen et al (1990b) describe the benefits of the Thanet Community Care Project in Kent. They state that social workers acting as care managers responded very positively to the flexibility and opportunities provided by the new style of working. They saw themselves as responding better to the needs of clients. It appeared that a number of the normal problems associated with the breakdown of community care for the elderly were avoided, for example, stress and the fear of falling. Similar results were noted in the Gateshead (Challis et al 1988) and Darlington studies (Challis et al 1989) both indicating lower levels of carer stress. Vass (1990) writing about the inherent waste of the existing system of care stated that the devolved budgets associated with care management means workers are more likely to take responsibility for their actions. English evidence about the effectiveness of Care Management comes mainly from the work of the Kent Social Services Department in the late 1980s and early 1990s. However a reduction in client stress and increased satisfaction was reported. This was achieved at a lower cost than normally expected. In one project Glendinning (1986) noted that the care manager experienced a lack of perceived authority, influence and credibility by other professionals.

Care management cannot be seen as a homogeneous concept, care managers may or may not become front line gatekeepers and service users may or may not have more of a say in the service they receive. This is rather a negative view of care management, in contrast to the favourable outcomes already mentioned in this chapter. However there are a series of problems for care management to solve if it is to be more widely accepted.

Kubina (1990) lists a number of questions that need addressing:

- 1) Whether the capacity to deliver a care management service exists.
- 2) Concerns about the care managers' ability to have access to resources to create packages of care with ease and flexibility.
- 3) How do you implement a standard assessment allowing both flexible choice and universal application?
- 4) Will care managers have the authority to conduct long term packages of care?
- 5) Will care managers be able to buy in packages of care which will change along with the individual over time?
- 6) Will care managers feel like recruiting agencies, competing for resources with their colleagues?
- 7) Will the volatility of the market place effect the process?
- 8) Have we decentralised the service enough to handle the care management system?
- 9) The American experience of care management points to social workers and community nurses being most suitable for the job of care manager.

The feedback document compiled by the Department of Health in 1992 on Implementing Community Care, consulted directors of social services and discovered that very few argued against the purchaser/provider split. The main fears they had concerned levels of investment and future finance around current service patterns. They voiced concern over the governments expectation that 85% of the provision in the community would be provided by the private sector. This work went on to indicate that some representatives of social service departments view care management as a set of values spread across several levels of an organisation from front line staff to higher management. Other representatives see care management as a specific set of procedures carried out by care managers for a particular client. This later view can be split into two, the care manager as a 'remote broker' for the resources required for a package of care. On the other hand they may be a front line worker with the client working around a devolved budget.

## **6.2 Individualised Funding**

When entering a discussion around individualised funding it is important to give some background to the Independent Living Movement (ILM). The ILM provides a framework for the individualised values that users of services pursue. It primarily questions the professionals' superiority in judging what is best for people with disabilities.

The Independent Living Fund (ILF) provides an insight into the reaction of users to an individualised funding project. What follows is a discussion on the pros and cons of direct payment schemes and service brokerage in more detail. Figure 19 represents the relationship between individualised funding, direct payments and service brokerage.

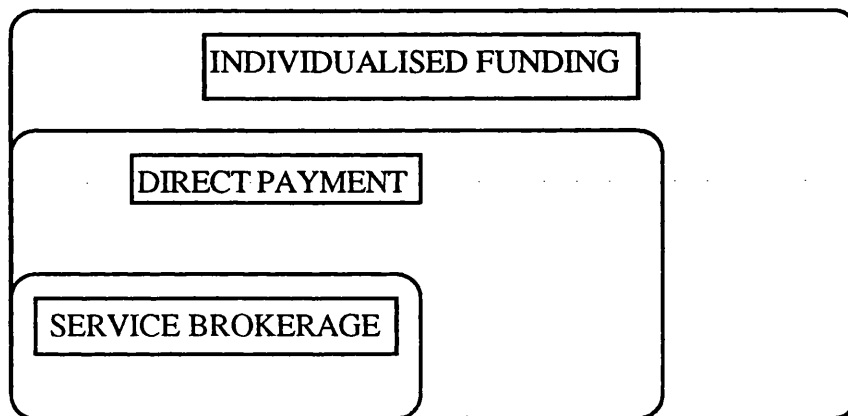


Figure 19

Individualised funding includes all the different ways of tagging money to individuals, the increasing use of computers means it is easy to tag and track the costs of services in a more precise and personal way. Direct payment schemes such as the ILF are part of individualised funding where money is given directly to the user to spend. Service brokerage in turn is a type of direct payment involving an independent worker aiding the process of service acquisition. The issues that need to be examined within any individualised funding service are:

- Does it provide a realisation of the actual cost of individual services?
- What is defined as a service?
- How creative can the process be with the money provided?
- In practice what will people buy and from whom will they buy it?
- Are we talking about a revolution in welfare provision or just another option?
- Will users be empowered by such a consumer service?
- Who will be the person making the decisions?

### The Independent Living Movement

The construction of the British Council of Organisations of Disabled People (BCODP) in 1981 provided the first national forum for independent living and its connected ideology. Morris (1993b) describes the philosophy of the raising ILM as:

- to value all human life
- everyone can exert choices.
- that disabled people have the right to assert control over their lives
- that disabled people have the right to participate fully in society

The ILM challenges the basic assumption of independence, proposing that the limitations of environments rather than people's actual disabilities make people dependent.

Morris (1993a) goes on to describe the value of a personal assistance system in Kingston: 'The package would allow each of us to arrange our own system of obtaining personal support, employing the personal assistants directly and controlling their conditions of service. In this way we would retain full control over our day-to-day living. It was to be a free service with the money paid directly into separate bank accounts which we would set up.'

### Direct Payments

We can consider direct payments as a system that unofficially has been around for as long as welfare and charity. When we give money to a beggar on the street it is a direct payment which the individual is empowered to spend on what ever they can afford, with no redress to us. Many people who receive benefits such as mobility and attendance allowance do not spend it on the intended services, rather on their private choices. Often it is used to pay rent, buy food or other 'absolute' or 'relative' needs.

The 1948 National Assistance Act makes direct payments illegal in England and Wales although it has been manoeuvred around by the creation of trusts, hosts or private companies. Over sixty quasi-direct payment schemes have been established already in England. The BCODP (1995) stated that 90% of English and Welsh authorities would implement direct payments once they were legalised. A number of key issues around the formulation of direct payments schemes follows:

- The need for pump priming money to start the process.
- Avoidance of running down mainstream services in response.
- Questions of eligibility.
- Avoidance of exploitation of carers.
- How and who co-ordinates it: recruitment, taxation and national insurance?

The Community Care (Direct Payments) Act (April 1996) made direct payments available to people with physical and sensory impairments, people disabled by illness (including mental health problems or HIV/AIDS) and people with learning difficulties. A person to receive a direct payment needs to fulfill the following criteria, in that they must:

- require a community care service
- be between the ages of 18 and 65
- be willing and able to manage the money alone or with support
- not be contained under the mental health act or a legal guardian
- direct payments can be used to buy support through agencies or directly
- residential care of more than four weeks cannot be bought with a direct payment

Under these conditions local authorities must not discriminate between people wanting direct payments, must consult people with disabilities about direct payments and ensure that direct payments are used as intended.

The Carers National Association (CNA) welcomes this direct payment legislation by stating that (Elkington, 1996) 'the Bill is not a substitute for family care nor an introduction of a "wage" for family carers. In CNA's view this would bring an unwelcome formalisation of family relationships that are largely undertaken out of feelings of duty, love or responsibility.' (p. 12)

Mental health campaign groups like Survivors Speak Out also have expressed their support of direct payments schemes, however there are still questions about the portability of payments between authorities. Greenwich Association of Disabled People (GAD) is described by Elsegood (1994) as an organisation managed for and by disabled people and states that 'direct payments, in my experience, are a vital component of freedom, choice and control.....Self-directed Personal Assistance Schemes are human and civil rights. They are economically viable. We at GAD demand rights in the future of welfare - not charity!' (p. 19)

Oliver and Zarb (1992) describe in detail GADs use of the Independent Living Funds money. This giving rise to what they call creative, cost effective and efficient services. Oliver and Zarb (1992), Smith (1995) and Whiteley (1996) all discuss the reduction in mainstream services when direct payments are made, users tend to go elsewhere for more person centred approaches. There may be a need to protect some of the existing

services from collapse if direct payments are widely introduced. The options for direct payments schemes include the following (adapted from Maclean, 1989):

1) Voucher Direct Payments: The individual is given a voucher that can be used to purchase goods and services. The person is therefore not actually involved in the transfer of funds. The funders may use vouchers if they are unsure about the persons capacity to deal with money directly. The new nursery voucher scheme was introduced in April 1997.

2) Programme Based Direct Payments: Set amounts of money are put aside for specific purposes. For example the Mobility Allowance.

3) Worker Based Direct Payments: A worker decides through some kind of assessment how much money an individual will receive.

4) Recipient Based Direct Payments: The consumer of a service, with or without help from a worker decides on the funding they receive.

5) Service Brokerage: An independent worker aids the acquisition of direct payments.

i) Government Official as Broker. In the Calgary region a government official acting as a broker develops services.

ii) Agency Broker. In the Calgary Community Living Society the broker is paid by an agency to devise service plans for the individual with a disability.

iii) Independent Service Broker. In the Calgary Association for Independent Living (CAIL) the broker is paid and supported by a board of persons with disabilities.

iv) Free Lance Broker. They are totally independent working only with an individual.

### Independent Living Fund

The Independent Living Fund (ILF) was set up in 1988 and was received with optimism by various disability lobbies, being seen as providing people with disabilities a way of asserting choice and controlling personal assistance. Its initial budget was £5,000,000 but by 1995-6 it had ballooned to £17,000,000 million. The present community care reforms have little reference to direct payments and the ILF appears to be winding down. From April 1st 1993 new claimants had to approach local authority social service departments to receive support from social service home care staff. If the cost of the services they require exceeds the amount that social services would pay for residential care, application may be made for additional funds to a successor scheme. There still seems to be a reinforcement of the power of professional judgement over user choice. There is a strict qualification to the scheme and on what the money can be spent, for example restricted to care staff.

Kestenbaum (1993) in reporting the experiences of independent living fund clients outlined the doubt that disabled people have in the ability of care management systems to give them the power they want. The Independent Living Fund was set up to fill the gap left by the Domestic Assistance Addition when the Supplementary Benefit scheme was replaced by the Income Support scheme. It has a charitable trust status being administered by ten trustees, five of whom are nominated by the Disabled Income Group (DIG). Kestenbaum's (1993) research into the ILF explored the advantages and disadvantages of employing relatives for personal support. The advantages of employing relatives using the ILF being the following:

- avoidance of danger
- avoidance of embarrassment over physical care
- relax immediately
- flexibility
- they know what to do
- more amenable to change
- live locally
- do more than they paid for
- allows reciprocity
- increase in self-respect
- commitment/consistency of work
- secure in dependence.

The disadvantage of employing relatives using the ILF being the following:

- difficult to maintain definite boundaries
- sometimes it can be embarrassing
- conflict of interests.

A cautionary note is sounded by Wilson (1995) in a study of elderly people buying their own services in the community, she states that for the older people interviewed 'paying for care did not bring market power. Elderly people were marginal customers and usually did not feel able to complain if they got poor services.' (p. 178)

Wilson suggests that although elderly people are the main designers of their own care, they were not seen to be in a 'buyer's market'. They are often poor and the withdrawal of their custom was of little consequence to the providers. There is also a fear that in

advertising for care the 'wrong sort of people' might apply, also a lot of criticism of agency carers' reliability, efficiency, quality and cost. More generally, the timing of care seemed to be a compromise between the clients' needs and the care assistant's availability. It was interesting how the ILF money was used in flexible ways by clients (Kestenbaum 1993) 'a client living alone who employed four different care assistants. He found it more appropriate to pay one of them in the form of gifts rather than wages (though this is not a procedure that the ILF endorses).' (p. 21)

In conclusion Kestenbaum (1993) writes that the statutory authorities will be unable to provide the same quality service for the users of the ILF: 'the findings from the research challenge the assumption that disabled people are incapable of exercising effective choice and control over their own care arrangements.' (p. 78)

Lahey (1994) makes the important point that independence is not about doing as much as possible or everything on your own, it has more to do with getting the right assistance. Also much of the effort by professional agencies goes into the training of people to do tasks without support which in fact are mundane. She suggests that 'Although the ILF did not explicitly set out to improve recipients social lives, this was often an incidental benefit of ILF funding'. (p. 124)

This occurred as more 'chosen' people came into the homes of people with disabilities and later as users are more able to get out to meet other people. Lipsky (1980) sees the move away from street-level bureaucracy coming from 'greater client autonomy'. One way of reaching this is via the elimination of public service workers buffering the public from government. He goes on to discuss the introduction of service vouchers to aid 'consumer sovereignty'. However vouchers themselves can limit choice on when, how and where you can spend them. Lipsky mentions problems with this approach such as the information required to inform users of the availability and quality of services. He does not mention the role of an independent 'broker' figure in such a process, but does support the use of advocates.

### Service Brokerage

There are no straight forward definitions of what service brokerage is, owing to its various forms and interpretation between England and Canada. A working definition of service brokerage follows: it is a system set up to arrange for the direct payment of money to an individual or individuals with a disability. An optional service broker provides a facilitatory role for the design and implementation of a service(s) under the



direction of the individual(s) concerned. The service broker is independent from service provision and a brokerage board of non-service providers monitors the whole system.

### Service Brokerage in the United States of America

Maclean (1989) writes that the first publicised cases of direct payments made by a government were those around returning Vietnam veterans. She writes 'Direct payment allowed the Department of Veterans Affairs to meet it's requirements to provide service without drawing public attention to the devastation caused by the war.....Not only were vets paid to purchase their own services, they were paid to be their own case managers.' (p. 15)

### Service Brokerage in Canada

Direct payment projects have been set up in the provinces of Ontario, Quebec, Alberta and British Columbia. Many of these small projects have been around since the 1960s. Service brokerage was developed in the 1970s by a small group of parents of profoundly disabled children in British Columbia, Canada. They were called the Woodlands Parents Group (Thurlow, 1992) and were reacting to their childrens negative experiences of a long stay institution, this is illustrated by the following:

- Low expectations of staff.
- Lack of control over their own lives.
- Lack of accountability.
- Lack of choices.
- Lack of meaningful relationships.
- Inadequate services and supports.
- Family and friends lacked status and influence.
- Not treated with dignity and respect.
- Lack of participation, membership and citizenship.

The Woodlands Parents Group in Canada was offered an advocacy project apparently as a sweetener to buffer complaints. They turned this project down in favour of what they saw as 'real power' in the form of service brokerage. They set up a service brokerage scheme where people with disabilities receive cash to purchase their own services. They can buy from ordinary people in their neighbourhoods as well as from non-profit commercial and statutory bodies. They have a formal financial contract with the funding agency framed around their personal needs. This means that service

brokerage moves away from block funding systems which encourage block treatment. With block funding it is hard to see exactly where the money is going, individualised funding systems are more easily accounted for. The idea being that with service brokerage, people also don't have to congregate to receive a service.

In Alberta the early direct payment systems were born from the consumer collation of people trying to gain individualised services from a surplus of block funding. When these were cut service brokerage evolved to be directly accountable to the user and their network of supports (often referred to as Joshua Committees). The Canadian Ministry of Social Services (MSS) (1995) has an operational overview of the service brokerage project run by the Community Brokerage Service Society (CBSS). The study assigned 50 MSS clients to a service brokerage model and 50 to a typical service. The brokers intention was:

- 'to establish a general service plan for the consumers;
- to identify potential community-based service providers or act as the impetus for the development of new services;
- to present options to the individuals/families so that informed decisions could be made by them;
- to foster the development of unpaid personal support networks;
- to negotiate with service providers and the Ministry; and
- to ensure contracted services meet individuals' needs.' (p. 13)

After four years only 17 users had received a service brokerage scheme. The MSS (1995) indicated a conflict between the role of the service broker and the social worker. The service broker having a 'significantly lower case load and more flexibility in planning and implementing services for people'. A problem also arose concerning negotiation of funding. The ministry considered that the service brokers did not plan within the availability of current resources.

### Service Brokerage in England

The history of direct funding and service brokerage in England is erratic. As a result of the illegality of direct payments under the 1948 National Assistance Act examples of direct payments up until recently did not tend to be advertised by local authorities. Schemes calling themselves service brokerage do exist, the main examples are located in Grampian (Nelson, 1991) Bristol (Love, 1994) and Southwark (Holman, 1994), Camden (Banks, 1988), (Brandon, 1994). Brandon (1994) writes on whether direct

funding will mean real empowerment within services in England. In Canada service brokerage was born from the concerns of a group of parents wanting a better quality of life for their children with learning disabilities. In contrast to England where service brokerage type schemes come from academic ideas and government policy initiative. On the one hand it perhaps has a better chance of being implemented at the national level, on the other it may not have the clarity and drive which makes the Canadian movement so dynamic.

In Bristol (Brandon 1994) a community based Service Brokerage Board employs staff, including brokers and perhaps book-keepers. Service brokers are monitored by a board and provide relevant and independent information about services, negotiate contracts and provide costings, all within the remit provided by the user. People who receive cash or credits to purchase services may need independent help to get information, draw up formal funding contracts and a wide range of other requested tasks. The service broker is like a travel agent in that he or she provides an optional service, makes suggestions but does not take over the responsibilities. The service broker may also be ignored altogether by the individual while they make their own choices.

Writers often fail to distinguish service brokerage from care management, some referring to service brokerage as an inferior form of care management or advocacy. Both care management and advocacy organisations use the terms 'brokerage' or 'broker skills' without explaining what they mean. They cannot be referring to service brokerage as individualised funding is almost always absent. They are following fashions; 'brokers' have a marketing image which sits well in the current trend towards quasi-market welfare language. In theory, brokers may enable people to have advocates or advocates may enable people to have brokers. Care management differs from service brokerage in a number of key ways:

- 1) Intensity of working. The degree of involvement with users is not prescribed but user-led in service brokerage.
- 2) The presenting problem may be the only one that the service broker is concerned with, not a whole assessment as in care management.
- 3) Individualised funding is not a necessary part of care management, it is vital to service brokerage.
- 4) The independence of the worker is not guaranteed in care management, while it is vital to service brokerage.

### Independent Funding Outcomes

There is little research into the effectiveness of independent funding in England. Some work (Holman, 1994) points towards the service broker tending to become a substitute for poor residential support systems. That is to say that the broker gets involved in small issues that a key worker should be responsible for. A recent survey by Zarb and Nadash (1994) into direct payments found that:

- The average cost of local payments is 30% cheaper than providing services direct (relates to administration costs).
- Direct payments empowered users of services and got over their dependency on social security systems.
- Nearly 60% of responding authorities were already operating direct payment schemes, 90% of these authorities would make payments direct to individual disabled people rather than indirectly through a third party if legislation permitted.
- Reduction in dependency on health and social services.

Dowson's (1995) review of service brokerage offers a general view of its potential to be taken up at a national level. He found that users of services were not keen on discussing service brokerage, brokerage being seen as just another professional system of control. Dowson writes about care management, independent living and service brokerage. 'Service brokerage is the only model which takes the assessment process out of the hands of the agency which holds the funds, and puts it under the control of the user. Support in the negotiation and planning processes is also built in, in the form of the broker.' (p. 43)

Service brokerage appears to be used as a job title more and more to describe someone who works in between the care manager and independent providers, and not necessarily someone who works between the user and care manager.

### **6.3 Care Planning**

It can be suggested that we all in one way or another have our own care plans, things that we like to do, things we would like to do, the priorities, strengths and difficulties we have in life. This may be to varying degrees conscious or unconscious in its conception.

There are many ways to describe the tailoring of services to meet people's needs and aspirations; profiling, assessment, service brokerage and care management are a few. They are all characterised by different formal and informal structures and strategies, degrees of user involvement and use of resources. For instance, care planning is more than a glorified assessment, it involves both elements of assessment and other approaches such as monitoring and quality assurance. In addition to this as Atherton et al (1996) point out assessment can be seen as a negative term associated with devaluing examinations. They in turn see care planning as evolving individualism, avoiding exploitation and discrimination and encouraging inclusion and advocacy.

Care planning in all its variations provides a pivotal point between services and the user. Atherton et al (1996) are concerned with the nature of the relationship between the worker and user, the story the user tells of their service and non-service related priorities. It is therefore concerned with a highly individualised approach removing any notions of block funding and instead tailoring services to the individuals, assessments not being done 'to' a person but led 'by' them within a partnership.

As Brandon (1995) points out, the Government White Paper 'Caring for People' (1989) tends to use phrases around assessment like 'attempt to' or 'taking account of' which cannot be considered as strong guidance. Brandon goes on to write that it is vital that care planning and assessment are perceived, even if conceived separately, as a seamless whole by the user. Welfare workers are faced with the dilemma of dealing with the issues raised by the person, or looking beyond using their own perception of hidden agendas. Brandon (1995) sums up the care planning approach as:

- 'Coherence in collecting information so that we would be happy with this process, if the roles of user and carer were reversed.
- Avoid turning people into clients.
- Respect for the privacy of the service user, so care management avoids excessive intrusion.
- Look at the person's whole life rather than through the resources microscope.
- Control over the process and the written report lies with the service user.
- Central to the process is the telling of the person's story.
- Language is kept free from jargon.
- The principle of transparency means that processes are as 'see through' as possible.' (p. 10)

There is evidence that users' self assessments are reliable and have validity and that they are often similar to those of carers and professionals (Brandon. T, 1995), though professionals may prioritise needs slightly differently. The work of organisations such as Acting Up have shown that people with severe learning disabilities can be actively and creatively involved in the planning of their own services. Acting Up uses a multi media profiling system of photos, video excerpts, tape recordings and other material to reveal individuals needs and strengths. The individual themselves is involved in the creation of this self profile and its presentation.

The document Community Life (1990) reports on care packages as reinforcing:

- 1) Preference for an environmental rather than a service provision solution.
- 2) Preference for a solution which reflects the informed choices and wishes of the consumer and carer. The emphasis on 'informed' is not accidental; choice is only reasonably possible after a full account of the options have been made.
- 3) Preference for a public-funded as opposed to a personally charged solution.
- 4) Preference for one named worker (case manager) for consumer liaison.

Ellis (1993) discusses the role of users in needs assessment. She refers to the Social Service Inspectorate's indication of the problem that front-line practitioners have accommodating individual perceptions of need within a framework of organisationally - defined needs. 'Assessors should not prioritise people's needs on the basis of 'disability' alone, rather the determinants of priority should be:

- capacity of the individual to deal with identified needs
- capacity of the individuals carers to deal with identified needs
- capacity of other services to deal with identified needs
- suitability of their living environment

It is the interaction of these five elements which determines an individual's level of functioning.' (p. 7)

This can be seen as a part of a larger move towards independency for users but not without support. Also an appreciation of the potential poverty experienced by users of services is required. Ellis goes on to argue that the contradiction faced within user participation in assessment is that professionals may argue for shared information to represent shared power within services. However they also state that people should not be given all the information for their own protection, as this will raise unobtainable expectations or overwhelm them. Shemmings (1991) in discussing clients access to

records stated that 'Communication of the worker's real opinion, however, would still take place but 'off the record' between professionals, over the telephone or at meetings and without the user present.' (p. 12)

Ellis describes further pitfalls in the assessment process for professionals and users. Does the assessment extend to carers? It is not clear in community care policies, if professionals tend to manage cases in a stereotyped way due to resources and time constraints. Ellis concludes that promoting participation involves a shift from the politics of technical assessment (neutral concept of need) to the politics of negotiation between the conflicting views of the users and carers concerned. I would add to this the interests of the professional(s) concerned.

Beresford and Croft (1993) provide a practical guide to citizen involvement. This covers personal dealings with agencies/services, the running and managing of agencies/services and planning and developing new services and policies. They point out the under representation of certain groups of people such as ethnic minorities within the user involvement movement. Bewley and Glendinning (1994) point out the growing interest in involving people with disabilities in community care planning. They list the types of consultation and discuss the groups often marginalised by the care planning systems. Beresford and Croft (1993) point out a number of key components for 'effective involvement':

- users are capable of dealing with the realities of budgeting and working out resources involved in the delivery and design of services
- the availability of information about services and how they can be improved by people getting involved
- training to aid people to work with budgets and allowing them to train and be trained
- an action and research model of continued evaluation of services and how they are changing
- the careful and considerate use of language. The use of audio tapes and other forms of communication of gaining and giving information
- access to and encouragement of advocacy services

They go on to indicate the possibility that 'There may be tensions between individual rights and collective well-being.' (p. 117)

The care programme approach (CPA) was devised as a response to the concerns of psychiatric patients being discharged, without the appropriate co-ordinated support in the form of a named worker and the pressure for psychiatric beds. CPA is an umbrella term for a procedure run mainly in the health authority involving an assessment of need around different levels. CPA is motivated in part by the protection issue for psychiatric patients living in the community. The intention is to focus on the strengths of the users and their community profile. Schneider (1993) discusses the confusion around the CPA approach and in particular its relationship to care management. CPA has a number of obvious similarities to care management, primarily those around planning and evaluation. CPA can be distinguished from care management in the following ways:

- CPA is concerned more with providing services than care management.
- CPA is health professional orientated, care management is social service orientated (although joint working is becoming more popular).
- CPA is more concerned with risk assessment for users than care management.
- Care management tends to do more intensive assessments than CPA.
- Care management tends to be regulated than CPA.
- Care managers are not viewed as key workers they have a separate identity.
- Care managers deal more with budgets than CPA key workers.

#### **6.4 Day Services**

Day services often offer the focal point for user's lives. The following section explores the background to day services, the reasons behind having them, the more recent innovations and the prospects of user involvement. Day centres or day units are a specific type of day service, they have other names such as adult training centres, family centres, community centres, sheltered workshops and drop-in centres. They cater for the elderly, people who use mental health service, people with learning disabilities, physically disabled people, families, and a mixture of them all.

##### **Background to Day Services**

Jan Carter's (1981) classic study on day services for adults in the late 1970s gives important background to this area. Carter states that day centres tend to be defined by what they are not; housing or institutions. She offers a definition of a day unit as: 'a non-profit making personal service which offers communal care and which has care givers present in a non-domiciliary and non-residential setting for at least three days a week and which is open at least four to five hours each day.' (p. 2)



Day centres are a relatively new idea according to Carter, arising after the second world war when a need was realised. It can be seen from table 9 that in the 1960s and 1970s the opening of day units increased rapidly.

Date	Number of Day Units (approximately)
1959	200
1969	800
1976	2,600

In 1976 four out of ten day units were in the grounds of residential institutions (usually hospitals), they were often referred to as workshops. The 1970s saw a massive reorganisation of social services, health services and local authorities boundaries. Institutional placements began to be challenged and integration in community care became the goal. Carter points out that the expansion of day services was profound but did not come close to accommodating the mass of potential users in the community.

The original models of day services according to Seed (1996) are as follows:

- Work.
- Social care.
- Further education.
- Assessment and throughput.
- Recreation.
- Shared living.
- Resource centre.

Day centres have been orientated towards buildings, traditionally the focal points of communities. In service design terms they are also an easily recognisable, clear purchase and subsequent asset. Carter's (1981) study of a day centre for people with learning difficulties showed staff eating separately from users. The most common activity by users being assembly contract work. Pay was the most important issue to users of the day centre, a finding supported by a Consumer Survey in Cambridge (1989). A 'special' transport system is usually operated. Carter's (1981) writes that 'the three most common obstacles likely to debar a potential user's admission to the

centre were cited by managers as aggressive or disruptive behaviour, incontinence and an inability to walk.’ (p. 51)

The main reason cited by staff for working in this area was personal knowledge of users, perhaps a family member with a learning disability. Carter states that the majority of users of the day centre can be expected to use it for the rest of their lives. If they leave it will most likely be to go to another centre. With this in mind the main aims of all the day centres studied were: practical training, the prevention of institutionlisation, assessment, rehabilitation, respite care; and provision of therapeutic environments, industrial production and the preparation for institutions.

From the 1960s to the 1970s there appears to be a shift from day centres as work places to places of education. Carter advocated for more integration into college education and user forums to encourage involvement. Seed (1996) also reviews day services going back to 1985. He states that not only have services expanded over the past ten years but so have people’s expectations of them. Wide spread unemployment has also had an effect on diversifying day services policy and practices. Seed cynically writes ‘The client derives satisfaction from pretending to be at work while the parents get respite and the tolerability of the home situation for both parties is sustained.’ (p. viii)

#### The Future of Day Services

Woolrych (1992) advocates the opening up of day centres to be a focal point of a ‘whole network of services in the community and there would be a constant traffic in and out...’ (p. 86)

He also sees that having separate special care units within day centres leads to an increased isolation for their users, as they do not interact with each other. He proposes that day services need to be more responsive to individual need, services being purchased on behalf of the user. Day centre users need to mix with non-disabled people, going to a day centres actually reducing this opportunity. Wright (1994) writes that the Department of Health circular in 1991 states “local authorities should plan to shift away from services based on the traditional adult training centre (para.15)” New services should be based on assessment of individual needs, which would then be met by personalised, planned programmes of the day time activities using ordinary community facilities.’ (p. 35)

To sum up it is suggested that the old style social education centres should open up into community resources, encouraging and enabling users to go to colleges, other social clubs, shops and other places of potential integration. McEvoy (1993) and Allen (1990a) both describe services that provide individual day care following ordinary life principles. Allen compared individual planning, community presence, nature, variety, and age-appropriateness of activities, and level of engagement. The community based individualised models had the most favourable outcomes. Ross (1994) advocates and discusses the benefits of increased user involvement in the designing of day services.

### **6.5 Residential Services**

Residential services whether they be supported living, that is group homes or independent living, are fundamental to the quality of life of disabled people. For most people the home provides more than the shelter, as it is the basis of our everyday existence, often the focus of our social lives and the nucleus of the families we nurture. What follows is an overview of some of the research around supported living for people with learning disabilities in England.

Collins (1996) describes the housing and support culture which often disempowers people with learning difficulties:

- Tendency towards bulk provider contracts which ignore individual rights.
- Notions of security are owned by the providers and not people with learning difficulties, overlooking the need for assured tendencies and well thought out operating philosophies.
- Ordinary living arrangements are often by-passed.
- People with learning difficulties are expected to accept the dual presentation of housing and support that providers decide is appropriate for them.
- There is a tendency for people with learning difficulties not to be able to change their support systems without changing where they live.

Collins (1996) sums up her research by saying she did not find a scheme that perfectly replicated what we might term 'ordinary living'. She suggests that what is needed are: 'systems which enable people to access mainstream resources, and which respond directly to the individual requirements of each person, in exactly the same way that other people seek out the particular arrangements which meet their own particular requirements.' (p. 47)

Simons (1995) sets out a number of criteria for housing and support services:

- Reflect individual needs.
- Allow a range of choice.
- The level of support should reflect the needs of the person.
- Services need to be flexible.

He goes on to define 'Supported Living' as compared to independent living as:

- Separation of housing and support.
- Focusing on one person at a time.
- Offering people with learning difficulties full choice and control.
- Having an open door policy.
- Focusing on relationships.

'Independent Living' is defined as:

- Having your own home.
- Having the right level of support to live comfortably and securely.
- Having the maximum amount of 'say' in the way support is organised.

### Alternative Systems of Support

The advent of the mixed economy of care and quasi-market service culture leads to a chance for new systems of support to evolve. The following arguments are predominantly taken from the work of Simons (1995) Collins (1996). I have chosen to present the ideas under a series of headings to summarise the practical aspects of developing alternative support systems in the community for people with learning disabilities.

### Individuality

With support it was possible for a person with a learning difficulty to take over his father's housing association tenancies. Money from the Independent Living Fund aided him to employ his own support. It is also possible for people with the label of challenging behaviour to get intensive support packages, individually tailored to aid them to live in their own homes in the community. The Kidderminster Intensive Support Team described by Simons is expensive but costs less than a hospital-based alternative. A person with the label of Autism who found it difficult to live with other

people using Southwark Consortium managed to rent an ordinary rented house. It worked well as a result of individually crafted staff arrangements and support tenants creating a consistent environment for the person.

### Choice

A couple living in Northumberland were able to get a mortgage based on the wage they received from SHAW. The Chichester, Bognor and District Community Team for people with learning difficulties helped one woman buy her own home using a trust fund. After the sudden death of a relative, a man was supported in the family home with intensive emergency support by the Hadfield and Glossop Community Living Project.

### Autonomy

Southwark Consortium is using service brokerage (see Brandon 1994) and experimenting with direct payments to give people with learning difficulties increased choice and power. Swallow is an organisation in South Wansdyke within which people with learning difficulties make up 50% of the management committee. The Plymouth Independent Living co-operative have aided people with learning difficulties to be directors of a limited company. The Clinical Psychology Division for learning difficulties for Dudley Priority Health made accessible information available on care homes for people with learning difficulties.

### Networking

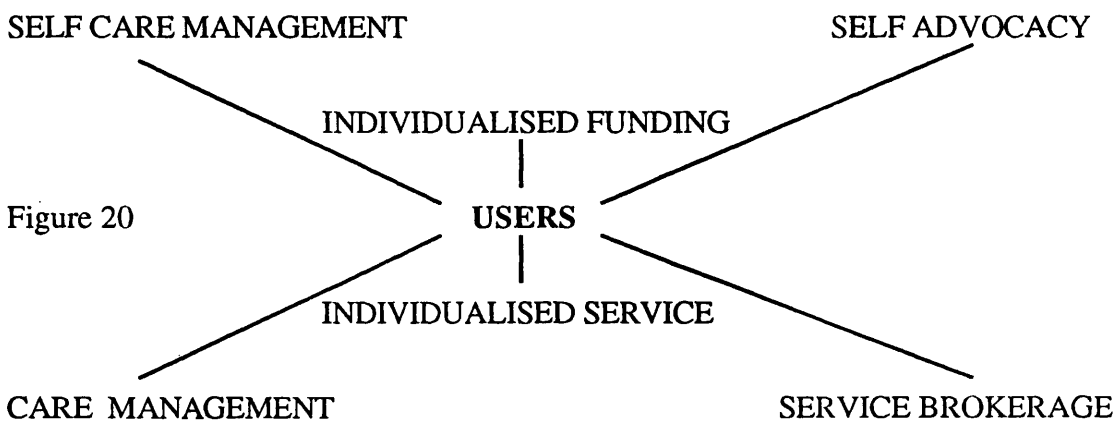
Keyring is a small independent provider which organises networks of people with learning difficulties in the community. These networks are supported by someone who 'lives around the corner' as part of the local community. Lifesharing is a way for a non-disabled person making a long term commitment to live with a person with learning difficulties on an equal basis, sharing a house and social activities. The role of an advocate can be vital in providing a way to network in a person's local community. The Federation of Local Supported Living Groups is a 'not-for-profit' group that helps form local partnerships between carers, users and professionals to help people to remain and enjoy living in their local communities.

Brandon (1996), researching the support and housing needs of people with learning disabilities in the London Borough of Richmond shows that support can be itself broken down into dimensions, from personal care through to physical protection. These dimensions are not exclusive but indicate that people's support needs may be in

distinct areas and can be individually addressed. The plurality and variety of services on offer is important.

## 6.6 Summary

Figure 20 depicts some of the pressures and ways forward around individualised funding and care management. The users of services and disability pressure groups are demanding not service brokerage but individualised funding and help in self-advocacy. Service brokerage needs individualised funding more than individualised funding needs brokerage, therefore we will have to see if individualised funding leads naturally to brokerage or not.



For any worker in the care management field planning care there are still difficult issues to be resolved:

- focus of work on therapeutic or task orientation
- the high degree of assessment complexity
- the recording of unmet need
- the independency of workers
- the role the work may play in creating new services

If care management is to give users of services more power then it will have to be more needs-led. Care management will therefore need to shrug off its inherent gate-keeping role and demonstrate more independency from the statutory bodies that pay their worker's wages. Practically that may mean the worker not sharing the same employers or offices with local social services.

It is not the purpose of this chapter to suggest that the government or future governments should outline policy that leaves the welfare of people with disabilities to market forces. If this were the case it would follow that any service provided by the state or local authority was to be avoided. This is not the case and users with direct funding would have these places as an option. Users do need protecting from manipulative services within the markets as much as they need protecting from the negative consequences of the institutions. Direct funding is empowering users if it allows them to encourage the development of service in the way they want, not what is sold the most effectively to them by a corporation.

Carter (1981) critically writes on day services 'Historically, social interventions for the mentally handicapped have veered between these two extremes; on the one hand attempting to "free" the mentally handicapped (by education), and on the other hand then trying to control their movements (by segregation), if this argument is acceptable, it follows that training centres are in a double bind.' (p. 165)

This double bind shows the conflict inherent not only in day centres but other services for people with learning disabilities. The role of day services, considering their tendency to be both segregated and congregated is unclear in the future. Will they be targeted at preparing users for employment or will they become far more individualised in their service delivery moving away from a focus on buildings? Similarly the future of residential care and the potential separation of its housing and support elements is an area of contention.

## **7 METHODOLOGY**

This chapter explains the reasoning behind the choice of research design. It begins by setting out the goals of this research and the theoretical and practical issues in its methodology. A discussion follows concerning the ethics of conducting research in this area. Finally the foundations of the analysis of the data are discussed, concentrating on the use of a specific computer software package.

### **7.1 Aims of the Research**

The research in its broadest sense is concerned with the relationship between power and disability. From the literature review it is clear that empowerment and user involvement are of great interest within services for disabled people. Both from the point of view of the disability movement and government policy, the location of power is a high profile topic generating much confusion in academic and applied settings. In response to this the main research question addressed in this study is how the perceptions of 'well-being' and experience in terms of 'quality of life' of people with disabilities are enhanced or modified by differing service delivery systems.

This is based on the assumption that disabled people have a unique knowledge about the services they receive, providing them with a fundamental understanding of the power issues concerning decision making. The core hypothesis of the study is therefore that different service delivery systems will affect users perceptions, experiences and feelings of power in different ways.

The ideologies connected with the perspectives utilised in the study are user autonomy, empowerment, social control, independence, interdependence, advocacy, respect and citizenship. The research focuses on a residential support and service brokerage service for people with learning disabilities, a care management and advocacy service for people with physical disabilities and a more traditional day centre service for people with learning disabilities. Chapter 6 provides a detailed examination of Care Management and individualised funding/residential support and day services.

The research examines issues within a multi-professional framework, aimed at achieving a triangulation of perspectives from participant observation, user/professional interviews and organisational documentation, upon services formally designed to empower their users following the guidelines of the latest government policy.



The research also addresses the personal requirements and professional attributes that make 'good workers' in this field; namely how does a worker practically construct independence, advocacy and accountability within a services system of positive professionalism? In a practical sense how do workers and users of services achieve, use and express power? To examine this the nature and structure of the relationship between the user of services and the worker is a major focus of the study. This dynamic (style of working and receiving services) is assumed to be the primary experience and expression of power for both individuals.

The research develops a critical and conceptual analysis of the components of user involvement and power in making decisions within service delivery systems. This includes both broad notions of value, social control and disability as well as more precise issues of personal identity, deviance and the potential stigma experienced by a disabled person. These structures and concepts are incorporated into models of connecting disabled people with services. It is difficult to abstractly identify, define and measure such concepts, therefore the research explores the issues of user involvement, power and identity in greater depth by focusing on the views and actual experiences of disabled people themselves. The research also looks at positive shifts in deviance, and explores how some disabled people come to tackle their difficulties in a spirit of active optimism. They may capitalise on the one thing that might have held them back, developing new skills and attitudes. The research explores how people perceived as 'deviant' gain these positive recognition systems.

The research poses the question of how to analyse a system whereby people with varying disabilities have access to resources and power to make decisions. The literature review discusses the issues surrounding the implementation of planned markets/quasi-markets in which people can buy services as consumers. There are many different types of service delivery systems. Disabilities are also extremely diverse in character along with their interpretations. The new community care plans produced by statutory bodies are officially aimed at meeting the needs of the user. The research is concerned with the extent that this proposition becomes reality, in other words is the spirit of government legislation being enforced within service delivery systems? The personal experiences of the users indicates their appreciation, or not, of this formalised change. The research investigates what elements of service provisions and peoples' personal coping strategies combine to facilitate a sense of self motivating power and well-being. The in-depth interviews and participant observations combine with written information about styles of service delivery across the comparison groups

to form case studies. From these case studies the researcher will tease out the relevant disempowering and empowering aspects of working practices.

## **7.2 Theoretical Foundations of the Research Design**

The following theories are not as distinct as they may appear. Role theory for example is part of a functionalist approach and much of Goffman's work in role theory can be viewed as ethnographic. In stating this it is still useful to separate and describe the different theoretical approaches to understand the contextual background to the design of the study. I intend to identify and discuss the relative merits of different theoretical approaches and present an eclectic research model to be used in this work.

A positivist's approach to this research would assume that a direct link between cause and effect could be located and thus tested. Positivism tends to ignore cultural and subjective elements in its analysis, wishing to reduce complex social phenomena to simple linear relationships (Perring, 1990). Strauss and Corbin (1990) suggest that with regards to traditional science and grounded theory what can be described as 'good science' - significance, theory-observation compatibility, generalisability, consistency, reproducibility, precision and verification should be retained, but need to be flexible enough to fit qualitative research. This research is concerned not simply with measuring the satisfaction people place on their experiences of services but with the broader issues that effect quality of life. These issues are placed in the context of the personal feelings and experiences of individuals and cannot be adequately examined using quantitative research methods alone. Walker (1985) suggests that qualitative techniques due to their less structured nature, are more responsive to the needs of respondents than quantitative ones. I therefore reject the positivist research design but wish to retain the rigor of its methodology structure. That is to say, the accurate recording of data and focused clarity of thought.

Functionalists study issues as a system of parts (e.g the institutions of production, education, human relations, belief) which should be examined not in isolation but in terms of their interrelationships and role as part of a whole. Everything can be seen as having an effect on everything else in terms of dynamic relationships. Perring (1990) states that the aim of functionalism is to see social systems as balanced wholes with normal social activity trying to maintain their equilibriums, this being true of socio-organisational power structures.

Phenomenology attempts to go beyond interactionism and its ideas of role and culture, in that you can never know something in a form which is uncontaminated by its own investigation. Things are redefined as they are focused on by consciousness. Knowledge is examined without the obsession of its correctness by how it came into being (in a sense knowledge of others' knowledge). It should be noted that shifts in power at one level of an organisation might well have ramifications throughout the organisation.

Any person in society occupying a position can be viewed as performing a role. This is the basis of what Parsons (1951) and Biddle and Thomas (1966) call Role Theory. A role is determined by social norms and rules which are programmed into the individual by external sources. Behaviour of people can therefore be analysed in terms of how it is shaped by the demands of these sources and other roles. Goffman (1958) formulated his own role theory, viewing people as having given 'social fronts'. Atkinson (1986) illustrates role theory by saying 'people with a mental handicap develop individual coping strategies to assist them in dealing with the business of everyday living.' (p. 23)

It is therefore important to be aware of the roles people take within hierarchies of power in the study situations. The issues are examined in more detail than defining people into simplified categories/roles of the powerful and less powerful. People are not necessarily fixed in a single role, they may change/alternate between many .

Glaser and Strauss (1967) along with Currie (1987) present Grounded Theory as the generation of systematic explanations grounded in comparative data analysis. They see theory as a process and an outcome in which a perfect description of a phenomenon is impossible. They look towards a theory based approach that develops the best account of the subject matter. This is a fluid not fixed situation. When using Grounded Theory it is necessary to remove as many preconceived ideas of existing theories as possible. However, as Walker (1985) points out there is no such thing as 'presuppositionless' research. In grounded theory you stop analysing when the data gives no more additional material therefore moving onto the next comparison group. Theories are systematically generated and interrelated, giving rise to conceptual linkages. The density of such linkages lends itself in this study to an explanation and exploration of power. Grounded theory stems from symbolic interactionism. As Layder (1993) points out 'instead of stressing the role of an objectively 'detached' observer whose task is to describe social behaviour in terms of causal forces external to the individuals

concerned, the Chicago school emphasised the more 'involved' role of the social researcher.' (p. 38)

This illustrates the main theoretical thrust of the study with people with disabilities. The research attempts to explore unattained levels of sophistication in explaining people's experiences of power. Grounded theory is chosen as it offers a way of entering into the process of power not only its outcomes. In a practical sense Abramson and Mizrahi (1994) discuss the application of grounded theory in social work research. They distinguish the three stages of analysis below:

- 1) The move from raw data transcripts to preliminary conceptual categories. Open coding on a sample of documents leads to comparisons and a saturation of the material.
- 2) The pinpointing of role related variables (axial coding). This includes both the creation of and the connections among and between categories. This leads to identifying underlying uniformities.
- 3) Discovery of an evolving typology.

Fielding (1993) lists the merits of the ethnographic approach as the ability to distinguish between 'official' aims and expectations of a situation and its 'unofficial' reality. Through the Chicago school it developed a critical almost anti-establishment role standing up for oppressed minorities. Goffman sees as essential the process of becoming part of the person's studied world. This world must be a 'natural setting'. Fielding (1993) states that to understand social behaviour fully we need to understand the 'symbolic world' in which people live, that is the meanings people apply to their own experiences.

This research is concerned with the understanding and meaning of power to users of services and the 'hidden agendas' that different services place upon users. An ethnographic approach for the study is chosen as it provides a way of attaining the richness of detail and the generation of hypotheses (in combination with Grounded Theory) required. The purpose of social science research is to describe and understand both at a Macro (study of large contributing units) and Micro level (study of smaller contributing units) a particular area of interest. Moreover, social science provides a means to make sense out of the patterns of social situations, and this may allow room for predictions for the future.

A main research design based in quantitative data was avoided because it will not be sensitive to the type of issues to be investigated. The subject matter under study needs

to be understood both internally and externally. A qualitative case study approach was the most profitable way of obtaining the data. Hakim (1975) states that ‘The great strength of qualitative research is the validity of the data obtained; individuals are interviewed in sufficient detail for the results to be taken as true, correct, complete and believable reports of their views and experiences.’ (p. 74)

Qualitative research in this context can answer the questions about why things occur within a social context; identifying patterns of association between factors and weighing their particular importance. In this research this means the contributing factors to what people call power, within their experiences of service delivery systems.

### **7.3 Research Design**

The research is an intensive explorative study of a relatively small group of people with disabilities and the professionals working with them in three community based organisations in London. The three organisations’ expression and denial of power for their users is characterised and examined through a case study design. These three case studies are constructed by the triangulation of participant observation, interviews and vignettes with users/professionals and the background documentation of each service. The research is based in grounded theory so original theories are continually modified and new ones created, as the data itself leads the work. The research gathers information and creates hypotheses about the following:

- the relative importance of different perceptions of power
- individual’s personal experience of service delivery systems
- the power relations between people with disabilities within a socio-organisational framework
- the practical and theoretical issues of power

Layder (1993) writes on the subjects of power, commitment and constraint that ‘The researcher must be sensitive to the existence of partly hidden social relations of control embedded in the setting and context of such firms (focus of study) and which lie behind the upfront interaction between workers and authority figures.....(grounded theory)...Concern with the meaningful and intentional nature of power relations has the effect of encouraging the researcher to “home in” on observable activities and relationships. However, this is at the expense of asking questions of a structural type’. (p. 156)

This 'embeddedness' is what this research is concerned with; i.e the contextualisation and examination of power within each organisation.

#### Definition of disability within the parameters of the study

People with a disability are not a homogenous group, whether disability is considered in its separate definition, physical, mental and learning, or as a whole. Following the work of Oliver (1990) this study supports the social construct theory of disability which, as Oliver describes, is 'located within the experiences of disabled people themselves and their attempts, not only to redefine disability but also to construct a political movement amongst themselves and to develop services commensurate with their own self-defined needs.' (p. 32)

Oliver goes onto define disability as 'the disadvantage or restriction of activity caused by a contemporary social organisation which takes no or little account of people who have physical impairment and therefore excludes them from the mainstream of social activities.' (Oliver, 1990, p. 45)

Therefore within the parameters of this study disability refers to not only the person using services with an attached medical/semi-medical label but the social context they are living within. Oliver attacks the previously 'grand' but flawed all inclusive theories of disability such as those which frame disability as a 'tragedy', disability being seen as a problem and disabled people as victims of events and circumstances. Oliver blames the professionals for the application of oppressive 'grand theories' such as the medical model which treats people as 'patients' and does not involve disabled people in a meaningful way except as 'passive objects of intervention, treatment and rehabilitation.'

The following lists of defining characteristics are developed from the literature review. These issues also feed into the topic guide to be used in the interviews.

1) The different realms of power potentially experienced by the respondents:

- individual (personal)
- family and advocates
- associated groups (small charities and organisations, self help groups)
- institutions and communities

2) The possible conditions for empowerment:

- access and control of resources
- perceived competence for use
- choice
- information
- control
- dignity
- belonging
- respect
- risk taking and the right to fail
- autonomy
- safety
- consistency
- predictability
- being consulted
- interdependency

3) The possible conditions to create oppression and thus deny empowerment:

- feelings of stigma
- feelings of fear
- feelings of depersonalisation
- guilt
- low self esteem
- degrading treatment
- loss of rights
- labelling
- dependency
- poverty
- prejudice
- low status
- rejection
- threatened identities

4) The effects experienced by living and working within a structural hierarchy and bureaucracy:

- degree of accountability
- degree of redress

5) Experience of being disabled including both positive and negative deviance. The understanding and self-awareness people have of:

- physical difference
- mental difference

The three organisations studied were selected for the following reasons; they represent two with post-Griffiths and one with pre-Griffiths objectives, structures and services, both for people with learning disabilities and people with physical disabilities. The Day Centre is a traditional unit for people with learning disabilities, the Residential Consortium and Care Management organisations being more contemporary in design. The Residential Consortium is a collection of services for people with learning disabilities. The Care Management organisation is designed for people with physical disabilities. This selection allows for the cross comparison of two types of organisational set up and impairment type. A brief description of each of the organisations follows:

Day Centre:

The largest social services establishment in the local area. Opened in 1972, it is built along conventional Department of Health and Social Security architectural guidelines. The age of clients is 16 to over 60 people with learning disabilities and additional physical disabilities and or behaviour disturbances. There are 130 potential users of the service. A special unit for people with more severe learning and physical disabilities is attached to the main day centre. It is open from 9.00am to 4.30am Monday to Friday every week. As an organisation the day centre is closely linked to the college year, September heralding the start of a new program of education and training split into:

1. Social and domestic skills.
2. Further education.
3. Work activities.
4. Recreation and leisure.



### Residential Consortium:

Is a service set up for people with learning disabilities in the community. It provides supported housing through a number of different organisations along the following guidelines:

- people should have the right to be present in the community and to live in ordinary housing
- people should participate in local community activities and have the opportunity to develop relationships with people who do not have a learning disability
- people should be enabled to make choices and take decisions about as many issues as possible
- people should be provided with the resources necessary to develop their skills
- people should be able to gain in self respect and be respected in their local community

#### *Organisation 1*

The project provides 24 hour cover to all project residents (with a learning disability) from the office base. Clients can call at the office at any time for urgent matters/emergencies, or if they need emotional support.

#### *Organisation 2*

The aim of the project is to support four people (with learning disabilities) who live at ..... in achieving full, satisfying and independent lives. It is a self contained four bedroom house. Staffing levels are reviewed as to the needs of the services users.

#### *Organisation 3*

This project aims to provide support to people with a learning disabilities living in the community either independently or in shared accommodation.

### Care Management:

The organisation was started in 1986 as a Case Management Project in the local area, being originally funded by the Kings Fund. The principles of this Care Management service being that:

- disabled people have the same human rights to a voice and to choice as do the rest of the population
- the range of community services should be brought together to enable the individual to take charge of his/her own life

- users should be actively involved in directing the planning, monitoring and evaluation of services
- case management should be a positive step towards equal access thus reversing the historical neglect of people with disability
- people with a disability should be able to use all the facilities and amenities available to the general public

Referrals to the care management organisation will be considered from anyone, including self referrals, providing the person referred is someone with a physical/mental disability aged 16 and over. The organisation had a preference for employing workers who were disabled themselves. At the time of this research all the staff in the organisation had a disability.

The following factors are accounted for in each of the three comparison groups:

- style of physical environment.
- Management and organisational structure
- history of working practice
- relationship of people living and working together
- impact of relatives
- number of users of services and workers within it and the ratio of workers to users
- length of time in operation for both users and workers within the organisation
- financial structure of the organisation - voluntary/statutory status
- aims for the future
- relationship with other organisations
- original remit of services and how it has evolved
- each organisation's consideration of equal opportunities policy
- each organisation's statement of value and philosophy

The numbers of respondents interviewed and the organisations they are connected with are contained in table 10.

<b>Table 10 Data Collection</b>				
<b>Organisations</b>	<b>Observations</b>	<b>User Interviews - Vignettes</b>	<b>Professional Interviews - Vignettes</b>	<b>Documentation</b>
<b>Day Centre</b>	3 Days	9	9	Obtained
<b>Residential Consortium:</b>				
<b>Organisation 1</b>	1 Day	3	3	Obtained
<b>Organisation 2</b>	1 Day	3	3	Obtained
<b>Organisation 3</b>	1 Day	3	3	Obtained
<b>Care Management</b>	1 Day	9	2	Obtained
<b>Total:</b>	7 Days	27	20	5 Sets

### Sample

A comparison is made between three organisations providing services for people with learning disabilities and physical disabilities. The attitudes of each group to different services has to be put into their respective contexts. There is however no need for a control group in this study, it is solely an explorative piece of case study work.

In obtaining a sample of users to be interviewed an attempt was made to select a 'typical mix' of respondents representing the relative proportions of gender, age and ethnicity served by each of the three organisations. This is shown in table 11. Diagnosis or detailed explanations of disabilities were not taken into account, but all the users interviewed could be considered to have 'mild' disabilities as they all used spoken words to communicate. Professionals working with these users and interfacing with the organisation under study were also interviewed. They represented all the different levels of the service delivery systems hierarchy.

Respondents were sampled as follows:

- In the Care Management organisation by obtaining a list of the service users and randomly selecting every third one until nine users had been interviewed. There were only two professionals in this organisation so both were interviewed.

- In the Day Centre by observing in the centre and allowing for a degree of self selecting. Some of the users were approached informally and then asked if they would like to be interviewed. Nine professionals were randomly selected from the staff list.
- In the Residential Consortium by randomly selecting three organisations and three users from each.

<b>Table 11 Demographics of Professional/Users Interviewed*</b>				
<b>Organisations</b>	<b>Gender</b>		<b>Age (mean)</b>	<b>Ethnicity (self identified)</b>
	<b>(Male)</b>	<b>(Female)</b>		
<b>Care Management Users</b>	4	5	48	Indian 1 British 5 Greek/Cypriot 2 Jewish 1
<b>Care Management Professionals</b>	1	1	Not Known	British 2
<b>Day Centre Users</b>	7	2	40	British 7 Irish 1 Jewish 1
<b>Day Centre Professionals</b>	5	4	33	British 9
<b>Residential Consortium Users</b>	8	1	46	British 9
<b>Residential Consortium Professionals</b>	5	4	33	British 7 Afro Caribbean 1 Irish 1

(\* for more detailed respondent demographics refer to appendix A)

#### **7.4 The Interviews**

The core of the study is constructed around the personal 'in-depth' words of the users and professionals of the services. The in-depth interviews are constructed around a flexible Topic Sheet of questions. A degree of equality is developed as similar topic guides are used for both the users of services and the workers within them. This means that the feelings of power and disempowerment for both workers and users were examined on a comparable footing. The researcher was however aware that in terms of the reality of an interview situation the line of questioning will be different. An 'internal' and 'external' direction of study was applied to the interview situation/topic guide with the users of services. In other words the constituent parts of the topic guide. O'Brien's (1987) five accomplishments provided a framework for looking 'inward' on the respondent in terms of the context of their lives. The care planning approach by A, D and T Brandon (1987) shows the 'outward' view of the person. 'Posture' refers to the set of values, attitudes and beliefs a person holds and develops in response to their life experience of disability, services and the combination of the two.

For the users of the services all topics covered were framed within a chronological context of life span development. Power is examined via the relationship the user had with the worker and services they both experience. What follows is a more detailed analysis of the topic guide. The user interviews include elements of:

- individual interpretation of personal service requirements
- the person's life history of power

The interviews took approximately an hour, being designed to not pressurise the user of the service. The researcher employed an informal posture aiming to be supportive and friendly.

The professional interviews looked at the elements of:

- perceptions of power distribution among professionals and users
- service providers' ability to meet and encourage the specific requirements of the individual and/or group of users they are working with

The interview with professionals was achieved in one session of approximately an hour. As with the user interviews a friendly and supportive approach was taken. This takes account of the individual's life in terms of their own evolving identity, rather than

a clinical history or their particular label. It was not the intention to present a exhaustive list of categories, topics and sub-topics accompanied by exact prompts and questions for the interviews, however guidelines were presented that the researcher employed while operationalising the study. The research therefore followed a balance between an over technologised research design where every question has been worked out prior to the interview and a totally open interview system with no structure or direction. What was required was an approach which retained some direction in addition to an ability to flexibly adapt to the respondents' style and content. From this position the researcher could generate and modify hypotheses as the study evolved. Therefore semi-structured interviews were the main research technique. This provides a qualitative opportunity to allow disclosure of sensitive information and the discovery of underlying attitudes. The key feature of semi-structured interviews is to take a naturalistic and holistic approach that induces in-depth data recording. It is difficult to construct a comprehensive list of questions before clarifying the exact direction of the study. Pilot interviews were designed and employed to understand and test the type and style of questions to be used.

#### Topic Guide

'External Categories' developed from the work of John O'Brien (1987):

1) Community Presence: means the sharing of ordinary places such as schools, libraries, swimming baths, restaurants and clubs that facilitate a valued community life and that avoid separate and segregated services, 'special' activities and different routines. Valued activities aim to increase the number and variety of ordinary places that a person knows and can use.

#### Issues covered by Questions

- what valued, ordinary facilities does the person currently use?
- how do these services help them feel more valued?
- what further facilities might they be encouraged to use?
- what support would be needed to achieve this?
- who would provide it?

2) Choices: involves the experience of personal power, both in the small everyday things such as what to eat and what to wear but also in large matters such as where to live and what sort of school to go to. Personal choices help define a person's identity by trying to increase the available options and provide support for decision making and

to move away from the passivity encouraged by services in the past. There is a stress on active engagement and participation.

#### Issues covered by Questions

- what degree of control do they have over their life?
- what do they like or dislike?
- how might that control be extended?
- how might the person make more choices from increasing options?
- what kind of support would be necessary to make this happen?

3) Competence: the opportunity to do meaningful activities with the necessary assistance. Without focused effort, people with disabilities may be deprived of the expectations, opportunities, instruction and assistance necessary for increased competence. People must be actively encouraged to gain increased social and personal skills and the assurance which goes with them.

#### Issues covered by Questions

- what skills do they have?
- what is the extent of their personal confidence in acquiring more?
- what training/teaching/support is necessary to extend those skills and personal competence?
- who should be responsible for helping develop this increase in competence and how?

4) Respect: means having a valued place and valued roles among an extensive network of people. It means to be seen as a worthwhile person. People with disabilities are often confined to a narrow range of stereotyped, low status roles in the community, which restricts their opportunities to be seen and valued as individuals. Their engagement in valued activities can challenge negative stereotypes.

#### Issues covered by Questions

- what activities are they engaged in that command respect from others?
- how might that range be extended?

- what support would they require to be seen in a more valued, high status position?

5) Community Participation: the experience of being part of a growing network of personal relationships that includes close friends. Without careful planning and implementation, people with disabilities will have unusually small social networks whose membership consists mainly of relatives, paid staff and other people with disabilities. Valued activities will aim to provide increased opportunities for someone to meet more people and develop greater variety and depth in their relationships.

#### Issues covered by Questions

- what is their social network?
- how many unpaid friendships does it include?
- how many intimate relationships?
- how could both the diversity and number of relationships be improved?
- what support would be needed and who should provide it?

#### General Open Ended Questions

- where do they spend their time?
- what do they do?
- who do they spend their time with?
- how are they seen by others?
- how do they feel about themselves?

#### Topic Guide: 'Internal Categories' D. A and T Brandon (1993)

1) Control: issues of race, gender and disabilism, moving away from the encouraged passive unassertive role. Increased self awareness, what Freire (1972) regards as 'conscientization' the process in which people, not as recipients, but as knowing subjects, achieve a deepening awareness both of the socio-cultural reality which shapes their lives and of their capacity to transform that reality.

#### Issues covered by Questions

- is the pursuit of personal power encouraged?



- can people take risks?
- do they participate in major decisions?
- what are the options for choice, are there many or few?
- do they choose with whom to spend their lives?
- are people helped to gain more control over their lives?

Examples:

- holidays?
- food and drink?
- T.V and radio programmes?
- activities?
- music?
- clothes?
- control of money?
- transport to get places?
- sexuality?
- relationships?
- can they help to appoint staff?
- are they involvement in planning services?
- are they able to express likes and dislikes and get them attended to; get taken notice of; treated in terms of age appropriateness?
- are they seen by someone as worthy of respect; perceived as being able to make wise choices, to take responsibility; seen as a person just like anyone else?
- are they seen as a complete citizen (holistic view) rather than as a client/patient and thus treated with more dignity and respect?

2) Skills: related to feelings of self-confidence. People who possess skills valued by others may find themselves valued as a result. Are people encouraged to increase their personal development and competence and provided with relevant resources?

Issues covered by Questions

Personal: self control, ordinary valued structure of daily routines and discipline; possessing assurance and confidence; developing insight and deepening self awareness; effective time management; ability to handle stress adequately; able to ask for help.

Social: ability to relate to others; communicate with sensitivity and accuracy; to express oneself effectively; capacity to develop empathy; to be assertive; to have fun and love.

Activity: acquires skills in some areas, at work; in sport; pastimes; hobbies like:

- music
- foreign languages
- public speaking
- sport
- sewing
- driving
- playing cards

Acquiring, possessing and improving skills assists the growth of self worth and confidence; in being seen as worthwhile by others.

3) Pain: and suffering or its absence is important to the way we feel about ourselves and others. There is often a disparity between the way we think and feel our life ought to be and how it seems to be. Pain as a concept both theoretical and practical is often ignored by workers as if it is too personal and private.

#### Issues covered by Questions

- is the pain of different individual's sensitivity recognised?
- is people's suffering seen in fundamentally human ways rather than being wrapped up in professionalised jargon and ideologies?
- feelings of disease; a sense of impermanence; feelings about getting older and losing capacities, especially memory, dying and death. Feelings of being isolated and cut off, echoing states of fear and anxiety.

Both psychological, physical and spiritual suffering; struggling against often overwhelming lusts and desires. Struggling to make sense of pain; to try to reduce and minimise the sense of suffering; to follow it back to the primary cause. Trying to reach for joy and love and avoid alienation. In what ways does the service assist this creative process? Do they develop an atmosphere of active/realistic optimism a move to positive deviance?

4) Contact: People's sense and experience of fun, sensuality, liking and loving.

### Issues covered by Questions

- does the above occur both in quality and quantity?
- does the person have both paid and unpaid links with the world?
- what is the nature of intimacy and warmth of relationships people have?
- what is the length of relationships for them?
- how do the people feel about sharing confidences and keeping secrets?
- are their relationships reciprocal in nature?
- do these relationships appear equal?
- are they a member of valued clubs and/or organisations?

For an example of the interview topic guide used in the study see appendix B.

### Why use Interviews

Kidder and Judd (1986) describe the advantages of interviews as 'The ability of the interviewer to notice and correct the respondent's misunderstandings, to probe inadequate or vague responses....Face-to-face interviewers can best establish rapport and motivate the respondents to answer fully and accurately, again providing quality data.' (p. 34)

It was felt that there may well be a problem of interviewer effect; the interviewer's expectations being communicated along with the questions. Hence it was important to have a clear and effective style and protocol. Being aware of the bias brought to the interview situation is vital. This includes issues of what is thought of as good and bad practice in services and what I personally believe is the best for the groups and individuals studied.

This indicates the importance of the researcher's awareness of their own 'posture' during research situations. It was important that I take the information given by respondents as true and not become obsessed with verifying it. Individual's stories are, over time, always open to re-interpretation, respondent's memories may be selective and elaborative. It is however their story still, a chance for them to tell about their lives in the way they want to. In that sense I am not pre-occupied with factual accounts but the sense that someone is making of his/her circumstances through the power they receive and express. Perring (1990) says on interviewing, 'experience has led me to the conclusion that, from the client's point of view, formal interviews are often an inappropriate and inaccurate way of eliciting their experiences. Such

interviews hold too many associations with the diagnostic or medical interview, in which the person feels s/he is being examined and tested. Similarly, a formal interview may reflect a particular occasion without understanding the situation in which it takes place - a respondent may brush off a question or give inaccurate, closing answers, because he resents the particular question asked, or suspects the interview is not revealing his real purpose.' (p. 165)

Other factors influencing the process of interviewing are the social desirability of some kinds of responses. The use of participant observations should reduce this error, allowing the researcher to get to know the more typical responses of the respondent in as 'near natural' a setting as possible. This hopefully would take account of any difficulties the respondents might have in expressing themselves verbally.

I therefore had to be clear in the process of self-presentation, making it clear that I am not directly associated with carers or any professional body that the user and professional subject groups may feel uncertain about. It was important to develop trust when interviewing people, to become familiar with the person and their surroundings, and to make sure that everyone knew exactly why as a researcher I was there. Hakim (1987) stresses the importance of allowing the respondent to steer some of the interview process.

The following prompts and guidelines in interviewing are adapted from a course run by Qualitative Research Unit at Social and Community Planning Research (SCPR) at the London School of Economics:

- 1) Make sure conditions of the interview are as ideal as possible: comfortable and quiet.
- 2) Deal quickly and efficiently with practicalities of the interview (e.g documentation).
- 3) Take care to consider where both respondents and the interviewer sit.
- 4) Remember to introduce the study clearly.
- 5) Do not pursue complicated or sensitive issues too early in the interview.
- 6) Probe answers until sure that respondent has replied to the question as fully as possible.
- 7) Pace the interview both in the interests of respondent and interviewer.
- 8) Watch for non-verbal clues and lack of understanding of any of the questions.
- 9) Rephrase question if required.
- 10) Try to end the interview on a positive note.

The following interview checklist was referred to after each interview:

- 1) Were all the relevant points during the interview covered/noted?
- 2) Were notes of the respondent's non-verbal communication taken?
- 3) Is it necessary to clarify anything before the next interview?
- 4) What was the probing like in the interview?
- 5) Where did the interviewer impose their own interpretation of what was going on?

### **7.5 Participant Observation**

Perring (1990) values the role of participant observation giving detailed insight into the experiences of the people studied. In trying to understand the experiences of being someone with disabilities living in a particular setting it is necessary to observe someone for at least a day. This provides the foundation for relevant questions to be asked of the respondent around their life experience. It also provides an opportunity for the respondent to begin to trust the researcher. The participant observation took place as far as possible in a natural basis, the observer taking part in activities during the session. Observations act as a more direct link with the data, interviews are a more second hand means to understand the respondent. It is however important that the observer should not be identified as a paid members of staff. Gordon (1975) points out the problems associated with participant observation in finding an intermediate position between being seen as an 'outsider' and an 'insider'. Extensive observational notes on the behaviour, actions and interpretations of respondents will be recorded for the full day period of observation. Table 12 demonstrates that firstly the time of the observation was recorded followed by the events taking place and finally any personal comments on the what had occurred.

<b>Date and Time</b>	<b>Observations</b>	<b>Comments</b>

The solution to Gordon's query is either to take a clear marginal role in the study or become a non-participant so one cannot consciously or unconsciously manipulate the situation. Non-participant observation is near impossible as any presence at all, no matter how small, can have an effect on the respondents. Gordon does state that on the other hand, observations of isolated physical actions may lack intent or clear motivation. Disabled people may have difficulties with recall, so participant

observation allows the respondent to express themselves in alternative (e.g non-verbal) ways. This provides a balanced format for understanding the practical dynamics of living and working in a particular service/environment.

## **7.6 The Pilot Study**

The pilot phase of the study consisted of one day participant observation and ten semi-structured interviews with people with learning disabilities and staff working at a day centre. This group was chosen as people attending the day centre would have mixed abilities and there would plenty of opportunities to make contact with them.

### **Notes on completing the interviews**

**Problem:** the research is interested in people's experience of power, it requires people to express their opinions in some way. People who are disempowered consequently have difficulty expressing power. For example the choice or preferences that people make.

**Solution:** need to construct a flexible supportive structure to the interviews that allows the deeper, gentle probing of the replies of people:

- a tendency for users to say 'alright' to every question
- a tendency for users to talk about current issues and not about the past or future concepts that are also sometimes difficult to unpack for people with learning disabilities
- a tendency for the researcher to move towards asking more questions quickly rather than fewer more slowly, thus collecting data that was not sufficiently in-depth.

### **Analysis of data**

The users' and professionals responses', along with the setting profiles and observations were converted to online NUD•IST documents. An indexing system was constructed using the NUD•IST nodes system. Text searches and index searches were carried out on the material. For example:

- a text search for units with U.A was made producing a document containing all of User A (U.A) responses including the specific questions answered as subheadings.
- an index search was performed into respondents' answers to questions around the theme of PAIN. (Code 6 1) was a union of two nodes (1 8) and (2 5).

Difficulties in learning the operations of this qualitative computer package:

- the need for precise and careful preparation of data before placing material into the document folders
- learning how to construct an indexing system before placing the data onto the system
- coding of each text unit and node-tree construction
- the sheer volume of nodes generated by coding

### Changes to the final study

With reference to the questions posed at the beginning of this chapter a number of changes were made to the final structure.

- 1) Need was identified to improve upon the prompts used for the user interviews in order to gain more detail from the respondents.
- 2) Users were selected with milder learning disability to aid the information gathering process. It is not vital to the study to interview people with more severe disabilities, so none appeared as respondents. I therefore need to check carefully the profile for each study organisation for the appropriate people.
- 3) It was decided to develop an interview topic guide for both users and professionals that shares and follows the key empowerment themes more closely.
- 4) Data would be recorded on a record sheet not taped as this is less threatening to the respondents. This is made easier by having a structured topic guide and specific/targeted questions allowing this quicker recording method.
- 5) The removal of obsolete or ineffective questions. What follows is a list of the questions that were rephrased or removed as a result of the pilot work:

### Professional Questionnaire

- what is the organisation's equal opportunities policy and complaints procedure?
- how much choice/control/power can you give/share with them? how could you improve this?
- what do you get out of your work?
- how do you see the future for these relationships?

### Users Questionnaire

- how could you have more choice over the things you do, who you do them with and when you do them?
- who could help you to make this happen?
- can you tell me something about how you came to live here?
- are you aware of changes made by the people 'at the top' of the organisation which might affect you?
- what would you like to know about?
- what training/teaching/help would you need to gain more skills?
- what would you describe are your strengths - what do you do well?
- what help would you need to do these things?
- how are you seen by others?
- how do you feel about yourself?
- do you do different things with different people or do you mostly stay with the same people?
- who do you not like?
- how could you spend more time with your friends?
- how could you meet more people and make new friends?
- what help would be needed to do this?
- important people in your life (already one like it)?
- what is it about your own group (and the people in it) that is different from the other groups/people?
- are you allowed to do things on your own, what can't you do on your own?
- do you feel that you are taken notice of?
- what sort of people do users like to help them?
- what changes would you make to the help you get?
- what is stopping you?
- do you think it would be possible to live in a different way/somewhere else?
- what are your wishes/dreams for the future?
- if you have wanted to make a complaint about the service or the agency, but did not go ahead with it, can you give a reason why?
- what are your current circumstances?
- how do you feel about the people who work with you?

### Vignettes

The pilot work indicated that the structured questionnaires for the users of services were not effective in gaining in-depth answers. The problem being that users found the questions uninteresting and not relevant to their experience. There was a tendency for



both the users and the interviewer to rush through the questions, only gaining superficial answers.

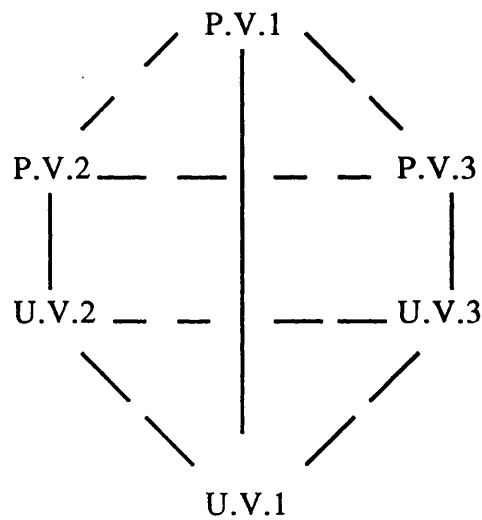
As a remedy vignettes give the person a framework of variables to comment on. A vignette in this context is a short description of a series of events. The most effective vignettes appear to be those where a conflict is created and the respondent is asked to make a considered and personal judgement. This allows insight into both the process and outcome of respondents' deliberations. The particular style and content of power both for users and professionals, in their lives, living environments and work place can therefore be recorded (Finch, 1987 and Crissey, 1982). It must be noted that respondents, in particular professionals, may tend to answer in a socially desirable way. The remaining structured questions in the questionnaire will hopefully verify or highlight contradictions in respondents' views over the key issues of power.

The specific details and wording of each vignette depends on the context of the organisation and particular person interviewed, whether they are female or male, their age, where they live and any other pertinent factors. The flexible set up allows this to be tailored to the person's day to day experience.

The same vignettes with slight alterations can be used for both the professional and user interviews. Therefore the same basic scenario is approached from two different angles, that of the user and professional. The expectations, prioritisation and actions of users and staff can be considered for a given situation. The themes brought out by the vignettes can be cross compared between and within users and professionals groups. The configuration of this analysis is illustrated in Figure 21.

Figure 21

Vignette Comparison/Analysis.



**KEY**

INTRA (Between Groups) \_\_\_\_\_

INTER (Within Groups) - - - - -

P.V (Professional Vignette)

U.V (User Vignette)

The variables in each vignette allowed the researcher to lead the respondent in certain directions while presenting the narrative. The variables used in each vignette also needed to be noted for each comparison group. Each vignette is accompanied by a series of prompts which allow for a method of eliciting responses from the respondent in a considered and controlled open-ended manner. The themes listed arise from the literature review and pilot work. They represent within the vignettes the issues most salient to people's perceptions of 'power'. For an example of a vignette used in the study see appendix C.

**7.7 Documentary Evidence**

Documentation may cover many different types depending on the extent and style of record keeping in an organisation. The documents were taken directly from the organisations' filing systems. The following represent the types of documentary evidence that were taken and used:

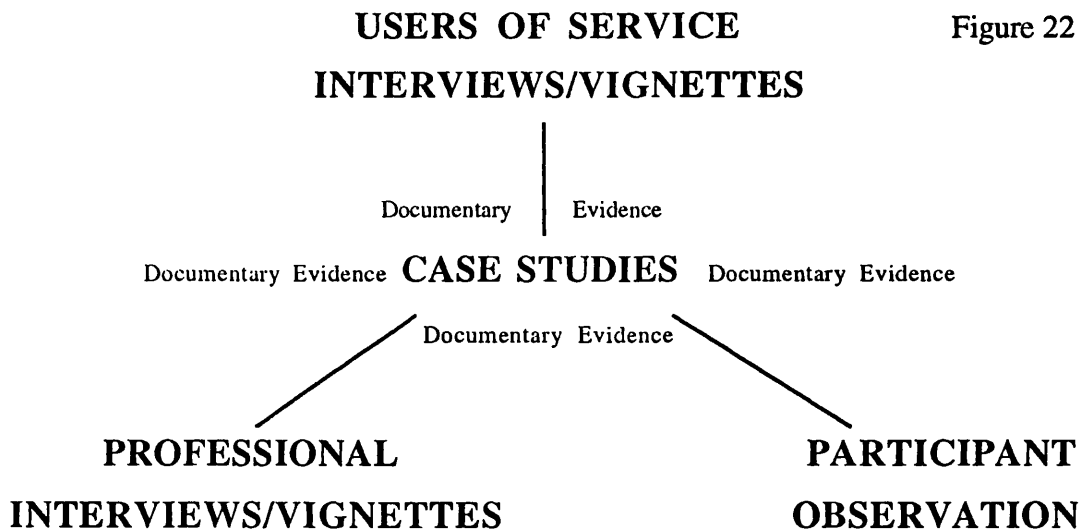
- User Information Forms
- Complaints Procedure
- Basic Information.

- Review/Periodic Summary
- Advocates
- Contacts (Key Points and Action)
- Consent Forms
- Policy on Clients' Access to Personal Records
- Social Service Records
- Duty Guidelines
- Organisations' Philosophy
- Users' Handbook
- Staff Handbook

The documents combine with the observations, interviews and vignettes to form case studies of the organisations.

### 7.8 Case Study Design

In the previous sections interview techniques, participant observations and the use of vignettes and documentation provided by each organisation have been explored. This section discusses the ways this data was brought together and used to build the foundations of the answers to the research questions. The study aims to construct a set of individual case studies of power for each organisation. Figure 22 shows the triangulation research design to be used with each of the three service delivery systems.



The specific personal characteristics in this study is the personal sense of power felt by people with disabilities within different services. Case studies are particularly good at detailing 'postures'; that is the collection of values, views and beliefs that constitute a person's position in a power structure. Hakim (1975) on case studies indicates that they are there to provide a richly detailed exploration of the individual's own perception and accounts of their experiences. Yin (1984) states that the case study allows the research to retain the holistic and meaningful characteristics of real-life events. Yin's investigation of the role of case study design in social science research divides case studies into the following:

*Description:* tracing the sequence of interpersonal events over time. For the purposes of this research the description of power structures for people with disabilities.

*Explanatory:* pose competing explanations for the existence of these power structures. Why are the power structures the way they are? Who benefits and who loses from their existence and distribution?

Case studies are therefore generalisable in a theoretical not a practical sense. The triangulation approach chosen allows for multiple inputs of evidence that verify the studies data. That is to say the establishment of operational structures and protocols in the study allows ease and accuracy of cross-case comparison from a single case data base constructed via a triangulation procedure.

Pattern-Matching in case studies is described by Yin (1984) in the following ways:

- 1) Making an initial theoretical statement or an initial proposition about policy or social behaviour.
- 2) Comparing the findings of an initial case against such a statement or proposition.
- 3) Revising the statement or proposition.
- 4) Comparing other details of the case against the revision.
- 5) Again revising the statement or proposition.
- 6) Comparing the revision to the facts of a second case.
- 7) Repeat the process.

### **7.9 The Ethics of Doing Research**

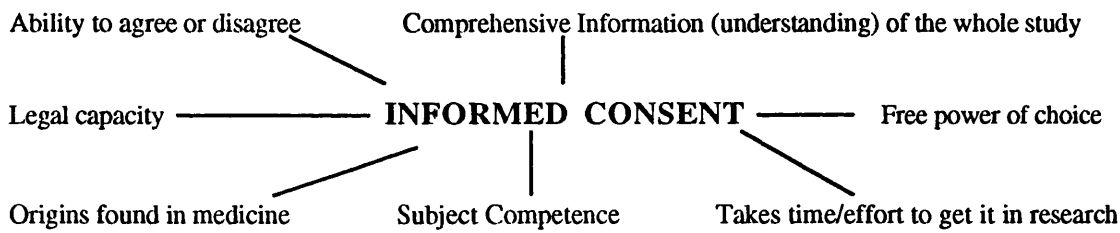
Ethics come more obviously into frame when doing research on sensitive topics. Lee (1993) borrows Sieber and Stanley's definition of this as 'Studies in which there are potential consequences or implications, either directly for the participants in the research or for the class of individuals represented by the research.' (p. 12)

Homan (1991) sees ethics as the science of morality connected to a sense of duty. It can also be characterised by the quality of interpersonal conduct and the norms and standards used by professionals. Oliver (1990) highlights the problems of doing social science research by saying it can have oppressive consequences when disabled people are seen and treated as passive recipients of the research process. He goes on to state that rarely does the outcome of research improve the quality of life for disabled people. It is vital to remember the impact of doing research with or about potentially devalued people. It is intended that this research will not become part of a disempowering/depersonalising history for disabled people. It will therefore be necessary to seek with care their permission and partnership, explaining the purpose of the interviews and terminating the interview if required. Beresford and Croft (1986) write on the subject: 'Whether people want to get involved in research depends crucially on what it entails. There is no reason why it should be a burden.' (p. 17)

It is therefore people's right not to be involved in the research. The researcher may be privy to information that would be harmful if passed on either immediately or later in the write up. It is vital to protect the identities of people in the study and be clear about the style of data recording, making it both accurate and respectful to everyone concerned. Identification of interview scripts must be kept separately from the scripts themselves and in the write up a coding system of abbreviations is used. The social scientist is in a powerful position, acting as an over-viewer for the work and its interpretation. Research is a process as well as a task/goal and we must therefore consider 'Positive' ethics in a holistic sense not only 'Negative' ethics. 'Negative' ethics are primarily concerned with how to avoid making simple ethical mistakes like taping interviews without permission. 'Positive' ethics move towards involvement of the objects of the research (people) at as many stages of the conception, planning, implementation and write up of the research as possible. Ethics in research can be considered in terms of privacy and informed consent. Privacy is the domain of transactions between people or groups of people. Therefore transactions can cause territorial conflicts. Privacy needs to be defined by the subject in terms of attention, physical access and personal information which may be positive, negative or just not true. On informed consent Homan (1991) writes 'The practice of informed consent, it is argued, shifts from researcher to subject the moral responsibility for delineating the bounds of privacy and for refusing access to researchers: this is especially problematic in view of the relatively powerless role and unpracticed negotiating skills of many human subjects and it renders their privacy the more vulnerable.' (p. 55)

Figure 23 adapted from Homan (1991) highlights some of the issues surrounding informed consent:

Figure 23



Homan (1991) goes on to describe informed consent as part of a larger ‘democratic practice’. ‘Consent is perceived not as a one-word and irrevocable utterance at the outset of a project but as a continuous process or review.’ (p. 79)

Who will benefit from the completed research is an important ethical question. The research could be commissioned by the respondents themselves. A care plan for people with disabilities is a good example of research in practice; an unfolding of an evolving case study. If this is a process and an outcome which empowers people with disabilities, they need to not only be aware and informed of the purpose of the care plan (or research) but also be able to contribute in the most direct way possible to its conception and implementation. If people are involved to this degree in research then they require rights, particularly because the research is about their lives and experience. They become jointly the researchers and the researched. Ownership of data generated in the research is another vital area; Mullender, Everitt, Hardiker and Littlewood (1993/1994) write on ownership of social work research from the practitioner perspective but this can be extended to users of services or even more widely to any respondents in research. The question also arises concerning what legal and ethical redress do people have over what is written about them. Researchers after the completion of the work may not return and explain their findings or if they do it is often to higher officials in organisations not to the respondents involved.

Research is not neutral in nature. Hidden agendas often arise as ideological points, perhaps unconsciously, make their mark in the study. This has to be watched for and accounted for in the final write up. The bias in this study is one towards the increased involvement and power of users of services, user involvement and their accounts of events, as their influence may have been limited in the past. Gordon (1975) sees the ‘human’ skills required for good social science research as empathy, participation and observation. This forms the basis of a trusting relationship with the respondents in the

study, thus allowing them to be empowered enough to express whatever issues they feel are important. As has already been pointed out, ethical practice in research is not just concerned with avoiding doing something wrong but actively pursuing good practice. It was therefore an aim to develop a positive, open and empowering relationship with the study respondents. It was also my intention to make a solid commitment to this and the organisations by making available to both users (if they agree) and workers involved in the study a clear explanation of my findings and how I obtained them. This may take the form of an oral or written presentation depending on their preferences. A major question is what 'posture' (set of beliefs, values and attitudes) does the interviewer bring into the interview situation? What will be the nature and style of the relationship between the interviewer and interviewee? As Clarke (1975) points out in his work on the effects of researching on researchers 'the researcher is his own research instrument and his reactions tell us something of crucial importance about the nature of the phenomena he is studying.' (p. 96)

Punch (1986) argues about the 'in your face' difficulty of doing social research by suggesting that 'both elements, political and ethical, often have to be resolved situationally, even spontaneously, without the chance of armchair reflection.' (p. 13)

He goes on to state 'I believe that most fieldworkers have only the haziest conception of what the philosophical and ethical arguments are and merely wish to immerse themselves blindly in the setting.' (ibid p. 81)

### Interview Postures

The five interview postures presented below are not intended to be exhaustive, but only to illustrate some of the dilemmas facing the interviewer and objections by the interviewee in advance of doing fieldwork. The postures typify the extremes that interviewers tend to assume when working with groups of people with disabilities. I list some of the 'pros' and 'cons' of each posture and then present an integrated posture, which intends to represent a solidarity of approach to the research.

#### 1) 'Just like anybody else':

Disabled people are no different to the rest of the population and should be treated accordingly. Following the principle of social role valorisation; people with disabilities should be treated in as near normal valuing environment as possible. From this they will adjust to society, reaping the benefits of the community they live within.

Pros:

- Based in equality.
- Less risk of patronising the respondents.
- Easier to construct and analyse without the need for 'special' considerations of the populations studied.

Cons:

- May miss issues that are salient to particular populations/individuals. eg. possible histories of abuse suffered by people in long stay hospitals.
- Social role valorisation and its predecessor normalisation have recently been criticised for failing to recognise bias towards ethnocentric views.

## 2) Consideration of 'Special' Qualities:

People with disabilities have unique qualities gained from their experience of having a disability. These factors have to be taken into consideration when interviewing, both in the gaining of information and its interpretation.

Pros:

- Opportunity to define and unpack these 'special' qualities, providing a consistent approach across the particular 'sub-culture' studied.

Cons:

- Tendency to be patronising. 'Special' treatment tends to marginalise people.
- There is a risk of an apartheid approach to respondents.
- How can you say that someone is 'special' in some way; compared to what or to whom? The only homogeneity for people with disabilities may be that they tend to be treated badly as a whole by society.

## 3) Therapeutic:

The interview is with a potentially devalued person. It must therefore be taken seriously that information of a sensitive nature will arise and the best way to receive and frame it is within a therapeutic environment.



Pros:

- Can allow deep analysis of power relationships for the individual within a supportive therapeutic environment.
- Good forum to deal with potential pain and suffering of people.

Cons:

- May not be supportive in the long term. Research naturally has a time limitation, at some point it has to finish and contact between those concerned ends.
- Patronising to believe that people may require a therapeutic set up. Some people's experience of therapy is negative and they may not want to have anything to do with it.
- It is very difficult to define and operationalise what a therapeutic environment actually is.

4) Investigative Journalism:

Single minded pursuit of information. The respondent is just like everyone else and the work is just to get as much relevant information as possible from them. Therefore it is a partisan approach.

Pros:

- Search for information to which the researcher has no ethical problem using and writing up. View that powerful people are trying to suppress information. Its tenacious in its approach.

Cons:

- Sensationalist (libel laws do control them to a certain extent). Can be a sloppy approach. Can be a forum to disregard ethics.

5) Story teller:

People have interesting stories to tell. Its an artistic approach. Makes information more accessible to a wider audience.

Pros:

- Owned by the person. Interested in people whose story is not usually told. Can work within the complexity of peoples lives.

Cons:

- Not a consistent or rigorous method.

Integrated Posture: A consideration of personal stigma within a political climate. The view that the person is an individual within a society which disempowers their particular labelled group. There is a need for elements from all of these approaches and more. The individual must be given the same respect as 'just anyone else' but with considerations for their unique life experience which may have led them to a feeling of stigma. The research design chosen attempts to construct an interview posture that takes account of the 'pros' from the five examples and avoids as far as possible their 'cons'.

- A degree of equality and consistency in the questioning of users of services and workers within a service. Thus avoiding patronising people in the study.
- Case studies by their definition focus on the individual characteristics that may or may not be shared by others. Thus 'special' qualities of the person can be understood and put in the context of a service.
- The design of a case study is led to a certain extent by the person being studied. It is not a forum for therapy but hopefully provides a potentially 'therapeutic' experience for those involved. Discussing the experiences of the person's power relationships can hopefully be a positive experience for them.
- The designing of the prompts and questions has its grounding in the work of social role valorisation and the advocacy movement approaches which are dedicated to the increased valuing of people with disabilities. The design of care plans also contribute to the research design. I view care plans as an opportunity to empower users of services, giving them the opportunity to express their un-met needs, dreams and wishes for the future.
- The researcher does not have a disability so a consideration of being an 'outsider' to the experience of disability is relevant while conducting the interviews and observations.

- Attempts were made to form a non-hierarchical/non-authoritarian relationship with the respondents. This aims to give them a pleasant experience of the research process and a sympathetic/positive opportunity for a conversation. The communication of value is attempted in that it is hoped that all the respondents will feel valued by being involved in the research.
- The researcher will disclose information about himself if asked by the respondent, reciprocity being of value in the research situation.

Johnson (1997) discusses research intervention in relation to observational work and nursing. He refers to nursing research as 'messy' thus requiring a reflective and contextual approach. This is a move away from the hygienic, in that every intervention should be carefully planned approach. Interventions should not only be based in the premise of 'do no harm' but 'do good' (be benevolent). To use a nursing term this means to relieve suffering. He finishes by referring to messy research requiring messy ethics. Johnson (1997) indicates the essential difficulty with a utilitarian approach to doing ethical research. This is in the complexity in predicting the consequences of any action or intervention on the sampled group and to balance out the subsequent costs and benefits involved.

Mullender, Everitt, Hardiker and Littlewood (1993/1994) describe a 'value base' for doing social work research 'which refuses to accept negative labels and recognises instead that all people have skills, understanding and ability. People also have rights including the right to be heard, the right to control their own lives, and the right to choose what kinds of intervention or research enquiry to accept in their lives - as well as the right to define its issues.' (p. 12)

Beresford and Croft (1986) write on what they call the 'hierarchy of credibility' which refers to the weight attached to official, professional and academic versions of events and experiences in contrast to those of people receiving services. Similarly Oakley (1981) highlights the same issue writing from a feminist perspective: 'The mythology of "hygienic" research with its accompanying mystification of the researcher and researched as objective instruments of data production (should) be replaced by the recognition that the personal involvement is more than dangerous bias - it is the condition under which people come to know each other and to admit others to their lives.' (p. 47)

Punch (1986) talks about the false image of smooth idealised research. Which gives the idea of neat, tidy and unproblematic work ignoring the actual pain, stress, openness and confusion of work. This itself should be considered a vital source of data within the confines of the study and for students entering future research.

It is important to consider users' involvement in research. This extends into the issues of involvement of people with disabilities in services and that citizenship. Beresford and Croft (1986) describe an empowering approach to research involving users as partners in, not subjects of, the research.

Schathsheiders (1960) writes 'organisation is the mobilisation of bias'. Therefore to understand what power users experience we need to observe conflict and assess people's real involvement, not a token involvement under professional/expert influence. The recognition of conflict is very important if you are to observe real choice. This is not easy for people with learning disabilities as their services are often designed to avoid conflict. Power in systems is often concerned with not letting conflict arise.

### **7.10 Use of Computers in Qualitative Data Analysis**

Fielding and Lee (1991) write on the use of computers in qualitative research 'The computer, for example, makes it easier to find deviant cases or to extract small but significant pieces of information buried within a larger mass of material. Furthermore, simply by reducing the amount of paper and the extent to which it needs to be shuffled, analytic processes become less unwieldy, more pleasant and less tedious for the analyst. As a result the mechanics of field research should become less likely to get in the way of analytic processes.' (p. 3)

It can be argued that computers gives the researcher more scope to 'play' with the material they compile, this being the vital, creative aspect of the whole process. Computers also take up a lot less space than manual filing systems. This is an attractive asset as I have over sixty separate documents (that is interviews/observations/policy statements) to work with in the analysis.

Computers do encourage researchers to take clear procedures when working, forcing an increased degree of self awareness and justification of action. The use of computers has been described as a methodological revolution. They can handle a vast volume and diversity of data being rigorous in standardization through routine. However, is the involvement of computers in qualitative data analysis supposed to make it more like

quantitative analysis, a more unified approach? Weaver and Atkinson (1994) make a point of celebrating the diversity of non-computer aided approaches available already in qualitative data analysis. Pfoffenberger (1988) argues that computers are not a mechanical tool of a sterile culture, they are developed in a social culture and for a social culture. The Richards (NUD•IST developers in 1994) and other software developers talk of the personal attributes and intuitive approaches they build into their analysis packages. In contrast it has been argued that using computers in this area takes away the craft work of research replacing it with a routine of pushing buttons. Bryman and Burgess (1994) state that '(computers) cannot substitute for the imagination that is a necessary ingredient of analysis.' (p. 221)

Fielding and Lee (1991) write on this subject 'Researchers, and their audiences, will be seduced by the convenience and credibility of the programs rendering of sense. As we celebrate the program's output, and especially its form, we will no longer have an awareness of the process by which this product was brought about.' (p. 8)

Like many innovative techniques the computer can be both an empowering and disempowering process depending on its use. The computer can only be considered a tool in the analysis process. Researchers want to do with computers what they have done manually already; cutting, photocopying and pasting of material into themes and concepts contained within a filing system. There is no combination of function keys you press in the program that runs off a full analysis chapter. Computer's software packages do not do the analysis, the researcher has to do that. One criticism of the potential use of computers in analysis is that they can distance the researcher from the data (text). The researcher gets lost in concept building, losing the original flow and direction of an interview. Many researchers talk of the close 'relationship' they have with their original scripts, how they know them almost off by heart and any computer software package should not be allowed to interfere with this relationship. Fielding and Lee (1991) write on this point 'The researcher must engage in manipulative activities such as locating words or phrases in the text, comparing words with a dictionary of terms representing analysis categories making lists of words and alphabetizing them, adding references information, counting occurrences of words or phrases, making relevant text segments, allocating numeric or mnemonic codes, inserting key words or comments, extracting and assembling topically or thematically related segments, etc.' (p. 25)

Weaver and Atkinson (1994) state that 'More specifically, coding is the strategy whereby data are segmented and tagged according to the researcher's definition of units of meaning, so that those segments which have a common or related meaning can be drawn together in one place for analysis.....it is the efficient retrieval of relevant segments for recontextualization which is the main goal of the coding segments strategy. (p. 31)

Table 13 is adapted from Weaver and Atkinson (1994, p. 43) and shows the areas of coding commonly used:

<b>Table 13 Data Coding</b>		
<b>Theoretical Position of Code</b>	<b>Genre of Code</b>	<b>Example</b>
<b>Abstract/conceptual/general</b>	Thematic, Topic, Cast	Social Control, Gender Individual
<b>Concrete/empirical/specific</b>	Episodic	At one time

Lexical searches, that is word searches, can be useful in checking the validity of coding i.e words that capture the already coded concept. It is very important to spell correctly on line material and be consistent to make these searches effective. Weaver and Atkinson (1994) question the origins of 'hands on' coding and whether a code really exists or is born out of the 'strange and peculiar relationship' between the data and researcher. This refers to the preconceived notions about the data the researcher has already collected or perhaps their basic common sense. They go onto to say, 'If the data are not naturally partitioned into meaningful segments, there may be problems about knowing where to demarcate segments of text or units of analysis.' (p. 32)

Particularly with powerful programs like NUD•IST there is a potential to over code and become confused around multiple coding. There is also the possibility to lose the original context of a segment upon its retrieval. The computer can act as a filing system allowing time and space for the researcher to reflect on the work, but it is important to remember that the computer does not provide the only way to do the analysis.

### Computer Software Packages

Richards and Richards (1994) discussion entitled 'From filing cabinet to computer' describes the development of their program NUD•IST (Nonnumerical Unstructured

Data Indexing Searching and Theorising). They list the enormous diversity and quantity of qualitative data that they had to work with on a project. They stated that 'Bulk records defied sensitive interpretation, and multiple data sources defied co-ordinated analysis.' (p. 147)

They searched for a means to control their data in a quick and efficient way, pointing out that there were very few agreed rules or even routines to qualitative analysis. So they developed and continue to develop NUD•IST. NUD•IST's remit (expanded from Richards and Richards 1994) in essence was to:

- 1) Have no limit on the number of times you could code material.
- 2) Support questions about the relationships of categories.
- 3) Have a memo writing facility to attach emerging theories within the process.
- 4) Have the flexibility to incorporate different types of text both 'online' and 'offline'.
- 5) Have the capability to tag any text used for easy retrieval in various contexts and spreads (headings/subheadings).
- 6) Encourage people to think about data (i.e 'play with it').
- 7) Have some kind of indexing system, a 'tree' to convey facts about background information, data types and the potential for links with statistical data analysis.

NUD•IST was born out of grounded theory and so is a theory building approach not a theory testing one. Bryman and Burgess (1994) suggest that it 'provides relatively few guide-lines when confronted with data.' (p. 6)

They go on to state that grounded theory tends to become a 'bumper sticker' for much qualitative research. It gives credibility where researchers have not thought through what they intend to do. Miles and Weitzman's appendix on 'Choosing computer programs for qualitative data analysis' in Miles and Huberman (1994) is brief but useful. They describe the types of generic programs available in order of sophistication:

- 1) Word Processors.
- 2) Word Retrievers.
- 3) Text base managers.
- 4) Code-and-retrieve programs (put text into coded chunks).
- 5) Theory builders (allow connections to be made between coded chunks).

Miles and Huberman (1994) go onto suggest that potential users of software should look for functions such as user friendliness, coding, memoing, data linking and search and retrieval, data display and theory development facilities. They emphasise the importance of any program being flexible, in that it can handle multiple sources of data

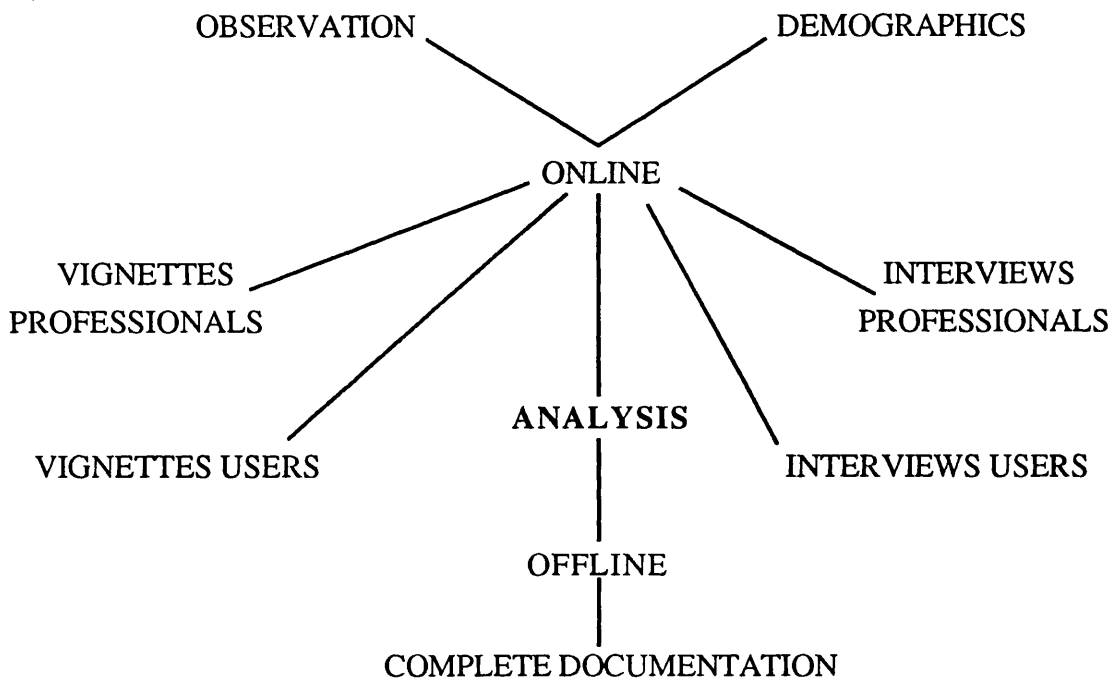
and cases, structured, unstructured and semi-structured data inputs and any size of data set. Miles and Huberman (1994) describe the coding system which is compatible with that offered by NUD•IST:

- 1) Open Coding - breaking down to examine, compare, conceptualise and categorize data.
- 2) Axial Coding - procedures in reconstruction of data, making connections between categories.

NUD•IST fits all of Miles and Huberman's suggested functions and appears to be a powerful tool for theory building in comparison to other programmes such as ETHNOGRAPH and QUALPRO. Silverman (1993) evaluates the available software packages by stating that 'ETHNOGRAPH allows you to code a text into as many as seven different categories. QUALPRO allows text to be broken into still more flexible units and codes. NUD•IST will store information in tree-structured index systems with an unlimited number of categories and highly complex index structures. You can then search your data by these indexes or look for overlap between data indexed under different categories. The NUD•IST program then helps in the generation of new categories and the identification of relationships between existing categories.'(p. 37-38) The tree structure is of particular use to me as I often work using flow diagrams and construct ideas in a visual way. The 'windows type' application on the Apple Macintosh is also very user friendly and this has been improved upon in the later versions of NUD•IST (e.g version 3.0). The data in the research comes from numerous sources both online observations, vignettes and interviews and offline documents such as organisations' policies. The interviews were semi-structured but required in-depth and varied coding. Complex coding was needed to gain insight into comparisons between organisations and individuals within and between these organisations. Programmes like ETHNOGRAPH have a limited coding capacity and no means of theory building. NUD•IST has these, as well as a network display, matrix building facility and a stronger search and retrieval system. Figure 24 demonstrates the relationship between the online and offline documents used in the analysis.

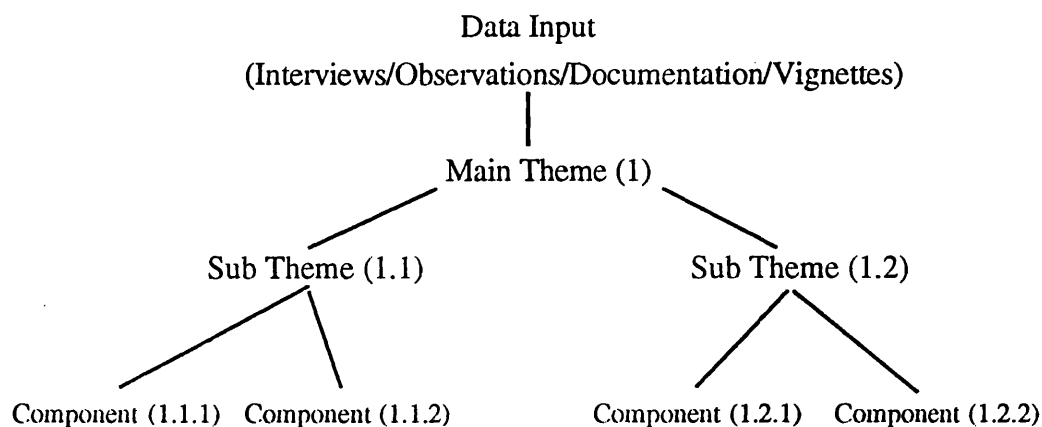


Figure 24



NUD•IST allows the researcher to introduce documents and code them on screen. The branching index system allows logical structuring of code information into a numeric hierarchy of nodes see figure 25. As NUD•IST's principles lie in grounded theory it is an excellent way of 'leveling the playing field' of data collection. Whether a response is made by users or professionals from whatever organisation, they are all coded in the same way. They are all on an equal footing without recourse to any personal bias.

Figure 25



Memos can be attached to the nodes in the tree and text searches can be formulated in a number of different ways and the output from them stored and printed from a Node

Clipboard. Command files can automatically do repetitive tasks such as a series of searches. Finally NUD•IST can search the index system by asking about relationships between categories e.g intersections. The choice of the text unit to be used is vital, a text unit being the smallest section of information that NUD•IST can retrieve. A paragraph may be too extensive and messy to use, whereas a line may be too small to impart a clear context. For this research the answers to any of the questions were not that large, so the whole answers were assigned as text units. For a list of the nodes generated in the analysis see appendix D.

The analysis of all data sources involved each document in turn being open coded on screen. From the first document to the last each text unit of interest was coded and those codes added to node list. This process was independent of the literature review and the original interview questions. Key words and phrases were also added as searches across all the documents to support/validate and add to the evolving codes. All the non-coded text units were examined to check that no coding had been overlooked and saturation of the material had been reached. Next by referring to the node tree and using merge and other facilities on NUD•IST the node trees were reworked as typologies evolved. Nodes containing limited numbers of text units and those perceived as having weak supporting material were removed from the typology. Other nodes were merged as code uniformity developed. At the end of this process a node tree representing strong typologies was left which then could be related back to the original questions set out in the introduction.

### **7.11 Summary**

This chapter has explained the reasoning both theoretical and practical behind the choice of the research design by comparing and evaluating different approaches. A qualitative approach has been chosen constructing case studies by the triangulation of professional and user interviews, vignettes and observations combined with the respective organisations documentation. Interviews are semi-structured in design following a topic guide taken from the researched literature around power and involvement. The discussion has focussed on the ethics of doing research with potentially devalued groups. An integrated posture has been constructed, which involves a consideration of the potential personal stigma within the service that the respondents may experience. The view is that the person is an individual within a societal situation which may disempower their particular labelled group. A non-hierarchical/non-authoritarian relationship with the respondents aims to give them a pleasant experience of the research process by utilising a sympathetic/positive opportunity for contact. Finally the

foundations of research analysis has been discussed concentrating on the use of a specific computer software package: Q.S.R. NUD•IST Power version, revision 3.0.4 GUI for the Apple Mackintosh.

In the next two chapters both qualitative and limited quantitative sources of data form a case study of power for users within the organisations studied. The ideas and themes explored are derived from the free coding of data: observations, interviews, vignettes, documentation and the extra notes compiled. The analysis makes reference to documentation produced by each organisation. The document in its entirety is held offline (not on the computer). A summary of the document is held in NUD•IST online (on the computer) where it is coded. There may also be reference to extra notes (which are dated) recorded by the researcher during the course of the study. These sources combine, contrast, validate, contradict in the triangulation case study design used. The interspersed quotes and extracts utilised in the analysis are true to the original recorded material, providing the reader with a direct link with a means of verifying the validity of the analysis. Using the principles of grounded theory the data predicts the main themes, sub themes and components that form the final analysis. The research also takes consideration of the following issues:

- Any inherent conflicts in data, for example between documented policy objectives of organisations and observations taken.
- The differences and similarities in the organisations' styles of working.
- The representative nature of any points made.
- The differences and similarities in experience and approaches to types of disability.

At the beginning of each section of the analysis a tree diagram (figure 25) adapted from NUD•IST maps out the themes and issues to be explored. The top level shows the sources of data leading down to the main, sub and components themes. It also illustrates the interrelationship between these themes.

Key to abbreviations used with quotations:

**C M** - Care Management

**D C** - Day Centre

**R C** - Residential Consortium (1/2/3 - Organisations)

**P** - Professional

**U** - User

**V** - Vignette

**O** - Observation

**I** - Interview

**D** - Documentation

**Numbers** refer to the individual interviews

## **8 DISABILITY AND RESPECT: Disabled People's Experience of Quality of Life within the Organisations**

This chapter explores the quality of life in terms of respect and disability experienced by disabled people within the three organisations studied. The main question to be addressed is how people with disabilities make sense and interpret their feelings of power. This is based on the assumption that people with disabilities have unique knowledge about services and disability, providing them with a core understanding of power around decision making and its effects. Therefore the nature of the relationship between the user of services and the worker is a major focus of the study. This inter-relationship (style of working and receiving services) is assumed to be the primary experience and expression of power for both individuals. This chapter includes both broad analysis of value and disability as well as more precise issues of personal identity, labelling and stigma experienced by a person with a disability. It is difficult to abstractly identify, define and measure such concepts, therefore the research looks at the issues of user involvement, power and identity in greater depth by focusing on the views and actual experiences of people with disabilities. What emerges is a description of the cultural regimes and routines of services which affect the quality of life and sense of power experienced by people with disabilities.

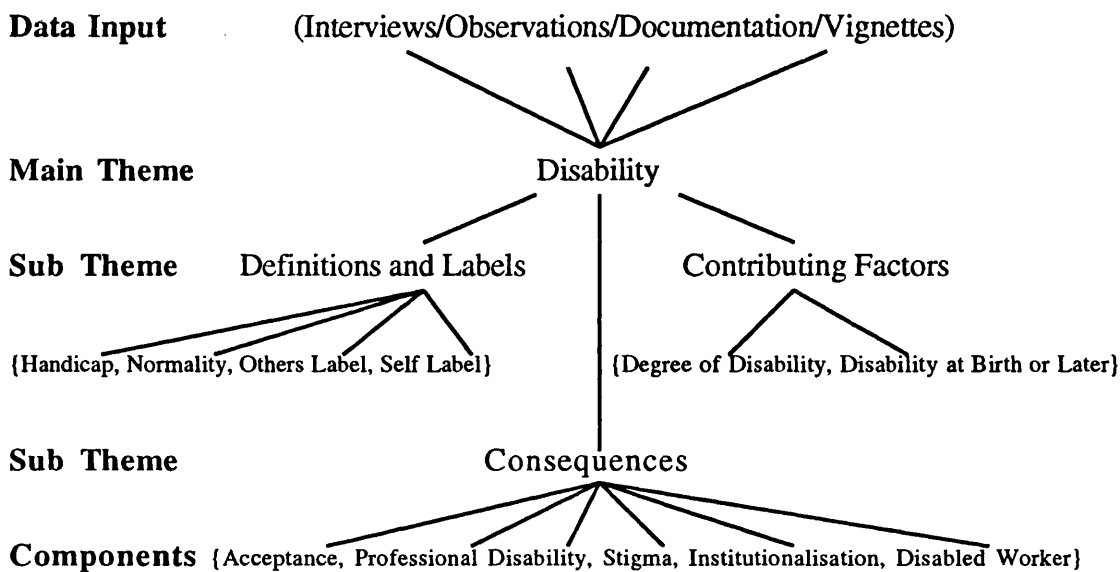
The first main theme considered is that of 'disability'. A number of general questions are asked of the data. What are the views held by professionals and users contributing to a sense of disability? Do the users of services consider themselves disabled and if they do what constitutes this 'disability'? How does being disabled affect the quality of their lives and their sense of power and control over their experience of the services they receive? How do the different organisations view disability?

The second main theme is that of 'Respect', that is what are the constituents of respect and do disabled people feel respected within the organisation studied? Do professionals work in a respectful way?

The following tree diagram (figure 26) developed from NUD•IST shows the structure of the themes and corresponding components of disability. Each aspect of this figure is unpacked and explained in detail in the text that follows.

## 8.1 DISABILITY

Figure 26



The recorded data showed that disability as a main theme was constructed from three sub themes; Definitions and Labels, Contributing Factors and Consequences. These sub themes are in turn constructed from the following components.

### 8.1.1 Definitions and Labels

One emerging theme from the free coding was the use of different terms to describe the users of services. The language and the use of labels around learning difficulties do not present a universal concept. Labelling by its very nature is relative to context, schooling, expectations and the attitudes of society as a whole. The labels used can act to disempower or empower people by creating or reinforcing social roles which in turn may led to stereotyping and stigma.

#### **Disability and Handicap**

Documentation in the day centre refers to mental handicap and not learning disabilities. Of all the organisations the day centre uses the most outdated language in its written policies.

'SOCIAL EDUCATION CENTRE (SEC): The document: Definition of mental handicap, aims of SEC, definition of client group, staff structure.....'  
D C Documentation.

Table 14 shows the number of times each phrase/term is mentioned in the recorded interviews, documents and vignettes. Mental handicap as a term is not generally as

commonly used as learning difficulties/disabilities. This supports the general shift in language within the services as a whole. Disability is used extensively within the care management organisation, understandable as it is set up for people with physical disabilities, whereas handicap as a term is comparatively rare. There may be a heightened awareness of the role of labels and a more progressive use of languages where the workers themselves have a disability. People with physical disabilities may have a stronger sense of identity due in part to a relatively lower sense of attached stigma. Learning difficulties/disabilities is referred to only once within the day centre, handicap is a more preferred term. 'Trainee' was a term used only within the day centre due to its educational context. 'Resident' was used primarily within the residential consortium due to its housing context. 'Customer' and client were almost never referred to by the subject groups. Finally 'user' was a term preferred by the services for people with learning disabilities (day centre, residential consortium) not physical disabilities (care management).

<b>Table 14 Frequency of defining terms used in each organisation</b>			
<b>Use of labels/term:</b>	<b>Day Centre</b>	<b>Residential Consortium</b>	<b>Care Management</b>
Mental Handicap	1	1	1
Learning Difficulties/Disabilities	1	18	0
Disability/Disabled	10	15	61
Handicap/Handicapped	8	6	4
Trainee	2	0	0
Resident	1	8	0
Client	4	26	4
Customer	0	0	0
Consumer	1	0	0
User	19	15	5
Each count refers to a document containing the referenced to term.			

Users of services were asked if they felt they had a disability and how they would describe this disability. Table 15 shows the responses to this question for each of the organisations studied. Users of the day centre were most reluctant to refer to themselves as having a disability. Whereas users of the care management organisation without exception referred to themselves as having a disability.

Disability	Day Centre	Residential Consortium	Care Management
Yes	1	5	9
No	4	3	0
No Comment	4	1	0
Totals	9	9	9

Two of the users with learning disabilities clearly stated that they were not disabled.

8) d) 'No. Not got schizophrenia any more. Was not handicapped. I have not got a learning difficulty either.' R C Interview (1) U I 2.

There was an asserted desire by two users with a learning difficulty to be seen as 'just like everyone else'.

10) c) 'I am the same as everyone else.' D C Interview U I 2.

This last statement is one of intention: Power seems to derive from social acceptance and social anonymity. Disability appears to be reportedly a thing that makes you different. One user did not understand what was meant by handicap, only having an understanding of it in terms of rejection. Handicap was seen by these users as a socially disempowering state. The context here is one of rejection and penalisation based upon a negatively perceived label.

2) c) '14 years before I was in a school. Day centre is better than the school, too much for me at school, school has handicapped people. I am handicapped don't know what that means except my mum does not want me to be at home. I had to pack up and leave.' D C Interview U I 7.

One user of the care management organisation draws the distinction between handicap and disability. She sees handicap as a negative consequence of a 'naive' uneducated view of the world. This is illustrated by her comments about her neighbour.

2) b) 'Other things can be more of a handicap than the disability, talked to a women in her 20s who has no education about Cerebral Palsy. I have to tell her about money, sex and everything. I could spend everyday with her but I have my own life, it makes me angry, that she is so unprepared for it all.'

CM Interview U I 3.

The question here is, whose role is it to educate this young woman; parents, friends or the schools? The type of education described here is a kind of 'streetwise disability approach' that has issues around access, sexuality and making the most of the systems available to her. This education, in a social constructionist framework would prevent the disability from becoming a handicap. It is reported that handicap and disability are described and valued in terms of their physical and mental characteristics. Table 16 shows the number of users who defined disability as a general mental or physical state:

<u>Disability</u>	<u>Day Centre</u>	<u>Residential Consortium</u>	<u>Care Management</u>
Physical State	4	4	9
Mental State	0	2	0
No Comment	5	3	0
Totals	9	9	9

All of the users of the care management organisation stated that they had a physical disability and predominantly described it in terms of 'Pain' (3 from 9) and 'Inconvenience' (3 from 9). Generally more users with a learning disability associate disability in terms of its physical state, particularly in relation to walking:

8) d) 'Sometimes I lose my balance. I have no handicap.' DC Interview U I 2.

8) d) 'Born with a handicap. I can't speak properly.' RC Interview (1) U I 3.

8) d) 'I am disabled when I was a baby in her (mothers) tummy I was disabled. I am disabled but I am a good walker I do not have a wheelchair, I do things by myself.' RC Interview (1) U I 1.

The exception was one user who defined handicap as a mental state by stating:

8) d) 'Handicapped - I am a bit slow in my head as I was born with yellow jaundice. I was a bit slow in lessons at school so they put me in a handicapped school. I can't read much or do proper writing.' RC Interview (3) U I 1.



Having a mentally based disability is perhaps viewed with more stigma than one physically based. This is supported by the attempts of some physically disabled pressure groups to distance themselves from groups representing people with learning disabilities.

Interestingly one professional's view of disability was seen as a lack of ability on behalf of the professional not the person labelled with a disability. The professional's challenge was therefore to find the best way to communicate with the person with a disability not the other way around.

4) a) 'Their disability I look upon it as just a difficulty that I have to explain things in certain ways. It just takes a different member of staff to get through to them.' R C Interview (2) P I 1.

The same professional went on to stress the capabilities and not inabilities of the users she works with. This was described in a personal way:

4) b) 'Learning disabilities need a little support, sometimes I see them as intelligent - they also have amazing memories 'it was cold the week I went into hospital.' (sixty years earlier) It's a different meaning of intelligence it's not memory it's a lack of education, they are not globally stupid.'  
R C Interview (2) P I 3.

She appears to be saying that having a learning disability does not mean that you function with a low common denominator of intelligence under all circumstances, but have both weak and strong areas like the rest of the population.

### **Normality**

The construction of parameters around what is 'normal' or 'ordinary' in service design are notoriously difficult. To create ordinary living by so called normalising service structures has been supported for many years by the independent living movement and other pressure groups. 'Normality' is presented by the care management organisation as their working philosophy.

'The CM Model of Work. 'Disability is a normal fact of life' - Rights of self determination, choice, taking risks and equality.' C M Documentation.

The disabled worker (see section 8.1.3) is reported within this organisation as having a greater understanding of the issues due to the fact they themselves are 'not normal'.

3) d) 'Normal people don't understand you 100% like they do. But a worker (disabled) does. You have to be in the same situation to understand.'  
C M Interview U I 1.

This statement frames disability as a shared belief system, a unique experience. This in turn has implications for the research as the researcher is not disabled, but has attempted to find a way of exploring this 'unique experience'. One of the day centre's policy documents states its aim is to treat people in a 'normal way'.

Aims of the Special Education Unit: '2) To respect each person's dignity as a human being and an adult in all areas of activities relating to them in a manner which is as normalised as possible.' D C Documentation.

'Normalised' in itself is a term worth unpacking, particularly given that it is not in everyday usage. We don't naturally talk about normalising people, we talk about support, encouragement and getting involved with people. Terms such as these tend to underline the individual's sense of powerlessness, things being done to them not with them. The separatist nature of specialist language denies the natural versions of support available in the person's world. The day centre cannot be considered an ordinary/normal environment. This therefore makes attempts at 'normalising' treatment difficult. Professionals in the day centre find it difficult to react in an ordinary or normal way to approaches by users, as the levels of stimulation such as noise and other activities in the centre are so intense. This overloads the senses and makes attending to all the user requests difficult. One option for professionals is to develop a filtering system where they only attend to certain stimuli. Requests for attention are therefore prioritised and dealt with in accordance with judged need. This was unique to the day centre setting.

10.30 COMMENT: 'Shouting at centre - cannot react in normal way because there is so much of it. Some kind of filter system going on here.'  
D C Observations 2.

A distinction by staff must be made between a common place shout and a scream warranting immediate attention. In return users may develop strategies to gain and compete for needed attention from staff: persistent requests or challenging behaviours are some of the ways to achieve this if communication is frustrated. The residential consortium and care management organisations, compared to the day centre, function within more 'normal' environments. They are not services based on congregation or segregation, they are based around the users' own homes with varying levels of support. These homes may be adapted and/or contain members of staff but they are not significantly different to 'ordinary' homes. Is it the professionals' role to model what might be termed 'normal' behaviour? The problem with such an approach, is what constitutes 'normal behaviour'? For instance a person could treat someone normally with no respect, or abnormally with a lot of respect. There is no universal measure of normality to refer to, it is culture and person specific.

Policy - Users. Holiday Policy - 'The project recognises that as part of a valued life, people with learning difficulties should have the same opportunities as other members of the community, including the chance to go on holiday.....1: Clients will be encouraged to book holidays - the 'normal' way, through travel agents, where appropriate.' R C Documents (1).

The last phrase 'where appropriate' could itself be considered a get out clause, in that 'appropriate' is undefined. It is unclear what is meant by treating people in a normal way. One professional attempts to describe it as to:

1) a) 'Live as normal life as possible in the community, you get benefits - support if possible. They (users) often came from group homes - so this is the final stage of independence. 'Normal' - who sets standards we have a range of clients with different skills. Let them set standards of living as they see fit. My home can be untidy. All their homes lives should not be the same. If in a shared home they have responsibility to clear up. There are so many different life styles.' R C Interview (1) P I 2.

Normality here is not being the same, but having equal opportunities. Whether these opportunities are acted upon is a separate, more personal issue. An issue around so called living in the 'real world' is a repeated theme by professionals in their descriptions of the behaviour of users in the residential consortium. The question arises: is treating people with respect being seen as treating them normally? In turn, does this mean treating someone the same as everyone else? This is interesting, as it was stated, with assertion, by a user with a learning disability earlier in this section. The professional approach has both a positive and negative side; a stated aim to treat users as they would anyone (hopefully with respect) but not with specific regard for their disability is confusing. Here there appears to be a difference between equality and equity. Are disabled people treated as the same as everyone else or with special consideration?

2) a) 'Honest as possible, try not to hide anything or make allowances for someone with learning disabilities, mental health problems. You are a support worker - sometimes treated like shit in someone's home. I say how I feel, don't shout at me I am a human being. In one way we are safe targets, outside in the real world they will be in trouble. They have limited social contact so they learn a lot from support workers. So if you are like a robot they will learn nothing.' R C Interview (1) P I 2.

The worker sees themselves as a role model who will put up with more than people in the 'real world'.

1) a) 'Sometimes I would say 'shut up' it's not disrespectful I would say it to anyone. I don't think using every day the five accomplishments is natural. Normalisation, she has more of a 'normal life' than others. Although I am paid to be here, I like her.' R C Interview (3) P I 1.

1) b) 'Nothing is written in tablets of stone - management is common sense, but if you were hit in the street you would pummel them back.'  
D C Interview P I 7.

Normal here is again seen as treating people with learning disabilities like anyone else and viewed as empowering even if they tell a user to 'shut up'. This being part of an educational system to prepare users for the emotional knocks of the 'real world'. This statement also clearly shows the classic misunderstanding of Normalisation as an attempt to make people normal, when in practice it is a philosophy about giving people socially valued opportunities in the community. In a wider context if someone with a learning disability becomes violent or challenging in some way, how are they treated normally? Does the organisation call the police or hit them back? Professionals may tend to use the normalising argument in a situationally specific way, thus justifying action from an interventionist, specialist position or alternatively allowing things to happen 'normally'. This has been evident from a number of previous extracts in this section.

'If I am in a group of five people and one of them is upsetting the group I would tell them to shut up. Treating people normally - if they hit you I would not hit them (like if you were in a pub) but it's not normal to ignore it. They have to learn to be in the real world. Parents go against treating them like an adult. If mum wants to give us a message she sews a note to the outside of his jacket.'  
D C Interview P I 8.

A day centre worker also refers to this 'real world' idea. There appears to be no deep analysis and awareness amongst staff interviewed in the role modelling they perform and the solidarity of their approach. In other words what are they modelling and why? There is a conflict here between the behaviour of the workers and the structure of the environment. The workers model and encourage normal behaviour, but with the provision of separate services and segregated living, only with other disabled people, abnormal behaviour is reinforced.

### **Others-Labels**

One professional working in the care management organisation stated that their aim was to reduce what they termed as 'nameosity' or labelling for people with disabilities. This would hopefully reduce the likelihood of a stereotype growing and its possibly deviant consequences.

'1) a) Not just being heard but what they are meaning. Reduction of nameosity/enabling people to have a dialogue.' C M Interview P I 2.

This emphasizes the importance of engaging in dialogue which is politically motivated towards changing the situations of people with disabilities.

'2) a) Own experience - to understand what it means to be in a position of using services - disempowered, discrimination against - because you have a certain label attached.' C M Interview P I 2.

One user of the care management organisation expressed an awareness and fear of getting what they term a 'difficult client' label (within social services). There appears to be a penalty attached to such a label in terms of the quality, speed and effectiveness of the service subsequently offered.

'8) b) Boring fighting all the time. I used to think if I made too much of a stink I would lose my carer. But I don't think I will get a difficult client label, being rude not right, you need to become detached to get what you want.'  
C M Interview U I 3.

What the user is advocating is a particular posture or approach to dealing with services to ensure that they get what they need and want, without incurring penalties such as losing carer time. A professional highlighted the use of degrading hierarchy labels for people with learning disabilities coming out of long stay hospital.

'5) d) Low grade and high grade like in a prison.' R C Interview (2) P I 1.

Another professional in the same organisation points out the continuing consequences of such labels.

'1) c) User X was a higher grade than user Y who is a low grade (in the hospital). That influence still goes on. User X ignores Y if another (User Z) high grade is around. It has improved enormously. User Y had angina, because of this problem everyone changed their view of him. They learnt to care about him individually not jointly. High grades are encouraged in the hospital to care for (bath/feed/dress/support) the low grades.' R C Interview (2) P I 2.

This gives insight into the social construction of institutional life and its continuing existence and influence in the community; users continuing to assume such labels in new environments. A third professional in the organisation indicates that users of services should be referred to as 'people'. Then she goes on to refer to them collectively as 'men'. This seems to be a neutralising collective term for the users of services. In this context it is used with genuine affection but it can be viewed in a benevolently nullifying way.

'1) a) 'Tenant', 'client,' 'service user' should be called just people. Allowing clients to do what they want to do.'

'3) a) Works well. Office being here - 'men' don't mind, they get visitors, phone does not stop ringing. They would miss it. They miss me if I am not here.' R C Interview (2) P I 3.

It appears from this extract that any collective term for this group of users has a potentially negative consequence. The term 'men' is a homogenous, generic reference which reports to give the collective view of all the users of the service. It denies the individuality of these people. The use of collective terms with devalued groups unless it is accompanied by active respect, tends to lead to this.

### **Self-Label**

The labels that users of services apply to themselves appear to be often based in humour. There is perhaps a desire here for irony and an attempt to reclaim the words that have been used by the non-disabled as insults and also an attempt to avoid any attached stigma. The following extracts appear to use self labels as irony, justification for non-action and to demonstrate fear.

'1) c) Education system needs to be improved for 'crips' (people with physical disabilities).' C M Interview U I 3.

'11.00 Bloke down the road saying stupid things, people playing videos all day - its OK for me to do it, well I'm a 'raspberry ripple'.' (Slang for cripple).

'01.00 Went passed a residential unit for people with disabilities - its where the 'poor crips' who can't get individual living arrangements end up.'

C M Observations.

One user puts the use of these words into a political context:

'1) a) Cripple, queer, reclaimed by two movements. Political correct for disabled people to use these words but not OK for able bodied 'Crip with a Chip', 'Pis on Pity'. I am quite balanced 'I have a chip on both shoulders'. I use these words as I'm politically active, I see myself as a disabled person first, not a queer cripple.' R C Interview (3) U I 3.

The anchor point or main self label for this person is his disability, over sexuality or any other defining characteristic. Gay activists organisations like Stonewall have attempted to reclaim words like queer. As a political statement movements for disability rights have also attempted to reclaim words like cripple (see also section 8.2.2 on sense of humour). Redefining terms and phrases this way could be seen as a sign of the progressive nature of an activist organisation. This reclaiming of phrases predominantly comes from people with physical disabilities and not yet people with learning disabilities. This could be due to the relatively underdeveloped nature of these organisations. The future may bring a more politicised movement of people with learning disabilities where self-labelling is more proactive and political in consequence.

## 8.1.2 Contributing Factors

### **Degree of Disability**

Some people with mild learning disabilities are encouraged by staff to take up 'helper roles' within the day centre. They receive a semi-staff status and a degree of power/value that goes with it. This type of structure evolves more easily in the day centre with its semi-institutional context.

'Conversations. Senior: Within each group people with different needs. Special needs - integration into main group. We like to include a 'helper' who is more able bodied to help out.' D C Extra Notes.

An examination of the costs and benefits bestowed by these roles is relevant. The staff may get a sense of control and power by the overseeing of these semi-staff members. Users may want the sense of worth and fulfillment attached to helping out and being perceived as socially valued to staff members. It is unclear whether users are valued for this role or they are being exploited by the system, or perhaps a combination of both.

12.00 14/10/94. 'A game of hockey has just finished the teacher walks off out of sports hall. One person (user) collects sticks, one person collects shirts, one person takes the people using wheelchairs out of the hall.' D C Extra Notes.

The day centre services for people with more severe learning disabilities are reportedly worse than for more able users.

'1) a) Improve people's life skills: some people get a reasonable service and some people get a poor service. For the less able they get a poorer service (lousy) the place is too big for them.' D C Interview P I 4.

Firstly the implication here is that the larger the unit the harder it is to give users with more severe disabilities a quality service.

'People with more severe disabilities get less choice. They get more of what we think they need, because of the communication problem. What we know they like, help them, stimulate them, decide that's the right thing (not our fault). He ..... (user) can't sit down and talk it through but he likes going out so he has a programme so he is channelled into these areas. He will just look at you and say mummy. Take experience to put them in right programme.'  
D C Vignette P V 6.

Secondly communication appears to be harder in the day centre when working with people with more severe learning disabilities. It appears that within the day centre it is acceptable for people with more severe disabilities to have less choice and subsequently less power, it is easier to make decisions for them.

## **Disabled at Birth or Later**

From two users' accounts of the care management service it is clear that there is a difference in terms of outlook between people who are born disabled and those who become disabled in later life. Becoming disabled in later life is seen as more distressing, as this group can make a comparison to being previously able bodied.

'3) d) Also it depends on whether you are disabled at birth or not. These people need different treatment. I was lucky because I was disabled as a youngster. Attitudes of being disabled depend on when it happens.' C M Interview U I 3.

'8) d) Two types of disability - born with it or happens to you (like me) you know the other side. Always thinking that something might happen to you.'  
C M Interview U I 5.

One professional states that those people who are born disabled tend to be treated as children all their lives, being trained into a role of accepting what they get in the way of services and never experiencing and learning from anything to the contrary.

'1) c) Acquired disability: this is what you can't do etc. People cut off from who and where they were before, ambitions are lost. Born disabled - infanticide by the system.' C M Interview P I 2.

This training could be viewed as part of becoming a 'professionally disabled person', a socialisation into the role of being disabled, part of an indoctrination into the overriding role of being a disabled person.

### **8.1.3 Consequences of Disability**

#### **Acceptance**

One disabled person spoke of not being accepted as being disabled due to him not visibly appearing disabled e.g not being in a wheelchair. The implication is that in order to gain power you need to have the accepted image of a disabled person.

'2) c) Free bus pass (More than just movement A to B it's about social world and easier than using money), she said I don't look disabled. She would not give me a pass. Had to ring the hospital. So I am disabled. I should die in four years.' C M Interview U I 4.

One user showed a resentment that another user might feel happy because of becoming disabled.

'8) d) At the C M annual general meeting someone said I am happy I am disabled - her home and husband were found through her disability, it's like saying I am glad I have lost an arm, I would like my health back.'  
C M Interview U I 6.



This highlights a difficulty for the political movement of disabled people. Disabled people may see their disability as a genuine problem not something to be celebrated. This contrasts with the black pressure movement, who see the social advantage of being white but without the desire to be white. Disabled people may wish to be able bodied, or they may not. Some activists in the user movement do see their positions as better due to their disability. Their identities are wrapped in the disability and they see it as integral to their sense of self. Another user describes the process of accepting pain.

'1) a) I can't not get into the building because I am in a chair but because there are steps. Quality of life? if you are born in a refugee camp where there is more of a chance of you having a disability than here would you kill the baby. Pain there are days I cannot move - feels like I am having nails bashed into me. Skin all over me hurts. You learn to live with it, when I was 13 I thought everyone was in pain.' R C Interview (3) U I 3.

This shows how someone can grow up with the disability of intense pain without realising it, it being very private in nature. A person's self-concept will contain the pain as normal without an external reference, an active acceptance of hardship through lack of this reference point.

### **Professional Disability**

Two people one a professional and one a user, spoke of 'professional disability'. The disabled person is seen as challenging other disabled people through acquisition of a particular role.

'1) c) I'm supposed to be owed something for being disabled - compensation - not to work as hard. Professional disability - A women I worked with wanted personal servants - home care support. Service was having to provide more and more services.' C M Interview P I 2.

'03.45 Woman at number 10 is a professionally disabled person. You ask her how she is everything is 'poor me', I feel like slapping her. After 6 months she suddenly decided to stop walking she can use both arms but can't make a cup of tea. People see someone is in a wheelchair and don't question what they can do or can't do.' C M Observations.

These quotes illustrate how disabled people can take on the role of being disabled to such an extent that they are seen as 'professionally disabled'. This role bestows power on the person; they have a better chance of gaining adequate or good service response. People around are encouraged to give a high level of care to the individual. Status and control is acquired through acting the role out. The cost is the negative reaction by the worker and other disabled people. By acquiring what appears to be a manipulative stereotyped role more acceptable to a wider society, they are seen as having 'sold out'. The worker may feel like a personal servant, is that what they are being paid to do? The professional role as indicated earlier does appear to contain an element of respect

and reciprocity in terms of its construction as a personal relationship. The professionally disabled person takes up a position of passive power, a learned helplessness which pays off as they get help from others on their terms. In so doing they perpetuate the stereotype of 'helpless' disabled people. Primarily people are disabled, but a secondary role can appear in the form of the professionally disabled person, a full time occupation and an overriding identification.

### **Stigma**

Users talk of fighting and confronting stigma. They talk of not being able to take on the full role of a member of the general public due to the stigma that can accompany the disability.

'3) g) A lot of disabled people cannot use public transport e.g stairs in the underground. I am a member of the public I can not use parking spaces. I had lost everything I was a mother/wife/person because of the disability. The underground is not a disabled world. I am sick and tired of fighting for parking spaces and having to come home. Problem with getting to interviews - car orientated world. The minister of disabilities should be fired as he does not have a disability. Why do I have to rely on you for help? It makes me angry! Disability is not an 'alien' condition it is just the obstruction to the way you do things.' C M Interview U I 7.

Disability is seen as having the potential to induce stigma which limits the ability of the person to be an active citizen, an alien, being as far removed from the general public as possible. Disability is seen as a role that engulfs all other valued roles. Here is a working definition of disability which is born out of the pressure of external situations and not internal ones. There is also an issue about challenging the image (the alien condition) that leads to stigma. On this subject one user from the care management organisation comments.

'03.45 I like to look a bit different, the other wheelchair looks better. I don't want stickers on the outside of the chair advertising some company, they might be crap. Might complain where the stickers are when they came around to service it, who cares?! C M Observations.

1) b) Used to go swimming but need support - with nothing to hold on to. Will not use zimmer frame - it's a bad image.' C M Interview U I 7.

The first extract here shows an expression of distinct individualism contrasting with the collective projecting image of the wheelchair. Workers also make attempts to counteract stereotyped images of disabled people.

'1) d) He was typical Down's Syndrome they dressed him too short, shoes too big. I was his keyworker. Got him clothes and new shoes. His actual shoe size was child's 3 and half they gave him an adults 7. I looked upon him as a brother (treated him like one) with Downs' Syndrome. I would not let him get away with things breaking his glasses as he would have none for a while.'

R C Interview (3) P I 2.

This represents a caring, benevolent but perhaps paternalistic approach to the man in question. Regarding someone as a member of your own family is a strong philosophy of working relationship's. Families can be caring and supportive but also controlling and incestuous. This empathetic effect of the stigma within a social situation has benefits and costs to those concerned.

'3.35 I took one user to the bingo and the old people move away from him, after a while they had a separate chair for him. I could not watch this happen even though he enjoyed it - so we stopped going.' R C (2) Observations.

This professional reported feeling stigma and rejection on behalf of a user. Stigma reportedly occurred at the college used by two day centre users. It was recorded as two of the main reasons for non-attendance of the college.

'Reasons for not going to college: 5) Stigma of having a learning disability at college. 6) Stigma of going to sports days not seen as able bodied - separate classes in college for people with learning disabilities.' D C Extra Notes.

'We cannot make her do something. Why do people want her to go to college; secure, safe, use to it, some people say there is a stigma with it. People get pushed and laughed at in the college.' D C Vignette P V 5.

The following extract shows the uncomfortable nature of stigma felt by a person with learning disabilities at college. Participation in disability games is seen as being devaluing, and disempowering. There is an acute awareness of the false value of the prizes involved. Competing is about winning and losing. Without this distinction the taking part becomes pointless for some users. The right to fail is ignored here as people are disempowered by never losing.

'1) a) At college the majority of people don't mix in classes and they have company at lunch. It's not real mixing, they are segmented. It's false - sports not winner but the effort that gets rewarded sometimes even random winners (observation extra notes). Supposedly treating people like adults but prize might be a teddy bear.' D C Interview P I 8.

Practical examples of stigma were recorded as:

'11.25 Another user worked in a pub for five years. Money went missing and they blamed him. They found it in the end. He did not want to go back after being accused of it. They may have done it to take advantage of him as he came from the hospital. They think you are soft soap.' R C (2) Observations.

'8) d) Some people on the street calling me names like fatso. My neighbour came out and said leave him alone he is my neighbour and they apologised and made friends. (Disabled fatso, fat monkey and eat like a pig). If a member of their family had a disability I would say it to them and see how they felt.'  
R C Interview (1) U I 1.

These two extracts highlight that people with learning disabilities are seen as an easy target for disempowering/oppressing attacks by some people in their neighbourhoods.

### **Institutionalisation**

One professional at the day centre referred to himself becoming institutionalised.

'5) a) I do find it difficult to be in a big staff team it's nice just to be in my room. Sometimes I get a bit institutionalised in a big group - pick up bad habits, staff culture, the more you hang out in the staff group the more you take the mick out of someone with learning disabilities if they enter the room. We are more powerful. Talk down to people with learning disabilities. Boss them around see them as problems. Take out our own problems on them. These is pressure to socialise with staff not users. Want to get on at expense of users. e.g Play sport with staff, get bored with playing with users.'  
D C Interview P I 5.

Another effect that institutionalisation has on the staff is also worthy of note. Staff appear to get a kind of dependency on the levels of attention from users. The reasons why people work in this area are varied, but can be explained in terms of a 'need to be needed'. This is a clear indication of what workers get out of working in this area.

'2) d) Yes I am lucky having two excellent managers encouraging me to find my own feet. We talk about empowering clients and not empowering staff to find their own way of working. As a worker you got all the focus of attention then when shifts change clients have someone new to tell all the new things to. It is a shock from being needed to suddenly not be needed. It dates back to institutional life. Took me a long time to deal with that. Not bad as you can get too close. It's the clients way of protecting themselves - clients are disposable.' R C Interview (2) P I 2.

Institutionalisation was more commonly being spoken about in the residential consortium than other organisations. Users of the residential consortium have often moved from long term care institutions.

'10.45 (User) hoovering the flat at the request of worker. Worker says that (User) is not as institutionalised as other clients, she lived at home until she was 20 years old. Her relations had a baby and she was really jealous at first its been two years now it can't do wrong. She has realised that she is not the centre of attention and it has done her some good. A bit like some husbands. Phone call from office - organise rota, check everything's OK. I'm all over the place today 2 hours in the office then I am coming back, well its splits the day up.' (User) knows quite a lot of people who work on the market, its a great market - great activity.' R C (3) Observations.

Institutionalisation is also described as having an action upon the person with a learning disability. The following extract shows the legacy of such institutionalisation.

'1) f) She says she is much happier here. Same bath water between 12 people is inhuman (in the institution). She is intelligent enough to say she wants something else but cheese sandwiches for lunch or make tea and put milk and sugar in the pot. Some clients can't get away from this.'

'2) c) User will not leave stuff in bathroom even if she is the only one here. Could not do it in the hospital.' R C Interview (3) P I 1.

## **Disabled Workers**

The care management organisation predominantly employs disabled workers. This section explores the effect that this has on the power and quality of service received by the users. The philosophy behind having disabled workers in the care management organisation is as follows:

'1) c) Flexible and responsive to service user in a real, not tokenistic way. Change because - recruiting people with disabilities from a non-social work background, changed the values/practice of the organisations.'

C M Interview P I 1.

The active avoidance of employing workers from a social work (qualification) background implies a recognition of professional prejudice of some kind.

'2) a) Important qualities - attitude to service user and empowerment, insight into what advocacy as a tool is, skills of: communication, prioritise work, relate to a range of people. Target people who have experience of using services build on empathy. In the last recruitment we employed 1 out of 3 disabled people. Being disabled does not mean you are automatically a good advocate. It is an important but not vital part.' C M Interview P I 1.

The valuing of personal experience is high within the care management organisation. The professionals here have a disability and have experienced being devalued themselves.

'2) d) I hopefully have an insight into the concept of power, personally I am very egalitarian, worker potential should be developed and used to their full in a team based approach. I have a danger of undervaluing my own experience as a service user. Psychology of being told that my experience is not of value.'

C M Interview P I 1.

Every user interviewed within the care management organisation (9 out of a possible 9) saw having disabled workers as a positive aspect of the service. Users views on having a disabled worker were:

'3) d) They understand so they are the best to do it. That is why they care a lot. Normal people don't understand you 100% like they do. But CMP2 does. You have to be in the same situation to understand.' C M Interview U I 1.

The experience to care and the experience to understand are very closely linked in these extracts.

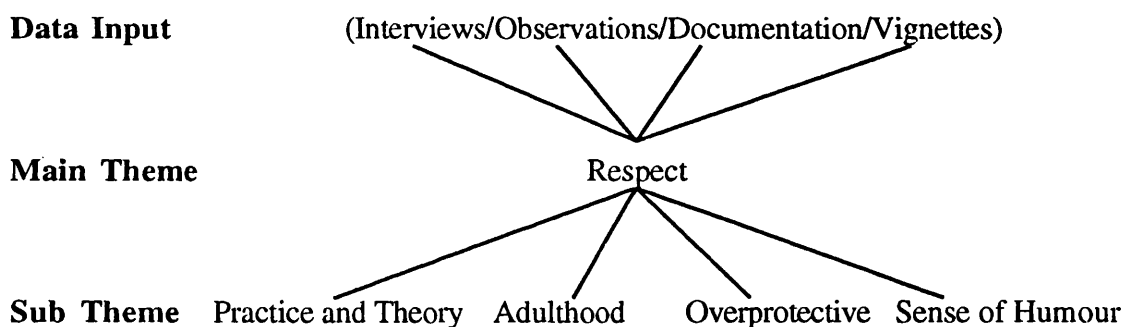
'3) d) He is in a chair (worker uses a wheelchair), he understands right away, not saying that you can not understand but he thinks it all through - difference in chair width for toilets.' C M Interview U I 2.

However it is pointed out that having a disability is no guarantee of good work. This approach attempts to avoid a tokenistic working structure.

'3) d) If you talk about cushions (in wheelchairs) to CMP2 he knows about them first hand. (He uses the same care (provider) as I do) At the end of the day it does depend on the individual concerned. There are a very few disabled people capable of doing these things. Does not mean you are automatically qualified to work with disabled people.' C M Interview U I 3.

## 8.2 Respect

Figure 27



### 8.2.1 Practice and Theory

The aims of the special education unit in the day centre were recorded as follows:

- '2) To respect each person's dignity as a human being and an adult in all areas of activities relating to them in a manner which is as normalised as possible.....'
- '4) To provide for people's needs in a way which respects and reflects their cultural background.' D C Documents.

Respect therefore is one of the primary aims of the day centre. It is also interesting to note the use of the term 'an adult' in relation to respect. I will return to the sub theme of 'adulthood' later in this chapter. Personal care is defined within the residential consortium as:

'1) Physical support of an intimate or personal nature may be required by some people. Personal care is a key area of a person's self-image and respect. Therefore, a person may choose, whether needing long-term provision or short-term teaching plans, to receive support in personal care. This support must be provided in a manner which recognises a person's dignity, and enhances their opportunity to develop their ability and competence, in order to maximise their independence. This support may range from advising and prompting or giving some physical guidance to actually providing care. To provide the most appropriate and competent support, intimate care should be provided by a same-sex member of staff.' R C Documents (2).

Dignity and respect are not defined here, but self-image is acknowledged as an important dynamic for people with learning disabilities. The residential consortium and care management organisations are clearer about some of the practical aspects around users' capabilities to choose and develop within boundaries of respect than the day centre. The aims of the day centre in terms of respect contrast with the observations made within the day centre itself, for example one staff member states:

'1.00 DESCRIPTION: '(Discussion with professional on behaviour modification) They (users) become dependent on rewards and will not respond to anything else, its' their world view.' Observations 1 D C.

There are assumptions here of collective difference, a homogenous world view allegedly shared by people with learning disabilities. A collective self-concept of what it means to have a disability is a questionable assertion. The advantage of such a collective construct is it allows the removal of power from such a group since assumptions are justified around need and intentions. At the same time this approach potentially isolates users and encourages apartheid services and on a personal level, controlling treatment of users by staff. One member of staff discussing what it is like to be on 'cover' states:

17/11/94 'I wipe bums and help out. If someone shits themselves I tidy it up. Basically there are some guys who just don't want to do this kind of work. They may be clearing some shit up and you can tell they hate doing it and some say it's horrible or these people don't deserve to live they should have died. I say they should get another job.' D C Extra Notes.

This section highlights a number of issues in staff attitudes around respect to users of services. Firstly the language used is debasing to users. Here a clear negative aspect is shown in that workers view users as not worthy to live. This is more than extremely disrespectful being a reminder of the eugenic arguments surrounding people with learning disabilities. However the worker's final comment is a positive one in that he does not see a place in a service for such workers. A further question of why these people entered the 'caring professions' in the first place needs to be addressed.

The following section indicates two issues. Firstly there appears a difference in attitudes between learning difficulties services and mental health services. It seems that the unique personal experience of having a learning disability is less accessible to professionals than having a mental health problem or physical disability. Staff have a barrier to empathising with users' experience of power and relationships. Secondly there is a notion that there is more respect for users within the day centre than in the community.

'1) a) We (professionals in day centre) respect users more than in the community but not as much as we could. We don't give the same respect as they (Mental Health my girlfriend works in that area) do in their work. It is in the tone of voice, we treat them like children. Relationships limit what we can do. More about gay relationships could be done. It relates to respect, their relationship are not given respect. Manager joking about people splitting up (relationships) - not taking the person seriously when they split up. Can be helpful but the joking should stop. We don't respect their serious side - their loss (not repeated to centre: a fire happened in which a user in a residential home was killed - told they don't need counselling as they are tough. Parents did not invite them to the funeral. I was keyworker for someone whose boyfriend died she was not told for a year. She was finally told he was pushing up the daisies).'

D C Interview P I 5.

There is a very negative assertion here that the emotional world of someone with a learning disability is less rich than their non-disabled counterparts, they are in effect more resilient to the effects of bereavement and loss. This can act as a self-fulfilling prophecy, if it is assumed that people are more likely to react this way, they will. The question here is whether professionals are more discriminating than lay people? Are professionals more likely to be prejudiced against people with learning disabilities? I will come back to this issue in section 9.2.2. This section demonstrates a recurring theme of the way people with learning disabilities are often treated in a childlike way. For example their relationships are not given the same status as others. Humour is used to disempower and thus justify the withholding of information and access to required services (counselling in this case). It is a well researched issue that personal and intimate relationships are vital in supporting our identities; increasing our sense of well being and expressing our sense of self. In answering a question about the qualities required by a worker a distinction of motivation is made by the same member of staff:

'2) a) Respect for people you work for, enthusiasm for work not just a sense of duty, that's bollocks. Are you using it for your own psychological sense of power or to get love.' D C Interview P I 5.

The staff member is indicating that professionals need to feel power, need to gain in the currency of caring. This is one aspect of what some workers get from working in this



area. In both the previous quotes the humour and the language used appeared to be key expressions of lack of respect within the day centre. This is also illustrated by the following observations.

'3.10 DESCRIPTION: Man with walking frame is referred to as 'shopping man' and the 'Nigel Mansell of the day centre' with affection.' Observations 1 D C.

Again this is an example of the disempowering role of humour.

'01.40 DESCRIPTION: Sport in the gym. 2 staff (inc me), hockey with plastic sticks. Talk about football at half time. Tea break. 'No biscuits, you're too fat.' Catering staff say to user, a rationing of biscuits.' Observations 3 D C.

This is another example of people with learning difficulties being seen sometimes as 'naughty' children. Humour here is used to belittle and control a user. The actions of workers within the residential consortium contrast with the stated policy:

'11.00 Worker told me on the phone I will have to tell one user to 'shut up' he does not mind - but you just have to.' R C (2) Observations.

The worker is therefore advocating a disempowering verbal statement. One worker does show that not all workers have a similar negative attitude as the one above. The following extract demonstrates the respect and status that can be given to a user of services.

'1) g) I am here to give users a good life, not push paper. I do come into work thinking I hope she does not want to go out. But if she says she does I will go. I could influence her but its not fair/ethical. It would be easier. I am paid to be here. If I worked in an office and my boss asked me to do something I would. User is my boss. Users Christmas do - support workers came in their own time. People watching thought we were two couples and we got drunk and left at 12.30. Not the normal party and cake and leave at 9.30 - staff going out after. It was like going out with girls from the office. My aim for this year is to go with user to a club in Greenwich for a night out. If its' her birthday I will pay.' R C Interview (3) P I 1.

This is acknowledgement of the users 'consumer power' over the service the worker offers. This service, according to the extract, is there to make the user's life better. The staff member acknowledges the ease of controlling users, the pay off for deciding on behalf of others. It comes across from this worker that controlling users is a temptation to be avoided. Table 17 shows users' responses when asked what others say about them.

Appearance (Only in Day Centre)	2
Positive	13
Negative	4
No Comment	8
Number of self responses made by users	

All the users reported being fairly treated. Users' comments recorded at the day service-users conference were key to their own expectations of respect and how to obtain it. In the day centre two users were discussed with reference to their physical appearance. This matched with the physical description of disability as shown in table 16.

The issue of respect through paid work is a recurring theme throughout the day centre analysis:

'We want to be able to get a job and earn money. We can learn to manage our own money and decide how to spend it. We can speak for ourselves!'  
D C Documentation.

The previous statement is one concerned with rights and needs, but action has not been taken on them. Users recognise the respect gained through contributing and gaining a wage. I will return to this issue later in the analysis. One user pointed out the relationship between respect and employment. A second user indicated the relationship of respect to self advocacy.

'5) c) Don't know You basically don't get much respect just sitting at home. No job, I just survive at home. I think some of my friends respect me, you would have to ask them. Silly cow smoking at home all day, would you respect me? (6/7 joints a day)' C M Interview U I 3.

'5) c) They respect me - If I find a thing that is not right a R C I will say it: e.g Paying bills for one, gas bill I took in they did not pay it. They had not paid it so I went round and had a go at them.' R C Interview (2) U I 2.

Paid work has a primary and secondary pay off for users, primarily having the money is good, also earning it increases people's sense of worth and self respect.

### 8.2.2 Sense of Humour

Humour is a notoriously difficult construct to analyse due to its subjective nature - for example 'no one would admit to not having a sense of humour'. A sense of humour is suggested by two staff members from different organisations as a desirable ability:

- '2) a) To be able to have a range of approaches at hand. Persistence, humour, ability to say when you need support.' C M Interview P I 2.
- '2) a) Sense of Humour. Talk to people, communicate well.'  
D C Interview P I 8.

One woman with a physical disability uses humour in relation to her own condition and my presence as a researcher:

- '10.45 Put a tray on a wheelchair it turns it into a highchair, you just have to stick a dummy in your mouth.' C M Observations.

Again this is another reference to child/adulthood issues for people with learning disabilities.

- '11.00 Dropping off bread/sega mega drive. Bloke down the road saying stupid things, people playing videos all day - its OK for me to do it well I'm a 'raspberry ripple'. He does not let the cats out treats them as possessions, he is a lazy fat bloke. Never goes out, he could get a job.' C M Observations.  
This extract shows the aggression and frustration behind some of the humour.
- '01.00 The invisible man (me) helped with slippery traction on the paths. Went passed residential unit for people with disabilities - its where the 'poor crips' who can't get individual living end up. Care homes my foot! The plans are to go there and die in there. I did spend 14 months in a residential home. Learnt what residential life's was like, important to get away from parents. We were all sharing together I had an OK bedsit but I was shoved together into a false situation of being with other people with disabilities.' C M Observations.

The use of slang words and irony along with deliberate non-political correctness and child like references used by people with disabilities, show a reclaiming of some political language and an exorcising of negative stereotypes. Staff also directed humour at me, perhaps out of insecurity as my role as a researcher within their work place.

- '12.25 DESCRIPTION: Staff member came up and asked me 'If I am writing bad things about her.' Staff collecting money 'humour is how we keep our morale up.' D C Observations 3.

Two users frame their description of self in humour and politicise the issue:

- '1) a) Happy, funny - often make people laugh, people always laugh when I make jokes. I am a good cuddler of people. I'm a good laugh.'  
R C Interview (1) U I 1.
- '1) a) Cripple, queer, reclaimed by two movements. Its PC for disabled people but not OK for able bodied 'Crip with a Chip', 'Piss on Pity'. I am quite balanced 'I have chip on both shoulders'. I use these words as I'm politically active, I see myself as a disabled person first, not a queer cripple. First thing they notice about me is I am not queer but in a wheelchair.'  
R C Interview (3) U I 3.

It is noted that humour is used as measure of improved sociability or 'happiness', of users by professionals, as illustrated in the following example.

'He has improved a lot - more out going, sociable, he will ask you, notice you've had a hair cut, good sense of humour.' R C Interview (2) P I 2.

Sense of humour can be considered as a major part of the larger picture of intelligence. If humour is broken down it involves an ability to reflect, a degree of creativity, abstract thought and potentially some elements of 'comic empathy'. Similarly life experience in many cultures is viewed as an indicator of intelligence. In Western culture such intelligence, most commonly referred to as wisdom, is undervalued.

### **8.2.3 Adulthood**

This section explores a theme running through much of the work discussed already, that of being seen as an adult if you have a learning disability. Being treated as a child is a denial of adult rights from voting to sexuality. It allows a worker or carer to disempower and remove choice from the user. One professional acknowledges the day centre's tendency to treat users as children.

'5) e) Users tend to relate to people not objects, they are task orientation, they (users) do not concentrate on the table wiping because always looking to worker for acknowledgement. Treat them like children and do not recognise their sexual needs and independency.' D C Interview P I 5.

'1.00 DESCRIPTION: They become dependent on rewards and will not respond to anything else, it's their world view..... One place used to be called the Peter Pan Club (the boy who never grew up.)' D C Observations 1.

The worker seems to be creating a separate world view for users in which they are dependent on rewards. An environment where it is easier for them (worker) to take control. The club named illustrates how services on a conscious and unconscious level are created to put people with learning disabilities into a disempowered child's role. The next quote clearly demonstrates professional disrespect of users through their child like treatment.

'11.00 DESCRIPTION: Staff shouting to user 'Start acting like an adult.' Tea time in dining hall (26 users). From hatch users queue up. 'Staff are making a pot. I took some from the hatch anyway. Staff shouts '(user) stop it' as she walks by a user and staff with different cups. COMMENT: Paternalism and patronising attitude towards users from some staff. Abrasive response by controlling staff. A lot of people and activities to watch and take in as an observer.' D C Observations 1.

One user demonstrates awareness of this childlike issue, and insists on making the point that she is an adult. This person seems to recognise the bestowed status of being treated like an adult.

'U V 1) I'm an adult and I don't hit people you can't get away with it. Don't want to hit someone. Get told off. It's noisy here (in the day centre) banging doors, crowded arguments and I don't like that, crying, screaming, raving and shouting.' D C Vignette U V 9.

'1) c) Makes me feel like a grown up person, not a baby.'

2) c) Because I want to and I like it. We get our own meals. Don't mind it, its grown up.' D C Interview U I 9.

The value attached to being seen and treated as an adult is great, being denied by some workers and acknowledged by some users in the study.

#### **8.2.4 Overprotective**

The issue of overprotectiveness naturally leads from users of services being treated like children. Children are themselves often overprotected. One professional in the care management organisation points to the equity of not overprotecting users and allowing them to take risks. Being overprotective is disempowering. By not allowing the disabled person any choice it effects a freezing of their capacity to take control of their lives. This is the denial of people's right to fail and succeed.

'5) e) Conflicts of interest over who you are there for, the person. Who do you listen to, users or carer'. You may not agree but you have to report the real issues for people. Particularly around people who acquire their disabilities, people can be overprotective about risk taking. Tell them what is involved and it is down to them. Around suicide threats tell someone or accept it. Everyone here has had some kind of counselling. People here have to question themselves, have to look at power issue, have insight into issues. It is not strictly counselling you may go in aid someone with a bath adaption but you also listen to them.' C M Interview P I 2.

Parents of people with learning disabilities are seen by two professionals at the day centre as the overprotectors of users.

'5) e) Great deal of influence here - ring up if ambulance is 5 minutes late. Mothers will say take care of him or bring him back safe. Undue care and involvement, overprotective.' D C Interview P I 1.

'5) e) Very powerful their values are formed by their families. Authority of parents are overwhelming. Not all bad - parents given up power to hospital. Being told instead now that they should only look after their children until they are 20 years old and then they should become independent.'

D C Interview P I 3.

This last quote illustrates the contradictions that services have communicated to parents: to care for their disabled children, but not too much as it denies their independence. The issue here appears to be the contrast between concern and overprotectiveness. Are parents challenging the system and being labelled as troublesome or are they holding their children back from taking needed risks?

### **8.3 Summary**

From the extracts and quotes used in this analysis chapter it can be seen that 'handicap' is a word that is still used in policy documents and by users of services. Within the day centre all but one of the users were unwilling to admit to, or were unaware, of having a disability. They tended to define disability in terms of a physical state. The users of the residential consortium reported that they were disabled but again only two used a 'mental framework' of reference. Professionals in all three organisations use the concept of 'normality' as a major goal. However there was little discussion of what actually constitutes normality and its use was selective and could justify various interventions. This means that the concept of 'normality' within services is not empowering but confusing. 'Abnormal' labelling by professionals of users occurs and users who in particular have a physical disability are noted as labelling themselves in a humorous way. For all the groups studied the degree of disability, visibility of disability and when the person became disabled are influences on the roles assumed by disabled people in response to services. Labels tended to become totalities which exclude other attributes and positive qualities of the person.

A disparity between respect as a stated policy and in practice existed in the day centre and residential consortium. The policies refer to respect, dignity and treating people as adults, but do not define them in any depth. The practice of workers is occasionally overprotective and patronising. This was seen particularly in the day centre. There is evidence of a tendency at the day centre for users to be treated as if they are children. This appears to have been internalised by at least one user who insists on the value of being seen as an adult, as recognition of adulthood was strived for as a position of status. Historically people with learning disabilities have been repeatedly viewed as childlike, from their dress codes to their intellectual development. This is reflected in their rights in terms of sexuality, competency and status.

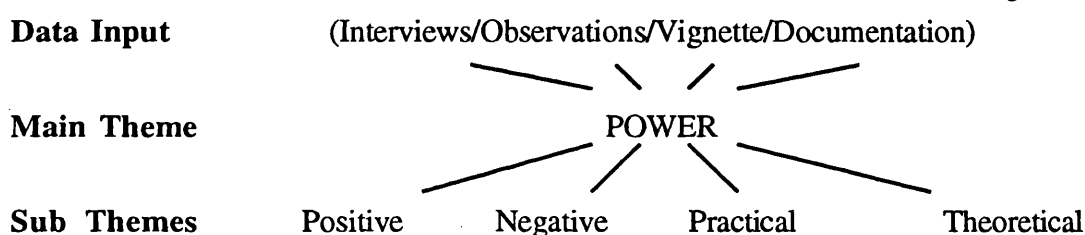
It is clear that workers responded in a number of different ways to people with disabilities, sometimes it was noted with prejudice and stigma. The question arises of whether workers should treat people with learning disabilities differently from the rest of the general population? If they should, then workers may need some kind of support to act as an antidote to potential community negativity. Some people with learning disabilities in the residential consortium are still dealing with the disempowering legacy of institutionalisation. Of the three organisations studied the day centre offers an environment which is the hardest for users (particular with more severe disabilities) to make decisions and express choice. The high importance of disabled

workers in the care management organisation is clear from users' views of the service. The experience of being disabled and a worker is a valued input into the service they offer.

## **9 POWER AND CHOICE: Disabled People’s Role in Decision Making and their Sense of Power within Organisations**

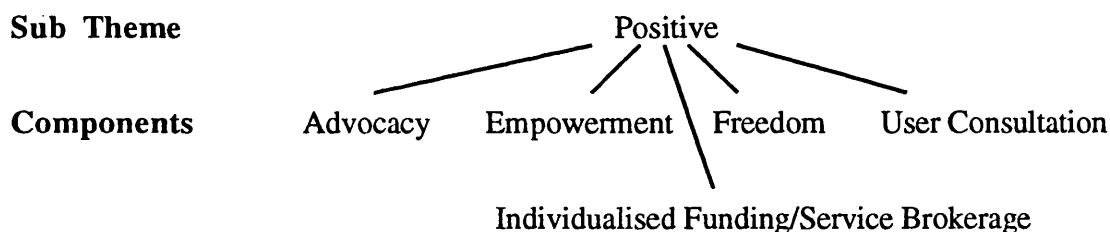
This chapter focuses on the main theme of power. In each organisation a series of questions are addressed in the component themes presented; what are the views held by professionals and users contributing to both a positive and negative experience of power? How do organisations empower or disempower the users of their services? What constitutes power in both theory and practice for users and professionals within services? The following tree diagram (figure 28) developed from NUD•IST shows the structure of the themes and the corresponding components of power constructed from the research data.

Figure 28



### **9.1 Positive Power**

Figure 29



The recorded data showed that power as a main theme was constructed from four sub themes; Positive, Negative, Practical and Theoretical. The sub theme of positive power in turn is constructed from the following series of components.

#### **9.1.1 Advocacy**

This section explores advocacy, paying particular attention to the care management organisation as their primary remit is one of advocacy. Advocacy as used by the organisations is a confusing concept being perceived as having both an informal and a formal structure. There may be professional and lay roles, paid and unpaid work, service and non service provision. Assistance may be warmly offered by friends or broken down into tasks by professionals.



Table 18 shows the reported use of an advocacy approach by professionals interviewed in each organisation:

	Day Centre	Residential Consortium	Care Management
Yes	4	5	2
No	2	1	0
Unsure	3	3	0
Total	9	9	2

From table 18 it can be seen, even though the numbers are small, that the care management professionals view advocacy as part of their approach:

'2) d) They (workers) like you for yourself - show you how to but not do it for you. This is good, encourages the person to do things for themselves. Learn and understand it all yourself. If you haven't got an official/professional body behind you then they don't listen.' C M Interview U I 3.

There was some user confusion as to the meaning of advocacy, but there was a clearer understanding amongst users of the care management organisation.

'3) e) A lot of people don't understand advocacy. Its' like a tree with lots of different branches with different meanings. It helped me find out that I had a right to live and sense that I had done great things.' C M Interview U I 7.

Concern was expressed over the misuse of the term advocacy. The following extract shows that advocacy was viewed as a potentially powerful medium, but could be abused by being used as a justification for bad management.

'2) e) Advocacy has become a sloppy term, a cop out, it is about mismanagement. We are moving towards informed choice. Not just saying it is okay for people to do anything.' D C Interview P I 9.

One user was unclear of what the exact role of the advocates was within the residential consortium. A recurring theme for workers was whether advocates are supposed to be paid task orientated professionals, or friends building supportive relationships? Are 'friendly professionals' the best compromise?

'2) e) Some clients have advocates - Citizen Advocacy in local area, they review our service. Independent letters of complaints. Important they see things you miss. Client does not understand advocacy - ask user how their advocate is they don't know - say how's your friend - he would know. Clients say I wish I had a friend. Staff may see advocacy as interference.' R C Interview (2) P I 3.

The independent function of an advocate in overseeing service delivery is stressed by one worker. This role may be to monitor the quality of service. The use of advocacy in a crisis is illustrated in the next extract.

'2) e) Advocacy don't really know - being there for some who can't represent themselves fully. Sticking up for them in a crisis.' R C Interview (3) P I 2.

The care management organisation stresses the independency of the worker from other services and elements of good advocacy practice in being accountable to the user. The importance of the dissemination of information for service users is also mentioned:

'Characteristics of Service Offered by the care management organisation: One point of entry and access to help, but independent of service provision. Access to information about all the persons concerned. A means of personal research for the person with disabilities, Advocacy Liaison and cooperation between services. Support and counselling. Feedback in a clear written action plan. Accountability to the service user. User Monitoring Group. Equal Opportunities Policy Emphasis on Disability Politics.' C M Extra Notes.

The importance of empowerment through one to one working is also stressed.

'1) b) Mission statement currently - Redeveloped advocacy for the Borough, professional and voluntary. i) Constitution around advocacy-user empowerment, advocacy forum/resources brings together complementary advocacy and develops new ones. Time Scale - 3 year (with 1 year funding). C M being for and controlled by service users. ii) 1 to 1 advocacy work in local area. iii) Provide nationwide, consulting and develop services. iv) National base - continue with Building Bridges and Advocacy United. v) Ensure financial security of organisation - fund raising. vi) Development of services in areas that are shown to have a need e.g HIV advocacy - looking for a pilot advocacy maker, children and advocacy.' C M Interview P I 1.

'Social Education Centre: The centre provides a programme of activities reformatted every September. They use college time table symbols, a list of courses at the Day Centre: .....Self Advocacy.....' D C Documentation.

From these extracts it appears that advocacy is not a major part of the policy aims for the day centre and residential consortium, compared to the care management organisation. The image or status of the advocate is of paramount importance within the care management organisation. Thus to be seen as powerful in the eyes of others (other agencies, professionals and users) was as important as actually exercising power under certain circumstances. The importance of self-awareness of power is also stressed.

'3) e) Work is needed around supervision. The role of an advocate is you need to be powerful related to that role - to be seen as being powerful. Understanding your own power is a start to challenge it. 2 roles - service providers.' C M Interview P I 1.

The care management organisation has recently undergone a move from what could be termed a 'scruffy' set up to a 'slick' set up. That is a move from an underfunded to a well funded working environment, with new computers, phones and fax machines along with a larger staff team. This may have moved the organisation away from a person centered approach to a more image/professional centered one. The limits of the 'familiarity' of the advocate/user relationship are again highlighted in the same interview.

'4) a) Professional - empathetic, supportive, challenging. Advocacy as a tool is a resource, we are selling ours and it needs to be fairly spread. We might all wish to become involved in people's lives but our approach means we cannot do that. Control conflict between time and involvement. Using effectively 15 hours advocacy, 10 giving people space, 5 action. We have less time for cups of tea, its not effective or empowering for users to have 24 hour advocacy. It could be argued that we could become another professional layer between service users, our values are strong enough to withstand that. C M Interview P I 1.

There appears to be a conflict of interests around whether advocates should provide a service or not. Counselling work and advocacy work are highlighted along with a wish to expand into new areas of need. The day centre sees advocacy as an option on the user timetable, thus bringing it into service provision, rather than a policy aim to empower users. The above extract highlights that the conflict in working styles for the care management organisation may lie in the mix of time management and relationship building approaches. It was noted that during the research users did not refer to the care management and residential consortium organisations by name. When asked questions about the nature of the care management organisation and residential consortium, they responded with the individual worker that they had contact with, the positive value of that organisation being encapsulated in the approach of that named individual.

There is a distinction between the interpretation of advocacy by the residential consortium in terms of a relationship, and by the care management organisation in terms of an action. One professional in the care management organisation does clearly state that advocacy does not result from the relationship that the worker and users have. The statement shows a professional distance can be sought in advocacy work, advocacy is almost defined here as a service provision.

'4) b) Advocacy is not about chatting and liking someone but structures for the long term removal of someone from isolation. Need to manage time for the purpose beginning/end for the person. In the future there will be less human contact, but it will be quality contact.' C M Interview P I 1.

This last quote sets apart advocacy from befriending schemes by the allocation of tasks, this sees a distinction in terms of advocacy as a relationship (residential consortium) and an action (care management). Both relationships and actions can be empowering depending on their motivation and context. Advocacy for people with learning disabilities appears to be more friendship/relationship orientated work in contrast to the advocacy for people with physical disabilities which is more task orientated. This could be due to the particular and sometimes acute social isolation experienced by people with a learning disability compared to the more socially accepted experiences of people with physical disabilities.

'6) b) Loads of friends, advocate, mum and partner, sister, me girlfriend and all my friends at R C (1). Advocate - someone from R C (1) said he was my advocate because we do things together. I have known (Advocate) as a friend for a long time. He is still my friend and advocate.' R C Interview (1) U I 1.

A description of the skills required for advocacy are provided by the care management professionals. The issues of disabled workers will be explored in a later section.

'2) a) Important qualities - attitude to service user and empowerment, insight into what advocacy as a tool is, skills of: communication, prioritise work, relate to a range of people. Target people who have experience of using services and build on empathy. In last recruitment we employed 1 out of 3 disabled people. Being disabled does not mean you are automatically a good advocate. It is an important but not vital part.' C M Interview P I 1.

Advocacy in action can be seen by users as a powerful force in an ongoing fight for power, from the following user story:

'13) b) He got in touch with the people over my car. CMP2 came along to the small claims court. CMP2 sent letters. At end they agreed to give me some money back. I really wanted to take the car back but I settled for the money. First it was £800 I did not agree as I had already paid out £200 for solicitors fees. Finally gave me more. Settled only recently as I suffered a lot without C M. I would have ended up in the hospital with a stroke/heart attack without them.' C M Interview U I 1.

It appears that a number of workers in the residential consortium believe that the advocates do not understand the service. This extract questions whose interests are paramount, implying that the advocate may be in control of the choices of the users. This may be explained by the workers feeling threatened by the role of the advocate. The idea of users' 'best interest' is an intriguing one and will be discussed in the concluding chapter. The following extract also shows that one professional in the residential consortium is critical of the advocate's susceptibility to being duped by the user over issues.

'2) e) User has one (advocacy) - clients choice he is the only one. It works well, except he comes when he wants to. He comes to the meeting, he does not understand the service, the things he wants they are not in the user's best interest. The user tells him things which are not true and the advocate will get a bee in his bonnet.' R C Interview (2) P I 1.

For two professionals in the day centre, the degree of people's disability was salient to the amount of self advocacy they were involved in. Therefore how representative are these users of those in the centre with more severe disabilities?

'1) f) People who can advocate for themselves are getting more work done with them. Quiet people and the non-verbal are contained. Can't do anything with these people. Way the organisation is set up I have four other people in the group. User..... sometimes locks the door because she is up and down all the time (not meant too). Relations have an influence: its a fight their babies - may be a burden but needs her because she needs the money (benefits). 'She has to come to school but she shits everywhere at home. What's the point of taking her to the pictures. I make a point of getting to phone and phoning their mums and saying how advanced they are.' D C Interview P I 7.

'2) e) Very different to get a keyworker group together at once. People who go to user council meetings are much more verbal. Need time to get comments from less verbal people.' D C Interview P I 4.

Parents are not pictured in the day centre as advocating for their children but appear to be perceived as interfering and being in control of them. There appears to be, within the day centre, certain language describing a battle between the staff at the day centre and the parents of users. The day centre users do not appear that interested in advocacy:

'3) a) No. D/K if there are some. Council meetings (UCM) don't know about them, not interested.' D C Interview U I 3.

'3) a) No - Yes one in area. Speak up for yourself - get your own way. So I can get my own flat - social worker is coming to arrange it.' D C Interview U I 9.

The above extract may be partly explained by the negative reaction of day centre staff to advocacy work. This occurs even though the keyworker's role is clearly defined as:

'11) Acting as an advocate on behalf of the person inside and outside the centre.'  
D C Documents.

The following up of existing self advocacy work in the day centre appears to be a difficult one, this is due to the lack of turning of user requests into action.

20/10/94 Advocacy support worker in centre. Seems to be a big difference between user raising issues and them being presented at the management committee and getting a change.' D C Extra Notes.

It is also inferred that staff may be trying to use the User Committee to gain support for the changes they want:

'1) a) Did not happen because of the long process of consultation with carers and

users. Not going to happen for five years. People First did an assessment three years ago but nothing was done about it.' D C Interview P I 1.

The following quote shows the importance of dissemination of information in advocacy.

'2) e) No. Because the establishment want to keep the lid on the place. Manager has said no to advocacy work, association with People First has been frowned upon. ....(Advocacy Organisation) are now in the Borough so it's easier. This centre could be run a whole lot better if people were informed from day one. These views of Users Council Meetings (UCM) have never been listened to before. Staff would get an idea and thought it might carry more weight if users were behind it. UCM - some views have been taken on board letters to senior management - responded to. Money for workshop work stopped 2/3 years ago. Some get very little money. One man got £12 a week so £4 (workshop payment) is a third of the money.' D C Interview P I 1.

A second staff member at the day centre stands out from the general scepticism of the others, he sees advocacy as vital in the day centre.

'5) i) Like to work in advocacy and do myself out of a job by users asserting themselves. Get out of this environment because it is trapping me. There is only so much I can do here.' D C Interview P I 1.

One staff member states a misconception of advocacy by implying that it needs to be forced onto users. The question here is how does this relate to empowerment issues?

'2) e) Making people speak up for someone else, get listened too.'  
D C Interview P I 2.

Finally the payment of advocates is seen as an important issue: this is also an important topic in the advocacy debate as a whole. If advocates are paid, do they necessarily acquire both the negative and positive aspects of professionalism? Whose interests will be best served?

'2) e) Not a great deal of experience of it as most of them are elderly or do not have a family. Difficult getting advocacy - see it as an extension of keyworking role. Client can be more relaxed with advocates that are not 'paid' members of staff. Brings a different perspective to it - removes the them and us syndrome.'  
R C Interview (2) P I 2.

This section highlights the confusion over defining and applying what is known as advocacy. The care management organisation has a clear advocacy objective and the professionals interviewed in the residential consortium stated that the organisation intends to implement advocacy. However no policy covers it and workers appear unclear about its usage. The day centre states that advocacy is used but from the reports of users and workers in this section its use appears to be in question. The lack of implementation of the People First conference findings and users' doubts about the

efficacy of the user committee provide support for this view.

### **9.1.2 Empowerment**

Empowerment is once again a term often used but seldom defined or understood within the organisations studied. Empowerment has its foundations in the personal, social and cultural realms. For the last few years it has been very popular to use empowerment language around the conception and implementation of services for disabled people. Empowerment aims in policy are most clearly stated by the care management organisation:

‘C M was started in 1989 from a formal case-management standpoint. It has developed into an empowering system based in a framework of advocacy. The style of working has become less formal. It is now a project staffed solely by people with disabilities.’ C M Extra Notes.

The following quotes illustrate some of the aspects of empowerment raised during the research; they include the role of the voluntary sector, information and the basic aims of empowerment:

‘1) e) The voluntary sector speaks on behalf of some people who are not allowed to - traditionally they are seen as the voice of the disempowered. There are good organisations. Some local organisations say they do, but don’t actually do it. Often individuals have positions of power in the organisations and it is difficult to change the organisations without removing them.’ C M Interview P I 1.

The value base of organisations here are seen as encapsulated by key professionals within them.

‘1) g) Organisations were user lead, we recognise that there was a difficulty for the service users in the management committee to take on a management role, not being used to committee structure, not understanding the full role of the organisation. Wanting to help but not having or knowing what skills they should have. Many voluntary organisations have this problem. Get money to look at organisations management. i) Re-structure management - specific roles/responsibilities for the key members of staff. ii) Empowering management committee to manage. The organisation is still very much managed by staff, power lies with knowledge. It is difficult for service users to give the quantity and quality of information to make it happen. Those users who do have knowledge don’t have. Time they have no time, because they are on all sort of other meetings.’ C M Interview P I 1.

The role of skills on these management committees is stressed, a recognition that it is not enough to be just present at a meeting but you have to take part. The issue here concerns the need for training of users so they can be involved in services in a meaningful way.

‘1) a) Recently developed one (policy) which empowers users to have a voice for

users to control services. Creating a dialogue between providers/users. Bringing people into somewhere they have been traditionally excluded from, not things being done for them by people who know best.' C M Interview P I 2.

There seems to be a move towards more user controlled organisations. It is unclear whether the presence of disabled workers is the most appropriate way of dealing with this lack of representation. A disabled worker like any other person cannot be expected to represent the interests of the whole disabled population.

'2) e) Empowerment: help, obtain skills and positive vision, awareness, confidence to become active, ordinary citizens.'  
C M Interview P I 1.

The rights based nature of empowerment to include people is also stressed. The question is asked, does being an 'ordinary citizen' necessarily mean political equality? Empowerment in action is characterised by the following extract, it can again be seen that users can be encouraged to be grateful for the services they receive.

'2) c) Empowering Model: people to use services may have a acquired disability and they may have very few resources. We must try and be creative with that person. Think about what they want not just be grateful for what is handed out. Image of C M - not falling into the stereotype of limits of what people with disabilities can obtain or not.' C M Interview P I 2.

Empowerment here is being seen as the creative use of resource management for people who often have few resources. This can involve the breaking of the expectations that others have of disabled people. It can also involve the removal of the idea that users should be passive and grateful for the service they receive. This quote portrays empowerment as a balance allowing users to gain some power and choice, but not allowing complete involvement if they are not ready for it. The question here is how do you make people responsible, punish them for not being so? It appears to be a difficult trade off between allowing others to do what they want and doing things for them.

'2) e) Yes working basis: empowering process, not going and taking control of person, this happens quite often - understand system, rights, what we need to change in different areas, how they (users) can be involved in the process. It's a personal process - some people say you should do it all for them 'just take this away and make it better.' Its not always a neat division of tasks down the middle, you don't allow it to occur, I explain to people what I am going to do. We have to make people responsible. This is not always easy. It's an individual load - you do not give people too much or too little to handle. People phone to use me as a self monitoring process. Reading what people say. Own experience, give people enough 'graceful exits'.' C M Interview P I 2.

Empowerment was also portrayed as ownership in terms of motivation for users' education in the following extract.

20/10/94 Manager: We need a pictorially/physical presentation of the work.



Makes people own their courses. Commitment to a course. Have a ceremonial day, avoids having to present the person/staff as an expert - needs led staff group. Empowerment based approach. Parents have said "his program looks like all fun". But there is a learning curve.' D C Extra Notes.

Empowerment for users is recognised by one staff member as part of giving up power by staff. They recognise the power building that has gone on in the day centre for staff but not for users.

'2) e) No. People should be encouraged to speak up for themselves. We do not listen to their needs we just make their minds up for them. They need confidence. Speak up, we have empowered ourselves that is not always a good thing for them.' D C Interview P I 6.

With regards to staff and empowerment, empathy was the highlighted issue. Empathy for workers with people with learning disabilities may be more difficult than other groups as having a learning disability is more of an abstract concept to the able bodied than say a physical or mental health disability. In other words it is perhaps easier to place yourself in the abstract position of having a physical disability than having a learning disability.

'2) a) Own experience - to understand what it means to be in a position of using services - disempowered, discrimination against - because you have a certain label attached. But also listen to peoples stories. To be able to have a range of approaches at hand. Persistence, humour, ability to say when you need support. Communication - receiving and giving. Ability to digest people's experience and utilise it back on an individual level and take out general issues for feedback - effect policy. Engage people and be engaged.' C M Interview P I 2.

The following quote shows the benefits and enjoyment of working in this area.

'3) c) Greater choice. Things you feel are good at doing you can do well structured - the power to make a change, you get a change. I would like to play football all day but I am here to provide a service. There are people who work like that. I do want to enjoy myself but I also provide a service (There is no pretence).' D C Interview P I 6.

One staff member emphasises the importance of empowerment issues for users in the day centre. As a result this person felt isolated from his colleagues, he advocated that sometimes users of the day centre should be rude to the staff that work with them. This is a challenge to the traditional regime of status within the day centre. Again he suggests that staff are there to serve users, even though this is not demonstrated by the observations or other data recorded.

'4) c) I am on the edge of staff group because I am seen to have a different view of user power, how users get this information - what the role of staff is supposed to be. I am and should be at the beck and call of users they are why I get paid. I owe it to them to give them the best of everything. Empowerment, say sometimes its OK to be rude to staff. Staff get free meals users have to pay £2.40. Bad practice: 1) Staff served first, users have to queue. 2) In staff meetings are staff orientated. They talk about room for staff, space for staff, staff rights.' D C Interview P I 1.

Users may feel that they are at the beck and call of staff. Power could be viewed as tied up in an environmental effect, the structure of the service.

'7) b) No. Other people have more power over me, tell me what to do. Sometimes I do it just to keep them quite, make them happy. I should not really do it.' D C Interview U I 1.

'11.20 DESCRIPTION: Conversation with staff - Power; 'It corrupts I feel I do things that take power away from users because I am lazy.' This place makes you take choice away from people (users). COMMENT: e.g Taking short cuts.' D C Observations 1.

Staff in the residential consortium recognise the influence they have over users of services. The issue of unpaid or paid work arises here again. The user is in the position of being the boss.

'1) g) Not much to do with this, let them get on with it. If I have a problem with it I will kick up a fuss and go higher. I am here to give users a good life, not push paper. I do come into work thinking I hope she does not want to go out. But if she says she does I will go. I could influence her but it's not fair/ethical. It would be easier. I am paid to be here. If I worked in an office and my boss asked me to do something I would. User is my boss.' R C Interview (3) P I 1.

Training is not as valued as might be expected within the residential consortium.

'1) g) Only 5 hours a day with user. I get on well, he hates one member of staff just tells her to piss off (she has to stay). R C furniture budget. Next thing is we have to get housing benefit sorted out. We have not been trained for this. I do not like courses - but they do provide them.' R C Interview (3) P I 2.

Users reported the only rules as follows:

Day Centre:

- 'Wearing an apron in the kitchen.'
- 'Not to fight.'
- 'No smoking areas.'

Residential Consortium:

- 'No smoking areas.'
- 'Pay rent.'

Care Management Organisation: there were no rules reported by users.

However from the observational data it is clear that there are more rules for what users cannot do than are indicated above. Is it impossible to run a large day centre without a comprehensive series of rules? The list above could be small for two reasons, firstly the users are aware of rules but did not report them as such, or secondly they are unaware of the rules they follow, seeing them as a usual part of everyday living. Users comments on rules were as follows:

'7) a) Must not help myself to my own money, I have to wait for worker. I got it all out the building society. I had to go put it back and I was on report. If any missing they think the staff took it. I was going to go to the market and buy records. I would like to spend my own money. But I am not allowed to spend it on rubbish. Too many sweets are not good for you.'

R C Interview (3) U I 1.

'10) c) One member of staff who I ask not to be sent here I find dominating. He will clean when I am not here, I don't like that. The rest are reasonable. One worker does take power away from me. Making assumptions about things (can't do things and what I want out of life).' R C Interview (3) U I 3.

### **9.1.3 Freedom**

The degree of freedom within each organisation emerged as a component of power. Freedom as a policy was highlighted in the day centre documentation. It was characterised as the avoidance of oppression and the fulfilling of personal potential.

'Anti-Bullying Policy: Which means that everyone in the centre and within the wider community served by the centre, should have the same basic rights of freedom and access to opportunities. This also means both freedom from all forms of harassment and active encouragement to develop personal skills and talents as fully as possible. This is what is meant by Equal Opportunities Policy.' D C Documentation.

Users reported varying degrees of freedom within the residential consortium. One user saw freedom as the avoidance of change.

'2) d) Plenty of freedom here. Can watch T.V no trouble. Things don't change here.' R C Interview (1) U I 2.

A second user saw it within physical dimensions.

'1) b) See to the dog, take him for a walk. Get my breakfast, wait until 9.00am get my bus pass and then just go anywhere it does not matter just where the mood takes you. I like going to Oxford Street, markets in the local area. Get back in early afternoon to take the dog for a walk. Stay in the evening and watch the T.V. I used to go to a day centre many years ago when my parents were alive.' R C Interview (2) U I 2.

Some staff put forward a desire for less, rather than more, freedom in the work environment.

'1) e) Depends on personal relationships. Paternalistic attitude a while ago: conveyer belt bathing. In bed by 10.00 pm to being completely free. People don't have the right to live like pigs.' D C Interview P I 3.

'1) g) Almost left to do what you want to do. For a while, a year, no one checked on what I was doing. It was nice but it would be good if someone took interest in what I did. D C P 2 (manager) likes food so he does keep an eye on you. In supervision they don't check on me, if they did it might make me look at what I am doing. D C P 2 is trusting or he simply does not care. He likes people and knows the users but his management is not that skilful.'  
D C Interview P I 4.

There is a contrast of enhanced personal freedom with a lack of interest by management, in essence a negative freedom.

'3) b) A lot of freedom within constraints of day centre tasks. No one looking over my shoulder. That can almost be a negative freedom. As your reputation increases you work more than you should be doing, this is the problem with the voluntary sector.'

'1) c) Five years working here. Philosophy has changed. I am on the edge of the staff group. Because no one agrees with me over choice and other issues. The value of a person. There has never been a clear cut definition of what it is to be a user in the day centre. You spend 15 years in a regime having to choose between two things. Choices are not informed. Informed choice is not that free here, it may be just to please a small group of people and how permanent is that change?' D C Interview P I 1.

Freedom seems to be defined by the roles that people take up, by boundaries and the power to exercise choice within these. The idea of having too much power seems to be a recurring theme for some professionals in the day centre.

'3) d) Sometimes I feel I have too much power I have three computers I could produce pictures all day and night and no one would ask any questions. I should be more accountable than I am.' D C Interview P I 1.

'11.20 DESCRIPTION: Conversation with staff - Power; 'It corrupts I feel I do things that take power away from users because I am lazy.' This place makes you take choice away from people (users). COMMENT: e.g Taking short cuts.'  
D C Observations 1.

#### **9.1.4 User Consultation**

The following extracts are taken from a document which goes some way to represent user views within the day centre. It is interesting to consider that very little has changed as a result of this report which was written in 1993 with the aid of People First, a charity run by and for people with a learning disability.

'Day Service-Users Conference: This document was written with the aid of symbols designed for people with learning disabilities. Things they (users) like to do: 'Work, go out, swimming, shopping and go on a bus. Some of us would like to stay at home one or two days a week. At the day centre we like pottery and drawing. We like to talk about our problems, cook and physiotherapy. We miss getting our £4 (wages for working in centre workshop). We want to be able to get a job and earn money. We can learn to manage our own money and decide how to spend it.' D C Documentation.

The following extract shows the views expressed by users in wishing to have control over their own money and the transport they take to and from the day centre. The importance of choice over making drinks at the day centre was also a priority.

'Some of us want to learn to use public transport. We do not like using ambulances and would prefer to use mini buses. We like to eat with our friends. Sometimes the day centre is too noisy. We would like to be able to make drinks whenever we want.' D C Documentation.

Some users see the day centre as a noisy and overcrowded place, which should have extended opening hours.

'We want people to stop pushing in the dinner queue. Things they (users) do not like to do: Arguing. Watching videos. When staff have meetings because that is when people start to fight. Doing paper rounds. We do not like being in a building all the time. We do not like people swearing. Sometimes the buildings are too noisy and crowded. Sometimes we get bored doing the same things all the time. Why can't the centre be open in the evenings and weekends. We can speak for ourselves.' D C Documentation.

These issues raised by the users have not been addressed by the day centre. It appears from the following extract that the appropriate use of the User Committee Meeting (UCM sometimes referred to as council meetings) has also not been addressed. The most important issue was the objection to the removal of paid work for users of the day centre. This point is made by both a user and a professional at the day centre.

'2) e) This centre could be run a whole lot better if people were better informed from day one. The views of the user council meetings (UCM) have never been listened to before. Staff had an idea and thought it might carry more weight if users were behind it. UCM - some views have been taken on board letters to senior management etc - responded to. Money for workshop work stopped 2/3 years ago. Some get very little money. One man got £12 a week so £4 is a third of the money.' D C Interview P I 1.

'3) b) We did have complaints about the £4 being stopped - went to council meeting but nothing happened - they are strong people they said they could not afford to continue it.' D C Interview U I 1.

The process of user consultation and advocacy are closely connected. The three following extracts are from one user's account of the consultation process.

'3) a) They do have groups every other Friday. D C P 1 does one - can't remember what it is called. I do not go because it really does not do anything. I want action and it does not get it, does not help. I thought it was better 'for users', getting our own dinners and stop other people putting it in front of us. Staff went back to queuing us up. Its good for us to get our own dinners. The group could not keep the change.' D C Interview U I 1.

These extracts clearly state the lack of faith that this user has in the user committee meetings.

'8) c) Things going on in the centre - they (staff) don't tell you about changes such as closing some of the rooms. I don't know what to do about it. When you talk to other users and they are annoyed that they don't really listen or talk to you.' D C Interview U I 1.

It appears that the day centre falls short of its own aims of user consultation. This final extract sums up this point.

'10) c) I don't feel the same as staff. Talk differently to them. I don't always agree with the changes in the centre like when the workshops were closed. I spoke to (staff) about it, but nothing happened.' D C Interview U I 1.

### **9.1.5 Service Brokerage and Individualised Funding**

Connected with the issues around money and finance is the role of a service broker within the residential consortium organisation. This section examines the effect of these workers on the power felt by disabled people. There is also reference to the care management organisation taking an interest in service brokerage without actually taking on a so called 'broker'. Issues around service brokerage and individualised funding arose in the care management organisation and residential consortium but not in the day centre.

DESCRIPTION of C M: 'C M and Case Management: Griffiths (1988) para 3.3. Care management has been developed to 'ensure that the resources available are used in the most effective way to meet individual care needs'. C M's strongest link is with the Disabled Person's Act (1986) which did not implement access to an independent representative as it was assumed that the Community Care Act would cover this later. The picking up of this professional independent advocacy/broker role is the heart of C M.' C M Extra Notes.

In the residential consortium service brokerage was seen as a innovative, creative way of looking for and forming alternative support.

'This is a provider organisation with a Service Brokerage contract. It works well, Service Brokers are the experts in looking for alternative support.'  
R C Extra Notes (1/2/3).

Individualised funding was also mentioned as an issue for improving services.

'1) g) Moving to a new system. Support workers can hold budgets for every day staff new manager wants to devolve budgets to team leader/team workers. In the end may even go to clients.' R C Interview (1) P I 3.

The service broker seemed to be not recognised by one user. As with the advocacy section 9.1.1 a 'person centered' not 'organisation centered' approach within the service was presented by the users interviewed.

'6) a) Meeting with my mum, her partner and the R C (1) people. Plus advocate he always comes over to the meetings, man talks to me. I don't know what advocate means. We just do things together. Don't have a service broker, don't know what one is (does have one according to staff).'  
R C Interview (1) U I 1.

Another user had a positive relationship with the broker but was unaware of their role.

'9) b) Sometimes I have a service broker seems a nice man does not do much.'  
R C Interview (1) U I 2.

The following extracts describe the actions taken by a service broker from the point of view of users.

'2) c) Had a meeting with my sister and a service broker, employer, brother and R C (1) support worker. It was a good meeting but too heavy, brother could not tell what they were saying. I talked about kids and moving and that. They listened alright. Things did basically change, the removal lorry came. Me and service broker had a talk about rent, support and rates in her office. Get on with her quite good. Service broker helps with rents and hours of support. I talk to the service broker if I got a problem. Tell everybody same thing. I get service broker if I have a problem with my house, I see housing office not service broker.' R C Interview (1) U I 3.

A second extract illustrates the work of service brokers.

'3) c) Down below in R C is service broker her and head of R C (2) have organised my support tenant. It was my idea when I moved here I thought I did not want anyone around. Then I got lonely. I told head of R C (2) and she got in touch with service broker. Interviewed 5 of them (tenants). All but one dropped out. I got some information about him from the service broker and I got some questions to ask him. He mentioned the dog by name. Service broker - she helps you, I used to go there and ask her, it's me that started it all off. I was a bit lonely at night. Support tenant lives here rent free, it's all about having a bit of company.' R C Interview (2) U I 2.

The relationship of service brokerage to money is again highlighted in the following extract.

'2) c) Service Brokerage is about hard cash - empowered to have it, if we advise in a family the phone will not stop ringing with parents of people with learning disabilities. Housing money - R C may take ages. I have to ring up and say now! Staff side is fine not now housing side is poor. Some small payment co-sign and get it. Counsellor service - cannot get it through psychology - keyworker gets person we reclaim it out of service costs.'  
R C Interview (3) P I 3.

A recognition of money as power is also shown by the same professional, along with the degree of disability that affects the role of advocate. The relation of more fuss meaning more money is suggested.

'2) e) Encourage, we just do it. Service brokerage clients get more money because they make more fuss. It is important that advocates have training etc. It easy to find advocates to work with people who have lots of needs. Staff do find it more difficult to work with people who are more able. Tea, no! I want to go out, you have to be more imaginative. Lots more skill in the job. The aim of the work is to make the job harder for yourself and ultimately put yourself out of work. Move from a 24 hour service to a 3 hour service. Everyone has access to a service broker - not all use them. There are 3 people using service brokerage directly at the moment.' R C Interview (3) U I 1.

This last extract shows the preferential treatment users may receive if the brokers apply pressure to the service. It may be considered that the work of the broker in the residential consortium is a replacement for a poor service. That is the key, hands on workers are not empowered or trained enough to improve the quality of service for the user's. The service broker therefore is called upon to make the service responsive to the users needs by using their semi-independence. The service broker acting against the keyworker provides a clash within the service and perhaps a confusing conflict for the user concerned.

'9) b) Don't need much, service broker I have her, she just comes around to see how I am and my family. She has come to the meetings with me. Helped me when my keyworker used to boss me about. She helps me, she used to be a manager here.' R C Interview (3) U I 1.

The action of broker from the view of users is shown in the following extract.

'U V 2) Go on one (course at college) I wanted to go on. Ask service broker. Takes less and less of a role in design of my service. Find appropriate people to do that.' R C Vignette (3) U V 3.

The power relationship of service brokerage to users is highlighted in the following extract.

'2) e) R C (3) they have some good workers. They do make changes to my service and they tell me when a new worker is taking over. Service brokerage - it works well for me because the power in the relationship is given to me.'  
R C Interview (3) U I 3.



The criticism is made that the service broker does not know the user as well as other staff members.

'P V 2) Service broker lives in 'cloud cuckoo land' and does not know the clients well, the second service broker.....user calls service brokerage 'pawn brokers'. You need the right people to do it give them tough interviews from outside.' R C Vignette (3) P V 1.

Another worker expressed doubt about the role of service brokers within the residential consortium.

'1) e) I'm confused about what she (service broker) does. I don't know what her role is, is she there to monitor or not? She writes contracts - why can't we do that as we write the service consistency. 75% of named support workers were named people - wanted to put in as part of contract - I tried to discuss it with her as she knows the service - she was on a heavy power trip - when I described it with .....(Worker)..... I'm unsure about service brokerage its a word you do not associate with people (users).' R C Interview (1) P I 1.

There is another issue here about the title of service brokerage. There was a desire to drop service brokerage as a descriptive title as it is too 'business like'. A second professional points out a series of problems around the work of service brokers.

'1) e) Service brokerage - staff feel resentment, the question of how they interfere in support, they may dictate to us. They are seen as part of quality of service assurance. How can they be sure it actually happens as they are not there all the time? We can just tell them it's Okay. There is a conflict between keyworker and service brokerage, service brokerage puts pressure on the client to move when they did not want to. We see her everyday unlike service broker. Maybe just tetchy problems about where the boundaries lie. The service broker is going overboard working for one client as does not check out other clients' needs.'

R C Interview (1) P I 2.

The role of the broker is to work predominantly with one client, similar to the role of the advocate. Is there a clash of interests here, is the service broker a quality checker or an advocate? What follows is a positive overview of the role of service broker by one member of staff.

'1) d) Changes especially for (user). Service is not right for her this year. User wants to move, service broker taken it on board, more therapy - service broker helping to get it sorted. Service broker - She is the overseer, if R C (2) don't help or user has a problem we go to service broker. She is good, going to do best she can for user. She has more power than other people. She says it must happen and R C (2) will listen and will try it e.g user being vulnerable. It's good because she does not work for R C (2) and she is on the outside - not directly involved. 'She has got more clout'. She will talk to everyone involved getting a full picture. The service broker is always available to the user even though she has a lot of clients.' R C Interview (3) P 1.

The service broker is seen above as having more power than other workers and therefore has a capacity to change the service for the individual rapidly. They are seen as an ‘overseer’ with a full picture of the users’ life to draw upon.

‘2) a) Patience - especially with user. Totally unshockable - you lose it all, new managers have a slight problems with my relaxed relationships with user. The users service broker has a Programme of Individual Needs (PIN) meeting - no bits of paper just informed chat about the users life over the next six months. Me and users, her mum go out and its not like working, its really a good day.’  
R C Interview (3) P 1.

The relaxed less formal working environment seems to be reported favorably for workers. Finally staff may be wary of brokers, perhaps threatened by them, or fearing the unknown.

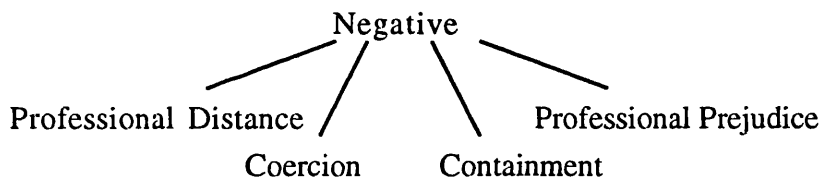
‘5) i) I could guarantee what is the best for her - budget, hours of support, needs. I would like to try that. This is not a next step up, so is it down? I am a trained masseur but they do not use me. User what she says she wants and actually wants may be different. Some of staff think service brokers are out to get them.’ R C Interview (3) P 1.

**9.2 Negative Power**

Figure 30

Sub Themes

Components



The majority of comments of a negative nature on power and its use came from the day centre.

**9.2.1 Professional Distance**

One professional from the care management organisation discusses the difficulties around keeping a ‘professional distance’ from and being ‘over familiar’ with users of the service. They also express here a desire not to be put at a high status by the users they work with.

‘4) a) It’s difficult sometimes to get the balance, I’m not there as a friend, a friendly approach perhaps but not to befriend them. You can do things in a professional way without being professional. Treating them as anyone else you might meet. Not put them on a pedestal, it can be helpful to destroy this when you make a mistake.’ C M Interview P I 2.

This is an issue of status, an approach treating the user the same as everyone else. The following extract shows the importance of time in dictating when and how professionals can become 'familiar' with users. A fear of burnout is a recurring issue in the work place, across all the organisations.

'4) b) Too friendly - there is usually a starting and finishing point between you both. The isolation they feel. I am not the person for them to link into, but someone else may be. You don't have unlimited time. It is hard to distinguish between friendly, interested in and 'paid'. Do you see them at the weekend? I do not tend to mix social and work lives anyway. To phone me Saturday evening is a loss of boundaries and I could become overloaded.'  
C M Interview P I 2.

At the day centre one professional stresses the importance of maintaining a professional distance.

'4) a) No not as friends - don't see them socially. If they are in a therapy group it is not healthy to see them - professional distance is important. I will be going out of their lives for 8 weeks to Australia. I therefore try to maintain some kind of distance.' D C Interview P I 5.

The same professional sees people with learning disabilities having a different 'world view' than non-disabled people. This following extract illustrates this stance.

'4) b) It is professional distance. We have different perspectives on life than they do. I recognise the difference. We have different life experiences, theirs is based around carers, helpers and professionals and other people with learning disabilities.' D C Interview P I 5.

Another day centre professional admitted that close personal relationships are actively discouraged in the organisational training at the day centre.

'4) b) Relationships take time. There is no limit except time. Professional - I have been told on a course that it has to be professional relationship. I work for a service and they use that service.' D C Interview P I 6.

The following extract refers to staff burnout and other perceived negative effects of user contact. Frustration at work can also lead to the blocking of creative ideas. The professional distance exists between staff and users as well as staff and management. The distance is not a simple linear one but has dimensions around management and other hierarchical levels.

'1) g) It works because D C P 2 has really fought to associate with staff. He has been told over the years to take a step back from being friendly with staff. You need to be friendly with staff. You are not a headmaster. Need more support - different staff/management turn over - not got consistency. Get 2/3 year burnout. Start off with great ideas. You end up doing nothing, blocked by what you can/cannot do, both practical and economic.' D C Interview P I 7.

The day centre appears to be an environment where it is hard to do one to one work. This allows professionals to protect themselves from getting close to users in terms of personal relationships. One professional illustrates this in terms of their self-protection concerning bereavement.

4) b) Old job I would feel that I should visit people - give me a lot of trouble. Only here 9-5 don't see their home life. eg when they are ill. I try to keep a professional distance from my work. As you can get over close and it hurts when they die. I am here because I am paid to be here.' D C Interview P I 8.

During the observations the manager made it clear that a professional distance existed between himself, the workers and the users.

'2.30 DESCRIPTION: Tea Time: manager has a special tea cup. 20 users for tea two staff on tea duty. One user shouts and causes a chain reaction of further shouting. Two staff trying to explain the principles of personal distance. A practical demonstration that on the face of it looks informative. But gives the feeling of the user being 'told off'. D C Observations 1.

There appears to be an agreement between the day centre and residential consortium that these environments allow closer relationships to form than in the day centre.

'4) a) Their disability I look upon it as just a difficulty that I have to explain things in a certain way. It takes a different member of staff to get through to them. It is not friendship like I have outside, as we do not communicate that well about everything in people's life. They see us as staff rather than friends, we are here for them - have a laugh and joke but we are staff at the end of the day.' R C Interview (2) P I 1.

The following extract shows that workers can be penalised for becoming 'too close' to users. The worker here refers to being deliberately moved on at work before a relationship can develop with the user.

'1) d) Over 2 years I could get him (user) to a situation where he could live alone. But they will move me. They don't like staff to get too friendly with the clients. He was typical Down's Syndrome they dressed him too short, shoes too big.....R C (3) they said I had worked too long with client. Had to move on. But another person in the organisation had worked for 7 years with one person. Life share - no reason why I could not do it.' R C Interview (3) P I 2.

Is friendship between professionals and users always desirable and possible? Can the professional be every user's friend? There can be no set rules of friendship formation. Intimate relationships can form between very unusual people in very strange circumstance. There needs to be a distinction drawn between friendships and friendly relationships. This area is of particular interest around challenging behaviour. Also some users will be generally more liked than others. What kind of quality of life exists for those more unpopular users? Further to this, what happens if friendship between professionals and users develops in a sexual way? How do we define abuse here?

### **9.2.2 Professional Prejudice**

The following extracts highlight professional prejudice in action. It may be possible that as a result of the training and experience of being a professional they become more prejudiced in comparison to ordinary members of the public. This connects with the earlier work on labelling in section 8.1.

'03.45 I am supposed to meet a doctor a specialist in the field I suppose, they are going to know more about me than I do. He will probably only see me for 5 minutes. He would not wash my wheels (on the wheelchair) he would have to scrub up first. One doctor asked me in all seriousness if I was waving my arms about on purpose (user has spasticity of movement in her arms).'

C M Observations.

17/11/94 On cover: 'I wipe bums and help out. If someone shits themselves I tidy it up.' Basically there are some guys who just don't want to do this kind of work. They may be clearing some shit up and you can tell they hate doing it and some say its' horrible or these people don't deserve to live they should have died. I say they should get another job.' D C Extra Notes.

Some of the training available appears to be helpful in combating and challenging negative attitudes held by professionals.

'2) h) Training has been good the opportunities are good. Changed many attitudes over the two years to working with learning disabilities. The people are a lot more capable than I first thought.' D C Interview P I 5.

The degree of negative attitudes can be extreme. The knowledge of services and the day to day understanding of the lives of people with learning disabilities has led one professional at the day centre to suggest considering having a termination if they discovered that they were going to give birth to a child with a learning disability.

'1) d) If I had a Down's Syndrome child I would consider getting rid of it. I know the problems they have. The Down's Syndrome programme on T.V. One of them (Person with Down's Syndrome in the day centre) said "The sadness is that they think we have such an unhappy life. We don't." It's our job to educate people.' D C Interview P I 8.

One professional at the residential consortium recognises that staff can be 'bigoted'. Work in this area being seen as not just another job, you need to have an understanding of general humanity. The following extract shows that one professional believes that if a worker is negative in their attitude to other members of staff they will be negative to users.

'2) a) Have to fundamentally believe in what you are doing. It is not just another job. Concern for equality and people rights, some sort rights, access. Disability comes last, person comes first. Sounds really twee its not making baked beans it's about people. Staff if you think one is being prejudiced - because of your sexuality we will have bigots working with people with disabilities. Bigots to other staff will be bigots to people with disabilities it runs right through it.' R C Interview (3) P I 3.

### 9.2.3 Coercion

One account stands out on its own in the day centre, one professional describes a violent act of abuse against one of the users of the service. This is framed by the worker as a mutually beneficial process allowing them future boundaries to work within.

'14/10/94 01.45 One teacher told me a story 'that a user used to be a bit of a 'bastard' when he first came here. One day (two years ago) came into his class and smashed up a machine. I pinned him against the wall and hit him. Not touched me since.' D C Extra Notes.

Staff are recorded as having a tendency to use users at the centre as 'gofas' (to act as someone who repeatedly goes for things), to gain a kind of 'professional perk'. This connects with the staff helper issue raised in section 8.1.2. This is not to deny the benefits and pleasures that users may get from this position in terms of status, but this is also not to avoid the possibility of exploitation.

'4) b) I like knitting and swimming I don't have time I'm always rushing around making pots of tea for staff. I used to always help my father I loved him when he was alive. He spoiled me.' D C Interview U I 3.

'2) a) Are you using it (work) for your own psychological sense of power or to get love. As a drama therapist we need to look at the motivation of work.'

D C Interview P I 5.

Individual power is lost when there is a large number of users of the day centre service.

'1) b) London Borough of ..... Social Services. Rights of individuals at centre. They are adults at the centre. You can give out leaflets on how to work but at the grass roots it's different carrying it out. A lot of stuff don't get carried out. As care workers the emphasis is on care, most people care, we are suppose to listen but we don't. (Policy says we should listen and understand). It's written by people who have never been to a centre. It's vague and spreads across the service (policy). Service is geared up so we are the masters they obey. There are so many people here (users) that the individual/personal care patterns are lost. People programs in smaller day centre are tailored to their individual needs. It ends up like a machine due to the number of people in this big centre.'

D C Interview P I 6.

A number of dilemmas are reported by professionals working in the day centre. The dilemma takes the form of the question; is it alright to do wrong now for good later, can the end justify the means? People appear to be viewed not as individuals but as parts of a larger mechanism. This mechanism demands to be run smoothly.

'1) b) Anti-discrimination. Working party - creating documents for use around challenging behaviour. There are guidelines but it is alright to try something for example: do a cooking course - they may not want to do it. They need to go to find out. Therefore force them to go to college - as a keyworker, but they don't like it they never go again. As a keyworker you can have more influence. Nick their woolly hat and dangle it in front of them so they follow it onto the bus. Need to do this to allow them to learn a new skill. The management sees your aims so turns a blind eye to it. I would not do something nasty. I would never pull someones hand but still try and get them on the bus, it's better than sitting around.' D C Interview P I 8.

The research vignettes are particularly useful in presenting and provoking such conflicts. From the following examples the question arises is it acceptable to perform a morally questionable act now for a benefit later?

'P V 2) I would push her with a quiet hand. Got my son to go on a slide once he did it he loved it. Pushing them to do it this they can make an informed choice. Try it and then decide. Knowledge of that persons needs, etc is vital.' D C Vignette P V 3.

The professional justification for such acts is in informed choice, that is you have to experience something to say no to it.

'P V 2) Most people like coming here. I can only think of one person who did not like coming here. We bend the rules, bundle people onto a coach on one day. Shout across room at users to do something'. D C Vignette P V 5.

The day centre worker admits here that rules about conduct at the day centre are flexible or broken in order to gain a desired effect. In the residential consortium dilemmas also occur, such as when do you force someone to clean their room, when it affects other people's quality of life? Do you force action when there is a health risk? Do you have a policy guidance for all of these dilemmas?

'P V 2) Let her go to the one she wants to go to (college course). If she loses interest then a 1 to 1 group may be better. She can try either group if she wants to. Why should we teach the 'men' in the home to cook because I have elderly parents, why should they cook? One user has major health problems and will not see a doctor I tried to force him and he ran away, it taught me a lesson. Should we have a policy on this? Forcing a man with a chest complaint to get out of bed and therefore not neglect him? I would encourage him to get up as I would my own father. They are my friends I care about them. We have to force them to clean because it affects other people.' R C Vignette (2) P V 3.

The day centre seems to be the most likely setting for these dilemmas to occur and they seem to be very clear indicators of the staffs' underlying philosophy around empowerment. The day centre is the most pressured of the environments with large groups of people working to deadlines for college and other courses. This lends itself to coercive techniques to keep everything moving and running smoothly. Users'

negative experience of power within the day centre were recorded as follows:

'1) d) Go to a fete. To raise money, to go on holiday and buy Christmas presents. I would like to go on a day centre holiday but the staff at the home say I have not got enough money so they decide.' D C Interview U I 4.

'2) e) Do not know (D C P 3) decides what to do in where we go, what to do and who with.' D C Interview U I 9.

It appears that basic choice and control over decisions is not available to these people in their lives. The issue of control is presented in the observations:

'02.50 DESCRIPTION: Tea's over 3 staff standing outside talking. Users at tables or walking around. Users move back to gym for sports. COMMENTS: People on tea duty 3 staff look/act more like bouncers than carers.'

D C Observations 3.

'U V 2) Do what staff want me to do, I do not want to get into trouble. They might argue about it with me. I am happy to please people.'

D C Vignette U V 1.

### 9.2.4 Containment

Professionals expressed some disappointment with the system they use:

'2.00 DESCRIPTION: Very quiet only one user and two staff in entrance. One user outside. The T.V is showing a film in the area that used to be the workshop. Group is also playing a game behind in the same room. Supervised by staff. Still arguing where user should be. COMMENT: With this many people there has to be an element of physical containment.' D C Observations 1.

'1) a) I thought it was about allowing people to do the things they want to do. It turned out to be a containment centre to fill peoples days to try and get results. The intentions were to teach them to move, independent living skills: hygiene/self providing and self esteem. The ideal place would be a small setting of 15 users with 3 staff doing work allowing people to move into the community. We are not reaching people at the moment.' D C Interview P I 7.

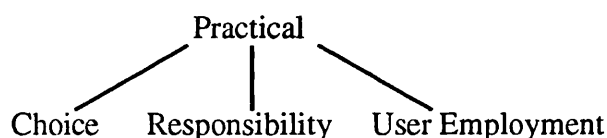
This day centre worker is expressing frustration at not being able to follow the ideals that first inspired this choice of work. Notions of education and personal development were replaced by control and containment approaches.

### 9.3 Practical Power

Figure 31

Sub Themes

Components





### 9.3.1 Choice

The areas explored in the users' experiences of choice are as follows: degree of disability, the responsibility that accompanies any choice, the attitudes of workers, the pressure on workers from outside sources e.g other staff, management and the public. In addition money, institutionalisation, fear, low expectations, risk management, the numbers of options on offer also affect real choice. Choice was not recorded as a major issue in the care management organisation, users expressing a high degree of independence:

'2) a) Power: To do things the way I want to do, I live alone and so I can please myself. I can sleep, I don't have to ask anyone, living with someone is hard they can be irritating.' C M Interview U I 6.

The selection of options for users of the day centre appears extensive.

'Social Education Centre: The centre provides a programme of activities reformatted every September. They use college time table symbols. List of courses at the Day Centre: Mixed Sport, Community Project, Woodwork, Basic Education, Cook Lunch Yourself, Puzzles and Games, Communication, Life stories, Projects, Dance, Outings/Shopping Domestic Skills, Craft, Swimming, Drama, Sensory/Tactile, Music, Moving on Changes, Looking Good Feeling Good, Art, Mens Group, Computer, Casting and Sculpture, Relaxation, Flower Arranging, Sandwich Making, Current Affairs, Using Rec/Money, Self Advocacy, Lets Talk, Pottery, Magazine, Gujariti Group, Needlework and Women's Group (The college timetable is also available in Symbols.) Part Time Courses: At the local college for people with learning difficulties to choose from: Local Walks, Printing, Drama, Literacy/Numeracy, Stained Glass level 2, Craft, Dance, Photography, How to complain, Play-reading, Life skills, Cookery, Singing, Speak with confidence, Yoga, Skills of card games, Travelling, Road safety, New Horizons.' D C Documentation.

The process of choosing courses is intended to be informed and empowering:

'Senior: Other day centres set down individual needs in an assessment. Here they have a large open day where everyone looks at photos etc and chooses a course to do. Thought it was for staff benefit, but it worked out really well. Within each group people have different needs. 'Took a lot of pride in timetable.' Focus on it, look to future, very impressive. Some of things on the timetable have been repeatedly offered. Some things not taken up. Popular: outings, sport and drama therapy. Many people still walking around doing nothing.' D C Extra Notes.

This last section highlights the pride that some users take in these timetables which they carry with them at all times in a waterproof packet. The limits of choice in action can be seen from the following extract.

'Only 1 out of 2 choices, allowed over salads on trolley for users. One user allowed to roam as it is difficult to keep her in one place for any length of time. Drivers are like delivery men - waiting to do things/take staff and deliver people. Another user sits on sofa in entrance for most of the day. Profound mood swings of staff in centre. One male user says nothing in centre as there are too many people; out of centre he says a lot.' D C Extra Notes.

The opportunity for choice here is low. People who are presumed to not understand choice are given less choice or no choice, they appear to be sometimes allowed to roam the day centre unchecked. Some workers in the day centre commenting on the choice made available to users:

'1) c) Five years working here. Philosophy has changed. I am on the edge of staff group. Because no one agrees with me over choice and other issues. The value of a person. There has never been a clear cut definition of what it is to be a user in the day centre. You spend 15 years in a regime having to choose between two things. Choices are not informed. Informed choice is not that free here, it may be just to please a small group of people and how permanent is that change?' D C Interview P I 1.

The freedom (see section 9.1.3) of choice was a raised issue. The influence of the day centre and residential consortium on choice for users appears profound:

'11.20 DESCRIPTION: Conversation with staff - Power; 'It corrupts I feel I do things that take power away from users because I am lazy.' 'This place makes you take choice away from people (users).' D C Observations 1.

'4) b) It's where they are coming from some have been in institutions for 50/60 years. We are not as bad as old staff but we are still staff, it is difficult to get across the choice as they are not used to it. They thought we were trying to catch them out years ago, when we asked then what choice they wanted.' R C Interview (2) P I 1.

Choice appears more difficult to give to users of the day centre as there is such a large number of users and a relatively small number of choices in the 'educational' set up. There also seems to be a negative reaction to choice by some users, having been 'trained' into believing that choice meant change things for the worse, or basically not being familiar with having any choice. Staff stated that users have a right to make the 'wrong choice', a right to fail and therefore learn from their mistakes.

'4) a) 'Friends' is primary opinion of people (users), started counselling not just do that and do this. Sometimes you know they are making choices that are wrong. Make them aware that they may be wrong. Day centre workers used to be in part social workers, can not spend time doing these things now. It is a difficult balance.' D C Interview P I 3.

In the day centre there appears to be a move away from the traditional role of social worker as hands on helpers. Workers felt that they were not able to spend quality time with people. Choice is likened to the concept of a market in the day centre. This also shows that in this market users have some control over staff.

'1) c) More focus on community care. The price of bringing people into the community. Choice has come in a bigger way. One and a half years ago we had to offer what we did in the hall. If we didn't get any takers we had to think again. Its like the salad bar, it's supply and demand. Do not know where these ideas came from, management I suppose.' D C Interview P I 5.

The currency of choice appears increasing in the market place as demand increases. There is not full agreement at the day centre about the idea and practice of informed choice.

'1) a) Informed choice. Some need to be told - parents may have died. Some residential workers may not insist that she has a bath - she is going around smelly. The residential workers let people do what they want to do 'can't get her to do things in residential home they could not understand how I got her to do things.' Always friction between residential and day centre staff - phone me up and say ..... They won't bath. I say show her a run bath. Do you want this No! Do you want this No! Do you \want this No! (They might be a month walking around in dirty clothes.) Can't give people too much choice too soon. I don't give a shit if they walk around in dirty clothes...but I know what it feels like to have comments made about me if I am clean. Similar thing is that I am a big lady one of the users is big and residential staff put her in leggings.' D C Interview P I 7.

The day centre appears to be evolving from a place of containment to a more rewarding environment, where workers can question themselves as well as others.

'That is not appropriate dress. Looking good feeling good group. Start off with hair, make up (not letting them put on loads) but do it for them so they look good. When I came here first we were a containment centre - chosen own groups now I get a lot more out of it. People come together as a group (pair up) they would not have mixed socially normally. A lot of people have opened up to me - chatting is really important that they relate to me. I grew up with one user - play together did not see her as having learning disabilities just a bit soft, lost touch - spoke to me the first time about her mother and her brother's sexual and physical abuse, no therapy etc. just spoke to me. I spoke about my dad - she was helping me come to terms with the death of my father. I do question my values 'what the fuck is it all about'? In my room: quiet room, sex therapy, bereavement, basically everything.' D C Interview P I 7.

An issue in the residential consortium was whether informed choice was in conflict with an impartial selling of options by staff:

'P V 2) Informed choice - give her an informed choice of both of them. Playing on the advantages of both. Does depend on how much you sell them both, sell the second more with a balance with the one she really wants to do. She may not stick at both. Knowledge is power I base my decisions on my experience, I do not want to be away from the shop floor.' R C Vignette (2) P V 2.

There was an awareness of knowledge as power in this section. User choice in action in the day centre is illustrated in the following extracts. Users decisions are shown as:

'2) a) I decide what to eat. I choose my clothes and get dressed alone. Mum gets my clothes for me. Holiday in Spain I choose, the one in the Isle of Wight was chosen by my keyworker. In the evenings I watch T.V, me and my mum both decide what to watch.' D C Interview U I 1.

'1) d) Both college and out. Try different new things. I choose my new programme - my timetable of what to do.

2) a) College and courses and everything else I make decisions about. I choose what to watch; the soaps on T.V.' D C Interview U I 2.

The mixture of choice with support is shown as:

'9) b) Need help to buy clothes, big things in my room. They (staff) don't come at the weekends, I would prefer to go shopping at weekends.'

D C Interview U I 2.

'2) a) I make my own timetable here. I choose what I want to do and its on my own. My mum decides where I go on holiday and what I eat and what I do in the evenings. We both decide what we watch in the evenings.'

D C Interview U I 6.

'3) c) D C P 2 in charge of this place he makes all the important decisions. I have no say in changes.' D C Interview U I 8.

The worker decides for the user on a number of occasions:

'2) a) We have two cooks who cook, they decide what we eat, I don't mind this, I'm not fussy. Holiday ..... on a Caravan Holiday there was a Cabaret and sands. Three people and two staff, the residential staff decided where we went. Watch T.V don't go out I would like to go to the pub but I don't go. I like it when there is a fire and its nice and warm. Have jobs to tidy my bedroom. Keyworker at (residence) helps me. I have two keyworkers.'

D C Interview U I 9.

The role of the service appears to be to offer choice but this is dependent on the degree of disability of the person. Again the issue of molding people to choose arises here. It seems possible for a person to choose a different college course each year, but in five years time they will end up repeating the same courses. This is not the way an ordinary education system runs. Education here seems to be more of a construction around keeping people amused or just 'something to do' rather than their individual development. There is also an interesting notion at the end of this extract about making a deal with the client.

'P V 2) Why only two groups (college course) - find out what interests 50 year old women. Physical exercise appropriate to her age. Does she want to live independently. She has only one choice - with mild disabilities, she must be able to understand how to be responsible and stick it out. This is what I think but its her choice. Try and combine the two. Make a deal go once but then its up to her. Then if she wants to sit around all day it's up to her.'

D C Vignette P V 8.

The limits of choice present an interesting juxtaposition between protection and empowerment. This causes conflict over issues like the health of users in the service. There is a reluctance to look at the individual value base of the professional.

'12.30 Tobacco shop in the shopping centre he spends £37 on roll ups. Worker continues discussion - Choice organisations talk about freedom to do this, choose the wallpaper freedom to choose what to eat. But they don't talk about the freedom to come down stairs to the kitchen at 3 in the morning and eat 28 jars of potted meat or do all the cooking in one day then hoard it.'  
R C (1) Observations.

The boundaries of policy guidance are not clear in the residential consortium.

'3.35 Still watching T.V two workers in office joking. Comment by staff: These people do not want choice when they have been in the hospital for 50 years. They would go back tomorrow if they could. The user has no desire to choose between channels on the T.V.' R C (2) Observations.

The real test of the empowering nature of choice comes with the harder choices that people make. Another factor here is the control of users expectation through limiting choice. Choice can be seen here as an evolving process.

'2) c) Some clients had little choice - they were frightened of it - over years they have taken more interest. We are trying to make clients have more expectations of services and hopefully the services will go with that.  
2) d) Common sense I must have shared, confidence building for clients. They learn to be less frightened, or confident in choices they have made.'  
R C Interview (1) P I 2.

Risk assessment becomes an issue when choice is taken to its limit. In the community environment of the residential consortium a risk taking approach is a higher priority than in the day centre.

'P V 2) Encourage to make a decision about either, encourage her 101% to do the one she wants. If she does not like it she can come out of that one. Just leave it up to her, whichever would be fine. Where does this choice stop. If they want to go naked in the street it stops there. If we see a danger they can't. Tell management to cover yourself as it is a dangerous thing to take a choice for somebody. Its difficult with hygiene and safety to support someone say who smells. (Is it for me, them, society or their self - dignity) Its not clear, training helps but you have to add 'do unto others' sometimes they cannot makes decisions we have to do for them. e.g Someone with severe epilepsy wanted to go mountaineering with a friend. The friend was a bit barmy and not capable of supporting them. We said no to them.' R C Vignette (2) P V 1.

### 9.3.2 Responsibility

The role of the voluntary sector and its responsibility to user groups was stressed by one professional in the care management organisation.

'2) c) Money is the obvious answer, human resources - working people/voluntary people, information, equipment, office space. Access to financial resources - part of my role is financial management, spending responsibility - management committee, application identified and use of volunteers. 80% of expenditure is salary based. Should be effective structures to avoid abuse of finance. Financial regulations are often designed for larger bureaucracies so are difficult in smaller organisations. Status of advocates does not come through law but through approach - so you need to be well equipped.'  
C M Interview P I 1.

We can ask who is responsible to whom and where does the ultimate responsibility lie?

How can people be made responsible, if at all?

'2) e) Yes working basis: empowering process, not going and taking control of a person, this happens quite often - understand system, rights, how they can be involved in the process. Its a personal process - some people say you should do it all for them 'just take this away and make it better.' Its not always a neat division of tasks down the middle, you don't allow it to occur, I explain to people that I am going to do. We have to make people responsible. This is not always easy. Its an individual load - you not give people too much or too little to handle. People phone to use me as a self monitoring process.'  
C M Interview P 2.

Here dangers and responsibility relate to risk taking, which is not explored enough within the organisations studied. Responsibility can be related to qualification of workers.

'3) d) Yes - that is where the bias is, can develop new ideas. But if you were not taking responsibility for yourself can do damage. They did not look closely at my therapy qualifications here. How do you define drama therapy well, how do you define it? Need quiet room, confidentiality and further training.'  
D C Interview P I 5.

Also a fear of too much responsibility was voiced by one member of staff in the day centre, with regard to work in the residential setting. It appears that the day centre does not encourage involvement with users

'5) b) Residential - being hit, safety, too emotionally involved, you know everything about 6/7 people lives and get very close to them. I was a senior and had a lot of responsibility. Had an accident at work I was hit left with ringing in my ears. Did not get much support.'  
D C Interview P I 8.

Responsibility can be viewed negatively as protecting yourself against unfortunate consequences:

'P V 1) Write it up to make sure you cover yourself from responsibility. Or if it becomes regular can advise on things not to do.'  
R C Vignette (3) P V 1.

The difference between responsibility and blame is an interesting one. Blame and its avoidance is a negative dynamic of looking back, while responsibility appears as a positive way to look forward. Users may be aware that the boundaries of what care professionals are prepared or not prepared to do are framed by the responsibility owned by the care management organisation. This structure effects the control the user has over the care and their sense of power and freedom in the community.

'2) a) Yes with help from friends. Social services like home-care to go shopping for you so I went with her down Sainsburys. Social services get upset because they don't want to be responsible for me there. But I sorted it out (insurance?) 'I am responsible for me.' Only on DSS do the trolleys, fit but can't get much shopping in them and can't reach top shelf. C M Interview U I 3.

So the degree of responsibility is dependent on the environment the user experiences.

'8) b) I am responsible for the way I feel sometimes I feel sad - that is called life. One thing I never do is complain about my condition.' C M Interview U I 6.

This extract shows the potential for active acceptance by the person of their disability through taking responsibility. Two keyworkers to one user may be confusing when it comes to issues around responsibility in the day centre (positive deviance). Issues of responsibility and who to turn to when in need may be important to the user.

'Role of the Keyworker: 1) Overall responsibility for ensuring that the needs and interests of the persons are properly met. 12) Responsibility for case reviews: - collecting views and information from the staff - writing report - attending review - reporting back to staff - ensuring review decisions are implemented. 14) Responsibility for the person's physical needs where appropriate. 16) Responsibility for the person spare clothing.'

D C Documentation.

### **9.3.3 User Employment**

Employment was an important issue for users of all three organisations. The value of employment is stressed by one user of the care management organisation. This user expresses a need to overcompensate for her disability by working harder and being tougher in the eyes of the other employees (positive deviance).

'2) a) I do talk up for myself. At a job interview they ask me if I can break a bone typing (user has brittle bone disease). If I break something I will go to hospital (in it anyway) and wheel myself back. He could not make his mind up about giving me a job. You have to talk up. Work harder than people who don't have a disability. People think if you break something you are off but I can work with a plaster on.' C M Interview U I 2.

The day centre users produce a magazine and sell it within the day centre.

'20/10/94 02.15 Selling copies of magazine (10p each) to users/staff in the dining hall. Three users: one counting money, one getting money, one helping out.' D C Extra Notes.

One worker in the day centre discusses the problems of gaining employment for users in the current work climate. He questions whether the role of the day centre is about job preparation or therapy for users?

'1) a) I started as a horticultural instructor to make jobs for people. Then compulsory and competitive tendering came in. The chance of getting into a work gang reduced. More able people left. A lot of cheap labour was around. To what extent could they (users) be commercial? Only the best students produced a lot of stuff. Is it all about money or therapy? They moved it all over to therapy. Theoretical not practical, provide the students with enough skills/abilities to lead a fulfilling life - job trainers. Don't want people just pushing trolleys around they must be multi-skilled..... our students are pissed off because they went to college and cannot get a job.' DC Interview P I 3.

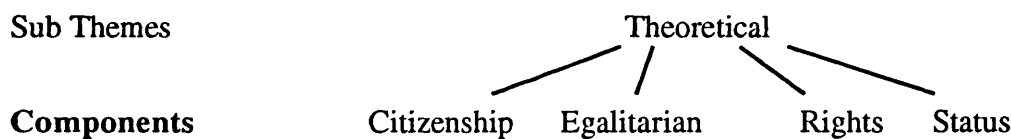
A user within the residential consortium does work and describes the benefits from doing so in the community.

'1) c) Like working, basically yes. I like what I'm doing and the atmosphere there. Paid for work £54 a week'.

'1) d) See employment lady on a Tuesday morning to look for more work. I would like more work.' RC Interview (1) U I 3.

## 9.4 Theoretical Power

Figure 32



### 9.4.1 Citizenship

Citizenship was only referred to as an important issue within the care management organisation. It was seen as a term that should be taking over from advocacy. Both the users and professionals within this service appear more political than the other organisations in the description and explanation of the role of the service. It was stated that advocacy should be available for anyone in the poverty trap or in need.

'1) d) Potential therefore to develop advocacy (drop term) in a bigger movement relating to citizenship as a tool used by anyone. The working class single mother needs an advocate as much as a disabled man. The general level of disempowerment in the community is important here. Services: I mean a general way, I mean a structure/systems.' CM Interview P I 1.

Active public membership is seen as fundamental to citizenship by the care management organisation.

'13) g) A lot of disabled people cannot use public transport e.g stairs in underground. I am a member of the public I can not use parking space. I had lost everything I was a mother/wife/person because of the disability. (Underground - not a-disabled world).' CM Interview U I 7.



### **9.4.2 Egalitarianism**

Egalitarianism is an issue that arose again only in the care management organisation. This may be due to the higher politicalisation amongst the physically disabled peoples movement.

'1) g) The organisation is still very much managed by staff, power lies with knowledge. It is difficult for service users to give the quantity and quality of information to make it happen. Those users who do have knowledge don't have time they have no time because they are on all sort of other ones. The management committee is not effective around service professions. Future return to an egalitarian approach within a team structure with overall responsible with a hierarchy.'

'2) d) Suppose so. I hopefully have an insight into the concept of power, personally very egalitarian, worker potential should be developed and used to their full in a team based approach. I have a danger of undervaluing my own experience as a service user. Psychology of being told that my experience is not of value.' C M Interview P I 1.

These comments made by the professional from the care management organisation show that they may undervalue their own experience as users.

### **9.4.3 Rights**

Rights are put into policy documents in the following organisations.

'As stated in May of 1989 the Principles of C M Care Management Services are: Case management: 'people not cases and we manage services not people'. Disabled people have the same human right to a voice and to C M as does the rest of the population. The range of community services should be brought together to enable the individual to take charge of his/her own life. Users should be actively involved in directing the planning, monitoring and evaluation of services case management should be a positive step towards equal access thus reversing the historical neglect of people with disability. People with a disability should be able to use all the facilities and amenities available to the general public.' C M Extra Notes.

Again the idea of the general public/citizens is present.

'1) b) London Borough of ..... Social Services. Rights of individuals at centre. They are adults at the centre. You can give out leaflets on how to work but at the grass roots its different carrying it out. A lot of stuff don't get carried out. As care workers the emphasis is on care, most people care, we are suppose to listen but we don't. (Policy says we should listen and understand). Its written by people who have never been to a centre. Its vague and spreads across the service (policy). Service is geared up so we are the masters they obey. There are so many people here (users) that the individual/personal care patterns are lost.

5) i) Qualification in social work. Make a difference to the whole service. We need people at the top with the right values. I really want to make a difference.' D C Interview P I 6.

Rights are recorded but are not being implemented by organisations. People do report not having rights, their boundaries being overstepped and sometimes ignored.

'1) e) Depends on personal relationships. Paternalistic attitude a while ago: conveyer belt bathing. In bed by 10.00 pm to being completely free. People don't have the right to live like pigs.' D C Interview P I 3.

Policy may not be a grass roots level and a mechanistic model may be present.

'U V 2) I would take my own advice. Its been my choice all along. Having a mild learning disability does not mean I can't support myself I tell people if they are wrong. Fight for my rights. Not like some houses in R C where everything is done for you. A right is having a say in what goes on in a house, staff just work there we have to live there.' R C Vignette (2) U V 2.

#### **9.4.4 Status**

Status has already been seen as important in advocacy (see section 9.1.1) and in the image of voluntary sector organisations. The giving up of power is frowned upon in terms of a loss of status.

'3) d) People are terrified of giving power away, professionals are being pushed into giving service users a say for several years. Some people are not sure about this.' C M Interview P I 2.

One user in the residential consortium reports seeing staff as having higher status than themselves:

'10) c) R C (1) are more important people than us, they say so. They helped me fill in a form for gas. They do things that are: more important. Would not want to be like them.' R C Interview (1) U I 3.

'10) c) I suppose that staff are more important than what we are, because they help out. They have more power because its their job, they have to help us, we have to do what we are told.' R C Interview (2) U I 1.

One staff member in the same organisation reports that some users only respond to power figures within the organisation. This does show that these users have a clear understanding of the power structure and hierarchy within the service system. The legacy of the institution is still with them.

'13) d) Not much power - it is done to authority the 'men' will sometimes respond only to the manager that comes from hospital. Only respond to power figure sometimes. Sometimes what I say has no say.' R C Interview (2) P I 1.

#### **9.5 Summary**

This chapter has brought together a number of themes and components that constitute power and choice for people with disabilities within the organisations studied. In doing so a number of questions have arisen. Firstly, is behaving in socially unacceptable ways a legitimate choice for disabled people? In other words should choice which is beyond the limits of socially acceptable behaviour be encouraged for disabled people, whilst being discouraged for the so called 'non-disable'? If empowerment is seen as

the ultimate goal for people, then choice is a priority and people could be supported to make choices which go against the accepted 'norms' of society. Within the day centre and residential consortium it appears choice of this kind is rarely encouraged.

In the day centre the dynamic appears that some users had too little freedom whereas some workers state they had too much. There also appears to be a conflict between care and control. For the day centre and residential consortium the language of care and control are intertwined and difficult to separate. For example 'choice' is seen as fundamental to 'empowerment' but also is described by one worker as something to be forced upon users. Professionals in these organisations also describe caring for people by doing what is in their best interest, but it is unclear what this actually means and whose best interests they are referring to?

Where users have power over professionals was another area of interest. Professionals on occasion were recorded craving attention from users. Challenging behaviour and subsequent issues around risk can also be an expressions of power by users over professional, for example a stated need for something to change. The role of workers as friends or professionals or friendly professionals is another recurring theme from this work. The issue about paid or unpaid support connects with this, can someone who is paid to care be a friend of the user? Friendship appears to have multiple meanings in the context of this study.

Professional distance was another recurring theme in the data collected. The problem of trying to convey an efficient professional approach without compromising equality. Also concern was expressed about where the professional boundaries lay. The day centre appears to be an environment where it is easier to have a clear professional distance. This may be due to the limited time available for one to one contact with users, the number of users present and the 9 to 5 working hours. The prejudice held by some professionals in the day centre and residential consortium is also illustrated by the work presented. The vulnerability of workers to burnout due to over involvement with users is described by a number of professionals in the studied organisations.

User consultation is a form of positive power for users. It is clear that the day centre does refer to user consultation in its aims and has had independent work carried out by People First to that effect. However the long term application of such work has not taken place. The User Committee Meetings (UCM) were viewed with skepticism from both users and professionals in the day centre. The importance of user employment is

expressed by users and professionals in all the organisations studied. The employment in the day centre workshops was stopped by management and is still the one major issue of complaint for users.

Service brokerage and the general empowering nature of individualised funding is mentioned by workers in the residential consortium and care management organisations. However professionals in the residential consortium pointed out a potential conflict of roles and interests for the service broker, particularly around the existing keyworker systems.

## **10 THE THEORY OF SERVICE FORUMS**

The previous two analysis chapters have presented a structure of main themes, sub-themes and components which arose out of the different sources of data collected in the context of the research questions. This collection and aggregation followed the principles of grounded theory laid out in the methodology chapter. The next two chapters present the conclusions from the research. This first chapter presents the theoretical context for chapter 11 which in turn addresses the three fundamental research questions which have driven the study:

- 1) How do the working styles of different organisations affect user's experiences of power and feelings about it?
- 2) How are service users blocked or incorporated in decision making and how do they develop a sense of power within the organisations studied?
- 3) How might a participatory service delivery system be constructed?

This chapter firstly summarises the literature review, laying the foundations for the answers to these research questions. Secondly, a section on the failings and successes of the research and how it might be improved upon in terms of both theoretical foundations and the practical aspects, is provided. This includes how different data sources have contributed to the overall case study, their resonance, interference and blending.

Thirdly this chapter presents the theory of 'service forums' as a means to interpret the transference and blocking of power within the organisations studied. The theory of service forums is an original contribution to the field. It provides a theoretical framework for analysis which can also be applied to other services structures in terms of future research and potential training needs. This work underpins the last section of the chapter which offers direct answers to the research questions above.

The policy implications of the work in terms of its key and significant findings are also presented in chapter 11. This includes the position of the research in the wider field of study and the direction and construction of future research projects.

## **10.1 Retrospective Methodology**

This section highlights the success and failures of the chosen methodology for the study. The complexity of the research was most profoundly felt in the practicalities of dealing simultaneously with a number of organisations, disability groups and disciplines. In one project contained within the residential consortium 'red tape' delayed the interviewing stage of the research by six months. It appeared that this was not, as stated by the organisation, to do with protection of 'vulnerable clients' but was more to do with a lack of motivation to arrange the meetings and interviews.

The semi-structured interview design used encouraged a focus on certain core themes but a more unstructured approach with a smaller subject group may have been of greater benefit. This would have given a greater insight into the issues of power and choice within a personal context. A fuller understanding of 'need' and 'power' would require their framing within the personal circumstances of the individual, however this takes time and effort and a more anthropological approach may be a better direction to take.

The methodology has provided a focus to explore the ethics of doing social science research. It has already been discussed that the social scientist is in a powerful position, acting as an over-viewer for the work and its interpretation. 'Negative' ethics are primarily concerned with how to avoid making simple ethical mistakes, 'Positive' ethics move towards involvement of the objects of the research (users) at as many stages of the conception, planning, implementation and write up of the research as possible. A number of 'postures' (sets of beliefs, attitudes and values) taken up by researchers have been discussed in the methodology chapter. An Integrated Posture in this kind of research involves a consideration of personal stigma within a political climate. The view is that the person with a disability is an individual within a societal situation which disempowers their particular labelled group. The individual must be given the same respect as 'just anyone else' but with considerations for their unique life experience which may have led them to a feeling of stigma. More involvement of the users of the services in the research process itself would have been preferred, hopefully giving them an opportunity to part own the work. As a result of the analysis it is clear that in the services studied, people with more severe disabilities have less choice and power than users with milder disabilities. Therefore there is a need to study this group in more depth.

The case study design used in this research allowed for combining various data sources in a constructive and meaningful way. These sources are the foundations for the theory of service posture and service cultures presented in this chapter. The case study design lends itself to this kind of comparative analysis through its inherent capacity for validity and reliability testing of the data sources.

## **10.2 The Analysis**

Practically speaking the computer qualitative data analysis software NUD•IST provided a good system for organising and coding of the research material. However there was a temptation in the program to 'over code'. The coding system is so powerful that self discipline and focus were required to keep coding within reasonable bounds. The spatial tree structure presented in NUD•IST was useful as it matches the style of thinking of the researcher, that is a representative diagrammatic analysis as apposed to chunks of raw text on paper or the computer screen. In using NUD•IST or any other similar software there comes a time when the material generated by the coding, categories and subsequent theory building needs to be ordered into a coherent narrative. NUD•IST is used as a tool to reach this point. Following the principles laid down by grounded theory no preconceived theory is applied to the analysis but the categories and themes which arose and are expounded in chapters 8 and 9 provide the bases for the theory of service forums which follows. This theory is presented as distinct from the work in NUD•IST in the sense that service forum are not mentioned but represents the clearest and fairest explanation of an on going process of analysis and theory building. What follows is the creation of an original theory which draws on and combines the literature review and research findings.

## **10.3 The Theory of Service Forums (Postures and Cultures)**

The core hypothesis of the study is that different service delivery systems will affect users' perceptions, experiences and feelings of power in different ways. The organising conceptual framework for the analysis of services born out of NUD•IST is that of 'service forums'. These encapsulate the routines and regimes both official and unofficial that transmit and block power, power that in turn is expressed and received by users of services. These forums can in turn be subdivided into 'service postures' and 'service culture'. According to the Oxford English Dictionary the Forum is a place of meeting for public discussion, the Posture a relative position of parts for an effect and the Culture a stage, types, form of development in civilizations. The idea of the service forum is likened to the Roman Forum both being places of organisation structure and organisational culture.

‘The whole population of Rome’s vast empire looked in the direction of the Forum.....Here was the nucleus of the business and commercial affairs of the empire....where elections were conducted and public notices posted and where every sort of political happening occurred.’

(Grant, 1970, p. 15)

Grant (1970) goes onto to stress the importance of active debate and the supreme power of the orator in the Forum. He also describes the myriad of events that took place in the Forum; killings, religious ceremonies, auctions, triumphant processions, shopping, how government was formed and laws passed. In fact as Rome was the centre of the civilized world at that time and the Forum was the centre of Rome, the Forum was therefore the centre of the world.

The Service Forum within the confines of this study refers to all that pertains to an organisation, both in its culture and posture. As with the Roman Forum, the rules of government and the culture of Rome. The Roman Forum is in essence a condensed version of what it is to be Roman, containing both physical laws and cultural expression. Service Forums in this study are both places where service postures are developed and debated along with the service cultures that are expressed. Neither the culture or posture exists in isolation, they feed off each other. The culture however is more fluid in nature, it has an attained action/direction which is designed by a group. The posture is an official set of responses which are more reactive and passive than the active/proactive nature of a culture within this contextualisation.

Service posture refers to the set of values and beliefs propertied by an organisation. This may also include the organisation’s rubric or its philosophical objectives. The service posture therefore is the inherent, internal and formal stance taken by an organisation. The organisations service culture is the unofficial presentation of the service. This culture may come from the service posture, it may be complementary, in opposition to it or even quite separate from it.



Figure 33 and 34 were developed in part from the work of Dowson (1991) and Lipsky (1980).

Figure 33

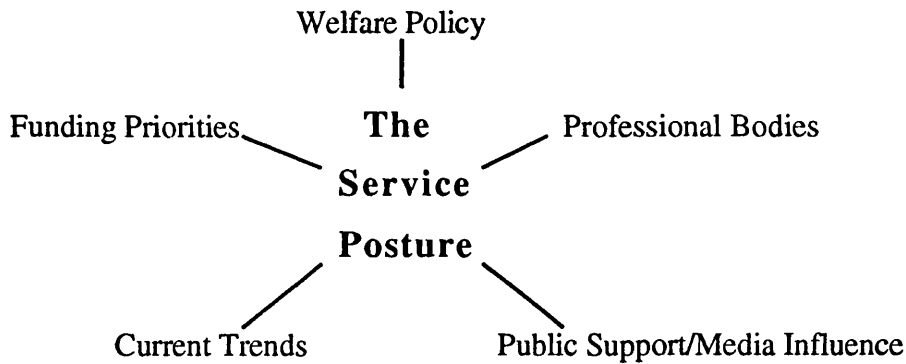


Figure 34

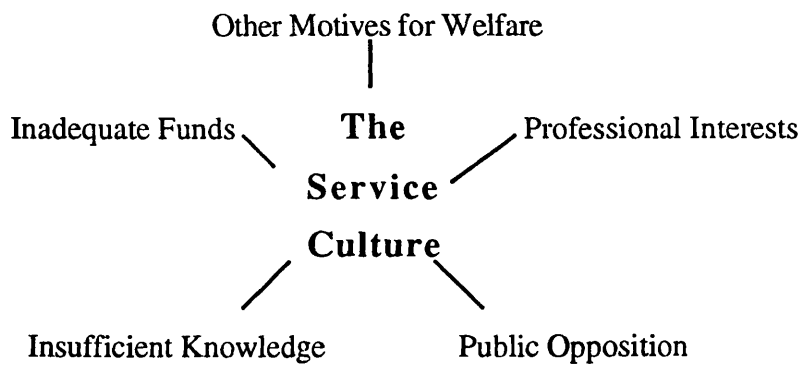
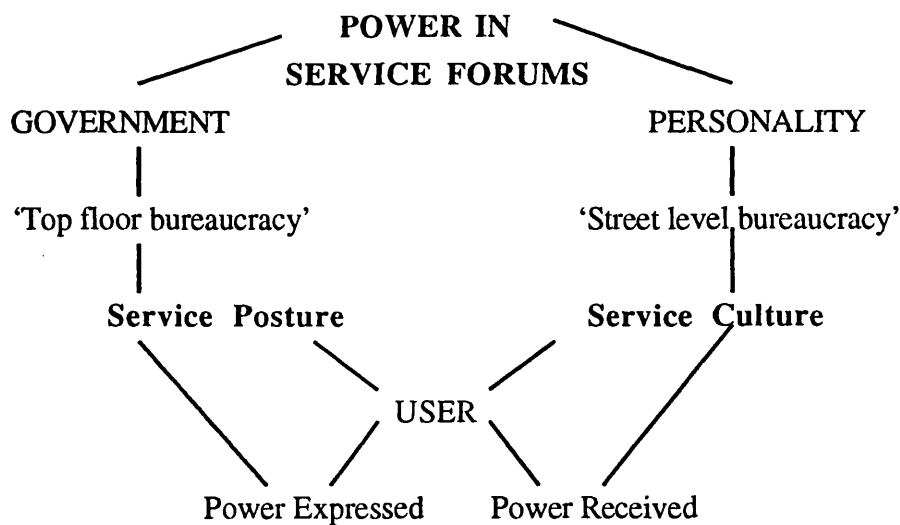


Figure 35 illustrates the relationship between service posture and culture within the service forum of an organisation.

Figure 35



In Figure 35 'Top floor bureaucracy' refers to the policy embodied in acts of parliament and the managers and structures put in place to enforce them. Lipsky's (1980) analysis of 'Street-level Bureaucracies' provides a vital aspect of the service culture. It explains how policy is structured by everyday workers through their systemic bias towards certain clients. Workers use many mechanisms for creating routines to cope with the pressures of their work. One such way is to distance themselves from users of services and create the potential for punitive action upon users who do not behave in appropriate ways within services. Lipsky would himself describe street-level bureaucrat's group action not as service culture but as 'agency behaviour'. Service cultures are harder to analyse than service postures due to their underground or semi-hidden nature. That is the unofficial, informal and potentially obscure nature of their actions.

The service forums of each organisation are the case studies being examined using a triangulation of perspectives; participant observations, user interviews and professional interviews and organisational documentation. This in turn gives rise to themes, sub themes and components which are now reconstructed into a theory of power for the organisations studied. This triangulation of data presented in the two previous analysis chapters therefore provides the material for the case study of each organisation's 'service forum'.

One criticism of this study's stance might be its reliance on verbal transmission of the service culture during interviews. Therefore the conclusions around service cultures are verbal reports, where in fact the service culture may be best understood in terms of the non-verbal. Observational findings are referred to, but in future work in this area greater emphases should be placed on this form of data collection.

#### **10.4 The Literature Review**

The literature review has served to provide a conceptual framework to the field of study, a theoretical base for the methodology and a context to place the findings. The working definition of Empowerment used in this study is Wolff (1985): 'The mechanism by which people, organizations, and communities gain mastery over their lives.....the aim should be to enhance the possibilities for people to control their own lives'. (p. 153)

This definition was chosen as it is less restrictive than many, allowing on a macro and micro level empowerment to be viewed as both personal and structural. Empowerment can therefore be seen as ownership, a belief that you will be listened to and as a result

action will be taken. This, for many organisations, involves a move from lip service to real participation for its users. In terms of the model of service forums, empowerment can be seen as the option for a person to seek non-services. Within services empowerment has an effect on both service posture and services cultures. Historically the definition and 'construction' of disability has been owned by non-disabled people, often professionals. As a result it can be considered part of a service postures. There is an empowering movement by disabled people to reclaim this 'disability mythology' or service culture away from professionals and the media. A new historical discourse of disability is being created and owned by disabled people, thus enabling, through what might be termed 'community empowerment', the potential for disabled people to become 'citizens' in their societies. This can include the integration of a minority group and the reframing of disability as a social construct. It is clear that the role of the advocate in this process can be a difficult one, as being both a professional providing a service (with a given service posture) and an advocate for people using that service (challenging this posture) can result in a conflict of interests. Empowerment at a local level can be a challenge to both organisations postures and cultures, where power can be blocked from education and access to quality information. This study has not set out to examine community empowerment, but it is touched upon in the presented work.

Social Control has a strong relationship with power and the roles that professionals and disabled people take or that are expected from them. Social control is an act which occurs at all levels and in all aspects of society, it is an expression of power often as a reaction to some form of conflict. It aims to influence, limit or eradicate deviance in reference to the norms and values that exist within that society. However in the assessment and response to need, professionals can use social controls explicitly and implicitly to create an environment that favours their own needs, which in turn may or may not conflict with those of the users of the service. The tension between care and control is an interesting one, as all services in some form are about control in relation to sets of norms enshrined in either service postures or cultures. The importance of this in terms of welfare and social policy is that people are not always that concerned with the design of the services they use, that is the service posture, but they may be more interested in more personal agendas for example having close friends and getting out more. Users in this research appear to be more concerned with the one to one relationships they have with workers enshrined in service cultures than the many policies and directives that represent service postures. They may have needs but they are not necessarily for services. Some people may require help and support that is perhaps best not defined within the parameters of a service, but in terms of funding and

structured provision of non-specific-services. The new Direct Payments Act (1996) may encourage creative, individualised and perhaps even 'non-service' support systems for people.

Expressing a Need is an expression of power, removing a need is also a powerful action. Having no needs is either a realisation of complete power or complete lack of power. The discussion around the definition of need has shown the importance of conflict in needs analysis and the confusion over demands and the consumerism that follows them. Historically professionals have had a tendency not to trust the voice of the user and their 'right' to make decisions about their own service provision, arguing they will choose an inappropriate package of care. This may be demonstrated through the service posture of an organisation or the service culture created by the professionals working within it. 'Informed choice' is in vogue in service postures but still cases of 'enforced choice' occur as demonstrated by the service cultures studied in the research.

Recent English Community Care Policy has certainly aided the move for people from institutional care into houses in towns and cities across the country. The extent to which these people have become legitimate members of their local communities is however in question. True citizenship involves both the political dimensions of participation and power sharing. Integration into routine life for people with disabilities again is a troubled area and what constitutes 'normal', 'ordinary' or 'homely' living arrangements are difficult to quantify and qualify. Findings from this work have shown that some of these phrases are hollow, recent research being focussed more on the multi-disciplinary, multi-sector and the cost outcomes of community care policy. Post Griffiths policy has been a move towards a restructuring of service postures in terms of needs-led objectives. As a result user involvement and empowerment have become the buzz words of the 90s. This thesis has shown the importance of service cultures for three organisations in relation to this paradigm shift. Policy rarely attempts to influence service culture directly but it does in directly have a strong effect even if it is rather unpredictable. Governments cannot legislate people into 'caring' or 'feeling responsible' for members of a community, policy can only act to educate, encourage and direct public thinking. The power of service cultures to make and shape actions and interactions within services is evident in the next chapter.

Debates around Service Design in the 1990s have been heightened through the rise in consumerism, individualism and interest in empowerment and quality of life. There is no evidence that the market will provide assurances to the quality, consistency and long term security that users require unless strong and clear accountability and inspection measures are put in place (by users themselves) in the form of clear service postures. If care management is to give users of services more power then it will have to be more needs-led. Care managers will have to shrug off their inherent gate-keeping roles and create a new service culture demonstrating more independency from the statutory bodies that fund them. Users do need protecting from manipulative services within these new markets as much as they needed protecting from the negative consequences of the old institutional systems.

## 11 CONCLUSION

This final chapter takes the theory of 'service forums' developed out of the case studies and applies it back onto the three organisations studied. It provides an outline of each organisation's service forum, unpacking each into its respective service postures and service cultures. Finally the initial research questions are addressed.

### 11.1 Overview

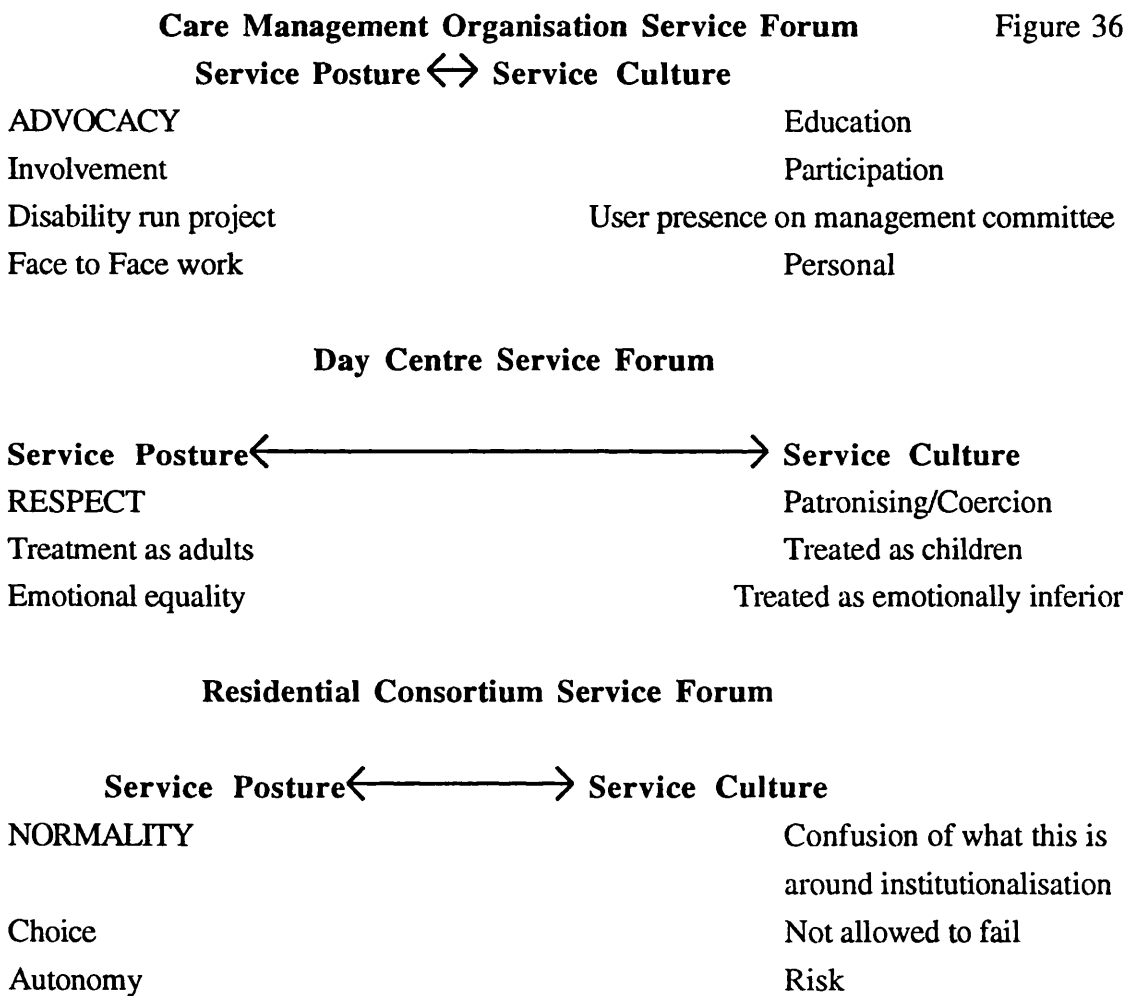


Figure 36 shows the relationship between each organisation's service posture and service culture along with its relative intra and inter positioning. The length of the intervening line between the service posture and culture indicates how close their relationship is. The service posture for the residential consortium can be summed up as 'Normality', that is to say that the organisation focuses on language around the concept of normality i.e. being normal, ordinary living and homely settings. The day centre's

service posture is one constructed around 'Respect'; that is contained within the language of documentation, interviews and the observations recorded. Respect is a recurring theme being seen as a primary goal in the running of the organisation. The care management's organisational service posture is one of 'advocacy', the service being concerned with a particular type of advocacy and the language and ethos connected with it. It is important to note that all service postures and cultures do not exist or act in isolation. They are part of a local statutory, voluntary and private services and a much wider welfare system.

A number of generalisable roles may be used to explain users and professionals reactions to service cultures and postures. These may include coping strategies and other actions. Any presented role is not intended to stereotype people into unchallenged position or the roles of victims but simply to illustrate emerging themes and theories from the work. They are therefore not all encompassing but highlighted aspects and interpretations of a whole.

### **11.2 The Care Management Organisation**

The service posture and service culture of the care management organisation were seen to be closely aligned and the intent of the organisation was reflected by the effect of the workers. The organisation could be said to show 'service forum coherency'. The service culture and service posture in the care management organisation is shaped by the workers themselves having a disability. The organisation can only be considered to be care management in the sense they aid (through advocacy) users to manage their own care. The workers themselves having a disability has a powerful influence on the image and credibility of the organisation in the eyes of its users. The workers have an experience of both primary and secondary deviation of having the label of being disabled (Farrell and Swigert 1982). They have a clear understanding of the potentially disempowering effects of having a disability. This in itself does not guarantee a high quality of service but it does indicate the philosophical backdrop to the organisation's approach. The service posture for the care management organisation is encapsulated in the provision of a named person, this is advocacy through a personal relationship between a paid professional and user. From the users point of view the work of the organisation is not seen in terms of the organisations rubric policy or even image but the one-to-one relationship with a worker. The presence of advocacy as self education is clearly demonstrated by users and workers in the care management organisation. This is supported by the consciousness raising work both used and described by Freire (1972). Scott (1969) also writes on how the process of socialisation and education

may counteract through self-actualisation the indoctrination of disabled people into a stereotyped 'disabled role'.

The 'professionally disabled' role (described in section 8.1.3) is a direct response and adaptation to the service culture which is evident outside of the care management organisation. Similarly one service user refers to 'naive disability'. This is, a position which means they do not understand how to use the wider services for people with disabilities to their advantage. The person does not appreciate the best way (positive shift in deviance) to make the most of services and others facilities on offer unlike the 'professional disabled' role.

Figure 37

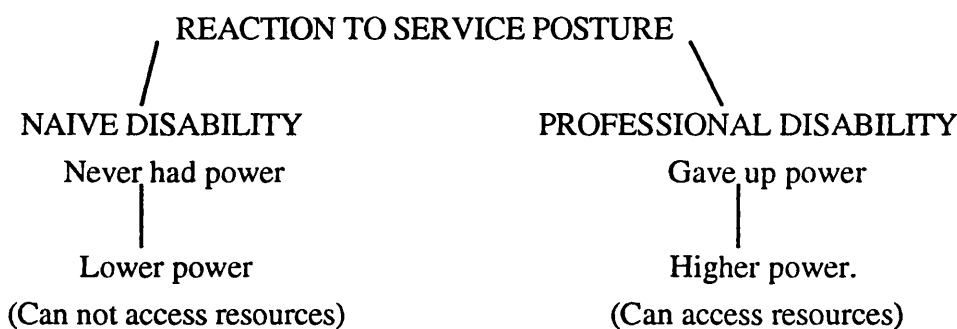


Figure 37 illustrates these roles in relation to power, the 'professional disability' role can be seen as a reaction to the service posture and service culture of an organisation and can be considered a positive shift in deviance. Such shifts are not defined by an attempt to act as if the disabled person was able bodied, but a positive utilisation of the circumstances the person finds themselves in. The ramifications framed within service posture of having a 'difficult client' label are complex, Lipsky's (1980) work on the potentially punitive response to this label is pertinent. The ideas of the wider society expressed in only accepting a selected few predictable images of disability also arose.

Advocacy in the care management organisation is characterised in the power of the advocate (within the service culture) having a positive image. This image of the advocacy organisation could be described in moving recently from a 'scruffy working' to a 'slick working' style.

Power and status was gained for one user of the care management service by an attempt to overcompensate for her disability (shift in positive deviance). This was pursued through working harder and longer hours, disregarding pain and physical discomfort compared to her non-disabled counterparts. This was a way of proving to the wider



society that a disability would not hold her back from pursuing a 'normal' job and living a full life. She appeared to view it as a personal challenge to overcome her disability and live without restrictions.

### **11.3 The Day Centre**

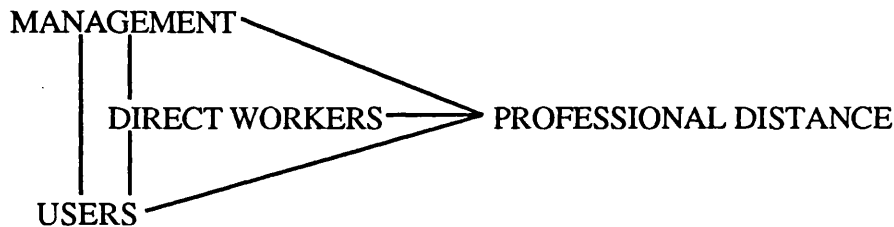
The service posture and service culture within the day centre were in many instances in opposition. The intent of the organisation was not reflected by the effect on the users. This is an example of 'service forum incoherency'. The service culture of the day centre frames people with learning disability within a common denominator of intelligence. That is, under all circumstances, they are limited by their 'condition' as a person with a learning disability (however defined). They do not have weak and strong areas, they have a standard 'world view', an all embracing 'global stupidity'. A user is therefore fundamentally defined by their label of having a learning disability and nothing else. Historically the measure of intelligence has tended to be narrow in conception and measurement i.e IQ tests, a limited view which does not take account of social experience. This view of intelligence and personal potential is naive, to paraphrase Rosenhan (1973) 'stupid people are not stupid all the time and intelligent people are not intelligent all the time.'

The response of the day centre to bereavement and the lack of counselling available to users is an example of this particular service cultures' approach to the view of people with learning disabilities internal psychological world. For example staff members are offered counselling at the death of a user but not the users that knew them. In the day centre and residential consortium people with learning disabilities are seen as having a less rich emotional world than their non-disabled counterparts. This is in direct conflict to the presented service posture described in the rubric of the organisations, that of normality and respect.

Clarke (1993) writes that a feature of the professional bureaucracy, or what is referred to here as service posture, is that it tends to develop two types of hierarchies: one among the professionals working 'hands on' and the other among the administrators who organise the service. This is evident within the day centre in terms of the professional distance from staff to users, the professional distance from management to users and finally management to staff, in total a three way split (see figure 38). This is most evident in the day centre as its structure is constricted by the boundaries of being in one building. The administrative staff sit in one office and are recognised by and labelled by users as the most powerful people, the people who make the decisions

about important issues. They often eat and take tea and coffee at separate times to other staff members and users, the manager even has a separate mug for tea. 'Hands on staff' eat and take tea and coffee at the same time as users of the day centre but they do not queue up for meals and have their own drinks, making arrangements quite distinct from users. Figure 39 illustrates the three way relationship of these groups.

Figure 38



People with learning disabilities within the day centre were notably unwilling or unable to label themselves as having a learning disability. There are two explanations for this, that they were genuinely unaware of having a disability or that they had a reason for not referring to it. Reasons for not referring to it could be connected to the potential stigma attached to such a label. From the literature it can be seen that definitions of empowerment are complex, often being inextricably linked with self-concept, self-awareness and self-consciousness. These concepts are quite often defined in terms of each other, seeming tautological. Scott (1969) suggests that inherent in self-concept is the ability to take the self as an object of its own perception, he goes on to say that to do this a person must learn to view themselves from the point of view of other people.

The reluctance to self label could therefore be caused by the negative potential of such a label. Any stigma felt can possibly be internalised. Self-concept in relation to empowerment must combine elements of consciousness raising, self awareness and realising the self as a political entity. Self-concept has both an internal and external element in empowerment. Externally the self is presented to others for evaluation and this itself can be an expression of power or potential power. Thus empowerment is tied in with identity and labelling becomes disempowering if it attacks the value of the person's self identity.

The users of the day centre may deny their disabilities within the parameters of the study in an attempt to avoid the stigma which may occur if this label is externalised and possibly internalised. The attachment of stigma appears to be higher for people with learning disabilities in the day centre than people with learning disabilities in the residential consortium and people with physical disabilities in the care management

organisation. Stigma can be characterised through the work of Goffman as a loss of dignity, ill treatment, shame, denial of citizenship, embarrassment and disadvantage in a place of low status. As Spicker (1984) would point out it does not have to apply to all people using the day centre. Stigma is not a necessary outcome but may arise if the interaction of the individual attending the day centre and other people is perceived as negative. People external to the day centre may be prejudiced against users of the day centre without any interaction taking place with such users.

There is a conflict in the day centre between the behaviour of the workers, expected behaviour of users and the structure of the environment. This is an example of the conflict between the service culture and service posture of the day centre. The workers following a service posture attempted to model and encourage what might be termed normal behaviour. In practice the service culture of provision of separate services and the segregated setting, only with other disabled people, reinforces potentially abnormal behaviour. As far back as the early nineteenth century (e.g John Conolly in 1830), criticism of the institutional system was evident. The association of people with 'deviant roles' in institutions continues to be questioned. The service culture presented by the workers in the day centre takes account for this in its organisational structure. The juxtaposition between the intended service posture built on respect and the encouragement of normal behaviour, with a service culture dealing on a day to day basis with the abnormality of a semi-institutional environment, is problematic. The consequence being the development of coping strategies for both staff and users to buffer the effects of resulting conflicts in power and respect. The initial impression of the day centre which is supported by the observations and user interviews is one of a noisy, crowded and overwhelming place.

The degree of disability or impairment of users has an effect on the service culture they experience. The service posture in the form of the documentation referred to in the day centre purports to give a service of an equal standard to all the users irrespective of their disability. However this contrasts with workers freely admitting that the service is worse for those with more severe disabilities. Their choice, power and control is limited by comparison to more able users. Choice particularly in the day centre is related to the degree of disability, it is reported that the higher the disability the lower the choice. More able users in the day centre often take up 'helper roles' doing unpaid 'cover' work for the attention and status that accompany the role. Brandon (1989) writes on the role of users with a learning disability living in a residential home. The highly verbal 'staff helper' role in the subunit studied for people with learning

disabilities was similar to trustees or star-prisoners in a prison. Within their peer group they perpetuate a social hierarchy, they are top of the so called 'pecking order'. The benefits they gain from this role are independence, competence, an increase in self-worth from the trust and confidence held by staff, and higher status and respect from those lower in the social order (pecking order). The benefits the institution gains are useful unpaid workers who help to maintain the equilibrium of the service culture and service posture. These roles are either formed by or perpetuated in the day centre. Some users expressed a feeling of being like the personal servants of workers, and these statements were supported by observations. This fits well with Goffman's (1959) work on role theory and the presentation of self. For the self to survive within a total institution such as a large mental handicap hospital the person may take on a role fixed in a hierarchical structure for both users and staff. This can be viewed as part of the process of identification and imitation with staff who are seen as powerful. Some users reported how they did not feel as important as staff. The role taken by users is a response to the selective nature of the day centre, preferential treatment is based on a hierarchy concerning the degree of disability of the users. This also fits with the high and low grade rating of users referred to by staff in the residential consortium, a legacy of institutional life.

The lack of participation of a few users in disability games at the day centres sports day was due to their feelings of being devalued. Everyone won a prize with no regard to their final position in the races. This was felt by some staff and users to be patronising and pointless. As mentioned one of the primary aims of the day centre as contained within the documentation available is that of 'respect'. In contrast in some of the recorded observations and interviews, workers actions varied from the paternalistic to those bordering on eugenics.

It was stated that people with mental health needs were treated with more respect than people with learning disabilities. It was observed that the day centre for people with learning disabilities is adjoining a day centre for people with mental health needs, thus staff had contact with both groups. It is interesting that this view is held despite the more usual observations concerning the unpredictability and potential violence associated with people with mental health needs. A possible explanation being that it is easier to empathise with people with mental health needs. A common assumption is that anyone can acquire a mental health problem. Whereas a learning difficulty is often considered to be fixed at birth. This may suggest a core attitudinal notion of 'subnormality' amongst some of the staff at the day centre. The level of people's

intellectual ability is of core importance in western society, people with learning disabilities being seen as less able and less articulate.

An issue arose around users being seen and treated as childlike, this was most intensely felt in the day centre. There was a desire by some users in the day centre to be seen as 'grown up' indicating their awareness and pursuit of social acceptability through adulthood. There was reinterpretation by some staff of the behaviour of users e.g. not 'anger' but 'tantrums', 'act grown-up' etc. Scott (1969) describes the acquisition of the blind role (service culture) by people under pressure from a multi-million pound disability business. Being seen as childlike was in direct contravention to the documentation in the day centre concerning respect. Both the service posture and the users of services recognise the status attached to treating people as adults. This also implies that children are not treated with respect or high status.

Humour here can also be viewed as a disrespectful aspect of the service culture of the day centre. The use of sarcasm was noted in the interviews and observations recorded from this organisation. It can be a way of diffusing difficult situations without tackling them. Humour can be supportive and respectful and affectionate, a way of dealing with stress but it can also be disempowering through labelling and reinforcement of stereotypes.

The justification of some morally questionable interventions by staff were made on the grounds that the long term benefits for the user would outweigh the short term costs. For example an immediate coercion or infringement on choice, e.g. being forced to participate in an activity, will benefit the user in the long term by giving them a point of reference for future informed choice. Reports of the management turning a blind eye to these practices is a clear example of service culture taking precedent over a service posture. This fits well with the Dirty Hands Problems (Situational Dilemmas) presented by Klockars (1979, p. 264). He asks can you do wrong by doing right? Should workers have higher morals standards than private citizens? This looks at the conflict between good ends in the form of avoidance of harm for everyone and dirty hands around the nature of action and deviance of the actors involved. Table 19 shows the relationship of positives (+) and negatives (-) around the situational dilemma of giving choice to a disabled person. The most negative moral outcome is labeled '--' indicating action that is easy for staff and coercive. The most positive action is one where informed choice and freedom to choose occurs hence it is labeled '++'.

Table 19 Ethical choice dilemmas			
MEANS			
ENDS		(Freedom of choice) Morally Good (+)	(Coercion) Morally Dirty (-)
	(Informed Choice) Morally Good (+)	+ +	- +
	(Easy for staff) Morally Dirty (-)	+ -	- -

Weber (1947) writes that the 'ethics of responsibility' involves a consequentialist or utilitarian approach. The benefits of an action must outweigh the costs for the person or group to continue with it. The 'ethics of ultimate ends' in contrast states that some ends are not worth compromising whatever the benefits involved in an alternative course of actions. The actions taken by some day centre workers account for an attempt at ethics of responsibility. They justify their actions in these terms by stating that an initial coercion will pay off at a later stage with the consequential enjoyment of a user later. This ignores the action as an immediate easy option to the worker. In terms of an ultimate end argument, any coercive act might be considered unacceptable.

Ethically a conflict was noted around choice in the day centre, as certain professionals saw choice facilitation as the selling of different options to users, a kind of 'rigged informed choice'. There is a relationship of choice to the management of expectations here in the day centre as choice for users was part of the market place, something to be selected weighted and sold to them. It was unclear who would benefit from the hard selling of options taking place; the users or the workers?

The issue of containment arose out of the reasons for coming to the day centre. It was noted that in the long term it would be possible to keep repeating the same educational courses for the users. Is education in day centres about personal growth and job market preparation or as Carter (1981) writes are day centres there for 'just something to do?'

Jan Carter's (1981) classic study on day services for adults in the late 1970s gives important comparative work for this study. Carter's work showed staff eating separately from users. Pay was the most important issue to users of the day centre, a

finding supported by a Consumer Survey in Cambridge (1989). The findings from this study support Carter's original work. Carter sums up what I present as the conflict between service culture and service posture analysed in the day centre studied as 'Historically, social interventions for the mentally handicapped have veered between these two extremes; on the one hand attempting to "free" the mentally handicapped (by education), and on the other hand then trying to control their movements (by segregation), if this argument is acceptable, it follows that training centres are in a double bind.' (p. 165)

There appears to be a move in the day centre, of staff away from the traditional social worker type roles around counselling and the best use of quality time, to more task and practical working styles.

Professional distance was a recurring service culture issue in the day centre. Getting too emotionally involved with users was reported as a lack of self protection within the service culture. This was one of the reasons expressed for some workers joining the 9 to 5 world of the day centre away from residential shift work. In practical terms this means the avoidance of sickness and potential violence by users in supported accommodation. All three organisations actively discouraged close relationships between staff and users of their services.

#### **11.4 The Residential Consortium**

The service posture and culture appear to be more closely aligned in the residential consortium than the day centre but there is still evidence of 'service forum incoherency'. As mentioned earlier the overall service posture of the residential consortium is one based in the projection of 'normality'. From this a series of questions arise:

- 1) Does it show a lack of respect to allow or encourage users to behave differently from the 'norm' (this could include harm to themselves and others), if they choose to do so? Following the norm encourages acceptability and norm violation appears to increase rejection, however the attitude that because someone is disabled they can do as they wish is patronising. This attitude, confirming deviant behaviour, does not help the person to learn new skills or become included into the community.
- 2) How do personal choice, respect and the right to receive meaningful instructions on appropriate behaviour relate?

Pressuring people into conformity can have negative results, it is not a positively valuing experience and may even lead to feelings of depression and oppression as seen in institutionalised living. Choice was also a major point of reference for the service posture of the organisation. Staff spoke about it a lot but it gave rise to a number of problems. Some staff in the residential consortium found it difficult to facilitate choice for some users as they had been 'institutionalised' and saw choice as either threatening, some kind of a trick or just irrelevant to their lives. Minor choices are often encouraged by staff, however major ones may not be, for example choices concerning holidays as opposed to choice of T.V. channel. Service culture here seems to have developed a hierarchy of choice options, that is things that are acceptable and not acceptable for users to make choices over. Any attempts to ascertain an understanding of choice through staff interviews is doubtful without a reference to both the quantity and quality of said choices. Furthermore staff may respond to questions about giving choice to users with agreement, but they may be limited to giving smaller choices. If choice is limited it can easily become tokenistic and irrelevant.

The right for a user to make a wrong or anti-social choice is also of interest here. A conflict exists between risk taking, autonomy, protection and responsibility. This was seen in the conflict between service posture and services culture. The service posture encourages the promotion of choice, seen as part of normal living. The service culture does not appear to carry this through, owing to staff members perceiving a lack of support regarding the opportunity for one to one work. The encouragement of genuine choice would require a more intensive support system, that is a change in staff shift timing and service structure.

A recurring theme of whether or not users live in the 'real world' appeared in the service culture of the residential consortium and also in the day centre. The definition and explanation of 'real world' was not forthcoming. However it appeared that they were referring to issues around protection. The vignettes supported this e.g challenging behaviour is viewed as acceptable within the perimeters of the organisation, but outside in the real world it would prove unacceptable.

One aspect of the service culture was that workers in the residential consortium reported becoming dependent on the level of attention that users give them (see section 9.2.1). One worker in the residential consortium reported that some workers see advocates as a threat. Here the disempowerment felt by workers is highlighted.



It has been demonstrated that there are a series of contradictions between the documentation of the services and the practices observed of staff and users and recorded in interviews. That is to say that there is a conflict between the service postures and service cultures of the organisations in terms of the ethos of their power structures.

### **11.5 Research Answers**

To return to the original research questions it was discovered that different working styles do affect users experiences of power and their feelings about it.

1) How do the working styles of different organisations affect users experiences of power and feelings about it?

The care management organisation is run by disabled people, and provides care management/advocacy for people with physical disabilities in the community. The workers are respected and even revered by the service users. Advocacy is seen by the workers as empowering through self education. Users can come to the service with a number of already well established roles e.g 'naive' and 'professional disabilities' and that of having a 'difficult client' label which will have an affect on their presented experience of power. Advocacy here attempts to challenge these roles. Power and status is gained by service users in the following ways:

- Over compensation for their disability, in effect a 'positive shift in deviance'.
- People doing more for themselves and setting agendas for work.
- A shared understanding of disability with the workers meaning that no issue is considered too trivial.
- Representation of a majority of users on the management committee giving the users more participation (and others were aware of this).
- Users being aware that they are not treated as cases requiring assessment but as ordinary individuals with genuine and specific needs.

The day centre caters for approximately 120 users with varying degrees of disability, in some ways it can be considered a pseudo-institution. The congregation of a large number of socially devalued people with the same label causes them to be treated not as individuals but a contained group. Users tended to be defined by their lack of ability rather than their ability, and restricted to limited learning as a result. They were considered to be emotionally underdeveloped which allowed for emotional neglect to occur. Power and status was difficult to gain within the service for users, the

following highlights this:

- Users felt that they were kept at a distance from staff. This was encouraged by some staff.
- Users felt that they were being used as staff helpers/servants without being paid.
- Denial of people's own disability may be an attempt to avoid stigma.
- Advocacy was not effective within the day centre, it was suggested that staff used user advocacy for their own ends.
- Staff freely admitted to coercive techniques from violence to bribery. Users were observed being disrespected both verbally and physically and at times appeared to be in distress.
- Users expressed concern at being treated like children. This was confirmed by the observations taken.

The residential consortium provides support to groups of people and individuals with learning disabilities in 'ordinary living' situations. Three separated organisations were studied. Power and status was gained by service users from the move from institutional to community care, but this varies within the three subsidiary residential consortium organisations studied. One organisation (2) had three elderly users who missed the institution they had spent their lives in. They gained a sense of power by living in their own home but transferred their understanding of institutional hierarchy to their new environments. Their sense of power was limited to their place in this social order (pecking order). One user in the second organisation (1) who had an advocate found himself in the middle of a conflict between staff and the advocate. This was not necessarily a weak position as he was able to use the situation to his advantage. Another individual living on his own had power over his life but was reportedly very lonely.

2) How are service users blocked or incorporated in decision making and how do they develop a sense of power within the organisations studied?

In the care management organisation users were facilitated in their choices actively by staff. They were encouraged to follow up and explore any options. Users discovered that they had a lot more choices than they previously thought. There was an appreciation of a shared culture of disability and an exploration of options and power that was available. The disabled worker acted as a role model, allowing the users to aspire to higher ideals of personal power, this can be viewed as a 'positive shift in

deviance’.

In the day centre although users were proud to be responsible for choosing their own courses, there were difficulties in their exercising of choice. Courses were not tailor made for individual users so there was a limited opportunity for long term growth. Interviews with staff and observations of users supported the view that opportunities were limited for those people who were more severely disabled. Due to the institutional nature of the organisation there was an infringement on personal choice with large numbers of people being controlled by a few staff. Staff justified coercion by alleging that users would subsequently be in a position of informed choice. Informed choice was being packaged and sold to the users as being in their best interests. Therefore choice degenerates into a rigged market-place, where respect, the main aim of the service posture, was lost.

In the residential consortium users in one home felt that choice was either threatening, some kind of trick or just irrelevant to their lives. Staff found it difficult to challenge this position. In another home an issue arose concerning a health risk and personal control. The user wanted to eat, the staff prevented him from overeating thus the user was unable to confront this and ate secretly. There was a conflict between a worker and an individual living alone in his own home, about who ‘knew best’, however this man was experiencing considerable power over his life. The confusion arising from the ‘service forum incoherency’, as shown previously, resulted in suspicion and subversive response from the users.

3) How might a participatory service delivery system be constructed?

What follows are suggestions for the construction of a general service delivery system based on the findings of the three organisations studied:

#### Policy

- Combining physical disability and learning disability pressure groups should be examined carefully. The physical disability movement tends to usurp the potential for the learning disability group to reclaim its own language and ideology. Freire writes on the subject ‘No pedagogy which is truly liberating can remain distinct from the oppressed by treating them as unfortunates and by presenting for their emulation models from among the oppressors. The oppressed must be their own example in the struggle for their redemption.’ (Freire, 1972, p. 39)

- If the market economy and consumerism is to be effective for people with learning disabilities then they have to be able to access adequate information. Their informed choice must then be acted upon.
- Individualised funding appears to be a way of providing quality services to people with learning disabilities, by moving away from bulk buying of services. Instead fitting services to people.
- The option for control of budgets and appointment of staff gives more participation to users.

### Service forum incoherency

- Power is traditionally exercised in areas of conflict. The conflict existing between service culture and service posture needs to be illuminated and resolved. Thus the hidden agendas of the service culture and the unfulfilled promises of the service posture are addressed within the organisations.
- Disabled people need to be able to influence their own service posture and cultures within the organisations they use.
- It appears that service culture has the greater capacity to change than service posture so awareness of the shifting value base requires greater understanding within organisations.

### Training

- Issues contained in the conflict between service culture and service posture need to be explored in training packages for workers in any participatory organisation.
- This training needs to be carried out by an external evaluator in order so as not to perpetuate the existing service culture. Such steps can avoid internal conflict within the service culture of the organisation.
- Organisations policy documentation needs to be kept up to date and under regular review, not only referred to in a crisis. This also avoids possible service posture to service culture lag.
- Training should include anti-discriminatory practice. Awareness should be revised concerning the devaluing of people with learning disabilities by assumptions about:
  - 1) Their emotional capacity being less than able bodied people.
  - 2) Their intelligence being fixed at a low level, and not multidimensional.

### 3) The attachment of a subnormal label to themselves

#### Advocacy and Empowerment

Lessons learnt from the care management organisation are as follows:

- The importance of the one to one working relationships.
- This working relationship can become more respectful and empathetic as people co-operate together.
- Status is a key factor in the potential for change within the advocacy/worker relationship.
- People with disabilities should be on the management committee of advocacy organisations in a non-tokenistic way. There should be provision of appropriate training and support for these people.
- The avoidance of segregating large numbers of people to avoid effectively isolating them. To encourage participation by including users in everyday living.
- The workers themselves having a disability has a profound affect upon the image and credibility of an organisation but it is not the only answer in terms of design for an empowering service. Representation of users but not necessarily domination of all such services by them is the key.

#### **11.6 Future Research and Policy**

There is a need for further research with users who have fewer words and limited use of conventional language e.g. non-verbal. Traditionally this group is under-represented in research on power, choice and decision making. This is due to the methodological difficulties and investment of time in interviewing them. It is clear from the research findings that these groups in the day centre are disempowered, receiving less choice and a poorer quality of service than more able groups. The service postures in the residential consortium and day centre clearly state that an equality of care for all users is a priority. The service culture fails to deliver this.

From the analysis of the care management organisation, future research on advocacy would be desirable along the following lines:

- 1) The evolution of advocacy services from an institutional base to community based projects. This would be important because of the changes in expectations of people as they become more empowered.

- 2) The move from 'scruffy' to 'slick' services delivery styles of advocacy. There is a need for adaptation and growth in the service. As an organisation with a near static service posture moves from 'scruffy' to 'slick' how does it affect the service culture? The motivation of status seems to be the key in 'slick' organisations.
- 3) The core nature of advocacy work and how it is defined. Definitions of advocacy within the care management organisation included counselling. Advocacy is also often confused with befriending. Research is needed into the role, definitions and outcomes of advocacy.
- 4) Collective empowerment was not explored in this study but it is an important area to research in the future.
- 5) The role of the professional advocate; their skills and conflicts of interests.

The theory of service forums can be applied as a research tool to other organisations, groups and settings in this area. In particular there is a need to examine policy and practice around disability in terms of service culture and service posture, with particular attention to the training of new staff. The tensions that occur between service culture and service posture, pull staff in different directions. In this era of post Griffiths policy making we need to consider how to get users involved in a meaningful way in making choices about their lives and what we mean by 'informed choice'. Users experience services in different ways through routines and regimes, these are captured in the service culture and posture, both of which need to be acknowledged and understood in relation to each. Then, perhaps institutional and other negative practices of staff and organisational structures can be challenged and changed.

The debate around research ethics has been explored alongside the importance of organisational settings. The description of different and conflicting ethical postures in research within the framework of 'negative' and 'positive' ethics is an original and stimulating contribution to a long running debate in social science.

This is not an easy area to study as power can be both obvious, subtle and illusory in its manifestations. This research clearly shows how three different community care services for people with disabilities in London, express and receive power in quite distinct ways. The study provides an original in-depth analysis of a day centre for people with learning disabilities. In addition a unique explanation of all three organisations' usually hidden mechanisms of socio-organisational power structures have been presented. The service forums, postures and cultures that form the power of these organisations show the conflicts and pressures that exist for people with

disabilities using these services. The theory of 'service forum coherency' provides a framework for future research and development in organisations concerned with welfare and in particular the power structures around care. This work has demonstrated that issues such as the inclusion of workers with disabilities in services and the expression of positive deviance for people with disabilities are areas of potential yield in welfare research.

I began the introduction to this thesis with a quote from Oliver (1996) who changes the words of Steve Biko, the murdered South African activist to illustrate the social struggle felt by disabled people to gain power on their own terms. Oliver challenges concepts of deviance, labelling theory, norms and recognised stereotypes for people with disabilities. Somewhat like the famous Groucho Marx (1987) quote 'Any club that would accept me as a member, I wouldn't want to join' (p. 52)

Oliver sees the potential for disabled people to become part of a wider non-disabled society to be gained only on their own terms. Therefore to join for disabled people is not to give up the power to express individuality and difference.

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## APPENDIX A

### Demographics of Respondents

Code	Gender	Age	Ethnicity	Length of Interview	Date of Interview
CMUI1	Female	67	Greek/Cypriot	95 minutes	07/12/94
CMUI2	Female	48	Jewish	90 minutes	24/11/94
CMUI3	Female	28	British	115 minutes	24/11/94
CMUI4	Male	35	Indian	80 minutes	24/11/94
CMUI5	Male	58	Greek/Cypriot	85 minutes	01/12/94
CMUI6	Male	40	British	120 minutes	01/12/94
CMUI7	Female	37	British	85 minutes	01/12/94
CMUI8	Female	48	British	80 minutes	09/12/94
CMUI9	Male	76	British	90 minutes	09/12/94

Code	Gender	Age	Ethnicity	Length of Interview	Date of Interview
CMPI1	Male	N/A	British	110 minutes	15/02/95
CMPI2	Female	N/A	British	120 minutes	12/12/95

**Table 22 Day Centre Users Interviewed**

Code	Gender	Age	Ethnicity	Length of Interview	Date of Interview
DCUI1	Male	42	British	55 minutes	24/10/94
DCUI2	Female	29	Indian	50 minutes	27/10/94
DCUI3	Female	41	Jewish	40 minutes	27/10/94
DCUI4	Female	59	British	60 minutes	27/10/94
DCUI5	Male	29	British	35 minutes	24/10/94
DCUI6	Female	39	British	40 minutes	24/10/94
DCUI7	Female	33	British	40 minutes	20/10/94
DCUI8	Female	30	British	40 minutes	20/10/94
DCUI9	Female	35	British	45 minutes	20/10/94

**Table 23 Day Centre Professionals Interviewed**

Code	Gender	Age	Ethnicity	Job Title	Length of Interview	Date of Interview
DCPI1	Male	33	British	Centre Worker	80 minutes	22/11/94
DCPI2	Male	46	British	Manager	50 minutes	22/11/94
DCPI3	Male	39	British	Acting Senior Centre Worker	75 minutes	10/11/94
DCPI4	Female	35	British	Centre Worker	85 minutes	10/11/94
DCPI5	Male	29	British	Centre Worker	75 minutes	18/11/94
DCPI6	Male	25	British	Assistant Centre Worker	70 minutes	18/11/94
DCPI7	Female	37	British	Centre Worker	80 minutes	22/11/94
DCPI8	Female	22	British	Centre Worker	70 minutes	09/12/94
DCPI9	Female	34	British	Senior Centre Worker	80 minutes	09/12/94

(Length of Employment: minimum 6 months/maximum 4 years)

<b>Table 24 Residential Consortium (1) Professionals Interviewed</b>						
Code	Gender	Age	Ethnicity	Job Title	Length of Interview	Date of Interview
R C (1) P 1	Male	28	British	Support worker	90 minutes	23/12/95
R C (1) P 2	Male	34	British	Support worker	70 minutes	18/01/95
R C (1) P 3	Female	29	British	Deputy Manager	90 minutes	17/01/95

(Length of Employment: minimum 6 months/maximum 5 years)

<b>Table 25 Residential Consortium (1) Users Interviewed</b>					
Code	Gender	Age	Ethnicity	Length of Interview	Date of Interview
R C (1) U 1	Male	23	British	80 minutes	16/12/94
R C (1) U 2	Male	21	British	60 minutes	06/12/94
R C (1) U 3	Male	25	British	90 minutes	09/12/94

<b>Table 26 Residential Consortium (2) Professionals Interviewed</b>						
Code	Gender	Age	Ethnicity	Job Title	Length of Interview	Date of Interview
R C (2) P 1	Female	31	Afro Caribbean	Support Worker	70 minutes	17/01/95
R C (2) P 2	Male	39	British	Support worker	110 minutes	28/02/95
R C (2) P 3	Female	43	Irish	Outreach Worker	100 minutes	13/01/95

(Length of Employment: minimum 3 years/maximum 12 years)

**Table 27 Residential Consortium (2) Users Interviewed**

Code	Gender	Age	Ethnicity	Length of Interview	Date of Interview
R C (2) U 1	Male	84	British	90 minutes	10/12/94
R C (2) U 2	Male	50	British	90 minutes	14/12/94
R C (2) U 3	Male	88	British	90 minutes	14/12/94

**Table 28 Residential Consortium (3) Professionals Interviewed**

Code	Gender	Age	Ethnicity	Job Title	Length of Interview	Date of Interview
R C (3) P 1	Male	25	British	Support worker	115 minutes	06/02/95
R C (3) P 2	Male	37	British	Support worker	110 minutes	03/05/95
R C (3) P 3	Female	32	British	Acting/deputy manager	115 minutes	02/08/95

(Length of Employment: minimum 2 years/maximum 6 years)

**Table 29 Residential Consortium (3) Users Interviewed**

Code	Gender	Age	Ethnicity	Length of Interview	Date of Interview
R C (3) U 1	Female	44	British	80 minutes	12/01/95
R C (3) U 2	Male	47	British	80 minutes	21/04/95
R C (3) U 3	Male	33	British	110 minutes	17/05/95

## **APPENDIX B**

### **USERS INTERVIEW TOPIC GUIDE (DAY CENTRE)**

**Date of interview:**

**Length of interview:**

**Gender of respondents:**

**Age of respondents:**

#### **1) BELONGING:**

**a) What words would you use to describe yourself? (see U.V.1)**

(PROBE: If someone phoned up and asked you to describe yourself what would you say?)

**b) What places do you go to?**

(PROBE: Where do you go to?)

Schools:

Libraries:

Swimming Baths:

Restaurants/Cafes/Pubs:

Clubs:

Churches:

Others: .....

**c) How does going to these places make you feel?**

**d) What other places might you like to go to? What would you like to do there? (PROBE: If you could go anywhere, where would you go?)**

**e) What help would you need to go to these places and come back here?**

(PROBE: Transport, workers, money and who would you like to go with you?)

#### **2) CHOICES:**

**a) What sort of choices do you make?**

What to eat?

Where to go on holiday?

Where to spend your evenings?

What to do when you are at home?

Who to do things with?

Others: .....

**b) What do you like to do or not do?**

At home?

When you are out?

Work?

Leisure?

Washing up?

T.V?

Others .....

**c) Can you tell me something about how you came to be here?**

(PROBE: Key events, choice, decisions)

**d) What are the rules and routines for living here?**

(PROBE: The things you can or cannot do here?)

**e) How are changes made?**

(PROBE: Generally speaking, do you feel things change much here? What sort of changes occur?)



### 3) INFORMATION:

a) Are you involved in any discussion groups, meetings or advisory groups ?

(PROBE: If they exist, do they have a positive effect. Do you feel people listen to what you say? How do you find out what is going on? Are you told by someone? Who? Is it written down?)

b) Are you aware of any 'official policies' designed by the organisation that you have contact with?

c) Are you aware of changes made by the people 'at the top' of the organisation which might affect you?

(PROBE: e.g Do you know who is in charge? Who do you go to complain to? What your rights are? Do you interview staff?)

WHO IS IN CHARGE. APPOINTMENT OF STAFF.

### 4) SKILLS:

a) What skills would you say you have?

Personal: self control and confidence.

Social: ability to relate to others, to have fun and love.

Activity: acquires skills in some areas:

Music:

Public speaking:

Sport:

Sewing:

Driving:

Playing cards:

Writing:

Reading:

b) What things would you like to be able to do?

(PROBE: see a)

### 5) RESPECT:

a) What things do other people like you to do or not do?

Sport:

Hobbies:

Work:

(PROBE: What do you receive praise for, things that make you feel good)

b) Do you like to spend time on your own and if so is this easy to do?

c) What do others say about you?

### 6) RELATIONSHIPS:

a) Who do you turn to if you have a problem?

b) Who are your friends?

Family:

Friends:

Girlfriends/Boyfriends:

(PROBE:

- Does the person have many or few relationships?
- Does the person have both paid and unpaid links with the world?
- What is the nature of intimacy and warmth of relationships people have?
- What is the length of relationships?
- How do the people feel about sharing confidences and keeping secrets.
- Are their relationships reciprocal in nature?)

c) How many friends come to visit you?

- d) **How do you get on with your family?**  
Do they help you with things?  
e) **Who do you spend the most time with?**  
f) **Who do you not like?**

**7) CONTROL:**

- a) **What are you not allowed to do?**  
b) **Do you feel you make the major decisions/choices in your life?**

**8) PAIN:**

- a) **Do you have any pain or trouble with your health?**  
(PROBE Do you feel out of sorts?)  
b) **Have you ever been sad in your life?**  
(PROBE: When and why and how do you feel about it now?)  
c) **What do you do when you feel low?**  
(PROBE: When you are on your own? When you are with staff?)  
d) **Do you feel you have a disability?**  
How would you describe this disability?  
How does it affect the things you do and who you do them with?  
Do you know anyone with a disability?

**9) SUPPORT:**

- a) **Do you have enough help or perhaps too much to do what you want to do?**  
b) **When would you like to see help given to you, e.g. evenings, weekends, public holidays?**

**10) EQUITY:**

- a) **Do you feel that you are fairly treated here?**  
b) **Do you have a chance to help other people do things?**  
c) **Do you feel that you are the 'same' (i.e. equal to) as the staff?**

**11) RESOURCES:**

- a) **Have you ever made a complaint about the service you use? What was it for? What happened?**  
b) **If you have wanted to make a complaint about the service or the agency, but did not go ahead with it, can you give a reason why?**  
c) **How do you feel about the people who work with you?**
  - What is your relationship like with them?
  - Do they deal directly with money?
  - Who do they work for?
  - Does this one person deal with all your problems and needs?
  - Do you have a say in who works with you?

**12) ASPIRATIONS:**

**a) Personal Landmarks:**

All of us can recall various events that have affected our lives up to now. These landmarks are important as they help us review the past and to make plans for the future. In the space below, write or draw the major events in your life. Next to each landmark put the year, your age at the time, as a guide. What is the most important thing that has happened to you?

**b) What would you miss about living here?**

(PROBE: positive and negatives)

**c) What are your wishes/dreams for the future?**

How were the questions I asked you?

**THANK YOU**

## **PROFESSIONAL INTERVIEW TOPIC GUIDE (DAY CENTRE)**

**Date of interview:**  
**Length of interview:**  
**Gender of respondents:**  
**Age of respondents:**  
**Length of time working there:**  
**Position:**

### **1) ORGANISATIONAL STRUCTURE:**

**a) Does your organisation have an agreed working philosophy and set of values? (PROBE: aims and objectives)**

**b) What policies does your organisation have?:**

Detailed Recording.

Client Information.

Mental Health Act Sections.

Complaints Procedure.

Basic Information.

Review/Periodic Summary.

First Assessment.

Closure or Transfer.

Contacts (Key Points and Action).

Consent Forms.

Social Work Service Client Record Form.

Children's Act 1989.

Referral Form.

Policy on Clients Access to Personal Records.

Social Service Records.

Duty Guidelines.

Others .....

**c) How do you think the organisation has changed over time?**

**d) What are your organisation's aims for the future?**

**e) What is your organisation's relationship with other organisations?**

(PROBE: List organisations)

**f) What are the priorities of your organisation?**

**g) What do you think of your organisation's management structure?**

(PROBE: Is it easy to get a services response to a problem/issue)

### **2) JOB STRUCTURE AND SKILLS:**

**a) What do you consider makes a good worker in this field?**

**b) What would you describe your skills are?**

**c) Do you have access to resources?**

**d) Do you have an opportunity to share skills?**

**e) Do you use an advocacy approach?**

**f) Who are you accountable to?**

**g) How much support and supervision do you get? (PROBE: Is it enough)**

**h) Do you have the opportunity to develop your own skills?**

### **3) STYLE OF WORKING CONTROL:**

**a) What do you think of the physical environment you work in?**

**b) How much freedom do you feel you have where you work?**

**c) How much choice do you feel you have where you work?**

**d) How much power and control do you feel you have where you work?**

**e) Do you feel you get enough training where you work, do you get the chance to ask for certain types of training?**

**4) RELATIONSHIP WITH USERS AND WORKERS:**

- a) How do you feel about the main user(s) you work with?  
(PROBE: friends, degree of understanding.)
- b) What is the main thing limiting your relationship with the user?  
(PROBE: Resources, time, other staff.)
- c) How well do you get on with other staff and your bosses?

**5) PERSONAL ISSUES AND PAIN:**

- a) Who do you spend the most time with at work?
- b) Could you tell me something of how you ended up working here?  
(PROBE: Motives, background. Reasons for being here.)
- c) How happy are you here? (PROBE: Feelings of well being.)
- d) How much support do you get from your relatives and friends in the work you do? (PROBE: Relationships and social networks.)
- e) What impact and role do relatives of the users you work with have?
- f) What is the worst thing about working here?
- g) What is the best thing about working here?
- h) What would you say your worst fault is?
- i) What are your wishes and dreams for the future?

How were the questions I asked you?

**THANK YOU**

## APPENDIX C

### INTERVIEW VIGNETTES (DAY CENTRE)

#### Professional Vignettes (P.V)

**P.V.1** “David Smith is 35 years old and has been living in a group home shared with three other people for two years. David has learning disabilities and has spent most of his youth in a large mental handicap hospital. His mother died of cancer two months earlier, and his father does not come to visit him any more. David does not communicate verbally, he occasionally uses MAKATON (basic sign language), this has been encouraged by staff. He has few friends, except for staff members. One afternoon he is at the day centre doing his favourite activity (woodwork) another user stands up and knocks his work on the floor, David walks over to him and hits him really hard on the arm. David then leaves the workshop, goes outside and does not come back. You watch this all happen, you are also the only person working in the room.”

#### Prompts:

What will you do?

How will you respond to the person who was hit?

Does your action depend on how hard David hits the person?

Why do you think it happened?

What courses of actions are open to you?

Will you record the incident (if yes then how)?

Who will you tell about the incident?

What would you do if you were the one hit?

#### Variables:

- 1) Time in mental handicap hospital.
- 2) Death of mother and absence of father.
- 3) Lack of friends.
- 4) Work interrupted.
- 5) Communication difficulties.
- 6) Living with others.
- 7) Response to violence.
- 8) Defending vulnerability.
- 9) Other people in the house.
- 10) Has he hit out before.

#### Themes:

**Pain.**

Complaints procedure within the organisation.

**Control.**

**P.V.2** “Nancy Gardener is a fifty year old women who has lived in a group home for six years. She has mild learning disabilities. Nancy has a love of conversation and classical music. The new academic year is starting and Nancy has been given a choice of two courses. You talk to her briefly about both. The first is a large group doing a simple fun type task (sport). The second is a smaller group with a more complex aim of independency skills. Nancy seems to prefer the larger group, however she appears to be capable of living more independently. She has done a number of courses before and tends not to stick at things.”

Prompts: How do you both come to a decision over the course (process)?  
Who would you ask for help in deciding which courses to take?  
What kind of place do you think she should move to?"

Variables: Nancy's abilities and others around her.  
Fun versus independence living skills.

Themes: **Relationships.**  
**Choice.**  
**Power.**  
**Skills**

### **Users Vignettes (U.V)**

**U.V.1** "Imagine that you are in your favourite class at the college and another student stands up walks over to you and hits you hard on the arm. You are alone and this person walks off to another class. What will you do."

Prompts: Photographs, flash cards, diagrams and symbols may be used to create a clearer illustration of the vignettes for people with learning disabilities who have limited verbal language.

Variables: What do you do?  
What if you saw someone else doing it to another student?  
Imagine if you are a member of staff watching this happen, what would you do?  
Who do you turn to for help?  
Does it depend on how hard you are hit?  
Is the person hitting you a friend or not?  
What would you do if you were a staff member?

Themes: **Pain.**  
Complaints Procedure within the organisation.  
**Control.**

**U.V.2** "You have to choose between classes at the beginning of term. You are given a choice of two. The first is something you like doing but you have done it before. The second is more difficult, but your key worker wants you to try it. How would you make a decision on where to go? Who would you ask for help in deciding where to go? What kind of classes do you like going to."

Prompts: Photographs, flash cards, diagrams and symbols may be used to create a clearer illustration of the vignettes for people with learning disabilities who have limited verbal language.

Variables: How do you come to a decision over the classes?  
Who do you ask for help?

Themes: **Relationships.**  
**Choice.**

## **APPENDIX D**

### **LIST OF NODES**

(Taken from Q.S.R. NUD.IST Power version, revision 3.0.4 GUI.)

- (1) /ORGANISATIONS
- (1 1) /ORGANISATIONS/Day Centre
- (1 2) /ORGANISATIONS/Care Management
- (1 3) /ORGANISATIONS/Residential Consortium
- (2) /ANALYSIS
- (2 1) /ANALYSIS/Free Themes
- (2 1 1) /ANALYSIS/Free Themes/Disability
- (2 1 1 1) /ANALYSIS/Free Themes/Disability/Consequences
- (2 1 1 1 4) /ANALYSIS/Free Themes/Disability/Consequences/Stigma
- (2 1 1 1 5) /ANALYSIS/Free Themes/Disability/Consequences/Acceptance
- (2 1 1 1 6) /ANALYSIS/Free Themes/Disability/Consequences/Professional Disability
- (2 1 1 2) /ANALYSIS/Free Themes/Disability/Contributing Factors
- (2 1 1 2 1) /ANALYSIS/Free Themes/Disability/Contributing Factors/Degree of Disability
- (2 1 1 2 2) /ANALYSIS/Free Themes/Disability/Contributing Factors/Disability-Birth-Later
- (2 1 1 3) /ANALYSIS/Free Themes/Disability/Definitions and Labels
- (2 1 1 3 1) /ANALYSIS/Free Themes/Disability/Definitions and Labels/Others-Labels
- (2 1 1 3 2) /ANALYSIS/Free Themes/Disability/Definitions and Labels/Normality
- (2 1 1 3 3) /ANALYSIS/Free Themes/Disability/Definitions and Labels/Disability-Handicap
- (2 1 1 3 4) /ANALYSIS/Free Themes/Disability/Definitions and Labels/Self-Label
- (2 1 2) /ANALYSIS/Free Themes/Attitudes
- (2 1 2 1) /ANALYSIS/Free Themes/Attitudes/Respect
- (2 1 2 1 1) /ANALYSIS/Free Themes/Attitudes/Respect/Practice & Theory
- (2 1 2 1 2) /ANALYSIS/Free Themes/Attitudes/Respect/Adulthood
- (2 1 2 1 3) /ANALYSIS/Free Themes/Attitudes/Respect/Overprotective
- (2 1 2 2) /ANALYSIS/Free Themes/Attitudes/Sense of Humour
- (2 1 2 3) /ANALYSIS/Free Themes/Attitudes/Likes
- (2 1 2 4) /ANALYSIS/Free Themes/Attitudes/Problems
- (2 1 2 4 1) /ANALYSIS/Free Themes/Attitudes/Problems/Conflict
- (2 1 2 4 2) /ANALYSIS/Free Themes/Attitudes/Problems/Limitation
- (2 1 2 4 3) /ANALYSIS/Free Themes/Attitudes/Problems/Boredom
- (2 1 2 4 4) /ANALYSIS/Free Themes/Attitudes/Problems/Apartheid
- (2 1 2 4 5) /ANALYSIS/Free Themes/Attitudes/Problems/Dislikes
- (2 1 2 4 6) /ANALYSIS/Free Themes/Attitudes/Problems/Worse Off
- (2 1 2 5) /ANALYSIS/Free Themes/Attitudes/Emotions
- (2 1 2 5 1) /ANALYSIS/Free Themes/Attitudes/Emotions/Fears
- (2 1 2 5 2) /ANALYSIS/Free Themes/Attitudes/Emotions/Depression
- (2 1 2 5 3) /ANALYSIS/Free Themes/Attitudes/Emotions/Pain
- (2 1 2 5 4) /ANALYSIS/Free Themes/Attitudes/Emotions/Happy
- (2 1 2 5 5) /ANALYSIS/Free Themes/Attitudes/Emotions/Pity
- (2 1 2 5 6) /ANALYSIS/Free Themes/Attitudes/Emotions/Empathy
- (2 1 2 6) /ANALYSIS/Free Themes/Attitudes/Grateful Service
- (2 1 3) /ANALYSIS/Free Themes/Power
- (2 1 3 1) /ANALYSIS/Free Themes/Power/Negative
- (2 1 3 1 1) /ANALYSIS/Free Themes/Power/Negative/Coercion
- (2 1 3 1 2) /ANALYSIS/Free Themes/Power/Negative/Containment
- (2 1 3 2) /ANALYSIS/Free Themes/Power/Positive
- (2 1 3 2 1) /ANALYSIS/Free Themes/Power/Positive/Advocacy
- (2 1 3 2 2) /ANALYSIS/Free Themes/Power/Positive/Empowerment
- (2 1 3 2 4) /ANALYSIS/Free Themes/Power/Positive/Freedom
- (2 1 3 3) /ANALYSIS/Free Themes/Power/Practice

(2 1 3 3 1) /ANALYSIS/Free Themes/Power/Practice/Choice  
 (2 1 3 3 2) /ANALYSIS/Free Themes/Power/Practice/Responsibility  
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 (2 1 5) /ANALYSIS/Free Themes/Work  
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 (2 1 5 7) /ANALYSIS/Free Themes/Work/Critic Service  
 (2 1 5 8) /ANALYSIS/Free Themes/Work/Work Conflict  
 (2 1 6) /ANALYSIS/Free Themes/Families  
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 (2 1 8) /ANALYSIS/Free Themes/Issues  
 (2 1 8 1) /ANALYSIS/Free Themes/Issues/Service  
 (2 1 8 1 1) /ANALYSIS/Free Themes/Issues/Service/5 Accomplishments  
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 (2 1 11 1 3) /ANALYSIS/Free Themes/Staff/S Structure/Delegation of Work



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 (2 1 21) /ANALYSIS/Free Themes/Fighting System  
 (2 1 22) /ANALYSIS/Free Themes/Transport-limitations  
 (2 1 23) /ANALYSIS/Free Themes/Research!  
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 (2 1 27) /ANALYSIS/Free Themes/Policies  
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 (2 1 31 2 7) /ANALYSIS/Free Themes/Care Man/C M Issues/DialaRide

(2 1 31 2 8) /ANALYSIS/Free Themes/Care Man/C M Issues/DABB  
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 (2 1 31 3 3) /ANALYSIS/Free Themes/Care Man/C M Value Base/C M-Friends  
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 (2 1 32 1 1) /ANALYSIS/Free Themes/Res Consor/R C Structure/R C Routines  
 (2 1 32 1 2) /ANALYSIS/Free Themes/Res Consor/R C Structure/R C Past  
 (2 1 32 1 3) /ANALYSIS/Free Themes/Res Consor/R C Structure/R C Shifts  
 (2 1 32 1 4) /ANALYSIS/Free Themes/Res Consor/R C Structure/R C Job Progress  
 (2 1 32 1 5) /ANALYSIS/Free Themes/Res Consor/R C Structure/R C Management  
 (2 1 32 2) /ANALYSIS/Free Themes/Res Consor/R C Issues  
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 (2 1 32 2 2) /ANALYSIS/Free Themes/Res Consor/R C Issues/R C Information  
 (2 1 32 2 3) /ANALYSIS/Free Themes/Res Consor/R C Issues/R C Office Access  
 (2 1 32 2 4) /ANALYSIS/Free Themes/Res Consor/R C Issues/R C System Limitation  
 (2 1 32 3) /ANALYSIS/Free Themes/Res Consor/R C Values  
 (2 1 32 3 1) /ANALYSIS/Free Themes/Res Consor/R C Values/R C Aims  
 (2 1 32 3 2) /ANALYSIS/Free Themes/Res Consor/R C Values/R C-D C  
 (2 1 33) /ANALYSIS/Free Themes/Day Centre  
 (2 1 33 1) /ANALYSIS/Free Themes/Day Centre/D C Structure  
 (2 1 33 1 1) /ANALYSIS/Free Themes/Day Centre/D C Stu/Building  
 (2 1 33 1 2) /ANALYSIS/Free Themes/Day Centre/D C Stu/Special Unit  
 (2 1 33 1 3) /ANALYSIS/Free Themes/Day Centre/D C Stu/Facilities  
 (2 1 33 2) /ANALYSIS/Free Themes/Day Centre/D C Values  
 (2 1 33 2 1) /ANALYSIS/Free Themes/Day Centre/D C Values/D C Closure  
 (2 1 33 2 2) /ANALYSIS/Free Themes/Day Centre/D C Values/Competition  
 (2 1 33 2 3) /ANALYSIS/Free Themes/Day Centre/D C Values/D C Future  
 (2 1 33 2 4) /ANALYSIS/Free Themes/Day Centre/D C Values/Attitude to D C  
 (2 1 33 2 5) /ANALYSIS/Free Themes/Day Centre/D C Values/Aims D C  
 (2 1 33 3) /ANALYSIS/Free Themes/Day Centre/D C Issues  
 (2 1 33 3 1) /ANALYSIS/Free Themes/Day Centre/D C Issues/Administration  
 (2 1 33 3 2) /ANALYSIS/Free Themes/Day Centre/D C Issues/Cover  
 (2 1 33 3 3) /ANALYSIS/Free Themes/Day Centre/D C Issues/Transport  
 (2 1 34) /ANALYSIS/Free Themes/Users  
 (2 1 34 1) /ANALYSIS/Free Themes/Users/User Consult  
 (2 1 34 2) /ANALYSIS/Free Themes/Users/User Employment  
 (2 1 34 3) /ANALYSIS/Free Themes/Users/User Motivation  
 (2 1 34 4) /ANALYSIS/Free Themes/Users/Userism  
 (2 1 34 5) /ANALYSIS/Free Themes/Users/User Led  
 (2 1 35) /ANALYSIS/Free Themes/Education  
 (2 1 35 1) /ANALYSIS/Free Themes/Education/Qualification  
 (2 1 35 2) /ANALYSIS/Free Themes/Education/Achievement  
 (2 1 35 3) /ANALYSIS/Free Themes/Education/College Business  
 (2 1 35 4) /ANALYSIS/Free Themes/Education/Education  
 (3) /SUB DEMOGRAPHICS  
 (3 1) /SUB DEMOGRAPHICS/Gender  
 (3 1 1) /SUB DEMOGRAPHICS/Gender/Male  
 (3 1 2) /SUB DEMOGRAPHICS/Gender/Female  
 (3 2) /SUB DEMOGRAPHICS/Status  
 (3 2 1) /SUB DEMOGRAPHICS/Status/Users  
 (3 2 2) /SUB DEMOGRAPHICS/Status/Professionals

