EXPERIENCE OF STIGMA AND THE SELF-CONCEPT OF PEOPLE WITH A MILD MENTAL HANDICAP

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ABSTRACT

Recently professionals and service planners have become increasingly aware of the consequences of stigma and of limited social experience for the self-concepts of people with a mental handicap. These issues have been central to the debate concerning the mainstreaming of children with special needs in ordinary schools and have become of major importance for those promoting the social integration of people with a mental handicap. However, there is little understanding of the relationship between the person's experience of stigma and his or her self-concept. Researchers have studied the self-concepts of people with a mental handicap using normative or standardised tests which produce quantitative scores. I argue that such studies provide little insight into 'handicapped' treatment and the participants' views of themselves. In contrast to these studies, the present research has followed the work of Edgerton (1967), who used intensive methods to study the relationship between the self-concepts of adult people with a mental handicap and their social circumstances.

Three groups of adult people with a mild mental handicap took part in this research. The first group lived in their family home, the second group moved from their family home to live more independently, and the third group came from a long-stay hospital. The instruments used in the research were open-ended interviews. In total 48 participants with a mild mental handicap were interviewed, and where possible, their mothers and staff were also involved. The interviews concerned the participants' experience of stigma and their views of themselves in relation to handicap and stigma. A longitudinal investigation with a sub-sample of the participants was also carried out to explore their pattern of social lives and networks.

It was found that participants led socially rather segregated lives, had considerable experience of stigma and were often regarded by significant others in their lives as 'handicapped' as persons. Despite this, most of the participants in each of the three groups rejected a 'handicapped' identity. These findings are discussed with reference to several social theories of the self and previous research. The practical implications of the results for future policy and services for people with a mental handicap are also considered.

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CHAPTER 1

A background to mental handicap, stigma and the social lives of people with a mental handicap

Mental handicap is to a considerable extent a social phenomenon which can only be understood in relation to its socio-historical context. Moreover, to be regarded as mentally handicapped carries with it a stigma. In this chapter the historical position of people with a mild mental handicap will be briefly sketched. It will be argued that the fortunes of people with a mental handicap, especially those with a mild mental handicap, are inextricably linked to their position as stigmatised individuals or their association with specialised services. The effects of stigma on the individual and the techniques which people use 'to manage their spoiled identity' (Goffman, 1963), will also be examined. The work of Wolf Wolfensberger who developed the theory of normalisation will be critically analysed. Wolfensberger's aim is to reduce, if not reverse, the 'devalued' status of people with a mental handicap in society and perhaps this has been the most influential school of thought over the last decade for professionals dealing with people with a mental handicap. Finally, the literature concerning the social lives of people with a mental handicap will be considered as this provides an important insight into their position in the wider society.

Mental handicap: a social definition

The term 'mental handicap' suggests that a person displays definitive or obvious characteristics which allow others to distinguish him or her from themselves as someone who is handicapped. This belief is bolstered by psychologists and other professionals who propose that an assessment of a person's I.Q. or mental age per se, gives insight into the nature of a person's handicap. However, their proposal relies on the mistaken assumption that a mental handicap lies simply within the individual. Rather, the individual is handicapped in so far as he or she lacks the intellectual capacities to meet the demands which society places on him or her. As Serpell (1982) comments, "an intellectual handicap can only be understood in relation to a set of cultural norms" (Serpell, 1982, p.1).

Assessment procedures have been devised, using normative data and common sense, which measure the individual's level of ability on a range of skills thought necessary to be socially competent (e.g. American Adaptive Behaviour Scale, Progress Assessment Charts and Copewell). The required skills are set out in hierarchical order so that the individual's strengths and weaknesses can be identified and a programme of training drawn up. Learning a skill does have positive consequences for the individual. For instance, a person with a mental handicap learning to cook might become less dependent and gain confidence and satisfaction. A person, by learning to use public transport, may gain a greater degree of autonomy. The focus of the skills model is on the individual with a mental handicap. He or she is expected to acquire tools whereby he or she may no longer be dependent on support in a manner demonstrative of his or her handicap. However, a person requires not merely the ability, but the opportunity and knowledge of when and how to use the skills. If the aim of such skills is to allow the individual to play a fuller and more dignified part in society then it is a mistake to believe that strict behavioural programmes carried out in artificial settings are a real preparation for, and in some instances an alternative to, life in the real world (Schalock and Harper, 1978, Willer and Intaglia, 1981, Locker at al., 1983).

In Adult Training Centres (ATCs) considerable emphasis is put on social education. One example of this education often found in ATCs is 'survival cooking' which comprises of a rigorous training in the use of a limited number of materials in a rigid fashion. Despite the belief that these assessments and training procedures are objective, any attempt to teach what boils down to a lifestyle is bound to be value laden. The fact that this kind of training often involves the imposition of values has rarely been considered or taken into account by researchers or practitioners. In the deinstitutionalisation research (Vitello et al., 1983, Challis and Shepherd, 1983), the social competence of people with a mental handicap is the most common measure of community adjustment. If they do not have the appropriate skills, or their behaviour does not come up to scratch, then they are said to have failed. But how many 'normal' people are self-sufficient or fit into the mould of ideal housekeeper and display good behaviour? Thus, despite Gunzburg's (1974) warning of the danger of 'turning people into efficient social automons' there is little attempt to encourage individuality and the development of a unique as opposed to a routine lifestyle.

The emphasis on social competence ignores the fact that people exist in a wider social framework and especially the problem of stigma. For instance, if the aim of training or deinstitutionalisation is to promote the independence of people living in hospital and restore them to the community then a wider social perspective has to be adopted. What is the point of teaching a range of social skills if people are always going to lead a life apart and be denied opportunity because of the stigma associated with their handicap?

Historical Outline

In order to understand the social nature of handicap and the attitudes held towards people with a mild mental handicap and their relative position in the social world, it is first necessary to briefly consider the historical perspective.

The term 'idiot', used to describe a person with a mental handicap in the nineteenth and at the beginning of this century, derives from the Greek, 'Iditas'; 'Idios'. This not merely meant that he or she had a lack of understanding, but also that he or she was, 'a private person...therefore, set apart - alone' (Barr 1904, p.18). Thus, the term 'idiot' reflected the social consequences of the person's handicap. The connotation that the person with a mental handicap was socially isolated throws doubt on the popular conception of the 'village idiot' who was an integral part of the community. However, information concerning the position of people with a mental handicap before the nineteenth century is a patchy and confused affair (Ryan and Thomas, 1980).

The specialist services for people with a mental handicap which arose in the last two centuries took the form of institutions. The common threads which led to the growth of institutions for people with a mental handicap cannot be understood with sole reference to this group. The institutional movement reflected the enormous upheaval of society caused by the industrial revolution. It is not incidental that institutions were also built for the old, the sick, the poor, law breakers and people who were mentally ill, and sometimes a combination of the aforementioned

(Foucault, 1977, Ryan and Thomas, 1980 and Skull, 1977). However, the humanitarian and educational endeavours of these early institutions for people with a mental handicap were unique. The first institutions were educational establishments. The pioneering work of Itard and his fellow Frenchman Seguin, in the educational sphere, gave credence to the possibility of reducing the handicap of people previously considered ineducable before returning them to society. To these ends the educationalists pioneered a range of educational techniques and philosophies which might be considered progressive by today's standards. As the purpose was to train people to live in the community (Lazerson, 1975), the education was also moral; to make people good citizens.

The concern with morality set the stage for a change of emphasis from the protection of people with a mental handicap to the protection of society from those with a mental handicap. Despite the fact that the benevolence of many of the early institutions were prompted by Christian principles, others believed that the behaviour of people with a mental handicap represented a regression back to a more 'primitive' state of man as a result of divine punishment for their parents' immoral behaviour (Ryan and Thomas, 1980). Thus, in an unscientific form, the concept of mental handicap as a form of moral degeneracy had already been mooted. Towards the end of the nineteenth century, the application of simplistic theories of inheritance reinforced fears that people with a mental handicap represented a throwback to a more primitive state. An illustration of these beliefs was calling people with Down's syndrome 'mongols'. This was because their distinctive features were thought to represent a regression to a mongolian race.

The alarmist projections of the eugenics movement led to a fear that people with a mental handicap would undermine the fabric of society. People with a mild mental handicap were thought to be the most morally degenerate. As a physician in charge of a large mental handicap hospital early this century wrote:

> The recognition of the moral imbecile [people with mild mental handicaps], and the absolute necessity of a life long guardianship, protection against temptation and all the horrors of criminal procedure, were long and strenuously insisted upon by Dr. Kerlin in the name of science, of sociology, as a matter of political economy, of the protection of homes, and all that man holds dear. (Barr, 1904, p.68.)

The term 'moral imbecile' was a category in it's own right, ranging from:

> Low grade:... temperament bestial. [to] High grade:... with a genius for evil. (Barr, 1904, p.1)

Begab (1975) commented that people with a more severe mental handicap continued to be perceived as pitiful for longer than those with a mild mental handicap. However, by the turn of the century people with a more severe mental handicap, were considered as part of the same wider social evil. As Barr commented:

> The protection which society demands and needs to be advised of is, first from the burden of the untrainable idiot both in the homes and training schools and also in the schools for the other kind of defectives, i.e. those

> for the blind and deaf and mute; second from the disadvantage resulting from those intermingling in the schools of normal with backward children; third from mischief which whether trained or untrained the iresponsible imbecile is likely to perpetrate if unguarded; still more from the tragedies certain to be enacted by the moral imbecile, and above all else, protection from an increase of an evil growth which if unchecked is inevitable. (Barr, 1904, p.89.)

During this period the emphasis of large institutions shifted from that of an educational to a medical model and a concern with aetiology and treatment. The metaphor of mental handicap as a sickness in society was taken literally, and as a medical problem it was thought it could best be tackled by 'the medical sciences' (Barr, 1904). However, despite the use of some rather dubious brain surgery the main biological concern was with the perceived threat of growing numbers of people with a mental handicap. People with mental handicap were considered to have abnormal sexual drives. Consequently, sterilisation was openly advocated and practised, even if not legalised. 'Asexualisation' was even suggested to improve the behaviour of individuals with mild mental handicaps and rid them of their 'moral degeneracy' (Barr, 1904).

The early twentieth century also marked the development of I.Q. tests, designed to separate those requiring special schooling from those who were to enter mainstream education. Unlike the innovative nineteenth century educational developments for people with a severe mental handicap there was apparently little that was 'special' about education for people with mild mental handicaps. The aim was to provide a vocational training for people with mild mental handicaps and prevent ordinary children from being held back (Lazerson, 1975, Ryan and Thomas, 1980). This original aim was characterised by Binet's (1905) attempt to identify the employment status of a group of ex-special school pupils. Studies carried out using I.Q. tests in the first three decades of this century bolstered the views expounded by the eugenics movement. People from ethnic minorities, the deprived and the poor, all performed badly on I.Q. tests (Begab, 1975, Lazerson, 1975, Ryan and Thomas, 1980). A belief grew that I.Q. tests measured a genetically endowed trait of intelligence which could not be improved.

On the whole, such simple hereditary theories have since been discounted, along with the view that people with a mental handicap are immoral or a threat to society. I.Q. tests are now regarded as culture bound measures and intelligence is not viewed as a fixed trait (Mittler, 1979). However, there are still a range of attitudes and myths which are held by the public and professionals which derive from widely held fears at the turn of the century. For instance, fears of the promiscuity and sexual deviance of people with a mental handicap which still exist in some quarters today derive from the alarmist days of the eugenics movement (Elwood 1981).

Another misleading view of people with a mental handicap arises from the idea that they have a fixed mental age or level of intelligence. The widely held belief that people with mental handicaps are child-like is given credence by psychological tests that assign a particular mental age to people with a mental handicap. The image of a 25 year old man or woman as having the mental age of an 8 or 9 year old is extremely powerful and carries with it a range of connotations about the person far wider than the intellectual capacities measured by the test. For example, men or women with a mental handicap might be prevented from having a relationship with someone of the opposite sex because they are presumed innocent of such matters. Greengross (1976) pointed out that many parents take it for granted that their son or daughter will never marry or lead an ordinary adult life, due to their 'handicap'. Therefore the thought of sexual relations never crosses these parents' minds. The idea of a mental, as distinct from a chronological, age is not merely a scientific one, but is interwoven with much older beliefs about the child like innocence of people with a mental handicap. Just as the origins of many currently held attitudes can only be understood with reference to the past, equally the genesis of new ideas concerning mental handicap can only be understood in an historical context.

Stigma

Goffman (1963), defined stigma as a particular attribute such as a physical or mental disability, skin colour or the following of a career of crime or prostitution, or the holding of particular religious or political beliefs, which deviate significantly from the norm and are negatively stereotyped by society. When this comes to be regarded as a central characteristic of the person the individual is 'stigmatised'.

Goffman wrote his account of stigma from a normative perspective. He referred to 'normals' and 'cripples', and appeared to accept the contemporary reality of stigma. For example, he did not feel that people with physical handicaps could enjoy the same social activities as able-bodied people:

> Tortured learning may be associated, of course, with the tortured performance of what is learned, as when an individual, confined to a wheelchair, manages to take to the dancefloor with a girl in some mimicry of dancing. (Goffman, 1963, p.21.)

Thus Goffman did not question the social norms and believed that such norms are fairly static. He did not think society's norms would change to accommodate stigmatised individuals or minority groups. Instead, Goffman proposed that to escape from their stigmatised identity people would have to hide their stigmata. Alternatively, minority groups would have to change their image in order to be accepted within the normative framework used by society. Following this line, if people with a mild mental handicap were able to appear as competent members of society, then they would not deviate from the social norms and would no longer be subject to stigma. However, stigma is a social phenomenon, and once people with a mental handicap have been differentiated through attending a special school or institutionalisation they will be negatively stereotyped. As such, they do not simply have to demonstrate competence, but have to live down the negative image.

One must understand Goffman himself as an historical phenomenon. When he wrote about stigma, he reflected attitudes and beliefs of his time. Now most people are 'aware' of the power of minority groups, such as the feminist movement and animal rights campaigners, in changing the attitudes and values of society.

The stigmatised treatment which people with a mental handicap face is not simply manifested in terms of rejection and disgust. Attitudes held towards people with a mental handicap are complex and often ambivalent. Many people who have little or no contact with people with a mental handicap may talk with concern about 'them' and treat 'them' kindly. At the same time when it is proposed to have a hostel or group home for people with a mental handicap in their street, these very same people will raise objections. This happened in 1987 in a 'conservation area' of Stirling. When the local mental handicap hospital proposed to open a staffed group home the local residents were up in arms. They mounted a campaign against the group home in the local and national press, on the radio and held protest meetings at the offices of the Health Board. Included in their number were lawyers, doctors, a minister and a researcher in the field of medical sociology. Such attitudes are therefore more deep rooted than one might imagine and are not simply counteracted by being better informed or being part of a caring profession.

While families know and love their sons and daughters as individuals it does not mean that they are immunised from negative attitudes towards 'handicap'. For example, parents very often hold protective attitudes towards their son or daughter with a mental handicap, however mild it may be. Card and Horton (1982) surveyed the parents of people with a mental handicap over the age of 16 living in the Eastbourne area. They found that over 90% of the parents wished their son or daughter to remain at home until they were too aged or infirm to look after their offspring anymore. Moreover, if and when their son or daughter moved on from the family home, the majority wanted him or her to live in a residential facility as protective as the family home. What is common in all stigmatised treatment, whether it be getting a yellow bus to a special school, being rejected and called names by their peers in the neighbourhood, or being protected by parents, is that people with a mental handicap are set apart and given an inferior social status. Moreover, people with a mental handicap do not simply deviate from social norms but have a particular social history and have been assigned to a particular position in society. As Goffman stated at the end of his book:

> Sociologically, the central issue concerning these groups is their place in the social structure;... and is something that cannot in itself be fully understood without reference to the history, the political development and current policies of the group. (Goffman, 1963, p.151)

Effect Of Stigma On The Individual's Handicap

The range of negative attitudes towards people with a mental handicap, and the inferior social status attributed to them, has practical repercussions on these people's lives. The very process of being identified as different and the accompanying lack of opportunity, overprotection, negative stereotyping and other facets of being a member of a stigmatised group, result in a debilitating secondary handicap. This derives in part from the self-fulfilling prophesy, decribed by Wolfensberger (1972). For instance, if people are expected to be unreliable because they are mentally handicapped, they will rarely be given the responsibility or opportunity to make important decisions. Hence when people with a mental handicap act irresponsibly, this will be seen as a consequence of their handicap.

Labelling theory, renamed as 'interactionist theory of deviance' by Becker (1973), provides an important analysis of the relation between societal norms and stigma. Labelling theory does not try to explain how the person came to break the social norms in the first place, but what happens when an individual is labelled. Deviance is a social phenomenon: it is only if someone has demonstrably broken social norms or has been accused of doing so that he or she will be labelled as deviant. It is the social processes associated with being labelled and how it affects the life and identity of the labelled individual which are the concerns of this theory. Mercer (1965) contrasted labelling with the clinical approach to deviance (often adopted by psychologists among other professionals), which places the emphasis on the individual as both cause and effect of deviance. Hence, the study, cure or prevention of deviants must be based on individualistic interventions. Society's norms and values are not questioned: the problems lie within the individual. The opposite approach taken by the labelling theorists examines how the social world impinges on the individual. As Mercer (1965) stated:

> The social system perspective, on the other hand, attempts to see the definition of an individual's behaviour as a function of the values of a social system within which he is being evaluated. (Mercer, 1965, p.77)

Work concerning the labelling of people with a mental handicap has largely focussed on the effects of special school attendance. The reasons why children with a mental handicap do not perform well in mainstream education, are set apart by their non-handicapped peers in mainstream education, or are originally sent to special school, cannot be explained by labelling theory, nor would Becker (1973) wish to do this. Mental handicap and learning difficulties do exist. However, for people who are identified by ordinary schools as mildly mentally handicapped and sent to 'special schools' the process of being labelled can be a traumatic event. Deep rooted prejudice against people with learning difficulties or a mild mental handicap who achieve little in the formal education system ('stupid people'), is likely to be reflected in their treatment by other children. Dexter (1964) considered that such attitudes arise as a result of the emphasis placed on schools and schooling in society. Furthermore, going to a 'special' school would seem to reduce their prospects of obtaining full-time employment, (May and Hughes, 1984).

On the other hand MacMillan et al. (1974) have strongly argued that the effect of the special school label has been overstated and is based more on hearsay than on sound empirical evidence. When reviewing studies on this subject, MacMillan et al. pointed out among other criticisms, that the consequences of attending a special school could not be abstracted from the negative experiences that may have led up to their special school placement. Moreover, the authors were not convinced by the evidence concerning the social isolation of special school children from their mainstream peers. They felt this was more likely to have been caused by lack of social skills on the part of the special school children than as a result of the special school label. Indeed, the authors pointed to experimental evidence indicating that greater tolerance was shown by non-handicapped children towards children labelled as 'handicapped' than towards non-labelled children.

MacMillan et al.'s first point about negative pre-special school experiences being confused with the effects of special schooling is relevant to the debate about the effects of special schools. However, this does not detract from the importance of labelling. If a person is set apart and treated badly by his peers before being sent to a special school because he or she is perceived to be 'stupid', then this is an 'informal' labelling process. This second point about the social isolation of people with a mental handicap is debatable. Rather than being the reason for being rejected by their non-handicapped peers, the children's lack of social skills might equally arise from being rejected by their non-handicapped peers. Moreover, experimental evidence about people's tolerance of labelled individuals tells us nothing about how willing they might be to accept them in real life situations. In spite of these reservations MacMillan et al.'s comments underline the fact that it is not a straight forward matter to isolate a particular label and measure its effects on a person's life. Schur (1971), a proponent of labelling theory, was also aware that there are no hard and fast rules from which one could predict the extent to which being labelled would give a person a secondary handicap. There are other aspects of an individual's personal history, abilities, personality and feelings that would also play a part in the labelling process.

In the end though, MacMillan et al. were hoisted by their own petard in their criticism of research concerning labelling theory. They discussed research on the effects of teachers' expectancy on their pupils' actual academic performance. When arguing that such work must take account of teacher experience, the authors gave the following explanation:

> For instance, a teacher who is naive regarding mental retardation might be fooled by a high expectancy given for a child who obviously has Down's syndrome. However, a teacher familiar with mental retardation is not likely to accept the high expectancy. At the same time, a high expectancy for a child without a physical stigma may be

> more 'believable' than for a child with a physical stigma (e.g., Down's characteristics) for both naive and/or knowledgeable teachers. (MacMillan et al., 1974, p.257)

In a review article Rynders et al. (1978) countered the still widely held belief that people with Down's syndrome had little educational capability. They started their article by quoting a major medical authority who had recently claimed that he had never seen an educable 'mongoloid'. On the basis of the research evidence Rynders et al. dismissed this claim and finished by urging him to tell the parents of Down's syndrome children:

> presently the limits of Down's syndrome children's educability are virtually unknown because past psychometric studies of educability have often been flawed, results from early education programs for Down's syndrome children are just emerging, and traditional psychometric measures by themselves are too limiting. Such a portrayal is not only appropriately optimistic, it is also appropriately fair. (Rynders et al., 1978, p.447)

MacMillan et al. (1974) had made the same mistake of presuming people with Down's syndrome to be ineducable. Thus MacMillan et al.'s criticism of work on the effects of labelling itself provided an excellent example of how prejudiced treatment and being given a 'handicapped' place in society cannot be simply abstracted from the consequences of the person's intellectual deficit.

Once stigmatised always handicapped?

After discussing whether a labelling process can be identified for people with a mental handicap in the special school system the next logical step is to consider how easily such labels can be shed. Mercer (1965) proposed that the stigma attached to handicap can only be understood within the framework of a particular group's social norms. She found that parents from a lower socio-economic or minority ethnic group background were less likely to consider their institutionalised mildly mentally handicapped son or daughter as deviant than parents from a higher socio-economic background. The former group's children were most often labelled after being in trouble with the authorities and their parents frequently sought their discharge. In contrast, the children from the higher socio-economic group had been considered handicapped by their parents and were referred to the services by their parents. These parents rarely sought the discharge of their children. Mercer's findings suggest that in the higher socio-economic group the children deviated more significantly from their local norms than the children in the lower socio-economic and minority ethnic groups did from theirs.

The flaw in Mercer's paper was that she assumed the two groups to be equivalent on the basis of I.Q. tests, themselves value laden and culture bound (Mittler, 1979). Thus the I.Q. tests were weighted against the children from lower socio-economic and ethnic minority backgrounds who may, in fact, have been more able than the middle class children. The important lesson in Mercer's paper, however, is that there is no such thing as a 'normal' social role. A person's handicap cannot be understood merely in terms of society's institutionalised norms, but only, in addition, by taking account of the role of the individual's social history and circumstances. This point was effectively made by Mittler (1979). He used two ficticious case studies, of individuals with very similar mild mental handicaps, to demonstrate the almost arbitrary circumstances which could result in each leading a very different life. One was institutionalised, while the other got a job, was married and led a very ordinary life.

Gruenberg (1964) showed that people with a mild mental handicap who had left special schools often had no further contact with the specialist services, at least into their mid-twenties. Granat and Granat (1973) suggested that a stable percentage of the population in Sweden have a mild or borderline mental handicap. However, only a proportion of these people are formally labelled as mentally handicapped at any one point in time. It is not clear, though, if this means that people are able to get rid of their handicapped identity, or that they simply avoid using stigmatising services.

The findings of Gruenberg (1964) and Granat & Granat (1973) lead us to ask whether people with a mental handicap are aware of their position in society and to what extent they seek to and succeed in ameliorating or hiding their handicap in public. Goffman (1963) described the stigmatised individuals' attempts to manage their 'marked identity' in face-to-face interaction, and the repercussions this has for their identities. He proposed that each individual in society is socialised to adopt a particular set of norms. These norms are a social ideal which every member of society would aspire to. Hence people who do not attain these norms or deviate significantly from them would be aware of others' negative regard. This leads them to hide or at least minimise the visibility of their handicap from others with whom they come into contact. Attempts to do this are further complicated by the fact that some stigmas are not immediately obvious to others, making those concerned 'discreditable' (Goffman, 1963). Thus people who attend an Adult Training Centre, and do not wish to publicise this aspect of their life, may not be obviously handicapped to others they meet at the shops. On the other hand, those with an obvious handicap or stigma, or whose association with stigmatised services is publicly known, are 'discredited'. For example, if people have Down's syndrome or are slightly spastic, there is no possibility of this fact going unnoticed when they go out shopping. Equally, if they are known throughout their locality for attending or having attended a special school, they cannot deny this. Hence, it is extremely difficult for the 'dicredited' to escape from being stigmatised.

Goffman (1963) thought that if stigmatised individuals sought to be treated as ordinary they may be resented, as their claims to normality would be threatening to the very norms from which their stigma arose. There is some support for this assertion. Katz (1981) carried out a series of experiments to study interactions between non-handicapped individuals and people with a physical handicap. He found that non-handicapped participants reacted badly when the people with a physical handicap did not behave according to their prejudiced expectations.

Whether people with a mental handicap are discredited or not, they are not socialised into a sub-culture (unless they are residents in a long-stay institution), nor are they a homogeneous group. They are individuals with a variety of interests, needs and aspirations, coming from a range of backgrounds. Thus people with a mental handicap are likely, deliberately or simply through the course of interaction, to assert their individuality. However, they face an enormous struggle.

Turner (1986) coordinated an extensive ethnographic investigation into a workshop for people with a mental handicap in California. Above all he found that the workshop was a 'haven' from the pressures of attempting to maintain their self-respect while being regarded by others as 'handicapped' individuals. Therefore, the emphasis in the workshop was on 'social harmony'. This was maintained through an 'etiquette', developed by the individuals who worked there, which encouraged a mutual respect that was lacking from the rest of their lives.

Another element of Turner's research was a discussion group set up for a number of those attending the workshop. Graffam (1985) analysed the group's meetings. In his conclusions he described how the group had managed to maintain its momentum over a period of years. Graffam felt it had become an important forum where those attending the workshop could share their common grievances and talk about the problems caused by their social situation. For example, he described how those that worked there were placed in a 'double bind situation'. This means on the one hand they were constantly reminded by staff in the workshop to behave like adults but infact were given little or no control over their situation and were maintained in a position of 'dependence'. Thus the group used the discussions, in part, as another way of maintaining their self-respect and asserting their individuality.

The added problem which individuals, and indeed groups of people with a mental handicap, face in their attempt to combat stigma, is that they are not taken seriously (Dexter, 1964). This does not simply mean that the person with a mental handicap is considered 'stupid'. As Dexter (1964) pointed out, their handicap is also believed or assumed, by many, to make them insensitive to others' negative regard. Goffman (1963) pointed out that people display an ambivalence towards the stigmatised because, beyond the negative stereotype, stigma is not an 'all or nothing' phenomenon. Everyone has had some experience of what it means to fall short of social ideals in their lives and are thus bound to feel some empathy. However, if people with a mental handicap are not considered by non-handicapped others to have such feelings, or insight into their own position, then even this sympathy which might heighten respect for the person with a mental handicap will rarely be present. Such respect, and a willingness to take the individual seriously, are both vital if the person is to break down prejudice.

Even where the person with a mental handicap is taken seriously and is liked as an individual it may be thought necessary to maintain him or her in a position of powerlessness. Koegel (1986) detailed an episode where a young man with a mild mental handicap was made very ill through drink by his father in order to discourage his interest in alcohol. His brother, in contrast, was introduced to alchohol in a responsible and sensitive manner by his father when he showed the same interest at a similar age.

Thus in theory if a person has a very mild mental handicap and no particularly discrediting features such as Down's syndrome, he or she might well be able to shed a special school label. In practice this is not easy, Edgerton (1986) made a case study of an individual who was 'delabelled' when he was found to have an I.Q. well above the level which denotes an intellectual deficit. In his conclusion Edgerton made clear that the individual could not simply discard the label of being mentally handicapped. This reason was that the label did not have the most direct effect on the person but on people in his or her social world such as parents, teachers and the providers of services among others. Therefore, if one is not taken seriously as a person one may not be empowered to alter one's circumstances, and one may be shaped into a 'handicapped' individual whether one deserves the label or not. Moreover, one may be driven, like the members of the Workshop society (Turner 1986), to provide mutual confirmation of each others' worth.

Normalisation

Normalisation was originally a Scandinavian concept, concerned with the right of people with a mental handicap to live as normal a life as possible. It is defined as:

> making normal mentally retarded people's housing, education, working and leisure conditions. It means bringing them the legal and human rights of all other citizens. (Bank-Mikkelsen, 1976, p.56)

Wolf Wolfensberger (1972, 1980a, 1980b,) was the first American exponent of this philosophy. He shifted the emphasis of normalisation to a consideration of the ways in which people with a mental handicap could overcome their 'devalued' status:

> One development is the recent insight that the most explicit and highest goal of normalisation must be the creation, support and defence of valued social roles for people who are at risk of social devaluation. All the other elements and objectives of the theory are really subservient to this end, because if a person's social

> role were a socially valued one, then other desirable things would almost automatically follow, at least within the resources of his/her society. Indeed, attributes of the person which might otherwise be viewed negatively by society would come to be viewed positively. (Wolfensberger, 1983, p.234).

According to Wolfensberger the socially defined negative 'role' afforded to people with a mental handicap is maintained through conscious and unconscious imagery. This imagery is reflected in how people with a mental handicap are talked about by others, and how others behave towards them collectively in the form of services, and individually within and outside services. Hence if a person receives punishment in a behaviour modification programme through the use of a cattle prod, then in Wolfensberger's terms the person is being treated like an animal. Wolfensberger (1972, 1980a) pointed to powerful social representations of people with a mental handicap as children or animals, the roots of which can be traced historically. It is certainly the case that professionals working within services may not be aware of the degrading way in which they treat people, and perhaps deny them the most basic human rights by failing to recognise their personhood. They may also be quite unaware of the historical origins of the attitudes which they hold. From these attitudes comes the self-fulfilling prophesy, already mentioned in the section on labelling. It simply means that if people are expected to behave in a particular manner, then the likelihood is that they will behave in this fashion.

Wolfensberger (1972) does not just regard normalisation in terms of living as normal a life as possible, and obtaining rights as full members of society. He proposes that to overcome the stigmatised image of people with a mental handicap they would have to be given a distinctly positive social position. This would be achieved by the people with a mental handicap leading 'culturally valued' lives. Concurrently an attempt should be made to break the self-fulfilling prophesy or, as Wolfensberger terms it, 'negative role circularity'. As part of this process behavioural techniques and positive interventions would be used to attempt to make people with a mental handicap more socially competent and their handicap less apparent. In order that the person with a mental handicap should be seen in the best light, Wolfensberger (1980a, 1983) put forward the 'conservatism corollary'. Thus to compensate for their handicap, people should ensure that they appear as ordinary as possible, or be seen to be conservative as opposed to unconventional. Goffman (1963), adopting the same normative and conformist framework, noted that the leaders of a stigmatised group seeking acceptance from the mainstream community would be likely to display many of the most favourable of the mainstream's characteristics. Thus what Wolfensberger is saying is that people with a mental handicap must live down their stigmata by being extra good citizens.

The problem with a simplistic approach to 'role circularity' is that it is not possible to make people 'normal'. However positive one's expectations may be of a person with a mental handicap, however ordinarily one may treat him or her, his or her intellectual deficit will not just disappear. The person may still be differentiated through a lack of literacy or numeracy or an ability to meet a variety of complex social demands required in everyday living. Moreover, if one has to set people apart in order to teach them to be 'normal', one will be differentiating them from non-handicapped others.

Tyne (1981) claims that Wolfensberger has frequently been misinterpreted, and that he does not simply want to make people normal but that he is equally concerned with the education of the public at large through promoting a positive image of people with a mental handicap. Wolfensberger maintains that people with a mental handicap should not only display culturally valued characteristics, but that they should come to be associated by non-handicapped others with the positive aspects of society and consequently be treated by them as valued people.

To present people in the best possible way, Wolfensberger (1980b) developed a set of ideal images based on middle class American values. It is impossible to evaluate their validity as they are not based on wider research with a 'normal' population. On the basis of these images Wolfensberger and Glenn (1978) developed a scheme to evaluate services for stigmatised people and to measure the extent to which they counteracted the stigma. A number of the items in this scheme are manifestly culture-bound. For instance, they claim that to use an abbreviation of someone's first name, such as calling James Jim, would be considered demeaning. Image, which is a central feature of American culture, was the focal concern of their evaluation. Hence, there was an instance where someone carrying out this evaluation came across people in an Adult Training Centre making brooms and brushes to be used by road sweepers. The evaluators interpreted this to mean that the Centre manager and staff regarded people working there as 'rubbish'. However, people in the real world make similar objects for a living, they dig graves, go down mines and do many other jobs which, if they reflected on the individual, could make the person far from valued. It could be argued that because people are paid to go down mines, dig graves and sweep streets, they are involved in 'valued' occupations, although from a middle class perspective these are 'dirty' jobs. Thus, there is no simple relationship between an image and a person's relative social standing.

The idea that there is an ideal position or social role within any given culture which is valued, is as wrong as the notion that there is a sharply defined social role which people with a mental handicap occupy. To justify such statements one would first have to define what is meant by a 'valued social role' and which element of society defines what are the valued social roles. When someone is obviously badly treated or lives in a dilapidated hospital ward, it does not take expertise to know that the person is being treated as qualitatively different from people in the mainstream of society. However, Wolfensberger (1972, 1980a, 1980b) and Wolfensberger and Thomas (1981) propose that all actions towards, or associations made with people with a mental handicap have to be carefully analysed in case they are consciously or unconsciously demeaning. Obviously the most subtle of such images are the most difficult to identify and eradicate. To interpret the underlying intention for even the most basic of actions towards another in the social world can be problematic, let alone attempting to do this with grey areas. For example, a picture from a fairy story hanging on the wall in a hostel for adult people with a mental handicap might signify that the residents are seen as child-like or, in contast, in a different adult context the picture might be admired as a work of art. Does the fact that a member of staff has a Mickey Mouse clock in his or her bedroom mean that he or she has a Mickey Mouse attitude towards his or her work with people with a mental handicap? If the residents of this hostel go out wearing clothes whose colours are badly matched, does this devalue people or do most other people really wear matching or complementary colours? The danger of using such criteria against which to judge and interpret the actions of people with a mental handicap, and the behaviour of others towards them, is that it is likely to reinforce the status of people with a mental handicap as an extraordinary group. It could also make professionals self-conscious in their dealings with people with a mental handicap and create barriers between both parties. Moreover, is individual dignity, spontaneity and choice made secondary to good appearances? The two are not always compatible.

Like Goffman (1963), Wolfensberger (1980b) presents a conformist perspective, where people are expected to conform to society's norms. Even if it is impossible for people with a mental handicap to become normal, Wolfensberger believes that they can only become valued in terms of the norms of the society in which they live. Underpinning this perspective is a conception of a static society, a society where people conform to unchanging norms, where social change is not taken into account. Wolfensberger (1983) used the example of the bound feet of Chinese women to present the case that stigmata could become valued. However, the bound feet of Chinese women were not stigmata but status symbols. These women were not positively regarded because their feet were crippled. Rather, their feet were positively regarded because they were symbols of the women's socio-economic status. Stigmata have a particular social history within any culture. People are stigmatised and given an inferior social position in society because they fail to meet, contradict or break what at any given time are the societal norms.

Social life

It is important to look briefly at studies concerning the social lives of people with a mental handicap. Evidence of their acceptance and rejection by non-handicapped others gives a better view than any other research perspective of the position such people occupy in society.

In his classic study 'The Cloak of Competence' Edgerton (1967) pointed to the isolation of a group of people with a mental handicap who had been discharged from a long-stay hospital to live independently in the community. One of the main features of his study was the participants' preoccupation with the idea of making friends with non-handicapped people and with being accepted in the community. Sixteen years later, in her Presidential Address to the American Association on Mental Deficiency, O'Connor (1983), too, was concerned with the social isolation of people with a mental handicap and emphasised the importance of providing them with adequate social support.

Some of the research into the social lives of people with a mental handicap has shown positive changes following deinstitutionalisation. For example, O'Niel et al. (1981) followed a group of ex-hospital residents for up to three and a half years, finding increased involvement after the move in various activities, the most notable of which were domestic tasks such as shopping, cleaning and cooking. Their new homes had become the foci of their newly developed social activities. In the authors' words, the residents' homes had turned out to be 'livelier' than the hospital wards. Erickson et al. (1985) compared the social lives of people living in community-based homes and in a long-stay hospital and found that the social lives of hospital residents were entirely restricted to activities carried out within the hospital. The authors were disappointed to find that people living in the community-based residences also had a low level of involvement and social contact with people outside their residences. Flynn (1986), who interviewed ex-hospital residents now living in their own homes, noted that the main contacts of many of the respondents were people in support services.

The above pattern of findings is not confined to deinstitutionalised populations. A survey of people with a mental handicap living in their family homes and hostels (Lundstrom-Roche, 1981) found that they often led restricted lives which revolved around their family, as well as around the day and recreational services organised for them. Furthermore, only a few of these people had non-handicapped friends and acquaintances. Cheseldine and Jeffree (1981) carried out a survey of adolescents living in their family homes. It was found that their social life was very limited and that they had no non-handicapped friends. The researchers claimed that this situation was due to several reasons. First, these young people were lacking in knowledge of available amenities and activities in which they could get involved; secondly, they were lacking in the necessary competence to take part in such activities; and finally they were overprotected by their parents.

A vital question which emerges in this work but that has rarely been addressed directly is the relationship between the participation of people with a mental handicap in ordinary community activities and their achieving acceptance by, or forming reciprocal friendships with, non-handicapped people. Atkinson (1985) followed up a group of people with a mental handicap moving out of an institution to live more independently in the community. She found that even the most sociable of ex-residents were unable to make friends or acquaintances with non-handicapped people. A review of the literature concerning friendship between handicapped and non-handicapped children by Gottleib and Leyser (1981) suggested that integration into mainstream schooling does not necessarily foster the development of friendship between non-handicapped children and children with a mental handicap. The authors concluded that positive intervention is necessary to promote such friendships.

Surveys and more detailed case studies (Lundstrom-Roche, 1981; Flynn, 1986; Langness and Turner, 1986) have indicated that people with a mental handicap are acutely aware of the deficiencies in their social lives. It has become evident that having a worthwhile social life and, in particular, making friends with non-handicapped people is a matter of great importance for individuals with a handicap. Kauffman (1984), in a participant observational study of people with a mental handicap living independently, offered a qualitative analysis of her data that went far beyond a description of the participants' social lives and their feelings. She identified different types of social life that were characterised by high or low levels of satisfaction and of social activity. She found that some people obtained satisfaction by involving themselves in specialist interest groups such as railway enthusiasts, while in other cases a person's lively existence was dependent on having a sociable spouse. In contrast, overdependence on their families resulted in people being dissatisfied with their social life. Others were unable to come to terms with their handicapped identities and felt rejected by society.

The picture which emerges from research indicates that people with a mental handicap are not readily accepted by non-handicapped others. While some people may have relationships or interests which are socially fulfilling, others remain dissatisfied with their lack of social contact with non-handicapped others and the narrow range of activities that they engage in.

Conclusion

This chapter has proposed that people with a mental handicap do not simply suffer from an intellectual deficit. They also have a secondary handicap arising from their stigmatised status. Such a stigma can only be understood in an historical context. Labelling theory has attempted to investigate the consequences of stigmatising labels on the lives of people with a mental handicap. The effects of labels are not straightforward and are mediated by a host of personal and social factors relating to the individuals concerned. However, once regarded as such, people with a mental handicap find it difficult to be accepted on equal terms by even the most significant non-handicapped others in their lives. Wolfensberger's work on normalisation suggests that people with a mental handicap can escape from their devalued social roles by being given a valued position in society. Unfortunately, it is is not clear how people are to achieve such a position within the framework of present society. Finally, a short review of studies of the social lives of people with a mental handicap indicates their marginal social status.

What is missing from this chapter is a consideration of the way in which stigma affects the feelings of people with a mental handicap about themselves. As a preliminary it is necessary to review some theories of the self-concept.

CHAPTER 2

Social Theories Of The Self

The previous section was concerned with the social stigma to which people with a mental handicap are exposed. The work of Goffman (1963) and the work of the labelling theorists was primarily focussed on the careers and coping strategies of stigmatised individuals or people regarded as deviant. However, these researchers were only peripherally interested in the consequences of stigma for a person's view of him- or herself.

This section will discuss theories of self-concept which may offer some understanding of the consequences of stigma and being labelled as handicapped for a person's self-concept. The crux of the matter is the relationship between the individual's concept of self, and his or her relative social position and manner of treatment by others. The theories to be considered deal with this relationship.

William James (1892) first introduced the hypothetical construct of the 'self' into the realm of psychology. He was also the first to make a distinction between the two aspects of the self, the Me and the I, describing this as follows:

> Whatever I may be thinking of, I can at the same time always be aware of myself, my personal existence. At the same time it is I who am aware, so that the total self of me being as it were duplex, partly known, and partly knower, partly object and partly subject...[but] I call

> these discriminated aspects and not separate things...(James, 1892, p.176)

James defined the self as known, the object or the Me, as the total sum of all that a person can call his own. The Me is comprised of the person's body, family, position, the awareness of his or her own mental processes, feelings and thoughts, and the existence of a multiple social self. Thus, one can think of the Me as the total content of the self.

The I, on the other hand, is the subject, the knower, which James called the organised 'stream of consciousness'. The I considers the objects of conciousness while not being an aggregate of them. The I is not an enduring entity but rather a dynamic process, the awareness of one's self and one's individuality.

James' work has led to more sophisticated approaches, all based on the distinction between the I and the Me, a number of which will be discussed in this section. One of the first and perhaps the most influential social construction theorist of the self was George Herbert Mead. Due to the importance of his work and the foundations which it lay for other thinkers in this area to build on, the greater part of this section will be spent introducing his writings. Mead (1934) thought that the duality of the self was made possible by the existence of society and a shared set of social symbols. The work of the psychologist Kenneth Gergen has been greatly influenced by Mead's theory of the relationship between self and society. Gergen has written extensively on the social construction of the self in the light of new evidence from social psychological experimentation. In his early work Gergen (1971, 1977) adopted an extreme social constructionist perspective, with the individual coming to see himself as he was regarded by others in any given social context. As his writing on the subject developed, he came to acknowledge the importance of other factors with respect to the person's self-concept, such as agency. The development of Gergen's writing on the self will be outlined.

Hamlyn (1977) criticised Mead and other social constructionist theorists for the emphasis which they placed on knowledge about the self gained from others in the social world. He asserted that real self-knowledge was obtained through the individual's agency. Markova (1987) provided a solution to the tension between the social construction of self and the development of self-knowledge through individual agency. She put forward a dialectical synthesis of social construction and agency and demonstrated how they were both necessary for the existence and development of the self.

These theories have consequences for the development of the self-concepts of all stigmatised people. However, this chapter will focus on their implications for people with a mental handicap. After introducing the work of each theorist there will be a section discussing the predictions which might be made on the basis of the theory about the self-concepts of people with a mental handicap. Social theories are essentially abstract conceptions and their explanatory power can only be demonstrated by discussing them with reference to a particular set of people.

George Herbert Mead

Mead (1934) adopted an evolutionary approach to the development of self-awareness. The key to the development of self-awareness is society. Society provides shared social structures and shared meanings of gestures which are internalised through interaction, and eventually lead to the development of language. Lower animals act and react to each other, they are caught in a pattern of interaction from which they cannot escape. The human mind, on the other hand, develops through the ability to reflect upon the situation in which the individual finds him- or herself, i.e. upon his or her own gestures and those of others. In other words a human being can escape from the fixed 'conversation of gestures' through understanding the meaning of gestures performed in the process of interaction. One becomes aware of oneself in so far as one realises that others adopt a particular attitude towards oneself:

> The individual experiences himself as such, not directly, but only indirectly , from the particular standpoints of other individual members of the same social group or from the generalised standpoint of the social group as a whole to which he belongs. For he enters his own experience as a self or individual, not directly or immediately, not by becoming a subject to himself, but only in so far as he first becomes an object to himself just as other individuals are objects to him or are in his experience; and he becomes an object to himself only by taking the attitudes of other individuals toward himself within a social environment or context of

> experience and behaviour in which both he and they are involved. (Mead, 1934, p.202)

It is through the process of socialisation that the child develops the ability to take the role of the other and ultimately integrates the view of others into his or her concept of self in the form of the 'generalised other'. In particular, Mead emphasises the importance of play and games in the individual's development of self.

At the <u>play</u> stage, the child simply plays at being someone, like a mother, a teacher or a policeman. The child has to understand what the particular role involves: the policeman has to drive a car, use a walkie talkie and catch thieves. But the child does not have to understand the position of the policeman from a wider social perspective. In contrast, in a <u>game</u> of policemen and demonstrators, and he or she is a policeman, there would have to be rules defining the relationship between the policemen and demonstrators. The rules impose a particular structure on the activity which all the participants have to obey. In contrast to playing at being someone, in a game the child has to be aware not only of the rules which govern his or her behaviour, but of those which govern all the other children's behaviour. The rules do not simply imply a code of behaviour; underpinning the rules is the common purpose of the group, and the rules provide the framework for a group conciousness which makes the activity possible. For instance, a group of children wishing to play a game of football all require certain knowledge not just about the rules of the game, but about the common goal of the activity. Furthermore, enshrined in such rules is the morality or spirit in which the game should be played. For example, baseball has flourished in Japan since the second world war. However, this does not mean that the Japanese are being Americanised.

Although the rules of baseball remain the same as in America, the spirit in which the game is played is distinctly Japanese. The incorporation of the views of the wider society and particular sub-groups into people's self-concepts is vital if they are going to understand the significance of their own actions and those of others, in particular circumstances. Even if one is merely observing, one needs to have active knowledge to make sense of events.

The end product of the process of socialisation is the incorporation of the view of the 'generalised other' into the person's self concept. Mead defined 'the generalised other' in the following terms:

> The organised community or social group which gives to the individual his unity of self can be called "the generalised other". The attitude of the generalised other is the attitude of the whole community. Thus, for example, in the case of such a social group as a ball team, the team is the generalised other in so far as it enters - as an organised process or social activity - into the experience of any one of the individual members.
> (Mead, 1934, p.218)

The incorporation of the attitude of the 'generalised other' into the individual's concept of self is necessary for the 'organic' relationship between self and society. In other words the individual plays an active part in society or particular social processes by being thoroughly immersed in them. A person who joins a campaigning body first has to understand the common set of attitudes which has brought people together and the aims of the group before he or she can function most effectively as a member of it. In any social context the self functions in relation to a complex set of social relationships, where particular rules and principles apply. However, by adopting the role of the 'generalised other' the individual can transcend the immediate set of social relationships in which he or she is embroiled and make sense of the wider social activity of which he or she is a part. Thus, a person acts in different ways in different situations, depending on what is deemed appropriate. In this sense Mead takes on board James' view that there is not one but a host of selves.

Thus the Me, the known self or object, consists of the internalised view of the self taken from the attitudes of others towards the self, in relation to the society of which the individual is a part. Each individual occupies a unique niche in society and develops a unique set of social relationships. Therefore Mead proposes that the development of a social self does not lead to homogeneity, but to individuality within a social system:

> I have argued that the self appears in experience essentially as a "me" with the organisation of the community to which it belongs. This organisation is, of course, expressed in the particular endowment and particular social situation of the individual. He is a member of the community, but he is a particular part of the community, with a particular heredity and position which distinguishes him from everybody else. He is what he is in so far as he is a member of the community, and the raw materials out of which this

> particular individual is born would not be a self but for his particular relationship to others in the community. (Mead, 1934, p.232-234)

In addition to the Me, the other component of the self is the I. The self does not simply reflect on its relation to others, or the attitudes which others are taking towards it. The self acts on its social world. Mead (1934) said little about the I, providing few details about its development and function. He proposed that the child is first painfully jolted into an awareness of the self when needs such as hunger or thirst are not satisfied. This child continues to experience his or her individuality most sharply when he or she breaks social convention or has wishes or desires that are deemed socially unacceptable (Miller 1982). The I is also the creative element of the self: it is the I which makes decisions, or thinks, or does something original (Markova, 1987). The prerequisite for originality is a knowledge of the current social organisation, or common set of attitudes held on a particular subject, which make up the Me component of the self. For instance, the development of the game of rugby to rugby league and then to the highly technical American football demonstrates how organised social activities are constantly changing as people stamp their individuality on to the structure. This sets the self and society into dynamic relationship with each other.

The I and the Me act together as the two components of the self. While the Me is reflexive, the I does not directly enter the consciousness of the individual. One may be aware of the possible reactions of others, or the outcome of various actions, but the I is not conscious. The I acts, and then the Me considers the consequences of the actions for oneself in the wider social world. Thus actions may be novel and surprising even to oneself!

Mead: the implications for the self-concepts of people with a mental handicap

Does the emphasis which Mead places on the social construction of the self mean that a person is locked into a particular view of him- or herself, or a particular role, consistent with the way he or she is treated in his social world? In other words, if a person is treated as 'handicapped' by significant others, is she or he likely to develop a 'handicapped' self-concept? This is a question that can only be answered by examining the relative weight which Mead gives to social construction and agency in the development of the individual's concept of self.

Mead (1934) claimed that children internalise the social structures and processes of society into their self-concepts. This means that they define the individual's position in society in relation to these attitudes and structures. Mead described the internalisation of the 'generalised other' as leading to the 'institutionalisation' of the individual. Thus, although one has a particular set of attitudes which afford a unique view of social processes, one first has to be part of an institution before one can express one's individuality. Since the individual is so tied to societal institutions the question arises as to how it is possible that he or she could develop a view of self different from the one which he or she has been socialised to adopt.

In contrast to such a deterministic approach, Ashworth (1979) felt that through reflexive thought and 'agency' Mead left the door open to allow the individual to play a part in determining his or her own self-concept. The power of a symbol is that it allows the individual to break out of the set of social relationships in which he or she is enmeshed, to be 'conscious of a past (remember) and anticipate a future'. (Miller, 1982, p.11) However, the use of symbols may not emancipate an individual from a particular set of social relationships. Language is rooted in the social institutions of society. As the previous chapter attempted to show, a stigmatised 'label' might in itself lead to a person being set apart and negatively stereotyped. If a person with a mental handicap leads a life apart in a 'handicapped' alcove of society, then he or she may be unable to avoid the stigma associated with handicap and perhaps come to internalise a 'handicapped' view of self into his or her self-concept.

A final point is that Mead's theory is based on an explicit value system. He is talking about an 'open society', where each individual has the freedom to act and develop society's social structures for the greater good of all. Unfortunately, even in an 'open society', the individual's ability to influence social structures varies considerably according to circumstances. People with a mental handicap may often be restricted even in the personal decisions which they are allowed to make, and have little opportunity or power to change the views of parents or staff about their 'handicapped' status.

In conclusion, there is uncertainty in Mead's work about the social construction of the self and the ability of people to determine their own views of the self through agency. However, if people can only experience themselves in so far as they are an object to others, then they first have to have the ability to influence social structures and others' views of them before they can play a part in determining their own self-concepts. Moreover, through internalising the 'attitude of the generalised other' they have already developed a powerful sense of their relative social position and responsibilties in society. Thus, on the basis of Mead's work, those with a mental handicap are likely to be aware of their stigmatised status through being able to take the point of view of the generalised other. Whether or not they internalise a stigmatised self-concept would appear to depend on whether significant others treat them in a stigmatised manner.

Kenneth Gergen

Gergen's writings represent a significant contribution to social constructionist theories of the self-concept. In order to grasp Gergen's position it is necessary to follow the development of his ideas over the past 17 years of his work.

In his earliest writings Gergen (1971) regarded the manner in which the individual conceptualises him- or herself and his or her behaviour simply as an extension of the way in which he or she conceptualises and understands the rest of the world. Thus there is no stable entity or structure called the 'self'. He saw the individual's self-concept as a central part of his or her conceptual framework:

> ...we have first hypothesised a process by which the individual defines or categorises his own activities, both internal and external. The resultant concepts of the self are multiple and often inconsistent. Concepts, primarily self concepts, play a crucial role in orienting the individual to the world around him and enable him to

> increase his rewards and minimise punishment. (Gergen, 1971, p.38)

The fact that self-perceptions orient people in the social world presupposes that people have an understanding of that world. One cannot evaluate one's actions, or evaluate the reactions of others, in a particular context without an understanding of that social world. Yet Gergen (1982) fails to make explicit the Meadian assumption of a shared set of social norms which provide a framework for perception of the self. Hence it is something of an understatement, if not misleading, for Gergen to say:

> ...the only significant limit over the individual's interpretations of his actions appears to be that furnished by social convention. (Gergen, 1982, p.143).

It is only in the conclusion that he admits the primacy of the individual's understanding of the social world:

> The manner in which people understand their actions, the manner in which actions are applied to themselves, their private ways of making sense of their actions are all primarily dependent on and limited by the particular support system in which they are enmeshed. (Gergen, 1982, p.145).

The central feature of Gergen's (1971, 1977, 1982) earlier writings was a proposal about the mechanisms involved when people translate information about themselves, gleaned from the social world, into their self-concepts. Gergen thought that people were unconscious of these processes because by reflecting on these processes they would lose their influence. He suggested the following processes operate in the formation of the self:

i. observation of one's own actions and feelings,
ii. evaluating the consequences of one's actions in the social world,
iii. reactions of others to one's actions,
iv. social comparison.

These processes were not mutually exclusive or distinct. For instance, let us take the example of a young boy, Peter, who helps an elderly neighbour with her garden. Peter may consider himself to be kind and helpful by the very fact that he is helping. At the same time he can see that he is making his neighbour happy and the garden tidier by dint of his efforts. Others may observe his 'good deeds' and praise him for being a helpful and generous person. Peter may reinforce this perception by comparing himself with his brother who refuses even to touch a garden spade.

According to Gergen, these processes generating people's self-concepts are reactive. They pick up clues in the social world to determine their relative social position. In this way Gergen presents people as passive recipients of external stimuli and fails to take account of individual agency or how people can alter or influence their social worlds. It is therefore not surprising that Gergen drew on evidence from social psychological experimentation. In such experiments the participants are often assumed to be passive subjects who react to external stimuli. Although Gergen (1982) stated that the individual has the capacity to reflect on how he or she would be seen in different contexts and at different times, he did not pursue or consider the consequences of such capacities. To a certain degree this would emancipate the self from its immediate social framework.

As Gergen's writings developed, he took more account of the agency of self, (Gergen 1984, 1987). However, the part played by agency remains secondary to the social underpinnings of the self. From viewing the self-concept as being 'restricted by social convention' and being shaped by the 'social circumstances' in which it found itself, he began to assert the primacy of society and in particular of social relationships to the nature of one's self-concept. For example, he no longer saw social comparison as providing absolute insight into a person's self-concept. A person might compare him- or herself to flatmates and decide that they were untidy compared to him or herself. However, he or she relies on the societal norm when making judgements about tidiness and untidiness. Ultimately then, the self, including its agency, and the shape it takes, reflect the very nature of the society in which the individual exists. Therefore, the theories of self:

> ...inform the society as to what the indivdual can or cannot do, what limits may be placed over human functioning and what hopes may be nurtured for future change. Further, they inform society as to the rights and duties, designate those activities to be viewed with suspicion and approbation, and indicate who or what is responsible for our present condition. To define the self is, thus, to sit in implicit judgement on society. (Gergen, 1987, p.2).

Thus Gergen (1987) has moved from a position where the self-concept is governed by the society in which it exists, to one where it reflects the structure of society. Thus the fact of agency does not force Gergen to reconsider his social constructionist position. He does not see social construction and agency as in opposition, but agency as emerging from social construction. In other words, it is in a social context that one is an agent, one acts on the social world; and it is society which acknowledges one's agency. Agency in Gergen's view is a social phenomenon, an integral part of wider social processes. By thus regarding individuality as an artifact of 'community' or relationships with others, Gergen (1987) avoids grasping the the thorny issue of agency and its implications for the social construction of self. Because psychological mechanisms serve the community, or social relationships, Gergen thinks that it is most fruitful to investigate these social processes. Gergen uses a chess metaphor when arguing why social processes should be investigated rather than adopting an individualistic approach to the study of self. He talks of having 'a rich language to describe rooks and pawns while we still do not understand the game of chess'.

Gergen: the implications for the self-concepts of people with a mental handicap

In his earlier work Gergen (1971) adopted a 'looking glass' approach to the concept of self. By means of a number of psychological processes a person's relative social position in a particular social setting is determined and that is the person's self-concept. Using the theoretical framework outlined by Gergen (1971), people with a mental handicap would simply come to see themselves in a fashion that is consistent with how they are treated. Whether they would be aware of the negative stigma attached to their position is doubtful. In Gergen's early work, unlike Mead's, individuals do not have to understand their relation to the society in which they live or take the role of the other.

In his more recent work, however, Gergen moved to a position where, like Mead, he regards the self as emerging from society. He takes account of agency and the importance of interaction between the self and society. However, whereas in Mead's work people play a unique part in society and their awareness of their uniqueness is the cornerstone of their selfhood, in Gergen's writings the individual becomes secondary to the social processes, a 'pawn' in the game. Thus, the question arises as to how far Gergen has moved from a purely social constructionist view of self? If the person with a mental handicap takes a 'normal' view of him- or herself in society, then he or she is likely to be aware of his or her handicapped and stigmatised status in relation to others. However, when the person with a mental handicap reflects on his or her position in the proverbial game of life, will the person accept or reject a handicapped role? Using Gergen's framework, if someone is treated by others as a handicapped person and his or her views are given little credence, then it is likely that his or her self-concept will come to reflect the 'handicapped' role afforded by society.

<u>Hamlyn</u>

Hamlyn (1977) took issue with the social constructionist position that to develop a concept of the self one first has to take the point of view of the other or become an object to oneself. Hamlyn regarded this as knowledge about the self and not self-knowledge proper. Hamlyn pointed out that if people acted purely on the basis of knowledge about the self they would constantly be looking over their shoulders to see what others thought - they would become destructively self-conscious. What distinguishes one's perceptions of self from the perceptions of others in the social world is that one has control over one's own life. One can make decisions and influence the direction which one's life takes, and this is something that no one else can do for you. Hamlyn acknowledges that a person has to understand his or her relative position in the social world in order to act. But, he does not think that beliefs which one holds about oneself can provide one with a working knowledge of the self as agent. Consequently, knowledge of self is concerned with the individual's insight into his self as an agent, and not with the 'beliefs' which he or she holds about him- or herself. This is achieved by involvement in one's own actions rather than reflection on them, which might lead to the destructive self-conciousness referred to above. Through taking decisions one is constantly changing, emphasising particular goals and values and re-orienting one's social position. To know oneself is to know that one is an individual, in a social sphere, with one's own momentum. To have knowledge about one's self is to know about one's position in the social world in a particular context and point in time.

Hamlyn: implications for the self-concepts of people with a mental handicap

What consequences does Hamlyn's work have for people whose agency is restricted? People with a mental handicap living in an institution do not even have the opportunity to choose the time at which they get up in the morning, what time they go to bed at night, when and what they eat, let alone make any major decisions about the directions they wish their lives to take. As a result of parental overprotection the autonomy of people living at home may also be curbed to varying degrees. Surely if people have less control over their lives, they are more likely to come to view themselves according to how they are seen by others and less likely to develop their own view of the self as an agent? Alternatively they might come to see themselves in a fashion that is consistent with the decisions they are forced to make. In both instances the end result would be the same: the more autonomy afforded to people, the more likely they are to decide the direction they wish their own lives to take and to reject a stigmatised view of the self.

Markova

Markova (1987) showed how the idea of a knowledge of self gained through experience was rooted in the work of Hegel. Hegel considered the individual to have a reciprocal relationship with his or her environment, at once altering it and being changed by it in this interactive process. She illustrated this point using the example of Mead's 'conversation of gestures', in which the person develops his or her knowledge of self and others through their mutual interaction. The gaining of self-knowledge is a continuous process because through acting on an object or interacting with another, the individual may gain a greater understanding of the characteristics of that object or insight into the views of the other person. Equally, others will become increasingly aware of what they do not know and so will be driven to further research of the object of their knowledge or in getting to know the person even better. And just as individuals' knowledge of others develops, so does their knowledge of self:

> ...it is clear from Mead's overall conception of mind that while interacting with each other participants progress to more complex levels their awareness as creative and reflexive individuals. (Markova, 1987, p.70)

While Markova agreed with Hamlyn that the emphasis of the self theorists has been on the social construction of the self, she did not accept that reflection necessarily leads to destructive self-conciousness. If a person is passive, then indeed he or she would find him- or herself looking over his or her shoulder all the time, to see what others thought of him or her. However, as an agent, the individual is acting and reflecting, hence the Meadian I and Me. The individual reflects on the actions of the I, and consequently the Me develops through the actions of the I. The I and the Me are not fragmented sections but parts of the whole process of self-conciousness accounting for the development of the self. As Markova explained:

> Action and reflection are two phases of one and the same process, and I and Me constantly alternate their positions and one changes into the other or one is relative to the other. ...But this kind of reflection and evaluation rather than leading to alienation, is simply a stage in the developmental process of self-knowledge. (Markova, 1987, p.71).

Markova also acknowledges the emotional content of a person's self-concept. As she notes, the individual does not simply internalise 'neutral' information about the self. Such information has meaning to the individual, and this meaning cannot be detached from the person's emotions or feelings. In contrast Mead considered the development of self to be solely a 'cognitive' exercise, while Gergen pointed to experimental evidence that the individual does not have an emotional life as such, but experiences generalised states of arousal which are socially defined.

Markova: implications for the self-concepts of people with a mental handicap

The predictions that might be made about the self-concepts of people with a mental handicap on the basis of an Hegelian approach are, in the first instance, positive. The individual influences his or her environment as well being influenced by it. One is not simply a product of one's social circumstances, one is an agent in one's own right and may consequently develop one's own view of self on the basis of experience with the world.

> In becoming human, one is working to become human, indeed one has to struggle for it, as Hegel made clear. Everything a human being achieves comes from active practical involvement rather than from sheer acceptance of information and attitudes. (Markova, 1987 p.68).

The fact that Markova highlights feelings allows the prediction, on the basis of her writings, that a person might reject the negative connotations of handicap. However, to develop self-conciousness, the person has first to be recognised by others as being a fellow human being:

> Therefore, the seal of a person's being cannot be impressed upon others by means of a physical manipulation as in the

> case of physical objects. Instead, human beings can be brought voluntarily to recognise each other as equals in their social, emotional and intellectual powers. By mutually recognising themselves as mutually recognising one another, human beings acquire self-consciousness, and the ability to take the attitudes of each other. By doing so, one recognises how the other participant feels, thinks and what he or she intends, and the one knows that the other participant knows these things about the knower himself or herself. (Markova, 1987, p.67-68)

Even though Markova rejected a strictly social constructionist view of self, the skeleton remains in the cupboard. What happens if the person is not recognised by others in his or her world as being an equal? What if the reciprocity is severely curtailed because one person's actions are severely limited, or if he or she is not taken seriously by others? Presumably this does not prevent the individual from developing self-awareness. If this were the case, how could people with extreme forms of cerebral palsy, who are unable to communicate or readily act on others, let alone on objects in their environment, develop a concept of the self? Does the mentally handicapped person's lack of power make him or her more likely to internalise the views of others, or will he or she continue to struggle to assert his or her common humanity? Certainly it would appear that the greater the individual's autonomy, the more likely he or she would be to reject his or her handicapped status.

Conclusion

It is difficult to make firm predictions on the basis of any theoretical writing, given that any theory is open to interpretation or that emphasis may be given to one particular aspect or another. However, setting a problem in its theoretical framework helps one to tease out the most salient points. The three elements which emerge as crucial to the development of the self-concept of people with a mental handicap are:

i. how they are treated by significant others,
ii. the range and nature of their life experience,
iii. the amount of autonomy or control which they have over their lives.

In the seminal work of George Herbert Mead (1934) the ability of the person to reject a stigmatised status depends in large part on the extent to which his or her interactions determine his or her self-concept. In the social constructionist theories of the self as typified by the early work of Gergen (1971), the self is simply a reflection of how an individual is regarded by others in his or her social world. Finally, the key issue for those who assert the role of agency in the development of self (Hamlyn, 1977, Markova, 1987) must be the extent to which the individual has control over his or her life, and the nature of his or her life experiences. For example, if a person's experience points to his or her position in society as being 'handicapped', and if the person's autonomy is restricted, will he or she be able to avoid internalising a 'handicapped' view of self?

CHAPTER 3

A Review and Critique of Research on The Self-Concepts Of People With A Mild Mental Handicap

When reviewing the studies concerning the self-concepts of people with a mental handicap, Wylie (1979) considered that:

> Theoretically the most interesting questions center round whether mentally retarded persons perceive themselves as belonging in a stereotyped group, whether they would have an accurate idea of the stereotype (if one exists), whether they accept the stereotype as being accurately self-descriptive and whether their overall self-regard or some aspects of their self-evaluation are poor, as might be predicted if the retardates recognise their severe limitations and the relatively low regard others have for them. (Wylie, 1979, p.359)

The above questions are interdependent. If people are aware of the stigma surrounding their handicap what consequences could this have for their self-concept? Unfortunately, most studies employing tests of self-concept fail to examine people with a mental handicap's awareness of a negative stereotype. Thus, they investigate what they assume to be the effects of stigma or their handicap for people's self-concepts. The first section of this chapter will consider how far such studies, testing whether people with a mental handicap have a positive or negative view of self, can actually provide insight into their self-concepts. Moreover, it is necessary to critically evaluate the considerable methodological problems associated with 'tests' of self-concept. The second section will concern those studies which have investigated the awareness of people with a mental handicap of the negative societal stereotype of mental handicap and whether they indeed share it. Finally, participant observational and interview based research in this field will be critically examined.

Children's studies

Measures of Self-Concept or Self Esteem

The first review of the literature on the self-concepts of people with a mental handicap was carried out by Schurr et al. (1970). The bulk of the work concerned the consequences of special class placement for the self-concepts of American teenagers with a mild mental handicap. Although Schurr tentatively concluded that special class placements resulted in children developing a more positive 'academic' self-concept than those remaining in ordinary classes, the results from the various studies were contradictory. While some found that special class placement led to more positive self-concepts (McAfee and Cleland, 1965, Fine and Caldwell, 1967) others obtained evidence showing that school children developed a more negative view of themselves (Meyerowitz, 1962, Piers and Harris, 1964). Schurr et al. explained this contradiction by pointing out that in the studies they reviewed different instruments were used, the ages of the participants varied and some of the children were from institutions. More fundamentally, Schurr et al. (1970) expressed dissatisfaction with operationalism as a basis for investigating the self-concepts of people with a mental handicap. They suggested the major problem with these kind of measures was that they 'reflect the thinking and biases of the researcher rather then the natural cognitions and concerns of the subject'. Schurr et al. also believed that a direct line of questioning would be fruitless because people with a mental handicap were 'especially suspect as subjects for research demanding obtrusive measures'.

Yet recent research has pointed to the validity of responses of participants with a mental handicap when they are talking about their work and their residences (Carter, 1981, Howie et al., 1984). In spite of this, research looking at the consequences of special school placement has continued to produce contradictory results (Silverman and Zigmond, 1983, Montague and Cage, 1974, Ziggler et al., 1972). One would not expect people's self-concepts to be stable unchanging entities. However, if stigma did have an effect on the self-concepts of people with a mental handicap it is likely that there would be a more distinct pattern to the results of studies investigating this phenomenon. Indeed, if the measures are insensitive to the feelings of teenagers with a mild mental handicap, then this would justify Schurr et al.'s criticisms that such tests fail to tap the perspective of people with a mental handicap.

A closer examination of self-concept scales reveals a number of problems. In common with many operational methods, such self-concept scales are too global and have no theoretical backbone. For example, Piers and Harris' test (1964) used Jersild's (1952) collection of children's statements covering a range of feelings and thoughts which the researchers believed to reflect a person's self-concept. The statements which made up Piers and Harris' self-concept test were grouped under the following categories:

a) physical characteristics and appearance,

b) clothing and grooming,
c) health and physical soundness,
d) home and family,
e) enjoyment of recreation,
f) ability in sports play,
g) abilities in school, attitudes towards school etc.,
h) intellectual abilities,
i) special talents (music / arts),
j) just me, myself and I,
k) personality, character, inner resources, emotional tendencies.

Piers and Harris started by attempting to obtain normative data in order to standardise the test. From the subjects' scores it was hoped to establish the 'normal' self-concept. Moreover:

> the instrument was designed to identify cases of children who are deviant as well as to establish norms, (Piers and Harris, 1964, p.92)

Thus when Piers and Harris standardised their test and found that institutionalised girls with a mental handicap had poorer scores than their non-handicapped peers, they felt this added credence to their test.

The operational basis of the Piers and Harris test is typical of self-concept measures. An operational definition is acceptable if it is sensitive to what it claims to measure. But what evidence is there that negative scores on this test mean that a person has a globally negative self-concept? The notion of a 'global self-concept' assumes that there are certain items which are central to how a whole population view themselves.

Thus an overall negative score would indicate that a person had a global view of him- or herself that was negative in relation to the rest of the population. Before such a claim could be made it would have to be ascertained whether the items in the test had the same meaning and equal salience for different groups of people within the population. Piers and Harris do not present evidence that people in institutions, special schools and ordinary schools hold the same issues as central to their self-concepts. Nor is it likely that questions on issues such as home and family are likely to mean the same thing to people who live in an institution as to people who are living in their family home.

A study by Lund et al. (1981) raised further doubt as to the validity of global measures of self-concept. The authors expressed concern at the lack of data obtained from people with a mild mental handicap when standardising measures of self-concept. Consequently Lund et al. set out to investigate the validity of the Tennessee Self Concept Scale (T.S.C.S.) for adolescents with a mild mental handicap. Like the Piers and Harris test, the T.S.C.S. is made up of first person statements like 'I am a happy person'. Half of the statements are positive and the other half are negative. The participant responds by marking a Likert-type scale from 'Completely False' to 'Completely True'. Lund et al. tested a group of 'educationaly mentally retarded' (E.M.R.) adolescents and retested them after a 10 week interval. They found only moderate reliability coefficients and concluded that:

> This finding strongly suggests that the self-concept of individual E.M.R. adolescents is a more variable psychological characteristic than has been previously indicated in the research literature. (Lund et al., 1981,

p.210)

I would rather suggest that this result reflects the test's lack of sensitivity to the specific situation in which the child might find him- or herself, and the consequences of that particular social environment for that person. Statements such as 'I am a happy person' are likely to tap relatively superficial thoughts and feelings. There is therefore no reason why the tests should demonstrate consistency over time.

An example of the insensitivity of such tests is to be found in the work of Montague and Cage (1974). Using the I-Feel Me-Feel self-perception scale they compared the self-concepts of institutionalised and non-institutionalised children with a mild mental handicap. In this test the participants were presented with 40 pictures of children engaged in a variety of social and school activities, both active and passive, on their own and with adults and peers. The participants indicated their feelings about the picture by marking one of five faces from 'very sad' to 'very happy'. Using this instrument Montague and Cage found that both groups had 'good' self-concepts relative to normative data collected with non-handicapped children, and that there were no significant differences between institutionalised and non- institutionalised children. In other words, the study told one nothing about how the different environments and experiences had affected the children's views of themselves - they all simply had 'good' self-concepts.

The necessity for a method which provides greater insight into the dimensions of a person's self-concept than a numerical score and a positive or negative assignation has been recognised by some workers in this field. Collins et al. (1970) concluded their discussion by stating:

> The results suggest that research in this area should investigate specific dimensions of the self-concept rather than employ a single global method. (Collins et al., 1970, p.289)

For instance with special class placement, the dimension of self-concept most affected might be related to school performance.

Carroll et al. (1982) found that the 'academic' self-concepts of special class children were lower than those of their non-handicapped and learning disabled peers in mainstream classes. This finding makes better sense, but there remains the difficulty of ensuring that these tests are measuring the effects of special school placement. As MacMillan (1982) explained, studies like Carroll's which compare the self-concepts of special school and mainstream children may not be measuring the effect of special school placement, but the reason why they have been put there in the first place. Special school placement may have been preceded by an acute sense of failure in an ordinary class, which could have affected the participants' self-concepts. It may also have been the case that the participants in Carroll et al.'s study did not attach importance to their academic self-concept. Jones et al. (1984) made the point that people with a particular disability may rate themselves low on a measure of self-concept, especially in those areas where they fail to achieve the norm. But this does not mean that they necessarily have a globally negative self-concept; they may lay greater store by other characteristics not tapped by the normative test. Thus in order to find the consequences of special school placement on the individuals' self-concepts, it is first necessary to gauge the importance to them of academic work.

Stager et al. (1983) looked at the stereotyped attitudes held by non-handicapped children towards their special class peers. They then investigated the relation between this stereotype and how a group of special school children characterised themselves, and their level of self-esteem. Stager et al. found that if a special school child shared a similar view of him- or herself to the stereotype of special school children held by their peers, then this resulted in a lowering of his or her self-esteem. However, if the informant's self-description was quite different to the stereotype, then his or her self-esteem was not affected.

These results showed that there is no simple relationship between stigma and a lowered self-esteem. The authors concluded that 'the labelled individual should be considered an active participant in this process' (Stager et al., 1983, p.10). However, in this study the children were only allowed to be as active as the experimenters let them. The children could only rate themselves on the adjectives which made up the stereotype held by their non-handicapped peers. Hence, although it is an interesting relationship, further investigation is required to discover what part these adjectives played in the children's self-concepts.

Another strand of work has been concerned with the relationship between the self-concepts of adolescents with a mental handicap and a host of different factors which included sexual knowledge (Hall, Moriss and Barker 1973, Hall and Moriss 1976), staying at a summer camp with therapeutic aims (Rosewal et al., 1986 and Zemke et al., 1984), and taking part in a Special Olympics swim training programme (Wright and Cowden, 1986). Simpson and Meaney (1979) looked at the consequences of learning to ski on the self-concepts of children with a mental handicap. It was perhaps not surprising that the children who had been involved in the 5 week skiing course had responded more positively on the self-concept tests than the control group who remained in the school. The lack of surprise is especially the case when the tests were carried out by researchers who had been involved in the training programme, which everyone had apparently enjoyed tremendously. This reflects a problem with all these studies: what is the focus of the test? Is it an indication of how much the 'subjects' enjoyed the course or camp? Or does it measure how the camp or course changed their view of self?

Experimenter Effects

Another way in which the informants in the above studies are 'active' is that they may attempt to work out what the tests are for, and what if anything will be the outcome or consequences of their performance. A lot has been written about the methodological problems of carrying out social psychological experimentation with suspicious psychological undergraduates, but how are children or adolescents with a mild mental handicap likely to interpret a self-concept or self-esteem test? These tests invariably take place in a school setting and are most often administered to groups of children. As the reading level required to complete the test items is sometimes too high for these children, the items are read out by the teachers or experimenters (Carroll et al. 1982). These children probably have a history of test failure and of being placed in test situations by specialists such as educational psychologists. This is likely to make them extremely sensitive to teacher expectations, even if they are told at the outset that there are no right or wrong answers. When Knight (1970) cast doubt on the validity of the answers given by children on these instruments she was probably right. However, the blame does not necessarily lie with the children and their lack of 'truthfulness', but rather with the instruments and procedures used.

In order to examine the potential effects of social desirability in studies of this kind it would be helpful for us to consider one example of school research which avoids many of the common methodological problems. MacMillan (1982) thought that Schurr et al.'s (1972) developmental study avoided the pitfalls of being a comparative study between a special school and mainstream group. Schurr et al. (1972) followed up a group of children from immediately before they were formally labelled as mildly mentally retarded and transferred to a special school. Schurr et al. found that these children's academic self-concepts increased linearly after their transfer to a special school. Interviewer and teacher variables were controlled for. The authors concluded that this increase was a consequence of the participants comparing themselves with their special school peers as opposed to the mainstream pupils. However, it does not necessarily mean that the pupils thought that they were generally brighter or academically more competent. Schurr's results could also be explained by pupils responding to teachers' or experimenters' expectations. The children were moved from a situation of low academic regard to one where they were relatively competent in the eyes of the teacher. Corrobative evidence for this proposal comes from Claudio Casparis' (1978) reinterpretation of Rheinberg and Enstrup's (1977) study into the difference between mainstream and special school students' self-concepts of academic competence. They found that as the pupils approached the end of their school career, their academic self-concept went down. Casparis (1978) considered that this was due to the children becoming more aware of their poorer competence relative to non-handicapped young people with whom they would soon be in direct competition as school leavers. But it is unlikely that the children suddenly became aware that others were brighter than themselves. Rather the answers they gave in the academic self-concept tests could have been influenced by others' expectations of their responses. Thus when the youngsters were about to leave school they believed that they were being asked to rate themselves, not in terms of their school academic ability, but relative to the wider population. In other words these tests did not tap, in an absolute sense, how the children regarded their academic self-concepts, but how they saw themselves relative to the particular reference group against which they believed they were being tested.

Further evidence in support of the argument that the above tests measured what the participants believed was being measured as opposed to what the experimenters thought they were measuring comes from a study by Strang et al. (1978). They investigated the effect of mainstreaming special class children for half of each school day. In the first of two experiments the authors found that the experimental group who were mainstreamed for half of each school day showed a greater increase in their self-concepts than the control group who remained in the special class. The authors thought this might be a consequence of the mainstreamed children's belief that they had succeeded academically by being mainstreamed, or that they felt more accepted by the school system. However, as the researchers were concerned with the effects of social comparison, they carried out a second experiment with the mainstreamed children. The researchers asked half of these children to compare themselves with their non-handicapped mainstream peers. They allowed the other half of the children to complete the self-concept test without instructing them to compare themselves with anyone (free choice). Strang et al. found that those children forced to compare themselves with their non-handicapped peers had lowered self-concepts than prior to being mainstreamed, while the free choice group still had increased self-concepts. The researchers thought that these findings demonstrated the validity of social comparison theory. Alternatively, it may be argued that the findings demonstrate the potency of experimental procedure in biasing the outcomes of such studies. In other words the results for the forced choice group may have been produced because the children felt that they were being asked to demonstrate their insight into their competence relative to that of their more able peers. This need not have been a reflection of the participants' wider feelings about their academic abilities at this point in time which may well have been more positive due to being mainstreamed. Even if this reinterpretation is ill founded, there is enough doubt to make researchers more wary in concluding that they are obtaining insight into the consequences of handicap or special school placement on the self-concepts of children with a mild mental handicap.

Clinical Approach

The use of tests or measures of self-concept often denotes a clinical or individualistic approach on the part of the researcher. Rather than attempting to understand the individual's views and feelings about himself or herself in relation to handicap and stigma as a social phenomenon, the 'handicapped' identity is considered to be a quality of the individual. Implicitly, it is assumed that the person has no real insight into his or her situation but is unwittingly shaped by external stimuli in a way which could be measured by applying a test. One consequence of this is that researchers in this field will often attribute their findings to an intellectual deficit. For instance, Silverman and

Zigmond (1983) came to the conclusion that students with a learning disability had self-concepts which were as good as those of non-handicapped pupils, according to the Piers Harris test, because they lacked the 'social competence' to realise that parents, teachers and their peers regarded them as 'incompetent or academic failures'. However, this conclusion is not substantiated by the study findings, as the researchers did not investigate their informants' awareness of stigma or the negative views of significant others.

Another example of such a sweeping assumption is when children with a mental handicap are found to have positive self-concepts on these measures and are described as having an 'unreal' or 'inflated' view of self (Willy and McCandless, 1973). Willy and McCandless could not accept that people with a mental handicap can have a positive view of themselves, believing it to be a form of self-deception.

Findings from self-concept tests are often considered in the light of personality theory. Once again such interpretations focus on the individual to prove that he or she has a 'healthy' self-concept. As MacMillan (1982) so eloquently stated when describing the consequences of Rogers' theory of personality for the self-concepts of people with a mental handicap:

> According to current personality theory, optimal personality developments and adjustment require that the individual feel a sense of self-worth and that the 'real self' and 'ideal' self should not be too discrepant. This dual requirement raises obvious problems for retarded individuals - they are damned if they do have a high

> self-concept and they are damned if they don't. For them an accurate self-perception would probably be negative - and according to current theory, a negative self-concept is a bad thing to have. (MacMillan, 1982, p.437)

Ziggler et al. (1972) adopted a contrary theoretical approach to Rogers and proposed that the greater the disparity between a person's real and ideal self, the greater his or her cognitive development and maturity. They found that a group of institutionalised and non-institutionalised children with a mental handicap had a lower real and ideal self-concept than a group of children who were not handicapped. Ziggler et al. considered that this was due to a lack of cognitive development and negative life experiences. But the question arises, why should lack of real self - ideal self disparity indicate a fault in the personalities of the children with a mental handicap that would decrease their 'optimal adaption'? This lowered real - ideal disparity could also be derived from an accurate assessment of their social situation.

The idea that personality is related to I.Q. has spawned a number of studies. Once again methodological problems make reasonable deductions difficult. Malenby (1973) made claims about the perceived self-acceptance of institutionalised children with a mental handicap on the basis of the distance they stood from 'normal' individuals during interaction. Mallenby found that boys with a moderate mental handicap were less self-accepting than either boys with a mild or severe mental handicap. He found that the girls with a mild or severe mental handicap were more aware and less self-accepting than the girls with a moderate mental handicap. For Mallenby (1973) to conclude that strong 'sex factors' influenced the perceived self-acceptance is hardly justifiable on the basis of this evidence. It could equally have been the 'normal' individuals' lack of acceptance of the children with a mental handicap that were responsible for the findings. Furthermore, there was no control group for the effects of institutional experience. What opportunities did these children ordinarily have to mix with 'normal' others, and was this largely confined to members of staff?

Other research with children adopted a more psychoanalytic approach to the study of their personality and its relationship to their self-concept. Calhoun et al. (1978) focussed on the relationship between the Goodenough-Harris Drawing Test and the Coopersmith Self-Esteem Inventory. Although they cautioned extreme care in the interpretation of the results of their small scale study, the authors concluded that the Goodenough-Harris Drawing Test could be used as a projective measure of self-concept as well as a developmental measure of intelligence. In another study in this vein, Panek and Wagner (1979) investigated the relationship between Hand Test personality variables and I.Q. Although Panek and Wagner failed to offer convincing evidence that the hand drawings measured the participants' personality rather than their intellectual capacities, they concluded by stating that:

> The results of the present investigation might also suggest that the conception of an 'overall global' conception of a retarded individual's personality is viable, provided it is acknowledged that the more retarded the subject is, the more 'global' the deficit.
> (Panek and Wagner, 1979, p.603)

A more fruitful adaption of a projective technique to investigate the self-concepts of children with a mental handicap was the use of 'Make A Picture Story Protocols' by James Ward (1973). He compared the stories made up by a group of special school and mainstream children. They were given a range of cut-out figures and background cards. They were then asked to place the figures on one of the backgrounds and tell a story about the scene they had created. The themes of the stories which the children produced were generally the same. The one salient difference was that the majority of non-handicapped children included themselves as a character in the story, whilst none of the special school children did. Because this method allowed the children to define their own world and their place in it, there was more possibility of gaining insight into the perspective of the children with a mental handicap.

Adopting a clinical approach appears to draw the researcher away from the wider social realities of disability for the individual. Instead of looking at the individual's situation and considering the consequences for his or her self-concept, the researcher sees the problem as residing in the individual. For instance, Slack (1986) investigated the effect of stigma on the self-concepts of people with a mental handicap and their views of others. She finished by suggesting that people with a mental handicap had to learn to become more self-accepting before they would be able to make friends with their non-handicapped peers. Unfortunately she failed to mention the unwillingness of many non-handicapped people to make friends with people with a mental handicap. Like Slack, other researchers who take this slant are in danger of falling into what Cross (1981) identified as the 'harmful' trap of much psychology of disability:

> In summary then I am suggesting that the psychology of disability so far has rested on a stance that, by

> ignoring the social realities of disability has perpetuated these realities (and the harm they do) for all people who are disabled by suggesting that the answers to this problem lies within themselves. (Cross, 1981, p.458)

Another branch of research pertinent to the self-concepts of children with a mental handicap was concerned with their expectations of success and failure. Rosen et al. (1971) compared the expectation of success or failure of groups of children with a mild mental handicap and groups of non-handicapped children on a manual task with their measured level of self-esteem. They found similarities between institutionalised and non-institutionalised children with and without a mental handicap of the same mental age (MA) with respect to their expectations of and actual performance. However, there were pronounced differences in the expectation and performance between handicapped and non-handicapped children of the same chronological age. Rosen et al. thought this was likely to reflect a 'developmental lag' on the part of the participants with a mental handicap. MacMillan et al. (1971) studied the attributions children made as to why they were interrupted while carrying out a manual task. He found that the children with a mental handicap were more willing to attribute personal failure as the reason for being interrupted than their non-handicapped peers of the same mental age. Although these participants may not display this lack of self-confidence in less formal settings, these findings may be indicative of past experience of personal failure.

Adult Studies

The discussion of children's studies and particularly of the application of measures of self-concept or self-esteem is equally pertinent to adult studies employing these methods. Gowans and Hulbert (1983), reviewing studies concerned with the 'Self-Concept assessment of mentally handicapped adults', felt that little progress had been made in this area and noted that the vast majority of work had been carried out in the U.S.A with school aged children. The authors went on to say that the problems with self-concept tests had been ackowledged by researchers concerned with the adult self-concept, but few had attempted to do anything different. Indeed one finds in the literature that children's tests are often developed for use with adults.

Zetlin et al. (1985) carried out a very important study examining the problems people with a mental handicap have in responding to self-concept tests. They used versions of the Piers-Harris' Self-Concept Scale and the Coopersmith Self-Esteem Inventory adapted for adults. The people all attended a Sheltered Workshop. Their first answers were followed-up either to help those who had not understood the statement or to get those who had given a clear 'yes' or 'no' response to qualify their answer. In the researchers' analysis of the tape-recorded tests they coded 'qualifying' responses according to whether the people did or did not substantiate the initial answer. Zetlin et al. found that problems with comprehension, having a 'personal agenda', or seeing the statements in terms of a particular personal issues, were three of the factors that made 39% of the qualified resonses 'problematic'. No simple relationship was found between I.Q. and the type of qualifiers used by the subjects. Therefore, the authors warned that great care should be taken in drawing conclusions from self-concept tests with people wih a mental handicap, as the rationale for giving particular answers may not be that assumed by the researchers. Moreover, through their content analysis the researchers identified examples of the widely found problem of social desirability.

The work reviewed by Gowans and Hulbert (1983) did not focus on the effects of stigma on the self-concepts of people with a mental handicap. Rather it was concerned with 'understanding personality and behaviour'. It typified the clinical approach and was concerned with how the self-concepts of people with a mental handicap related to their 'social adjustment', 'personality adjustment' and 'rehabilitation'. Nevertheless, several of the studies were exceptional in so far as they made a more serious attempt to tap the perspective of the person with a mental handicap. Nooe (1977) investigated the usefulness of a self-concept test as a measure of the readiness of people with a mental handicap for living outside the hospital. With a very small sample of seven participants, Nooe found that his self-concept test was a good predictor of the level of independence they had reached. In this study Nooe (1977) made several important departures from ordinary self-concept measures. Firstly, his subject matter was concerned with the move to live more independently, and secondly the items used in his test were drawn from statements recorded by the participants themselves. This test therefore had greater validity in that it was more sensitive to the participants' feelings about the issue under investigation.

Spindler-Barton et al. (1976) used the repertory grid technique with a group of institutionalised people with a mental handicap in order to gain greater insight into their 'social disabilities or personality disorders'. The constructs used were those considered by the researchers to be most pertinent to the individuals' problems or world view. Once again this approach had the advantage of being tailored to the specifications of the group under study. Moreover, the repertory grid technique allows participants to use the constructs to actively display the nature of their self-concepts. The draw-back was that the contructs chosen by Spindler-Barton et al. determined, in large part, the kind of self-concepts that the participants could have. Thus, only part of the picture would have been uncovered.

One important aspect of the self-concepts of people with a mental handicap is how they see themselves in relation to others, and which reference groups they use to determine their view of self. Investigating how people with a mental handicap view labelled others in relation to non-labelled others helps one to understand their self-concepts and points to their awareness of the negative attitudes held by non-handicapped people.

Gibbons and Gibbons (1980) investigated the 'group concept' of institutionalised adult people with a mild mental handicap. The researchers did this by reading the people with a mental handicap one favourable and one unfavourable story about a particular character. The character in one of the stories was an 'institutionalised' person and the character in the other was a non-labelled person living in the community. On hearing the story the participants had to rate the character on a number of adjectives and answer 'social distance' questions about them (how friendly they would like to be with the character in the story and whether they would like to live near to the person). After hearing both of the stories the participants were asked to make comparisons between the institutionalised and non-institutionalised characters. When the institutionalised and non-institutionalised characters in the story were presented in a positive light they were rated favourably; when they were presented negatively, they were rated as such. On the social distance questions however, the participants were more positive about living near to and having as a friend the non-labelled individual rather than the institutionalised person. In the questions where the participants were asked to make a direct comparison between the institutionalised and non-labelled characters the latter were again looked upon most favourably in the social distance questions.

The authors interpreted these results as demonstrating that the participants did not look down upon or derogate people labelled as being institutionalised, but wished to dissociate themselves from the stigma that was attached to their institutionalised peers.

In further research Gibbons (1985a) extended his previous study to look at the sociometric preferences of participants with a mental handicap, both institutionalised and community based. In this research the participants were asked to evaluate opposite sex labelled and non-labelled pictures, using a number of adjectives. In this instance the label used was 'mental retardation', which avoided the possible ambiguity of 'institution'. The authors also asked the participants to rate the physical attractiveness of the person in the pictures. It was found that the labelled pictures were less positively evaluated on a number of adjectives and in the social distance questions (i.e. how friendly would you be with the person?, how near to the person would you live?). The results were consistent with the findings of the previous study, with institutionalised and community based groups tending to rate the non-labelled individuals more positively than the labelled individuals. In addition, the women's extremely negative evaluations of labelled men on social desirability and social distance questions were considered noteworthy.

In a second part of this study Gibbons went on to look at how the participants evaluated themselves on the same indices they had used to judge the pictures. To check the validity of the participants' self-reports the researchers asked staff to judge the participants on the same indices. Most participants' responses were significantly correlated with those of the staff, but there were significant differences on the judgements made about 'smartness' and 'physical attractiveness'. This does not mean, of course, that the staff were right and the people with a mental handicap were wrong. For instance, one possible explanation was that they were using a different set of criteria or were comparing themselves to a different reference group. In the comparisons between the participants' self-evaluations and their judgements of the pictures it was found that they tended to see themselves equal to, if not more positively than, the labelled person, and roughly equal to the non-labelled individual. Only on 'social success' (relationships and marriage) did the participants rate themselves more negatively than they did the labelled or non-labelled characters in the pictures. Once again the exception to the rule were the community based women, who were extremely critical of the labelled male individuals.

Gibbons (1985a) thought that these results might be explained by 'downward social comparison', in other words by the participants judging themselves more favourably than their labelled peers to increase their self-esteem. The more modest self-assessments of the community-based groups were due to the inclusion of non-handicapped people in their reference groups. Furthermore, Gibbons thought that the greater sociability of the community based women led to their having more contact with non-handicapped men, which resulted in their exceptionally harsh judgements of the labelled men. Once again, downward social comparison could not be the whole story. Although the participants rated themselves positively relative to their handicapped peers, they did not show an inflated view of themselves. Moreover, they did not consider that they would necessarily enjoy the same 'social success' as non-handicapped individuals.

The results of this study provide some insight into how people with a mental handicap regard themselves relative to their non-handicapped peers. The problem is that, using these methods, the participants can only rate themselves and others on the indices laid down by the researchers. Consequently, there is no way of knowing on what criteria and for what reasons they rate themselves and others as they do. Thus, the evidence is far from clear and we are left guessing how much they have a negative view of labelled others, how much they are aware of and wish to escape from stigma, and how much they value their non-handicapped peers and seek to be associated with them. When he reviewed his own and other research in this area Gibbons (1985b) discussed the ambivalent feelings which may be evoked if one has a negative stereotype of people with a mental handicap, and yet is oneself identified as a handicapped individual and socialises and works with people from this group. Thus, while experimental work may provide clues, the relation between stigma and self-concept is too complex to tease out using such methods. Yet, in raising these questions Gibbon's (1985a) paper should provide the impetus to investigate in more detail both how people with a mental handicap view themselves relative to others, and the stigma associated with handicap.

Participant-Centred Studies

Although the majority of work still uses approaches based on the researcher's point of view as outlined above, there is growing concern with the need to obtain the perspective of people with a mental handicap in the study of their self-concept. The growth of the self-advocacy movement, particularly in the U.S.A. (Williams and Shoultz, 1982, Rhoades et al. 1986), has demonstrated the acute awareness of stigma among many people with a mental handicap and their own efforts to tackle the resultant prejudice. In psychiatry, the threat to the mental health of people with a mental handicap caused by stigma (Judge, 1983) is being taken increasingly seriously. Reis and Benson (1984) pointed to 'labelling, rejection and ridicule, segregation, infantilization, social disruption, restricted opportunities and victimisation' as causing serious problems for people with a mental handicap:

> The view that mentally retarded people often develop emotional problems because of slow development and deficiencies in social skills is plausible. However, many of the emotional problems seen in mentally retarded people are very much what mental health researchers would expect if non-retarded people were exposed to negative conditions for long periods of time. (Reis and Bensen, 1984, p.10)

Despite this interest there have only been a small number of studies which have set out to investigate the meaning of handicap and stigma for people with a mild mental handicap, and the consequences for their self-concepts.

Robert Edgerton (1967) carried out one of the first and most important 'participant-centred' studies. He introduced the 'emic' anthropological approach to gain insight into the daily lives, thoughts and feelings of people with a mild mental handicap. In his classic study 'The Cloak of Competence', he used participant observation to investigate a group of people with a mild mental handicap who had been discharged from a large mental handicap hospital in California. Edgerton provided a vivid account of the lives of the ex-hospital residents, who struggled to get by, often with a lack of basic self-help skills, with little support or help and in extreme social isolation. At the same time they had to deal with the stigma associated with their lack of competence and hospitalisation. The 'emic' method meant participating in the lives of the people being studied in order to 'enter their world of meaning'. However, this is somewhat contradicted by the need to step back from this world of meaning in order to make sense of it. As Edgerton's (1984) explained:

> ...although the attainment of the 'natives'' view requires long-term immersion in the world of the people being studied, the approach also requires disciplined detachment from that world, an objective or outsiders' assessment of what these people actually do and how well they say they do fits with what they actually do. (Edgerton, 1984, p.498)

A disciplined detachment is necessary if one is going to obtain a deeper understanding than a mere descriptive account. However, rather than generating concepts from insight which was gained into the 'native' view, Edgerton (1967) applied an external framework within which to interpret the ex-hospital residents' lives and make sense of their statements. He took his framework from Goffman's (1963) discussion of stigma and the way people cope with having a 'spoiled identity'. In particular, Edgerton discussed how they attempted to 'pass' as competent and to deny their handicap with the aid of 'benevolent conspirators' or 'benefactors'. In interpreting his findings in this way, Edgerton was treating the ex-hospital residents as 'natives' in an alien culture. For example, he regarded their interpersonal relationships as different from those of non-handicapped people. Edgerton described the ex-hospital residents as having no real friends, only what he called 'benefactors', whose motives ranged from 'exploitation' to 'altruism'. Into this category fell employers, neighbours, relations and even husbands and wives. However, he was overlooking the fact that most people are dependent on others for various kinds of support, leading to a network of interdependence. As a consequence of institutionalisation and the stigma associated with their handicap, socially the ex-hospital residents were extremely isolated. Given this state of affairs it was not unusual or surprising that they relied heavily on the few social contacts that they had. Moreover, this did not mean that their needs for interpersonal relations were different from anyone else's, nor that they had nothing of human value to offer others apart from dependency.

Central to Edgerton's account of the ex-hospital residents' lives was the way they coped with their handicap and the stigma associated with having been institutionalised. Edgerton thought that they were obsessed with passing as 'normal' because:

> These persons cannot both believe that they are mentally

> handicapped and still maintain their self-esteem. Yet they must maintain their self-esteem. Clearly then passing and denial are vital. The point is critical, for the stigma of mental retardation dominates every feature of the lives of these former patients. Without an undertanding of this point, there can be no understanding of their lives. (Edgerton, 1967, p.208)

Edgerton's terms 'passing' and 'denial' are interdependent. The individuals attempted to 'pass' because they could not cope with admitting their incompetence. The 'denial' of their handicap was necessary because their incompetence was so transparent that they could not help being aware of their own incompetence. Hence the implicit reference to the Emperor's clothing in the title of Edgerton's book 'The Cloak of Competence'. But from Edgerton's own account of the ex-hospital residents' lives it is apparent that the concepts of passing and denial did not adequately explain their reactions to stigma. Given their situation it was not surprising that they made an attempt to pass as ordinary members of society. These people had been 'discharged' from hospital, they were not supported or overseen by statutory services. They had to lead their own lives: to obtain work and accommodation, to create their own social lives and all the other things necessary for their survival. For them to have admitted they had problems with literacy or numeracy or had spent a great deal of their time in an institution for people with a mental handicap would not have enhanced their opportunities to obtain employment or to make friends. Thus whether or not their attempts to 'pass' were incompetent and they made few friends and relied on a small number of people for a great deal of support, their efforts were simply aimed at getting on as best they could, and part of this process was the avoidance of stigma.

One example Edgerton gave of 'passing' was 'managing material possessions'. In this section he described how those who had left the hospital with few if any personal possessions, bought various items such as old photograph albums, china and even old letters in order to give the impression of having a personal history. It would be difficult to imagine that this was primarily a device to counteract stigma. Rather it could have been a real attempt to buy a past which they had in fact lost through institutionalisation. To obtain a sense of belonging or to have foundations on which one can build a future is also a common concern of people who have spent their childhood in care.

Edgerton (1967) began his discussion of the ex-hospital residents' 'denial' of their handicap by placing this reaction in its historical context. In an earlier paper entitled 'From mortification to aggrandizement', based on observation of hospital residents, Edgerton and Sabagh (1962) outlined the transformation 'patients' went through from the time they were admitted to the hospital until they were about to be discharged. He believed that on entering the hospitals their self-esteem would have been at an exceptionally low ebb. This would have been further reduced by the 'stripping' procedures through which an individual is forced to knuckle under the institutional regime. However, once established in the hospital, they would have found themselves in the upper echelons of the institutional culture, other residents being more handicapped than themselves, and this would have resulted in self-aggrandisement through downward social comparison. The belief that they were superior to the rest of the residents then led them to assert that they were misplaced in the hospital. These feelings of superiority would have been bolstered by a strong peer group of other mildly handicapped residents. Moreover, Edgerton and Sabagh (1962) considered that these feelings would have been reinforced by the hospital staff who were concerned to maintain the participants' feelings of self-worth. When the residents left the hospital the 'shock' of discovering the reality of their incompetence would have necessitated an attempt to 'pass', and to 'deny' their handicap, in an effort to maintain their self-esteem. To come full circle, the 'excuse' the ex-hospital residents then made in an effort to 'deny' their handicap was to attribute their relative incompetence to the depriving experience of institutionalisation. An example Edgerton (1967) gave from one of his case histories was this:

> The problem is that when you have been locked away in there for a long time you get nervous and also you don't learn about how to live outside, so when you get outside you can't act like a normal person - even when you're smarter than outside people. I was in there I thought I was going to rot. It's not right. I never belonged there and they kept me so long that now I'm confused and nervous and can't get a job. (Edgerton, 1967, p.71)

Edgerton's commentary on the above woman's quote was:

> And so the excuse continues, with variation for as long as anyone will listen. (Edgerton, 1967, p.71)

Bogdan and Taylor (1982), who used the same example in a discussion of Edgerton's findings, asked the question: 'whose truth should the participant accept?'. Edgerton was undisputedly accepting the 'official' version of the truth. In following the contemporary wisdom, he considered the hospital to be in general a positive experience, with staff concerned about individuals' feelings of self-worth. The ex-hospital residents were incompetent, and naive about the wider world in which they lived. In his paper about the self-concepts of mildly handicapped hospital residents Edgerton and Sabagh (1962) made it clear that they had an extremely limited world view and could not anticipate problems which they might face when living in the community. Consequently, he dismissed the feelings which the ex-hospital residents expressed about the effects of institutionalisation as 'excuses'. Moreover, this allowed him to explain the results in terms of the coping mechanism of 'denial' outlined by Goffman (1963). Unfortunately, because he failed to take seriously the perspective of those with a mental handicap; he overlooked the meaning of stigma for them or its effect on their self-concept. Rather, his work (Edgerton, 1967) was concerned with the ex-hospital residents' avoidance of or battle with with stigma in order to maintain the integrity of their self-esteem:

> Probably the most accurate understanding of the ex-patients in their struggle for 'denial' is to see them as participants in a self-destructive dialogue that is a constantly changing dialogue between a highly rationalised denial and gnawing self-doubt. (Edgerton, 1967, p.171)

Edgerton's stated aim was to understand the perspective of people with a mental handicap. As Bogdan and Taylor (1982) pointed out, such aims were not compatible with a disregard for the thoughts and feelings of those with a mental handicap. However, the excellence of Edgerton's study lies in the completeness of the pictures he paints of the participants' lives which allows one to draw different conclusions from his own. Once again, if one takes the evidence Edgerton himself presents one may reach the conclusion that the ex-hospital residents do, in fact, have considerable insight into their own lives. After ranking the subjects on their 'level of dependence' as a measure of their level of competence, he found that competence was not related to the individual's I.Q.. This led him to concede that:

> Other factors such as age, personality characteristics, education or training, class or ethnicity or the like are found to be much better predictors of community adjustment. (Edgerton, 1967, p.197)

It would be unusual if many years of institutionalisation were found to have had little or no effect on a person's 'personality', 'education' or 'training'. Moreover, one would suppose that the ex-hospital participants' self-confidence and experience of dealing with money, shopping and a host of daily tasks and skills would have been far greater if they had spent the equivalent time in the community.

Although Edgerton takes the explanantory concepts of 'passing' and 'denial' from Goffman (1963), he does not appear to use stigma in the same sense as Goffman. For Goffman being stigmatised went beyond being identified as having a negative trait: it meant coping with a negative stereotype associated with a negative trait. Thus, it was not simply that the ex-hospital residents could not cope with being identified as 'stupid' or as people who had been institutionalised; they had to cope with the associated stereotype that set them apart from ordinary others. This puts their 'denial' of their handicap in a different light. Furthermore, it may help to solve the ex-hospital residents' 'paradoxical' denial of handicap while happily relying heavily on others for help, a paradox that was noted by Edgerton. If they accepted that they had particular difficulties but rejected the negative stereotype, then the two reactions would be compatible. It would appear, then, that stigma is a more complex phenomenon than presented by Edgerton (1967), as were the ex-hospital residents' self-concepts.

Edgerton did, however, demonstrate the importance of stigma in the lives of people with a mental handicap, their acute awareness of it and the hurt it caused. The problem with Edgerton's study was that he interpreted the lives of his participants according to concepts external to the participants' own frame of reference. While there might have been some validity in the explanatory basis of passing and denial, these concepts prevented Edgerton from taking seriously the responses of the participants and from understanding the consequences of stigma for them. It was acknowledged earlier that it is necessary to step back from the the participants' world in order to reflect, as objectively as possible, on what they say and do. The danger is that one's analysis may be based on a perspective which distorts rather than clarifies one's understanding of the participants' lives. This same point was brought out by Edgerton and Berkovici (1976) himself in a follow-up study some 10 years later of the same ex-hospital residents. He decribed the difficulties of attempting to define their 'social adjustment':

> In our efforts to assess or predict the social adjustment of mentally retarded persons, researchers have relied on experts to define adequate or optimal adjustment. We, after all, have been responsible for them. They must be

> helped to live with our standards. Given the nature and history of mental retardation in the West it could hardly be otherwise. However, after many years of community living, persons once institutionalised as mentally retarded could, as the persons in this study appear to have done, develop their own collective and individual views of what constitutes good social adjustment. (Edgerton and Berkovici, 1976, p.495)

In a subsequent study, Koegel & Edgerton (1982) interviewed black people with a mild mental handicap who had recently left school. They found that the majority of participants acknowledged that they had a 'handicap' or disability of some kind, the remaining respondents either 'denying' that they had a handicap or avoiding the subject. Koegel and Edgerton's work made a valuable contribution to the study of the part played by the label of 'handicap' in the lives of people with a mental handicap. However, its primary aim was not to gain insight into the participants' experience of stigma and the consequences for their self-concepts.

An important investigation utilising participant observation was carried out by Zetlin and Turner (1985) to examine the retrospective accounts of the transition from adolescence to adulthood of people with a mild mental handicap. The authors obtained their information from individuals with a mental handicap and their parents. They found that this period was marked by an attempt to obtain a personal identity and autonomy. The conflict which this produced with parents was compounded by their growing awareness of the consequences of being regarded as 'handicapped'. These people experienced over-protectiveness, social rejection and a feeling of frustration at being left behind by siblings and peers who had left home and gained greater autonomy. These experiences led to a catalogue of behaviourial problems, and the parental strategies for dealing with their son's or daughter's behaviour appeared to determine the future 'adult adjustment' of the person concerned.

Zetlin and Turner demonstrated that adolescents with a mental handicap have ordinary aspirations and want to feel part of society. This work has indicated, once again, the insight of people with a mental handicap into stigma.

Zetlin and Turner (1984), carried out another study using the same cohort of subjects who had moved from their family home to live more independently. In this paper they considered the participant observational data pertaining to the subjects' 'self-perspectives' and the nature of their 'social adjustment'. Further information was also obtained from interviews with the subjects' families. Like the earlier work of Edgerton (1967), the subjects' self-concepts were categorised according to their method of coping with their stigmatised identities. On this basis they produced four categories of self-concept, 'acceptors', 'qualifiers', 'vacillators' and 'deniers'. The 'acceptors' were quite prepared to accept that they were 'mentally retarded'. They did not feel this was a major problem in their lives as they had already made considerable strides towards achieving what, in their minds, was a relatively normal 'adult' lifestyle. The qualifiers were similar to the acceptors, differing from them in their unwillingness to label themselves as 'mentally retarded'. Instead, they talked about being 'slow' or 'below average'. They were more sensitive both towards the problems they faced as a consequence of their handicap and the associated stigma. However, they still did not consider their handicaps as being major obstacles towards achieving a relatively normal lifestyle. The 'qualifiers' were younger than the 'acceptors'. Zetlin and Turner noted that, in the course of the study, several subjects had shifted from being 'acceptors' to being 'qualifiers'. Thus, the researchers believed the participants' self-perspectives were fluid and they thought that growing into an 'acceptor' might have been the natural progression for the 'qualifiers'. However, one difference was that the 'qualifiers' had used services which had been developed for people with a mental handicap, while the 'acceptors' had never had a system of services to graduate from. Zetlin and Turner thought that the participants' involvement with a network of other people with mental handicaps contributed towards making their disabilities of continued importance to them.

The last two categories of participants had the least realistic way of coping with their handicaps. The 'vacillators' were extremely sensitive about being labelled as 'mentally retarded' and claimed instead that they had particular problems such as with reading and writing. This concern with their handicapped status meant that they were extremely aware of the consequences of their handicap for their lives and the negative attitudes associated with mental handicap. There was considerable tension between a wish to play down their 'mentally retarded' label and an acute awareness of their dependency on others. The method of coping with this was apparently to emphasise or fabricate achievements they had attained in their lives, or explain how able they were relative to people more handicapped than themselves. Finally, the 'deniers' simply denied that they had a disability. Along with the vacillators they were the most dependent on other people for support and help in their daily lives. They were able to maintain this 'self-deception' of being non-handicapped while requiring considerable support by leading highly routinised lives. Moreover, they avoided taking risks, or situations which might highlight their incompetence. The 'deniers', like the 'acceptors', were an older group of participants and were quite content with their lives.

The authors suggested that the parental attitudes and socialisation practices were the key to understanding the development of the subjects' self-perspectives. The parents of the acceptors and the qualifiers had taken the most realistic view of the participants' handicaps. They never avoided the subject of their disability while encouraging them to be independent and to make realistic targets for their lives. This allowed these individuals to put their 'mentally retarded' status in the context of the steps they had taken towards a 'normal' life. In contrast, the parents of the 'vacillators' had attempted to play down the problems associated with their handicaps. While wishing their sons or daughters to become independent they were not prepared for them to face the consequences of their actions. The parents of the 'deniers' were also unable to accept their children's problems for what they were. On the one hand they would attempt to explain away their offsprings' handicap or simply deny it, while on the other the parents would protect them from the problems they faced as a consequence of their handicap.

Thus, while the researchers felt that the older 'acceptors' and 'deniers' had, over time, adapted a lifestyle to suit their self-perspectives, they identified a clear set of background factors responsible for their self-perspectives.

This study contributed a great deal to understanding the self-concepts of people with a mental handicap. It demonstrated that the study of handicap and identity is not a peripheral issue but is central to understanding the lives of people with a mental handicap. Nonetheless, several problems remain. By focussing on the ability of people to cope with a 'spoiled identity' there may, once again, have been the danger that the researchers did not adopt the perspective of people with a mental handicap but fitted the views they expressed and interpreted the lives they led according to an external framework. There appears to be a clear set of assumptions about the mechanisms which lead to people adopting the most or least 'adaptive' self perspectives. Furthermore, it remains unclear as to whether stigma refers to the intellectual deficit itself, the negative stereotypes associated with the handicap, or both. What happens, for example, if a person makes great strides towards achieving such 'normal' goals as getting married and having work and yet is still subject to considerable prejudice and discrimination? Moreover, social dependence on family or non-handicapped others could result as much from prejudice and discrimination as from lacking sufficient skills to make non-handicapped friends.

More light has been thrown on this issue by such case studies as those presented by Flynn and Knussen (1986) or the autobiographies collected by Bogdan and Taylor (1982). The authors vividly convey the feelings and experiences of people with a mild mental handicap, and there is much to be learned from these accounts. For example, the individuals whose autobiographies were collected by Bogdan and Taylor (1982) showed considerable insight into their situation by going well beyond a mere coping mechanism. They empathised with the stigma faced by other people with a mental handicap and made the distinction between the problems caused by their particular skill deficits, and those due to discrimination and the prejudice with which they faced. However, in spite of the importance of these studies they have the drawback of remaining essentially descriptive.

Conclusions

Thus, the bulk of past work on the self-concepts of people with a mental handicap used tests standardised for the general population. The result of this psychometric approach is some kind of quantitative statement about where on a continuum from positive to negative the self-concepts of people with a mental handicap are located. These scores are abstracted from the real experience of people and as such are singularly uninformative. They do not help in understanding the common experiences of people with a mental handicap.

Furthermore, the psychometric approach and studies carry with them assumptions about the meaning and consequences of stigma. Few of these studies attempt to investigate what stigma means to people before going on to look at how it affects their self-concepts. For instance, some studies assume that special school placement could result in children having a lowered 'academic' self-concept. However, academic ability might not be of concern to children placed in a special school, but they may suffer greatly as a consequence of social isolation or teasing from their non-handicapped peers.

There has been very valuable research attempting to obtain the perspective of people with a mental handicap. This work has demonstrated that these people are aware of the stigma to which they are exposed, and that being identified as 'handicapped' does influence people's self-concepts. The problem with the research is that it has tended to interpret the responses of the participants according to an external framework, while the case studies have the disadvantage of being purely descriptive.

CHAPTER 4

Research outline and methods

The first section of this chapter will start by briefly introducing the aims, and providing an overview, of the research. This will be followed, in the second section, by a more detailed account of the research methods. As well as describing the selection of participants and the development of the interviews, it will explain the preconditions that were considered to be necessary for successful interviewing. Finally, the procedures for two out of the three studies which constituted this research will be given.

1) Overview of Research

A) Aims of research

The review of the previous work on the self-concepts of people with a mental handicap, along with the theoretical writings on the social construction of the self, provide indicators for research on this subject. It appears that normative measures or standardised tests do not enhance an understanding of the self-concepts of people with a mental handicap and even less about how their disability and unique set of social circumstances influence the development of their view of self. Criticisms were made of Edgerton's (1967) work. However, the emic approach which he pioneered with people with a mental handicap attempts to uncover their perspective and examine how this relates to their particular social situation. Social constructionist theory (Mead, 1934) also argues that to understand the development of people's self-concepts one must also know how they are seen and treated by significant others, and the particular social status which they are afforded in society.

There were three main aims of this research. First, to achieve some understanding of the self-concepts of people with a mild mental handicap and in particular of their views of themselves in relation to handicap and stigma. Secondly, to investigate how the self-concepts of people with a mild mental handicap are influenced by their experience of stigma and by the problems associated with their disability. Thirdly, to examine the social lives and networks of people with a mild mental handicap as this provides an important indication of their relative social status and level of experience. Where this work will differ from Edgerton (1967) or Zetlin and Turner (1984) is that it will take more seriously the perspective of people with a mental handicap themselves.

B) Studies and Instruments

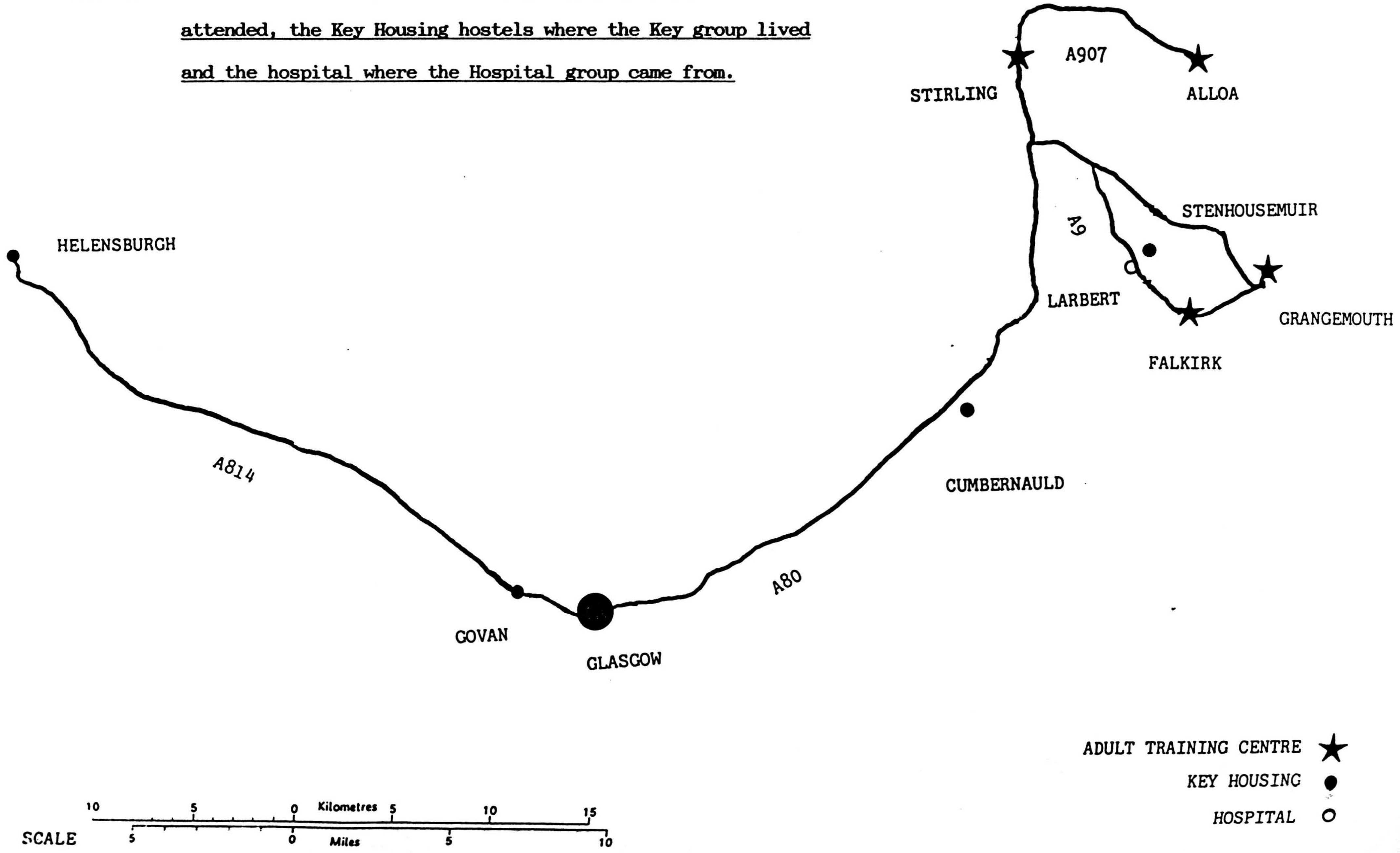
There were, therefore, a total of three studies carried out as part of this research investigating: i) the participants' experience of stigma and their perceptions of their social environment; ii) the participants' view of themselves in relation to handicap and stigma; and iii) the participants' social lives and networks. As Edgerton (1984) has argued, there are no short cuts to obtaining qualitative insight into people's lives: labour intensive methods are unavoidable. Thus, the instruments used to obtain the data in the research were semi-structured interviews. Three such interviews dealing with i) stigma, ii) self-concept and iii) social life and networks were developed in a pilot study involving 25 people with a mild mental handicap. Pilot work was also carried out with three mothers.

C) Sample and location

Forty eight people with a mild mental handicap were selected to take part in the stigma and self-concept studies. The sample was drawn from the participants in a larger project supported by the Scottish Home and Health Department examining the move of people with a mental handicap from home and hospital to live more independently in community based residences. These 48 people came from three groups. The first one included 20 people who remained living in their family homes and attended Adult Training Centres (ATCs) during the period of the study, they will be called the Family group. The second, which will be called the Key group, were 10 people who had left their family homes to live in housing for people with a mental handicap provided by the Key Housing Association, a Scottish organisation. The third group, which will be referred to as the Hospital group, were 18 people who were living in a hospital at the beginning of the study. The locations of the four ATCs which the Family group attended, the four Key Housing hostels which the Key participants came from and the Hospital are detailed in Figure 1.

With the permission of the participants with a mental handicap, 41 members of staff who worked most closely with them and 19 family members were interviewed. Seven of the relatives came from the Key group and twelve from the Family group. Three mothers from the Key group and eight from the Family group did not participate due to difficult relationships with their sons or daughters or owing to illness. No mothers were interviewed in the Hospital group because the very few family members who still kept in contact with them lived some distance from the area.

Figure 1. Location of the Adult Training Centres which the Family group attended, the Key Housing hostels where the Key group lived and the hospital where the Hospital group came from.



The Family group's staff all worked in ATCs and the Key group's staff all worked in Key Housing Association hostels. There was insufficent time to collect data from hospital staff on the issues of stigma and self-concept but eight hospital and eight community based staff were interviewed for Hospital group participants as part of the social life and network study.

The term 'participant' in this research will be reserved for the people with a mental handicap, and the staff will be referred to as such. Although one set of parents, an aunt and a sister were interviewed along with the mothers they will collectively be called mothers. Where the interviews with the parents, the sister or the aunt are being dealt with individually they will be identified as such.

The longitudinal social life study used a sub-sample of 25 participants drawn from those selected to take part in the self-concept and stigma studies. Additional information was also obtained through interviewing either a member of staff or parent at the two stages of the study.

D) Background work

Prior to the interviews a considerable amount of time was spent getting to know the participants and gaining their confidence. This involved making at least two visits to meet with the participants and on occasion accompanying them to social events. Informal observations were also made in the ATCs where the Family participants worked, the Key housing hostels where the Key group lived, and at the Hospital before and during the period of interviewing.

E) Interviews

The studies of stigma and self-concept were mutually dependent. For example, when discussing the participants' experience of stigma, they might have raised issues relating to self-concept and vice versa. Therefore, there were a set of at least two interviews covering the subjects of both stigma and self-concept.

The longitudinal study concerning social life and network required two interviews with a gap of eight to nine months between the first and second. The first interview took place eight to nine months before the stigma and self-concept studies began and the second interview ran parallel with the stigma and self-concept set.

In total an estimated 206.25 hours of interviewing were carried out. Details of the approximate length of interviews are given in Table 1.

F) Analysis of data

The interviews were tape-recorded and transcribed verbatim. The emphasis of the research in the self-concept and stigma studies was on gaining insight into the participants' perspectives and experience. Consequently, the sample was relatively small but the investment of time and richness of the data for each participant was very substantial. It was attempted to retain the character of the findings through the use of qualitative analysis.

Table 1. Approximate length of sets of stigma and self-concept, and social life and network interviews.

	Set of stigma and self-concept interviews		
	Approx. Range	Approx. Mean	Estimated Total
participants	1.5-4 hours	2 hours	96 hours
parents	1.5-3 hours	1.75 hours	33.25 hours
staff	1-2 hours	1.25 hours	31.25 hours
	Combined length of 1st and 2nd social life interviews		
participants	.83-1.5 hours	1 hours	25 hours
additional parental/ staff interviews	.75-1 hour	.83 hours	20.75 hours
overall estimated total			206.25 hours

The qualitative analysis was inspired by the methods employed by Edgerton (1967) and those who have followed his work in the University of California. Their research uses intensive means and is most often concerned with a group of participants rather than with case studies. Their analysis went far beyond traditional case study analysis. They produced a summary for each participant on a particular dimension, which was a synthesis of observations, building up an over-all picture. For example, in Kauffman's (1984) study a summary was produced concerning each participant's social life. The summaries were then ranked as to the opportunities they offered in terms of high or low levels of satisfaction and high or low levels of social activity. This allowed Kauffman to compare the participants and see what characterised those participants who had a high level of satisfaction and high level of activity and so forth.

In contrast to stigma and self-concept, the analysis of the social life and network data in the present research was primarily quantitative, attempting to build up an understanding of the pattern of the participants' activities and social contacts.

2) Methods

A) Selection of participants

Two criteria were applied to the selection of participants. First, that they should have no severe communication difficulties. Secondly, they had to be considered by their respective staff groups to have the potential to live in settings requiring only limited staff support, and to be able to shop, cook and wash clothes for themselves. The potential of the hospital participants for this form of living was assessed by a hospital multidisciplinary team on the basis of the Wessex scale. The Family group participants were not formally assessed for their potential to live independently. Their selection was based on the informed opinion of the management of the Adult Training Centres concerning their client group's domestic and social competence. The Key group met the above criteria by having been accepted to live in a setting which offered only limited staff support and which demanded of their tenants that they acquire the self-help skills outlined above. The term 'mild mental handicap' in this study is thus used rather broadly and does not refer to the results of psychological testing. Socio-demographic characteristics of the Family, Key and ATC groups are shown in Table 2. (Details of the individual participants who took part in ths study are given in Appendix 1.)

<u>Family group</u> The 20 family participants were selected as follows. As part of the above-mentioned larger project, supported by the Scottish Home and Health Department, a socio-demographic survey was carried out on all people attending ATCs in one Scottish region. It covered people aged 20-40 years whom the ATC managers considered to have the potential to live more independently in community residences with only limited staff support. This meant having to display a reasonable competence in domestic skills, or to be considered to have the ability to acquire such competence. The population identified made up over 50 per cent of those attending ATCs in the region. It was from this population that the Family group was randomly selected.

<u>Key group</u> The 10 Key participants were selected from people who moved from their parental homes during the period September 1985 to December 1985 to live as tenants in staffed hostels run by the Key Housing Association.

Table 2. Socio-demographic characteristics of participants.

Charactersitic	Family group	Key group	Hospital group
Number	20	10	18
sex	8 males 12 females	3 male 7 females	15 male 3 females
Age range	22-40	20-40	20-55
Mean age	26	32	37
Attending ATC	20	9	0
Officially recorded - cause of handicap known	14 unknown 6 known	8 unknown 2 known	15 unknown 3 known
Physical disabilities or speech problems	3	2	4
Epileptic	6	3	1
Spent most of life in hospital	0	0	11
In hospital or other forms of institutional care since childhood	0	0	9

Hospital group The 18 participants were selected from the residents in the rehabilitation unit in May and June of 1985 who fulfilled our selection criteria.

B) Development of interviews

Pilot studies

There has been a growing number of studies attempting to gain the views of people with a mental handicap on issues that concern them, using questionnaires and formally structured interviews. Project 74 (London Borough of Wandsworth, 1976), and Carter's (1981) survey explored the lives of people attending Day services in England. Particularly important was a study by Howie et al. (1984), which found that people with a mental handicap reported reliably on features of the residences in which they lived.

A number of sources were used to develop the interviews used in this study. A great deal of information was gained from an undergraduate dissertation (Jahoda, 1983) in which 18 people with mild/borderline mental handicaps (according to Gunzburg's Progress Assessment Charts) attending day services had been interviewed. This work was concerned with the self-perceptions of people with a mental handicap in relation to their perception of their non-handicapped peers and those more handicapped than themselves. Their treatment by those in services, parents, and the public at large were issues which often evoked a strong response, throwing much light on these participants' experience of stigma and their self-image. It also indicated the importance they attached to friendship and social life.

The survey carried out by Lundstrom-Roche (1981) for the International Year of the Disabled stimulated ideas for questions concerning the social lives of people with a mental handicap. Finally, a number of questions concerning the lack of autonomy of people with a mental handicap living at home were drawn from Project '74.

Issues to be covered were also developed from open-ended pilot interviews with 10 people attending Adult Training Centres. Four of these people lived at home with their families. A further 4 participants had recently moved from a long-stay hospital and two from their family homes to live more independently in group homes run by the social work department. In these interviews the researcher talked with the participants about their background, their feelings about the day services they attended, their family/group home or hospital, their social lives and their aspirations for the future.

As a result of this work two rigid interview formats were developed which were piloted with 15 participants attending ATCs. Nine of the participants lived at home with their families and the other 6 had recently moved from long-stay hospitals to live in group homes run by the local social work department. The interview formats covered; a) the participants' perceptions of their social evironment, experience of stigma and self-concept and b) the participants' social activities and social networks, The interviewer wrote down the answers or ticked the appropriate category on a pre-arranged sheet during the course of the interview.

The first interview

The aim of this interview was to find out what the participants felt about their social environment. In the context of talking about their lives as a whole, questions were asked to evoke their feelings in relation to handicap, stigma and view of self. The following issues were covered:

i) The participants' home life / life in the hospital,
ii) Their attendance of specialist services,
iii) Their feelings about their treatment by significant others including members of their family and staff from services,
iv) Their thoughts about the views that non-handicapped people outwith such services had of those who attended them,
v) Their feelings concerning their social life and friendships,
vi) Their views of themselves relative to non-handicapped others, their peers at the ATC and people more handicapped than themselves,
vii) Their aspirations for the future.

<u>The second interview</u>

The purpose of the social activity and social network interview was to gain an overall picture of the activities in which the participants engaged and the nature of their social networks. In particular, the interviewer focussed on the following topics:

i) What activities they carried out,
ii) With whom they carried out these activities,
iii) Where they carried them out,
iv) With what frequency they engaged in them.

Problems with rigid format.

The researcher spent a great deal of time with people with a mental handicap through various leisure activities and carrying out open-ended interviews for an undergraduate dissertation. Moreover, he was aware of the work of the self-advocacy movement and of the fruits of the anthropological approach adopted by Edgerton (1967) and others. Consequently, he thought that the participants had more to offer than the stereotyped answers produced by rigid interviews. The more interested the participant, the greater the investment he or she is likely to make in his or her answers. Yet, the impersonal nature of the rigid interview made it a rather dull experience for the participants, no matter how the interviewer endeavoured to make it otherwise.

The rigid interview method also leads to problems of social desirability (Orne, 1962). In other words, it encourages participants to present their situations in the best possible light or to give the answers which they believe the interviewer is looking for. For example, the researcher knew that participants in the pilot study engaged in a narrow range of activities in their lives. However, the rigid format of the interview often resulted in the participants emphasising the positive elements of their social lives which in several instances belied the impression given in informal discussion. When dealing with the most sensitive issues, of stigma and disability, the problems were even worse. Edgerton (1984) warned of the problem of social desirability as a by-product of questionnaire or formal test-like methods when describing his participant observational approach in his work with people with a mental handicap.

Attempting to write down the answers during the interview interrupted the flow of communication and made it difficult to sustain a meaningful dialogue. At the very least this resulted in the loss of qualitative information.

Interviews with mothers

Open-ended pilot interviews were carried out with the mothers of one man and two women with a mild mental handicap aged 25, 30 and 45 respectively. At the time of these interviews the 3 offspring with a mental handicap were living in their family homes and attending ATCs. None of the mothers required any encouragement to speak. In fact the interviewer was given little opportunity to ask any questions. Prior knowledge of the researcher by two of the parents probably contributed to their willingness to talk freely. However, the interviewer had not met the third mother who talked most freely of all. Without doubt the matters discussed were of great concern to the mothers.

No real conclusions could be drawn on the basis of three pilot interviews. However, they brought out a number of topics which had potential for further investigation. Above all, the early experiences of the mothers appeared to be crucial in understanding the development of their attitudes towards their children. They had brought up their children without professional help but often with a negative prognosis of potential ability and life expectancy. The children themselves, by their mothers' admission, had had to prove their own ability. The mothers talked about their son's or daughter's strengths and weaknesses and their own willingness to afford their offspring choices and opportunities in some areas of their lives and not in others. In addition, parents' attitudes towards independence were determined more by the extent to which they saw the participants as 'handicapped' than by their actual disabilities.

The mothers' views of their offspring's rather isolated social lives also contributed to an understanding of how they saw their son's or daughter's place in society. Two of the mothers regarded the time their son or daughter respectively spent at home as a matter of concern. The other mother thought that her very able and active 25 year old daughter was quite content to spend the greater part of her leisure time alone in her bedroom. She did not feel there was a problem. In the same way the mothers' attitudes to stigma and their insight into their son's or daughter's feelings conveyed a great deal about how they viewed them as persons.

The mothers obviously played a pivotal position in the lives of their apparently isolated son and daughters. Therefore in the main study the views of the parents were given major consideration so that the identities of the participants with a mental handicap could be better understood.

Final instruments.

Due to the problems with the rigid interview as an instrument for eliciting information from people with a mental handicap, it was decided to make the interviews semi-structured. The interviewer had checklists to cover areas that had emerged from the pilot work, while attempting to promote a dialogue and allowing the participants to raise questions which they saw as important. These interviews were tape-recorded and transcribed verbatim. It was decided to have three checklists covering the topics of:

a) their perceptions of their social environment and stigma, b) their self-concept, and c) the participants' social life. As stated previously, the topics of stigma and self-concept were covered in one set of interviews as the subject matter overlapped. However, within this flexible framework the interviewer was careful to cover all the points on the checklists. Where he remained uncertain about an issue, he would raise it again or from a different angle, before ticking it off his checklist.

Giving an outline of what the issues covered only goes part of the way to explaining their nature. Equally important was how the interviewer went about obtaining the information. We shall therefore consider the <u>content</u> and the <u>approach</u> taken for each of the three interviews, i.e. participants, staff and mothers.

1) <u>Participant interviews dealing with perception of the social environment, and experience of stigma.</u>

a) <u>Content</u>

The issues covered in the checklist were as follows:

i) What they felt about their school days.

ii) How they thought their non-handicapped peers saw the special school.

iii) What they felt about attending a special school.

iv) Participants' daily life in the family home / hostel / hospital, including autonomy, rules and routines.

v) What they felt about living at home or in the hostel / hospital.

vi) How they thought their non-handicapped peers or people 'outside' viewed the hostel / hospital.

vii) How they thought parents and hostel or hospital staff treated them.

viii) Participants' daily activity in the Adult Training Centre.

ix) How they felt about attending an Adult Training Centre / college or any other work / training setting that they had been in previously.

x) How they thought ATC staff / college staff / previous work-mates treated them.

xi) How they thought their peers or people 'outside' viewed the ATC.

xii) How they felt about their friendships and social life.

xiii) Whether they wished to have more or fewer activities and friends.

xiv) Whether they had ever experienced teasing and abuse from their non-handicapped peers.

xv) Participants' aspirations for the future.

b) Approach

The nature of the questions varied according to the participants' circumstances. For example, in terms of autonomy the Hospital and Key groups lived in residential settings with an explicit set of rules and routines. Again, it was known that the Key participants could go out in the evenings as they wished, while in the ward or rehabilitation unit they had to be back at a particular time. Hence, these 2 groups of participants were asked in general terms about particular freedoms or restrictions they faced in their environment. In contrast, the subject of autonomy was covered in a direct line of questioning to the Family participants in order to ascertain the degree of autonomy afforded to each participant. This included such points as whether they could decide what time they went to bed and if they had a key to their front door.

In terms of the participants' perceptions of their social environment the interviewer attempted to discover the participants' views and feelings about the issues outlined above. Once again this meant starting with questions which would get the participants to talk freely. They might have been asked to describe what they did at the Adult Training Centre, or what they liked best and least about staying at home.

The aim, with regard to the participants' experience of stigma, was to deal with the subject in the context of talking about their everyday lives. The interviewer did not assume that they felt stigmatised in any way. Instead he explored their experience and raised subjects which were pertinent to stigma or the experience of discrimination and prejudice. These explorations were aided by the use of questions or particular lines of enquiry that had proved successful in eliciting the views of the pilot participants. How Family participants felt treated relative to their siblings proved successful in obtaining their views about parental treatment. Simply talking to Hospital participants about the daily routine and the rules and routines of the hospital usually stimulated considerable discussion about stigmatising institutional practices.

Although the points on the checklist concerning the participants' experience of stigma were covered in the interviews, there was no set pattern of questioning. The danger of a set pattern is that the questions tend to define the nature of the individual's responses. The aim of this part of the interview was to gain insight into the participants' perspective and experience. Hence it was important not to prejudge, but to provide every opportunity for them to express their views about their everyday lives. This included their experience of stigma.

2) Participant interviews dealing with self-concept

a) Content

The issues covered in the check-list were as follows:

- i) How the participants saw themselves relative to others more handicapped than themselves, their peers in the ATC, Key Housing or the hospital.
- ii) When they first became aware of handicap or experienced being labelled.
- iii) How they felt treated by and accepted treatment by: their non-handicapped peers; staff at the ATC, Key Housing and the hospital; members of the family and any significant others.
- iv) What if anything they regarded as their handicap/disability and how they felt it had affected their lives.
- v) In what respects, if any, they felt that being labelled as a 'handicapped' person or being a hospital 'patient' had affected their lives.
- vi) In what ways they would like to change or be different both in themselves and their circumstances.
- vii) What were their wishes for the future.

b) Approach

The approach was parallel to that taken in the stigma interview. When dealing with the issue of self-concept it is vital that one's line of questioning should not predetermine or limit the nature of the participants' responses. In other words, one must be sure one is dealing with the perspective of the participants and not one imposed by the interviewer. As Edgerton (1984) pointed out:

> In general, direct questioning fails not only because it invites deception but also because it imposes the questioner's sense of what is important onto others rather than allowing them to talk about what matters to them when they choose to do so. (p.500)

At the same time one has to find ways of broaching the subject. This is not necessarily because the participants have never thought about the topic, or are likely to deceive themselves and others about their identity. The reason is that if there is too much ambiguity the participant may misunderstand what issues the interviewer wishes to cover. For example, ambiguity may arise if the interview is taking place in a service setting like an ATC and the participant is asked: What is the difference between people working in here and people working outside the ATC? Given the context, the participant may consider it obvious that the Centre is for people with a mental handicap and think of other factors, like the number of hours they work. Alternatively, he or she may choose to avoid the subject because it is hurtful, embarrassing or simply something he or she never talks about. There has to be a balance between ensuring that a topic is covered and not channelling the participant's views in a particular direction. Therefore, the interviewer attempted to open up a <u>mind set</u> in the participant. He used particular strategies that would make it clear that he wanted the participant to talk about him- or herself in relation to handicap and how this had affected him or her as a person. At the same time he attempted to ensure that the discussion was wide-ranging and that he did not lead the interviewee in a particular direction.

An historical approach was one method which avoided a narrow line of enquiry likely to produce a defensive or negative reaction. Initially this meant getting the participant to talk about his or her background memories of childhood and first schooling, and then working towards the present. The start of 'special' school, or the transference from an ordinary local school to a special school was often a watershed in the life of the participants, and a start of their 'handicapped' career. This opened up the issue of how they saw themselves in relation to handicap and set the scene for discussing their current feelings. In the case of the Hospital participants their imminent or recent move from the hospital and their perception of the difference between those living outside and inside the hospital proved a good area to build on. Another topic which proved very fruitful in getting the participants to talk about themselves in relation to others was social life and friendship.

<u>Probe</u> questions were used to pursue points or to evoke views and feelings on particular points under discussion. Moreover, verbal and non-verbal prompts were often necessary to sustain the dialogue and make it clear to the participant that his or her point of view was of value. If done properly this enabled the participant to talk freely and overcome reservations to reveal thoughts and feelings not normally expressed. While such prompts were used in all of the interviews they were of most benefit in the self-concept interviews, where considerable time was spent talking round sensitive topics before a participant was ready to deal with them directly.

As the participants were given a set of interviews dealing with self-concept and stigma, at least two sessions were spent exclusively dealing with these subjects. This allowed the interviewer to reflect on the development of one session before the next, and consider areas that deserved closer scrutiny or where the participant was being defensive. Thus the interviewer could work out ways which might best tap the participant's views in a succeeding session.

Wherever possible the interviewer ended the set of interviews on a lighter note by discussing the participant's aspirations for the future.

3) Mothers and staff self-concept interviews.

The same line of questioning used in the participants' interviews was adapted to cover the same issues with mothers and staff. The pilot interviews with mothers indicated the type of questions that were particularly effective in tapping their attitudes towards the participants as persons.

4) Participant social network interviews

a) Content

The issues covered in the check-list were as follows:

i) What does the participant do at home?
ii) Where does he/she go out to during the week?
iii) What does he/she do at the weekend?
iv) (If living at home.) What does he/she do socially with family members?
(If in hostel or hospital.) How much contact does he/she have

with the family?

v) What friends does he/she have at ATC, Key housing hostel, hospital?

What friends does he/she have outside ATC, Key housing or hospital?

vi) What friends come to visit him/her at his/her present abode?

viii) What friends does he/she visit?

iix) What contact does he/she have with his/her neighbours?

b) Approach

The interviews were carried out in a sensitive but systematic fashion. The interviewer started by getting the participant to talk about his or her social life in general terms, for example, asking what he or she had done the previous week. Once the participant had started talking about his or her social activities the interviewer would follow up with probe questions about particular activities to find out, if it had not already been mentioned, where it took place, with whom he or she did it, and how often. Using this strategy the interviewer would attempt to develop a clear outline of the individual's social life, including what he or she did at home as well as when he or she went out. Another angle taken by the interviewer was to talk about the participant's friends, acquaintances and family members, and to ask where he or she saw them and what he or she did with them and how often this happened.

The interviewer took great care to ensure that the participant was not made to feel a failure because he or she had an inadequate social life. For example, after talking at some length about a participant's attendance at activities organised for people with a mental handicap, he might ask if the participant had 'bothered' to go out anywhere else the previous week.

In most cases the interviewer had a good idea of the participant's interests from previous conversations during the period of getting to know the participant. He also knew of any local activities organised for people with a mental handicap or the situation in the hospital where he or she lived. This helped to maintain the flow of the interview and build up a considerable body of information on this subject.

5) Mothers and staff social network interviews.

The same interview content and format was used when interviewing a parent or staff member about the participant's social networks and activities.

C) Necessary pre-conditions for successful open-ended interviews.

Insight into the participants' wider social context

Using this approach, the participants' handicap was rarely found to be a limiting factor. When participants were talking about matters of interest to them they talked fluently and clearly about their lives, as one might expect anyone to do when discussing a deeply meaningful issue.

In fact it appeared that the cognitive 'deficit' most likely to interrupt the flow of an interview related to the interviewer! The interviewer must have an understanding of the wider framework of the participant's life if he or she is going to understand what the participant is talking about, pursue areas of interest and maintain the flow of the interview. If one takes the extreme position of people who have been living in an institution for many years, the very language that is used by the interviewer may be understood differently by the participants and some of the language used by them might be unique to the hospital setting. For example, for the interviewer to discuss the subject of choice meaningfully with the Hospital participants, he has to know the concrete situations in which choice presents itself to people living in the hospital, and have a feel for what it means to them. Thus the interviewer must understand how it feels never to have a bath when one wishes and on one's own, or not being able to decide who sleeps in the next bed, let alone the other five or ten in the room, or not being able to choose what clothes one can wear.

People with a mental handicap attending an ATC or living in a community residence are still, to a certain extent, cut off in a handicapped world not of their own making. Their lives most often revolve round services organised for people with a mental handicap. If the researcher is to understand their perspective, he or she must have some insight into the social context in which the participants live and which they fluently discuss as insiders.

Interviewing was the primary tool of investigation in this study. But in order to gain the necessary insight into the lives of the participants, informal contact and observation were essential components of the method because they gave awareness of important issues that could not be fully understood from the interview alone. Only through spending time in a hospital ward and observing what is going on can one begin to imagine what it is like to live there and appreciate the differences from living in some other environment such as a house or a hostel in the community. In this way one can come to an awareness of how different environments impinge on people - the manner in which this affects the way they see themselves and how they respond to their environment.

Researcher - Participant relationship.

Another aspect of the participants' lives is that almost all the staff, professionals and non-handicapped people with whom they have contact are likely to be in (and to emphasise) a position of power over them. Moreover, the views of people with a mental handicap are rarely listened to or asked for.

As Farr (1982) noted, the interview is a social situation and does not take place in vacuo but in the wider framework of people's lives. Consequently, the participants in this study were very often initially unwilling to speak openly to the interviewer and were wary of making outspoken or critical comments. This tension was not manifest, in any degree, with parents or staff.

If mentally handicapped participants are to have the confidence in an interview to express their views openly, the interviewer must show that he is genuinely interested in their situation, that he is coming to obtain their views, and that what they tell him will not in any way be used 'in evidence against them'. Nor must the researcher appear as a tester and someone who possesses all the right answers. The spirit of the interview should be made clear to the participants. They are the experts and the researcher is the novice. To break down the barriers that can so easily arise, and base the interviews on a relationship of trust and mutual respect, considerable time must be spent getting to know a participant.

In forming a symmetrical relationship with the participant, the interviewer also takes an ethical responsibility towards the person. He or she should have a commitment to the participant and an interest in what the participant says. Moreover, since the researcher has taken the initiative in forming a relationship of friendship between him- or herself and the participant, it is difficult to avoid giving the participant an expectation of long-term social contact. It is necesary to make it clear at the begining of such a study that the relationship is of a temporary nature, although in some cases the researchers in this study did maintain some kind of contact beyond the duration of the project. Under no circumstances should the researcher raise the expectations of the participants with respect to their relationships, collect data and then disappear.

In field research where the social psychologist is discussing issues important to a participant he or she may heighten the person's awareness of particular subjects, open up hurtful subjects and encourage him or her to express deep rooted feelings. Thus an interview must be tackled with sensitivity by the researcher. At the same time, if the researcher allows a participant to express his or her feelings, he or she is tapping a source of material that is very rich and rarely taken into account by traditional research methods. Taking emotions seriously provides great insight into the issues that are of importance in a person's life.

D) Procedure

The stigma and self-concept interviews were given as one set and the procedures used in each of the studies were therefore the same. As the findings concerning the participants' experience of stigma and perceptions of their social environment will be presented in Chapter 5 and the self-concept data will be presented in Chapter 6 the procedures used in the two studies will be described below.

The background work for the participants' interviews is detailed on pages 96-97. Before begining the interviews an undertaking was given to the participants to maintain strict confidentiality. A set of at least two interviews was carried out with each participant, and one with the mother and staff member. Details of the estimated length of the interviews are given in table 1. The interviews were tape-recorded and transcribed verbatim (a full transcript of a sample interview is given in Appendix 2).

The interviews with the participants, staff and parents were carried out separately. The Family participants and their staff members were all interviewed at their ATCs. The mothers for the Family and Key participants were interviewed at home. With the exception of one participant, who had moved into a supported flat next door, the Key participants were interviewed in Key Housing hostels. These were all the hostels which the participants had moved to from their family home some 8-9 months previously.

The interviews with the Hospital participants took place some 8-9 months after they had moved from wards to the rehabilitation unit. At this stage, 10 of the participants were still in the rehabilitation unit and were interviewed there. The remaining 8 participants had moved on to live more independently in the community. They were interviewed in their new abodes which consisted of a variety of residential settings. Two participants shared a group home with another two people with a mental handicap. Three participants were living in facilities run by the Key Housing Association, one of them in a supported flat and the other two in hostels. One man had moved to a local authority hostel. One 55 year old man was given a place in a private nursing home for old people, which also accommodated older ex-hospital residents. After an unsuccessful placement in the same nursing home, the remaining hospital resident discharged himself and ended up in a Salvation Army hostel.

Methods for the social life and network study

The social life and network study was longitudinal and based on a sub-sample of participants. For these reasons the details about the selection, sample and procedures will be given at the begining of Chapter 7 where the social life and network findings are presented.

CHAPTER 5

Life settings and participants' perceptions of their social environment and their experience of stigma.

A central question addressed in the introduction to this thesis was whether or not the external pressure to conform to a particular role resulted in the acceptance of such a role identity. Hence in this chapter we will start each section on the Family, Key and Hospital group by providing background information on the Adult Training Centres, Key hostels, and the hospitals where participants worked or lived. It is to be hoped that this background information would allow us to find out whether notable differences between the environments of the three groups did produce differences in the participants' self-concepts (see Chapter 6). As these services were a central part of the participants' lives, the data will also provide us with a context in which to understand the participants' views. Moreover, it gives us a benchmark against which we can gauge the level of insight that the participants had into their situation.

Another fundamental question raised in the introduction (see Chapters 1 and 3) was whether or not the participants did face stigma or felt that they were discriminated against or experienced prejudice. If the answer to this was 'no', then one would have to ascertain whether the participants in reality had no experience of stigma, whether they were deceiving themselves, or finally whether their handicap meant that they had little insight into their social situation.

Background data for each group will be followed by a section examining the participants' views about their social environment, their lives and experience of stigma. However, presenting such perceptions from interview data is not straightforward. Farr (1983) described the interview in the following terms:

> Interviewing is an everyday social phenomenon as well as being a widely used technique for gathering data both in professional practice and in social research. It is essentially a technique for establishing or discovering that there are perspectives or viewpoints other than those of the person initiating the interview. (Farr, 1983, p.151)

An interview that attempts to obtain a point of view is not the same as one asking for a set of answers to particular questions. Therefore, if one attempts to put across the nature of the collective experience of the three groups of participants who were interviewed, it is not sufficient to present a block of data or to say that so many people said this and so many that. Rather, by embarking on such a process one wishes to take account of other aspects of the dialogue: for example, how the participants said what they said, what they showed most interest in talking about, and areas about which they were defensive. Moreover, in an attempt to convey the insight that the interviewer was given, the data will be presented as a coherent thread of thought. By presenting these views one may gain some clues as to the effect of the environment on the participants and consequently the part that it played in determining their identity. In addition, one may learn the common strategies which participants had developed to cope with stressful aspects of their social situation or how they were able to resist pressures to adopt a particular role or view of the self.

Analysis of the data

For the purposes of analysis and the presentation of results, the participants are all given pseudonyms (see Appendix 1). The use of first names is not due to a lack of respect but reflects the nature of relationship that the researcher developed with the participants.

The data in this chapter will be presented in three sections: the first section will be concerned with the Family group, the second section with the Key group, and the third section with the Hospital group. Each section will have two parts. In the first part, background information will be given for the group. In the second part, data from the group participants' interviews concerning their perceptions of the social environment and experience of stigma will be presented.

Background information

Details about the day or residential services used by the three groups was gathered through informal observation over the years of contact with the services. Local documents produced by the services and wider literature provided additional sources of information. Obviously the researcher could not carry out informal observation of the Family participants' home circumstances, but a picture was built up of the Adult Training Centres that they attended. For the Key group background information was obtained about the Key housing association, and in the case of the Hospital group, the wards and rehabilitation units were covered.

It may be argued that as the hospital group had moved on to live in community-based settings their earlier hospital background could not be considered as salient, by the time they were interviewed. However, as they had lived in the hospital for a great part of their lives, and 'outside' for only a matter of months, it is reasonable to suppose that it was still an important influence on their self-concepts.

Perceptions of social environment and experience of stigma

The mother's and staff's views contributed to a background understanding but only the participants' interviews were used for analysing their perceptions of their social environment and experience of stigma.

The information concerning perception of social environment and stigma on each of the participant's interview transcripts was summarised. The responses of the participants in each of the three groups were collated from the summaries. The aim of this process was to obtain some understanding of how the participants collectively viewed the environment in which they lived and what was the nature of their experience. This was done by systematically working through each summary and noting the responses. For each different view about their social environment or experience of stigma a category was developed and a list opened for others who made such responses. For example, one of the ATC group might have said how he or she felt that sometimes the staff treated people as though they were 'children'. A list would be opened for those complaining of child-like treatment. If it were found in the next participants' summary that she felt treated by ATC staff as if she were still at school, then she would be added to this list. She may also be the first person in the ATC group to mention that she has never managed to make friends with her non-handicapped peers, or felt that they were particularly friendly towards her. Thus, a new list would be opened up for those who believed they were socially isolated from their non-handicapped peers. The researcher then went on to the next participant's summary to discover if the participant shared or held different views from those which came before. Further new categories were opened for novel views or experiences which were mentioned. The final product of this analysis were the kinds of perceptions and experiences reported by the Family, Key and Hospital groups and the number of participants in each of the groups that expressed these views.

The summaries also included typical and noteworthy quotes of the participants. Some of the quotes will be used later in this chapter to illustrate the participants' views and feelings about their lives and experience of stigma.

While this analysis was as systematic as possible, no reliability check was carried out on this data. This was partly due to the fact that this analysis was extremely time-consuming. Moreover, in order to carry out such an analysis and sift through a large amount of material, the person doing the analysis must have considerable background knowledge to make sense of the data. Unfortunately no such person was available at this stage of the analysis. As stated previously, the concern of this section was not only to present a body of data but to capture the common views of the participants. With the small number of participants involved more importance was attached to providing insight into the nature of their experience and viewpoint than quantifying it exactly.

Results and Discussion

1A) Family Group Life Setting

Background Information

Adult Training Centres

The Family participants all lived in their parents' homes and in one case in the home of a relation. They all attended ATCs.

The Adult Training Centres had evolved from several models of service. The first day services for adults with a mental handicap were set up in the 1950's and 1960's and were called called Occupational Centres. These were merely holding operations concerned with giving people some daily occupation. The method of keeping people busy adhered to the work ethic. The Centres did contract work for firms which consisted of rather boring repetitive work such as sticking on labels. The ATCs themselves often developed their own workshops, making simple wooden items for sale or producing woollen goods. Some Centres called themselves Work Centres and operated on the premise that there is an intrinsic value in making people work. A further influence on the Centre structure was the move towards 'social education'. This consisted of domestic training, learning to use public transport and to read social signs, and basic educational skills such as the use of money and signing one's own name. The emphasis on social education was for the stated purpose of making people more independent, or indeed preparing them for independent living.

The participants in the Family group attended one of four ATCs in a Scottish region catering for between 50 and 100 people with a mental handicap, run by the local Social Work Department. Two of the ATCs also provided places for people with physical handicaps, but these people were most often in different groups. In one of the Centres people with the most severe handicaps were segregated in a special unit.

Those attending the ATCs were in groups with an instructor in charge. The work in which the group engaged was largely craft-orientated in accordance with the special interests or skills of the instructors. Apart from that there was a limited amount of domestic training and social education, and at particular times the participants also took part in various leisure activities. With a number of exceptions, such as wood-work groups which consisted of the more able men, the groups contained men and women of varying levels of ability.

The physical structures and settings of the ATCs reflected to some extent the models on which they had been based. One was to be found in an industrial estate, and was a modern, one storey, industrial-looking building. It largely consisted of open plan workshop-like areas. There was also a small kitchen area for domestic training and a classroom for basic education. The second ATC, although based in an old small hospital, was once again in an industrial area of the town and had workshops built on. There was only one very small room for basic education and the rest of the building consisted of woodwork shops and work rooms for knitting and sewing. The third ATC was based in a large house in a residential area and had originally offered day care under the auspices of the local health authority. The spirit in which the craft type work of knitting, sewing and woodwork was carried out appeared to have the goal of keeping the 'trainees' occupied. The fourth and final ATC was also situated in a residential area. While it had several work-groups doing skilled jobs, others concentrated on social education.

The lack of contact between staff and the participants' families in this study, and the lack of local authority provision, meant that the training had little influence on their lives outside the ATC. In real terms, work training was also of limited value because apart from one extremely innovative scheme, the ATCs generally did not seek employment for their members. Hence there was no common goal which the ATCs attempted to attain. This was borne out in the range of terms used to describe the participants attending ATCs, namely 'members', 'trainees' and 'clients'.

The ATC played a major part in the participants' lives. Most of their friends also went there, and they had few social contacts outwith their family and the ATC. There were members' committees for people with a mental handicap attending the ATC, but these bodies had little if any real say as to how the Centre was run. Moreover, individuals had limited choice over what they did on a day to day basis. The lowly status of those attending the ATC was not compensated for by financial reward for their labour, since they only received a token wage of £2-£4 per week.

Although the participants had a slender range of social experience (see Figure 3), the ATC could not be considered as a sub-culture in the sense of a total institution. It did not represent a way of life, but was simply the place where the participants spent their day. Outwith the ATC they had their families and some form of social life, even if it was specially organised for people with a mental handicap.

B) Family group's perceptions of their social environment and their experience of stigma.

On the basis of the analysis of transcript summaries, described in the methods section of this chapter, categories were extracted which fell into following five areas: school days, adult training centre, family home, money and social life and friends. Details are shown in Table 3.

School days

The Family group's attendance at school had particular significance for them because it was at that time they had been officially labelled as 'mentally handicapped'. The realisation that they had been given such a status came sharply into focus for some when they were moved from ordinary to special schools. Others who started out in special schools grasped their situation when they became aware that they went to a different school from non-mentally handicapped siblings or peers living in their neighbourhood.

There were only a few participants who were unreservedly enthusiastic about the special schools that they had attended, or felt that they had gained educationally. Many of the participants indicated that they would rather have attended an ordinary school and several felt that the special education they had received was inadequate, and had contributed to their intellectual deficit. While talking about her difficulty with reading and writing, Jackie commented:

Table 3

Family Participants' Perceptions of their Social Environment and Experience of Stigma.

	Number of participants who expressed views. (out of 20)
School days.	
- unreservedly positive about attending a special school.	3
- would rather have attended an ordinary school.	9
- special education had received was inadequate.	3
- teasing abuse or feeling rejected by non-M.H. peers.	9
Adult Training Centre.	
Purpose of ATC.	
- to obtain employment for M.H. people.	8
- as an alternative to open employment.	12
Relations with staff & ATC rules.	
- good relation with particular staff members.	20
- complained of authoritarian attitudes or being treated like children.	10
- complained of rules which gave them a child-like role.	4
Feelings about ATC.	
- enjoyed some aspect of the ATC or at least found it preferable to staying at home.	13
- ATC had lost freshness or were bored with it.	16
- wanted to obtain open employment or at least try it.	17
- would not want people to know they worked in an ATC.	16
- complained about yellow social work minibuses.	9
Family Home.	
- felt restrictions on movements outside family home were unjustified.	7
- domestic restrictions on the use of cookers, choice of clothes, when went to bed etc.	10
- noted that not afforded the same treatment as siblings.	10

Table 3 continued

- women who felt that they faced additional protectiveness.	5
- bitter about differential treatment from siblings and non-M.H. peers.	7
- wished to move on from family home in future.	14
- could not imagine life away from the family home.	2
Money.	
- controlled own income.	4
- received a personal income of £10 or over each week.	4
- less than £10 or no personal income each week.	12
Social life and friends.	
- felt leaders at clubs for people with M.H. were authoritarian.	2
- expressed dissatisfaction with social life and wish to broaden social experience and make more friends, in particular non-handicapped others.	11
- Experienced teasing, abuse or felt rejected by non-M.H. peers.	17

> See at school they never learned you nothing, they never even learned me to read and write. It's always your work (crafts), -'take your work out'- that's all.

The most common ill-feeling the participants expressed about attending special schools was the rejection by non-handicapped peers. Many of the participants, including the enthusiastic ones, reported they had been teased or made outcasts for attending special schools. Jane explained how she had felt treated by children going to ordinary schools:

> They didnae like us a lot, just 'cos they're normal and we're not, we used to get treated badly from the normal folk...'cos they went to a normal school and we didnae.

Hence, these participants were not only made aware of the fact that they were being set apart from their non-handicapped peers in special education but, in addition, that there was a stigma associated with special schools.

Adult Training Centre

Five of the participants went directly from school to the ATC, while the other 15 were unemployed for short periods of time or went on Youth Opportunities Programmes and/or college courses before going to the ATC. The participants put forward two explanations as to the purpose of the ATC. On the one hand, a minority regarded the Centres as places that attempted to obtain open employment for people with disabilities. In contrast, the majority thought the ATC provided alternative daily occupation for individuals who could not get a job because of disabilities or who were simply unemployed.

The participants all reported having good relationships with particular members of staff. Derek, who lived with his father and sister, said that one instructor had been like 'half a mother' to him. The quality often appreciated in staff members was the willingness to treat them as 'adults'. However, half the participants complained of staff members' authoritarian attitudes or instances where they were treated in a 'child-like' fashion. As Cathy explained:

> I feel rotten about that sometimes. The staff treat you like a school bairn - when you're not even at school.

In addition, some participants were unhappy about certain rules which gave them a child-like role. For instance, they could not understand why they were not included in review meetings and felt that the members' committees were not given the respect and attention they deserved. In addition, they also objected to having to ask to go to the toilet, or not being allowed outside the precincts of the ATC at lunch time.

Despite these problems, the majority of participants said they enjoyed some aspect of the ATC, or at least that it was preferable to remaining at home. An important attraction for them was the social element, because most of their friends attended the ATC. Moreover, some had found the ATC helpful and enjoyed learning crafts and domestic skills. However, the most common view expressed was that it simply got them out of the house and gave them something to do during the day. Even those who were most critical of the ATC, like Derek quoted below, were grateful for having somewhere to go:

> Down here [at the ATC], to me it's just a dump, I don't like it. If I didn't come here I would be round the twist at home. I guess it's just somewhere for me to come and go.

Marie expressed the same sentiments:

> To take us out of the house - away from our parents. in case our parents are out working and they don't want us in the house ourselves. We'd be bored in the house, that's why we came here.

However, it appeared that after a period of time, the activities and training offered at the ATC had lost their initial freshness and challenge for the majority of those interviewed, and had become more of the same. The participants did not embrace the role of being life-long learners. Indeed, even those who believed that they had gained from the ATC did not feel that it was leading anywhere in the long-term. As one woman put it:

> It's alright in a way, it gives you help and keeps you out of trouble. The daytime goes in much quicker. It's better coming to [the ATC] than sitting in the house doing nothing. I would still be doing nothing if I were no working in the ATC, terrible isn't it?

Four participants had been given voluntary work to do by the ATC at a nursery and with old people, which they had greatly enjoyed. Indeed, most of the participants expressed their preference for ordinary employment, or at least wanted the chance to try it. Apart from wishing to meet people from 'outside' the Centre, the other reason put forward for obtaining employment was to gain a greater degree of financial independence. When interviewed, the participants received £2 - £1 per week from the ATC, described by one individual as 'sweetie money'.

The participants were acutely aware of the stigma attached to the ATC's they attended. Most of them said they would not want people whom they met to know they worked there. They considered that people who knew they worked in an ATC would look down upon them. Dan said that if he was asked by people he met where he worked, he would reply:

> I just tell them I had a job outside and so I didn't tell them where. - (Why?) - I didn't want to because they'd say that's where the handicapped people are. And to me everything's alright.

One of the features of the ATCs which many of the participants felt drew most attention to them were the yellow Social Work Department mini-buses. It appeared to be young people and school children who had been most abusive.

Family home

With several exceptions, the participants felt very close to their parents. This mutual dependence was often characterised by overprotection or parental restrictions. For example, many participants considered that it was unjustified that their movements outwith the family home were strictly controlled. Others resented not being allowed to use the cooker, do ironing, choose their own clothes, or having to be home by a certain time. Half of the participants noted that they were not afforded the same treatment as their non-handicapped siblings.

It was noteworthy that five women felt that they faced restriction from their family members. This was due to fears about their sexual vulnerability. A few of them therefore felt that being 'lassies' resulted in further prejudice.

It would be wrong to suggest, however, that the participants always discussed their dissatisfactions with home life in an openly rebellious or resentful fashion. It was their families that were being discussed, and many had extremely close, interdependent and loving relationships with them. Even some of those who had most problems with their home lives were not always overtly critical, apparently wishing to maintain family loyalties. It was only over a period of time, or as the issues were explored in some detail, that the frustrations and resentments about circumstances in their family homes emerged. For example, while discussing how they were treated relative to others, many of the participants expressed bitterness that they were treated differently by their parents from their siblings and non-handicapped peers. In addition, those in the Family group did not often initiate discussion about moving away from home. However, when the subject was raised they would often admit to being attracted to the prospect of moving on to live independently, even if the idea had not been previously discussed or if the family were against it. The majority of participants expressed the wish to move on at some stage from the family home. They thought this entailed the possibility of having more control over their own lives, greater choice and freedom as well as the ability to do more for themselves and gain wider experience of the world.

There was a residue of participants, however, who simply could not imagine life away from the family home. They wished to remain in the 'care' of their family and regarded anything else with fear and suspicion. In other words, rather than it being a positive move they felt that leaving home was like being sent away, or meant that your family did not care about you.

Money

The financial state of the participants was also a reminder to many of the participants of their total dependence on their parents. The majority of them only received their meager allowance from the ATC, any extra money being in the form of a small personal income from their families. In some cases the personal income was paid at regular intervals and in others participants were only given money for specific activities as required. The remainder were given at least nominal control over their allowance. They either paid their parents rent or were given over £10 of personal income to do their own personal shopping such as clothes and toiletries.

Social life and networks

Although activities specially organised for people with a mental handicap often formed the nucleus of the participants' social lives and were enjoyed by most, they were not without their critics. There were two participants who thought that the 'leaders' at the club were authoritarian or treated them like children. As Jackie commented:

> We get treated like wee yins at the club sometimes - You're not allowed to do this, you're not allowed to do that.

This made her feel 'terrible'.

Others reported getting rather bored with their social lives and the barely changing pattern of activities at the special clubs. They often wished to take part in a greater number of ordinary activities and to make friends with non-handicapped people. However, the participants were aware that this was not easy. Perhaps the most salient finding was that the great majority had experienced teasing or abuse from non-handicapped people, or at some stage felt rejected by their non-handicapped peers. The hurt that this caused was clearly illustrated by Terry:

> They see you going to a place like that [ATC] and they see the buses. They make a fool of you when you go out on the buses. It really gets up my nose. It's no our fault we're like that. I didn't ask to be the way I am, it's just one of these things you've got to live with. You try and talk to someone and tell them where you work, they've no time for you. Makes me feel that size, as though I could just crawl into a hole and curl up.

2A) Key Group

Background Information

The Key housing association was set up in 1977 to provide accommodation in the community for people with a mental handicap. Key housing hostels aim to serve as a resource for individuals living in the area, although they often take people moving out of long stay hospitals who have originally come from the locality. Hence they offer the opportunity for people with a mental handicap to move from their family home to live more independently. These are not facilities where people usually go out of necessity, when a parent dies or where there are problems in the home. Indeed, in the present study, with the exception of two participants who urgently required a residential placement, the participants made the move to Key housing hostel either because they themselves, their parents or both parties considered that it was a positive step to make. Prior to moving to Key housing hostels all the participants had been living in their family homes.

The running of the hostels was financed by individual DHSS payments for the tenants. From the £176 that the participants were given, they received £16 for food and £9.45 for personal income each week. They had to use the £9.45 to buy clothes, toiletries and other items of necessity or personal interest. In addition, this money had to pay for any socialising they did.

The hostels or developments were purpose-built. The four developments where the participants lived consisted of one staffed hostel with 8 single bedrooms and 4 bedsits for more competent residents. There were also a number of satellite flats for mainstream housing and supported tenancies for people with a mental handicap. As they were newly built, the developments tended to stand apart from other houses in the locality. However, they did not follow a set design and some were more in tune with their surroundings than others.

People living in Key housing hostels were referred to as 'tenants'. Although in Scottish law people with a mental handicap cannot have a formal tenancy, accommodation agreements were drawn up. The term 'tenants' was used to indicate that people living in the residences deserved the same rights as ordinary people. The Key Housing Association recognised that it was difficult to sustain such a philosophy when they were providing hostel and not ordinary housing. This point was made in their statement of objectives:

> Key as an Association generally believes that mentally handicapped people have a right to ordinary housing within the community and in some respects 'hostel' accommodation is therefore a compromise.

The participants to whom we spoke all had single bedrooms. One married couple started off in a room in the main hostel before moving to a satellite flat after it had been built. The tenants had keys to their own rooms and, with the exception of people in one hostel, had their own keys to the front door. They were largely free to come and go as they wished, although they had to inform the staff of their movements.

The objectives of Key were to facilitate as ordinary a home life as possible for the tenants while at the same time encouraging them to be as independent as possible. However, there was a tension between the roles of trainer and home maker. At one extreme, where training was emphasised, the staff tended to be quite authoritarian, with tenants being expected to do what they were told. In these establishments there was a definite divide between staff and residents, with staff toilets, cutlery and plates. At the other pole, tenants were left to get on with their lives with very little intervention from staff. The hostels tended to lean in one or the other direction, reflecting the many and often divergent aims of the project.

The objective of Key that participants should become as independent as possible, together with the fairly low staff/participant ratio, meant that the great majority of tenants were people who were more able or who had the potential to be domestically independent. There were communal living areas such as the kitchen, one or two living/dining rooms, and toilets and bathrooms. This meant that there were communal chores to keep the hostel tidy. The hostels were newly furnished at the time of this study and the bedrooms were decorated and kept clean by the residents themselves.

Thus, the Key hostel was not a particularly institutional environment that imposed a particular identity on the tenants. Indeed the very term 'tenant' indicated that the participants were given a great deal of responsibility for their own lives.

2B) The Key participants' perceptions of their social environment and their experience of stigma.

The categories extracted from the participants' summaries fell into

TABLE 4

Key Participants' Perceptions of Their Social Environment and The Experience of Stigma.

	Number of participants who expressed views. (out of 10)
<u>School days</u>	
- regretted move to special school.	5
- felt schooling of a poor quality and had offered few opportunities for advancement.	3
- teased and abused by non-MH. peers.	5
<u>Adult Training Centre</u> (out of 9 participants who attended the ATC.)	
- felt had gained something from the ATC.	9
- wished to gain open employment or at least to try it.	8
- felt could not obtain work because 'handicapped'.	2
- worried that would be victimised in open-employment.	2
<u>Adult Training Centre Staff.</u>	
- felt treated them like children, did not take them seriously.	7
- staff treatment conditional on good behaviour.	2
- awareness of stigma associated with the ATC.	5
- thought that could not obtain jobs because employers would discrimininate against people with a mental handicap.	4
<u>Key housing.</u>	
- felt that the move to Key was a positive step in their lives.	9
- had some difficulty with staff member.	5
- felt some of hostel rules demeaning.	3
- wished to have more social contact with staff.	4
- did not envisage moving on from the Key development.	3
- had ambition to have a detached house of their own.	4

Table 4 continued

- wished to get married and settle down.	5
- felt stigma attached to hostels due to design of hostel buildings.	2
Social life and networks	
- had gained socially from moving to Key.	6
- felt cut-off from or rejected by non-handicapped peers.	7
- had experienced teasing/abuse from non-handicapped peers.	8
- lack of social confidence due to limited social experience and having few friends.	2
- specific instances of discriminatory treatment that emphasised their feeling of social marginality.	5
- would like to go out more and make more friends, particularly with non-M.H. others.	8

the following five areas: School days, Adult Training Centre, Adult Training Centre Staff, Key Housing, Social life and networks. These are detailed in Table 4.

School days

As for the Family group, it was a traumatic period in the lives of the Key participants when they moved from ordinary to special schools and were officially labelled as 'mentally handicapped'. Indeed a number of the participants expressed regret at having had to make this move because they thought that this set them apart from their siblings or non-handicapped peers. Several people felt that their education had suffered as a consequence of going to a special school, which had been of a poorer quality than mainstream education and had not offered the same opportunities for advancement, as Anita explained:

> I missed out on a lot of things. Missed exams, like anybody else would do. Had to teach myself, reading, writing and knitting, had to do it all myself.

In addition, many of the participants recalled with bitterness the teasing and cruelty they had received at the hands of their non-handicapped peers. Lisa explained what happened:

> I don't know. All the weans [children] were at an ordinary school and I was at ... They used to say that I was daft 'cos I went to that school... It doesnae bother me now, but it hurt me then. Ken [you know], when I was younger.

Adult Training Centre

On leaving school, one participant obtained a job in a laundry and two others did college courses for special school-leavers before going on Youth Opportunity Programmes. However, with one exception all the participants were attending ATCs or Work Centres at the time of the study. These participants all felt they had gained something positive from attending the ATC, whether it was learning a particular craft, getting help with reading and writing, or simply getting out of the house and family home. The activities enjoyed most were those that had been set up outside the ATC. For instance, one ATC had a scheme whereby participants had the opportunity to work in a factory; other participants were given voluntary work with children or the elderly, and finally there were people who went part-time to college. It was these activities that produced the most enthusiasm and had appeared to provide the participants with the greatest sense of dignity and purpose. However, at this stage most were keen to move on to open employment where they could earn a living wage, and meet new people from 'outside' and have a change of scene. Above all, the impression was given that the daily occupation offered to them at the ATC did not lead anywhere positive. For example, Lisa expressed the following feelings about the ATC:

> I don't feel I'm getting anywhere going to the Centre anymore...when I first went I enjoyed it, 'cos I was only supposed to be staying for 5 weeks. That's coming up for 6 years now...Don't get me wrong, the Centre's done a lot for me but it's getting kind of boring.

A few participants felt that they could not obtain work because they were 'handicapped', while others expressed fears that they might be victimised by non-handicapped people if they went into open employment. Although Bob stated that he did want to obtain open employment, he expressed his fears earlier in the interview that people in open employment would 'make a fool of you' which made him feel, 'like you're no good, you're no wanted.'

Adult Training Centre Staff

On the whole, the participants reported having good relationships with ATC staff. However, a number of the participants complained of particular staff members who treated them as children, as though they had little or no ability, or simply did not have time for them. In addition, two of the participants said that staff treatment was conditional on their behaviour. Mary began her comments by explaining how she felt that a particular staff member treated them:

> Like adults, Mrs. ... just treats us like adults. No children, no like in a primary school. She says, - You're not at a primary school, you must act like an adult, not like a child. - ...I feel like getting called adults instead of children.

Hence, from Mary's perspective the staff did not take it for granted that she was an adult, instead she had to prove it by her actions.

Half of the participants expressed awareness of the stigma associated with the ATC or that going there meant that they would be subject to prejudice or classed as a different kind of person. For this reason, Kevin had not wanted to go to the ATC in the first place:

> Well, it was mainly the idea that folk would see me as really handicapped and a lunatic and all that kind of thing because I came to ... Centre.

Despite the fact that most of the participants wanted employment, many of them thought that they would face extraordinary difficulties because employers would not think that people from Adult Training Centres could 'cope' with work and would discriminate against them.

Key Housing

With the exception of Bob who went to a Key hostel against his will, the move to Key housing was regarded as a positive step by all the participants we interviewed. For Susan it meant the fulfilment of a life-time's ambition to get married and learn to live more independently. For the remaining participants it meant the chance to break away from a claustrophobic home situation. Despite close and loving relationships with parents, they still felt restricted or unable to develop their own lives. Anita explained her feelings about this:

> I say: [to mother] - I'm no a wee wean, I'm an adult. I'm entitled to dae what I want, I'm entitled to go out when I want and come in when I want. I'm no a wee wean, don't treat me like one. - But she still does - You're still my wee lassie - she [mother] says. I say - But I'm no a wee lassie. Don't treat me like one.

Most of these participants' complaints were about being restricted in their movements outside the house or having to return home by a certain time. Resentment was also often expressed about having all the domestic activities done for them. For example, not being allowed to use the cooker in case they burned themselves. Their sense of injustice and frustration stemmed partly from the recognition that their siblings and non-mentally handicapped peers received differential treatment. Other participants were struck by the progress their siblings made, such as leaving home, getting jobs and getting married. These were steps which the parents often would not countenance for the participants.

In Key housing great emphasis was often put on becoming domestically competent. With one exception, the participants saw this as one of the main functions of Key housing. They reported having learned a variety of tasks, including shopping, cooking and budgeting. However, there was a lot more to living independently for the participants than obtaining self-help skills. Among other factors they mentioned were greater freedom, increased self-respect and the opportunity to widen their social horizons.

Budgeting was regarded as a problem. This was considered by the participants to be more a consequence of lack of money than of budgeting skills. The participants only received £9.45 per week personal income.

The participants felt generally very positive about their relationships with staff members and spoke about them in familiar, first name terms. However, half of these participants indicated they had experienced some difficulties with their Key worker or other member of staff. In some instances, the participants felt that certain staff members were authoritarian and difficult to approach, or just bossy.

A small minority were unhappy with hostel rules which they considered belittling. Lisa objected to the bathing rotas and the public humiliation of being told when to go for a bath:

> As if I was a bairn, at my age, 30 odds. I dinnae need to be telt to have a bath. My mother says, 'they're right' and I'm 'wrong'...I was embarrased Andy. I couldnae say a thing.

Objection was also made to having to inform a staff member about their movements and not being allowed to have a fiancee to stay over-night in the hostel.

It should not be imagined, however, that the participants wanted to cut adrift from staff members. On the contrary, there were several participants who expressed a wish to have more contact with, and support from, staff members.

A number of those we spoke to did not envisage moving on from the Key hostel they lived in or at most considered that they might stay in a bedsit or one of the hostel's satellite flats. Others, however, expressed the ambition to have a house of their own with a back and front door. Half of the participants expressed the wish to get married and 'settle down'.

A few of the participants considered that there was a stigma attached to living in Key housing. Anita and Bob both felt that the design of the respective buildings set the hostel apart from the rest of the street.

Social life and networks.

Many of the participants felt they had gained socially by moving to Key housing. More specifically, they enjoyed the sociable atmosphere of the hostel. However, most of the Key participants still felt cut off from or rejected by their non-handicapped peers. The majority had also experienced teasing and some form of abuse from non-handicapped people. When asked if he had ever been teased or called names Kevin explained that he wished to know more non-handicapped, people but was frightened of rejection:

> No, well there was a couple of folk who thought I was stupid and that, but my dad always stuck up for me when I was younger. I mind... He didn't like folk saying that about me, my dad, neither did I. I sometimes wish I was accepted more by boys and about my own age and all that. I would like to be able to participate with folk that aren't handicapped, but I'm scared for the reason that they put me off because I go to xxx Centre and all that kind of thing.

Participants also regarded lack of money as an obstacle to the development of their social lives. How could they finance a social life on £5 a week? A few participants felt that the cumulative effects of lack of friends, not knowing where they could go out or not having anyone to go out with, had led to a lack of confidence on their part.

Participants also reported specific instances of discriminatory treatment which had emphasised their feeling that they occupied the margins of society. For example, Bob was refused service at a pub because he was 'handicapped'.

3A) Hospital Group Life Setting

Background Information

The Royal Scottish National Hospital was one of the first institutions for people with a mental handicap in Scotland (Barr 1904), and its history reflected the changing role of institutions for people with a mental handicap. Its original aims were educational (Scottish National Institution for Imbecile Children). Later it was extended, and the 'colony' was built, as a long-stay residential establishment at a site one third of a mile away. The 'colony' (east wing) is still known as such by people living in the locality and the original part of the hospital (west wing) is still known as the 'institution'.

The hospital is situated on the outskirts of an industrial town in central Scotland, on the edge of the green belt. There are many open areas of grass in the west wing while the east wing is surrounded by spacious grounds and a farm which used to be run by the hospital. On the other hand the walled grounds also have the effect of setting the hospital apart from the surrounding community. Neither wing was designed to be accessible to the local community, and residents would have a ten to fifteen minute walk from the wards to local shops or facilities. However, as it had been a national hospital (admitting people from all over Scotland and parts of England), it was built less than a mile away from one of the main train routes in Scotland.

When the study was carried out there were still over 900 residents in the hospital. Thus, this hospital, and a mental illness hospital situated about half a mile away, have been a major source of local employment. The fact that the hospital has been long established meant that many husbands and wives, and often several generations of the same families, have worked there. In Goffman's (1963) terms, the hospital was a total institution. Goffman noted that total institutions where people work, eat, sleep and spend most of their leisure time are not simply a place to live but a way of life. In such segregated communities a unique institutional culture develops.

Wards

The wards in which the residents lived were self-contained villas accommodating roughly 40-50 residents. These villas were sparsely furnished buildings with a day room, a television room and a dining room as the only public rooms. If the residents were fortunate they slept in dormitories with 6-8 others, but the majority of dormitories slept about 20. This meant that privacy was at a minimum and at best the residents had a small locker in which to keep personal possessions.

There was a rigid regime of rules and routines, with residents being woken up early in the mornings and, most often, expected to be in bed by a certain time each night. Activities such as shaving, washing and brushing teeth were supervised by staff at prescribed times, and male residents would queue up in the bathroom in the morning to be shaved. On particular days they were bathed by the nursing staff. They were not allowed to bath themselves and only allowed into the bathroom under the supervision of staff. At all other times the bathrooms were locked.

Meals of limited choice and amount were delivered from a central kitchen. Staff members themselves commented on their poor quality. Outside meal and supper times, the residents had no access to food. The kitchens were locked, and the residents did not even have a kettle available to make themselves a cup of tea. The pots of tea made up by staff were already milked and sugared.

A number of residents had been kept in locked wards, either because they had been admitted through the courts, or because they behaved in a manner considered unacceptable while they were in the hospital. Male residents were allowed to come and go as they pleased round the hospital grounds. However, the ward was locked at a particular time of night and they were only allowed outside the hospital grounds on a set day each week, with consent from one of the hospital consultants. Apart from that, the residents only went outside the hospital accompanied by nursing staff. Women residents were not allowed to walk freely round the hospital grounds, being chaperoned everywhere by nursing staff. Each night the residents were counted, in order to make sure that they were still there.

During the day, the residents worked at a variety of jobs. Some were employed as helpmates for tradesmen working in the hospital, while others worked on vans delivering meals or in the laundry. Their hours were often long although the work was unpaid.

There was a sharp divide between the nursing staff and the residents above and beyond the wearing of a uniform. They used separate cutlery and dishes which were clearly marked. I was firmly warned on a number of occasions not to use 'patients'' cups and cutlery. In addition, the staff never ate or even had a cup of tea with the residents. Staff rooms and toilets were strictly out of bounds for the residents. There were other rooms such as the office and kitchen that the residents were only allowed to enter with permission.

The residents lacked even many of the most basic personal possessions. The majority had one good set of clothes, bought with their own money for special occasions, the rest came from a general hospital store. The residents were given a 'bundle' (i.e. a clean set of hospital clothes) after a bath. Because these were hospital clothes, they were all 'tagged' with the initials of the hospital. The initials were even sometimes cut into the inside of leather shoes.

Rehabilitation

There was a 'training' hostel for 20 residents several hundred yards inside the back entrance of the East wing of the hospital. The training provided in the hostel was highly structured, each resident being allocated to one of four colour-coded groups, who worked, cooked and ate together. There were several single bedrooms, but other residents shared rooms with 3 or 4 others. Nonetheless, the atmosphere was much more relaxed, with people able to have baths by themselves and come and go more freely within and outwith the hospital. Moreover, the nurses did not wear uniform and at night there were no nurses on duty. However, in other respects, the residents' lives were still quite strictly controlled. The nurses had all worked in the hospital for a long period of time, and therefore still assumed a great deal of control over the lives of the residents. Most foodstuffs were locked away at night when the staff left. All meals, even the kind of biscuit that the residents would have with their supper, was decided a week in advance. Few of the residents had acquired any personal possessions and most of them still relied on hospital clothing. Even though there were no staff on duty overnight, there was still a nurse who came round every night at 9 o'clock to make sure that everyone was there.

Therefore both the geographical situation of the hostel and some aspects of the regime were a constant reminder to the residents that they were still inside a hospital. Moreover, if they were considered unsuccessful or unsuitable candidates for independent living, then they were sent back to the wards.

In addition, there were three bungalows, built in a semi-circle, a few yards inside the back gate of the hospital. Moving there was quite literally the residents' next step towards leaving the hospital. There was a lower staff ratio in the bungalows and residents were expected to do more for themselves. A nursing station was built into the middle bungalow, from which the other two bungalows could be seen.

The bungalows were furnished and equipped like 'show' houses. However, their perfection and the residents' total lack of choice over the contents of the houses reflected the fact that in reality they were a temporary abode. The fact that the bungalows were still inside the gate was not lost on the residents, and they realised that they were still under the jurisdiction of the hospital authorities and that a placement 'outside' the hospital depended on their good behaviour.

B) Hospital participants' perceptions of their social environment and the experience of stigma.

Some of the participants did discuss their experiences before moving to the hospital, and in the case of those who had left, what it was like 'outside'. However, the main concern of all the hospital participants was with the lives that they had led in the hospital. All other events were discussed in relation to these experiences. For this reason the focus of this section will be on the participants' perceptions of life in the hospital.

The categories extracted from the participants' summaries fell into the following three areas: staff treatment, rules and hospital hierarchy and social segregation and stigma associated with the hospital. These are detailed in Table 5. A further area dealing with the sub-cultural nature of the hospital has been included in this section. There is no data in Table 5 referring to this. The sub-culture part deals with the unique language which the hospital participants used to talk about their environment.

Staff treatment.

All the participants reported that they had had good relationships with particular members of staff. However, the majority of them resented being dictated to or not being listened to and taken seriously by staff or just felt treated like a child. Agnes expressed her feelings in the following fashion:

> I don't like the way they (hospital staff) tell you, wash

TABLE 5

Hospital Participants' Perceptions of Their Social Environment and The Experience of Stigma.

	Number of participants who expressed views. (out of 18)
Staff treatment.	
- good relationships with a particular member of staff	18
- resented authoritarian attitude of the staff.	15
Rules and hospital hierarchy.	
- complained of the humiliation of public bathing.	13
- complaints about lack of privacy and of opportunity for peace and quiet.	9
- felt had managed to avoid becoming 'institutionalised'.	6
- felt hospital environment was unjustifiably restrictive.	15
Social segregation and the stigma associated with the hospital.	
- physical separation made it difficult to get to know people outside.	16
- experience of cheek, abuse or rejection because a hospital resident.	15
- complained of hospital tags on clothes.	7
- complained of being taken out by uniformed nurses.	17
- did not want to live in vicinity of the hospital.	6
- not wanting people from outside to know that they came from the hospital.	17

> your hair and that, because that's my business. We don't like to tell them to go and do things, because I know that's cheeky. You see we're no kids. It's different with kids. We're grown-up...I just want to be happy.

Rules and the hospital hierarchy.

The participants did not feel that the behaviour of the staff members was the main source of the stigmatised treatment which they faced in the hospital. Rather they realised that the nurses were often merely enforcing hospital 'rules' and that the power they had was vested in them by the hospital authorities. As Hugh explained:

> You hadn't got a chance. You had to stick to the rules of the staff. 'Cause when you're down in the ward, the staff are in charge of you. You cannae say to them. - I want to do my own things. - You wouldnae get a chance to run your own life. They wouldnae let you. It was too risky- they had to stick to the ... Health Board rules.

Furthermore, the residents all appeared to understand the way the hospital operated and what their place was or had been in the hierarchy. One person explained why he was powerless to influence what happened in the hospital:

> They'll no listen to you, what the residents in this hospital says. No look at our point of view. Staff help staff, residents haven't got a say in anything. Residents will never have a say, no in a hospital like this.

When discussing their treatment by staff, the participants mentioned explicit and implicit rules which they considered discriminatory. The explicit rules and routines included the system of obtaining permission or a 'pass' to go outside the hospital grounds for a day at the weekend. They also resented being restricted to the hospital grounds at all other times, and having to be back to the ward for a particular hour. They wanted their own clothes and to be able to get changed into fresh garments when it suited them. Other rules which were less explicit included the lack of opportunity to do things for themselves and particularly to make themselves a cup of tea or a sandwich. Another complaint was that they were not allowed to form a relationship with someone of the opposite sex and a couple were never given the opportunity to be alone together. Both men and women alike felt that women were very closely watched in order to prevent them from having anything more than trivial contact with male residents.

Many of the participants felt that they were subject to rules and a life style which not only characterised the residents as having different needs from 'outsiders', but lacked a respect for individual dignity. Most of the participants felt that being bathed by nurses in full view of a queue of other residents was humiliating. Mark clearly expressed these sentiments:

> The bit that sickens me, if you're able to bath yourself, you should be allowed to say to the staff - I'm going for a bath, I can manage -. But you get a nurse to bath you. Grown men. High-grade boys who's able enough to bath themselves, but they're no allowed...It's a piece of

> crap. (Makes you feel) Rotten.

Moreover, half of the participants complained about the lack of privacy and opportunities for peace and quiet which they were given in the ward.

A number of the participants expressed great insight into the effects of living in such an environment upon the individual resident. In fact six residents even stated that they had managed or attempted to avoid becoming 'institutionalised'. They used this expression with a full and practical knowledge of what it meant. Hugh explained how the 'institutional' practice of pacing the corridors started:

> In villa ... sometimes there used to be just the television, nae record player or nothing. When you got fed up watching the T.V., with nothing else to do but go to your bed or walk up and down the corridor...It makes you *institutionalised*.

The majority of participants felt that the lifestyle which they led in the hospital restricted them in an unjustified way. They thought that by leaving the hospital they would be in a position to assert more control over their own lives and could lead a more ordinary existence. Agnes put it in the following terms:

> I'm not wanting to miss my life. I don't want to miss the world. I want to get my freedom, my age you know...

The word 'freedom' was used by most of the participants who expressed these sentiments.

Social segregation and the stigma associated with the hospital.

The participants were aware that their physical separation gave them little opportunity to meet with and get to know people outside the hospital. However, the participants did not think this was the only reason for their difficulty in making social contact with people from outside the hospital. They also felt that there was a strong stigma attached to living in a mental handicap hospital. Most of the participants reported first hand experience of negative treatment as a consequence of being identified as a hospital resident. They had been given cheek and abuse (particularly by young people and children) and on occasion felt rejected by people 'outside' the hospital. Agnes explained her feelings about being called names by people outside the hospital:

> It upsets us you know, inside. Hurts me, it feels like breaking heart. If they were in hospital, what we are, if we were outside, we wouldnae call them names.

The participants did not feel that they were allowed to forget or escape from the stigma of the hospital, when they lived in the wards. A number of the participants complained that hospital tags on their clothes made it difficult for them to keep secret their place of residence. Hugh explained his frustration about wearing tagged clothes:

> You feel alright in a way. But if I was likes of going out, people might come up and say to you. - Where do you come from? - And you hate telling them, you've got to try and keep it to yourself. Then they take a look at your

> clothes tag and they say - Oh is that where you're from?
> - See that's what I mean, that's what I hate.

Many participants also complained about being taken 'outside' by uniformed nurses, far preferring, if they went at all, to wear ordinary clothes. Alice expressed her frustration that the nurses who took her on holiday told people from 'outside' that their party came from a hospital:

> Well they shouldnae have said that to them. They should have said they were outsiders, and they was just friends that was taking them their holidays. That's what they should have said. It made me (feel) terrible

The great majority of the participants said that in future they would not want people 'outside' to know that they had lived in the hospital and would not tell them that they had come from there. Bill made this point in the following way:

> No I wouldnae tell nobody I came from a hospital. Dinnae like telling anybody you came from a nut house. Just laugh at you so they would.

Many of the participants also said that they did not want to live in the vicinity of the hospital, in order to avoid being identified with it.

Sub-culture

The Hospital participants had experienced what it meant to be treated as hospital 'patients' and were acutely aware of the stigma associated with a mental handicap hospital. In addition, many felt that the discrimination they had faced on a daily basis reflected the way the hospital was run and their place in the hierarchy. Their expressed wish to be part of a wider social system indicated that they felt part of a sub-culture.

This sub-culture was reflected in the terminology used by residents and staff, which would mean little to people who did not live or work there. For example, 'van boys' were residents who helped van drivers to deliver meals and laundry round the wards. A number of wards had 'box rooms'. These were exclusion rooms, in psychological jargon, or 'punishment rooms' in the view of the residents, where they were put if they misbehaved. Obviously, particular villas were known by residents and staff because they fulfilled certain functions or had specific groups of residents in them. For example, a number of wards were locked, others were for the most or least able residents, and one was known as the 'punishment' villa, where male residents were sent if they had behavioural problems or broke the rules.

Perhaps the most distinctive terms described the characteristics of residents and staff which identified their position in the hospital hierarchy. An easy way to identify the staff was by their uniforms. Hence, nursing assistants were described as 'grey wrappers' and trained nurses were 'white wrappers'. Both the residents and staff referred to the most able residents as 'high-grades' while the least able people were called 'low-grades'. However, these terms were not merely a classification of ability, they were also an indication of status. On a number of occasions I heard residents calling a person 'low-grade' as a term of abuse. A 'fit-case' referred to a person who suffered from epilepsy. Once again, the term 'fit-case' carried with it a stigma. The generic expression used to describe an individual who was angry, upset, being obstreperous, difficult or aggressive was 'being high'. However, this had a subtly different meaning from saying that someone got angry, upset or started fighting, hitting out or shouting. It was different, because it generally referred to a personal state without any causal link as to why or what had made a person 'high'.

If one stated that a person had got angry or upset, one would assume that this had happened in a particular causal chain of events. It was very rarely that a resident or staff member referred to a reason for being 'high'. One may hypothesise the reasons for using this generic term instead of the more usual adjectives. It could have been that the staff more readily attributed the cause of any undesirable behaviour to the individual, because they considered it indicative of his or her clinical condition. Alternatively, referring to the person might have been due to the fact that it was easier to manage people than deal with the circumstances which cause anger, upset or frustration when nursing staff had little control over the inflexible, rule based environment.

The sanctions used when a resident broke rules or behaved in a manner considered to be unacceptable by staff were referred to by residents as 'punishments'. If a person was 'booked', their name was put down on a 'report' book and their 'bad' behaviour noted. This may have resulted in them seeing the doctor to recommend a further sanction. In more extreme cases, they might have been given the 'needle'. This meant that the resident was given an injection of paraldehyde or some other tranquiliser in order to calm them down.

Finally, the sense that the residents belonged to a community set apart from from the ordinary world was apparent in the references which they made to 'outsiders' as people living outside the hospital. Moreover, when they were allowed 'outside' the hospital once per week with the official permission of a hospital consultant, they called this, 'going out on pass'. It was as if they were living in a closed religious order and once a week they were given special dispensation to go out into the ordinary world. When the residents moved on to the 'bungalows' which were just inside the grounds, from where most of them ultimately left the hospital, they still talked about being 'inside the gate'. Moreover, leaving the hospital was often referred to as 'getting out the gate'.

Conclusion

The background information indicated that the ATC and Key staff may have expected participants to conform to particular codes of behaviour. However they were not expected to adopt a peculiarly 'handicapped' life style. In contrast, the hospital was a 'total' institution where every facet of the residents' lives was controlled by the hospital, from when they got up to when they went to bed. They were consistently treated as, and had to lead the life of, 'patients' in a long stay mental handicap hospital.

From the views expressed by participants in all three groups it was clear that stigma had played a part in all their everyday lives. Retrospectively they appeared to have been aware of their marginal social status from a young age. Moreover, many of them had a subtle insight into the consequences of the prejudice or restrictions that they had faced; for example, those in the Hospital group who explained how they had managed to avoid becoming 'institutionalised'. The participants' perceptions did not seem to be based on a very narrow view of the world. For example, they had an understanding of how they were treated relative to people 'outside' in the case of the Hospital group and siblings and non-handicapped peers in the case of the Family and Key groups.

Perhaps the most interesting difference between the three groups in this section emerged not only from what was said but also from how it was said. The Family and Key participants shared exeriences of prejudice such as being teased by children, and reported instances of being looked down upon by relatives or staff in the ATC. However, their criticisms were often of people, like their parents, whom in other ways they loved and respected. It was notable that the Key participants talked far more freely about their life in their parental home than those in the Family group. Hence, with some distance they were able to be more critical as well as more open in their expressions of affection than the Family group. Nevertheless, in both the Family and Key groups their emotions were often ambivalent because many of those who treated them in a childlike fashion, such as their parents, were also people they were close to. In contrast, the Hospital participants saw the stigma they faced as being a consequence of their position in the social system in which they lived. They talked as insiders about a hospital culture they neither liked nor respected. Thus, living in the hospital had given the participants a common language with which they could vent their feelings about the institutional practices and discriminatory treatment which they had faced there.

CHAPTER 6

Self-concept

This chapter will present the findings concerning the participants' self-concepts. The last chapters have presented background information about participants' life settings and experience of stigma. The context that it has provided will hopefully give greater insight into the self-concept data. One should have an idea both of the social forces working on the participants and the opportunity which the participants had to influence their environment. These dovetail with the two aims of this chapter. Firstly, to consider the factors which shape the self-concepts of the individual. Secondly, to attempt to understand the meaning of handicap and stigma to the participants or the position stigma and handicap occupy in the participants' concepts of themselves.

In the first part of this chapter the quantitative results from the categorisations of the participants' self-concepts and the attitudes of the parents and staff members will be presented. While the numbers were small and the quantitative analysis limited, those findings which were significant were particularly salient. Such categorisations are necessary as a stepping stone to a more detailed qualitative analysis of the material.

The second part of this chapter will present the results of a qualitative analysis of the participants' self-concepts. Qualitative analysis was based on the study of the summaries of the participants' interviews. In addition, the participants' self-perceptions were compared with the attitudes of the mothers and staff to obtain a fuller understanding of the origins of their self-concepts. Furthermore, trying to make sense of the subtle and even contradictory views expressed by certain participants provided further clues as to the development of their self-concepts. In other words, one may be able to categorise a clear statement or feeling but it is often difficult to get to the roots of the feelings expressed. If, instead, an individual presents differing views in varying contexts there is more than one reference point for seeking to chart the origins of such views.

The qualitative section will therefore present some examples of the self-concepts one can discern in participants, including cases of quite subtle or seemingly inconsistent facets. Examples will also be given of the attitudes expressed by mothers and staff concerning the participants' handicaps.

Analysis of self-concept data.

The information concerning the participants' self-perceptions from the self-concept interview transcripts for each person was summarised. A scrutiny of these summaries revealed a common and highly salient thread in the self-concept data: the participants' perceptions of themselves are relative to non-handicapped people, and in the case of the hospital participants to those living 'outside' the hospital (i.e. ordinary people). These perceptions were directly based on the participants' acceptance or rejection of a stigmatised view of themselves. Since these perceptions stood out from the remainder of the interviews as a central feature, it was decided to use them as the framework within which to analyse the participants' concepts of the self. This does not mean that the participants' self-concepts remain static over different contexts and over time. The individual's concept of the self and his or her social world are interdependent, and when the individual's personal and social circumstances change so does his or her self-concept.

The purpose of the categorisation described below, therefore, is to provide a framework for the understanding of the individual's perceptions based on his or her own diagnosis of the self. The following categories were adopted for the analysis of the participant's responses:

1) Essentially different from non-handicapped people.

Participants who fell into this category felt globally handicapped. They did not just regard themselves as having a disability but accepted the stereotype of a handicapped person or, in the case of the hospital participants, 'patients'. Thus, on the whole, these participants did not expect to receive the same opportunities (i.e. for work, leisure, or having a relationship and taking everyday risks) as non-handicapped people or those living 'outside' the hospital. Their belief that they needed 'special' treatment was justified by them by their 'handicapped identity', as opposed to their actual disability. For example, participants may have felt that it was quite impossible to go out on their own in the evening like their non-handicapped siblings. However, this would not be because they felt unable to cope with the situation but because they considered themselves to be one of the 'handicapped', who simply cannot go out at night unsupervised.

2) Essentially the same as non-handicapped people.

Participants who fell into this category felt that they were only different in so far as they had a disability, learning difficulty or, in the case of the hospital group, lived in the hospital. They did not feel that their handicap affected their personhood or that they deserved to be treated as less worthy individuals than non-handicapped people or those living outside the hospital.

Participants in this category who were not allowed to go out at night like their non-handicapped siblings would have been expected to take exception to such differential treatment. Indeed, while they may have accepted that they had a disability, they would not feel that their disability justified having to adopt a different lifestyle or being given less opportunity than non-handicapped others in many domains of life such as work, independence and leisure.

These categories also provided a valid framework in which to place the mothers' and staffs' views of the participants. Thus, the materials from mothers' and staff's summaries were also examined to determine the category which their view of the participants best fitted.

A second judge rated a sub-sample of the participants' summaries to check inter-rater agreement of these categories. The summaries were rated by a second judge for 14 participants, 8 mothers and 11 staff making a total of 33 judgements. There was agreement between the two judges on 29 out of the 34 ratings (85 per cent). Disagreements were negotiated until the two judges reached consensus. The basic elements used to identify the participants who saw themselves as <u>essentially the same</u> or <u>different</u> from

Figure 2. Basic elements used to identify the participants who saw themselves as essentially the same and essentially different from non-handicapped others.

(The participants would only be expected to hold a proportion of the following attitudes and views of self.)

Participants' Self-Concepts

Essentially Different	Essentially The Same
A) How the participant saw him- or herself in relation to non-handicapped peers and / or siblings.	
Viewed self as unequal or not deserving the same opportunities.	Viewed self as inherently equal and deserving the same opportunities.
B) Feelings about services and leisure organised for people with a mental handicap.	
Accepted that he or she should attend services and leisure activities for people with a mental handicap even if aware of the associated stigma.	Wished to escape from or was resentful of the stigma associated with services and leisure activities for people with a mental handicap.
C) Attitudes towards treatment which the participant recognised as discriminatory and unjustified by his or her actual disability.	
Accepted certain kinds of such treatment, even if hurtful, because he or she viewed him- or herself as one of the 'handicapped'.	Rejected all forms of such treatment as unfair and hurtful.
D) Attitudes towards the label of 'handicap' or 'patient'.	
Accepted the global label of 'handicap' and being part of a distinct social group, even if he or she found the label hurtful.	Rejected the global label of 'handicap' or at least the negative steroetype which it conjured up.
E) Aspirations for the future.	
Felt that he or she must always lead a life which is limited by his or her 'handicapped' status.	Had aspirations to lead as ordinary a lifestyle as he or she could

non-handicapped people are shown in figure 2. However, a powerful support of these categories is found in the subsequent qualitative analysis of the data which was carried out. This involved producing further sub-categories of the participants' self-concept summaries. Hence, a more comprehensive outline of the different kinds of views expressed will be presented in this chapter, dealing with the subtler aspects of the participants' self-concepts. The same process was carried out with the summaries of the staff's and mothers' views.

1. Quantitative data from the self-concept categorisations

A) The Family group.

Table 6 shows the number of Family participants' self-concepts and the views of mothers and staff in the essentially different from non-mentally handicapped others and the essentially the same categories. It can be seen that the majority of participants considered themselves as essentially the same as non-handicapped people. In contrast, a majority of mothers perceived their sons and daughters as essentially different. A small majority of ATC staff also regarded the participants as essentially the same.

Table 7(a) shows the relation between the participants' self-concepts and the views expressed by the mothers. Five of the participants who saw themselves as essentially the same were seen as essentially different by their mothers. Using a one-tailed Sign test the difference between the self-concepts of the participants and the views of the mothers was found to be statistically significant (p=0.03). Four of these five participants who saw themselves as essentially the same were

Table 6. Family participants' self-concepts and the views of mothers and staff.

	Participants' self-concepts	mothers' views	staff's views
Essentially different	3	9	6
Essentially the same	17	3	10
Total	20	12	16

Table 7. Comparison of Family participants' self-concepts with the views of parents and staff.

		(a) Mother			(b) Staff		
		ED	ES	Total	ED	ES	Total
Participant	ED	3	0	3	1	2	3
	ES	5	4	9	5	8	13
	Total	8	4	12	6	10	16

ED: Essentially different.
ES: Essentially the same.

(a) one tailed Sign test p=0.03.
(b) one tailed Sign test n.s.

also seen as essentially different by their staff members (table 7(b)). Apart from those 5 mothers who held contrasting views to their offsprings the remaining mothers' attitudes were in tune with their son's or daughter's self-concepts. None of the mothers saw their son or daughter as essentially the same while the participants saw themselves as essentially different.

Using a Sign test, there was no statistically significant difference between the participants' self-concepts and the views of their staff members at the ATC (table 7(b)). Unlike the mothers there were two staff members who saw their participants as essentially the same as non-handicapped others while the participants saw themselves as essentially different.

B) The Key group.

Table 8 shows the number of Key participants, mothers and staff placed in the essentially different and essentially same categories. Once again the majority of the participants rejected a stigmatised identity. More than half of the mothers interviewed saw the participants as essentially the same as non-handicapped people. Only one mother (Mary's) had a perspective that was in conflict with the participant's self-concept (table 9(a)). Using a one tailed Sign test no statistically significant difference was found between the participants' self-concepts and the views of mothers.

Eight out of the 9 staff members saw the participants as essentially the same while 7 out of the 9 participants' self-concepts fell into this category. Therefore, using a Sign test no statistically significant

Table 8. Key participants' self-concepts and the views of mothers and staff.

	Participants' self-concepts	mothers' views	staff's views
Essentially different	3	3	1
Essentially the same	7	4	8
Total	10	7	9

Table 9. Comparison of Key participants' self-concepts with the views of mothers and staff.

		(a) Mother			(b) Staff		
		ED	ES	Total	ED	ES	Total
Participant	ED	2	0	2	0	2	2
	ES	1	4	5	1	6	7
	Total	3	4	7	1	8	9

ED: Essentially different.
ES: Essentially the same.

(a) one tailed Sign test ns
(b) one tailed Sign test ns

Table 10. Hospital participants' self-concepts.

	Participants' self-concepts
Essentially different	2
Essentially the same	16
Total	18

difference between the participants' self-concepts and the views of staff were found (table 9(b)). However, two participants who saw themselves as essentially different from non-handicapped people were seen as essentially the same by their member of staff.

C) The Hospital group.

Table 10 shows the distribution of hospital participants' self-concepts in the essentially same and essentially different categories. Most participants rejected a stigmatised identity, with only two out of the 18 participants regarding themselves as essentially different.

Conclusions

In all three groups the great majority of participants rejected a stigmatised identity, in total 40 out of 48 participants (83%). This compares with 8 out of 19 mothers interviewed (42 per cent) and 18 out of 25 staff members (72 per cent). There were significant differences between the self-concepts of Family participants and their mothers' views and 4 participants who saw themselves as essentially the same were seen as essentially different by both their mother and staff member. These results conflict with the social constructionist theory that people simply internalise the views held by significant others. The contrasting finding of the considerable overlap between the views of Key participants and the attitudes of their mothers is not necessarily inconsistent with the above conclusion. This is because the move to live more independently may have changed the mothers attitudes towards their offspring. In other words, seeing her son or daughter make the transition from home to a more independent lifestyle could have resulted in a mother viewing him or her as essentially the same. Alternatively, mothers who regarded their offspring as essentially the same may have been more likely to allow them to move on to live more independently.

What makes this finding particularly interesting is that the social life data (see Chapter 7) indicates that the participants were extremely socially isolated and had limited social experience. Their lives tended to revolve round services for people with a mental handicap and, in the case of the Family and Key participants, their families. In such circumstances, one might have presumed that the views of significant others would have had especial influence. Given their limited social experience this raises the question of how they developed a view of self that is essentially the same as non-handicapped others.

While the majority of the ATC staff interviewed for the Family group saw the participants as essentially the same, a sizeable minority regarded them as essentially different. The fact that the overwhelming majority of staff in Key housing saw the participants they worked with as essentially the same gives the impression that a different attitude prevailed at Key housing establishments than in ATCs.

Two Family and two Key staff members saw their participants as essentially the same while the participants saw themselves as essentially different. None of the mothers held such conflicting views: all the participants who saw themselves as essentially different were seen as such by their mothers. This might indicate that the mothers had greater influence on the self-concepts of those who saw themselves as essentially different than their staff members did.

2) Background factors and development of the self.

Although the two categories essentially the same and essentially different were broad based they made an important distinction between two kinds of participants' responses. Therefore, we can examine the relationship of background factors to the pattern of results outlined. This process should contribute to an understanding as to why the participants accepted or rejected a handicapped identity.

A) Sex, age, cause of handicap, physical handicap and length of institutionalisation.

The findings in Chapter 5 pointed to women living at home and in hospital as often being more protected than the men. Thus, one might imagine that women would be more likely to internalise a stigmatised identity. However, using a chi square test no significant relationship was found between the sex of the participants and the nature of their self-concept (Table 11).

In addition, using a Mann-Whitney test the participants' ages were found to be unrelated to whether they saw themselves as essentially the same or different from non-handicapped others (Table 12). However, Table 13, which divides the data at the middle of the age range, appears to show a greater proportion of the upper age group viewing themselves as essentially different.

The fact that the causes of the handicaps of 37 of the participants were officially cited as 'unknown' is not surprising. Clarke and Clarke (1978) estimated that people with mild mental handicaps make up 75 per

Table 11. The relationship between the participants' self-concept and sex.

		SEX		
		Male	Female	Total
Participant	ED	3	5	8
	ES	23	17	40
	Total	26	22	48

ED: Essentially different.
ES: Essentially the same.

chi square test ns

Table 12. The relationship between the participants' self-concepts and age.

		YEARS OF AGE							
		16-20	21-25	26-30	31-35	36-40	41-45	46-50	51-55
Participant	ED	1	2	1	0	0	3	0	1
	ES	1	14	9	4	5	3	2	2
	Total	2	16	10	4	5	6	2	3

ED: Essentially different.
ES: Essentially the same.

Mann-Whitney test ns

Table 13. The relationship between the upper and lower half of the age range and the participants' self-concepts.

		AGE		
		16-35	36-55	Total
Participant	ED	4	4	8
	ES	28	12	40
	Total	32	16	48

ED: Essentially different.
ES: Essentially the same.

chi square test ns

cent of those classified as mentally handicapped. For the great majority of people with a mild mental handicap no syndrome or pathology is identified. It might still be argued though, that the reason the participants whose cause of handicap was unknown saw themselves as <u>essentially the same</u> as non-handicapped others was because they did not really have a handicap. However, using a chi square test no statistical evidence was found to support this hypothesis. As Table 14 shows, the vast majority of participants whose cause of handicap was known saw themselves as <u>essentially the same</u>.

Another factor which might have subjected a person to 'special' treatment could have been some form of physical handicap or speech problem which immediately marked them out. However, using a chi square test no significant relationship was found (Table 15) between having a physical handicap or speech defect and the acceptance of a handicapped identity. Only 1 out of the 9 participants with a physical handicap or speech problem internalised a handicapped identity. However, the one problem with this line of enquiry might be that other behaviours rather than a physical handicap were responsible for setting the participants apart from non-handicapped others.

The final background factor worth attention, peculiar to the hospital group, is length of institutionalisation. It may be considered that the longer people live in an institution the more likely they are to internalise a stigmatised identity. Once again using a Mann-Whitney test on the data (Table 16) no statistical evidence evidence to support the hypothesis that length of institutionalisation was related to the acceptance or rejection of a 'handicapped' identity. Although the sample is small, 11 of the participants who have lived the greatest part of

Table 14. The relationship between the participants' self-concepts and whether the cause of their handicap was known or not.

		Cause of handicap		
		Known	Unknown	Total
Participant	ED	1	7	8
	ES	10	30	40
	Total	11	37	48

ED: Essentially different.
ES: Essentially the same.

chi square test ns

Table 15. The relationship between the participants' self-concepts and whether or not they had a physical handicap or speech defect.

		Physical handicap		
		PH	NO-PH	Total
Participant	ED	1	7	8
	ES	8	32	40
	Total	9	39	48

ED: Essentially different.
ES: Essentially the same.
PH: Physically handicapped.
NO-PH: No physical handicap or speech defect.

chi square ns

Table 16. The relationship between the Hospital participants' self-concepts and their length of institutionalisation.

		LENGTH OF INSTITUTIONALISATION (Years)				
		1-10	11-20	21-30	31-40	41-50
Participant	ED	0	1	0	0	1
	ES	4	9	2	1	0
	Total	4	10	2	1	1

ED: Essentially different
ES: Essentially the same

Mann-Whitney test ns

their lives in hospital did not view themselves as essentially different.

B) Environmental factors

A central question addressed in the introduction was whether or not the external pressure to conform to a particular role resulted in the acceptance or rejection of a particular identity. The information given in Chapter 5 indicated the extent to which participants in the three groups were forced to adopt such an identity. There was a clear gradation, with the hospital being the most institutional and Key housing promoting the most ordinary lifestyle, with the families coming in between. However, the Hospital participants were no more likely to accept or reject a handicapped identity than the Key participants. Nor were the family group any more or less likely to accept or reject a handicapped identity than the aforementioned. Hence, while such institutional pressures existed in the hospital (see Chapter 5) they did not result in the participants accepting the role of hospital 'patients'.

The Family participants might have been expected to adopt a particular code of behaviour at the ATC. Yet they were not subject to the common features of institutional practice like the hospital group, nor were they treated according to the philosophy of residential care subscribed to by the Key housing establishments. Instead they lived in their family homes. Therefore, to investigate the influence of the participants' home background on their self-concepts, information was obtained from a sub-sample of 12 participants and their mothers about the amount of autonomy afforded to them. The following 9 points were included: having a key to the door, choosing clothes to buy, choosing one's time to go to bed, being allowed to stay in the house on one's own, being allowed to go out on one's own, being allowed out at night on one's own, choosing where to go out to, choosing the time to return to one's home and having control over one's money. The items were scored 0, 1 and 2, depending on whether the participants had no autonomy (0), some autonomy (1) or full autonomy (2).

A relationship was expected between a high (above the median score of 10) score on autonomy and the participants' rejection of a globally handicapped identity (Table 17). However, using a Fisher's exact test no statistical evidence was found for this relationship. There were 4 participants who were given a low level of autonomy and yet still regarded themselves as <u>essentially the same</u>. A statistically significant relationship was found between the amount of autonomy given to the participants and the mothers' views of them (Table 18), using a one tailed Fisher exact test ($p=0.03$). It was found that the majority of mothers who saw the participants as <u>essentially different</u> gave them less autonomy, while all those mothers who considered the participants as <u>essentially the same</u> gave them a higher level of autonomy. Thus, the level of autonomy in the family home did not necessarily determine the participants' acceptance of a stigmatised identity. Several people who were not even allowed to make the most basic decisions, such as the time that they went to bed, still rejected a primarily handicapped view of self. In contrast, the mothers' attitudes towards the handicap of their sons or daughters were related to the level of autonomy given to them.

C) <u>Experience of stigma</u>

One hypothesis which has been used to explain why people with a mental handicap have such positive self-concepts is that they lack insight

Table 17. The relationship between the Family participants' self-concepts and the level of autonomy they were afforded.

Participant's self-concept	High Autonomy	Low Autonomy	Total
Essentially different	1	2	3
Essentially the same	5	4	9
Total	6	6	12

one tailed Fisher exact test ns

Table 18. The relationship between the Family mothers' attitude towards their son/daugher as a person and the level of autonomy they were afforded.

Mother's attitude towards participant	High Autonomy	Low Autonomy	Total
Essentially different	2	6	8
Essentially the same	4	0	4
Total	6	6	12

one tailed Fisher exact test p=0.03

into their social situation (Silverman, 1983). However, the findings outlined in chapter 5 show that the participants in all three groups had had experience of stigma. Therefore, it appears unlikely that the participants would have rejected a 'stigmatised identity' because of a lack of awareness of their position in the wider social world.

The situation of the Hospital group was unique. These participants lived in a rigid institutional culture. However, as chapter 5 indicates this did not simply force people to adopt the role of a 'patient' in a mental handicap hospital. Ironically, living in the hospital also gave the participants a common language for expressing their resentment about the institutional practices and discriminatory treatment they felt they faced there. Such a sub-culture may also have been the means by which the participants could have rejected a handicapped identity and retained a view of self as <u>essentially the same</u> in the face of considerable pressures.

Qualitative Results

The participants' self-concepts and the views of parents and staff.

1) Family group

A) Participants' self-concepts.

Essentially different. The 3 participants who saw themselves in this fashion felt they could not engage in the same kinds of ordinary activities as non-handicapped people.

For example, Sarah felt that relative to others in the ATC she was 'quite able' and 'not as bad'. However, this did not lead her to doubt that she was 'handicapped', which her mother had told her when she was a child. She resented her inability to lead a more ordinary life, but accepted the difference between the handicapped and the non-handicapped as a fact of life:

> Well, the people who are outside working, the shops and the bank and everything...I says to myself, they're alright, they're no handicapped, they can do anything outside the Centre they like, which I cannae you know. Not that it really bugs me, but I like to do these sort of things and I just cannae do it. It's just one of these things that happens.

A second participant in this subcategory, Joan, did not resent lacking many of the opportunities afforded to non-handicapped people. She lived in an extremely protected home environment. Following a change of management at the ATC, there was some discussion about Joan getting public transport to and from the ATC. Joan reported that if this happened her mother would stop her attending the ATC. Joan thought that her mother's course of action would be correct. In addition, she readily accepted that she was not allowed to go out on her own, shop, use an iron, cooker or kettle or even bath on her own. Joan not only agreed with her mother's sentiments that she was not able to do these things in case she 'hurt' herself but expressed fear on her own part. Furthermore, she shared her mother's horror about the possibilty put forward by the local Social Work Department of her moving on to live more independently. In a sense she embraced the child-like view of self implied by her protective relationship with her mother.

However, Joan appeared to hold contradictory points of view about other aspects of her life. Sometimes she presented herself as an adult and explained how she was more able than others in the ATC, and at other times referred to herself as a 'handicapped' person. For example, she said the role of the ATC staff was 'to look after' her, and later strongly asserted that ATCs were for 'adults'. This contradiction may be solved by considering the kinds of child-like treatment that she was happy with. She enjoyed being dealt with as a 'handicapped' individual when it meant a 'special' or even 'priviledged' status or preserved her rather cosseted home life. At one point she described with pride how she had experienced preferential treatment as a 'handicapped' passenger on a flight to Ireland. At the same time she resented the negative aspects of being regarded as a 'handicapped' person. Joan explained her upset at being teased by two girls who lived in her locality and how she disliked people staring at her when she went with her mother to a shopping centre.

Therefore, she emphasised that she was an 'adult' or that her mother had explained how she was not 'backward' but 'just slow at some things' because she resented the associated stigma. However, she did not expect, or appear to wish, to have the same rights or lead the same kind of life as her siblings or non-handicapped peers.

Essentially the same. It is possible to put down a range of 6 different perspectives that characterised the self-concepts of these 17 participants, and the reports will be grouped accordingly. i) two adopted a *minority group approach* and showed solidarity with their more handicapped peers; ii) eight participants, who were *progressors*, also showed solidarity with their non-handicapped peers but wished to make progress towards leading a more ordinary life; iii) one participant *blamed himself* for his predicament; iv) three participants saw themselves as *superior* to other people with a mental handicap; v) one participant came close to *denying* his handicap; and vi) two participants expressed *minority* group and *superior* views.

i) *Minority group approach*

The two participants in this group rejected discrimination directed against people with a mental handicap, as one would expect a member of a marginal group in society to do. Although they recognised that their disability was very mild relative to that of their peers in the ATC, the participants showed solidarity with these people.

John was one participant who adopted such an approach. He was quite aware that his disability was very mild relative to those in the profoundly handicapped unit in the ATC whom he described as 'vegetables'.

However, he did not mean to use this term in a derogatory fashion and went on to explain that he liked the individuals concerned and he felt even the most profoundly handicapped people were not qualitatively different from non-handicapped others. His belief in the 'humanness' of people whatever their disability was enhanced by his strong religious beliefs:

> Nobody is different on this earth, nobody is different, you are in this world what you are and how God made you. You've got your nature, everybody has, you've got your feelings.

Although John rejected the stigma which everyone with a handicap faces, he did not wish to change his personal circumstances. He was happy with the rather protected and comfortable home life that he led with his elderly mother. Furthermore he enjoyed his work at the ATC and felt that he had to accept the authority of the staff. In a sense, he accepted his position in the world with the firm belief that he was as good as anyone else.

Karen was in many respects similar to John. She felt that unlike most people in the ATC she had the potential to get a job. However, she was not willing to differentiate herself from her peers at the Centre or those working outside the ATC whom she considered were 'just the same people'. She was not quite as supportive of the status quo as John. She was critical of the ATC and hoped, in the long-term, to obtain work in a cafe. Furthermore, Karen's main ambition in life was to have a child. However, she was not prepared to criticise her mother, and said that she was treated like an 'adult' at home despite reporting that she was not allowed to go out after dark or cook bigger things in case she 'burned' herself. Karen also realised that if she went out with a man or had a child that her mother would 'chase' her out of the house.

Like John, Karen's lack of criticism might have been due to the fact that she enjoyed many aspects of her life at home and loved her parents a great deal. Therefore, she was unwilling to rock the boat as long as she was secure in her own mind that she was 'an adult'. If Karen's life experience had been widened and her frustrations about unfulfilled ambitions had grown correspondingly, then she might have become less passive.

ii) Progressors

There were seven participants who were progressors. They adopted a minority group approach but additionally hoped for a change in their circumstances that would allow them to lead more ordinary lives.

Dan was one such person. He freely admitted that he had problems with reading, writing and arithmetic, and particularly liked learning these subjects at a further education college. Although not unduly critical of the ATC he resented instances of child-like treatment. He was acutely aware of the stigma associated with the ATC and felt that those attending had to face considerable prejudice.

While he felt more able than most of his peers at the ATC, Dan did not look down upon less able people. Like the 'minority' group he appeared to realise that to do this would make him, in turn, guilty of stigmatising others. Like John, Dan invoked God to support his argument that as far as they are able, people with a mental handicap deserve the same rights and opportunities as non-handicapped people. When asked what difference there was between those who worked inside and outside the ATC, he replied:

> I think it just means they are the same people. God makes you the same as everyone else.

The difference between Dan and those in the 'minority' group was that he was not content with his situation. Rather than wishing to dissociate himself from other people with a mental handicap he felt that if he could lead a more 'ordinary life' he would have the chance to transcend the stigma that he faced. For example, he believed passing his driving test would be one such milestone:

> I want to pass my driving test, to get a job and I'd like to get married. That's my plans, but I don't know if they will work.

Dan was aware of the obstacles to achieving these ambitions as a consequence of unemployment and discrimination by employers, but his wish to change his circumstances was very important because it helped him to sustain the belief that he was the same as everyone else and that the future held the opportunity for improvement.

Clare also expressed a view of self that fell into this category. She explained that the reason she went to a special school was because of her learning difficulty. However, she felt that going there had sentenced her to an educational and social backwater from which she had never managed to emerge. She felt that she had never been given a 'chance' and had learned 'damn all' at the special school. Referring to people who worked outside the ATC, Clare said:

> ...they all went to perfect, normal school, you went to a thick, stupid school.

She reported being abused when she went to a 'special school'; 'folk make a fool of you' because 'they think you're a dumbo'. Clare felt that this rejection had continued since she left school. Clare said:

> They still treat you as if you were at ...[special school]. If they see you in the mini-bus they make faces at you.

Clare had reached the stage where she no longer 'bothered' with her non-handicapped peers because they 'take a loan of you'. However, she felt that people who worked outside and inside the Centre were 'just the same'. She asserted that people in the ATC were, 'just normal like any other people'. Although she distinguished between the 'able bodied' and the people with a physical handicap in the ATC, she was quick to assert the right of people with physical handicaps to equal treatment.

Clare's account of her home life reflected the contradictions of living with parents who were her main social support and at the same time rather restrictive. For example, she expressed her dissatisfaction at her parents' attempt to stop her attending a club for people with a mental handicap where she met her boyfriend:

> It's my life. I says, I thought it was a free country, if it's a free country I can do what I want, no one can stop

me.'

At another point she said her family 'just treat me as if I was normal'.

Clare was not particularly positive about the ATC, explaining that she had gone there because her epilepsy had prevented her from obtaining employment. For the most part she felt 'treated normal' at the ATC but resented the staff being 'responsible' for her, thinking: 'well, that's just treating you like a child again'.

Clare's most negative experience with the authorities was after she became pregnant as a result of a sexual assault. She had wanted to have the child but:

> ...the social worker said I was unfit to be a mother. Things like that, all these things.

This had made Clare feel 'suicidal'. As a result of this episode and being treated by the authorities and her parents as incapable, she felt as if she had had lost confidence in herself. Moreover, it made her realise that it was her sex as well as her disability that resulted in her being 'protected' and being afforded different rights from her two brothers.

A sense of helplessness was contained in Clare's comments. She did not doubt that she shared the same rights as non-handicapped people. However, she appeared to feel that the forces which had resulted in her becoming a recipient of 'handicapped' services and a stigmatised person were largely out of her control. Therefore, she felt that it would take a drastic change in circumstances for her situation to change. This point was highlighted in her answer to the question as to whether there was anything about herself she would like to change:

> My sex for one...I hate being a lassie. What else can I change? My brain? Get a better brain ... I can be clever.

If she could, she wanted to get 'right away' to somewhere like Australia where she would like to live:

> ... just a normal life, a normal kind of life, settle down.

Thus, although her belief that if given a different set of circumstances she could 'progress', unlike others in the group she did not have any great hopes for this happening.

iii) Self-blame

Perhaps the central aspect of Harry's self-concept was that he blamed himself for his predicament. Like many others, he led a quiet life at home with his mother and grandfather, almost never going out. He had only recently started using public transport to get to his new ATC, as his old ATC was being renovated. He drew enormous satisfaction from travelling by bus and described it as a 'great experience'.

The importance of travelling by bus to Harry would appear to be related to the extremely isolated life that he led at home, with no friends of his own. This had led to a self-confessed lack of confidence. He worried about going out to public places in case people stared at him. There was no reason why Harry should be stared at as he is an extremely presentable person with no obvious characteristics that would set him apart from other people of his age group. Despite his situation he explained that he was not physically or mentally handicapped like the rest of the people at the ATC. However, he did not adopt a superior stance to other people with a mental handicap and argued that many people with handicaps could do jobs that 'normal' people do and said that they should not be 'made a fool of' or discriminated against in the field of employment.

Harry did not believe that he would escape from the stigma associated with the ATC and was aware that people outside the ATC would think that he was 'handicapped'. Moreover, his assertion that he was not 'handicapped' like the rest in the ATC slipped when he was asked how people reacted when they found out someone worked at an ATC:

> 'Cause you're working in a handicapped Centre and they make a fool of you 'cause you're handicapped.

Although he immediately added that this situation did not apply to him his reponse still betrayed an ambiguity. Indeed he went on to explain that because he worked with trainees in the ATC all day, every day, he did not regard himself as any different to them and felt that it was quite right that they should all be treated as 'equals' by the staff.

One reason that he gave for differentiating himself from others in the ATC was that he was not handicapped in the way 'mongols' or those in wheelchairs were. Rather he said he had particular problems with literacy. He felt that this was 'nothing to be ashamed of' and asserted that he could 'read a bit'. Harry considered that he was treated in the same way as his older sister who had left home and that the staff at the ATC treated him as an equal, although he spoke about them in a very subservient fashion. The reason that he had not done well at school and ultimately ended up in an ATC was because he had not 'listened to his teachers':

> No being clever, no to listen to the teachers. If I listened to the teachers I would probably have a fifty fifty chance. If I listened to those teachers I get higher grades. I'd probably get a higher grade and I'd probably make my life a little bit better than it is the now, go out a bit more too.

Harry expressed a great deal of enthusiasm about the possibility of acquiring more self-help skills and becoming more independent and going out more.

Thus, at one level Harry wished to maintain that he was not 'handicapped' like other people in the ATC. At another level, he did not want to dissociate himself from others in the ATC and objected to the stigma that people with a mental handicap were subject to. In part he felt that his predicament was his own fault, and felt that if he had been 'cleverer' he might have got a 'more educated job'.

iv) Superior

There were two participants who adopted a 'superior' stance to other people with a mental handicap. Marie was one of these participants. She said she had gone to a special school because she was 'backward'. Although she felt 'bad' that her brothers and sisters went to ordinary schools she appeared to accept this state of affairs. Marie now lived alone with her widowed mother. When her father was alive Marie had resented his protectiveness. She recalled that he would not even let her walk down the road to her grandmother's. Marie felt that:

> The rest [her siblings] all got out more, I wasn't allowed to go out with me being handicapped.

Ever since she started at school she felt rejected by her non-handicapped peers. She talked movingly about her experience of loneliness and isolation:

> Nobody wants to be bothered with me being handicapped. they all say I don't look handicapped, I look a normal girl.

At another point she explained why people called her 'handicapped':

> They say that 'cause I can't take a job in a shop. I can do everything else... I can go messages and I'm beginning to judge out my money a wee bit better, I can count up a big load now...

She considered herself to be superior to others at the ATC, viewing the staff as her 'equal' and regarded only one other 'trainee' as being as 'capable' as her. She had recently started a part-time voluntary job in an old people's home and she desperately hoped that this would lead to full-time employment. Marie thought that by obtaining employment she could escape from the name calling and abuse she got:

> If folk see me working I don't think I'll have that

problem.

She wished to dissociate herself from the services she attended and said that if she got a job 'outside', 'I wouldn't go out with the girls in here (at the ATC)'. Marie did not think that she deserved stigmatised treatment and laid the blame clearly on those who gave the abuse:

> They're no right in the mind. They just don't know what they're saying. I'm going to lead my own life from now on, just like normal.

Her wish for a new life was not simply an escape from stigma, but a move to a more ordinary life of which she considered herself both capable and deserving:

> I'd like to leave here altogether and get a new life where I'm going to work, begin to make new friends.

v) Denial

Perhaps Paul, who lived at home with his elderly mother was the participant who came closest to denying his handicap. Apart from one incident with two women who ignored him, he did not show any insight into the stigma associated with services for people with a mental handicap. Indeed, he thought that the large yellow 'ambulance' minibuses were better because they provided more room. Paul did say that he knew none of his non-handicapped peers in his locality and commented at one stage that many people outside the ATC did not want 'to know' him. Even as a child he recalled playing by himself on the pavement outside his house.

Paul felt that the ATC staff treated the trainees well and like 'adults'. He accepted that if the trainees did anything wrong they were given a 'row'. He complained about a number of 'rules' and that one member of staff did not take him seriously.

One may conclude from what Paul said that he did not regard himself as essentially different. Moreover, due to a lack of insight into stigma or the consequences of his handicap he did not appear to find anything other than minor elements of his life out of the ordinary. He was a lively and entertaining character who showed interest, and passed informed comment on a great number of issues unrelated to his situation. An alternative explanation might have been that he considered himself to be 'normal' and yet was aware that others defined normality differently. Therefore, he chose to ignore this other view of normality that would have chararacterised him as handicapped. If he took it seriously it might have led to a painful reassessment of his situation.

vi) Minority and superior views

These two participants,in the views that they expressed, sometimes showed solidarity with other people with a mental handicap and at other times adopted a superior stance.

Mike was one of those who fell into this subcategory. He described the ATC as being a place for people with disabilities who could not obtain employment. Moreover, he spoke at times as though he was a mouthpiece for all others who shared his predicament. He considered that 'special' services or activities were not organised because people with a mental handicap were 'special' but rather were for the 'benefit' of people with a mental handicap. Indeed he complained that some of the 'special' services, such as his schooling, had been of a poor quality. At another point he expressed dissatisfaction at the way he and and others were sometimes treated by staff in the ATC. He even criticised the local authority hostel for people with a mental handicap because it allowed 'any type' in:

> ...would you or any normal person, would they share a home with a person who steals or has stolen other things? I don't think they would, why do they do it with us?

Mike told how he had organised a 'friendship club' for people with a mental handicap. He explained that he had started this:

> Because I felt I wanted to do something for the mentally handicapped on our own scheme. Because a lot of normal people run clubs and organisations for the mentally handicapped but we thought it would be good because we really know more about the mentally handicapped, to work with them and all different things. Because we are in the same capacity, normal people are not, because they have to learn.

At another time he stated, 'mentally and physically I am normal'. He went on to explain that he was not employable because of 'nerves'. He also expressed his wish to do 'God's work' with people with a mental handicap and explained how well equipped he was as a result of his daily acquaintance with 'these people'.

Perhaps somewhere in between these two perspectives was his story about telling visitors to the ATC that he was an instructor. He felt that he could claim this status because he had the same 'rights' as anyone else. He added that nobody would be able to tell whether he was an instructor or not. However, this is not plausible because he has Down's syndrome. Thus on the one hand he resented the common stigma that he and his friends from the ATC face, on the other he desperately wished to be seen as 'normal', and to achieve this he wanted to emphasise his difference from the others at the ATC.

It seemed that Mike's awareness of being seen by non-handicapped others as <u>essentially different</u> made normality of central importance to him. He was happy with his home life with his widowed mother and the routine they had worked out. However, this did not prevent Mike from being aware of how he was seen by others and his relative position in the wider world. It was difficult to persuade others of his abilities; for instance he disagreed with the reason for his being transferred to special school:

> ...because I never got on at school or anything like that. They found out that I was too slow. The thing was, slow then was frowned on, but it's not really. Because I may have been slow but I got there. What's the matter about rushing about on to reach the same target as the rest and then make mistakes. Rushing can cause mistakes and disasters... slow people get there eventually, what's the mad rush?

Like the other participant who held these contradictory views, Derek, Mike had little enthusiasm for obtaining employment. It appeared that unlike the progressors or superior participants they did not believe that a change of circumstances would allow them to escape from their stigmatised status. While aware of the stigma associated with the ATC, he did not dare face the rejection of his non-handicapped peers in an ordinary job. While he spoke out against the stigma that all those attending the ATC faced, he maintained his self-worth by adopting a superior stance to his fellow 'members'.

B) Mothers' Perceptions

Essentially Different There were two distinct levels of 'global' handicap presented by mothers. i) the more extreme group of four mothers perceived the participants to be different as persons; ii) four others saw their sons or daughters as handicapped in a wider social context.

i) Different as persons

Karen's mother's views fitted into the former subcategory. She freely admitted she was protective of Karen and did not let her cook or use the iron in case she burned herself. Karen was only allowed out alone during the day very occasionally, and never at night.

She had great concern for Karen's literacy and numeracy skills and her understanding of the value of money. Her feelings were so strong on this subject that she had started a night class at which Karen was given individual tutoring by one of the volunteers.

There was some contradiction in Karen's mother's criticism of the

ATC for not teaching self-help skills such as cooking, shopping and the value of money. This was because Karen was given no regular income by her mother to control. Even her two pounds from the ATC were banked. Moreover, she considered it quite appropriate that Karen, aged twenty nine, should be sent to bed at 9 o'clock every night and play with dolls in her bedroom. In fact she did not envisage Karen living more independently for another 20 years or until they were unable to look after her any more.

Karen was only allowed out with relatives, family friends, or female friends from the ATC. This was due to her mother's deep fears regarding Karen's sexual vulnerability and that Karen might seek a sexual encounter. She obviously found the idea of Karen having a sexual relationship with anyone both abhorent and immoral. She would not even allow Karen to have a boyfriend, and had turned away someone that once called round for her.

She did say that Karen could hold an 'adult conversation', but in other senses considered that she was not 'adult':

> Emotionally, emotionally, I would say she's not. I don't know, she can be quite sensible and quite astute at times but when it comes down to the bottom line she's still a child. Definitely, she's still a child. We tried, I tried every way but there's no way you can change her. And I think the majority truthfully are like that. And if you think about it and even maybe years ago before I even thought about Karen being as she is, if you look at them they do not age.'

She felt the reason Karen stayed so young was that she did not have any of the 'cares and troubles and the worries' of everyday life. In part she felt this came about because 'they always have someone to look after them'. Furthermore, she felt Karen was not capable of having any resentments or 'deep feelings' about her life and that her 'biggest' concern was her next meal. She had explained to Karen that she had a 'handicap' which meant that she was unable to do particular things. However, she did not think that Karen had any resentments about the greater freedom enjoyed by her older sisters or awareness of the stigma associated with handicap. Her mother believed that, despite sharing with many 'handicapped' people the trait of being 'self-centred', Karen was more than content with her life:

> ...they all just really live in a wee world of their own, a utopia, because they are all really very happy.

The notion that people with a mental handicap remain in a child-like state was put forward as an explanation by three of these mothers.

ii) Handicapped in a wider social context

The other set of four mothers saw their sons or daughters as equal to anyone on a person-to-person level, but handicapped in a wider social context. For example, Sarah's mother was very positive about many of her abilities and just felt that she had difficulties with particular skills:

> I've never had any bother with Sarah, it's just not being able to read and do her writing and her money and things like that you know. I don't know what to say about her...I never had any bother with her with anything

> else...'

However, she felt at the same time that she had to 'get it through to Sarah' that she could not fulfil her aspirations of getting employment or going out and about like 'normal' people. Hence, when Sarah went to a special school her mother explained to her:

> ...you're handicapped, you're special, you're different from other people...'

She was sensitive to Sarah's feelings about attending the ATC and her experience of the associated stigma. While her mother saw her as 'handicapped' in the wider social world, she said that at home they 'treat her just as normal' and on a personal level did not want her to be discriminated against:

> I want folk to feel she's real, she's just as good as the next person.

Mike's mother took a similar approach. She thought that for a 'Down's syndrome boy' he was 'very high grade', and added that at school 'he did remarkably well for his type'. However, she felt dispirited that people like Mike were 'getting absolutely nowhere'. She felt that there was no real outlet for his abilities, no sense of achievement afforded to 'them' in the present structure of ATCs. It made her wonder what point there was in trying to 'educate them or encourage them'. On the other hand she felt that if he were employed he would be 'exploited'.

These sentiments did not mean she saw him as 'normal' or as a person who deserved the same rights and opportunities as non-handicapped people. In her opinion:

> No, Mike's not normal, course he's not, he is to me...

For example, she was quite willing to respect on a personal level his wish to join a particular church, but in a wider social sense she considered him <u>essentially different</u>. Moreover, she said he knew he was 'different' and told a moving story of Mike asking her if his young niece would still like him when she grew up and realised he was 'handicapped'. Mike's mother did not think that 'handicap' should be a 'bad word'.

<u>Essentially the same</u> There were two different perspectives adopted by the mothers who saw their sons or daughters in this fashion. i) two adopted a <u>supportive</u> stance, they recognised that their daughters had a disability but strongly resented the stigma that they faced; ii) a further two were <u>disbelievers</u>, and did not believe that their son or daughter was one of the 'handicapped'.

i) <u>Supportive</u>

Lorna's mother was a member of this sub-category. She thought that some people had been 'put off' because of Lorna's hemiplegia and talked of the 'cruelty' she had experienced from neighbouring children because 'she wasn't quick enough'. Lorna's mother felt this was quite avoidable:

> It's just that they [neighbours and children] don't understand, they have no been educated. And I blame the authorities for a lot of that because they segregate -

> it's them and us, because they're segregated right from school.

She did view Lorna as 'handicapped' and as having some form of brain damage. She felt that if Lorna were to do a job it would have to be something 'simple'. As her mother explained:

> I mean she's no stupid, don't misunderstand me, but if you show her practically, it will stay there, if you tell her it goes away. It's still the same.

However, she strongly believed Lorna should have the same 'right to have a job' which she was as capable of as non-handicapped people. Her mother described a 'dust-up' she had had with the careers office over this issue:

> ...I says - they've every right to work, it's their right the same as everyone else's - I says - they're not a nation apart, it's not their fault they're handicapped.

She thought that discrimination made people like Lorna feel they had to perform extra well. Lorna had had work experience when she left school and someone commented to her mum about how hard Lorna had worked. Lorna's mother replied:

> I'll tell you why she works better than anybody, because they got to prove to themselves and to everybody else that they're as good as anybody.

Her mother thought that in the future Lorna would like to get a job, marry, have a home of her own and if possible a family. Her mother echoed these wishes, hoping especially that Lorna would get a good job because 'it would make all the difference in the world'. Moreover, she thought that Lorna would make 'a good wife and a good mother'.

Thus, these two mothers recognised their daughters' disabilities but resented the discrimination which resulted in their exclusion from mainstream social activities or employment, and rejected negative stereotypes of people with a mental handicap.

Disbelievers

Dan's mother came into the sub-category of two mothers who did not consider that their offsprings were really handicapped. She gave a long account of how his brain damage had been caused by fits in early infancy. She felt that this could have been avoided if the doctors had heeded her reports that Dan was having fits earlier.

At school age he had had to go to a special school because they said that he needed 'more attention' than he could get at a 'normal' school. Her mother said they would not take her word that Dan had been toilet trained by the age of two and had started feeding himself at an unusually young age. She felt this was a grave mistake and that despite certain problems with reading and writing she thought that:

> Dan would have come on perfect at an ordinary school...
> Dan's not really backward when you look at the kids going
> about nowadays from a normal school.

She had held onto this belief despite being told by a doctor that Dan had no I.Q. to speak of and would be doing well to learn to sign his name. A psychologist had given helpful advice about not being overprotective and letting Dan play with children in the neighbourhood.

Dan's mother was disapointed when he went straight to the ATC from school. She had still hoped that he would obtain employment. Despite Dan's problems with literacy and numeracy she still considered him to be an intelligent and socially sensitive person. She wanted him to have the 'normal' future which she felt he deserved and did not appear happy with him associating with people more handicapped than himself. For example, Dan had been going out with a woman attending another ATC. His mother did not think she was suitable for him. She gave the following reasons:

> I tried to get it through to him that, I didnae mean she wasnae the wee lassie for him if you know what I mean, but with her condition... I tried to explain that there's nothing wrong with him, that he wasnae born like that you know.

When Dan split up with his girlfriend his mother explained to him that he would eventually get a 'normal' girlfriend. Although she talked of the terrible teasing he had been given as a child by neighbouring children, she did not appear to think that stigma or prejudice were of any importance in his life. She considered his feeling that he would not be able to find a 'normal' girlfriend stemmed from a lack of self-confidence. His mother therefore had to explain further:

> I've tried to explain he will get a wee girlfriend, there's nothing wrong. He knows that them out at the

> Centre, there's something wrong with them. But he wonders why he can't get a wee girlfriend who's got nothing wrong with her and who's not at the Centre. He says, - I'll no get a girlfriend like that. - I says, - How will you no son? There's nothing wrong with you. - He says, - But I'll not get a girl, they're not for me mum. - I says, - They are, you've not got to think things like that son.

Thus the two mothers in this group did not think their son or daughter respectively were one of the 'handicapped' and did not regard stigma as a problem.

C) <u>Staff's Perceptions</u>

<u>Essentially Different</u> One staff member held a rather different view from the others in this group: i) one thought her participant was <u>unaware</u> of his situation; ii) five viewed their participants as <u>globally handicapped</u> individuals.

i) <u>Unaware</u>

John's staff member reported he had led a very protected home life and had been brought up with the knowledge that he was a handicapped person. However, she thought he had no real insight into his situation or of the stigma surrounding services. As she explained:

> John does not resent anything at all Andrew. John is a very placid person who accepts life as it comes along, each day as it comes. He accepts situations very, very

> readily, be it either at home or in the Centre. He's not the type of person to get flustered, he's not the type of person to show a great deal of emotion one way or another. He'll just fall into the system as he goes along. He would not argue with his set up at home, he just accepts it.

In addition, she did not think he was aware of any differential treatment compared to what his brother or other non-handicapped peers received. She felt that he saw his life and the Centre as 'normal'. She believed that John saw himself as the same as non-handicapped others because he was not aware of the difference between handicapped and non-handicapped people. Hence, the implication was that John was really a 'handicapped' person who felt 'normal' because he was totally unaware of what the realities of his situation were. She thought that this lack of insight was in itself due his being a 'handicapped' person.

ii) <u>Globally handicapped</u>

These five staff members saw their participants as globally handicapped individuals. Perhaps the person who held the most extreme view was Mike's staff member. As a person he admitted having a 'grudging respect' for Mike because he worked so hard. If he had been 'normal' he thought Mike would have been the kind of person:

> ...that got through University on hard work rather than intellectual merit...'

However, Mike's staff member saw him as a 'handicapped' individual and in particular a Down's syndrome person:

> As far as it goes, Down's syndrome, he's probably the most advanced we have.

He thought that Mike would probably pick up many self-help skills and could definitely look after himself. However, he felt that Mike had passed the age at which people with Down's syndrome could progress any more and he could not 'pump much more' into Mike. He also thought that in the social sphere Mike had achieved as much as could be expected: 'I think for his mentality it is quite satisfactory'.

One of the peculiar characteristics that he felt Mike shared with other people with Down's syndrome was a tendency to make excuses for lacking particular skills. Mike's excuse was that he was right handed.

Other staff members in this sub-category, such as Paul's and Karen's, did not view their participants in such a wholly 'handicapped' fashion. Nevertheless they still thought that their participants had an outlook on life and personal characteristics which did not arise from their disability, but because they were handicapped as persons.

Essentially the same There were two perspectives that characterised the views of these staff members. i) Four saw them as people with specific (as opposed to global) handicaps; ii) six considered they were too able to be labelled as handicapped.

i) Specific handicaps

Sarah's staff member typified this 'specific handicap' perspective. She regarded Sarah as being very competent in the voluntary work that she did at a local nursery. On the other hand she felt Sarah 'might not cope with the academic side of doing a nursery nurse course'. She thought Sarah had specific disabilities and was not a globally handicapped person, an outlook which she felt Sarah shared:

> I think to Sarah it would be the bits that she can't do that would be where she felt she was slower at things. Maybe that she would feel her handicap more rather than being an all over mentally handicapped person. Come to something she really, really couldn't do, she would then feel - Oh my goodness, I can't do this sort of thing... - If there is anything that comes up that she can't do then I think she feels a bit handicapped in that area. You know, but not an all over handicapped person, just in the things she can't do. I mean there's things I can't do, I feel handicapped in areas like cooking.

These staff members also had ordinary aspirations for their participants' futures. For example, Cathy's staff member felt Cathy had more difficulty with skills than she liked to admit. In one instance she had got into an awkward situation with sponsor money due to her problems with handling money. However, the staff member was positive about Cathy and talked about the many skills which could be built on. She considered Cathy to be an 'ordinary person' and as such had ordinary aspirations for her future.

ii) <u>Too able to label as handicapped</u>

Harry's staff member was typical of the five who saw their participants as too able to be labelled as handicapped. As he explained:

> Well there's nothing specific in his records. I don't see Harry as being handicapped in any way. I mean he may be slightly, it may be the wrong word to use; 'backward'. But more of lack of, it's no backward, it's more of self-confidence over the years. But there's no specific handicap that I could attribute to Harry.

He thought that his mother regarded Harry as someone who had never grown up. Although she was very sensitive and caring, he felt that she overprotected him. However, he felt that Harry was content and did not regret his socially isolated life at home. Moreover, he never reported being teased or experiencing stigma. He thought Harry just saw himself as a 'normal' person:

> I think he sees himself just as a normal person. He acts like a normal person, he's got the manners.

He considered Harry to be 'among the higher grade people that work in the Centre' and felt he 'fits in well with everyone else'. He hoped that in the future Harry would become more independent, obtain employment and lead a more ordinary life. However, due to Harry's sheltered background the staff member thought that he had a limited world view and that such aspirations 'wouldn't enter his head'.

Several of these staff members believed their participants' main disability was social, resulting either from their marginal social status or sheltered home backgrounds. Perhaps the most extreme case was Joan, whose staff member felt exasperated by her family's over-protectiveness. Joan's staff member gave the following explanation as to why her worst handicap was caused by familial treatment:

> All it boils down to, Andrew, is that they still look down on Joan as a 2 or 3 year old, that is the simple trouble of everything. I mean my daughter is 10 now and she gets to cook and things now because she's 10 years old. But come to the time when you decide she's old enough to try something that's fine - but you see Joan has never been let do that, she has always been kept at a stage where you keep a bairn back from everything.

According to her staff member Joan displayed how capable she was when she was doing activities in the Centre, but when she returned home 'she's back to being the child'. For example she had refused to use a hair dryer at the ATC until assured that she would not do herself any harm. Once she accepted this she proved 'quite capable'.

Although she had been 'brought up to see herself as different from non-handicapped people', the staff member reported she saw herself as superior to others in the ATC. She took some pleasure in pointing to their problems with literacy, numeracy and their lack of personal hygiene. At the bottom line, Joan's staff member felt:

> Her mother, her family...they are her handicap...Given independence she would realise that she's just the same as people on the street.

Therefore, the staff member simply saw Joan as too 'capable' to be regarded as really 'handicapped' and different from non-handicapped people. Like others in this category, if she had had more severe disabilities her staff member might not have considered Joan to be like anyone else in the street at all.

2. The Key Group

A. Participants' Self-Concepts.

Essentially different There were three participants who were judged to fall into this category and there were only subtle differences in their self-concepts.

It was in some respects surprising that people who had achieved such a great deal in moving towards a more normal life style should continue to regard themselves as different from the non-handicapped. Perhaps none more so than Susan. She had a limited world view and ambition, with a small closely knit set of social relationships. She said she had led an extremely restricted life in her family home and did not attend the ATC. Apart from an occasional visit to her sister and brother-in-law, her days were filled helping her parents with household tasks and taking their dog for walks. She had long since stopped attending a club for people with a mental handicap, but had sustained a 20-year engagement with her boyfriend, Howard, whom she had met at a club. He attended an ATC but had faithfully visited her house three times a week throughout their engagement.

Susan said she had enjoyed her quiet existence. However, her one ambition in life had been to marry Howard and they finally did so when she reached forty. She was now content to lead a life that she considered typical of a 'housewife'. She did not aspire to obtain any of the other opportunities, social and otherwise, that she had missed out on in her life at home. Although she was hurt that she could not have children, she did not regard herself as a person with the same rights and needs as a non-handicapped person. When asked why she had not got married earlier, Susan replied that her mother had not allowed her to, and she did not know if the 'authorities' would permit it. In the same fashion, she saw bringing up children as something 'handicapped' people were not allowed to do.

Talking about the difference between 'handicapped' and 'normal' people Susan made the following distinction:

> They have a different way. They go to real dances and they dance with their own kind and the handicapped dance with their own kind.

Susan viewed her disability as a tangible problem and talked of brain damage resulting from something that had happened to her ears. However, she regarded people more handicapped than herself as 'childish', but did not look down upon physically handicapped people, having a relative with spina bifida who, she said, was 'intelligent'.

She had made no new friends outside the hostel since moving to Key. In fact she appeared to avoid her non-handicapped peers, having experienced teasing and abuse in the past. She wished to have old people as neighbours because they were 'quiet'.

Helen and Kevin also thought that they could not lead the same kind of lives as non-handicapped people. Kevin felt that he had a very mild mental handicap and did not want to go to the ATC in case other people thought he was a 'lunatic'. He was saddened by his rejection by his non-handicapped peers which he could remember happening as a young child. Ultimately, though, he felt he would have to accept his destiny as a 'handicapped' person, however slight his disability actually was. This meant he accepted his sister being afforded freedoms and a lifestyle he was not. In order to escape this scenario he felt that he would have to 'be born again with no handicap'.

Helen also believed that her disability had destined her to a quiet pattern of life. Although she talked little of the stigma she faced, she fully realised the social opportunities she missed:

> I would like to do what other people are doing. It's because I can't do them, that's why I get a wee bit upset, seeing people doing things that I would like to do. Like being like normal people. That's what upsets me a bit...I can't be like the rest, because I'm handicapped and I know that.

Helen went on to talk about her wishes to go out and get jobs like ordinary people, 'but I know I can't do it because I'm different from them'.

<u>Essentially the same</u> The 7 participants who regarded themselves as <u>essentially the same</u> fell into 4 sub categories. i) two had an <u>elitist</u> view of self, or wished to make clear their abilities; ii) two thought that their handicap was <u>social</u>, or was more due to being treated as handicapped than their actual disability; iii) three appeared to <u>deny</u> that they had a disability.

i) Elitist

The two 'elitists' wished to emphasise their greater ability than other handicapped people. For example, Anita was fiercely proud of her domestic competence and the independence she had gained. She reckoned her mother had given preferential treatment to her older sister and continued to be overprotective towards her. However, it was about the child-like treatment that she expressed greatest resentment.

Anita wished to emphasise her superiority over other people with a mental handicap and talked of 'handicap' as a physical disability:

> People you call handicapped have got spina bifida. You class them as handicapped. We're not handicapped, we're just human beings.

On the other hand, she talked of instances such as when her nephew had laughed at a handicapped person and how she had rebuked him for doing so. As she explained:

> I said, - that's not very nice. You could end up like that one day - they just laughed at me. You just can't get through to kids to explain what it's all about.

It appeared that even though Anita wished to distance herself from other people with a mental handicap she could not escape the prejudices they faced. Thus, she could not prevent herself from empathising with their predicament. For example she reported that despite making an effort she could not make non-handicapped friends. In addition, she herself recalled being made a 'fool' of by her nephews. Perhaps the deepest hurt was caused by her involuntary sterilisation and her powerlessness to prevent it. It appeared that as a consequence of moving on to live more independently and becoming aware of her potential had made her especially bitter of the prejudice which she faced. However, in terms of her own identity she wished to emphasise her relative 'normality' as compared to other people with a mental handicap.

The second participant felt that her problems stemmed from attending a special school where, she said, she was sent because she was 'slow at sums' and she 'fidgeted'. She felt that this resulted in her being rejected by her non-handicapped peers.

> All the wains were at an ordinary school and I was at Benson Park. They used to say I was daft 'cause I went to that school...It doesnae bother me now but it hurt me then. Ken, when I was younger...It never worked out going to that school.

After leaving school she worked in a laundry, where she was apparently ill-treated by a number of fellow workers before being laid off. This reinforced her feeling of failure and further reduced her self-confidence. Despite her confessed lack of confidence, she did not doubt her own abilities:

> There's not much wrong with me - my abilities - I can fill forms in. My capabilities are I can do everything. So maybe I could get a flat quicker than N. [another resident].

She did not consider herself to be 'globally' handicapped, but felt that she had problems with specific tasks such as using a washing machine. Although she was aware that people with physical handicaps could be more 'intelligent' than her, she felt that their disabilities put them in the same category as the 'handicapped'. At the same time she commented that there were others in the hostel who were more able than herself. Lisa thought she was different from 'the wee ones' at the Centre, or the 'mongols' with whom she had travelled in the bus to school. She described how this she felt about going to the ATC with these people:

> It's just the thought of going to a Centre, to get classed as disability, when I'm no. That's all in the past, now I dinnae bother.

Lisa explained what she thought non-handicapped people would think if they knew that she worked in an ATC:

> Well I think they think I'm stupid. They all think, why should I go to the Centre ken, because I'm no handicapped like their wee yins. Well, I feel that anyhow.

Lisa's wish to leave the ATC because she was different from others there was contradicted by her comment that 'now I dinnae bother'. It was clear that despite being critical of certain practices, she considered it a positive move going to Key housing and enjoyed the friendship and camaraderie that she found there. But her resolve not to be 'classed as handicapped' meant that she would not get a bus pass for 'disabled' people even though it would have given her a substantial financial boost. There appeared to be a conflict between her wish to preserve a non-handicapped identity and a pragmatic wish to accept her circumstances. In other words, by accepting that her move to a Key housing hostel had been a positive step in her life she was moving to a position where her public label was less important than her private feelings.

The two 'elitist' participants therefore considered themselves to be quite superior to other people with a mental handicap and did not consider themselves to be really handicapped. While they wished to dissociate themselves from the stigma associated with handicap and specialist services, the common experiences they shared with people with a mental handicap meant they could not simply set themselves apart.

ii) Social handicap

Gavin considered that he had a disability but like Grace, the other participant in this subcategory, it was the social consequences that he had found problematic. He felt that the attitudes of others towards his handicap had led to a life of overprotection and constituted an artificial barrier between himself and non-handicapped people. His move to a Key housing hostel and the resultant sense of independence and worth had served to confirm this view of self.

When he talked about friendship, he expressed most clearly his feelings about the consequences of being regarded as 'handicapped':

> Even with pals, I never got a pal in my life. There's fellows I knew at school, that's all they are, but they were never my pals, they wouldnae mix with me. Put it bluntly, I was never good enough for them. I used to just say, - well, if I'm no good enough for them, that's

it, finished.

He explained that he had always found it hurtful being overprotected and had never accepted the underlying implication that he was a more vulnerable individual and less able to reach his own decisions. He made this point when he described the discussion he had had with his brother about moving to a Key housing hostel:

> It's no you that's making my mind up for me, I'm making my own mind up for me. I'm making my mind up myself, just the same as everybody else, I only take epileptic fits but I've got a mind of my own.

Indeed, Gavin gave examples of instances where he had asserted his rights. For example, he had cashed his own pension book despite the skepticism of the post office employee. He considered that his move to Key had vindicated the position he had adopted all these years. With support, he felt he could demonstrate his independence and worth. He told with pride about when he used a train for the first time to visit his sister in Glasgow. He questioned why people in the past had worried so much about him, explaining, 'now if I'm no worried, I don't know what they were worrying about'.

He viewed people with more profound mental handicaps as being less fortunate, but did not regard himself as being any different from his fellow residents in the hostel. Moreover, he did not see himself as in any way subservient to the ATC or hostel staff and complained of instances when the ATC staff had not taken him seriously.

iii) Denial

There were three participants who came closest to denying their handicap, or held such contradictory views that one felt they had difficulty reaching a clear view of their own identity.

One participant to hold such a self-concept was Bob. On certain occasions he talked about his wish to walk away from his situation; to get married, pass his driving test and get his own house. At these times he would imply that all his problems were caused by those who were responsible for sending him to a special school, and that the school had not taught him to write. He blamed a social worker for sending him to the ATC, and in turn thought that it was the ATC management that were responsible for his being sent to a Key housing hostel.

On the other hand, Bob said that the hostel had made him more grown up and independent and that he would rather work with people in the ATC because they were more understanding than non-mentally handicapped people who might 'make a fool of you and that'. He reported several instances of prejudice. On one occasion a publican asked him and a fellow tenant if they were 'handicapped'. When they replied that they were, the publican refused to serve them. A neighbour had also objected to Bob cutting the grass outside the hostel, saying that he was not sufficiently able. In addition, he took objection to the authoritarian attitude of some staff members in the hostel. Although he spoke of no other experience of stigma, it seemed likely that there had been other instances. For example, after denying that he had ever been called names, he was asked what this would make him feel like. His reply was:

> I feel like going away and smashing all their windows in.

For someone who has never been teased or called names it appears a very strong response.

His relationship with his (adopted) parents was very important to him. His parents' natural children, who were considerably older than him, had never approved of the adoption. This made him frightened that one day his parents might also reject him. Hence when he discussed the ways in which being seen as a 'handicapped' person affected his life, preventing him amongst other things from gaining employment, he said that it made him '...feel like going out and showing them'. In other words, he felt he had to prove his worth to others and live down his special school status.

This wish to 'show them' may go some way to explain his two apparently contradictory stances. Bob may indeed have wished to dissociate himself from other people with a mental handicap and the services provided for them. However, he may have felt that such tasks were beyond him and that the setbacks he might face on such a road were more than he could cope with. Therefore at other times he was content to state his preference for an ATC and show solidarity with other people with a mental handicap in rejecting discrimination and prejudice.

He also showed a lack of consistency in his view of people less able than himself. On a number of occasions he talked patronisingly about people who he thought were less able and a different kind of persons from himself. However, at other points, he complained that less able tenants in the hostel did not have to do as much for themselves. In saying this Bob was comparing himself directly with people less able than himself, and obviously did not view himself as so terribly different.

A second participant, Anne, expressed similar views to Bob. At times she, too, went to considerable lengths to deny that she had any kind of disability, or was aware of any prejudice. However, as the interviews progressed it became apparent that she had had a great deal of experience of stigma and spoke openly about particular learning difficulties with reading and writing. Moreover, she spoke of the stigma associated with the services and contradicted earlier denials of teasing and abuse by recounting a number of instances. Even her schooling, which she had earlier described with rapture, she later talked of having found unsatisfactory and expressed the wish that she could have gone to the ordinary 'High' school instead of the special school. It was as if by admitting to the stigma that she faced she was opening to question her belief that she was on a par with non-handicapped people. This sense can be taken from her description of what it felt like when she was asked where she worked:

> I remember one time someone says to me; - where do you work? - I says - Kelvinbank - They goes - Is that the luny place? - I says - that's no the luny place. Cheek! It's a bit of a nutter place right enough, but it's no a luny place.
> [makes you feel] Rotten if someone says that to you.

She considered that those who had physical disabilities could be described as 'handicapped', but she did not adopt a superior stance to them. She helped out with a profoundly handicapped group in the ATC and described them as not being able to do 'as much as what we can do'. Anne also said that her sister was 'brainier' than her because she had attended a 'higher grade' of school. But once again this did not mean she thought that non-handicapped people were superior to her, and she described her staff member at the Key housing hostel as being 'like a sister'. Indeed, she did not think that her actual disability was a bar to her leading an ordinary life in the future. Anne wished to have a job, get married and settle down.

In the ATC she thought that one got treated according to how one behaved. As she explained:

> It means you're an adult. If you act like a baby, they're going to treat you like a baby. If you act like an adult, they treat you like an adult.

Therefore,in the ATC Anne had to 'prove' her worth.

In contrast to Bob, Anne left home against the will of her parents and moved to Key housing. She literally packed her bags one night without the knowledge of her family and left her house the next morning before they had got out of bed to take up her tenancy in Key housing. This produced a crisis of conscience. She moved from home because she felt that she was treated as though she could not look after herself. Anne had not been allowed to cook, had to share a room with her 16 year old brother who, she said, was insensitive to her feelings, and she had no control over her finances. Indeed, according to Anne, her parents' greatest motivation to keep her at home resulted from the income her benefits brought into the family. Despite these circumstances, Anne felt a great deal of loyalty to her family and wanted to give the impression that everything had been ironed out between them and that they now got on well. However, although she went home frequently, her family had never visited her and had not even sent a card for her birthday. She had therefore sacrificed her relations with her family, not only in a bid to gain greater independence, but also to demonstrate her competence. Anne summed this up when she talked about the reason why her mother had not wanted her to move to Key housing:

> She didn't think I could look after myself. So I've proved that I can.

The last Key participant had a similar view of herself to Anne. While Mary readily admitted to having specific problems with reading, writing and arithmetic, she did not believe that this made her a globally handicapped person who deserved to be treated differently from non-handicapped people. However, like Anne, it appeared that to discuss the ways in which she was treated differently or the stigma that she faced, was to admit she was indeed a different kind of person. However, Mary did indicate that she felt she was treated in a fashion at home which was unjustified by her level of ability. Once again she was able to say this because she could support her case with the proof of her success in Key housing. As Mary put it:

> My mum says I'm no right, I won't be able to cope. But since I moved in here I've been coping great. I've been doing well in here.

She added how 'pleased' the staff were about her progress. She strongly felt that she was capable of looking after herself, having greater autonomy over her life and a job. In short she felt able to lead a more 'normal' life and did not feel that she deserved to be seen as a 'handicapped' person.

She did complain about being treated in a child-like fashion at the ATC, making the point that she should not have to earn the right to be treated as an adult.

She looked down on those less able than herself, but regarded her peers at the hostel and in the ATC as being in the same position as herself. Although she claimed that she had never experienced name calling or abuse, she showed great sensitivity of her position as a person who was seen as 'handicapped'. For example, Mary talked about marrying her fiance, an ex-hospital resident, and having children. She wondered what these children would think when they grew up and 'learned more about their mother and father': a sad acknowledgement that while she could dismiss the consequences of being seen as a 'handicapped' person, this did not diminish the dread that her own children could come to share such views.

B) Mothers' Perceptions

Essentially different There were 3 mothers who saw their daughters as essentially different. i) Two of the mothers' attitudes could be described as belonging to the handicapped category which meant that they could never be seen in the same light as non-handicapped people; ii) the third mother considered that she treated her daughter as if she were normal. However, it was apparent that the mother did not consider that her daughter deserved the rights or had the sensibilities of an ordinary person.

i) Handicapped

The mothers of Helen and Susan adopted the first perspective outlined above. We shall consider in more detail the views expressed by Susan's mother.

Susan's mother thought that she had 'a lot of common sense'. Apparently she could read a newspaper and tell the date but had some problems with arithmetic. In terms of her handicap, her mother did not think she was 'bad that way...she's just in between'. Moreover, she felt that Susan was able enough to 'wish she was normal'.

In another sense, though, she regarded Susan as someone who 'had never grown up'. When she first learned about Susan's mental handicap, she was told that at 12 years of age Susan would go into hospital for life. She explained how this had had a devastating effect on her and:

> it made me feel it would be nice if just the two of us walking out in front of a bus. That's what it made me feel, but I didn't. That's the feeling. You take these things in life, somehow my body was prepared for it. I just knew in my mind that there was something wrong and I knew she wasn't learning and I wanted to know if it was something that could be helped. I didn't actually think it would be mental handicap...It's terrible to bear a child that doesn't grow up.'

She did adopt a positive approach to Susan and was extremely close to her. She described Susan's move from the family home as being 'like a death' in the family. Apparently Susan had been extrememly jealous of her sister when she left home to get married and it was this event that had fuelled her own aspirations. According to her mother, Susan had always been sensitive to stigmatised treatment such as being stared at and had asked why no 'normal boy' would 'look at her'.

Howard regularly visited Susan throughout their 20 year engagement and her mother explained how she had kept a close watch on them:

> Howard came up to see her every Tuesday and Thursday for three hours. Then on Saturday he came up between 1 and 9 every saturday. He did that for 20 years except in the holidays...I didn't let them be just like an ordinary courting couple. I just sort of let them play the records...As a matter of fact we wouldn't go out when Robert and Susan were in...Well I didn't know how they got on apart from anything else...We always said these were Susan's nights.

She had opposed the marriage of Susan and Howard and it was only with the intervention of Howard's parents that they did get married and moved on to live more independently. Susan's mother still saw her as a 'wee girl', requiring a great deal of guidance and shelter from some of the harsher realities of everyday life. While she was disturbed at the amount of freedom Susan had in the satellite flat she had not liked Susan living in the hostel for fear that her bahaviour would be influenced by the other 'handicapped' individuals. Susan's mother loved and respected and got 'great fun' from her daughter and wished to get a house nearby so that she and her husband could offer more support.

ii) Normal

Mary's mother considered that she treated her daughter as 'normal'. At one level Mary's mother claimed to see her not as a 'handicapped' individual but as a slow learner whose main problem was a lack of concentration.

However, she did not think that Mary being sterilised and never being informed of this fact was a cause for concern. For unknown reasons, her mother had hospitalised Mary between the ages of 12-16. Before leaving hospital Mary was sterilised. She had never been informed of this but was told instead that she had had her appendix removed. Mary was now 25 years of age and wanting to marry and have children. Her mother could not understand the fuss being made by the Key housing staff about telling Mary that she had been sterilized. Furthermore, she wished to prevent Mary and her fiance from getting married as she felt they had little idea of the 'implications'. Such views contradict her claim that she always treated her daughter normally.

Like the sub-category of mothers in the Family group, the three mothers in this sub-category viewed their daughters as 'handicapped' persons in the wider social world.

Essentially the same. There were three distinct points of view that characterised the mothers who saw their sons or daughters in this way. i) Bob's parents felt he had been mislabelled due to the lack of opportunity he had been given and the prejudice that he faced; ii) Grace's sister's views almost fell on the borderline between the same and different categories; iii) the remaining two mothers believed the main problems their daughters faced were the social consequences of their handicaps.

i) Mislabelled

Bob's parents thought his handicap was negligible and that his lack of progress had mainly been due to prejudice and a resulting lack of opportunity. His father did feel that Bob was slower at some things, but thought that these were compensated for by his 'head for figures' and his map reading ability. He felt that Bob had been given little chance at the ordinary school he had gone to at first, and that attending a special school had stigmatised him. He was paricularly embittered about the firm he himself worked for refusing to take on Bob:

> I said, - you're not the only firm, there are thousands of you up and down the country. You look down on people because they're a wee bit, they havenae got it up there. - I says - After all, they're human beings the same as what you or I are.

In general he felt that people like Bob were treated like '2nd class citizens' and that firms like his 'condemn people before they give them a trial'. His father also considered that the small amount money that Bob received from the DHHS was discriminatory and limited his opportunity for experience and set him apart from his non-handicapped peers.

Bob was an adopted child. However, their daughters, who were grown-up at the time, were against Bob's adoption and had never accepted him as one of the family. The parents found the negative attitudes that their own daughters held towards Bob and his disability were particularly hurtful. Moreover, this made the father determined to 'prove' Bob's ability. Therefore, Bob had not only to prove his own ability but that his parents' faith in him had been well founded. Indeed his father regarded Bob's success in Key housing, and in particular in phoning hotels to arrange the Christams dinner for the tenants, as 'a feather' in his own cap:

> I'm really over the moon about him because he's really proved himself, and it shows it can be done by any type of person like Bob, it can be done...... [Added later about the possibility of Bob getting a job] If that boy can do it and he does it, I can say - I've been proven right and they've been proven wrong. There's a feather in my cap. I would be chuffed at it.

While his father thought that the special school system could produce M.P.'s and councillors, he did not equate Bob's position with the more handicapped pupils or those attending ATCs. He felt the 'really' handicapped should not be pitied but at the same time should be segregated from more able individuals. He had observed that Bob did not like getting the bus to school with those who 'were mongol and different things'.

For the future, his father thought that Bob would pass his driving test with the minimum of lessons, get a job and possibly marry and settle down. His mother was less optimistic about him obtaining employment or getting married, but it was his father's forceful views that held sway.

It was apparent that his parents saw Bob as being wrongly labelled as 'mentally handicapped'. But just as they thought that he had come to be regarded as handicapped through a lack of opportunity and prejudice, so he had to grasp the opportunities that came his way in order to prove his own worth. This was not only for his sake but in order to justify their investment in him as a son adopted against the wishes of their daughters.

ii) <u>Borderline</u>

Overall, her sister saw Grace as being the <u>essentially the same</u>. She explained that Grace's handicap had been caused by meningitis which she had contracted in infancy. She did not regard Grace as being very disabled:

> Grace was alright, just a wee bit slower than the rest.

Apparently Grace had been very badly treated by her teacher at primary school, who was totally intolerant and if anything set her back further. When Grace left school her mother did not get her a job in the factory because she had known someone with a disability who had been given a lot of 'stick' by her fellow workers. Instead they found out about the ATC and her mother sent Grace there. However, this was not a straight-forward decision as her family did not regard her as a globally handicapped person. Grace's sister said:

> I think she [Grace's mother] was in tears that day, the thought of leaving Grace who she thought there was nothng wrong with. Well some of them were quite handicapped I suppose...My mother never thought Grace was as bad as

> that...Well the mongols and things like that you know.

Grace's sister did think though that her father had been very protective of Grace and her granny referred to her as the 'wee yin' and treated her as such. Despite her mother and the rest of the family treating her in a 'normal' way, the sister thought her father had 'ruined' Grace.

Grace's sister did not think that Grace had had to face any experiences which had left a mark on her identity or influenced her life. For example, she believed Grace had been unaware of the stigma attached to her special school and simply regarded the ATC as her work. She laughed about Grace's wish to leave the ATC and did not think that this was anything to take seriously. She thought that Grace regarded her peers at the ATC and Key housing as 'normal'.

She did think that Grace's early experiences had made her rather immature and recognised her family's tendency to be protective. As she explained:

> I mean you get people that go through primary school and high school and they're a lot slower than everybody else, but they still manage it ...I know people I was at school with and I don't think Grace's any worse than any of them... Grace's better at arithmetic than me, she can count, she can do her English, she can write, she can read, a lot of people at the school couldn't do that, at the High school. I don't really see Grace as being disabled at all. Just for the fact that she was at xxxx

> [special school], she couldn't look after herself. And at that time she was having a tantrum at the least wee thing, I just couldn't have managed her but I don't see why I couldn't manage her now. That's all she's really needing, a bit of independence, I think, to bring her out, to let her see. But we're just too feared to let her go I think.

iii) Social consequences

In the first instance, Anita's mother thought her retarded progress was largely due to the drugs that she was given to counteract her epilepsy which had 'dulled her brain'. She took this view because Anita's development had been quite normal up until that point. Although she started in the ordinary school, she was moved to a special school because she had epileptic fits. This was apparently a 'disasterous' move as the school did not offer her 'a fair chance of an education'. Moreover, Anita 'hated' the school and caused so much disruption that she was sent home all the time. She was also aware of the associated stigma and disliked travelling on the special school bus.

Although her mother said that she had 'always tried to treat her as normal as possible', she found that other neighbours and friends tended to patronise her:

> My friends have always treated her as retarded, they humour her. I have one friend who talks to Anita on the same level as she talks to me and got good responses. I've always preferred that to people who treat her as not

quite normal.

She added that Anita never complained about being treated 'like a 3-year old' by her friends, but enjoyed those who talked to her at a 'higher level'. She did not think that Anita was particularly aware of being stared at or regarded as different from non-handicaped people. However, she did 'resent' the differential treatment afforded to her siblings or non-handicapped peers. Even when Anita was young her mother remembered her being upset at her siblings being allowed to go to the park while she had to stay at home due to her bad road sense.

Anita was aware of her epilepsy and discussed this problem with her family. However, she regarded herself as 'normal' and adopted a motherly attitude towards those less able than herself. Her mother did not think that Anita wished to dissociate herself from other handicapped people to avoid stigma, because she attended activities explicitly organised for people with a mental handicap.

Anita's mother discussed how her attitudes to Anita had changed as a consequence of Anita seizing the initiative and moving on to live more independently. Until recently Anita had apparently been very content with life in her family home which her mother admitted to be a very 'protected' environment. Her passive acceptance made her mother feel that she neither wished nor was capable of any other existence. So it came as quite a shock when Anita started at the ATC and saw people moving on to live more independently and decided she would like to take that path herself. As her mother explained:

> Maybe it's just something you don't want to admit - I

> mean every other young person strikes out on his own at one time in their lives, she really was entitled to do that too. I was reluctant - I just felt she wasn't capable of doing it. Now I see she was capable of doing it.

Indeed she indicated that she was pleased to encourage Anita's development and progress. However, there were particular characteristics which Anita displayed that her mother thought were characteristic of people with a mental handicap. In particular she considered Anita to be incapable of having deep and meaningful relationships, and thought she was a very self-centred person. But overall, her mother saw her as a person who deserved to be treated and have the same opportunities as non-handicapped people:

> I would hope she was able to get married and settle down and live a resaonably normal life. As far as anyone can do in married life.

Lisa's mother, the other parent in this group adopted a similar perspective. She did not feel that Lisa was 'really handicapped'. She had never considered her to be slow learner, pointing out that she was not slow in reaching the usual land-marks in infant development of walking, talking or being toilet trained. She was 'shocked' when the school said that Lisa had a learning difficulty. However, she maintained that Lisa's problems had been primarily due to lack of concentration and disrupting the class. Indeed the first school doctor she dealt with explained that Lisa was not 'handicapped' but a 'slow developer'. A second, and apparently unsympathetic, doctor insisted that Lisa should be transferred to a special school. Her mother still felt that although there were some things that Lisa 'cannae cope with' she only had a very mild disability:

> She's no really awfy badly. There is that part that is no as it should be. But, she's no too bad. I mean she can read and write.

She had two theories as to the cause of Lisa's handicap, one related to being knocked on the forehead by a swing when she was a small child. After this incident she noted a marked change in her child's behaviour. In particular she observed that Lisa was more aggressive and had no concentration. She said that a neighbour had independently reported the same changes and that she had mentioned this to various professionals but was told it was not a possible cause. Her second theory was that Lisa was overdue when she was born and that her birth had been particularly difficult.

However, her mother did not consider Lisa to be different from non-handicapped people and felt that the stigma she faced had had a devastating effect on her life. She reported that Lisa had been a confident and extremely pretty child. As a consequence of going to a special school and being subject to abuse and rejection, she had totally lost her self-confidence and had developed such a negative view of herself that she would not even look into a mirror.

Lisa herself had always rejected a handicapped identity. She was still unwilling to get a disabled bus pass. Her mother reported one incident when a child from Lisa's school, of whom she had always spoken highly, came to visit her. The girl was apparently considerably more handicapped than Lisa. Lisa was ashamed to be associated with her visitor and had refused to have anything to do with her. In addition, her mother felt that Lisa had been greatly damaged by abuse she had received from her fellow workers when she was employed in a laundry.

Her mother reported that the social isolation of Lisa had bonded them together in an extremely close manner:

> I fashioned it [mother's life] on her. I made Lisa my life. That's why I didnae have any friends. I'm friendly with everybody but I dinnae have any friends.

Although their relationship had been, in her mother's words, very loving, Lisa also took out her 'hurt' on her mother. Lisa's mother explained how this was caused:

> People, people caused it. I mind the first time I heard somebody speaking to her as if she were simple. I could have choked them. You know the way they talk to somebody, they talk louder, - Aye, I ken what you're doing, I ken what you're after - ... I had to start taking it the same as her. There was no other way was there? I mean I couldnae turn round and say, - who do you think you're talking to? What manner is that you're talking in? - Well I was going to make L. feel different too, wasn't I?... The only ones who were different were her own family.

She felt Lisa's move from home had considerably increased her confidence because she was treated by people there as an equal. Although her mother desperately missed her and described her absence as being like a death in the house, she wished that Lisa had made this move earlier:

> I only wish it had been 10 years ago when she was younger. Then she might have had a chance of meeting somebody and maybe getting married. She would have lived a normal life like anyone else then.

Therefore, although she considered that Lisa did have a disability, she felt that her life had been effectively ruined by her rejection by non-handicapped others.

C) Staff's Perceptions.

Essentially Different The one staff member who regarded his participant as essentially different did so as a consequence of the professional distance that he kept from her. In other words, he did not see her as he would any other person, but rather as a professional problem. This led to him attributing problems to her which were, in fact, outwith her control. For example, Grace was wanting to buy a new wardrobe and he insisted that she should save up and buy a new, good quality, piece. He considered that Grace's opposition to this resulted from her being unable 'to envisage larger things' and lacking a 'sense of quality'. However, he failed to mention that buying such a piece of furniture would leave her with only £5 per week to spend on herself over 5-6 months. In addition to social expenditure, she had to buy clothes and toiletries with this £5. It did not occur to him that Grace could not 'envisage larger things' because she could not afford them.

Grace's staff member reckoned that her family background, and particularly the negative attitude of her father, had caused emotional damage. He thought this had contributed to the development of a very negative view of self and that she saw herself as inferior to non-handicapped people and superior to those more handicapped than herself.

He used 'double-speak' to describe his relationship with Grace. On the one hand he said that there was no barrier between staff and residents. However, on the other hand he said that he was in a position of power over Grace and if he told her what to do she would comply. He therefore felt able to control her life as he saw fit. Consequently, he saw Grace as his charge. He summed up his attitude towards her when he was explaining why he considered it necessary to keep tabs on Grace's movements:

> I feel very much like a parent of a wee young adolescent who may be going out glue sniffing, it's very hard not to think like this. If something does happen to one of our residents a parent can turn round and say - you're responsible, we're taking you to court. The philosophy we work under wouldn't hold sway in court, it would be interpreted as negligence, when what we're trying to do is give people their own steam, the opportunities to make decisions for themselves.

It is apparent, from what this staff member said, that he worked with people on the basis of a philosophy abstracted from the people themselves. Therefore, Grace did not have rights but was afforded certain liberties as he saw fit or felt comfortable with.

Esentially the same These 8 staff members could be split up into 3 sub-groups. i) Two staff members regarded the participants as being too able to label as 'handicapped'; ii) four considered that the participants' problems lay not in their lack of ability but due to personality problems; iii) the remaining two staff thought their participants' limitations were due to being socialised as 'handicapped' individuals.

i) Too able

Gavin's staff member saw him as someone who had never been particularly handicapped but had just fallen on the wrong side of the fence. As such, he felt that Gavin was very able and not really in the same category as the other tenants in the hostel. Although age and delicate health meant he did not think that Gavin would move on from Key housing, he hoped that Gavin would have the opportunity to become more independent and participate in a greater number of ordinary local activities.

Anita's staff member also regarded her as very 'capable', the most 'able' tenant in the hostel. He did not think there was any way in which he could identify Anita as a 'handicapped' individual:

> I couldn't honestly say that that woman is clinically handicapped. I find it hard to see a reason for Anita being here. There's been nothing really we've had to do. There's been no need for us to put input into Anita. Okay the pot incident. I don't think that's going to stop

> Anita doing much with her life - leaving a pot dirty. I don't see any reason for Anita to be labelled mentally handicapped.

He added that it was only at 'a deep level of conversation' that you would realise that she 'was functioning at a slightly lower level than other people'. Indeed, he felt that many people who were probably less able than Anita had 'never been identified as handicapped'. Consequently they did not face the problems of stigma: 'they're quite accepted in society and they get on fine'.

He considered that Anita regarded herself as superior to others in the hostel and identified with staff. Because she saw herself as being on a par with the staff members, she did not like being given any instruction:

> She gets angry with staff if she's pulled up for anything. You can see it in her face - What right have you to tell me, you're showing me up in front of the rest of them. You're making me out to be the same as them. I'm the same as you, how dare you pull me up.

He also thought that Anita was acutely aware of the stigma associated with services for people with a mental handicap and so wished to dissociate herself from group activities. He claimed that she avoided those with an apparent handicap such as a man with Down's syndrome who lived there.

Because he did not regard Anita as handicapped he thought it inappropriate that she lived in a Key housing hostel and attended an ATC.

He felt that a job would add much more purpose to her life. However, he clearly saw Anita as using the hostel as a means to an end:

> As far as I'm concerned she is a member of mainstream society. She only stays here 'cos she's got to...For her, this is a game. To be independent she's got to go through this system.

There was an acknowledgement that being labelled, spending time in hospital and being seen as a 'handicapped' person by her parents would have had a profound influence on her self-concept. Furthermore he said that people with a mental handicap had few opportunities to meet non-handicapped others and were rarely accepted as friends. Thus, although he saw her as resenting the stigma associated with services for people with a mental handicap, and felt she was too able to be classed as 'handicapped', he considered that it was not easy to break out of the 'handicapped' circle of which she had become a part.

ii) <u>Personality problems</u>

Another three staff members thought that their participants' problems mainly stemmed from their personalities. Lisa's staff member stated that:

> Her mental handicap isn't that much of a problem at all, it's her personality and her attitudes.

She was very critical of Lisa as a person, describing her as 'manipulative', 'sneaky', and 'most of all she's lazy'. However, the staff member later suggested that Lisa's annoying characteristics might have been caused by the sheltered life she had led at home, being treated like a child and never doing anything for herself. In addition, she thought the problems were amplified by Lisa's 'sheer lack of self-confidence'. This was so bad that she took no interest in her personal appearance or hygiene, would not look at herself in the mirror and would gaze skywards rather than make eye to eye contact with anyone. The staff member thought this started when she had worked in a laundry. During this time she had experienced a lot of abuse from the people that she worked with.

Despite her lack of confidence, the staff member did not think that Lisa saw herself as a 'handicapped' individual. For example, Lisa would not get a 'disabled' bus pass even though it would have meant a tremendous saving on her limited income. Her awareness of stigma meant that she did not like going to the ATC but enjoyed the college because she felt it was more adult 'and a normal thing to do'. Lisa described herself as 'slow' and not mentally handicapped. The staff member felt that Lisa was aware of the relative opportunities of her non-handicapped peers and jealous of her sister and what she had achieved. While the staff member sympathised with Lisa, she felt that for pragmatic reasons Lisa would be better served swallowing her pride and accepting her travel pass.

Lisa's staff member was fairly consistent in stating that her 'handicap' was not her problem. However, she discussed Lisa's friendships with other tenants as though she had different characteristics and therefore needs from non-handicapped people in this sphere of her life. This gave the impression that, while she viewed Lisa as too able to describe as 'handicapped', she did not necessarily regard other people with notable handicaps as <u>essentially the same</u>.

Mary's staff member adopted a very similar perspective to Lisa's. While she did feel that Mary had a disability and needed help with particular self-help skills, she did not feel that Mary's problems arose from her disability, rather, they were a consequence of her personality:

> She's just got problems, I don't see her as very handicapped. She's just got different problem areas and maybe her handicap causes her to behave in certain ways. It must be something but I don't see her as awful handicapped. I just see her as having behaviour problems more than anything else.

Anne's was the final staff member in this group. She hoped that in the future Anne would lead as 'normal a life as possible' including getting married. At present, though, she found Anne 'immature' in her outlook. As a consequence she felt Anne was rather unwilling to learn the necessary skills and accept the responsibilities that were associated with 'independence'. Anne tended to gloss over deficiencies with particular skills or emotional difficulties. For example, rather than attempting to come to terms with being rejected by her parents she preferred to deny there was a problem.

At the bottom line the staff member did feel that Anne had 'the skills you need for this world'. It was just that she had 'a lot of growing up to do'. Anne did not regard herself as globally handicapped but merely felt that she had difficulties with particular skills. The staff member felt that by leaving her family home of her own volition, she had demonstrated her belief that she was not willing to accept being treated as a globally handicapped person. At the same time she was apparently quite happy to have her picture in the paper as part of the ATC's sports team.

iii) Socialised as handicapped

The final two members of staff viewed their participants as being very able but suffering from having been brought up as handicapped and having internalised a 'handicapped' outlook on life. For example, Helen's member of staff saw her as someone with a 'learning difficulty' who was 'intelligent' and capable of meeting the 'challenge' of open employment and independence. However, she thought Helen had been desperately overprotected at home by her mother, even sleeping in the same room as her. This had made her a very passive person. Consequently she required prompting from staff with respect to personal hygiene and domestic chores. She felt Helen was still greatly influenced by her mother who regarded her as a globally handicapped individual.

The staff member indicated that Helen was very aware of her handicap and the stigma surrounding such a status. Helen had told her how as a young person she used to think of herself as a worthless individual:

> She used to say when she was young she was hopeless and nobody wanted her. She used to cry herself to sleep and wonder why she was born and nobody wanted her, she was no good for anything and why didn't she have any friends.

The final staff member thought Susan, who was married, was quite a mature individual who regarded herself very much as a woman and not in any way as 'a wee girl' despite coming from an extremely shelterered home background. Susan's ambition in life was to be a 'housewife'. Moreover, she reckoned that Susan and her husband neither wanted nor required much help or support from the staff and that a good neighbour or someone who would help her and her husband with the bills was sufficient.

The one problem which the staff member felt had resulted from her sheltered background was Susan's very narrow view of what it meant to be a 'housewife'. Consequently Susan quite literally stayed at home and looked after her husband when he got back from the ATC. The member of staff felt that Susan could enjoy more of a social life and widen her experience of the world.

3. Hospital group.

A) Participants' self-concepts.

Essentially different. There were only two participants who accepted a stigmatised identity or saw themselves as different from people living 'outside' the hospital. One of these participants, Ken, did not seem to be particularly aware of the stigma associated with the hospital. He simply saw people living outside the hospital as different from people living in the hospital. For instance, he thought that people outside could get jobs, not simply because they were 'outside', but because they were a different kind of person.

The second person, Peter, was a 55-year old man who had lived in hospital since his childhood. He wished to make a new life for himself, to get to know and become accepted by people 'outside' with whom he could go to the pub and talk to and go to new places and on holiday with. However, he was placed in a nursing home for old people with a number of ex-residents from the hospital. This was in a small picturesque town which was a tourist attraction for a nearby city. Peter spent his time walking round the town, feeding the ducks in the park and going into a particular pub where his efforts to make friends had been unsuccessful. Peter felt that the staff at the nursing home gave priority to the elderly non-handicapped people and the only time that he reported getting attention from the staff members was when he was ill. The whole purpose of Peter's life in the community was to make friends and his failure to do so filled him with self-doubt and a belief that he could not escape from his past. Consequently he did not feel equal to people from 'outside' and thought that he would remain a 'patient' until he was able to overcome or escape from his stigmatised identity. As he explained, he would not be able to fulfil his aspirations until he could become an 'outsider':

> Well, I don't mind being called a patient but I'd like to be an outsider for a change, you ken. I'm still a patient here, but I wouldnae mind being outside and being called an 'outsider' for a change, instead of a patient. But if you're somebody like 'outsider', you'd be whatever you'd want to do...likes of gardening.

Essentially the same. The nature of the views expressed by these participants, who saw themselves as essentially the same as people outside the hospital, could be brocken down into six further groups as follows: i) Six believed that they had been wrongly placed in the hospital; ii) three thought that they had outgrown the hospital; iii) four adopted a minority group approach and rejected the stigma ascribed to all people living in mental handicap hospitals; iv) one participant expressed views which fell into all three of the above mentioned sub-categories; v) another's views came into both the first and second sub-categories; vi) the remaining participant came into the first and third sub-categories.

i) Wrongly placed

Six of the participants felt that they had been wrongly placed or simply did not feel that they belonged in the hospital. They believed that their high level of competence set them apart from the rest. Hugh had lived in the hospital since childhood. He had recently moved out to a Key housing hostel and felt that he belonged 'outside' and not in the hospital. He talked in a pitying fashion about those less able than himself and his underlying attitude was one of superiority. Hugh believed that only others who could display the necessary ability and behaviour would be able to live 'outside'.

Being 'picked' for independent living had enabled Hugh to 'prove' his worth and that he was not a hospital patient:

> There was nothing wrong with me. But the staff and the doctor thought I was a bit of a nutcase, that I couldnae look after myself. But I proved them wrong. I am happy the way I am, doing everything.

At the same time Hugh did not deny that he had difficulties with particular skills including reading or writing and that he required assistance with bills. However, he did not believe these deficiencies had 'handicapped' him. Rather he felt that it was living in the hospital that had curtailed his own 'rights' and 'freedoms'. Hugh said that he had always known what these were and had never let the staff gain the upper hand. Therefore, he claimed that in recent memory he had never doubted his 'right' to live outside and to lead a more ordinary lifestyle. In other words he considered it was living in the hospital that had made him <u>essentially different</u>.

Other participants in this group differed from Hugh in that they felt more tainted by the stigma associated with the hospital. They did not talk with pity about those more handicapped than themselves but were resentful about being associated with them. Perhaps the person who took the most extreme position was Andy, who had been admitted to the hospital under a legal section. He was a very talented footballer and felt that a promising career had been wasted because no club would want someone who had been in a hospital for people with a mental handicap. He went on to explain that when he moved out of the hospital he would not want to have contact with other 'boys' from there.

> You dinnae want the boys coming down your house. I dinnae anyway...What happens if you've got visitors, or my mum and dad's come through...I just wouldnae let any hospital boys come down to my house...I want normal boys. They're no normal in here.

He did not want to move out straight away, but remain in the rehabilitation unit until he found something that suited his purposes. Andy felt the hospital had had a devastating effect on his life and that he would have to take his next steps carefully.

Like others in this group he quoted a professional who had told him he should never have been sent to the hospital. He reported what the doctor had told him:

> She knew I should never have been in Villa 5. You should have seen some of the boys...'cause the boys in there, they're all stupid, their minds away, right. They'll be there the rest of their days, 'til they kick the bucket.

Thus, these participants felt that living outside the hospital would allow them more 'freedom' to develop their lives. Moreover, a number of participants expressed the view that they would be able to use the opportunities afforded in the outside world to present a new image of themselves, or to become different persons.

ii) Outgrown the hospital

Three participants who considered that they had been hospitalised for justifiable reasons thought they had reached a stage where they had outgrown it. They therefore felt they had left the hospital to enjoy the fruits of life 'outside' to which they were entitled.

Iain had a lifelong history of institutionalisation and thought he had been sent to the hospital because he 'never got on very good outside'. He later explained that he had got into trouble and could not look after himself. Now that he was able to look after himself he saw no reason why he should not live outside the hospital. As he explained:

> I got fed up with the hospital. I didn't like it at all.
> I got fed up with the same things all the time.

It was not just that he had been in the hospital too long, but he also aspired to a new life, 'I like to get a lot of freedom outside and meet lots of friends outside'. He talked about his problems with literacy but did not seem to think that his difficulties should set him apart from non-handicapped others. Indeed, while he did not think the most handicapped people would get a chance to live outside the hospital, he saw no reason why anyone living there should be regarded as different from those living outside. Therefore, he did not want to differentiate himself from other hospital residents and said that he liked 'all the boys' from there. What he did want to dissociate himself from was the hospital. He said that he would not tell people that he'd lived there, 'because they can talk about you'. Furthermore, he did not want to live in the vicinity because 'it's near the hospital...no way'. He was therefore aware of the stigma attached to the hospital and wanted to leave, not just because he had been there for too long but because he wanted to lead a new life.

Although the other two participants in this group displayed little awareness of the stigma associated with the hospital they shared the aspiration of Iain to develop new lives. As another man in this group, Grant, said of his new status as 'resident' in a hostel:

> It's residents no patients...Because I'm big, I'm no a patient...That's wee boys, patients...I'm a grown man now...I'm no a child anymore.

iii) Minority group

Four participants adopted a minority group approach. Like that Family group, they displayed a united front as a minority group might do in the face of prejudice or oppression. Even those who did feel that they had difficulties with reading and writing considered that they were essentially the same as people living outside the hospital. As Mark who had moved to the hospital from an orphanage explained:

> There's a lot of things I'm no very good at. I guarantee everybody that works here, and all over, they all got things they're not very good at doing, everyone.

Mark did not think he had been placed in the hospital because he was different from those 'outside'. Rather, he thought that it was living in the hospital that made him essentially different. This was because he had been segregated from people outside the hospital and had consequently been regarded as a 'patient' in a mental handicap hospital. Moreover, he felt that the hospital regime in which he had lived treated people as though they were less than human. Although he was living in the rehabilitation unit at the time of the interview he still felt that this was part of the same system and desperately wished to leave.

While he was aware that he was more able than most other people in the hospital or was 'high-grade', he felt everyone would gain from living outside the hospital, including the least able. He rejected the 'high grade/low grade' categorisation because it was based on the premise that one group was superior to another:

> We're all classed as residents anyway, we're all made the same. There's nobody better than anybody else, not in this hospital. Nobody gets put in a hospital for nothing. We're all here for something. We're all classed the same. There's no patient better then another not in this hospital.

Mark went on to describe his feelings about being called a patient :

> A lot of bullshit. I dinnae ken who thought of that...I don't like it. We werenae classed as patients in the orphanage, just ordinary human beings same as anybody else.

Bill, Mark's best friend, who was also in the rehabilitation unit, echoed his comments:

> Well when I came in here at first, I didn't ken I was called a patient. I was always wondering what a patient was at all. I know now, I'm patient. I thought patients were in a hospital lying in bed. I mean I never kenned of a place called xxxxxxx. In this hospital you're classed as patients, residents, high-grades, low-grades and all this. I never kenned I was a patient. I thought how was you to get treated just the same as anybody else outside. It should all be stopped - classed as patients...we're no dogs or animals or that. We're just the same as anybody else. They should stop all this.

Thus these participants displayed a strong sense of injustice at their status as hospital residents. Like some Family participants, they realised that to set themselves apart from people more handicapped than themselves would make them guilty of stigmatising others.

iv) Wrongly placed, outgrown the hospital and minority group views

One participant, Bill, expressed views that could be considered to fall into all three sub-categories outlined above. He had recently moved out into a hospital group home.

Bill gave a number of different reasons why he had been admitted to the hospital, including epilepsy, a nervous breakdown and to cure him of his drink problem. His final explanation that he had come through the courts was correct. He had arrived at the hospital via a prison due to drink-related crimes. Bill explained how he had had preferred to serve his time in hospital rather than prison. Thus, he believed he had been sent to hospital for a reason and as soon as he had overcome his drink problem he should have left.

At other times, though, he felt that his placement in the hospital was wrong because he did not have a disability. He claimed that he could have taught the staff 'a thing or two' in terms of self-help skills. He was very concerned to reject any connection that he had with the hospital or any of the other residents. Bill simply felt he should not have been there because he did not have a disability and strongly asserted he was more 'advanced' than the 'low-grades'. He considered he was on a par with the staff and sympathised with the problems they experienced dealing with less able residents.

Finally, Bill could not help identifying with the experience of other hospital residents. He objected to the attitudes that people 'outside' held about residents and also discussed how he had avoided becoming institutionalised during his stay in the hospital. He felt that others suffered the same plight:

> I think there's far too many people in these hospitals that shouldnae be in them...They're kept in that long they've reached the stage that they're that institutionalised...they might not want to go, they might just want to stay in the hospital until they die...I think it's terrible, the length of time they've kept them in the hospital

These different points of view do not necessarily denote an inner conflict in Bill's identity. Rather, they indicate that he had regarded himself as one of the 'advanced' residents in the hospital, but that any feelings of sympathy or solidarity with fellow residents were swamped by his wish to make a new life for himself. He wished to bury his past, his drink-related crimes as much as his stay in the hospital. As Bill explained:

> When I left there, I left all that behind me. That's the way I felt. I said to myself, when I leave the hospital, I'll forget about the hospital. I don't even tell people I've been there. If you start telling people, they'll start telling everybody else and all of them will start making a fool of you.

v) Wrongly placed and outgrown the hospital views

Agnes' views came into the first and second sub-categories. She had first been admitted to hospital due to an emotional breakdown. However, her feeling was not only that she had spent too long in the hospital but that it had ruined her life. She considered herself to be superior to residents with more severe handicaps and deeply resented being subject to the same 'bairn-like' treatment. She desperately wanted to leave the hospital and be an 'outsider'. Although she disliked the way hospital residents were regarded by those 'outside', she said that she could not imagine having a long-term relationship with her present boyfriend because he was an ex-hospital resident. She may have gone to hospital for a purpose, but she felt that her life had stopped in the meantime; and she expressed her wish to leave the hospital in the following terms:

> I'm not wanting to miss my life - like I don't want to miss the world. I want to get my freedom, my age you know.

vi) Wrongly placed and minority group views

Frank's views came into the first and third category. He had recently left the hospital and not only wished to achieve acceptance as an 'outsider' but also wished to obtain the benefits which were due to a handicapped person. Therefore, he balanced his rejection of stigma and a 'handicapped' identity with concern for the rights of 'handicapped' individuals. In practice this meant he argued that his difficulties with literacy and numeracy did not justify his hospitalisation. However, he went to great efforts to obtain a bus pass for persons with a handicap, which provided free travel in a nearby Scottish city.

There was no reason to disbelieve Frank's deeply held belief that he should not have been sent to a hospital. As he was living in a Salvation Army hostel at the time, he desperately needed some means of travelling to the libraries and museums in which he passed his days.

Discussion

This discussion will examine a number of factors which appear to have influenced the development of the participants' self-concepts. It will start by considering the relation between the participants' self-concepts and the attitudes of the mothers and staff, before going on to deal with emotion and experience. Finally, it shall examine the belief expressed by a number of participants that they had the potential to lead a more ordinary life.

Relation between participants' self-concepts and the mothers' and staff perspectives.

There was a significant tendency for the mothers in the Family group to view the participants as essentially different from non-handicapped people, while the majority of participants saw themselves as essentially the same. However, all the participants in the Family and Key groups who saw themselves as essentially different from non-handicapped people were seen as such by their mothers. For example, Joan embraced a child-like view of herself which characterised her mother's attitude towards her. Joan may have done this because the rewards associated with being treated as a 'special' person at home outweighed the negative aspects of the stigma. Consequently, it is likely that Joan wanted to maintain this cosseted home life, while her mother pointed to childish aspects of Joan's behaviour as reasons for treating her as such. In contrast, Sarah found her handicapped identity a source of pain. It meant that she could not enjoy the same lifestyle and opportunities she saw others were having. Her mother explained that she had had to make this clear to Sarah when she was a child. Thus there was evidence that the mothers' perceptions of their offsprings as being essentially different influenced their self-concepts, but not in the same ways.

There were also parallels between the self-concepts of a number of participants who saw themselves as essentially the same and the views of mothers who saw them in this light. In the Family group Clare and Lorna's mothers shared their daughters' heartfelt wish to lead a more ordinary life. While they realised that their daughters did have particular intellectual difficulties, they deeply resented the discrimination they faced in terms of employment and making friends with non-handicapped peers. In the Key group Lisa's mother said that she had shared her daughter's 'hurt' at being set apart from non-handicapped others, and being treated as though she were incapable. Her mother, and Lisa herself, described how such treatment led to her loss of self-confidence. It was clear that Lisa's mother had at no time consciously undermined Lisa's belief that she was essentially the same as non-handicapped others. She wanted her daughter to have the opportunity to lead a life more appropriate for someone of her age group. Hence, she was saddened that Lisa had not had the opportunity to get married. These cases suggest that the mothers' perspectives could be supportive of the participants' views of themselves as essentially the same.

It should not be imagined that the influence was always one way or from the mothers to the participants self-concepts. There was evidence from the Key group that the participants were also able to influence their mothers' perceptions of them. Anita's mother explained how her attitude towards her daughter had been radically altered when Anita changed from passively accepting her protective home background to actively seeking greater independence. This happened when she started attending an ATC where she met other people who were living more independently. Thus, while Anita had apparently been jealous of her sister leaving home to get married, it was not until she saw people in a similar position to herself making this transition that she was galvanised into action. Along with this change, Anita was seeking a considerable shift in her relationship with her mother. However, when her mother gave Anita the kind of freedom that she wanted and let her travel on her own, taught her to do some cooking and so forth, she discovered Anita had abilities which she had never suspected. Thus, through Anita's own efforts her mother came to foster the development of Anita's independence as something positive and helped her to achieve her ambition.

There were also mothers in both the Family and Key groups who had had great difficulty with their sons or daughters as children or who had been given a negative prognosis from professionals about their future potential. In many senses these childen, as they had grown up, had had to prove to their mothers their potential as human beings and that they deserved respect as individuals. One such case was Susan's mother who described her feelings of despondency when she first became aware of Susan's disability. Although she never came to regard Susan as <u>essentially the same</u> as non-handicapped others, she grew in some repects dependent upon Susan, describing it as 'a death in the family' when Susan left home and got married.

There were many instances where the staff showed considerable insight into the participants' feelings. However, the staff views were not as clearly related to the participants' self-concepts as the mothers'. Quite apart from the fact that the staff members' relationships with the participants were not of the same intensity as familial relationships, their views of the participants stemmed from a professional perspective as well as from their feelings about the individuals concerned. For example, there were ATC staff who saw participants as too able to be considered <u>essentially different</u> from non-handicapped people. Their emphasis on relative ability reflected their professional concern as instructors. Therefore they were not so much considering the individual's right or desire to be treated on a par with non-handicapped others as whether his or her behaviour or abilities came up to standard within particular domains. Many of the Key staff also tended to view the people in their charge within the framework of their somewhat limited professional objectives. The focus of their concern was with the participants' need to acquire the necessary skills and maturity for living independently.

Probably the most interesting participants were those in the Family group who were regarded by both mothers and staff as <u>essentially different</u> and yet still saw themselves as <u>essentially the same</u>. For example, Karen's mother thought that she lived in a 'wee world of her own' and was still child-like. She thought that the furthest Karen could think ahead was her next meal. However, in the interview Karen talked about getting a flat of her own, having a job, and her tremendous yearning to have a child. Her mother's belief that the hours Karen spent playing with a doll in her bedroom were purely childish (Karen did not admit to this herself) might be reinterpreted in light of this information.

How could Karen's views come to be so radically different from her mother's? One explanation could be that they were locked into a relationship of such closeness that her mother could not see her daughter in relative terms except as a 'handicapped' girl who who would never grow up. Hence she maintained her firmly held beliefs about Karen and other people with a mental handicap. Another consequence of such a close relationship might have been an unwillingness on Karen's part to challenge her mother or make her views apparent. Indeed in the interview Karen was loathe to criticise her home background. This was despite the fact that she desperately wanted to have a relationship, but knew that her mother would not tolerate her having a boyfriend.

Experience and the development of self-concept

The last section ended by speculating that the closeness of the relationship between Karen and her mother could have been what allowed her mother to hold a radically different perspective from Karen's self-concept. However, if Karen was seen by her mother as a 'handicapped' person and Karen had so little experience of the wider world, how did she come to see herself as essentially the same as non-handicapped others in the first place? One explanation could be that despite being largely set apart from other non-handicapped people, she was still socialised into the same world. Hence, she knew about the opportunities, such as marriage and employment, that are usually open to others. Although being aware that she had a disability, she need not necessarily have accepted that she should hold a fundamentally different position in society to others. Therefore, her lack of experience may not necessarily have led to her internalising the views of her mother. However, it may have been responsible for her passive acceptance of her situation. It would have been very difficult for Karen to challenge the attitudes of her mother without having firm ideas about what she wanted to change about her life and the knowledge of how she could achieve such change.

John and Mike both of whom had Down's Syndrome, were two other Family participants who saw themselves as essentially the same despite being seen as essentially different from non-handicapped others by their mothers and staff. Unlike Karen, their mothers had great personal respect for them and only regarded them as handicapped in a wider social context. Indeed, in both cases their fathers were dead, and their mothers acknowledged that they were in many respects dependent upon their sons for company and help round the house. This produced a crucial difference in the participants' acceptance of their home situations. While John and Mike recognised that they had differences of opinions on many issues with their mothers, they also realised that they had been given a position of respect in the household and felt needed. Their relationships with their mothers were a central part of their existence. In the longer term John and Mike wanted to share a house with each other. They therefore did have insight into their social situation and in certain respects had made a deliberate choice to continue the same lifestyle.

Once again the question arises, how did these two men with Down's syndrome, whose limited lives outwith their families had consisted largely of specialist services for people with a mental handicap and social events organised for people with a mental handicap, manage to retain a firm belief that they were essentially the same as non-handicapped others? The answer would appear to lie in the participants' awareness of their position in the wider social world. Through such an insight they were not tied to the views of their mothers nor moulded by 'handicapped' treatment. Instead they were able to differentiate between their disability and the discrimination and prejudice associated with handicap. They were quite happy to admit to having particular difficulties or being 'slower' than non-handicapped others, but they did not accept that they deserved to be treated as 'handicapped' as people. The religious beliefs of these two participants also played an important part in helping them to maintain the view that they deserved to be treated on a par with non-handicapped people.

So far, in this section, we have considered how the participants were able to reject a 'handicapped' identity despite a lack of social experience and autonomy. But it appeared that experience or knowledge of independent living was one important factor that led some Key participants to seek a more ordinary life. For example Anita, another Key participant had apparently passively accepted her quiet home life with her mother until she started attending the ATC and met people who were living independently. In the same fashion, Anne had made the move to live independently against the wishes of her parents, after building up social links with tenants at the Key hostel to which she later applied. She had also had the opportunity to talk at length with staff who worked there. Thus, it was the knowledge of how to achieve greater independence and the realisation that other people in a similar situation had made the move that prompted the participants into action. If participants like Karen in the Family group also obtained knowledge of the means to gain greater independence, then their aspirations could boil over into frustration and cause considerable friction at home. Indeed there were participants who expressed frustration with their home situation. However, living in an over-protective and sometimes claustrophobic home situation was often balanced by the participants' loyalty to their parents, with whom they had a loving and mutually dependent relationship.

The hospital participants were also able to reject the role of patient despite being relatively cut off from the 'outside' world. It has been suggested that this was achieved through a residents' hospital sub-culture. However, this counter-culture was not merely a rejection of unfair or dehumanising practices in the rather isolated world of the hospital. Instead, the participants often had quite a sophisticated view of the hospital and the effect which it had on their lives. In other words they were aware of the position of the hospital in the wider social, world and how hospital practices differed from what one would expect to find in the 'outside' world. Like those in the Family group, who accepted home situations which were rather unsatisfying, the hospital participants generally passively accepted their situation because they were not sure of alternative residential settings in the community, or because they were powerless to achieve change in their lives. However, in anticipation of leaving the hospital, some participants talked about not wishing to be associated with the hospital any more and how they might avoid other ex-residents, even if they were friends. Unlike the Family and Key participants' ties to their family home, those in the hospital did not have close personal relationships which bonded them to the hospital. But like the Family and Key participants they were not able to actively seek change unless they had the knowledge of how to do so.

Emotions and the development of self-concept

The discussion so far has explained that the participants' self-concepts did not simply reflect how they were seen by significant others, or influenced by the 'patient' role imposed on those in hospital. It has been suggested that it was the participants' awareness of their own deprived position in the wider social world which emancipated their self-concepts from the views of significant others. However, this was not just a cognitive process. There must surely have been some motivation for people to continue to see themselves as essentially the same when they were assigned an essentially different position in society. Yet for most such an outlook did not bring any obvious rewards, nor was it often sucessful in changing other people's views of themselves. To see one's self as essentially the same, when seen by others as essentially different, has little obvious purpose.

The reason for the participants' rejecting a stigmatised identity becomes clearer when one takes into account that they did not merely express cognitions but a rich blend of ideas and feelings. It is impossible and inappropriate to attempt to separate these elements. Emotions were expressed as much by how people put across their views as in what they said. For example, Gavin described how he asserted his personhood despite the skepticism of others. He made it clear that it was the hurt and feelings of degradation that made him wish to emphasise to others that he was as good as anyone else. At one point he told of an instance where he wished to pay his own way in a snooker club after playing with a non-handicapped friend called John. Although a very long quote and missing the tremendous well of emotion evident in his expression, it is worth repeating in full what he said:

> After the game [of snooker] I went up to John [and said], 'I'm ready to pay'. [John replied] 'Alright, I've payed it.' I says, 'who's payed it?', kind of crabbit, I was kind of cheeky because of that. John says, 'I payed it'. I says, 'I telt you I was going to pay', I says, 'I've got the money for it John boy, don't put me down'. I says, 'I'm not a wee boy now, I'm a man now, I've got the money, I want to be independent, to pay for myself'. He

> says, 'that's alright Gavin, I'll tell yo what we'll do, I payed for it the night, you and I are going to play tomorrow night'.
>
> I says to him, 'I'm coming along tomorrow night and we're going to play and I'm going to pay the table for the two of us'. He said, 'Ah, but I don't pay when I'm going to play'. I says, 'it doesnae matter I'm going to pay it'. He says, 'well that's alright then, you want to pay it, be independent Gavin, I'm just trying to help you out'. I says, 'I know you were trying to help me out'. I says, 'I've had that nearly all my life John'. He says, 'what?'. I says, 'folk trying to put me down all the time and I didnae like it'. He says, 'why?'. I says, 'because everyone's trying to put me down and I want to do things for myself, I want to be independent, I'm sure you do!'

The importance of this quote is that it demonstrates that people like Gavin had great insight into their relative social position. Just because they were brought up and treated like 'handicapped' people did not make them any the less socially sensitive. It did not dull the pain of being rejected by non-handicapped others or of being denied opportunities such as going out like their non-handicapped siblings or of being treated in a child-like way. Thus, a wider social awareness may tell us how the participants <u>could</u> reject a 'handicapped' identity. In addition to this, feelings such as those expressed by Gavin may tell us <u>why</u> the participants rejected a 'handicapped' identity. People are not only socialised to have an understanding of the workings of the society but also to have the accompanying desire to be a self-respecting member of such a society.

Belief in potential to achieve a more ordinary lifestyle.

It was perhaps understandable that part of the participants' desire to achieve a more ordinary status in society should include the aspiration to break out of their marginal social status. Among other things this included obtaining greater autonomy, making more non-handicapped friends, widening their social horizons and obtaining employment. This was one of the main differences between those who saw themselves as essentially the same and those who saw themselves as essentially different from non-handicapped others. Many of those who saw themselves as essentially the same felt they could lead a more ordinary life if they were given the opportunities. In contrast, the participants who saw themselves as essentially different felt that they could not lead a more ordinary life even if they wanted to.

There were also differences across the three groups concerning the participants' feelings on this subject. These differences can be seen to be reflected in their different living circumstances. Family group participants felt that much of the proof of their right to be treated as essentially the same as non-handicapped others lay in their potential to lead a more ordinary life if they were given the opportunity to do so. The Key group had made the transition towards a more independent lifestyle. Hence, many of them pointed to their sucess in moving to Key housing as evidence that they had never deserved to be treated as though they were essentially different from non-handicapped others.

Those who were still in the hospital also emphasised their potential to lead a more ordinary life. A number of them cited the opinions of doctors as evidence that they should be living 'outside'.

Participants who had moved on to live more independently were able to point to their success as evidence that they should never have been in a hospital in the first place. A number of participants in this group felt that moving outside did not merely afford them a different lifestyle but, in a sense, also gave them the opportunity to be a different kind of person. In so far as they were no longer expected to conform to the role of a patient there was some justification in the belief that they were able to adopt a new persona.

There was a basic difference between the attitude of the Hospital group in contrast to the Family and Key groups' views about leading a more ordinary life. This was regarded as an important step forward for those living at home or who had moved to Key. However, the hospital participants saw living in the hospital as the cause of their being set apart from non-handicapped others and given the status of hospital patients. Thus, moving out of the hospital was not just a positive move forward, it meant getting their 'freedom'. The fact that these sentiments were expressed by the majority of the hospital participants adds further support to the view that a hospital sub-culture, rejecting the institutional system, helped prevent the participants from internalising the 'patient' role.

CHAPTER 7

Social life and social networks

This chapter will start by describing the methods used in this longitudinal study of the social lives and networks in a sub-sample of the Family, Key and Hospital paticipants. It will then present analysis of the data. The analysis deals first with the change in the pattern of activities which took place over the course of the study, and secondly with the development of participants' social networks over this period of time.

Whatever theory of the self one subscribes to, people's views of the self are concerned with defining themselves in relation to others in the society in which they live. Therefore, their self-concepts are likely to be influenced by their experience of the social world in which they live and by the particular individuals with whom they have greatest contact. These data are important because they show the extent of the participants' experience of the wider social world and the nature of their social networks.

Sample, Interviews and Procedures.

Longitudinal data were gathered for a sub-sample of 25 participants from the Family, Key and Hospital groups who had met the selection criteria outlined in part one of the methods section in Chapter 4. The 7 participants from the Key group were those who moved from their family homes to live in one of four Key Housing Association hostels between

September 1985 to December 1985. Circumstances surrounding the move of the remaining three participants who took part in the stigma and self-concept studies made it impossible to interview them immediately after they had gone to live in Key housing. Similarly, the eight Hospital participants were those who moved from wards to the rehabilitation unit in the Hospital between May and June of 1985. The 10 participants from the Family group were randomly selected from the Family sample using a table of random numbers. These participants were interviewed on two occasions, with the second set of interviews taking place 8-9 months after the first. Socio-demographic details of the members of these three groups are given in Table 19. With the permission of all the people listed in Table 19, thirty three members of staff who worked most closely with them and 12 mothers were included in the study.

The social life and network interviews lasted approximately 20-30 minutes and were spent systematially questioning the participants on the following issues: i) the activities in which the participant engaged, ii) how the participant spent his or her time at home or in the hospital ward, iii) with whom the participant socialised and how often (for details of the interviews see chapter 4). The same issues were covered in interviews with staff and mothers, with the purpose of building up a more comprehensive picture of the participants' social lives and networks. For each participant we therefore had two pairs of <u>before</u> and <u>after</u> interviews, one pair with the participant him- or herself, and one with his or her mother or a staff member intimate with the participant's social life.

The first set of interviews with the Hospital group was carried out in the week before or after they moved from the hospital ward into the

Table 19. Socio-demographic characteristics of the social life participants.

Characteristic	Family group	Key group	Hospital group
Number	10	7	8
Age range	23-40	20-40	20-55
Mean Age	27	30	34
Sex	4 males 6 females	1 male 6 females	8 males
Attending ATC	10	6	0
Spent majoriy of life in hospital	0	0	7
Abodes at the begining of study	family home	family home	hospital
Abodes at the end of study	family home	key housing	3 key housing 2 group home 1 local authority hostel 1 private nursing home 1 Ssalvation Army hostel

rehabilitation unit. The interviews were concerned with their social lives and social networks when they were in the hospital ward. The follow-up interviews with them, were carried out in their new abodes (details are shown in Table 19), and were concerned with their social lives there.

The first set of interviews with the Key group took place in the second week after they had moved to the hostel. The interviews were concerned with the participants' social lives and networks when they lived in their family home. The second set of interviews took place in the same hostels and were concerned with their lives there.

The Family group and their staff members were interviewed on two occasions in 1985 at their ATCs, the interviews covering the same issues as for the other two groups. The mothers for both the Family and Key participants were interviewed at home.

Analysis

Transcripts of interviews with the participants, staff and mothers were examined to identify all leisure activities in which each participant was involved. This was achieved as follows: starting with the participant's interview, the researcher carefully perused the transcript. Each activity identified by the researcher was listed on a record sheet together with the following information: with whom the activity was carried out, where it took place, and how often the participant was involved in that activity. Once the participant's interview had been examined, the parent's or staff member's transcript was perused. Only new activities, i.e. those not mentioned in the participant's interview but mentioned by the parent or staff member, were added to the participant's record sheet. Thus, the listing of activities was an additive process building up as complete a picture as possible of the participant's social life and networks. Only activities performed relatively regularly, i.e. more often than once every two weeks, were listed. Three hundred and seventy seven activities were identified in the first sets of interviews and 353 in the second sets. Three independent judges then placed each of these activities in one of the following 4 categories, according to how much potential it was considered to offer the participants for integration:

i) Special activities: activities organized specially for people with a mental handicap, e.g. social club, sporting club, night club or hospital dance.

ii) Ordinary activities: activities offering almost no potential to meet and mix with non-handicapped people outside the circle of family, friends, people in services and clubs for the mentally handicapped, e.g. watching television, playing records, walking in the hospital grounds, interacting with family or friends at home or in hospital.

iii) Semi-integrative activities: activities offering limited contact with non-handicapped people outside the circle of family and family friends, or people in services and clubs for the mentally handicapped, e.g. shopping, having a snack out, visiting a library or museum or going for a walk in town.

iv) Integrative activities: activities holding the potential for interacting with and getting to know non-handicapped people outside services and clubs organised for people with a mental handicap or outside the circle of family and friends, e.g. going to a pub, social club, church, or clubs and societies attended by non-handicapped people.

After completing this process, the three judges met together and reached consensus about the categorisation of each activity.

Each activity was also placed in one of the following 3 groups of categories:

a) with whom it was carried out: alone, with family, staff, a person with a mental handicap, neighbour, a person without a mental handicap.

b) whether it was carried out <u>inside</u> (hospital, home, community residence), or <u>outside</u> (pub, church, club, etc.).

Two independent judges coded all the activities of two randomly selected participants (56 out of the total 730 activities) on the latter 3 dimensions. There was 86 per cent interjudge agreement on the coding concerned with whom the activity was carried out, 95 per cent on where the activity took place and 82 per cent on the frequency with which it was carried out.

<u>Results</u>

<u>Social Life</u>

The changes in the pattern of activities were identified using analysis of variance with repeated measures (before and after interviews).

1. Opportunity for integration.

Figure 3 shows the means for each type of activity, i.e. special, ordinary, semi-integrative and integrative, for the before and after interviews for each of the three groups of participants. The total means of all the activities for the Hospital participants are lower than those for the other two groups, producing main effect for group ($F(2,22) = 3.5$, $p<.04$).

Special activities form a substantial part of all participants' social lives. Most of the Key and Family participants said in both interviews that they attended a club for people with a mental handicap. Many of the participants also went to evening bible classes, and sporting activities for people with a mental handicap. In the hospital, events were organised for residents and therefore the number of special activities reported in the first interview by Hospital participants was much higher than in the second interview.

Inspection of the data in Fig. 3 shows that all three groups reported more ordinary activities than any other type of activity. Ordinary activities included pastimes such as visiting or being visited by friends and relatives, watching TV and videos and listening to tapes. A main effect of group ($F(2,22)=4.38$, $p<.02$) was due to lower group means for ordinary activities of the Hospital participants both in the first and the second interview. Hospital participants, while living in the hospital, did not visit other friends with a mental handicap outside the hospital or meet up with relatives on a regular basis. Instead, the hospital residents went for walks round the grounds and visited friends living in other wards. Results from the second interview showed that the Hospital

Fig. 3 Mean number of social activities with respect to opportunity for integration.

participants continued to have little contact with family and non-handicapped friends. As they were no longer involved in ordinary activities within the hospital grounds, this meant that the mean number of reported activities dropped even further.

The drop in the number of ordinary activities by the Hospital participants was matched by an increase in the number of <u>semi-integrative</u> activities. An increase in the number of semi-integrative activities in the Hospital and Key participants, with the Family group remaining at the same level, resulted in an interaction between group and time of interview, [F(2,22)=20.79, p<.001]. Inspection of the data shows that all 8 Hospital participants and 5 out of the 7 Key participants were involved in more semi-integrative activities after moving from hospital and family homes. This increase in activities resulted from the greater freedom of the Hospital and Key participants to come and go as they pleased and from the increase in involvement in domestic tasks. Thus, a greater number of residents went for walks, shopped, used libraries, ate out or went to cafes.

Although there was no statistically significant rise in the number of <u>integrative activities</u> of the Hospital participants when they moved on, there was a welcome trend in this direction. Living 'outside' appeared to offer the participants more opportunity to engage in integrative activities. However, the number of integrative activities in which all three groups took part, both before and after, was very small. The most frequently reported activities in all three groups were going to the pub, to social clubs such as working men's clubs, night clubs, church and activity courses, or to sporting or skills clubs such as weight-lifting and first-aid courses. Where the participants initiated activities on their own, these often revolved round other social events organised for people with a mental handicap. For instance, with one exception, Family participants who regularly went to a pub with friends did so either before or after a club organised for people with a mental handicap. Thus, the participants had few opportunities to get to know or become known by non-handicapped people.

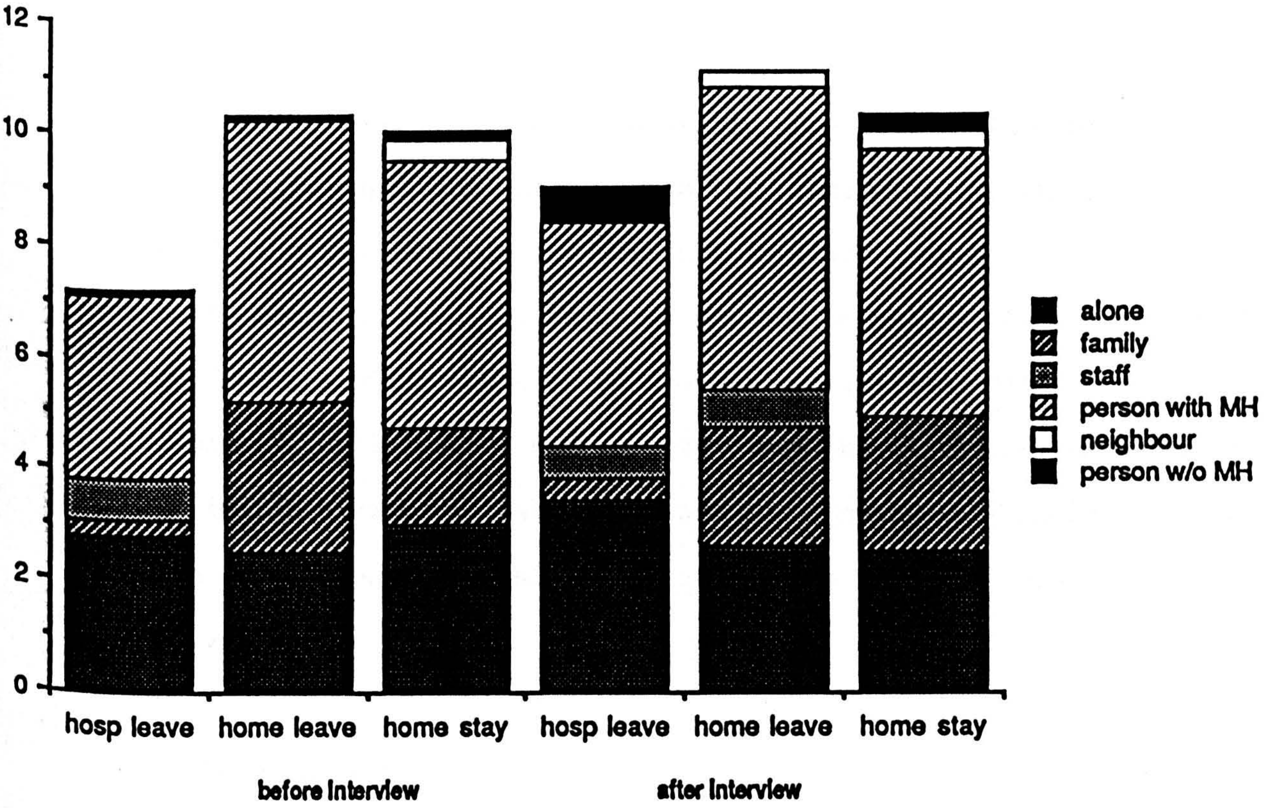
2. Social networks

Figure 4 shows the means for each social network category in the three groups of participants. All three groups of participants reported in both before and after interviews that they were involved in activities mostly with other people with a mental handicap. Five out of the seven Key participants socialised more with other people with a mental handicap when they moved to Key than when they had lived at home. One may reasonably deduce that this happened as a consequence of socialising with other hostel residents.

The family played an important part in the lives of the Family and Key groups. A main effect of group was found [F(2,22)=7.27, p<.004]. This effect was the result of the little, if any, contact that the Hospital participants had had with their families when in the hospital.

Only two participants reported having a non-handicapped friend with whom they had a reciprocal relationship. There were 8 participants who had acquaintances with non-handicapped friends with whom they met with differing frequency. If it was not someone whom the participants met in passing at a club, pub or in the street, it was invariably the participants who initiated the contact or went round to meet the

Fig. 4 Means of activities for social networks.



non-handicapped person. In one instance the participant, who was at Key housing, invited a shop assistant to visit her. The shop assistant came, but the invitation was never reciprocated. Despite the fact that the Hospital and Key participants took part in a greater number of semi-integrative activities when they moved on, they had little success in establishing relationships with non-handicapped people.

There were individual changes in Hospital participants' socialising with staff, depending on the kind of residence to which the individual moved. The Key participants were not involved in regular activities with staff members when living at home, but when they moved into Key Housing they had a similar number of social activities with the staff as the Hospital participants had reported when they lived in the hospital. This may indicate either that there are not enough staff members to socialise with tenants or that staff's priority was to help tenants with domestic activities.

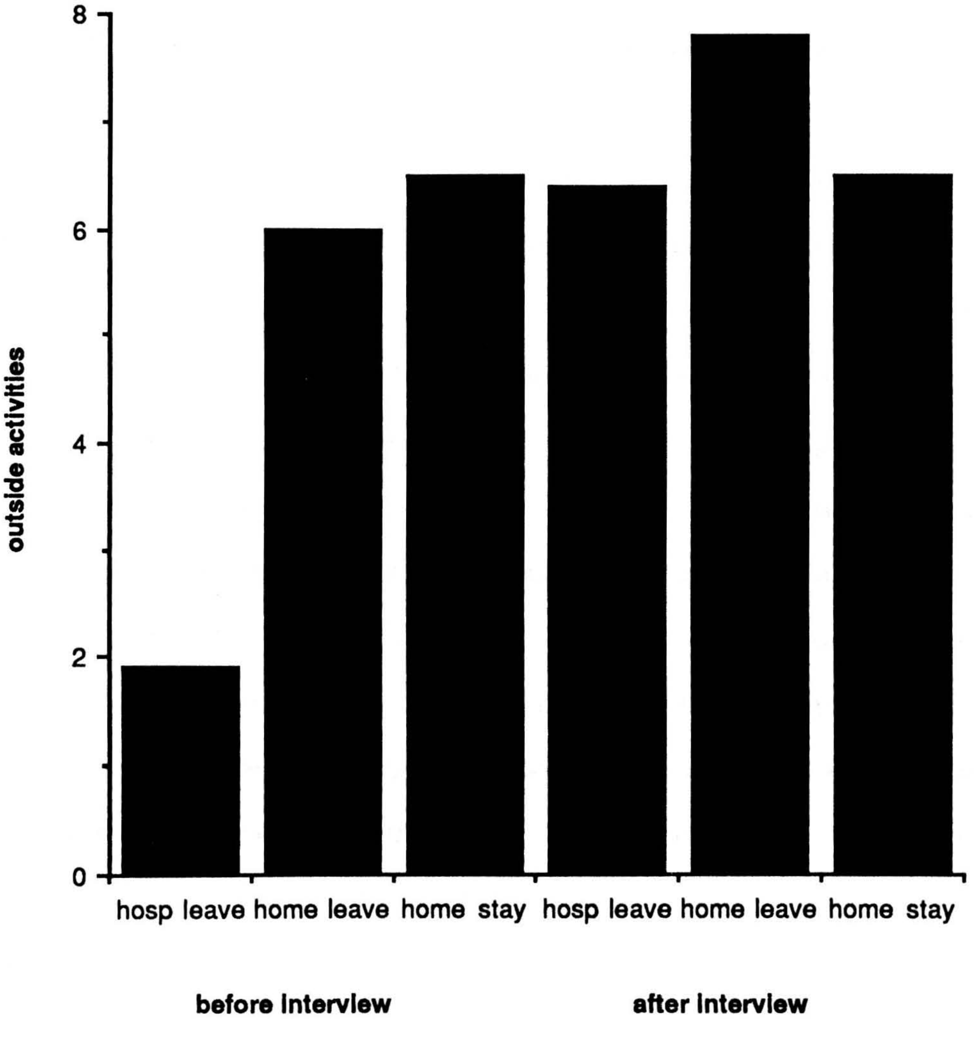
3. Where the activity was carried out.

Figure 5 shows the means of activities carried out inside and outside the place of residence. An interaction between group and time [F(2,22)=6.3, p<.007] was found. It resulted from the rise in the number of outside activities in which the Hospital group were involved when they moved out of the hospital.

Discussion.

The findings of this study clearly show that the move of people with a mental handicap to live more independently in the community does not, as

Fig.5 Mean number of outside activities.



such, promote their integration with non-handicapped people, even though it affords them the opportunity to take part in a greater range of activities. There is no clear link between taking part in more integrative activites and forming friendships with non-handicapped people. In spite of that, it is encouraging to find that people with a mental handicap do take part in more semi-integrating activities when they move from hospital and family homes to live more independently. A great proportion of these activities, however, are a matter of domestic necessity rather than a result of planned changes designed to improve their social lives.

Taken as a whole the results were rather negative. They demonstrated that the social experience of the participants was generally very limited. Those in the hospital were largely cut off from the 'outside' world. The lives of those living in their family homes tended to revolve round activities organised for people with a mental handicap and their families. The same pattern existed for those who had moved from hospital and their family home. The participants socialised almost exclusively with other people with a mental handicap, staff and family members. Even those who took part in the greatest number of semi-integrative or integrative activities had few, if any, non-handicapped friends. Hence as concerns the breadth of the participants' experience and the variety of their social contacts, the general pattern was similarly bleak across the three groups.

From observations of the remaining participants' social lives, and from discussing this topic with them, there would seem to be no reason to consider that their social situation was any different from the sub-sample studied. The marginal social position these results indicate has considerable consequences for the participants' self-concepts. For example, if the social constructionist view of the self is correct, then one may hypothesise that a limited range of social experience and contacts would make the views of significant others even more potent. This is particularly the case when those significant others such as parents and staff are in a position of power or authority. Equally, the pressure upon a person to conform to the role of a hospital patient would be greater where this person lacked broader experience or a range of social relationships with non-handicapped others outwith the hospital setting.

CHAPTER 8

Final discussion

This discussion will consist of four sections. The first section will relate the theories of self-concept, outlined in the introduction, to the findings of this study. The second part of this chapter will consider how the present results fit with past research. Thirdly, a number of methodological issues, arising from this study, will be raised before outlining the possibilities for future research. The fourth section will deal with the implications of the findings for the policy and practice of services. It will also consider wider issues of social policy arising from the findings.

1) Implications of the results for theories of self-concept

There was evidence indicating that many of the mothers' attitudes did influence their offsprings' self-concepts and vice versa. This can be explained quite straight-forwardly by Mead's (1934) social constructionist theory of self. Furthermore, a number of the participants' self-concepts did appear to evolve through achieving greater independence or realising that they had the opportunity to achieve such independence. Such results add credence to the emphasis that Hamlyn (1977) and Markova (1987) placed on the self as an actor and the importance of experience and action in determining one's self-concept.

However, a number of the findings discussed above have particularly important theoretical implications because they cannot readily be explained in terms of social constructionist theories of self-concept; nor can they be explained by those theories which put greater emphasis on agency. For example, in his early work Gergen (1971) suggested that people simply internalise the views of others, or cues concerning themselves in a given set of social circumstances. If this were the case how would the majority of Family and Hospital participants have come to reject a 'handicapped' view of self? In his later work Gergen (1985) argued that the self-concept was only given meaning through social processes. This means that the participants could only be agents in so far as their agency was aknowledged by others in their social world. How, then, were participants able to develop self-concepts which contrasted with both their marginal social status and how they were viewed by parents and staff despite having limited social experience and autonomy?

According to Mead (1934), the views of significant others are crucial to the development of people's self-concepts. Why then did the Family mothers, with whom the participants were still living, not influence the participants' self-concepts? It would be hard to find another instance where mothers play such an important long-term role in their offsprings' lives. The participants' marginal social status and their lack of contacts outside the family meant that their relationships with their mothers took on a particular significance. Their mothers' attitudes towards the participants were even related to the amount of autonomy the participants were afforded. Those who saw their son or daughter as <u>essentially different</u> gave them least autonomy. Therefore Mead's theory could not explain how those living at home with few social contacts outside a 'handicapped' niche of society came to reject their mothers' view of themselves as <u>essentially diferent</u>. Nor could it explain how the Hospital participants came to see themselves as <u>essentially the same</u> as people living 'outside' when they had lived most of their lives in an institution where they were treated like and expected to conform to, the role of a 'patient'.

The importance Mead attaches to internalising societal norms or the view of the 'generalised other' may account for the participants' insight into their social situation. If participants internalised the view of the generalised other then they would be able to understand their position relative to societal norms and values. For example, they would be able to use these norms and values as a wider frame of reference within which they could compare how they were treated relative to non-handicapped peers and siblings. However, Mead did not make it clear if and how people could set about changing their self-concepts when they were aware of their social status and did not like it. If people can only be objects to themselves in so far as they are objects to others, then they must first change the views of others before they can alter their own self-concepts. Such a conceptualisation could hardly explain the findings of this study. Those participants who were seen as <u>essentially different</u> in the Family group were the least likely to have the autonomy to prove that they should be seen differently. Nor for that matter were such mothers' perceptions of their son or daughter particularly open to change. Thus, apart from acounting for the participants' awareness of their situation, Mead's conceptualisation of the self does not provide much more insight than Gergen's theory as to why such participants were able to reject a stigmatised identity. According to Mead (1934) the participants would have had to be able to convince their parents and others that they deserved to be treated as <u>essentially the same</u> as non-handicapped people. Otherwise they remained as tied to their 'handicapped' identities as the 'pawns' in Gergen's metaphorical game of chess.

Hamlyn (1977) and Markova's (1987) theories which emphasised the importance of agency and social experience also cannot fully explain these results. Knowing oneself as an actor does not account for the fact that several of those who were unable to make the most basic decisions about their everyday lives, such as the time at which they went to bed, could view themselves as essentially the same. Markova (1987), using Mead's conversation of gestures as an illustration, argued that change in a person's self-concept through acting in his or her social world is a reciprocal process. The conversation of gestures indicates how taking on board the response of the person with whom one is interacting alters one's initial position. In turn, the attitudes of the other person are changed by the views one expresses, and so forth. However, a prerequisite for such a mutual process is reciprocity. What if one party in the interaction does not take the views of the other seriously, or is in a position of power over him or her? Surely this would severely curtail the ability of the powerless individual to alter the views of others or to develop his or her own self-concept?

The social life findings from the present research indicated that the hospital participants had been largely cut off from people 'outside', while the Family participants had few if any non-handicapped friends outwith the family home. The non-handicapped people with whom the Family participants tended to have most contact were staff members in services or people who organised social activities for people with a mental handicap. Given their lack of social contacts, how could the participants have developed a view of self as essentially the same as non-handicapped people in their voyage through life? A number of the mothers did not even think their offspring were aware of stigma, let alone take their views on the subject seriously.

Emotions: a missing factor?

In the first section of this chapter it was suggested that emotional response and social sensitivity could help to explain the rejection of a globally 'handicapped' identity. Given the apparent importance of these two factors, it is worth indicating once again how they might allow someone who was seen by significant others as *essentially different* to view him- or herself as *essentially the same*. This will point to a gap in the predominately cognitively oriented theories of self-concept which will then be discussed.

Social sensitivity can be seen as a likely prerequisite for the rejection of a handicapped identity. It was felt that participants had to realise what it meant to be treated as an ordinary person in order to assert their right to be treated as such. Even if participants had less experience of the social world, they were basically socialised into the same society as their non-handicapped peers and siblings. It appeared that they internalised many of the same aspirations for their futures, such as obtaining employment, getting married and having children. However, it would seem that being socially sensitive means more than just sharing such larger goals and aspirations. In addition, it means that people internalise the same subtle awareness of particular moral codes of behaviour. They realise what is fair, respectful, friendly, helpful or embarrassing. In other words, they apprehend the subtle social cues that define one's relative social status and, more importantly, such cues elicit a similar range of emotional reactions. The participants were not simply aware of being treated in a stigmatised fashion: they also expressed hurt, anger, bitterness and frustration at their powerlessness.

This meant that participants generally did not simply internalise a stigmatised identity: rather their stigma was an important facet of their identity which they tended to find hurtful. The participants' seeming acceptance of their situation, or their passivity, did not necessarily signify contentment. For example, being bathed by nurses in the hospital was part of a routine, but for most it did not appear to lose its embarrassing qualities.

The hospital participants may have been able to maintain their rejection of the role of a 'patient' in part through collective dismisal of 'the system'. However, it was their individual awareness of the relative lack of 'freedom' and the degrading aspects of the hospital routine that fuelled their rejection of the hospital system in the first place. It was curious how people who have lived in institutions for the greater part, if not all, of their lives could know how people were usually treated outside the hospital, or indeed that there was a stigma attached to living there. Yet, this is in line with the findings of Hughes et al. (1987). They showed how children with moderate to severe handicaps being brought up in a long-stay hospital were able to acquire quite sophisticated social knowledge from the limited sources available to them. Television, and their contact with the world outside the hospital, extremely limited though it was, played a part; but the nurses were the main source of 'cultural knowledge'. However, the nurses' concern with the smooth running of the ward, and getting the children to behave correctly, meant that the information which they fed directly to the children was limited; and on subjects such as sex the nurses tended to confuse rather than clarify the issues for them. Despite the deprived nature of life on the ward and the extent to which it deviated from the experiences of children growing up in the ordinary world, Hughes et. al. concluded by expressing their surprise at just how much the children did know:

> The puzzling thing for an observer is perhaps not so much that these adolescents know so little, but that a few of them with age come to know surprisingly much. (Hughes et al., 1987, p.405)

Perhaps we underestimate the sensitivity of people to social knowledge, or fail to realise the active part that children play in building up a conception of the world that extends beyond their narrow range of experience.

Thus social sensitivitity, as well as a central role played by emotion in determining peoples' self-concepts, may go some way to explaining the findings. Certainly, with the exception of Markova's (1987), social constructionist theories fail to take emotions seriously. It is not easy to deal with both emotions and cognitions when examining people's responses. Consequently, most researchers ignore the emotional element and deal solely with what people say on a cognitive level. It is difficult to get a sense of what people feel from a self-concept score or from answers to a formal interview. However, analyses of tape-recorded discussions of topics about which people with a mental handicap feel very strongly, can show the powerful role of emotions in their self-concepts.

As previously stated, obtaining an insight into independent living and gaining the knowledge of how the transition from home could be made, were both influential in prompting some Key participants to seek change. What still cannot readily be explained by the social constructionist theories of Mead (1931) or the writings of Markova (1987) is how the Family participants could realise that they had the potential to lead a more ordinary life. Indeed, how could the participants be creative and develop and sustain their own self-concept with little experience or autonomy? Perhaps it is wrong to simply consider the 'I' and the 'Me' as two distinctive parts of a process. There may be different kinds of reflection, and on occasion people's reflection may have creative qualities. In this sense, people who are given little autonomy may be able to develop a view of self which is not merely socially constructed, but which also takes account of their insight into their own potential. Christopher Nolan (1987) was born with such an extreme form of cerebral palsy that he was not able to communicate until a muscle relaxant drug enabled him to use a typewriter. He proved to be an enormously talented and creative writer and his first work was published while he was still a teenager, shortly after this means of communication had been opened up to him. It was entitled 'Dam-Burst of Dreams'. From his autobiography, in which he refers to himself as Joseph, it is apparent that he had not been dreaming all these years but had had a very firm view of himself and his potential. He movingly described how desperately he wanted to learn to type in order that others could also realise his qualities:

> Joseph was well used to all the weeping-Jesus comments about his cross. He was now trying to break free from society's charitable mould. He saw how others saw him but he wanted to show everyone how truly wrong they were. Fenced in on all sides he heard things he was never meant to hear and he saw things he was never meant to see. Now could he get his chance to let folk see what they never thought existed? (Nolan, 1987, p.76)

2) Past work and present findings

The present research findings concerning residents discharged from a long-stay hospital differ in several important respects from those of Edgerton (1967). Firstly, in contrast to Edgerton's work there was little evidence of self-aggrandisement among the Hospital participants. Nor did it appear to be the case that the participants were, like Edgerton's subjects, able to reject the 'role' of a hospital 'patient' through being cut off from the ordinary world where their incompetence would have been apparent. Instead, here it was the hospital participants' awareness of the lack of dignity afforded by the hospital regime, and their knowledge that they were missing out on opportunities and experiences ordinarily taken for granted, that led them to reject the view of self as 'patient'. Nor was there evidence that the participants in the Home or Key groups rejected a 'handicapped' identity because they were sheltered from their lack of competence or awareness of their stigmatised status.

On the other hand, in agreement with Edgerton's account, the importance of a peer group who shared a common 'counter-culture' in the hospital did appear to be crucial to maintaining such a view of self. The two Hospital participants who saw themselves as <u>essentially different</u> were described by staff members, in informal discussions with the researcher, as 'loners'. They were therefore not a part of the peer culture in the hospital. This might explain in part why they viewed themselves as <u>essentially different</u> from people living 'outside' the hospital.

It was in the emphasis which Edgerton placed on competence that the fundamental difference from the present study lies. For Edgerton, 'incompetence' was the main source of the participants' stigma. Hence the participants strove to deny their incompetence or to pass as competent in order to escape stigma. In contrast, while competence is acknowledged to be a problem in this study, it was not regarded by the participants to be the main source of stigma. Few participants attempted to deny, or in the course of the interview avoid talking about, their problems with literacy, numeracy, or doing things for themselves. Rather, the participants appeared able to differentiate between treatment that was justified by their handicap and prejudice and discrimination which arose from being treated as though they were 'handicapped' as persons. Perhaps this awareness is best expressed by Mike, a 36 year old man with Down's syndrome, talking about how he was treated by people he met:

> Generally they're good towards me, anyway, but not because of what I am, because they know me. Not becuse of what I am, but because they know me personally. Because you don't judge a book by the cover. When we walk on a street or a bus or a train it's wrong to confront a person with a picture from a different source. Because people should realise that we are people like them and want to be treated like them, so that you are in the same standards. But not saying, -Well, I want to be your friend because you're handicapped. - To me that's wrong, totally, generally. It would be much nicer to know people coming up to say, - I'm you're friend and I want to know more about you as a person not just that big word that doesn't mean anything.

Zetlin and Turner's work (1984) was also primarily concerned with how people coped with their lack of competence. While they ackowledged that stigma does extend beyond a lack of competence, they believed that the abuse and discrimination were only problematic for those who had not yet become adjusted to their handicapped status. However, the present findings indicate that the self-concepts of people with a mental handicap are profoundly affected by the stigma associated with their disability. Zetlin and Turner also found that the nature of their participants' self-concepts was largely determined by the attitudes and treatment of their parents. Those parents who denied that their children had a disability encouraged dependency in an effort to cover up the consequences of their offsprings' handicaps. Those parents who were quite happy to accept and discuss their offspring's disabilities with them set realistic goals for achieving an ordinary lifestyle. Thus the offspring of the denying parents also denied their handicap but were at the same time the most dependent. The offspring of the accepting parents were the most accepting of their handicap, while being the least dependent and content in the knowledge that they had made strides towards leading an independent lifestyle.

The mothers' views in the present research clearly had an important influence on the participants' lives and often affected their self-concepts. However, a crucial relationship between parental attitudes and their offspring's self-concepts, as described by Zetlin and Turner, was not found. What underpinned mothers' attitudes was not their acceptance or denial of their offspring's handicap, but rather the extent to which they saw them as 'handicapped' as persons. In other words, it depended on the extent to which the mothers felt that the participants should enjoy as ordinary a life as possible, or whether they felt that they were handicapped as people and could not enjoy a more ordinary life style, even if their actual disability did not pose much of a problem. It did not follow that the participants who were seen as 'handicapped' as persons and were afforded least autonomy necessarily came to see themselves as such. Some notable examples were discussed in Chapter 6 where the participants' self-concepts contrasted with their mothers' views of them. As has already been argued, the social constructionist perspective, such as that proposed by Zetlin and Turner, largely ignores the agency of the individual with a mental handicap and other factors which may play a part in the development of their self-concepts.

Zetlin and Turner also stated that by achieving independence these participants believed they had become competent and were therefore no longer 'retarded'. In the present study the participants did not merely feel that they had to prove their competence, but that many of their problems were created by the discrimination and prejudice associated with handicap. Therefore those who had become independent did not only refer to their success as evidence that they did not deserve the label 'handicapped', but also wanted to indicate that they should never have been made to lead a protected existence in their family or a long-stay institution. Indeed it was important to many of those who were still living in their family home or in hospital to believe that they could lead a more ordinary life if they were given the opportunity to do so. These participants were clearly differentiating between their actual disability and the consequences of 'handicapped' treatment and prejudice. If they could believe in their potential to get jobs, get married or have a house of their own with greater personal autonomy, then they were able to sustain a view of themselves as people who deserved to be treated on a par with non-handicapped others.

Another aspect of Zetlin and Turner's study was partly congruent with the present findings, namely how the participants saw themselves relative to people more handicapped than themselves. In their study, participants who were quite settled in their acceptance or rejection of their handicapped identity were found to be superior or patronising towards those more handicapped than themselves. Those participants who had not come to terms with their mental handicap emphasised their difference from those more handicapped than themselves in order to make clear that they were not like such people. There were also participants in the present study who felt superior to, or wished to set themselves apart from, people more handicapped than themselves. However, others showed solidarity with people more handicapped than themselves and asserted the right of people with the most severe handicaps to be treated on equal terms. Finally, there were those who at times emphasised their difference from people who were more handicapped than themselves, and at other times showed solidarity with them.

The last group who expressed both perspectives perhaps best highlighted the forces which shaped the participants' attitudes towards people with more severe disabilities. Their wish to dissociate themselves from the more handicapped was not simply because they felt more competent, but because they wanted to emphasise that they did not deserve to be treated as 'handicapped' and set apart from non-handicapped others. However, at the same time they knew that they were, in a sense, stuck on the 'handicapped' margins of society and that to claim they were different from people more handicapped than themselves was not going to alter their situation. These participants therefore adopted a different tack and argued on behalf of their peers, even those more handicapped than themselves, that no one deserved to be treated as though they were a less valuable person than anyone else. Even the participants who adopted a superior stance to the more disabled were careful to distance themselves from those who scorned or mocked people with handicaps. It appeared that their own experience of such treatment made them careful not to do the same to others.

Thus the main difference between the findings from this study and those of Zetlin and Turner outlined above might lie in the approach to and the definition of stigma. Zetlin and Turner examined how the participants coped with their lack of competence and their consequent 'handicapped identity'. The present study did not assume that stigma was largely a consequence of people's disability. Rather it explored the nature of their view of self in relation to handicap and stigma. As a result it was found that the participants had to deal with the problem of the stigma as well as their actual handicap. Hence they felt that they did not merely have to prove their competence, but that they also had to escape from the associated stigma.

An alternative explanation for the differences between the results from this study and the work of Edgerton (1967) and Zetlin and Turner (1984) could be cultural. If social experience is likely to influence the participants' self-concepts, then the differences in the findings might in part be due to certain differences between Scotland and California. While it is legitimate to make comparisons, there are considerable social and demographic differences between these cultures. Scotland has a largely homogeneous and stable population, while California has a growing, mobile and heterogeneous population. It is interesting to consider whether the concept of 'denial' of handicap may perhaps in part be the product of a society where people are seeking or able to create new identities or lives for themselves?

The present results also challenge some of the findings of research on social comparison. Studies with special school pupils such as the one by Strang et al. (1978) have been based on the premise that special school pupils view themselves in relation to one set of peers at a time. Therefore, if they have a positive self-concept in a special school class, then they are comparing themselves with other handicapped children and are engaging in downward social comparison. It is certainly the case that some participants wished to set themselves apart from handicapped others. But as has been explained above, this was not simply a process of self-aggrandisement. They set themselves apart from handicapped children because they wanted to achieve acceptance from non-handicapped others. Hence these participants wanted to emphasise the difference between themselves and more severely disabled people precisely because they were so aware of how they were negatively perceived by non- handicapped others. Gibbons (1985) found that his adult subjects did not only negatively rate their handicapped peers but also made extremely pessimistic ratings of their own chances for social success. This also points to Gibbons' subjects' awareness of their social status relative to non-handicapped others. Thus those studies, such as the one by Strang et al. (1978), that only examine the participants' view of themselves in relation to one set of peers, fail to bring out how the attitudes of people with a mental handicap towards their handicapped or non-handicapped peers relate to their wider insight of their position in the social world.

3) Methodological points and areas for future research

The present study has examined the participants' self-concepts in relation to handicap and stigma. It is hoped that the light the study has shed on the nature of the participants' self-concepts has justified the use of a qualitative approach. It would not have been possible to obtain this insight through using global or normative measures confined to producing a numerical score.

The present research was tied to a sample used in a larger Scottish Home and Health Department project concerned with training for independent living. It is important to realise that such field research has its own problems. The researchers cannot control who moves into Key housing hostels or into the rehabilitation unit of a hospital. This meant that in the design of the present research it was not possible to ensure that there were equal numbers in each group, or an even distribution of sex and age. Furthermore, there was the problem that some people had recently moved out of the hospital, and some people remained in hospital, at the time when the interviews took place.

As well as dealing with these problems there are a number of other ways in which the study could be strengthened if it were to be repeated. Firstly, making the research longitudinal would make it possible to examine the part that increased knowledge, life experiences and changing circumstances, such as a move towards independence, contributes to the development of self-concepts. It would also be possible to chart how the participants' views of self changed over time in relation to the views of significant others in their life, such as parents and staff. Thus, one would have a clearer insight into the relative strengths of various determinants.

Another criticism that could be made about the research concerns the absence of intelligence test scores or other forms of assessment data. But there was a potent reason for this: it was not considered compatible with the spirit in which the interviews were carried out for the researcher to be seen as a tester. The test or assessment data in the participants' records, if there at all, was often out of date and came from such a wide variety of instruments, both *ad hoc* and standardised, that it would not have been possible to present a coherent overall picture. Moreover, given the common threads running through the self-concepts of participants who had differing levels of ability, it would be unlikely that such assessment data would have provided a greater understanding of the results. However, if sufficient manpower were available to carry out assessments, independent of the interviewing, then the possiblity that ability is a significant factor in participants' self-concepts could be tested.

A number of suggestions for future research could be made on the basis of these findings. One of the factors considered to have been responsible for participants' rejection of a stigmatised identity was their considerable social awareness. However, given the participants' lack of experience, it was something of a mystery how they were able to obtain the social knowledge necessary for such an awareness. It would be interesting to investigate the sources of such people's social knowledge and how they build up a picture of their social world and their relative position in it.

The self-concepts of people with a mental handicap determine how they see themselves relative to the world around them. As such it is likely to affect their actions in the social world. For example, it is not enough to train people for independent living. As well as providing people with a mental handicap with these skills, they also require the confidence and knowledge of how to use them. There was evidence that seeing others living independently gave certain paricipants more confidence and encouraged them to take a more active role in determining their lives. Given the range of personal histories, there may be considerable variation in the circumstances which would shake people out a of a passive acceptance of their situation. It would be interesting to examine whether certain pre-conditions or particular information tend to make the participants more assertive and self-confident.

A further area which deserves study concerns the origins of parents' protective attitudes towards their son or daughter, and how these change as their offspring grows up It would be interesting to determine, for example, the part that the participants play in determining their parents' views of them. In a case study by Korbin (1986) it was shown how the attitudes of the mother of a Down's syndrome child became less positive as she grew up and fell more and more behind the intellectual development of her non-handicapped peers. However, the present research points to another angle: if parents have negative views of handicap, or have extraordinary problems with their children, then they may have to be convinced of their chidren's potential. It may be that the offspring have to work to prove their ability. Therefore it might not be until much later, when sons or daughters grow up, that their parents begin to aknowledge their adult status, or that they deserve respect and similar opportunities to those open to non-handicapped people. In order to find out the extent to which people with a mental handicap have to prove their potential to their parents, one could study parents' reactions to people with a mental handicap who wish to have greater autonomy in their lives, or who make a move towards independence. In addition, by investigating why parents' attitudes do or do not change, one may gain insight into how some parents come to regard the move of their son or daughter towards independence as a positive step forward.

While a number of hypotheses have been put forward as to how participants could have rejected a stigmatised identity, only limited suggestions have been made as to how they might have internalised a 'handicapped' identity. Further research should attempt to identify the background factors responsible for this.

Finally, while discussing the relationship of the present findings to past work, it was noted that most comparable research has been carried out in California by Edgerton and others at the University of the State of California. While their findings are based on participant observation as opposed to interviewing, it could still be the case that part of the differences in the findings are due to differing socio-cultural circumstances. It would therefore be interesting to carry out a cross-cultural study. Could the concept of 'denial' of handicap be the product of a 'melting pot' society like California, where many flock to make new lives for themselves and create a new identity? Alternatively, is 'acceptance' of handicap more likely if one has greater opportunity in the areas of employment and housing? If this were the case in California, as it appears to be, then people might be far more happy to accept their 'handicap', in the knowledge that they may still be able to lead a relatively ordinary life.

4) Some policy implications

The findings do have implications for the services for and treatment of people with a mental handicap. The fact that those parents who viewed the participants as primarily handicapped gave them less autonomy and less opportunity to take part in ordinary activities demonstrates that attitudes do count. Ideally parents should be counselled as soon as possible after their infant is found to have a mental handicap or, if their learning difficulty is not identified until later, when the child is transferred from an ordinary to a special school. Parents should both be helped to come to terms with their child's handicap and informed of the myths and stigma surrounding handicap. After all, such parents are likely to have the same spread of attitudes towards handicap as are found in society at large. It should not be up to the children to prove their worth contrary to the negative or sketchy prognosis of a professional. A lot of work could be saved in the long-term if on-going support and advice were provided. This is because when such attitudes become entrenched, they are harder to shift. It is so much more difficult for a person with a mental handicap to learn to use public transport at an ATC when he or she is rarely allowed out of the house on his or her own, or learn to cook when he or she is only allowed to make tea or toast at home. When the parents are convinced that their son or daughter is a globally handicapped person they are likely to be unduly protective and unwilling to promote their children's independence and expose them to a wide range of social experience.

One answer to a situation where a parent is overprotective, which I have heard recommended by staff in ATCs, is that adults with a mental handicap are adults, and as such they do not and should not have to gain the consent of their parents to branch out on their own. While some people with a mental handicap will take the initiative and gain the support of their parents in making changes in their lives, for others it is a far more difficult task. As the present findings have shown, participants often had an extremely close relationship with their parents due to their relative social isolation. Participants often showed considerable loyalty to their parents, even when they were quite frustrated with their life at home. This could make it very difficult and particularly upsetting for such people to challenge the views of their parents. Therefore, people with a mental handicap should be given help to alter their parents' views about themselves, and not be forced to enter into conflict with those who have been, and may continue to be, their main source of social support. Moreover, there may be many instances where people would quite simply be unwilling, or feel unable, to challenge their parents without outside intervention.

Thus where possible, parents should be given early counselling and support. This could be done by professionals, or even by self-help groups of parents. When parents hold entrenched protective attitudes, professionals should not seek to change their views in an adversarial fashion but in an on-going partnership. This involves having some understanding of how the parents' attitudes towards their offprings developed. It would appear that, apart from a generally negative prognosis for their child's future development, parents in the study had been given little in the way of support and had been more or less left to get on with bringing up their son or daughter on their own. Thus, overcoming the anxiety and suspicion of those parents unwilling to allow their offsprings to lead a more ordinary life would require long-term planning. There would have to be a clear policy of having long-term contact with such families, rather than making it contingent on family difficulties.

It is, however, important to stress that many mothers did view their son or daughter as essentially the same as non-handicapped others. In some cases participants grasped opportunities that were open to them and, in the process, altered their mothers' attitudes towards them. In addition there were mothers who deeply resented the stigma and prejudice which their offsprings faced. During the study it was noted that many of the staff had a very negative view of parents. A number of staff members made the mistake, because certain parents were over-protective, of considering them all to be clinging or reactionary. To counteract negative views of parents as people who say 'no', staff should be made aware of the importance of the parental lobby in the develoment of the day and residential services which currently exist. They can and do play a progressive role in promoting new ideas. For example, the philosophy of normalisation was originally developed by Scandinavian parents.

There were also staff who regarded their participants as globally handicapped, and many more who appeared be unaware of the participants' depth of feeling about handicap and stigma. Perhaps another effective method of countering these negative views of parents and staff would be to try and make them aware of the sensitivity and feelings of people with a mental handicap who are hurt by such attitudes. Similarly, those in the services for people with a mental handicap should take account of the sensitivity of those they are there to help, and seek to create and enhance the individual's sense of personal worth. Unfortunately it is not always a straightforward task to make staff sensitive to such feelings. This became apparent to the researcher when he discussed with staff the practical implications of the larger project funded by the Scottish Home and Health Department. The most common response was to say that they knew all about the participants' feelings! While staff accepted that 'ambulance' buses were stigmatising, none of them recognised that they themselves could be responsible for treating anyone in such a fashion. Perhaps role-play and exercises involving people with a mental handicap would make people conscious that everyone can be guilty of treating people insensitively. What may be regarded by those working in services as quite acceptable, such as having to ask a staff member if one can go to the toilet, may be seen as demeaning by the person with a mental handicap.

If participants' feelings about handicap and stigma are to be taken seriously, then it is not simply a matter of a number of staff changing their outlooks. It is also a matter of changing the nature and structure of the services so as to take serious account of their clients' feelings. Wherever possible, steps should be taken to eradicate stigmatising procedures that are under the control of services, such as using conspicuous mini-buses labelled 'ambulance'. Moreover, practices such as staff-only sitting rooms, which create a social barrier between staff and people with a mental handicap, should be abandoned. Staff members should be encouraged to eat with and share the same facilities as service users, from crockery to toilets.

People with a mental handicap require support to achieve more of the rights and opportunities in the social and other spheres of life that are ordinarily taken for granted. They should not be restricted to services and activities which reinforce a 'handicapped' identity. For example, in terms of domestic and educational skills, F.E. colleges should have a growing role to play because, compared to ATCs, they can provide a more ordinary environment for learning, and offer a greater degree of integration with non-handicapped people. If something more specialised is required, then Centres which offer programmes for school leavers could be developed. There are good examples of such Centres in existence which, due to the fact that people only attend them for a finite period, maintain a fresh and challenging outlook. In addition there should be an attempt to promote opportunities for real employment and contact with non-handicapped people, using such facilities as job placement schemes and fostering the development of cooperative or community businesses to employ both mentally handicapped and non-handicapped people. However, this does not mean simply placing people on Manpower Service (MSC) schemes or in employment, and then just leaving them to get on with it. There should be sensitive and adequate back-up to ensure that people do not experience rejection and abuse, and to facilitate integration with the other workers.

In addition, there are a number of steps that could be taken to enhance the social lives of people with a mental handicap. First, the social segregation of those living in mental handicap hospitals is not a feature that can be overcome by institutional reform. As long as people are cut off from the wider community they will not live on the same street as non-handicapped people, or have the same opportunities as non-handicapped people to use ordinary facilities such as shops, post offices and cafes. Their relationships with staff are bound to be stilted by remaining inside the institutional framework, even if the present large wards were replaced by small units on the hospital sites. Moreover, it appears very difficult for such people to maintain contact with family living outside hospital. Hence services should take the problem of the social life of people with a mental handicap very seriously and not regard it as a sideline to training for independent living. The meaning of such training would be totally lost if people were not allowed to play a greater part in the community. When people finish the cleaning, cooking and washing-up for which they have been trained so meticulously, there are still other parts of the day to be filled. It was a very important aspiration on the part of our participants that they should have wished to fill those parts of the day by developing their social lives and networks.

Secondly, the people with a mental handicap participating in this study made it quite clear that integration and participation in the local community was a matter of priority to them. Their degree of satisfaction with their social lives and networks was central to their sense of identity and belonging somewhere. While preference for different kinds of social life will vary from person to person, there is no reason why people should lack social experience or live on the margins of society because they have a mental handicap. Staff working in both residential and day services should be encouraged to see it as one of their responsibilities to create opportunities for people with a mental handicap to experience a wider range of social activities. The emphasis should shift from providing segregated social and sports events specially organised for handicapped people to encouraging people to participate in leisure activities alongside non-handicapped people. Residential staff should be willing at least to accompany a person to an event in order to facilitate this participation. In cases where this in itself proves insufficient to promote the development of social relationships and friendships between a person with a mental handicap and non-handicapped people, more active interventions could be tried. Volunteers could be used for this purpose, or friendship schemes could be set up. Staff or volunteers could encourage and support the participation of people with a mental handicap in ordinary leisure activities such as going to sports centres, the cinema, photography clubs, art and adult education classes.

The specially organised clubs and activities run by the voluntary sector could also be made more aware and alert to the needs of their club members. None of the participants reported meeting non-handicapped friends at these clubs. Instead of maintaining these barriers, they should aim to foster an atmosphere which promotes friendships between club members and non-handicapped volunteers which extends outside club hours.

The participants' lack of money also made it difficult for them to sustain a social life. There were those among the Key participants who even found it difficult to visit their parents because of the expense involved. If benefits for those leaving home are so inadequate that they cannot support even a modest amount of socialising, then they ought to be increased. Equally, the parents of those living at home should be encouraged to give their son or daughter a greater degree of control over their benefits. Only by developing a modicum of financial independence will people have the opportunity to develop a lifestyle of their choice.

Finally, the integration of people with a mental handicap into the community is a two way-process involving those people and the general public. Professional efforts at integration would be totally lost if the general public were not prepared to accept people with a mental handicap. The solution to this problem must lie in the dual approach of attempting to educate the general public while, at the same time, fostering the integration of people with a mental handicap. Perhaps one form of public education would be to make people more aware of what it feels like to be set apart from non-handicapped others. The excellent posters produced by the Spastics Society highlighted both the potential of people with cerebral palsy and the way in which such people are pushed to the margins of society. The media might also be asked to focus their attention not just on the views of professionals but on the experiences and feelings of people with a mental handicap themselves.

The last implication concerns the use of the term 'mentally handicapped'. It may appear hypocritical to raise this point, given that the term has been used throughout the thesis, but it was apparent that many of the participants who were interviewed found the term 'mental handicap' pejorative and hurtful. While there is little purpose in employing euphemisms which eventually come to take on board the same negative connotations, this is a serious point which cannot be ignored. People should be able to understand and describe their disabilities in a manner with which they feel comfortable. It is problematic to find alternatives. For example, one would associate the label 'learning difficulties' with children of school age rather than adults. However, just as 'idiot' and 'mental defective' became outmoded, so perhaps it is time to find an alternative to 'mental handicap'. This might mark a shift towards a greater sensitivity to the feelings of people with a mental handicap and promote an awareness of the consequences of stigma on their lives and self-concepts.

Conclusion

This thesis challenges two fundamental positions in the literature concerning stigma and the self-concepts of people with a mild mental handicap. First, it challenges the social constructionist view that powerful external social forces are likely to shape the self-concepts of those such as the mentally handicapped. The present research found that the participants' marginal social status and the stigma they experienced did not necessarily result in them internalising a stigmatised identity. Indeed the majority of participants in the Family, Key and Hospital groups rejected such an identity. Second, the research contradicted the assumptions of previous work by Edgerton (1967) and Zetlin and Turner (1984), concerning the self-concepts of people with a mild mental handicap. These authors asserted that people's self-concepts are underpinned by their need to deny or come to terms with their incompetence. Hence, the self-concepts of people with a mental handicap have to be understood in terms of a coping mechanism. In this study participants showed considerable insight into their social situation and did not show signs of struggling to come to terms with the consequences of their incompetence. Instead, the participants were willing to aknowledge that they had disabilities but did not feel this justified stigmatised and discriminatory treatment to which they were subjected. On the positive side, the present research has pointed to the importance of emotions in understanding the consequences of stigma for people's self-concepts. Emotions are rarely taken seriously in social constructionist theories of the self or in work concerning stigma and self-concept. Above all though, this work contributes to the growing body of literature that suggests that people with a mental handicap have an important perspective which needs to be investigated and understood in its own right.

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APPENDIX 1

PSEUDONYMS AND INDIVIDUAL DETAILS

The purpose of this appendix is to a present a few personal details of the participants who took part in the study. All the participants were given pseudonyms. It is hoped this information may contribute towards the reader's sense of the individuals who took part in the research. The 'causes' of handicap given below may sometimes appear vague. However, these are all reproduced from the participants' records and files.

NAME	AGE GROUP	SEX	HANDICAP	PHYSICAL H/CAP	EPILEPSY
A) Adult Training Centre Group					
PAUL,	26-30,	MALE,	DOWN'S SYNDROME	NO	NO
MIKE,	36-40,	MALE,	DOWN'S SYNDROME	NO	NO
DAN,	21-25,	MALE,	PERINATAL DAMAGE	SLIGHT HEARING PROBLEM	NO
FRED,	21-25,	MALE,	UNKNOWN	NO	NO
JOHN,	36-40,	MALE,	DOWN'S SYNDROME	NO	NO
DEREK,	21-25,	MALE,	UNKNOWN	NO	NO
HARRY,	26-30,	MALE,	UNKNOWN	NO	NO
TERRY	26-30,	MALE,	SPINAL MENINGITIS	NO	CONTROLLED
JOAN,	21-25,	FEMALE,	UNKNOWN	NO	NO
MARIE,	36-40,	FEMALE,	UNKNOWN	NO	NO
CLARE,	21-25,	FEMALE,	UNKNOWN	NO	CONTROLLED
PAULA,	21-25,	FEMALE,	UNKNOWN	NO	NO

NAME	AGE GROUP	SEX	HANDICAP	PHYSICAL H/CAP	EPILEPSY
LORNA,	21-25,	FEMALE,	ANOXIA	HAEMIPLEGIC	NO
KAREN,	26-30,	FEMALE,	UNKNOWN	NO	NO
JACKY,	26-30,	FEMALE,	UNKNWON	NO	CONTROLLED
CATHY,	21-25,	FEMALE,	UNKNOWN	SLIGHT HEARING PROBLEM	NO
JEAN,	21-25,	FEMALE,	UNKNOWN	NO	CONTROLLED
JANE,	21-25	FEMALE,	UNKNOWN	NO	NO
GAIL,	21-25,	FEMALE,	UNKNOWN	NO	CONTROLLED
ROSE,	21-25,	FEMALE,	UNKNOWN	NO	NO

B) Key Group

BOB,	21-25,	MALE,	UNKNOWN	NO	NO
KEVIN,	16-20,	MALE,	UNKNOWN	NO	NO
GAVIN,	41-45,	MALE,	UNKNOWN	NO	YES
MARY,	26-30,	FEMALE,	ANOXIA	NO	NO
SUSAN,	41-45,	FEMALE,	UNKNOWN	SLIGHT HEARING PROBLEM,	NO
HELEN,	41-45,	FEMALE,	UNKNOWN	NO	YES
ANNE,	21-25,	FEMALE,	UNKNOWN	NO	NO
ANITA,	41-45,	FEMALE,	UNKNOWN	WALKS WITH LIMP	CONTROLLED
LISA,	31-35,	FEMALE,	UNKNOWN	NO	NO
GRACE,	26-30,	FEMALE,	MENINGITIS	NO	NO

NAME	AGE GROUP	SEX	HANDICAP	PHYSICAL H/CAP	EPILEPSY
C) Hospital group					
MARK,	36-40,	MALE,	UNKNOWN	NO	NO
LENGTH IN THE HOSPITAL					
26 years in the hospital					
BRUCE,	16-20	MALE,	UNKNOWN	NO	NO
10 years in the hospital					
IAIN,	31-35,	MALE,	UNKNOWN	NO	NO
17 years in the hospital					
FRANK,	51-55,	MALE,	UNKNOWN	APHASIC, TOES & REMOVED FROM ONE FOOT	NO
28 years in the hospital					
BILL,	21-25,	MALE,	UNKNOWN	NO	NO
7 years in the hospital					
JOE,	46-50,	MALE,	UNKNOWN	NO	NO
17 years in the hospital					
PETER,	51-55,	MALE,	UNKNOWN	NO	NO
46 years in the hospital					
SIMON,	36-40,	MALE,	UNKNOWN	NO,	NO,
19 years in the hospital					
DAVID,	31-35,	MALE,	HEAD INJURY	HAEMEPLEGIA	NO
7 years in the hospital					
JIM,	21-25,	MALE,	KLEINFELTER'S SYNDROME	NO	NO
12 years in the hospial					
HUGH,	31-35,	MALE,	SMALL CRANIAL CAVITY	SLIGHT HEARING PROBLEM	NO
18 years in the hospital					

NAME	AGE GROUP	SEX	HANDICAP	PHYSICAL H/CAP	EPILEPSY
PAT,	51-55,	MALE,	UNKNOWN	NO	NO
38 years in the hospital					
ANDY,	26-30,	MALE,	UNKNOWN	NO	NO
5 years in the hospital					
GRANT,	26-30,	MALE,	UNKNOWN	NO	NO
14 years in the hospital					
KEN,	26-30,	MALE,	UNKNOWN	NO	NO
14 years in the hospital					
FIONA,	41-45,	FEMALE,	UNKNOWN	NO	NO
19 years in the hospital					
ALICE,	46-50,	FEMALE,	UNKNOWN	NO	NO
18 years in the hospital					
AGNES,	41-45,	FEMALE,	UNKNOWN	SLIGHT HEARING PROBLEM	NO
16 years in the hospital					

APPENDIX 2

STIGMA / SELF CONCEPT INTERVIEW

This sample interview was the second in a set of five interviews concerned with stigma and self-concept in which Lisa participated. It was not selected because of any particular merit but because of its average length (it lasted approximately 1 hour) and because of its typical form. In total, over four hours were spent discussing the topics of self-concept and stigma with Lisa.

Lisa - (interviwee) A. - interviewer.

A. I thought tonight we'd just have a sort of general chat about your feelings about your life in general. I don't know, I've got this idea - what do you remember about your childhood?

L. Childhood? I didn't have much of a childhood. You mean when I was a lot younger. Well things were allright at first. When I was 18, my father took a nervous breakdown. I cannae mind anything...it's that long.

A. Can you remember way back, when you were young and that. When you were a wee lassie?

L. I cannae mind far back. I havenae got a good memory.

A. Neither have I, I can tell you. There must be some things you can remember when you were young. Anything, any incidents. Anything that sticks out in your mind when you were dead young.

L. I cannae mind far back.

A. ...Is there anything at all you can remember about it?

L. I remember when I was younger, about 10 or 11, my mother took me into the shops. Och I was just wee at the time... she dressed me in a sailor suit and I felt really proud of myself. I was only 10 year old at the time.

A. Very nice.

L. Funny minding back all they years. The wife in the shop says, 'She looks nice 'n all'. And I'd blond hair. I never felt so confident, and I was only 10 year old at the time. Then my nephew, he was wee at the time, he had blond hair and I used to take him out in his pram and play with him and things like that. That's all I can remember really.

A. Do you like your nephew?

L. Och he's .?. My sister cannae have any mair. She's lucky to have him. That's how I think that much of him.

A. Do you see him at all.

L. No very much. He's a lad. How often do you see laddies of 17 year old. He goes out a lot, ken.

A. Can you remember - social life and that when you were young?

L. My life's better now than what it was when I was younger.

A. What was it like then?

L. See my minds no good. I think of now and no of then.

A. Why do you not like thnking of then?

L. They werenae happy times. About 14 years when I was younger. That's when my father took a nervous breakdown, and it was it was like 13 or 14 years, he was like that... He used to take tantrums, ken hit me on the head and things like that. Now that was because he took a nervous breakdown, ken.

A. Can you remember going to school at all?

L. Och I remember that. It was a rotten school. It was the infant school, ken, in xxxx. Miss Jones was there, and I can mind when I went to school she always had in for me. She used to put a chair and I had to stand on that chair for hours and I was the only one that got it done to me.

A. Why was that?

L. I think she just had it in for me. But some teachers are like that - they were years ago. Stricter than what they are now.

A. So what happened after that then?

L. She says 'You're a figit L.' I was right enough, when I look back on it. But that was only when I was just starting school.

A. So where did you go from there?

L. After that school I went to McDonald Park [special school]. I should have went to McD. Park when I was 7 year old but my mother kept me back frm going there till I was 16. And I only went to McD. Park cos I was slow at sums. McD. Park in those days was like a prison camp. It's all changed now. It's fo mentally handicapped children.

A. How did you feel about going there at the time?

L. Oh Rotten, my mother persuaded me I greeted every night when she said I was to go. 'You've go to go. I'm telling you now, you should have went when you was 7.' I should have, she kept me back 'till I was 11 year old. The teacher there said I should have been there [McD. park] from I was 7. They didnae learn me much there.

A. Did they not?

L. 'cos that school [McD.] was like a prison camp. When I went into the wash room there were three bullies. They were a lot older than me - they're nice now - that's years ago. They used to take me into the toilet and batter me. I never said anything to my mother about that I kept that into myself till I left. I only tellt her about last year or 2 years ago. She says, 'if I had kenned that I would have been up to see them'. One day I went to the washroom and there was 5 of them punched and kicked me in the stomach. Constant pain I was in becuse of that. She [her mother] never found out till I left years and years ago.

A. What was it that made you feel rotten about going to school at first?

L. Cos I didnae think I had to go that school. It was just 'cos I was slow at sums.

A. In what way do you think it affected to you now, going to that school?

L. Because I ken another lassie, she should have went and she just went to an ordinary school. I think it was cos I fidgeted too much that's what they put me there for. Ken I never sat down for 5 minutes and I disturbed the class, supposed to have done anyway. I didn't even ken I was supposed to be going when I was 7 till, I found out when I left the school. That's how I think of the future now, I didnae like to look at the past. My mother says if she had kenned they had battered me she would have given them hell. See I only tellt her no that long ago.

A. Did you ever get any hassel off other kids when you went to the other school [ordinary primary].

L. Especially laddies, they were cheeky buggers. They cried [called] me names... not very nice.

INTERRUPTION.

A. We were talking about the school there, were we not?

L. Aye the school was rubbish. They were hard on you all the days from when I went to that school 'till I left it.

A. Why were they hard on you?

L. I ken sometimes when you're away and you dinnae dae... but they just picked on you for the sake of picking on us. I felt that anyway. Maybe I'm saying that the wrong way round.

A. In what ways do you think things changed for you, going to that school?

L. I was glad to leave, I was glad to leave the school.

A. Sorry?

L. I was glad to leave the school.

A. But what ways did it change your life going to that school?

L. I don't know. All the wanes were at an ordinary school and I was at McD. Park. They used to say I was daft cos I went to that school.

A. What do you feel about that?

L. It doesnae bother me now but it hurt me then. Ken when I was younger.

A. Do you think it changed anything really for you?

L. Aye.

A. In what ways did it change?

L. I used to get a special bus for McD Park. I used to go out for the bus outside where I stayed then. They used to say, 'there's dafty going', ken, just 'cos I was at a special school. It never worked out me going to that school. My mother said I just had to go. I never stayed off, at that kind of school they thought you were acting it, you know.

A. What, were there any friends lived round about you?

L. No.

A. How was that?

L. I didnae bother about friends. I had a friend but she kept on yapping ken, when she came to my house. Doing things with her hands, no nice things, ken what I'm meaning. That's years ago, right enough. There wasnae much of a friendship with it. I never really made friends 'till I came in here (Key Housing).

A. Did you have, were you friendly with any children round about you before you went to that school?

L. No. It was like a prison camp.

A. But before you went to that school?

L. No.

A. What about when you left school then?

L. I didn't have any friends when I left the school. Except for 'till I came here.

A. What did you do when you left school?

L. Well I worked in the laundrey for twelve and a half years catching sheets. It was boring but I still stuck it for twelve years.

A. What was it like?

L. It was a boring job but I stuck it. Stood and catched sheets all day.

A. What were the folk like?

L. Och they were allright, some of them. But some of them niggled me.

A. In what kind of way?

L. Well there was this other lassie. She was a lot older than me. They paid me off. But my case was proved I wasnae lazy but this other lassie got kept on. I got paid off 'cos they thought I'd passed stuff that was creased, it was this other lassie. I couldnae prove it wasnae me, 'cos she shoved her stuff on top of mine - all creased ones, ken for me to get a row. So I took all the rows for her. Just 'cos she had longer service it ended up with me getting the sack and she got kept on. She's retired now. She's about 61, 62. But I got proved I was right and she was wrong.

A. Did it make any difference?

L. No, but when I think back on it. I wasted two and a half years in that place.

A. Why?

L. Well 12 years, working at a place, and somebody on your back all the time.

A. Who was on your back all the time?

L. That lassie, passing stuff that was creased so that I got the sack.

A. What were people like then?

L. What here?

A. No in the work that you were in, what were they like?

L. Well there was one wife, she wanted me out, I ken. She says, 'you've only got another week to work', Maggie Smith, she's never spoke to me since she gave me the push. The other one that was there, was my - the one I worked for, Mr. R. He's got a lower job now. He won't be feeling proud of himself now 'cos he's got a step down from a manager to a van driver. So now when he sees me he talks. My mother says I shouldnae really answer him 'cos she says it's him who throwed me out of a job. But I didn't like to - ken with the past, ken what I mean, I like to forget. But there's a wife, 5 years and she's never spoke to me yet. It's about 6 year from I left there but my mother says, 'dinae worry about it', but sometimes it bothers me.

A. How were folk with you when you were there? How did folk treat you when you were there?

L. Some of them were allright, some of them werenae. Sometimes I had nightmares about that place, I never slept.

A. What was it?

L. Just worrying about if I was going to get the sack or no. I ended up with the sack right enough. But my case got proved, I was right and they were wrong.

A. How did you find, you're friends, say, who went to the ordinary school and you whowent to McD. Park. How did that make you feel like?

L. Sometimes made me feel as if I could burst. 'Cos they going to the ordinary school and I was going to McD. Park. But it's just something you've got to live with.

A. So how do you find folk now? Ones you work with of your own age. What are they like now?

L. Well it's changed nowadays that place. It's just all young ones that work there now. It was a place, I didn't know if I should've went to it.

A. How's that?

L. If I Kent I was going there ...I never got any help there.. 'Cos I got a letter, my mother hid it from me, that was ages ago. She said 'You're going to that school [special school]', But she kidded me on I wasnae going 'till I was 11, it was 10 when I went. She says she fought my case. She says, ' the age you should have gone to that school was 7'.

A. What did you feel about your mother when you went to that school?

L. I felt rotten. When she says I was to go I was mad. An' I says 'what've I to go to that school for?' Because they never learnt me anything.

A. What did she say to you?

L. She says, 'you've got to go'. The worst of it was I was never off that school. If you stayed off you got a row, you had to have a good reason.

A. How do you find folk of your own age, outside the Centre now? Folk you meet?

L. Allright now.

A. I mean do you find people helpful an frinedly or do you find some folk are unhelpful and nasty?

L. They're all nice at the Centre.

A. May be outside the Centre? How do you...

L. Outside the Centre?

A. I mean do you find some folk helpful and friendly, some folk unhelpful and nasty? How do you find people?

L. They'e nice at the Centre. That was at school they were like that.

A. Since you've been at school have you ever had anything like that?

L. No.

A. Have you ever been made to feel that kind of way, that kind of rotten way you were saying, any time in the recent past?

L. No, they're allright outside, they never used to be right enough. They are now.

A. What did they used to be like?

L. They use to say I was daft 'cos I was going to that school. That hapened everyday, when they seen that bus going. Right enough, in these days there were about 300 folk went to that school. Ken, the bus was full.

A. Really.

L. Aye, 'cos there was mongol ones right, but they went to Torwood. But that school now they'e only got 20 about, and it's for mentally handicapped that go there. The school's different, it's mair like school now, ken. No bossy teachers now. Some of them were bossy, they thought they kent everything. It's changed now.

A. That's good. How did you feel then about ging to the Centre at first?

L. I didnae like the Centre, 'cos I was only going to stay there for 6 weeks.

A. How did you decide to go at first then?

L. My mother got a letter - well my sister, she was the one that asked if I could go the Centre. I wouldnae be here [at Key Housing] if I didn't go to the Centre. They said at the Centre there was a place for me.This is when I went full time. I didnae want to go 'cos I thought I was only going to stay there for 6 weeks.

A. Why didn't you want to go?

L. I wasn't that fussy about going at first.

A. What was it about it?

L. It was just the thought of ging to a Centre to get classed as disability when I'm no. That's all in the past, but now I dinae bother.

A. I noticed the other ay you said that you didn't take a zonal card. Why is that?

L. A zonal card, what's that?

A. You know, one of the bus cards.

L. Bus passes?

A. Why did you not want to take one of them?

L. Och I was...

A. You're own feelings about it.

L. It would be a lot cheaper. See I went through a medical for that, what you're talking about and he says I was classed that I could work again. That's why I never got a pension book, 'cos I only get a Giro. That's what they turned round and says, I was classed to work. That's why they wouldnae give me a pension book I went through a great big medical for... I says to Mary, 'I'm not going through that again, it was just a waste of time'.

A. Would you want one if you could get one?

L. What?

A. A Zonal.

L. A bus pass?

A. Aye. Would you want one if you could get one?

L. If I could get a bus pass I would, 'cos it would be cheaper. I wouldnae get a pension book 'cos I'm too late now.

A. So when you went to the Centre and that, how did you find going to the Centre and the people that are there.

L. They're all right - at first it was strange.

A. In what kind of way.

L. Just you feel funny, going to the Centre 'cos I was used to being in the house.

A. How about the folk you work with? What is the difference between folk you work with there and the folk you were working with when you worked before.

L. At the Centre it was different from the folk I worked with before. It was nicer because you're no in beside machines.

A. Do you think there's any difference between folk you work with now and the folk you worked with before?

L. Aye working in a work place and working in a Centre is different isn't it. 'Cos you're working for money, ken what I mean?

A. Are there any other kind of things?

L. No... Because they're some handicapped ones. You think you're worse 'till you've seen somebody worse than yourself. That's one thing ken, 'cos I think I'm lucky, you've maybe seen Jane Gillespie. I bet she wishes she could walk. It doesnae bother her now but maybe sometimes it does 'cos the day she was going to see somebody, right, in the car. When I saw her getting thingmyade into that car, it made me wonder. You ken what I'm meaning, I bet she wishes she could walk inside the car. It's true what I'm saying though eh? Instead of getting lifted into a car. Do you no think so. It made me think I'm lucky that I can move. 'Cos she's in the group home in xxx St.. Her and Mark in xx St..

A. Where is she?

L. At xx St., she comes here sometimes. She's got a headpiece and she can type out, what to tell you things. This headpiece and it tells you what she's saying.

A. That's marvellous.

L. You could have a good chat with her 'cos she's good.

A. That's great. Are there other people you feel,. In what way do you think Jane is different from you then.

L. Jane. I'm no saying she's different, she's brainier than me because she can use a typewriter. It's only because she canny walk.

A. You said she's worse than you. What did you mean when you said that.

L. Worse.

A. That's what you said.

L. Oh I never meant it that way, I mean, I feel sorry for her but I wouldnae show any of it. That's what I'm meaning and I'm lucky I can move. I'm probably saying this all the wrong way round.

A. No, no, you're saying...

L. I'm no saying she's worse, I'm meaning I can more and she cannae walk, you know. That's what I'm meaning... I'm saying this all wrong.

A. No not. As usual you're making a lot more sense than I am. I'm probably confusing the issue marvellously. No, honestly, what you are saying is really, really good.

L. I'm just thankful I'm the way I am. It just made me wonder, when she was getting lifted into that car.

A. If you could change in any way, what way would you like to change?

L. How?

A. If you could change anything about yourself. You know, you said if Jane, if she wanted to walk or whatever. If you could change anything about yourself what would you change?

L. Nothing.

A. Nothing?

L. Nothing.

A. Nothing at all?

L. No, just to stop being snappy with folk.

A. You're not at all snappy.

L. No, no wi' you...

A. How do you feel folk outside the centre treat you?

L. They treat me allright. I'm only at the Centre Monday and Thursday. You dinnae really see many people. Because I go to the playgroup every time on a Monday and I'm only in the Centre from twelve o'clock to half past three and I use a typewriter. But after that you dinnae really see many folk. By the time I come outside it's time for my bus.

A. Do you see many folk outside the Centre?

L. No, no really.

A. Would you like to.

L. No.

A. How's that?

L. You don't really see much of them at our Centre. After you're finished, that's you 'till the next day.

A. How do you feel about that?

L. I feel allright about that.

A. But, I mean, seeing other folk from outside the Centre, folk from outside, you know?

L. I speak to everybody that speaks to me.

A. What are folk like?

L. They're all right.

A. When you meet them.

L. They're fine.

A. Have ever been outside the Centre on any trips or anyting?

L. No, we were supposed to be going to a Rotary club thing before the holidays.

A. That sounds good. How do you find folk are like when you go out on these trips?

L. They're nice, They gave us crisps and juice and everything you want you can eat. All for nothing.

A. Really?

L. Really, and it's no just the one thing, you can take loads of stuff and they didnae say anything.

A. Do you say. What would you sy you're best at doing in the Centre?

L. Well typing. I'm learning that.

A. Is there anythone else who's better than you at it.

L. No, 'cos you dinnae really do that much at the Centre.

A. Really, how do you feel about that?

L. I think I learn more at college.

A. Really. What are folk in the college, like with you?

L. They're good, when Mrs. T. (lecturer at college) seen me at first she thought I wouldnae last, 'cos ken how it took me a while in here (Key hostel) to adjust, but she says I've improved from then.

A. How do you get on with other students and that?

L. Allright.

A. What about folk doing other courses?

L. They're allright wi me as well, at first they were strange. I think you keep to yourself in that college sometimes to.

A. In what way were they strange?

L. Well sometimes they were nasty, that's when I first started. But they are allright now.

A. In what way were theu nasty.

L. Just ken what like young ones are, sixteen year olds, boys, ken what I mean. Shut the door on your hands and all that . They'd try to anyway. But that's when I first .... cos ken, they wouldnae ken me. They ken me better now.

A. Good. How about staying here then? What differences does that make to your life?

L. Staying here? I don't know, I am on a flat through time but I think I'd be feart.

A. Why would you be feart?

L. Because to be on my own. I ken I've got to think of that.

A. Do you find it hard making friends then?

L. Aye.

A. How do you think that is?

L. Well it took me a while to get used to in here.

A. How do you feel folk are with you, say?

L. They're allright, just yin [one] lassie in here [fellow tenant at Key Housing], but that'll maybe change.

A. Do you ever wish that staff at the Centre or here (Key housing) treated you as though you were more able to look after yourself?

L. Sometimes I think that, oh I ken Jean's (Key staff member) got her way, but sometimes she niggles I think. I'm maybe sayiong this - I don't want it to go back.

A. No, nothing'll go back.

L. Jean, maybe by being younger than me, sometimes she bugs me.

A. In what way?

L. This won't go back.

A. No.

L. Sometimes she's in the kitchen when I'm trying to make my dinner. I'm older than her, I ken what I'm doing. But I suppoe it's just her job.

A. What's she saying.

L. Well she sometimes says, ken 'Hurry up.' I don't like saying that about her but it niggles me.

A. No. Well it's a good point. Do you get treated like that by other people. What about at the Centre do people...?

L. No, they treat me allright.

A. What is it the terms people are called who go to the Centre.

L. Well some of them are physically handicapped.

A. Are you called 'members' of the Centre or are you called 'clients' or what?

L. What.

A. Is it clients people are called?

L. I don't know. Clients? What do you mean?

A. I don't know, is it workers? You know, what is the sort of thing people say? What is it workers, clients or members? Different terms are used in different Centres for folk working there. I was wondering what it was in

Grangemouth; clients, trainnees or members. What do you feel you should be called there?

L. They just say 'clients' to us?

A. Clients, how do you find that?

L. That's allright.

A. Has anyone ever made you feel or treated you as though you were different?

L. No. They just treat you just the same as in here [Key housing].

A. At the Centre?

L. Just the same?

A. What do they treat you like in here then?

L. Sometimes they annoy me..... I don't need anybody to turn round and say to me, 'what are you wearing for your dance? Ken what I'm meaning. That annoys me. I ken what I'm wearing. I dinnae like folk - ken what I'm meaning. I like to wear what I want to wear no what they tell me to wear. I'm old enough to make my own decisions. That annoys me.

A. What's that?

L. Folk telling me what to dae. In some cases I'm right, in some cases I'm wrong.

A. Does that happen a lot?

L. No, very rarely.

A. What about the Centre?

L. Oh the Centre's boring sometimes. Oh the Centre got me in here. I can't pack the Centre in. If it were doing anything, like what Bob says, digging gardens I would dig the garden out there 'cos you only get £4 bus fares. What's that, that's only your bus fares, what's that?

A. What does that make you feel like?

L. Sometimes I feel like as I could do a job, but Kathy says I can't 'cos I'd have to earn a lot of money [to pay the Key rent]. Susan [Key staff] .... thinks I'll never work again.

A. Why is that?

L. Where am I going to get a job. You ken that yourself.

A. What do you feel when people outside ask where you work?

L. I wouldnae feel anything 'cos I'd just say I was at a Centre. I always used to get tellt I was stupid because I didn't have a job.

A. When was that?

L. Oh that was years ago. When I left the school at first, they mentioned the word work and I went daft - I didnae want to work.

A. How's that?

L. I don't know, I just didn't want to work. When my mother mentioned that, I ran away. I'm no kidding.

A. Why did you do that?

L. I don't know but whenever she mentioned work - you'd think it was a bad word. Honestly, I'm no kidding, I did... I mean there were jobs then, there are no jobs now.

A. Yes, that's true. What was it that upset you about it then?

L. Just the mention of work.

A. Was it the folk you weren't keen to work with or was it just doing the work?

L. I just didnae want to work when I left school.

A. How do you find other folk that work at the Centre?

L. Staff and all that?

A. Uhu.

L, They're good, Anne's (staff member at the ATC) quiet now though. She's changed now, she's went awful quiet, she used to be cheerier. Ken.

A. Really?

L. I think she's changed. She argued with me - she wouldn't have agreed with me before. She says 'I have changed a lot'. She turned round and said that to me. She wouldn't have said that to me about 2 years ago. Honestly. She says it's something to do with her own course and I thnk she's missing her son. He was only 13 when he went and stayed in a boarding school. That's maybe what's wrong with her, she misses him. He's away 'till he's 17. Maybe that's - it's taking her a while to get used to it.

A. That's very young isn't it?

L. He's only 13.

A. Do you feel - you say there's some people who were in a sense, different from you in the Centre. Is anybody different from you here?

L. No.

A. Do you think there are people here who can do more than others?

L. Aye there's really only one - Jim. He's the oldest, he's lazy. But Mary (staff member at Key Housing) says he'll never move on.

A. How's that?

L. 'Cos he's got a - he cannae really do much skill - I mean it takes him hours and hours. Mary say he'll be one of the persons who'll be here for all his days. He'll no move into a flat. His mother brought him because she wasn't wanting to put him into xxxxx (local mental handicap hospital). His mother's 84 and Jim's 47. But he's one of the persons that'll never move (from a Key Housing hostel). He's just one, out of all of us.

A. Do you think there's any difference between him and other people who live here then?

L. Well he's lazy 'cos he waits on the staff making his tea for him. From what Mary says he's not got the ability I've got 'cos when I'm on my training day I do my work and that's me finished. When he's on his training day it takes him 'til night time to finish it - before he's finished his ironing 'cos he's slow. I shouldnae say that about him.But it's the same with his supper, he'll wait 'till 11 o'clock 'till he has something, wating on somebody making it for him. Well, that's what Mary says, he was shifted - only put in here, he'll never move. He's the only resident that'll no move.

A. Would you think there's any difference between any of the other people that live here then?

L. All the rest do thir chores.

A. How do you feel about handicap and that then? You were saying earlier on - how do you feel about this sort of thing?

L. I like all the handicapped folk though. I'm no caring if they're in wheelchairs or no, I like them. I wouldnae say anything about them 'cos it's no their fault the way they are.

A. Do you think people who are handicapped are different from anyone else?

L. No, they're just the same, do you no think so?

A. Aye, yea.

L. 'Cos it's no their fault they were born no to walk. It's just something that happens I suppose 'cos Jane's (physically handicapped person at the ATC) brainy, she can do things I cannae do. Likes of working typewriters. She uses this head piece to count money.

A. Do you feel there is anything you can't do that other folk can do?

L. I can do quite a lot in the Centre.

A. Do you thnk there's some people in the Centre who can do more than others?

L. Well Ellen's class, they've no got the capability I've got, they're slower 'cos they cannae tell the time. I can dae all these things. It's just 'cos it's their abilities, Maureen says.

A. Right, right..

L. You've got me saying that too!

A. What would you say were your best points then? Tell me what you think?

L. Falling asleep..... going to the toilet.

A. Tell me your best points.

L. Falling asleep, I dinnae ken if I've got any best points. I can dust and polish and things like that. I couldnae dae that at first.

A. What other things would you say are your best points?

L. I can hoover, that's all, and fall asleep.

A. Anything about yourself you like, you thnk is good?

L. No, I don't think so.

A As a person, do you think there's anything else?

L. I'm being honest about it, aye falling asleep.

A. Don't be rotten, is there anything else you think.

L. I've never thought about it.

A. Do you think you've any bad points? What do you think they are?

L. Sometimes when the staff niggle me, when they say 'the voice from the gallery that annoys me, 'cos there's no need for that. That's when I sometimes feel I'm no liked, maybe I'm imagining.

A. What do you feel are bad points that you don't like.

L. No, no, no dear.

A. How do you think the staff treat folk who live here then?

L. See all the Key workers. Mary was saying (this'll no go back?) Mary says like the rest of them. See when I want to talk, I'll no talk to Mary but all the rest I go and talk to. Mary doesn't understand why I don't want to talk to her.

A. But why is that?

L. I don't know, it's just a feeling that I get because I dinnae like to pester her.

A. How do you see Mary then?

L. I like her, don't get me wrong. But that time round about me being selfish and no going home, kinda angered me. 'Cos mind what Mike was saying what it meant. It angered me that, so I said I'd better go home now. 'Cos Jean (another staff member at Key) says, 'one point is you'll no always have you're mother, two is she's no getting any younger and three is she could die'. And she says, 'just say she died and you didn't go and see her, you'd have that on your conscience'. She's right enough there. But no way do I take, I dae get things, I wouldnae have clothes if it wasn't for her (mother). But I don't know how I'm selfish that's what bothers me.

A. See when you go out and that, how do you find folk when you go out?

L. Allright.

A. When was the last time you went out?

L. I go out on a Saturday.

A. Where did you go?

L. Falkirk.

A. Where do ...

L. Shut up. You're like my mother.

A. Like you're mother, why?

L. Be quiet, you're as bad as her.

Side 2 Of Tape.

A. That's rotten. Are you no feeling well?

L. I'm no feeling very well the night. I dinae mind chatting it takes my mind off it.

A. But what you are saying - people are good. And from what you're saying you like people to tell you what to wear?

L. I ken what I'm putting on, ken what I'm meaning?

A. Uhu.

L. In a meeting like this I'm snappy, ken what I'm meaning. If I was feeling up to the mark. But that's what - sometimes I'm feart to say anything in case I'm one of the bad yins, I don't know it's a feeling I've got inside. I often have nightmares thinking that I'm no liked by some of them (staff). Mary says that's rubbish.

A. Have you felt that for a long time though?

L. Just for the past 2 or 3 weeks. Sometimes I think about my father, ken 'cos he was just across there - 5 minutes away [in local psychiatric hospital]. I think that's what gets me depressed. I'm no feeling well but I wouldnae tell the staff I wasnae well. You see that's what Mary says, if you're no well, you tell. I'll suffer it, I just go quiet.

A. What difference would you say there was in the way Mary used to treats you and your mother treated you.

L. Mary says she's no fell out with me, but she says she would wring my neck if I was selfish, no really wring my neck ken, you know what I'm meaning, be hard on me. If I was to treat - 'cos she says she wouldnae treat her mother like that. She's maybe got a point though.

A. You know at home what you're mother used to be like with you. What is the difference between how your mother used to be with you and the way Mary is with you?

L. What time is it?

A. It's eight forty nine, time flies.

L. Well, Mary's understanding, don't get me wrong, they're all understanding. Mary's got a different way from my mother, ken what I'm meaning, she says I shouldnae be like that with her [her mother] and if it wasnae for her I wouldn't be in this place, my sister spoke to me too. And young Jean she says the 3 points, you'll no always have her, she's getting on and she could die. I says, 'well if she dies, I'll die with her'. Mary said, 'you cannae...' Oh, I know the other point was I was a lot younger, ken, than her. And eh, that why I don't think my sisters comes much, I don't go and see her. That could be another thing as well.

A. Do you see much of your sister?

L. No really.

A. How did you used to get on with your sister?

L. Fine, but my mother says she's working now but it wouldn't take her long to come and see me. Once I've been to Butlin's and get my £10 pocket money again I'll go more and see her. 'Cos it's dear to go to Henderson, it's dearer than xxxx.

A. When's the last time you went to see her?

L. When I first came in here, once, I'm better being honest about it. Honestly, that's what, I've been here 8 months. Once.

A. See when you were young, how did you get on with your sister?

L. Oh, we fought like cats and dogs. Sisters do though eh? he says 'You do this, you do that.' But don't get me wrong, she's no mean. But no way would I ask her for money. In all the years I haven't asked her for a penny. Well, she's got her ain family. If I'm skint, I'm skint, that's the problem. When I used to say, 'Right mother ...' I cannae dae that now though. I can take bus fares off her, Mary says. Oh, Mary would be angry if I took money off her.

A. Who from?

L. My mother.

L. Well, Mary says I'm no staying with her, she is an old age pensioner, ken what I mean. She feels it harder now though, but it's no wi' me. She says things go up, eh.

A. Does she work?

L. She works in a school, she's coming up for 64. But I says to Jean, and I'm no caring if she came in the now, 'if she dies I would die with her', 'cos my heart would break. Maybe that's the point of being here eh, they're thinking of the future.

A. What are your wishes for the future then?

L. Well I want to get a flat outside and share with Sandra, I tellt you about that, and to be more independent.

A. What does that man to you - being independent.

L. Well I had everyhing done for me all my days. I didnae ken what it was like to use a washing machine and put stuff in and wash dishes. I got all that done for me.

A. Does it mean anything else for you?

L. It means I'm more independent. My life's changed, 'cos I would just be the house [at family home] sitting getting bored. 'Cos you get a laugh and a joke [in Key Housing].

A. How did you feel when you used to sit in the house?

L. Oh, miserable, 'cos I just used to look at four walls, that was befre I went to the Centre.

A. Did you ever want to go outside and meet people?

L. No.

A. How was that?

L. I shut myself in the house.

A. Why did you do that, though?

L. I don't know.

A. Did you want to make friends from outside?

L. Well the place I stayed in was like a prison camp. 'Cos say you went up the stairs to your bedroom, right, if you look outside, they all stared at you in the window... See in here you can go upstairs to your room look out the window and there's naebody looking in, it makes a difference. Ken what like it is yourself, you can go up the stairs look out your window if you want, even though folk are staring. But they felt as if I was staring at them. See when I go up the stairs to my bedroom, I look out, there's naebody there though.

A. Did you want to make more friends then outside?

L. No.

A. How was that?

L. I just liked shutting myself in.

A. Why did you want to shut yourself in? What was it that made you not want to meet other people then?

L. I don't know, I'v never thought about it.

A. What were folk like with you.

L. They were two-faced.

A. Were they? How's that?

L. 'Cos one minute they were speaking, the next minute they didnae.

A. How was that?

L. It was just the way I feel, like. I wouldnae tell them I wasnae feeling well in here. Mary says I'm wrong, she says I should but I wouldnae, I suffer if I've got a cold. I just go up the stairs and then they say you're shutting yourself in, see that's the problem. When I was at home, if I said I was going up the stairs, then that was that and they'd just leave me alone. In a place like this if you're no well they think you're kidding. Right enough I didnae hide now but when I first came in I did.

A. How was that?

L. Just nervous ken.

A. What were you nervous about?

L. I don't know, just thinking everything I was doing was wrong, you ken?

A. Who made you nervous?

L. Well you ken Stephen is nice [deputy at hostel] but I felt strange with Stephen at first. Now I get on allright with him.

A. What about people from outside here. Do you know any of the neighbours?

L. Just Liz next door and her mum.

A. Any other folk you've got to know?

L. Aye, there's Angus, he's out there, and Mrs. Thompson and her son, that's all.

A. Would you like to make more friends from outside hee?

L. No, I'm happy the now with the folk I've got. Maybe through time when I've got a flat but Mary says take one stage at a time. She says it doesnae just come, it takes a couple of years, she's right enough.

Sometimes I feel that Stephen, Colin [Officer in charge at the Key hostel] and Mary dislike me, and Catherine [staff member at Key] and the rest didnae. I shouldnae say this but it's just a feeling I get.

A. Why do they feel they don't like you?

L. I don't know what it is, I seem to do the wrong thing sometimes, ken. 'Cos sometimes when they're saying 'have a bath', that annoys me at my age, being tellt, reminded.

A. What does it make you feel like?

L. Sometimes I feel like bursting out greeting - but I dinnae show them it. I just go upstairs and have a bath and greet, and then wipe my eyes and no say anything.

A. Why does it make you want to greet.

L. Because I ken when to have a bath I don't need to be reminded.

A. How do you feel you're being treated then when people tell you that?

L. I don't know. Especially when you're amongst a crowd [at Key Housing] and they turn round and say, 'have a bath'. That's annoying to me. My mother says they're only doing their job though.

A. Do you think it would be fair enough if they said othr people here were to have a bath?

L. There's two or three of them dinnae have them, they do have them, but no as much as me. Like what Mary says, men don't need to have the every night.

A. Do you think it's bad that they say that to you just or do you think it's bad they say that to everyone?

L. They say it to two or three of us.

A. Do you think that it's bad that they say it to everyone or do you just feel personally it's bad?

L. Personally, how many baths do you have?

A. Not a great deal, do you think it's fair enough they say it to the other people though.

L. Aye just me and Anthony and Anne get tellt.

A. Do you think it's fair enough that they say to Anthony and Anne?

L. I don't know, they don't seem to bother. But Jim that's been in here, God knows when he had a bath. Ken Jim, that's what I mean, they take him and shove him in yin (one).

A. If you could change anything in here what would you change?

L. I don't know you couldnae really change much.

A. What about home then? Did you get told to do things at home?

L. Aye, do the dishes and that. You couldnae sit inside here and look out the window 'cos if you did folk would think you'd be staring at them. It's the atmosphere of the old town (family home).

A. And your mum, how do you think you're mum was like?

L. She still misses me, dinnae get me wrong, but if I did have plenty money I would go home every night, 'cos I ken it's only a 5 minute journey. That's the only thing that bothers me.

A. Did you ever wish, when you were at home, that your mother treated you as if you were more able to look after yourself?

L. Sometimes, but I go a bit spoilt.

A. In what way?

L. Like I got whatever I wanted, especialy plenty of money. Now I feel the pinch ken what I'm meaning.

A. Were you happy at home though.

L. No, no really.

A. What do you think made you unhappy?

L. Well being honest I got everything going in money, I didnae need to worry about money, like here you've got to live off a budget.

A. Are there any things you would have liked to have done at home that you never got a chance to do?

L. No.

A. What about here are there things you'de like to do?

L. No, I would like to go to 10 pin bowling. Mary says she was going to take me to the 10 Roller Coasters but I said I'd rather go to 10 pin bowling because 10 pin bowling would be good.

A. Did she take you?

L. No, she never took me yet, but she is going to, me and Sandra.