

Department for Work and Pensions

Research Report No 188

Diversity in disability

Exploring the interactions between disability, ethnicity, age, gender and sexuality

Donna Molloy, Tim Knight and Kandy Woodfield

A report of research carried out by the National Centre for Social Research on behalf of the Department for Work and Pensions

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Summary

Introduction

The *National Centre for Social Research (NatCen)* was commissioned by the Department for Work and Pensions (DWP) to undertake a study exploring the interaction between disability and other personal characteristics, chiefly: ethnicity, gender, age and sexuality.

Existing research and policy information suggests there are three key areas where 'compounded' or 'multiple' disadvantage might occur. These are in the spheres of education, employment and service provision. In addition, there is also existing evidence of the scope for similar issues arising in people's social lives and in their relationships with friends and family.

The aim of the research was to provide a greater understanding of the life experiences of a diversity of disabled men and women with different ethnic identities, of different ages, and of differing sexual orientation.

The specific research objectives were to explore the attitudes and experiences of disabled people from different groups, their perceptions of social exclusion, and their experiences of discrimination and prejudice, within the context of factors such as ethnicity, age, gender and sexuality.

The study was conducted using a qualitative approach to allow the full exploration of the complex conceptual and personal issues surrounding disability, ethnicity, age, gender and sexuality. The research was designed to include a combination of one-to-one depth interviews and group discussions.

Respondents were recruited through two methods; by re-contacting people who had participated in previous studies and associated surveys, and by contacting people through local voluntary organisations for disabled people.

Throughout the fieldwork, provisions were in place to ensure the research was as accessible as possible, not only to people with different types of disability but also for people whose first language was not English. This included the use of BSL

interpreters in interviews with deaf respondents and the use of researchers with skills in languages other than English to interview respondents who wished their interviews to be conducted in their first language.

Identity and disability

Exploring self-identity is a hugely complex issue both in terms of research approaches and in terms of the challenges it presents to participants.

A persistent finding was that people were reluctant to single out individual characteristics, such as age, disability, or gender as dominant features of their identity.

Of all the different facets of identity being explored in the course of this study people were most comfortable engaging with the concept of ethnic identity.

Even where people were comfortable with seeing their identities as formed from several different sources they remained resistant to attributing experiences of discrimination to one or another factor.

Findings about the role of disability in self-identity reflect the evidence presented in the previous report¹. No significant patterns were found between ethnic groups to suggest that this is a factor which affects whether or not a person will perceive themselves as disabled or not. Similarly, there was no evidence to support the premise that sexuality might affect individuals' likelihood of describing themselves as a 'disabled' person.

Evidence relating to the relative importance of different elements of identity suggests that, compared to ethnicity and sexuality, for gay and lesbian participants, disability was less immediately seen as a defining characteristic of personal identity.

Ethnicity was the one characteristic that participants were most comfortable using when describing their self-identity. Across all samples, participants used some form of ethnic label to describe themselves, but there were no patterns relating to age or gender to suggest anything more than personal preferences affected the level of comfort people felt in describing themselves in terms of ethnicity.

Ethnic identity, in various forms, was frequently cited when people were asked to discuss their personal identities. However, the importance of this element of identity to people's lives varied in intensity. Differences were also found across the five different ethnic groups who took part in the study. Principal amongst these was that South Asian and black African and Caribbean participants tended to volunteer some description of their ethnicity in their initial descriptions of their identity. White participants were less likely to volunteer their ethnicity without questioning.

¹ Woodfield K. et al. (2002) *Disabled for Life? - Attitudes towards, and experiences of, disability in Britain*, DWP Research Report 173, CDS: Leeds.

Sources of ethnic identity included: country of birth, or the country of parents' birth, country of permanent residency, personal affiliation with a regional area in their country of birth/residency, use of common language (often linked to the previous), membership of a religious or faith community, and race or colour.

Age was rarely cited as a key element of personal identity. However, women were more likely to describe themselves in terms of gender than men and this particularly true amongst women from minority ethnic groups.

Sexuality formed a key component of personal identity for lesbian and gay people, with only a few exceptions.

How people viewed the differing components of their personal identities interacting was mixed. Some felt unable to isolate single facets as central to their identity whilst others were happy to. Where people were comfortable in prioritising one aspect of their identity it was either because this facet was valued above all others as providing relevance to that person's life or because it was perceived as the aspect of their identity which required the most active consideration in their daily life, that which makes life most challenging and is likely to produce barriers which need to be overcome.

The relative priorities of people's sense of self-image change over time and vary depending upon the environment they are in and the nature of the people they are interacting with. Some change over time may result from disruption to established life patterns, for example the onset of disability, migration or awakening sexuality. Other change evolves gradually as people age or take on new roles, as parents for example.

Understandings about what constitutes disability were similar to those found previously, with people broadly adhering to either a social or a medical model of disability. Similar patterns showed age to be a critical factor in which attitudes people expressed about the nature of disability.

As with the previous research, there was a widespread belief that non-disabled people, unless they had a close disabled friend or disabled family relative, lacked awareness about disabled people's lives. As will be shown in the following chapters, disabled people frequently felt they had experienced prejudice, or different treatment as a result of this lack of awareness and knowledge about disability.

There was often the sense that experiences of prejudice and different treatment were exacerbated when non-disabled people encountered gay disabled people or disabled people from minority ethnic communities.

A primary cause for poor reactions and lack of disability awareness was a perceived absence of disabled actors and presenters on mainstream television programmes. Disabled minority ethnic people argued that the problems with the mass media representation of disability were compounded when ethnicity was added to the equation.

Personal and social lives

The effects of disability on childhood experiences varied considerably across the sample and experiences of family life reflected a broad range, with 'over-protectiveness' on the part of family and friends being cited as one key difficulty. Disability was reported to have specific effects for disabled people from the South Asian groups. This related to stigma perceived to be attached to disability within this community which could lead to disabled people being 'shut away' by families. In particular, women were felt to be particularly affected by this and felt to lack opportunities for education, work and marriage. Language differences between minority ethnic people born in the UK and their parents also complicated relationships.

Being disabled was felt by people from all groups to affect the experience of finding a partner and forming relationships. People from white, black and other minority ethnic groups felt that disability can '*get in the way*' of forming relationships because people '*see the disability rather than the person*'. Among people from South Asian groups, there was evidence that disability can have some very specific effects upon people's, particularly women's, chances of forming marriages and partnerships.

People had received a range of help and support from their families when disability was present in later life. However, feeling dependent or a burden upon family members did cause some difficulties, as did the sudden onset of disability which was frequently reported to disrupt the balance in relationships, even if only temporarily.

The way in which people had responded to the emergence of their sexuality and the realisation that they were lesbian or gay varied. This did not appear to be linked to the presence of disability. Older lesbian and gay people had often concealed their sexuality for years, some were still concealing it for fear of the impact on older family relatives. Others, who had disclosed their sexuality, had received mixed responses, whilst some were supported often there were, at the very least, temporary disruptions to family relationships. Evidence also suggests that being disabled can make it more difficult for parents and family to accept and deal with a disabled person being lesbian or gay. This can be because of parental concern and fear their child may suffer '*multiple discrimination*' due to this combination of characteristics.

Being lesbian or gay was felt to be harder for disabled people than it was for non-disabled people because of society's attitudes towards disability and sexuality. In particular, those with visible disabilities felt it was hard for society to accept the idea of lesbian and gay sexuality among disabled people.

Disabled people included in the sample were involved in a range of different types of social and leisure activities. The inaccessibility of social activities was a dominant theme in people's accounts of how their social and leisure activities were affected by having a disability.

Disabled people often reported losing friends with the onset of disability and how their opportunities to make friends and expand their social circle were affected by

factors related to new, or growing, barriers experienced in accessing the everyday world and the changing attitudes of friends.

People's experiences in their neighbourhood and wider community were mixed. Some spoke of living in a supportive community and had neighbours who they could call on if they needed anything. However, others had experienced harassment in the area in which they lived. In some cases the reasons underpinning these different types of harassment were clear. Sometimes, however, the characteristic at the root of these types of intolerant reactions was impossible to unravel.

As might be expected given the ethnic mix included in the sample, people followed a range of religions which included Christianity, Judaism, Hinduism, Sikhism and Islam. Religious belief was often used as a coping mechanism in one way or another and provided a clear source of strength to people from all groups in coping with the experience of disability. The importance of religion in the lives of some of the minority ethnic disabled people meant that the physical accessibility of religious ceremonies was a source of concern. Ethnicity was rarely cited as a factor in access to religious worship. White respondents were much less likely than the minority ethnic groups to cite faith communities as being important in their lives. However, people in this group who did attend church and religious ceremonies cited far fewer problems around the accessibility of services than did minority ethnic respondents. Some of the lesbian and gay disabled people had faced intolerance of their sexuality within their religious community.

Statutory day centres and local voluntary groups were an important source of social activity and support for many disabled people. The findings from this study and positive accounts of those who had become involved in local clubs or groups for disabled people confirm earlier research in suggesting that such groups can be a lifeline. Some problems were experienced by lesbian and gay disabled people where it was felt that such organisations were less inclusive than desired. People from minority ethnic groups tended to attend culturally-specific disability groups and organisations. This type of provision was viewed as very important, particularly for older people from this community. People's experiences of these culturally-specific disability groups were unanimously positive.

The lesbian and gay community was criticised for its response to disabled members. Some lesbian and gay people commented that the 'disability community' was much more accepting of lesbian and gay people, than the 'lesbian and gay community' was towards disabled people.

Experiences of education and training

Levels of educational attainment among sample members covered a whole spectrum. This ranged from people who were very highly qualified to those who had not received any schooling. Ethnicity was a factor affecting experiences of education. Disabled people from all of the minority ethnic groups had often not received a great deal of schooling, both in the UK and elsewhere (for those who had migrated to the

UK). However, some of those in the latter group believed that their educational opportunities had been enhanced by migrating to the UK. Gender was also relevant with lack of attendance at school being more common among women than men in this sample. However, given the qualitative basis of this sample, it should be noted that these findings are not statistically representative of the population at large.

Disabled people from all groups had received varying levels of support and encouragement around entering education and attending school. Parental attitudes towards education were a significant influence upon how important education was perceived to be by disabled people and the type of education people had accessed.

Experiences of compulsory education were similar to those already described in the previous report, both in mainstream and special schools. However, some new factors emerged as negative influences on school experiences, particularly for those whose disability was located primarily within specific minority ethnic groups (such as sickle cell anaemia). In such cases, people felt there was a particular lack of awareness within schools which often led to children being refused equal access to daily life in school.

Ethnicity, rather than disability, was sometimes cited as the cause of negative school experiences, particularly where children had been the only, or one of few, black or Asian pupils at their school. Experiences of racism were reported, and for those who moved to the UK during their early childhood, language barriers were also reported to cause difficulties, even if these proved to be transitory.

The experiences of the lesbian and gay sample in relation to disability mirrored those of other groups. Disability was often the only issue which raised problems for lesbian and gay disabled people at school. Issues relating to their sexuality were much more exceptional.

Support for mainstream or special schools was mixed. Overall, there were people who argued equally strongly for each type of schooling and many of the views that were expressed mirror the findings of previous work.

Disabled participants had participated in a wide variety of courses and further education subsequent to completing compulsory education, this sometimes much later during their adult lives. Views about the accessibility and attractiveness of further education varied. For some young South Asian participants, continuing education was seen as a way of ensuring a route to independence. This was also cited by people from other groups who had a strong desire to live independent lives.

In contrast, older respondents had sometimes not considered this because the lack of adaptations that were available at the time they had left school had been perceived to create insurmountable barriers to attending further education.

Despite the benefits associated with participation in further education, negative experiences of post-compulsory education were also common. Difficulties created

by lack of awareness and unresponsiveness around disability were recurrently cited, as was the lack of suitable adaptations and equipment in mainstream universities and colleges. The significance of this factor differed with age and, overall, younger disabled people tended to describe having had more access to necessary adaptations. Different types of access needs were felt to be catered for, to varying degrees, within educational establishments. Physical access needs were felt to be better catered for than needs for academic support. Sometimes those with multiple disabilities commented that whilst one set of their needs were well provided for, others were neglected.

Racial discrimination was also mentioned in relation to post-compulsory education by some people from minority ethnic groups. Overall, this was more exceptional than different treatment on the grounds of disability. Although again fairly exceptional, some of the lesbian and gay disabled people also felt they had encountered discrimination in further education in relation to their sexuality.

Despite difficulties, post-compulsory education was seen as extremely beneficial by: helping to build confidence and self-esteem, providing opportunities to increase educational attainment, and, importantly, by providing people with the chance to meet 'others like them' which was found to have profound effects on the way some disabled people perceived their personal identity.

Significant progress was felt to have been made in recent years towards making education feasible for disabled people and removing barriers to this. In addition, attitudes towards the education of disabled people were also felt to have changed fairly significantly in recent decades.

Experiences or work

A range of positive attitudes were expressed towards work across the sample. These related to feelings of self worth, a sense of independence, overcoming feelings of isolation, and being able to earn money.

Decisions people made about whether to work (and the type of work they wanted to do) were influenced by the physical or mental impacts of their disability, knowledge and perceptions of workplace adaptations and support available, financial considerations, perceptions about the potential for prejudice and discrimination on the part of employers, and the advice of family members.

Fears that employers would discriminate on the grounds of disability were widespread. Ethnicity, sexuality, age and gender were seen as additional grounds on which employers might discriminate.

Family members were generally supportive around employment issues. There was, though, evidence to suggest that some younger disabled Pakistani and Indian people had felt discouraged from working by their families.

In seeking work, the main barrier reported was the attitude of employers towards disability. Employers were felt to be prejudiced against disabled applicants in a number of ways, by being: dismissive of the abilities of disabled people, unwilling to making adaptations in the workplace, and overly concerned about the amount of time disabled people would take off work.

The attitudes of some employers relating to the ethnicity, age or gender of applicants were also seen as additional barriers to finding work. In these cases, people described feeling that they had faced compounded disadvantage when seeking employment as they felt discriminated against both because of their disability and one of these additional factors.

Mixed views were reported about the assistance received in seeking work from Jobcentre and Jobcentre Plus offices. For example, Disability Advisors were sometimes criticised for not giving people enough practical support in accessing job opportunities. In contrast, however, people were generally positive about their experiences of NDDP.

Relationships with work colleagues varied. Prejudice based on disability was commonly described. Others described how they had also encountered prejudicial treatment from colleagues on the grounds of their ethnicity, gender or sexuality. This was in the form of racist, sexist or homophobic comments, and also social isolation from colleagues.

Treatment by employers was similarly mixed. In the most positive examples employers were praised for their flexibility and supportiveness. However, less positive experiences were also reported. It appeared that treatment by employers was determined primarily by the attitude of the employer to disability, but there were some instances where sexuality, ethnicity and gender were perceived to have been additional factors.

For those not in work at the time of interview, a range of factors were reported as having led to their situation. People had either taken the decision to stop work themselves or been made redundant or offered early retirement by their employer. People were unhappy about retirement if they felt they had been unfairly made redundant by their employer, and also if they had not qualified for a substantial pension when they stopped work. People who had been forced to retire at a younger age were also greatly disappointed by losing the opportunity to work during their adult lives.

Accessing support and services

Despite the generally positive attitudes towards claiming benefits, some negative attitudes were expressed. These appeared to reflect cultural differences between ethnic groups in relation to claiming benefits.

The process of applying for benefits was perceived to be over-complex and time consuming, to the extent that some people were deterred from engaging in the process at all. Language barriers exacerbated the difficulties of the process for people from minority ethnic groups whose first language was not English.

People in the sample reported receiving help or advice in applying for benefits from a range of sources. These included formal sources, such as Benefits Agency/ Jobcentre staff, GPs, and social workers, and also more informal sources, such as family, friends and voluntary organisations for disabled people. It was clear that these sources of help and advice had often proved crucial in helping people access benefits.

In terms of informal sources of help and advice, disability organisations were widely praised by people in the sample who had accessed them. As well as information about what they were entitled to, people also reported receiving practical help with completing forms.

Health services were also widely praised for the support and assistance they had offered. Nevertheless, there were those who reported negative experiences. In these cases, people were critical of the service they had received and felt they had been treated differently by health professionals because of their disability, ethnicity, sexuality, age and/or gender.

The information available about services and support for disabled people was routinely criticised as lacking. This was particularly noted at a local level with people reporting being unable to ascertain what, if any, local services were available to them. Information that was provided was also criticised for only being available in English.

There were variable experiences reported of accessing services for disabled people. The role of social workers, and other support workers, was often crucial in accessing services. People did not generally feel they had been treated differently by their social worker because of factors such as ethnicity, sexuality, age or gender.

Among Indian and Pakistani participants, some reported reluctance within their communities to access external support or services for disabled people, with families preferring to provide support themselves.

A number of problems were reported by people accessing housing services. These related to long waiting times and housing that did not meet their needs as a disabled person. Some Indian and Pakistani people had also been critical of housing if it was not large enough to accommodate their families, or if it was situated outside their local communities.

Experiences of accessing financial services were limited amongst those who participated. However, where people had accessed services, there were reported instances of discrimination by financial institutions on the grounds of disability, ethnicity and sexuality.

Exploring disadvantage

People differed as to whether or not they felt they had experienced discrimination or prejudice. Across all groups were people who reported discrimination as well as those who did not. Overall, disability, ethnicity and sexuality were all cited with a similar amount of regularity in descriptions of discriminatory treatment and prejudicial attitudes. Gender and age were also mentioned on occasion. However, overall, these factors were cited as being relevant much more occasionally.

The terms 'discrimination' and 'prejudice' were often used interchangeably. As found previously, these were often not perceived to be discrete categories. Discrimination was often defined as anything which treats certain sections of the community differently than others because of aspects of their identity. A distinction was made between 'overt', 'covert' and structural discrimination.

A number of factors were recurrently cited as sources of prejudicial attitudes against others. Overall, the causes of prejudice in relation to disability, ethnicity and sexuality were all felt to be very similar. Ignorance or a lack of awareness were prime factors, fear was also felt to underpin discriminatory and prejudicial attitudes.

It was not always easy for people to ascribe the links between an experience of discrimination or prejudice and specific aspects of their personal characteristics. In some cases, the links were made overt by those perpetrating the different treatment, on other occasions '*the subtleties of discrimination*' meant disabled people said they had had to make assumptions about why they had experienced different treatment.

The extent to which different groups included in the sample felt they were vulnerable to discrimination and prejudice varied. People from the black groups were much more likely to speak of prejudice and discrimination as being part of their experiences. The South Asian community was much less likely to speak of experiencing discrimination than the Caribbean, African, white and lesbian and gay groups. Also within this group, older people spoke less commonly of experiencing discrimination. The lesbian and gay group were also fairly likely to feel they had experienced discrimination and prejudice. Whilst some people were fairly conscious of having suffered discrimination and prejudice in relation to this aspect of their sexuality, overall this was more exceptional. Generally, experiences of this were more frequently felt to be in relation to disability than sexuality.

The tendency to perceive or acknowledge discrimination seemed linked to disabled people's levels of consciousness about the rights of disabled people and the 'social model' of disability.

Education and socio-economic position were felt to be key influences on people's experiences of discrimination. These factors, along with age and gender, were felt to be strongly linked to the likelihood of being discriminated against and also people's ability to challenge this when it occurs. These personal characteristics were seen by some to be just as important in heightening or lessening vulnerability to discrimination and disadvantage as disability, ethnicity and sexuality.

Discrimination and prejudice in relation to disability, ethnicity and sexuality were all reported to have similar types of impacts upon people who experienced them. Impacts included: lowered self-esteem and confidence; lowered expectations as to the type of treatment you are entitled to receive; decreased trust in others, with resulting impacts on people's willingness to socialise and interact; and, finally, debilitating effects on physical and mental health.

The concept of '*multiple disadvantage*' received mixed responses. Some people did not feel they had encountered discrimination or prejudice related to any aspect of their identity. Others felt that only one aspect of their identity had ever created issues or problems. There were those for whom this idea had no resonance and who disagreed with the idea that people might be inevitably disadvantaged by different aspects of their identity in combination. However, others believed the concept had salience to their lives. As with perceptions of discrimination generally, people in the black groups and the lesbian and gay group were much more likely than those in the South Asian groups to perceive this as relevant.

Certain combinations of characteristics appear to increase the possibility that people will encounter discrimination and prejudice, which can in turn, place multiple pressures upon self-esteem. The significance of this would appear to lie in the fact that this pressure upon self-esteem and self-identity must make it much more difficult for people to produce the very assertiveness which is said to be needed by disabled people in living their everyday lives.

Strategies for the future

Participants believed that a great deal of progress had been made in relation to the position of disabled people in society and that the opportunities for disabled people had substantially increased. The experience of growing up black or Asian or lesbian or gay in Britain was also felt to be very different now to how it had been 30 or 40 years ago. However, people from all groups felt that a great deal of prejudice and discrimination still remains against disabled people, people from black and minority ethnic groups and lesbians and gay men. Obstacles which relate to gender and age were cited less frequently and generally viewed as less significant than those caused by these other factors.

The extent to which people were aware of current policy initiatives or had views in this area varied greatly. Older people from the South Asian groups were least likely to be aware of current policy initiatives or to have strong views on them.

Among those with some awareness of policy and provision aimed at disabled people, a recurrent criticism was that this was inconsistent. It was felt that the services people received were often determined by what was available in the area in which they lived rather than by people's needs. In addition, another area of inconsistency people highlighted was the level of support and help available to people with different types of disability. It was felt that provision was far better for some 'disability groups' than others.

Some people in the sample were entirely unaware of schemes such as New Deal for Disabled People (NDDP) and were surprised that this type of provision existed. A degree of frustration was expressed about the fact that more had not been done to make them aware of programmes which might be extremely beneficial to them. There was also evidence of a large amount of misunderstanding about the requirements of NDDP. Despite these reservations, those who had awareness of the scheme, or who had participated in the scheme, were overwhelmingly positive about its impact.

Overall, the Disability Discrimination Act (DDA) was welcomed and the work of the Disability Rights Commission (DRC), in representing the rights of disabled people, received favourable comments. This said, however, legislation was perceived to be weak and a number of people commented that it should '*be given more teeth*'. Those who held this view also felt that the rights of disabled people were not forcibly enshrined in legislation and that new legislation should be introduced to help secure equal opportunities for disabled people. In contrast, others felt existing legislation was sufficient to ensure equal opportunities.

Strong support was given to the idea that society needs to change if disabled people are to have equal social rights. It was felt that to bring about social change it was vital to raise levels of awareness about disability among non-disabled people. Similar points were also raised in relation to raising awareness about the types of discrimination people who were lesbian and gay or from black and minority ethnic groups can encounter. It was felt that wider public understanding about the disadvantage that can be linked to different characteristics was necessary to augment policy and legislative change in these areas.

The importance of funding to provide adaptations and support for disabled people was recurrently emphasised. It was consistently felt that disabled people were denied the adaptations they needed largely because of the cost of these.

It was also felt that issues relating to disability should be considered as a matter of course in the formulation of policy, provision of services and in other areas rather than viewed as being a separate or side issue.

People from all groups called for the heightened involvement and consultation of disabled people in the formulation of all levels and types of policy. There are also calls to involve disabled people in delivery of services.

Existing services provided for disabled people were criticised for not recognising the diversity of the population of disabled people. Recognising the diversity of disabled people was felt to include providing specific or targeted services. This point was made particularly by minority ethnic disabled people who sometimes differed substantially from white respondents in their preference for specific services.

1 Introduction

The *National Centre for Social Research (NatCen)* was commissioned by the Department for Work and Pensions (DWP) to undertake a study exploring the interaction between disability and other personal characteristics, chiefly: ethnicity, gender, age and sexuality. The *National Centre* had previously conducted a major study of people's attitudes towards, and experiences of, disability.² This research highlighted how individuals' perceptions of their own and others' disability was likely to be influenced by socio-demographic factors such as age, gender and ethnicity. This, and other research conducted in the field, suggested that the interaction between different socio-demographic factors, and being disabled, might lead some disabled people to experience '*multiple*' or '*compounded*' disadvantage. For example, that the life experiences of older disabled people may differ from younger disabled people or that disabled people from minority ethnic groups might experience different treatment when searching for work than white disabled people.

Within the broad remit of the previous study it was difficult to explore in detail the ways in which individuals' assess their experiences of disability alongside their personal feelings about their ethnicity, age, gender or sexuality. The focus of the previous study was around individuals' perceptions and experiences of disability rather than the specific interactions between different types of personal identity and related experiences. Yet these issues are clearly key for policy-makers in designing and shaping policies which will be successful in overcoming barriers to the full inclusion of disabled people, from all walks of life, both in the workplace and elsewhere.

As a result, a new qualitative study was commissioned with a specific focus on exploring these complex interactions and to examine how and why people view

² Woodfield K. et al. (2002) *Disabled for Life? - Attitudes towards, and experiences of, disability in Britain*, DWP Research Report 173, CDS: Leeds.

their disability, ethnicity, age, gender or sexuality as affecting their life experiences.³ The research was commissioned to inform the Government's policies to promote equality by helping disabled people with different identities to overcome the barriers that may exclude them from learning, employment and other aspects of society.

This introductory chapter sets out the background to the study, the aims and methodology of the project, and the structure of the report.

1.1 Existing knowledge about diversity in disability

Existing research and policy information suggests there are three key areas where 'compounded' or 'multiple' disadvantage might occur. These are in the spheres of education, employment and service provision. In addition, there is also existing evidence of the scope for similar issues arising in people's social lives and in their relationships with friends and family.

In order to assist with the research design a brief review of existing literature, exploring the interaction between disability and other aspects of personal identity, was undertaken at the start of the study. Most published research which does explore issues of identity focuses on the interaction between disability and ethnicity. Even so, there was very little research evidence specifically focusing on issues for disabled people from minority ethnic groups. What did exist tended to focus on experiences of service provision, rather than education or employment. Similarly, few pieces of research explored specific issues looking at age, gender or sexuality and their relationships to people's experiences of disability. In addition to a paper review of the evidence the research team undertook a series of consultation interviews with key organisations providing information, support or assistance to disabled people. Representatives of these organisations were asked their views on the existence, nature and likely causes of 'compounded disadvantage' as well as providing key information about ways of accessing the target samples. The organisations interviewed included: GLAD, SCOPE, UNISON, DRC and GLA.

The following briefly reviews the findings from this preliminary stage of research. However, as this exercise was primarily undertaken to inform the research design, the review focused on policy-relevant research and was not a systematic review of all published work relating to issues of identity and disability.

1.1.1 Educational experiences

Research exploring the experiences of disabled people from minority ethnic groups

³ Discrimination on the grounds of disability, age, gender and ethnicity is currently prohibited under a series of separate pieces of legislation (for example the Race Relations Act, the Disability Discrimination Act). Further regulations outlawing discrimination on grounds of sexual orientation are planned to become effective from December 2003.

in education⁴ identified two key issues requiring attention:

- The low expectations teachers held about young minority ethnic disabled students and pupils. These were presented as having profound ongoing effects on attendance in education, achievements and future aspirations towards further and higher education.
- The isolation felt by young disabled people from other young people who share their culture or ethnicity, particularly apparent for those educated in special schools, outside of mainstream education, where representation of minority ethnic pupils is low. This was sometimes described as being compounded by a lack of cultural sensitivity, with pupils feeling their opportunities to observe religious or cultural practices were limited (for example, participation in religious festivals, eating food from their community, wearing culturally-styled clothes).

1.1.2 Employment experiences

Research relating to the experiences in employment for disabled workers from minority ethnic groups tends to focus on issues of discrimination, both in applying for job opportunities and in experiences once in work. Existing research suggested that the causes attributed to discrimination were complex, whilst some disabled people felt either their disability, ethnicity or gender were primary causes for different treatment, others described more complex reasoning, for example that the discrimination stemmed from the fact that they were both black and disabled, or female, Asian and disabled.⁵

1.1.3 Access to goods and services

Research relating to service provision covers a range of different areas including: public transport, health services, residential care, counselling, and advice. However, two key issues which cut across this broad category were identified by prior research: concerns about low take-up of services, and worries about the range of services offered.

The literature review and consultation interviews highlighted concerns about the low numbers of disabled people from minority ethnic groups accessing services. For example, interviews with SCOPE, and GLAD representatives all raised concerns about low numbers of disabled people from ethnic minorities accessing services. This concern was echoed in other research which demonstrates that disabled people from minority ethnic groups are less likely to claim benefits per se⁶ and for disability and access benefit initiatives. Similar concerns have been expressed in relation to the low numbers of young disabled people, and disabled gay/lesbian people accessing

⁴ Bignall, T. & Butt, J. (2000) ;A., Hughes-Dennis, C. & Swain, J. (2001); Hussain, Y., Atkin, K., & Ahmad, W. (2002).

⁵ Vernon, A., Hughes-Dennis, C. & Swain, J. (2001) ; Drake, F. (1999).

⁶ Bloch, A. (1993) ; Law, I., Hylton, C., Karmani, A. & Deacon, A. (1994) ; Nesbitt, S. & Neary, D. (2001).

services. The low numbers of disabled people from ethnic minorities accessing services was often linked to a perception of low awareness of services available in these communities. Specifically that: services are often not advertised widely, and knowledge of them is spread by word of mouth, and this often misses minority ethnic communities. Advice is available through disability support organisations and local groups but few disabled people from minority ethnic groups are members of this community. Finally, the information about services that is available is often not provided in the range of languages necessary to make it accessible to people from a range of different minority ethnic groups.

Following on from this were discussions about how, or why, different groups within the disabled population might be discouraged from taking up services. For example, that disabled people from minority ethnic groups are discouraged from accessing services by the perception that services are intended, or designed, for the white population; that younger disabled people are discouraged from accessing services that they perceived as being for older people (such as for example: dial-a-ride service); and, finally, that different cultural responses to disability might make it harder, or less necessary, for some disabled people from minority ethnic groups to access services.

The mainstream services available for disabled people from minority ethnic groups and disabled gay men and lesbian women were also subject to some criticism.

Services were widely criticised for not addressing the needs of disabled people from minority ethnic groups. Specific criticisms included the ongoing barrier that older people, or those more recently resident in the UK, related that not having English as a first language caused in accessing appropriate services. This was often felt to be compounded in health settings, where a lack of communication could lead to misdiagnosis and in settings where interpretation services were limited or unavailable. The reliance on family members to interpret in such settings was not always felt to be appropriate or effective, especially where sensitive issues were under discussion. The literature and consultation exercise also highlighted problems around cultural insensitivity. There was a sense that services tended to be designed for white users and that diet, religious observance, dress, food, hair and skin care issues were not being effectively addressed for people from minority ethnic groups. Similar issues were raised about services targeted at specific groups, however. For example, women, gay and lesbian disabled people and those from different minority groups also argued that groups specifically set up to cater for their community often did not consider their particular needs as disabled people, which could leave them excluded. A similar issue was identified in relation to the focus of disability services on the older, rather than younger, age groups.⁷

⁷ Shah, S. & Priestley, M. (2001); MIND. (2000); Evans, R. & Banton, M. (2000).

1.2 Aims and scope of the research

The aim of the research was to provide a greater understanding of the life experiences of a diversity of disabled men and women with different ethnic identities, of different ages, and of differing sexual orientation. It was hoped that the study would provide evidence illustrating how diversity affects, or does not affect, the life experiences of disabled people from different communities, of different genders and ages. The focus of the research was to provide policy makers with evidence which might assist in:

- understanding the nature of discrimination for disabled people who might be subject to 'multiple' or 'compounded' disadvantage;
- finding effective means of combating or avoiding discrimination;
- establishing appropriate targets and formats for equality awareness campaigns;
- providing a more focused context for those developing strategies to target discrimination;
- identifying issues appropriate to be dealt with by government/quasi-governmental bodies addressing different areas of discrimination (for example the work of the Social Exclusion Unit, or of bodies such as the DRC, EOC and CRE).

The specific research objectives were to explore:

- the attitudes and experiences of disabled people from different groups; specifically to understand their own perceptions of their identity in relation to disability within the context of other factors such as ethnicity, age, gender or sexuality;
- disabled people's perceptions of social exclusion again within the context of other factors;
- disabled people's experiences of discrimination and prejudice in day-to-day life and perceptions of their source; for example, their experiences in the areas of employment, training and non-work areas (such as the provision of goods and services).

1.3 Design and conduct of the research

In this section we present an overview of the research methods employed during this study. The research was conducted between November 2001 and July 2002.

The study was conducted using a qualitative approach. The issues on which this project focused were complex and unsuitable for quantitative investigation. The previous study had already shown how challenging it can be asking people to consider their own identity as a disabled person. Once this was additionally complicated by raising issues of gender, age, ethnicity and sexuality, it was clear that a standard quantitative approach would be ineffective. Qualitative research is particularly suited to exploring and untangling complex conceptual and personal

issues. The work was conducted using a combination of focus groups (of between 4 and 10 people) and one-to-one depth interviews. Depth interviews allowed participants to consider, in detail, their personal experiences and to reflect upon the different experiences they have had in their lives and what factors might account for those experiences. In contrast, group discussions provided a mutual forum for sharing and contrasting life experiences and views about the relative importance of different factors in life experiences. Both components provided invaluable insights for the research. In broad outline, the research was designed to include up to 16 depth interviews and one focus group with each of the sample groups. Three focus groups were planned with the white sample (to allow comparisons around age and gender to be made).

The following sections outline key challenges and decisions made during the design and conduct of the research. In addition to providing a context for the later findings they also give an indication of the challenges researchers face when seeking to effectively explore experiences across such a diverse sample.

1.3.1 Designing the research – choosing the sample populations

In designing the research it was critical that the sample was able to reflect diversity within the disabled population effectively. Given the study was to be qualitative, this then meant ensuring that valid purposive samples could be drawn from different populations which would allow both reliable cross-group analysis (so for example, to allow comparisons between older and younger disabled participants from different minority ethnic groups or between men and women from different groups) whilst still providing an effective and reliable map of each community (for example, ensuring that gender, age and disability type could be explored within each community). For this reason the decision was made to focus on specific minority ethnic groups rather than to attempt to achieve a spread across the full range.

After discussion, four primary groups were decided upon: Indian, Pakistani, African and Caribbean. These choices were made to reflect different geographical locations of key populations, different patterns of migration and to ensure some diversity around issues such as religious affiliation and language. It was expected, and hoped, that some interviews would be conducted in first languages other than English.

In addition, two further sample groups were identified. A white sample was included to ensure that comparisons around age and gender could be made. Having this comparison group allowed for any differences relating to ethnicity to be clearly identified. Although the white disabled population had been adequately included in the previous study, they had not specifically been asked to consider the comparative influence of their age, gender and disability on their life experiences. Secondly, it was felt that a study of diversity in disability would be lacking without the perspective of disabled gay men and lesbian women whose experiences it was felt would add to understanding of issues being explored. Given the sensitivities involved in revealing sexual orientation, this information was deliberately not

collected amongst the other samples, although where sexual orientation was volunteered during interviews with these participants, it was noted.

Across all six samples the study aimed to be pan-disability, that is including the experiences of people from the broadest possible spectrum of types of disability, in addition to including people whose disability affects their daily life to varying degrees. For example, some participants found that their disability played a major part in their daily lives, others less so. We sought to include people with the following types of disability/impairment:

- **mobility** (including wheelchair users);
- **sight** (including partially-sighted and blind participants);
- **hearing** (including partially-hearing and profoundly deaf participants);
- **learning difficulties** or disabilities;
- **mental illness**;
- **long-term medical conditions or illness** (including asthma and diabetes for example);
- **other** forms of disability (for example disfigurement).

Within each sample the aim was to achieve the greatest diversity possible by including men and women, people of different ages, people with different impairment types, different working situations, different socio-economic groups and different housing situations. This was an important, if sometimes difficult, consideration during the recruitment process. Given the already complex composition of the target sample it was decided to restrict the research to England. However, within England, five broad locations were selected to take account of rural-urban differences and other regional factors, including the presence of relevant minority ethnic communities. The research was conducted in the Greater London area, Bristol, the North East and West of England and in the Midlands.

1.3.2 Sampling and recruitment

As qualitative research seeks to provide explanations of attitudes or behaviours rather than quantify their extent in the population, it requires a specific approach to sample design. It is neither necessary nor desirable for qualitative samples to be as large as survey samples or to be statistically representative. Instead, in order to provide robust explanations from which wider inferences can be drawn and to generate conceptual frameworks applicable to the broader population, it is essential that qualitative samples are selected purposively to encompass the range and diversity present in the target population(s). The robustness of qualitative research and the ability to draw wider inference from qualitative studies are dependent on rigorous purposive sampling.

Purposive sampling facilitates the production of a coherent and comprehensive map of circumstances, attitudes, behaviours and experiences which enable the generation

of salient explanations to answer research questions. Within this study, purposive sampling was used to ensure that the study could explore and explain different experiences and views of disabled people of different ethnic backgrounds, ages, genders and sexual orientation. Purposive sampling requires the setting of quotas for key dimensions in the sample wished for. In this study, given the complex blend of personal characteristics desired among participants, quota setting was complicated and serious consideration had to be given to the most effective way of accessing people in the target groups.

One clear source of participants were those people who participated in previous studies and associated surveys, these people having already given consent for future contact for research purposes. However, given the low numbers of minority ethnic participants and their geographical spread across England, Scotland and Wales this source only proved effective for the white sample. Similarly, none of the earlier studies had collected information relating to sexual orientation so this was not a viable sampling frame for the sample of gay men and lesbian women.

A second potential recruitment strategy was to send recruiters door-to-door to recruit participants. However, given the complexity of personal characteristics sought this would have been impractical and time-consuming.

A far more effective sample frame was created by contact with a range of different local organisations in the target areas. Over 100 organisations were contacted during the recruitment phase and asked for assistance in finding participants. The organisations ranged from social organisations for disabled people from specific communities (for example, leisure groups for disabled Asian people), disability advice and support networks and more political campaigning groups. Obviously there are several concerns about using such an approach. Namely, will organisers act as gatekeepers and limit access and secondly, are those people who belong to such groups likely to reflect the views of disabled people outside of such organisations?

In practice, we found that organisations were very willing to help and did not offer significant gatekeeper resistance. In order to minimise the effect of gatekeepers 'hand picking' participants, each organisation was sent a form on which to record the details of people willing to take part in the research, this form collected basic demographic information (such as age, gender, type of disability, stage of onset) but also information about how best to communicate with the potential participant (for instance, whether a letter, brailled letter, tape, telephone call or contact through a third party was most appropriate). From an early stage then, this approach ensured that the research team could take steps to ensure the process did not exclude people because of the nature of their disability. In fact, although gatekeepers are often viewed as problematic in recruitment in studies such as this, where potential participants may require assistance with responding to invitations to participate, then their assistance and role can be invaluable. This was certainly the case in instances where people had learning disabilities or translation requirements.

Gatekeepers were asked to gather details from a broad range of people and given targets about the numbers needed for the research in their area. This meant that the research team were able to make a final purposive selection of participants based on the returned forms and were not limited by the lists provided by organisers. In most areas, and across most groups, therefore, the sample was constituted of people from a range of different organisations. This was slightly different in the case of some of the groups where the particular characteristics required and locality meant that maybe only one or two organisations existed with relevant memberships. However, as with the last group, this was not found to affect the quality of the data. In fact there is some evidence to suggest that group members having existing bonds and friendships helped to encourage discussion and debate.

It is difficult to judge how much membership of specific organisations affects people's experiences of being disabled but the sample included those who did not participate or belong to such groups (mainly drawn from the existing survey sample) and those who had only a moderate involvement as well as those more actively involved. Similarly, as noted above, the groups ranged from gardening clubs, social organisations to campaigning groups. There was far more evidence of common experiences across people from all of these groups rather than stark differences, suggesting that the evidence from this research is valid and reliable as an indication of people's life experiences.

Finally, throughout the recruitment process, provisions were in place to ensure that the research was as accessible as possible not only to people with different types of disability but also for people whose first language was not English. Provisions included research team members with language skills undertaking recruitment, sending out brailled or large print letters, tapes of invitation and liaising with third party facilitators (such as BSL interpreters, family members or friends). Recruitment generally took place by phone but where telephone recruitment was not possible due to the nature of the person's disability then members of the research team either wrote to or visited participants to fix appointments and make arrangements.

1.3.3 Sample profile

Full details of each of the achieved samples are shown in the Technical Appendices. In this section we provide a brief overview of the people who participated in the research. It should be remembered that, given the nature of purposive sampling (see Section 1.3.2), the figures shown hold no statistical significance to the wider population. In summary, 107 disabled people participated in the research from five broad geographic areas across England. Thirty-three did so by taking part in one of five group discussions, the remainder of the sample participated in one-to-one interviews.

The following table represents the composition of the five group discussions. It had been intended that each group should represent a different form of disability coupled with ethnicity type and, where appropriate, sexuality or age. However, in practice, given the constrained sample frame, most groups included people with a mixture of ages and disability type.

Table 1.1 Composition of group discussions

	Ethnic group	Age	Gender/ sexuality where approp.	Nature of disability	Location
Group One (5)	Indian	Mixed	Mixed	Mobility	Midlands
Group Two (5)	African & Caribbean	Mixed	Mixed	Mental Health	Greater London
Group Three (4)	White	Mixed	Male (gay)	Mixed	London
Group Four (6)	White	40+	Mixed	Mixed	North West
Group Five (10)	White	Mixed	Mixed	Mixed	North West

Figures in brackets indicate number of participants.

Table 1.2 shows the disability type, ethnicity, age and gender of participants in the depth interview component of the study. Again it should be noted that the achieved sample composition is the outcome of a qualitative sampling methodology which aims to ensure maximum diversity across key sampling criteria rather than to reflect actual statistical trends within the wider population.

It should be noted that the African sample was much smaller than anticipated. Although a number of groups were identified as sample sources for the project, they were fewer in number than for other minority ethnic groups and yielded less successful outcomes. There were no clear indications of why responses for this group were less successful, and analysis of recruitment returns did not indicate higher levels of refusals to participate amongst this community than others. The research team made every effort possible to boost this sample when early returns from recruitment showed this sample to be lower than anticipated but these were less successful than hoped for.

Table 1.2 Sample profile for depth interview participants

Characteristics	Male (33)	Female (41)	Total (74)
Age			
16-29	5	7	12
30-49	12	17	29
50-59 (females)	-	7	7
50-64 (males)	8	-	8
60+ (females)	-	8	8
65+ (males)	8	2	10

Continued

Table 1.2 Continued

Characteristics	Male (33)	Female (41)	Total (74)
Ethnicity/Sexuality			
Caribbean	2	9	11
African	2	4	6
Indian	9	8	17
Pakistani	6	8	14
White	9	2	11
Gay/Lesbian (all white)	5	8	13
Ethnicity (other)	-	2	2
Current activity			
Paid employment	9	10	19
Voluntary work	1	2	3
In education/training	3	3	6
Not working due to ill health	11	19	30
Unemployed but looking for work	3	2	5
Retired	6	5	11
Qualifications			
None	8	10	18
GCSE/O level	4	3	7
A level	2	2	4
Vocational qualification	9	9	18
Degree	7	9	16
Other	3	8	11
Living circumstances			
Renting from LA/HA	11	10	21
Renting privately	2	1	3
Home owner	12	17	29
Living with family or friends	7	12	19
Living in supported accommodation	1	1	2
Disability type			
Single impairment	21	18	39
Multiple impairments	12	23	35

Continued

Table 1.2 Continued

Characteristics	Male (33)	Female (41)	Total (74)
Main/only disability			
Mobility	12	20	32
Visual	7	4	11
Hearing	2	4	6
Mental	3	3	6
Learning	5	3	8
Other	4	7	11
Onset of main disability			
Less than a year	-	-	-
1-5 years	3	8	11
6-10 years	2	8	10
Over 10 years	14	11	25
Life	14	14	28

As noted before, information about sexual orientation was only collected from those invited to participate in the sample of gay men and lesbian women. Therefore, of the total participants in the study, 17 identified themselves as either gay or lesbian.

Full details of personal circumstances, including information about qualification levels, employment etc. are provided in the Technical Appendices for each group. In summary, the research achieved considerable diversity across a range of key secondary dimensions including educational achievement, current employment status, personal circumstances, onset of disability and other issues such as migration history or religious affiliation. Given the nature of the sampling complexity, it was impossible to control and ensure diversity across these secondary variables but the approach taken in recruitment and careful monitoring throughout the recruitment process allowed the research team to include people with varying differing experiences of all of the above.

1.3.4 Conduct of interviews and discussions

As the study was exploratory, the research team sought to encourage participants to discuss their views and experiences in an open way without foreclosing issues which might have proved important to the study. Therefore, unlike survey or semi-structured interviewing, questioning was responsive to the interviewees' own comments and situations. Questions were not pre-set, and the order in which issues were addressed and the amount of time spent on different themes varied between interviews and between focus groups. All interviews and discussions were conducted with topic guides, designed in collaboration with DWP, which were used as signposts allowing researchers to respond to participants' own accounts of their

experiences and attitudes. Interviews generally lasted between one to two hours, whilst group discussions lasted between one and a half to two and a half hours.

The research team believed it was important to ensure that the approach taken during interviews and group discussions with disabled participants avoided the assumption that their disability or impairment, ethnicity, age, gender or sexuality had affected their experience of, for example, the social world or equally that their disability was the key defining factor in their self-identity or life experiences. Therefore, both topic guides were designed to allow participants to identify the relative importance of different elements of their personal identity, in comparison to other circumstances or issues in their lives. It is important to note that, given this approach to the research, and the broad ranging scope of the research, not all areas were covered in the same level of detail by each respondent. A clear example of this would be in cases where onset had occurred in later life, less time was spent reflecting on experiences of early childhood.

Interviews and group discussions were conducted by members of the research team, all of whom have extensive experience of conducting research with members of the public and with disabled people. The entire research team attended a half day of disability awareness training at the outset of the project to provide an opportunity to reflect upon the issues which might arise and to consider best practice in the conduct of the study.

Interviews with disabled participants were generally conducted at their home or at another location chosen by them (for example, at the home of a friend or their place of work). Group discussions were held in accessible locations, sometimes a local hotel or conference facility, more often in a local community centre or hall. All participants were given a gift of £15 at the end of the interview or group discussion as a token of appreciation. In addition, clubs and organisations who had assisted either in the recruitment process or through providing a group venue were offered a small payment as a gesture of thanks.

A range of different provisions were put in place to ensure that nobody was excluded from the research due to nature or severity of their disability. These included the use of third party facilitation (such as BSL interpretation), the presence of carers and the provision of, or finance of, transport to and from group venues. During the course of groups and interviews participants were asked about any specific requirements (such as regular breaks) which would facilitate their participation.

Similarly, the research team included three researchers with skills in languages other than English, allowing people who wished their interviews to be conducted in their first language the opportunity to do so without the need of an interpreter. This is often important in sensitive research where participants may feel wary of disclosing issues or views of a personal nature in front of a third-party, particularly if the translator is a family member, friend or acquaintance.

All interviews and discussions were tape recorded for subsequent transcription. This is essential for the form of analysis used (see below) and allows the interviewer to

give full concentration to exploratory questioning during the interview. Where interviews were conducted in a language other than English the interview was translated and then transcribed by the researcher who conducted the interview.

1.3.5 Analysis

Verbatim transcripts of all the interviews and discussion groups were analysed using 'Framework'. 'Framework' is an analytic technique developed by the Qualitative Research Unit at the National Centre. The method involves ordering and synthesising verbatim data within a series of thematic charts (the structure of the framework used for this study is shown in the Technical Appendices). Further classificatory and interpretative analysis was derived from these analytic charts.

As the study was qualitative in design it is possible to describe the range and nature of perspectives held by those who participated in the research. It has also been possible to identify the factors that have contributed to differing life experiences. However, this research cannot provide any statistical data relating to prevalence of views or experiences; nor does it seek to infer any general patterns relating to different groups within the wider population who do not share similar characteristics to this sample. Where suggestions of sub-group differences are suggested by the data, they are presented only as hypotheses to be tested by later research. Throughout the report the authors have highlighted where differences arose between the key sub-groups – for example, differences relating to membership of minority ethnic groups or different age groups. The absence of reference to one or more of the key dimensions (age, gender, ethnicity or sexuality) in the text indicates that no evidence was found to suggest, within this sample, differences relating to these dimensions.

The key criteria for analysis were the different experiences of people along five main criteria: ethnicity, sexuality, gender, age and disability type. Alongside this the research team also explored the data for differences which might be accounted for by other factors such as personal circumstances, onset of disability or religious affiliation, and where found these have been noted.

The report uses verbatim quotations and case studies throughout. Where necessary the details of the contributors have been moderately changed to protect anonymity.

Quotes are labelled to indicate where the participant, 'sits' in the sample, i.e. key characteristics have been noted. As sexual orientation data was only available for the participants in the gay and lesbian sample details of sexual orientation are only shown for this group.

1.4 Structure of the report

The report consists of seven further chapters. **Chapter 2** explores the nature of personal identity and the roles that disability, age, gender, ethnicity and sexuality play in shaping disabled people's self-identity. **Chapter 3** examines disabled people's experiences of their personal and social lives and how these experiences are

affected by their identities. **Chapter 4** explores experiences of education, both in mainstream or special schools and in post-compulsory education. **Chapter 5** examines the world of work and explores experiences of seeking work, being employed and transitions to retirement. In **Chapter 6** access to goods and services are examined, with a particular emphasis on how access is, or is not, affected by disability, ethnicity, age, gender and sexuality. **Chapter 7** considers how, and if, the notion of 'multiple' or 'compounded' disadvantage fits with the experiences of those interviewed and reviews the evidence on discrimination and prejudice. Finally, **Chapter 8** explores strategies for the future and people's views about government and social responses to disability.

1.5 Summary

The *National Centre for Social Research (NatCen)* was commissioned by the Department for Work and Pensions (DWP) to undertake a study exploring the interaction between disability and other personal characteristics chiefly: ethnicity, gender, age and sexuality.

Existing research and policy information suggests there are three key areas where 'compounded' or 'multiple' disadvantage might occur. These are in the spheres of education, employment and service provision. In addition, there is also existing evidence of the scope for similar issues arising in people's social lives and in their relationships with friends and family.

The aim of the research was to provide a greater understanding of the life experiences of a diversity of disabled men and women with different ethnic identities, of different ages, and of differing sexual orientation.

The specific research objectives were to explore the attitudes and experiences of disabled people from different groups, their perceptions of social exclusion and their experiences of discrimination and prejudice, within the context of factors such as ethnicity, age, gender and sexuality.

The study was conducted using a qualitative approach to allow the full exploration of the complex conceptual and personal issues surrounding disability, ethnicity, age, gender and sexuality. The research was designed to include a combination of one-to-one depth interviews and group discussions.

Respondents were recruited through two methods; by re-contacting people who had participated in previous studies and associated surveys, and by contacting people through local voluntary organisations for disabled people.

Throughout the fieldwork provisions were in place to ensure the research was as accessible as possible, not only to people with different types of disability but also for people whose first language was not English. This included the use of BSL interpreters in interviews with deaf respondents and the use of researchers with skills in languages other than English to interview respondents who wished their interviews to be conducted in their first language.

2 Identity and disability

Understanding individual perceptions of identity are clearly central to the issue of diversity in disability. A key focus of this study was to understand which, if any, aspects of their personal characteristics and lives disabled people see as central to their life experiences. For instance, would a disabled Asian woman view her ethnicity, gender or age as central to her life experiences or are there other factors, for example, religious beliefs, which are viewed with greater importance? Similarly, do disabled gay men see themselves as disabled or gay first? Age might similarly be critical in people's self-perceptions.

Exploring self-identity is a hugely complex issue both in terms of research approaches and in terms of the challenges it presents to participants. The preceding study⁸ clearly showed the complexity of asking people to reflect on whether or not they viewed themselves as 'disabled' or found the label of 'disabled' to have any significance in their lives. In this follow-up study we wanted not only to revisit the issue of 'disability' but also to ask people to reflect upon other elements of their identity, whether they be gender, sexuality, ethnicity, age or related to other factors. Without doubt this was a difficult task and one that some people found challenging to engage with. Often people were being asked to consider issues which they had never purposefully considered before about who 'they were' and what impact that might or might not have on their lives.

In this brief opening chapter we try to untangle some of these complex issues and provide a context to the findings in later chapters. Each of these chapters explore people's experiences within different spheres of everyday life and their views about which, if any, facets of their identity have affected these experiences.

2.1 Exploring identity

In this section we examine participants' feelings about their personal identity and what elements come together to help shape those identities.

⁸ Woodfield K et al (2002), Chapter 3.

During the research, questions were asked in an open fashion and reassurances given that there were no right or wrong answers. Generally, interviewers would ask something along the lines of: *'If you had to describe yourself to someone who did not know you how would you do that...?'*. This approach allowed participants to prioritise areas of their lives, or their personal characteristics which they deemed to have most importance, and tried to avoid people feeling they were being solely asked to describe themselves in relation to their disability, gender, age or sexuality.

As would be expected, some people found these questions less or more challenging than others. There were no clear patterns to the responses but a persistent finding was that people were reluctant to single out individual characteristics, such as age, disability, or gender as dominant features of their identity. Of all the different facets of identity being explored in the course of this study people were most comfortable engaging with the concept of ethnic identity, although this was not universal.

People tended to be more comfortable with describing their role within the family or workforce, for example by describing themselves as a 'mother' or as an accountant rather than describing themselves in relation to their age, gender or sexuality.

Overall, the complexity experienced in teasing out these issues during the interviews and groups reflect an underlying challenge posed by the research which sought to identify key components of people's identity and how life experiences were affected by individual components of identity and, or, combinations of several facets of identity. Even where people were comfortable with seeing their identities as formed from several different sources they remained resistant to attributing experiences of discrimination to one or another factor. This response is quite understandable, not least because (unless something has been explicitly stated by the person treating them differently) this task requires a degree of hypothesis, placing themselves in the position of the person treating them differently and presenting an opinion about why they reacted in the way they did. More fundamentally, perhaps, people described how hard they found it to break down their own identities into discrete boxes and a common response was *'I am all of those things rolled together... a complete package'*. These issues are returned to in **Chapter 7**. Nevertheless, as will be seen below, some groups tended to demonstrate a greater engagement with the notion of their identity as being multi-faceted and, despite these methodological difficulties, differences were found when the evidence relating to identity was explored and these are illustrated in the following sections.

It is important to note that the focus of this part of the study was to explore how *disability* interrelated with other aspects of identity, specifically gender, age, ethnicity and sexuality. The research was not designed to explore in depth each of these latter components of identity but rather to see how they contributed, or not, to disabled people's sense of self-identity. Understandably, given the complexity of the issue, any one of these factors, as well as others such as religious faith and socio-economic class which are touched upon in this report, would warrant a full study in their own right to effectively explore their role in forming self-identity.

2.2 Sources of identity

In this section we consider people's responses when asked to consider how they would describe themselves. As noted previously, the typical response was to describe oneself in relation to a role played, either within the family or the workforce rather than in relation to socio-demographic characteristics.

2.2.1 Disability as a component of personal identity

Findings from Woodfield K et al (2002) demonstrated the complexity of trying to understand and explore personal and collective attitudes towards disability. A key finding from this study was that just under half of all those disabled people who participated (48 per cent) considered themselves as disabled. Precise proportions varied depending upon whether the disability was current or past and also slightly by disability type and age (with those with depression or mental health difficulties most likely to consider themselves to be disabled, and younger people less likely to think of themselves as disabled). Combined with qualitative data, the findings from the survey provided powerful evidence about the critical factors which affect whether or not someone is likely to consider 'being disabled' as a key part of their personal identity, these were:

- onset of disability;
- nature of the disability;
- age; and
- extent of involvement in disability campaigning groups or organisations.

This study sought to explore whether similar or different attitudes were held by people who participated in this research and to examine whether there were any differences by ethnic group or sexuality. In broad overview, the evidence from this new study mirrors earlier findings and these are shown by illustration below. No significant patterns were found between ethnic groups to suggest that this is a factor which affects whether or not a person will perceive of themselves as disabled or not. Similarly, there was no evidence to support the premise that sexuality might affect individuals' likelihood of describing themselves as a 'disabled' person.

Previous research demonstrated that where disabled people tended not to think of themselves as disabled this was either because they viewed themselves as ill, or getting old. Others felt they were not as 'worse off' as some. Not seeing oneself as disabled was particularly critical for people who perceived themselves to be fit or able⁹. This was also evident in the accounts of disabled people interviewed during the course of this study.

⁹ Woodfield K et al (2002).

Sunita, is a 48 year old Indian woman who developed arthritis and asthma in her middle age. She is reluctant to accept the label of 'being disabled' as she still sees herself as an 'active' person.

As in the previous study, others rejected the term as too generic in the sense that they did not see an affiliation between themselves as someone else with a different type of disability, and preferred to describe themselves as deaf or blind, rather than disabled. For example, Gita described her feelings about the term 'disabled':

'People, [often just say] disabled, but there's a load of different types and they all come under one umbrella, but they can't come under one umbrella, it's different ... , there's physical, there'll be someone with mental [health] issues, there's always [sensory] disability, there's deaf and everything, and I see a lot of able-bodied people put them all under one umbrella, but it can't be... sorry, this is the one umbrella, but it isn't the case, there's different issues.'

(Female, 30, Pakistani, mobility impairment and progressive congenital condition)

In contrast, as with previous evidence, others did see themselves as disabled and this was viewed both positively and negatively. Positive associations with being 'disabled' were commonly rooted in personal or political self-identity and were often found amongst those involved actively in disability campaigns, or working within disability organisations.

Negative associations were found where people reluctantly accepted the identity of 'disability' as reflecting their perceived sense of loss at being 'disabled' or 'less able' than others and was particularly evident where people had experienced the onset of disability in later life.

Janet, is a Caribbean woman aged 32, she has sickle-cell anaemia. She finds it difficult to accept the label of 'being disabled' which she sees as a negative term. However, like others, she accepts that she is in some way 'disabled': *'I think for me the term disabled renders me that way, it's almost like I'm telling myself I am wearing a hat that I can hide under'.*

People were generally unlikely to describe themselves as 'disabled' when providing opening descriptions of themselves whilst, as will be seen, people were far more willing to assert their ethnicity as a core part of their personal identity. The evidence that a significant proportion of disabled people dislike the label 'disabled' is clearly one factor accounting for this finding. Nevertheless, other reasons may be more related to the nature of the research. Everyone who was invited to take part did so knowing the study was about issues relating to disability and that the research was exploring the views of people with long-term health conditions or disabilities. On

this premise it is understandable that people may have thought declaring themselves as 'disabled' was redundant given that everyone taking part was 'obviously' so. Similarly, knowing the focus of the research, people may have been expecting to discuss these issues in great depth later during the interview or groups and so chose not to focus on this element during the early stages. Despite these caveats, evidence relating to the relative importance of different elements of identity does suggest that compared to ethnicity and sexuality (for gay and lesbian participants) disability was less immediately seen as a defining characteristic of personal identity.

Further issues relating to attitudes towards disability are discussed in Section 2.3.

2.2.2 Ethnicity as a component of personal identity

Ethnicity was the one characteristic that participants were most comfortable using when describing their self-identity. Across all samples, participants used some form of ethnic label to describe themselves, there were a few exceptions of people who were unhappy using such signifiers but these were found in all groups and there were no patterns relating to age or gender to suggest anything more than personal preferences affected the level of comfort people felt in describing themselves in terms of ethnicity.

It is important as context to the following evidence to note that of the disabled minority ethnic participants there was a history of first or second generation immigration to Britain. In all four of these samples a significant number of participants had migrated to England during their childhood or adult lives.

The importance of ethnicity to personal identity

Ethnic identity, in various forms, was frequently cited when people were asked to discuss their personal identities. However, the importance of this element of identity to people's lives varied in intensity. Analysis showed that whilst, for some people, it was of paramount concern when they thought about their lives, for others it was an issue rarely considered. The following quotes illustrate the differing importance of ethnic identity in people's lives:

'I'm a Londoner and that's all there is to it ... I'm British, I'm a London British person – excuse me from saying that, but that's the way I am and that's the way I'll always be. I'm sorry, I don't care what the Government says, that you can't use the word British – you can use the word British.'

(Female, 74, White, mobility impairment)

'I have never thought about this, about who I am or who I am not, we are all men of Allah and we are all equal whether Muslim or Hindu.'

(Male, 71, Pakistani, mobility impairment)

Differences were also found across the five different ethnic groups who took part in the study. Principal amongst these was that South Asian and black participants tended to volunteer some description of their ethnicity in their initial descriptions of their identity.

'Just that I am black, a black woman.'

(Female, 59, Caribbean, mental health impairment)

'Whenever I'm filling in forms, any application, I just put British Asian... my children would be British citizens now, they wouldn't put Asian.'

(Female, Asian, mobility impairment, did not give age)

White participants were less likely to volunteer their ethnicity without questioning though once prompted found it relatively straightforward to describe their ethnicity as *'white'*, *'white, English'* or *'British'* or, more unusually, *'European'*.

Sources of ethnic identity

The sources of ethnic identity have long been subject to protracted debate and discussion and it is not the purpose of this report to revisit these debates. However, in order to understand how, and why, people associate with certain aspects of their personal identity it is useful to explore the different sources of people's stated ethnic identity.

The study found that people sourced their ethnic identity in a myriad of different ways. People variously described their ethnicity as being grounded in their:

- country of birth, or the country of their parents' birth;
- country of permanent residency;
- personal affiliation with a regional area in their country of birth/residency;
- use of common language (often linked to the above);
- membership of a religious or faith community; and/or
- race or colour.

For those born outside of Britain, ethnic identity was often rooted in a sense of affiliation to their country of origin. Yet, in some cases, lengthy residence in Britain and British citizenship appeared to mediate this component of self-identity with some older people describing how, over time, their sense of ethnicity had changed as they became more rooted in British society. Change over time was a recurrent theme in people's discussions of personal identity and was often mentioned when parents discussed how their ethnic identity was different to how their children saw themselves.

'Well, I'm African - I think my children would say they're British, but I consider myself African because I was born in Nigeria and I came here in my teens to study, hence I stayed and didn't go because of change of circumstances... I'm a resident here, but I consider myself as African.'

(Female, 38, African, mobility impairment)

'The passport is British but I have never thought of myself as British, I consider myself Pakistani... Because it is my country, I was born and brought up there.'

(Female, 60, Pakistani, mobility impairment and chronic medical condition)

In contrast to the sentiments expressed in the quote above, the country of permanent legal residence was also an important underlying factor in some people's sense of ethnicity. For example, several people mentioned how, whilst they might be Pakistani or Indian, their British citizenship now meant they saw themselves as British. This range of views was also reflected in the accounts of white participants who had moved to Britain from other countries in the European Union.

Amongst the sample of South Asian and white participants were those who saw their ethnic identity as rooted in regional, rather than supra-national affiliations. For example, seeing oneself as Punjabi or Gujarati. In the white sample, participants originally from Wales and Scotland cited these as their primary source of ethnic identity rather than being British. It was common to find that these views were underpinned by a sense of a membership stemming from the shared use of a language.

Membership of a faith community was also a factor underpinning ethnic identity. This was particularly so for participants from the South Asian sample. Here people described being Muslim or Hindu when they considered their personal identities and this element of identity was given higher prominence than their nationality, country of residence or country of origin. Identification with a faith community as part of ethnic identity was rare amongst white participants except for those who were Jewish. These people were exceptional amongst the white participants in associating their ethnic identity to a faith rather than national identity.

Finally, for some people, perceptions of race or colour were fundamental to their sense of personal identity. Amongst the African and Caribbean groups there was a strong sense of ethnic identity related to being Black and much pride was usually taken in discussing this element of personal identity:

'Usually I put Black Caribbean down, because my parents came from the Caribbean but usually I just see myself as a black person.'

(Male, 36, Caribbean, mental health impairment)

In the white sample too, people often described themselves as white English or British but it was not generally given the same intensity of importance as that shown above. Finally, in rare cases, South Asian participants described being 'Asian' as relating to their skin colour and saw that as an important part of their identity:

'I am British Asian, I always say British Asian. I put British first and then Asian... Asian's my colour but I'm a British citizen.'

(Male, 25, Indian, mobility impairment)

2.2.3 Age and gender as components of personal identity

Age was rarely cited as a key element of personal identity and nobody talked about how being a 'young' or 'old' person shaped their sense of self. Nevertheless, as will

be seen in later chapters, it is clear that age can, and does, play a role in shaping disabled people's life experiences.

Women were more likely to describe themselves in terms of gender than men and this is particularly true amongst women from minority ethnic groups. There was often a sense of being a woman as a political as well as personal identity, particularly amongst black African and Caribbean women. Similarly, amongst South Asian women, personal pride was evident in descriptions of their role within the family and community, whether as a wife, mother or sister. Although it did not emerge in this study, previous research in this area has also suggested that older South Asian men can have a strong sense of identity linked to their position as head of the family, which relates directly their gender and age.¹⁰

2.2.4 Sexuality as a component of personal identity

Chapter 3 explores in detail participants' experiences of 'coming out' and of adjusting to their sexuality. Gay and lesbian participants clearly saw their sexuality as a critical element in their personal identity. However, as with disability, few began by describing themselves as gay, given that they knew this was why they had been invited to participate in the research.

The intensity of importance attached to sexuality did vary across the sample and this seemed to be affected by two principal factors. Firstly, the age at which participants had first recognised their sexuality and secondly, the extent to which individuals were actively engaged with gay and lesbian campaigning groups or the gay and lesbian 'scene'. For example, Vanessa, is 41 years old. She has been out as a lesbian since her time at University in her early twenties. Whilst at University she felt the need to explore her personal identity, partly as the result of her family and faith community's negative reactions to her 'coming out'. She found strength in exploring various different aspects of her identity with women who had experienced similar problems. Being able to identify as a lesbian woman was a very important support in dealing with the negative reactions she had received initially.

Gay and lesbian participants who had established their sexuality at an early age tended to place less priority on it as a feature of their self-identity than those who had discovered their sexuality later in life. This bears some resemblance to patterns found relating to onset of disability and the way in which people discuss its importance to their self-identity. Both this and the previous study found that people who had had a disability from an early age placed less emphasis on it as an element of self-identity than those who experienced onset later in life (with notable exceptions being respondents who had been partially or profoundly deaf from birth).

A myriad of factors might account for these differences, but there is clearly some impact over time. This might mean that people become settled in their sense of

¹⁰ See, for example: Barker, J. (1984); Blakemore, K. & Boneham, M. (1994); Fenton, S. (1987).

identity or simply that having been gay, or indeed gay and disabled, from a relatively early age means that it is not perceived as a centrally defining characteristic. Indeed, the accounts of some disabled lesbian and gay participants state this explicitly. One gay man, for example, did not see this as a particularly important aspect of who he was and referred to this characteristic as *'boring'*.

Conversely, it could be argued that a dawning awareness of sexuality at a later age can be disruptive to how people view themselves and their lives. As will be seen in **Chapter 3** this was certainly the case for some of those who took part in the research. Disruption to settled patterns of life can cause people to re-evaluate their identity and in these circumstances it is easy to see why sexuality might gain importance as an element of personal identity.

2.2.5 Combined or multiple identities?

The preceding sections have explored how different participants considered the multiple features of their personal identity. This section considers if and how people see these different factors interacting. Do certain characteristics take priority, for example?

This was particularly complicated data to investigate. Participants found it challenging to isolate the different elements of their identity and then to, in some sense, qualify which were most central to them. Nevertheless, as later chapters will demonstrate, people found it far easier to identify which facets of their identity caused impacts on their everyday experiences. John's response to questions about how his sexuality and disability interrelated in his self-image was typical of the feelings of many people interviewed:

*'I'm gay and disabled, it comes as a package... you can't just like one and not the other. If you don't like either, well, ***** off. Because I'm just one package and what you see is what you get [if you have a less visible disability] you can hide your disability, you can hide your gayness ...having a visual disability in a sense people see that but being gay and disabled you can choose who you want to let, who you want them, the people to know if you're gay or not, it's up to you. So that's something that is personal, you can hide it if you want to. But then I say to myself, but if I hide it then I'm going back into the closet and ... it's part of my character. I'm still the same person... But the thing is as well, when people say, 'Well that's not normal,' well define the word normal. Because my disability's normal to me. And being gay is normal to me.'*

(Male, 42, gay, white, mobility and hearing impairment)

In contrast, others did clearly perceive a type of ranking in how they saw the different elements of their identity. For example, Susannah was quite clear about how the different facets of her identity fitted together:

'I'm a Caribbean woman first and foremost and then black second, that's why I keep calling myself Caribbean woman.'

(Female, 46, Caribbean, mobility impairment and mental health impairment)

Various different factors account for how facets of identity were ordered in importance. Firstly, for some people, a single aspect of their identity, whether it be being Caribbean or black, a woman or a Muslim, was a pivotal aspect of that individual's life. It could be argued in these cases that personal identity was shaped around a single defining characteristic. Whilst other aspects might, and were described to, have impacts on everyday life this single facet was valued above all others. It was seen to be the element which provided the most relevance in that individual's life. Strong religious faith was frequently mentioned in this way, but equally powerful statements were made relating to ethnic identity, sexuality and gender.

Secondly, some people made judgments based on which aspect of their identity they perceived to affect their lives most. This was often phrased in terms of the aspect which required the most consideration or response in daily life.

'I think the issues about my deafness are forefront because there's always an issue about communication that has to be got over. Do you see what I mean? So that's the thing – and sometimes the other issues just get lost because people just focus on the deaf bit. All three [sexuality, deafness] and gender [are important].'

(Female, 46, lesbian, white, hearing impairment)

Others, like the respondent above, described focusing on the aspects of their identity which made their lives most challenging. Amongst minority ethnic respondents, for example, much of the importance of ethnicity was attributed to the need for a personal sense of association and belonging. Nevertheless, equally important to some was the need to be constantly aware of your ethnicity as it was likely to create difficulties in everyday life and produce challenges which would need to be tackled and overcome, such as racism or prejudice.

The complexity of trying to understand how and why people attribute importance to different aspects of their identity is further complicated by the clear evidence that identity is fluid. Whether examining ethnicity, sexuality, disability or age in the data, the research revealed just how unstable personal identity is. The relative priorities of people's sense of self-image change over time and vary depending upon the environment they are in and the nature of the people they are interacting with. Some change over time may result from disruption to established life patterns, for example the onset of disability, migration or awakening sexuality. Other change evolves gradually as people age or take on new roles, as parents for example.

The final sections in this chapter turn back to issues solely relating to disability.

2.3 Definitions of disability

We have established that not all disabled people interviewed were comfortable with being labelled as 'disabled' and have shown the patterns in the data which provide

evidence of which groups of people are more or less comfortable with the term. In order to fully understand these attitudes, it is also important to understand what participants thought constituted disability, 'what makes a person disabled?'

Again this is a challenging question as this respondent reflected:

'How [do] you verify yourself that you're disabled, you're not able-bodied? I think that's pretty difficult to do sometimes...'

(Female, Indian, mobility impairment, unwilling to reveal age)

The previous study explored in detail how attitudes towards disability were formed and identified three basic models of disability expressed by both disabled and non-disabled people:

- **Disability as impairment** – people argued that physical or sensory impairment produce disability, leading to incapacity, a permanent inability to be independent and visible 'difference'. This model shares many features with the established 'medical model' of disability.
- **Disability as impairment compounded by social exclusion** – here people held many of the views as those detailed above but felt that the negative everyday experiences of disabled people were compounded by disabling processes in the everyday world which restrict disabled people's access to that world.
- **Disability as social exclusion** – the attitudes of people in this group mirror those in the established 'social model' of disability whereby people believe that it is social processes and structural inequality in society which produce disability by preventing disabled people from playing a full role in the everyday world. Disability was therefore not assumed to be about incapacity and dependency, neither was it argued that disability would necessarily be 'visible' as difference.

The data from this study was explored to examine whether or not similar views or attitudes were held amongst these participants. A high degree of concurrence was found to exist between the two datasets, with the same three models emerging across all six sample groups.

In addition, similar patterns in relation to age were found with older people more likely to subscribe to the first two models, whilst younger people expressing the more inclusive values of the social exclusion model. As previously there was limited evidence to suggest that gender was a factor in determining which model people most closely identified with. A final pattern which reflects that found within the qualitative stage of the last study was that people who were still relatively active and routinely using the everyday world, as well as those with disability types other than mobility impairment were more likely to subscribe to the social model than others.

The study did reveal some differences between and within different groups.

For instance, amongst the South Asian group of older respondents the idea that disability was directly related to incapacity and the inability to do certain tasks and be

independent was dominant. In contrast, younger South Asian participants were more closely aligned to the social model of disability.

'I am a disabled person, I accept that but I really think that if a disabled person is made to feel disabled, it really is because society is not accepting them.'

(Male, 28, Pakistani, visual impairment)

Age is obviously a critical explanatory factor for the differing attitudes across the sample, although as **Chapter 3** will examine in more detail, strong religious beliefs also affected how people in these communities thought about disability.

Although less stark in the black and white groups, the belief that disability begins once you begin to be unable to do things you were previously accustomed to (such as care for yourself, work, drive, garden etc.) was commonplace. As before, patterns were found around age in relation to this issue.

'I'm not different but I am disabled, once you can't do the things you're accustomed to doing it's disability.'

(Female, 79, Caribbean, mobility impairment and chronic health condition)

In sharp contrast, the accounts of lesbian and gay participants were dominated by attitudes most closely resembling the social model or social exclusion model, regardless of age.

2.4 Views about non-disabled people's perceptions of disability

Finally, in this chapter we turn to disabled people's feelings about how they think non-disabled people perceive disability and their views about how these attitudes are formed.

As with the previous research, there was a widespread belief that non-disabled people, unless they had a close disabled friend or disabled family relative, lacked awareness about disabled people's lives. As will be shown in the following chapters, disabled people frequently felt they had experienced prejudice, or different treatment as a result of this lack of awareness and knowledge about disability. Common responses experienced included making assumptions that if someone has a visible disability (for example, is using a wheelchair or is clearly blind) then they also have a mental impairment. Numerous examples were cited of disabled people being ignored in favour of their non-disabled companions when assumptions like these were made. Other experiences included non-disabled people showing unease or distress during social conversations or service interactions and non-disabled people asking insensitive questions about disability. In one example given, a young gay wheelchair user was in a bar enjoying an evening out when he was approached and asked several highly personal questions about his sexuality and sex life by strangers. Other disturbing responses included prejudicial comments, taunting and abuse.

As mentioned above, and this is an issue we will return to in later chapters, there was often the sense that experiences like the one above were exacerbated when non-disabled people encountered gay disabled people or disabled people from minority ethnic communities:

'I can remember when I first started working for the organisation that I work for, and I was booking appointments to go out into these community centres and places of worship, and my first contact was normally over the phone. And I don't think the half of them knew who I was. And when I got there the look on their face was normally shock, horror, when an Asian disabled person walked in. They expected me to be, you know, a Joe Bloggs Asian person who didn't stick out of the crowd, but I did. I wore a suit. I purposely make all my staff wear shirts and ties and dress smart, because I want to project an image of a disabled person positively. And I was well dressed, well shaved, carrying a briefcase and talking professionally. And I think that kind of made a lot of people feel unsure about their own perception of disability. I don't think it had any long-term effect on them.'

(Male, 33, Indian, mobility impairment)

A primary cause for these reactions and lack of disability awareness was a perceived absence of disabled actors and presenters on mainstream television programmes. Disabled minority ethnic people argued that the problems with the mass media representation of disability were compounded when ethnicity was added to the equation. Not only did these people argue that disability is not represented fully in the media but that there is a complete absence of disabled people from minority ethnic groups in the mainstream media. The treatment of disability in the media was commonly seen as far worse than the representation of different ethnic groups and worse than media representation of gay and lesbian people's lives:

'I think some of the magazines use real life stories to portray positive views of disabled people and people's struggles with disability, but on the whole I still think that it's an invisible issue... and I think more so than the lesbian and gay issue– it's the in thing, it's chic isn't it – I mean you look at every single soap now, it's got a lesbian or gay man on it... and black people as well [yet] we're still invisible.'

(Female, 50, lesbian, white, hearing impairment and mental health impairment)

Other factors cited reflect the range of issues raised in the last study including a lack of education for children about disability and a lack of integration in education.

Chapters 3 and 7 return to some of these issues by specifically considering experiences of local communities, friends and family and experiences of prejudice and discrimination.

2.5 Summary

Exploring self-identity is a hugely complex issue both in terms of research approaches and in terms of the challenges it presents to participants.

A persistent finding was that people were reluctant to single out individual characteristics, such as age, disability, or gender as dominant features of their identity.

Of all the different facets of identity being explored in the course of this study people were most comfortable engaging with the concept of ethnic identity.

Even where people were comfortable with seeing their identities as formed from several different sources they remained resistant to attributing experiences of discrimination to one or another factor.

Findings about the role of disability in self-identity reflect the evidence presented in the previous report. No significant patterns were found between ethnic groups to suggest that this is a factor which affects whether or not a person will perceive of themselves as disabled or not. Similarly, there was no evidence to support the premise that sexuality might affect individuals' likelihood of describing themselves as a 'disabled' person.

Evidence relating to the relative importance of different elements of identity suggests that, compared to ethnicity and sexuality, for gay and lesbian participants, disability was less immediately seen as a defining characteristic of personal identity.

Ethnicity was the one characteristic that participants were most comfortable using when describing their self-identity. Across all samples, participants used some form of ethnic label to describe themselves, there were no patterns relating to age or gender to suggest anything more than personal preferences affected the level of comfort people felt in describing themselves in terms of ethnicity.

Ethnic identity, in various forms, was frequently cited when people were asked to discuss their personal identities. However, the importance of this element of identity to people's lives varied in intensity. Differences were also found across the five different ethnic groups who took part in the study. Principal amongst these was that South Asian and black African and Caribbean participants tended to volunteer some description of their ethnicity in their initial descriptions of their identity. White participants were less likely to volunteer their ethnicity without questioning.

Sources of ethnic identity included: country of birth, or the country of their parents' birth, country of permanent residency, personal affiliation with a regional area in their country of birth/residency, use of common language (often linked to the previous), membership of a religious or faith community, and race or colour.

Age was rarely cited as a key element of personal identity, women were more likely to describe themselves in terms of gender than men and this was particularly true amongst women from minority ethnic groups.

Sexuality formed a key component of personal identity for lesbian and gay people, with few exceptions.

How people viewed the differing components of their personal identities interacting was mixed. Some felt unable to isolate single facets as central to their identity whilst others were happy to. Where people were comfortable in prioritising one aspect of their identity it was either because this facet was valued above all others as providing relevance to that person's life or because it was perceived as the aspect of their identity which required the most active consideration in their daily life, that which makes life most challenging and is likely to produce barriers which need to be overcome.

The relative priorities of people's sense of self-image change over time and vary depending upon the environment they are in and the nature of the people they are interacting with. Some change over time may result from disruption to established life patterns, for example the onset of disability, migration or awakening sexuality. Other change evolves gradually as people age or take on new roles, as parents for example.

Understandings about what constitutes disability were similar to those found previously with people broadly adhering to a social or medical model of disability. Similar patterns showed age to be a critical factor in which attitudes people expressed about the nature of disability.

As with the previous research there was a widespread belief that non-disabled people, unless they had a close disabled friend or disabled family relative, lacked awareness about disabled people's lives. As will be shown in the following chapters, disabled people frequently felt they had experienced prejudice, or different treatment as a result of this lack of awareness and knowledge about disability.

There was often the sense that experiences of prejudice and different treatment were exacerbated when non-disabled people encountered gay disabled people or disabled people from minority ethnic communities.

A primary cause for poor reactions and lack of disability awareness was a perceived absence of disabled actors and presenters on mainstream television programmes. Disabled minority ethnic people argued that the problems with the mass media representation of disability were compounded when ethnicity was added to the equation.

3 Personal and social lives

This chapter reports findings in relation to the personal and social lives of disabled people. This includes details about early life and family relations, family attitudes to disability, relationships and partnerships, friendships and social and leisure activity. It also discusses experiences in the wider community such as local neighbourhood, religious communities, the disability community and the lesbian and gay community.

3.1 Experiences of family life and relationships

Disabled people were asked to describe their early lives and their experiences of growing up. As might be expected there were clear differences between those who had been disabled as a child and those who had experienced the onset of disability in later life. This section considers the effects of disability on the early lives of those who experienced this during childhood.

3.1.1 Impact of disability on childhood experiences

The effects that disability can have upon early life varied greatly across the sample. The evidence collected about the ways in which disability affects childhood confirms previous work which has specifically explored experiences of disability.¹¹ Impacts of disability on early childhood include being physically or practically excluded from activities that other children could do, being treated differently by friends and family, finding opportunities restricted and experiencing limited independence or over protectiveness from family and carers.

A consistent theme in people's accounts of disability in childhood was the impact of being unable to participate in activities that other children could do. Those with mobility impairments described feeling *'upset'* or *'left out'* as children whilst watching other children running around. People with visual impairments, similarly described how this affected the activities they were able to participate in as children. A partially sighted man, for example, described feeling *'left alone and ignored'* by his six brothers as a child when they laughed and joked about films they were watching

¹¹ Woodfield K et al (2002), Chapter 5.

which he was unable to see. Certain types of disability such as hearing impairments were perceived to have created difficulty in communicating with others as children. When people had experienced continual difficulty in communicating with hearing friends, this had sometimes resulted in them becoming withdrawn.

Disability was not always perceived to have affected childhood. In particular, some of the deaf people came from families including other deaf people and said they rarely saw their deafness as an issue when they were young. Others from all of the disability groups said their disability had been prevented from being an issue by the attitude of their parents. Being brought up '*positively*' and encouraged to do things independently was felt to have prevented disabled people perceiving themselves as being disabled or any different to anyone else as children.

In cases where people had spent their childhood in another country, it was sometimes felt that their disability had been much more of an issue in their country of origin than it was in the UK. This point was made particularly by people from all of the minority ethnic groups in the sample and the perspectives of these groups are considered separately in Section 3.1.4. However, this view was also found among those who grew up in other European countries. A Spanish man with hearing impairment, for example, felt that attitudes towards disabled people in Spain were very negative and disabled people were '*treated as useless and are not trained or given any opportunities*'. For this reason moving to the UK was sometimes seen as leading to better facilities and opportunities which had not been previously available.

3.1.2 Impact of disability on family relations during childhood

The way parents, siblings and other family members react to disability is a significant influence on shaping disabled people's experiences of childhood. People from all groups in the sample had experienced very supportive reactions from their family.

Despite this, people cited a range of ways in which their disability had affected family relationships. As found by previous research¹² people often experienced '*over protectiveness*' from parents and siblings when they were growing up. There were no clear patterns to suggest these experiences differed by disability type, age, gender or ethnicity. People from all groups described similar experiences of parents being concerned about their ability to cope with new activities. Whilst the concern of parents was often appreciated, it was sometimes felt this was excessive and lead to people being sheltered from experiences they might otherwise have wanted to participate in.

For those with disabilities or long-term chronic medical conditions which required regular intervention, the need for frequent medical treatment was felt to have been disruptive to family life. This was because it prevented them spending time together and enjoying days out, holidays and other family activities. Another effect of

¹² Woodfield K et al (2002), pp.95.

disability in early life was the stress this was perceived to inflict on parents. In particular, those with fluctuating conditions described how difficult this sometimes made life for their parents. One Caribbean woman with sickle-cell anaemia for example, described how her mother would often need to take her to hospital in the middle of the night or would have to leave work at short notice whenever a crisis developed. As a result she said she *'saw myself as a burden to her'*.

Although much more exceptional, there were those who described their childhoods as extremely difficult and experienced very difficult early lives and very unsupportive attitudes to their disability from family members. For example, a man with cerebral palsy from birth described how his family saw his condition as a *'meal ticket'* which he felt his family saw as opening the door to various social security benefits which were not always used as he thought appropriate.

The issues associated with disability in early life raised by lesbian and gay people were entirely consistent with those raised by heterosexual sample members. There was no evidence that disability affected early life any differently for this group. However, this of course may, in part, be due to the fact that people were often unaware of their sexuality or felt that this had not yet developed during their early lives.

3.1.3 The experience of growing up as a disabled child in black and minority ethnic communities

Indian and Pakistani disabled people felt that there were some very specific ways in which disability was viewed within their community. Disability was said to be a *'taboo'* which was viewed by many people from these communities as bringing *'disgrace'* or *'stigma'* upon a family. In a handful of cases participants felt this stance was linked to a religious belief in *'karma'*, the idea that being born or becoming disabled is a result of wrong doing in a previous incarnation. This viewpoint was more exceptional amongst white participants, despite this there was often discussion about families and friends being *'ashamed'* of their disability.

South Asian participants particularly reported that a consequence of disability being seen as *'taboo'* meant they experienced a lack of sympathy and support from within their own community. It was felt disabled people were *'looked at with hate'* by members of their own community. As one Pakistani woman put it *'Our people point their fingers at them they don't support them. Some say who knows what bad things they have done, they are being punished'*.

As a result, South Asian communities were reported to try and keep disabled people at home and out of sight as an attempt to prevent or minimise this *'stigma'* brought upon their family. Disabled people from these groups described how their family had tried to hide the fact that they were disabled.

'Stigma is mainly community and cousins and family, they start hiding the fact that you go to a special school and the van that comes to pick you and hide

your magnifiers, the visual aids that you use. My sister used to do most of the hiding. She just...couldn't accept the fact that I had a disability so I had to be hidden'.

(Female, 32, Indian, visual impairment)

Some of those interviewed in the research worked with disabled people from minority ethnic communities so had both a professional and personal perspective on this issue. Those involved in this area in a professional capacity often had very strong views on this point, which were formed through experiences of working with this group. It was argued that gender has a significant influence on this situation and it can be more difficult for women than it is for men. Some argued that disabled South Asian women are often '*shut away*' by their families and not allowed to speak for themselves. This corresponded to some extent with the accounts of some of the disabled Asian women who alluded to struggle with their families to be allowed to do things for themselves and decide the direction of their own life. People described their families wanting to keep them at home and take care of everything. However there was evidence that these attitudes among family can be overcome, where disabled people were determined to lead an independent life and demonstrated to their families that they were capable of this. In other cases, people felt that these ideas had not affected their lives because their families had rejected these ideas and developed more '*open-minded*' attitudes.

The feelings of South Asian disabled people about the prevalence of these views in their community varied. Some of the younger people in particular were very dismissive of these notions, describing the attitude towards disability in their community as '*medieval*'. Others, however, appeared to subscribe to the idea that their disability was connected to previous actions and this could make it difficult for them to come to terms with their own disability. In this situation, family rejection of these ideas could be helpful. Some people commented that they had only managed to overcome these ideas through the help and support of their family.

African disabled people sometimes made a similar point about the way that disability was viewed in their culture. One African woman with a mobility impairment caused by polio described how, in Nigeria, her birthplace, there was a very negative attitude to disability. Disabled children were said to be viewed as a disadvantage because they would need looking after and were unlikely to be able to work to ease poverty. These attitudes were perceived to be linked to socio-economic status and the woman in this case saw herself as '*lucky*' because her parents were educated and had jobs which she saw as leading to more enlightened attitudes and encouraging her to learn to be independent.

Language differences between minority ethnic people born in the UK and their parents also complicated relationships. For example a young Indian man who had dyslexia described how his parents did not understand that he was disabled, and how he found it very difficult to communicate this because it was difficult for him to use their particular Indian dialect. In another example, a Pakistani woman with a mobility impairment was cared for by her mother who was unable to understand

any English. She described the distress which had been caused by a situation in which both the woman's father and health services had failed to explain her disability to her mother.

People from ethnic minorities sometimes contrasted attitudes towards disability in the UK favourably with those in their own community. When people had moved to this country in later life, they sometimes highlighted the differences between the attitudes they had experienced here in comparison with those in their country of origin. Indian people described how disabled people were often shunned at home because of the belief they had sinned in a previous life. For this group, coming to the UK was viewed as bringing about better treatment and a more tolerant reaction. These different attitudes were also felt to endure within the UK. The sister of one Pakistani respondent with severe learning and physical disabilities described how their English neighbours '*were great*' with the respondent, whereas '*Our people... they just say she is ill. Lets keep our distance and stuff like that... they won't even dare go near her*'.

3.1.4 Impact of disability upon family relations in later life

Existing evidence demonstrates how the experience of disability in later life can affect relationships with family members. There were people from all groups who received a great deal of help and support from their family. This ranged from partners' and children being full-time carers to situations in which people helped out occasionally. In many cases the disabled person's quality of life appeared dependent upon this assistance. A range of different attitudes to this support were displayed.

Feeling dependent or a burden upon family members can cause discomfort. Many older disabled people from all groups felt guilty about the level of support and assistance they needed from their family. This was particularly acute for older people when their children or other younger family members were providing this assistance. This situation was often felt to be preventing younger family members from getting on with their own lives. A Pakistani woman in her 50s with arthritis for example described how her dependency meant her daughter-in-law always felt 'pressured' to return home quickly in case she should need anything.

Conversely, others saw the help they received from close family in a very different light. In particular, older South Asian people talked about the importance and significance of family support which was sometimes viewed as being a particular strength of their culture and community. The terms in which this was described differed considerably between men and women. South Asian women greatly valued assistance with cooking, cleaning, shopping and errands provided by children and relatives and saw this as a manifestation of their 'love'. Asian men, however saw this type of help as demonstrating 'respect' and felt that this was very important. There was felt to be a great deal of stigma attached to a situation where children were not seen to be assisting their parents '*people will not respect you, if your own family don't respect you then other people won't*'.

Sometimes people were disappointed with the level of support they received from their family and wider community. Asian groups (in particular) emphasised this and sometimes appeared nostalgic for their earlier days in the UK when their family and community were perceived to be much closer. As one Indian man put it '*they do not come very much at all now ...everyone is so selfish and they all have their own families and their life is for their own families*'. Similarly, older African and Caribbean disabled people spoke about their surprise at the lack of help they received from their children and contrasted this with the way their generation had always helped their parents. Sometimes people linked the fact that family and friends did not visit as often as they might to their disability. A Caribbean woman with multiple disabilities for example described how her children came to see her less and less now that she was disabled and felt certain that her disability meant '*I'm not wanted*'.

When family members tried to provide help or support which was unwanted, this could also be a source of irritation to the disabled person. People who had suddenly become disabled as adults sometimes found their families' reaction to their disability overpowering or stifling. A 50 year old man who suddenly lost his sight for example, described his frustration at his brother's attempts to '*mollycoddle*' him and insist on doing things he was perfectly able to do himself.

3.1.5 Impact of sexuality upon family relationships

The way in which people had responded to the emergence of their sexuality and the realisation that they were lesbian or gay had varied. This did not appear to be linked to the presence of disability. People who were disabled at the time they became aware of their sexuality and those who were not because of late onset, reported similar reactions to realising they were lesbian or gay.

Primarily, people's attitudes to their sexuality seemed influenced by their levels of awareness and experience of lesbian and gay sexuality. Some of the older women in particular had lacked any awareness of this and consequently their sexuality had caused them significant confusion sometimes for very long periods. Some described themselves as '*very naive*' and spoke of how they suppressed the idea that they might be lesbian for years. This lack of awareness and understanding could lead people to feel that their sexuality was something to be ashamed of and to feel very negative about this part of their identity. This was in stark contrast to younger people, none of whom had attempted to suppress or deny their sexuality for this long or to this extent. This contrast is obviously linked to cultural change in British society and the growth in profile and acceptance of lesbian and gay sexuality in recent years and this issue will be returned to in **Chapter 7**.

Concealment of sexuality

Some of the older lesbian and gay disabled people had concealed their sexuality from family members for long periods. It was common for people who were in their 50s and 60s to have parents and siblings who were still unaware of their sexuality. The main reasons people gave for the decision to conceal their sexuality was the feeling that family members would find this difficult to accept or cope with. Some of

the older respondents had very elderly parents and felt that telling them that they were lesbian or gay at this late stage would only cause unnecessary stress. In some cases there was evidence that the strain of long periods of concealment had taken their toll. One gay man cited the stress of hiding his sexuality as one of the factors underpinning his attempted suicide.

Disclosing sexuality

Some people's relationships with their family had been adversely affected by coming out and disclosing that they were lesbian and gay. Some people had received very negative reactions to their sexuality from family members. One woman who came out to her family when she was 21, for example, was thrown out of home by her parents and ostracised by her whole family, community and support networks. The way in which intolerance of lesbian and gay sexuality can damage and strain family relationships has been well documented among non-disabled lesbians and gay men.¹³ It seems that these experiences occur in the same way for disabled lesbians and gay men as they do for non-disabled people.

There is some evidence, however that being disabled can make it more difficult for people to 'come out' and disclose their sexuality to parents and family. In one case where a young woman's parents has been very upset and concerned about the harassment she had received in relation to her disability, she was loathe to tell them she was also a lesbian as she knew this would heighten their concern.

It is possible that the experience of 'coming out' can also differ for disabled people. Some people had come out to their families before the onset of their disability. When they had received a very negative reaction to their sexuality, the onset of their disability had sometimes brought about a reconciliation with their families.

Family attitudes to sexuality

Among those people whose sexuality was known by their families varying attitudes to this was reported. Some felt that their families had accepted and come to terms with this. This was reflected in the acceptance and inclusion of their partners and a general openness in discussing sexuality. Some people described problems their sexuality had initially caused in their relationships with parents and families but felt these issues had been resolved.

Others had experienced very intolerant and upsetting attitudes to their sexuality from their family. These usually took the form of anger and verbal abuse and in the worst cases people were rejected and ostracised by their families. In some exceptional cases families had enlisted medical help to try and 'cure' what was perceived as an affliction or illness. One older gay man described how his mother refused to accept his sexuality and sent him for therapy and to a psychologist. The experience of growing up in small rural communities was felt to make being lesbian or gay more difficult and was contrasted to the experience of life in large cities such as London.

¹³ O'Connor, W. & Molloy, D. (2001) .

One gay man from such a community described how attitudes were more intolerant in this environment and sexuality was impossible to conceal. His mother had been very concerned about '*what the neighbours would think*' when his sexuality was discovered. An older gay man from a very similar environment was certain the shock of his sexuality had been the cause of his mother's death.

There is some evidence that being disabled can make it more difficult for parents and family to accept and deal with a disabled person being lesbian or gay. This can be because of parental concern and fear their child may suffer 'multiple discrimination' due to this combination of characteristics. This is explained by a lesbian woman with a hearing impairment.

' One of the reasons they were so upset when I told them I was gay was that [they were worried] society would exclude me even more than it already had done and I wouldn't be able to stand up for myself. This would be another reason to be attacked.'

(Female, 42, lesbian, white, hearing impairment)

Some of the lesbian women had children and 'coming out' in these circumstances had often affected relationships with children quite dramatically. Women in this situation described how their children had reacted very badly to their sexuality and refused to accept this. One woman described how her son had threatened to kill her first female partner. In other examples children had refused to accept this and broken off contact with their mothers for a while. Frequently however these relationships had been repaired over time and many of the women said their children now accepted their sexuality. Sometimes, the onset of disability had led to these difficult relationships being strengthened.

3.2 Family relationships and partnerships

This section explores the accounts of disabled people relating to finding a partner, forming relationships and experience of marriage and partnerships. It considers how these experiences are affected by disability and highlights any issues around this which are particular to disabled people from black and minority ethnic groups and disabled people who are lesbian and gay.

3.2.1 Impact of disability on forming relationships and partnerships

Being disabled was felt by people from all groups to affect the experience of finding a partner and forming relationships. People from white, black and other minority ethnic groups felt that disability can '*get in the way*' of forming relationships because people '*see the disability rather than the person*'. In addition, certain types of disability can lead to obvious issues in forming relationships. People with learning difficulties for example, felt this made it difficult for them to establish relationships because of the difficulties they experienced in communicating. Disabled people with disabilities which were not immediately visible also felt their disability made forming

relationships more difficult. It was felt that prospective partners were often put off or lost interest when they realised that a person was disabled.

Among people from South Asian groups, there is some evidence that that disability can have some very specific effects upon people's chances of forming marriages and partnership. Gender appears to have a particularly strong effect here. Some people from this background described Indian culture as being one where '*women service men*' and being disabled was viewed as affecting women's ability to fulfil this role. As a result it was felt women were '*written off*' to some extent by their families. Some of the South Asian men described disabled women being '*treated like dirt*' by their families. They were seen as being unable to work and unlikely to get married because it would be harder for their families to find a prospective husband for them.

' Women...[are] the most disadvantaged people in India because...– by Hinduism and Indian concept women are supposed to be second to man... the woman comes next... she shouldn't play a primary role in anything, the man plays a primary role...and the woman always gets the secondary role... and when the male child comes along then the male child picks up the secondary role and the woman goes still one further step backwards. She is there to serve man, she is there to please man and, you know, that sort of thing. So if you're a disabled woman, you cannot work, nobody wants to marry you because you've got a disability, nobody wants a wife who's useless, even in this country.'

(Male, 27, Pakistani, visual impairment)

This was supported by accounts from South Asian women. For example, a woman with a hearing impairment described how her non-disabled sisters had all received marriage proposals while she had '*just been left alone*'. This experience appeared to have changed her attitude to the prospect of marriage and although her parents had offered to try and find somebody for her she had decided to stay unmarried. Others felt it had been very difficult for their parents to arrange their marriages because they were disabled. One Indian woman with visual impairment described how her mother had faced a great deal of stress in trying to arrange her marriage. She felt this had placed her mother under tremendous pressure, which had contributed to her mother suffering a nervous breakdown around the time of her marriage.

Less frequently disability was also mentioned as affecting the chances of marriage for South Asian men. One Indian man with cerebral palsy described how his wife's parents opposed the marriage because of his disability. He described how this attitude had made him very '*angry*' with the Asian community and he had become committed to working to change these attitudes as a result.

3.2.2 Impact of sexuality on forming relationships and partnerships

Being lesbian or gay was felt to be harder for disabled people than it was for non-disabled people because of society's attitudes towards disability and sexuality. Previous work, such as Woodfield K et al (2002), has shown that disabled people feel that there is an assumption from the rest of society that disabled people's lives are

asexual. The findings from this research indicate this was a particular issue for gay and lesbian disabled people. Those with mobility impairments in particular felt that society finds it very hard to accept the idea of lesbian and gay sexuality among disabled people. Some felt that society felt the idea of people with mobility impairments being sexual *'repulsive'*. Others felt that there is an assumption that disabled people are asexual and an assumption that they will not have a sexuality or want a physical relationship. Some people pointed out that they had been sexually active before becoming disabled and asked why did people assume this was something no longer relevant to their lives. These attitudes were felt to be *'frustrating'* and *'annoying'* by lesbian and gay disabled people.

'I feel society does not look at disabled people as sexual beings...if you're disabled they don't expect you to have sexuality or want a physical relationship, which is quite hard...They don't think you're capable, they sometimes don't feel you have emotions and feelings like everyone else, for a disabled person to be sexual and a lesbian, then God, that is outrageous!'

(Female, 46, lesbian, white, mobility impairment)

It is very difficult to gauge the precise impact of these attitudes on lesbian and gay disabled people's lives. They had certainly not prevented many lesbian and gay disabled people from forming relationships. However, the prevalence of these attitudes were felt to create an atmosphere in which lesbian and gay people have to struggle to form partnerships against this universal assumption this is not something they will want.

Some of the lesbian and gay sample had experienced long-term difficulties in accepting their sexuality. These feelings can greatly affect the choice of partner. A significant number of the older lesbian women had had heterosexual relationships when they first left home. Many of the women described these earlier experiences in terms of their own naivety about their sexuality and attempts to suppress this. For example, one woman described how for years she would drink heavily and sleep with men *'to prove I wasn't queer'*. A number of women had been married and had children. They described how they had done this so that they could tell themselves that they could not be gay because they had a husband and children. Others had much more pragmatic reasons for getting married and had done so simply to escape difficult or abusive situations at home.

Being a lesbian woman with children was felt to create a variety of difficult issues. Some women described how having had a child meant society continually viewed them as heterosexual. The implication of this was that life was made more difficult as a result of society continually misconstruing or disputing their sexuality. Other people with this experience described issues these circumstances caused for their children. One lesbian woman worried that this situation would become an issue for her son at school and wondered what effect this might have on him in the longer term.

3.2.3 Impact of disability on marital relationships and partnerships

Disability did not always have any perceived effects on relationships and partnerships. There were people from all groups who did not think the disability of one partner had affected the relationship or that relationships had been greatly affected because one partner experienced the onset of disability later in life. In some of these cases, the value of external support to assist independent living via benefits such as 'Motability allowances' was striking.¹⁴ Some people said the assistance this provided with 'getting about' may have saved their relationships as it prevented the disabled partner becoming totally dependent on the other.

As found in previous research, however, disability can have negative effects on longstanding relationships and partnerships.¹⁵ Becoming dependent on partners after onset of disability had caused relationships to break up for some.

This was particularly evident among the white groups of disabled people and within this group, the lesbian and gay disabled people. It is difficult to say with any certainty why this might be. This may be linked to the fact that these relationships were often less longstanding than those of heterosexual disabled people. For example some of the lesbian women who had been married before 'coming out' had often formed lesbian partnerships later in life. These relationships were consequently less longstanding than those formed by other white disabled people and the ethnic minority disabled people. It is also possible that these relationships may sometimes be more vulnerable because of the intolerance or hostility they sometimes received. For example, intolerance either among family or within the local neighbourhood may mean these relationships are less able to withstand the strain brought about by the onset of disability.

Although much less pronounced, there was some evidence of disability placing a strain on relationships among African and Caribbean groups. This could be a source of great distress as described by a woman with rheumatoid arthritis whose husband resented her disability and was so unhappy she had told him he should remarry.

'There is not much to enjoy in my life now, I cannot go anywhere because he doesn't like to take me anywhere...he feels ashamed...I can see that I will not look good amongst well people...he wants a perfect wife who can do things for him...he asks me why was it in his kismet that he got someone like me?'

(Female, 54, Pakistani, mobility impairment and mental health impairment)

¹⁴ Although respondents used this phrase the package of support referred to is actually the motability component of Disability Living Allowance for those receiving the higher rate of DLA, which gives recipients access to the Motability Scheme. If Higher Rate DLA recipients wish they can use their higher rate component to finance a leasing or hire purchase agreement for a car from Motability, a charity set up for that express purpose.

¹⁵ Woodfield K et al (2002), pp. 98.

Fewer African and Caribbean people had experienced relationship break-up. However, among Caribbean people in particular this may be as much to do with the fact that people were often not in formal marriages and were often widowed, divorced, separated or never married than the fact that relationships had withstood this strain.¹⁶

This type of experience was much less common among South Asian disabled people. This group were more likely to be married than other groups and often received a great deal of support from their spouse or partner who had sometimes changed their lifestyle in order to provide full-time care.

However, marriages within the South Asian community could come under strain due to attitudes to disability within the wider family and community. The way in which the stigma attached to disability within this community could make it more difficult for disabled people to marry has been mentioned in Section 3.2.1. These attitudes could continue to affect disabled people after their marriage, as described by an Indian woman with a visual impairment below.

'My husband's family here isn't that nice because of my sight... not very nice at all. It's just centred around beauty... they just make comments that she's not beautiful, she's not nice or she's got an eye problem, just those sorts of critical comments that will cause arguments.'

(Female, 32, Indian, visual impairment)

There was also some evidence that within the South Asian community, gender may be a factor in affecting how disability is experienced within marriage. Women from this community sometimes expressed significant distress when discussing how their disability prevented them from tending to the needs of their husbands and carrying out other domestic tasks. This is illustrated in the words of the following respondent who became upset at this point in the interview.

'I cannot stand for very long either, after two minutes I am in such pain and I have to sit down on a stool...sit for a while and then I get up and do a little more. I cook alternate days, I knead the flour and leave it, I make roti for my husband ...I cannot make too much roti. He does not like food from outside and he doesn't like it when anyone sends food, he only likes the food cooked at home. He likes perfect things [respondent breaks down]...'

(Female, 54, Pakistani, mobility impairment)

Age did not arise as an issue in discussions about impact of disability on marital relationships and partnerships.

¹⁶ For detail on ethnic differences in marital status and partnerships see Modood, T. et al, (1997).

3.3 Friendships and the social world

Disabled people included in the sample were involved in a range of different types of social and leisure activities. This section discusses these experiences and focuses upon the barriers cited by respondents in relation to this area of their lives. This includes perspectives on the way disability is perceived to affect accessing the social world and leisure activities and how this can differ for different groups.

3.3.1 Social and leisure activities

The types of social activities experienced by disabled people varied. Different disability types obviously have very different implications for the types of activities people can or can not access. Broadly speaking, mobility and sensory impairments tended to affect people's ability to participate in social activity to a greater extent than did epilepsy, learning difficulties such as dyslexia or mental health problems such as psychosis. In a few exceptional cases people with mobility impairments were involved in an extensive range of social activity. For example a wheelchair user in his 50s spoke of how discovering a special holiday company which arranged holidays for disabled people had enabled him to visit many different countries. Such positive examples, however, were more exceptional and people from all groups recurrently described how their disability prevented them from taking part in activities and had affected their friendships.

Accessibility, or inaccessibility, was a dominant theme in people's accounts of how their social and leisure activities were affected by having a disability, the remainder of this section explores the different issues associated with accessibility.

Lack of access was a recurrent issue for people from all of the disability groups. As highlighted in previous research, inaccessibility can be a major barrier to the social world. Some people commented that their disability was much more of an issue in their social lives than in their working lives. Obviously the way in which this occurs differs with disability type.

For people with mobility impairments, physical access was often a problem due to the inaccessibility of restaurants, theatres, cinemas, friends' houses and other social venues. People with mobility impairments frequently highlighted the wide range of physical restrictions faced in trying to access a range of types of social activity. One recurrent issue mentioned by those with mobility impairments was access to toilets which could be a particular concern for wheelchair users. These barriers sometimes combined to decrease disabled people's motivation to go out and try and access different forms of leisure activity. When people had experienced onset of disability in mid or later life this could affect the level to which people engaged in social activity dramatically. Those with late onset of disabilities affecting mobility had often become unable to participate in a range of sporting, cultural and social activities that they had often previously enjoyed. Disabled people who had experienced late onset, regularly commented that they did not go out as much as they used to.

Those with other disability types spoke of various other problems relating to the inaccessibility of venues. For example, those with sensory impairments often were unable to participate fully in social interaction in noisy venues. In addition, younger

people with sensory impairments and conditions such as epilepsy described how these prevented them from going to nightclubs with strobe or flashing lighting which could affect them adversely. Venues such as those with air conditioning systems were difficult for people with respiratory conditions. One impact of these issues was said to be the removal of any 'spontaneity' in relation to going out as every outing had to be planned and access facilities investigated. Fluctuating conditions such as sickle-cell anaemia were also described as disruptive to social activity. Some people with this condition described how this could prevent them from arranging outings or booking holidays because they were unable predict whether they would be well enough to attend.

Those with hearing impairments were very critical of the failure of television and cinema to cater for them. People described how they had to rely on other people to explain and summarise this form of media. The provision of subtitled programmes was felt to be inadequate: *'they hope to have subtitles on five per cent of programmes by 2008, it's so small and they think that is marvellous!'* Deaf people also described how difficult it was for them to attend other forms of cultural events such as the theatre. One deaf man who was passionate about the media and the arts was very critical of the fact that there is still no theatre for deaf people in this country. Whilst the provision of occasional performances for deaf people was valued, this was felt to be insufficient and the exceptionality of this type of provision meant deaf people have much less choice than hearing people. This was because they might only have one opportunity to attend a performance which was accessible for them in the life of a production.

In addition, public transport frequently came under criticism for its inaccessibility for disabled people. The inaccessibility of public transport was cited by all groups as being a critical factor in limiting social activity. For example, those with hearing impairments described how it was impossible for them to understand travel announcements such as train platform changes. This could be very confusing and cause obvious difficulties and it was thought these messages should also be communicated by visual methods. Public transport issues were particularly acute for those living in rural areas with less frequent services but even those living in metropolitan and city areas were critical of the accessibility of public services such as buses, trains and trams.

Some disabled people reported instances where people running leisure activities had been helpful in making their facilities accessible. For example a man with cerebral palsy described the way people at a clay pigeon facility had tried to make the venue wheelchair accessible. However these experiences were more exceptional and instances of unhelpful attitudes were reported much more commonly.

Older disabled people from South Asian groups were less likely to comment on the barriers to social and leisure activity that were described by others above. In contrast to the other groups, no one from the Pakistani group and very few from the Indian group mentioned for example, the theatre, cinema, pubs or restaurants. For these groups social activity revolved almost exclusively around their home, family and temple or mosque. Because they did not choose to access wider public activities they were less likely to feel excluded from these. However, when people from this group were not in close contact with family members this sometimes meant they rarely

participated in any social activity. Some did not go out at all other than occasional trips to day centres. When the disabled person was cared for by a spouse there was some evidence that the onset of disability for one partner could increase the social isolation of both members of a couple.

It is important to note that whilst this section has focused on the limitations imposed by inaccessible services such as buildings or transport on people's social and leisure activities, similar issues were reported in relation to all aspects of everyday life. For example, limited accessibility of public transport restricted people's access to shopping, access to work and other everyday activities. These findings reflect those discussed in the previous report.

3.3.2 Forming friendships

As documented in previous research, losing friends was reported as one effect of becoming disabled.¹⁷ In particular, those suffering from mental health problems highlighted this impact of their disability. A woman who developed mental health problems after she was attacked described how her friends had stopped contacting her '*because they don't really understand what it is*' and others described how their friends and associates began to '*look at you differently*'. Others had lost friends due to being unable to participate in social activities which had sustained certain friendships or because their own feelings about going out and socialising had changed. This was not always perceived to be a negative development. A young Indian man who no longer kept in touch with any of his non-disabled friends had formed a new social group comprised entirely of disabled people and said this was where he felt most at ease.

Opportunities for disabled people to make friends and expand their social circle can be affected by factors related to disability. The decision to restrict social activity because of frustration or weariness with the barriers faced, which was cited above, has obvious effects on people's potential to form friendships. The impacts of disability on people's ability to work also had implications for friends and social networks. Work was a clear source of friends for many disabled people in work. However, for others, giving up work (often linked to onset of disability) had resulted in a reduction in their social circle and social activity. In addition, there was some evidence that forming friendships may become more difficult with age. People commented that they found it very hard to make new friends as they had become older.

Among South Asian disabled people social activity often revolved around spending time with friends and offering hospitality. When the onset of disability had interfered with people's ability to provide this hospitality then it could be felt to have reduced social activity. A Pakistani woman whose visual impairment meant she could no longer prepare tea and food for example, felt that her friends now came to visit less frequently because she was no longer able to feed them. These views may

¹⁷ Woodfield K et al (2002), p 100.

well be linked to the strong domestic role older women in this group perceived for themselves and a consequence of the way disability can interfere with this. Older men from these groups spoke of the way that disability prevented them from visiting relatives and taking gifts.

Among the lesbian and gay sample, some had lost friends when they disclosed their sexuality. Whilst this experience was obviously painful, many said they had ceased to regret losing contact with people who allowed such factors to get in the way of friendship. Being lesbian or gay was sometimes felt to make forming new friendships difficult. One woman spoke of how she found it difficult to know how soon to tell people she had recently met that she was a lesbian. If she did not reveal this information, she felt she was not being truthful, but was worried that telling people she was a lesbian might mean she would lose them. These concerns were felt to make the whole business of meeting new people more stressful.

In some cases people reported negative reactions from others which they attributed entirely to their ethnicity rather than other characteristics. One older Caribbean woman for example, described how people in the Salvation Army refused to walk down the street with her which she was certain was due to her colour.

3.4 Experiences in wider communities

People were also asked about their experiences of wider groups such as their local neighbourhood, faith community, the disability community and the lesbian and gay community. In particular, people were asked to compare their experiences in different communities. For example, the experience of being from an minority ethnic group in the disability community, versus being a disabled person within the black or South Asian community.

3.4.1 Local neighbourhood and community

People's experiences in their neighbourhood and wider community were mixed. Some spoke of living in a supportive community and had neighbours who they could call on if they needed anything. However, some people in the sample had experienced harassment in the area in which they lived. This ranged from fairly mild to very severe and included incidents like staring, laughing, verbal and physical abuse, windows being broken and other forms of vandalism directed at people's property.

In some cases the reasons underpinning these different types of harassment were clear. Sometimes people were certain that these negative and intolerant reactions from others were due to their disability. For example, a bisexual man with severe learning difficulties, who experienced abuse on the estate on which he lived and had had bricks thrown through his window, was sure his disability was at the root of this. This was because his disability was a characteristic that people were easily able to perceive. He felt sure his sexuality was not a factor in this treatment as this was not something people would be aware of because he was married.

Some of the ethnic minority disabled people had experienced incidents which were felt to be entirely racially motivated. A visually impaired Pakistani man who grew up in East London was attacked on a number of occasions and had had eggs and other items thrown at the windows of the house where he and his family lived. He was certain these incidents were racially motivated as there had been a lot of resentment towards Asian families in East London at that time. In another case an Indian man had been physically attacked on a number of occasions and subjected to verbal abuse relating to his ethnic origin while walking in his neighbourhood.

Sometimes, however, the characteristic at the root of these types of intolerant reactions was impossible to unravel. People were often unaware of what it was about them that other people had objected to. It seemed likely, in some cases, that harassment and abuse were linked to certain combinations of characteristics. Indeed the relentlessness of some experiences suggest that more than one characteristic might be relevant. This is apparent in the words of one Caribbean woman:

'Well I face racism every day, you know, it's a common thing that black people suffer, but with this face as well it make it worse for me. I used to have windows broken, graffiti, children scorn, children laugh, they say it's me kill my husband, they call me a witch.'

(Female, 60, Caribbean, facial disfigurement)

A lesbian woman who was a wheelchair user who had suffered recurrent abuse and vandalism from young people on the estate in which she lived, also felt that a number of aspects of her identity underpinned this behaviour. She felt that her disability, her sexuality and also the fact she was Jewish were all characteristics that those people harassing her disliked *'I sometimes wonder which part of me they hate the most'*. She also felt her gender had an impact on her situation because if she had been a *'muscle white male'* other residents would be less likely to act in this way.

There was some evidence of intolerance being particularly pronounced for lesbian and gay disabled people. Some of the worst examples of verbal abuse, in relation to sexuality, involved links between these characteristics being made. For example, a lesbian woman who suddenly became disabled in her 40s described being told that her disability was punishment from God for being lesbian.

In some cases experiences of harassment were so severe that they extended beyond the disabled person and affected their families. Some of those with very visible disabilities such as the woman quoted above, felt that this had affected their children's lives adversely. She described how local children were told by their parents not to play with her children because of her disfigurement and her children were picked on at school. She felt that this has lowered her children's self esteem and made them feel ashamed of her.

Overall, these types of experiences were fairly exceptional. Other disabled people from all groups did not describe encountering these types of reactions in the area in which they lived.

3.4.2 Participation in faith communities and religious worship

As might be expected given the ethnic mix included in the sample, people followed a range of religions which included Christianity, Judaism, Hinduism, Sikhism and Islam. Religious belief was often used as a coping mechanism in one way or another and provided a clear source of strength to people from all groups in coping with the experience of disability.

Faith and religion were particularly important to people in the minority ethnic groups in the sample. This confirms quantitative evidence about the high levels of religious adherence among these groups.¹⁸ The frequency with which the importance of religious belief was raised as an issue, suggests this may be more relevant to the experiences of disabled people from minority ethnic groups than other groups of disabled people.

Recurrent comments were made as to how faith had helped people come to terms and live with their disability. Caribbean people in particular said they took comfort from the sense their religion provided of being part of a wider community or family. Many had received a great deal of support from their church community during times when they had been in hospital or particularly unwell. Those with disabilities which were felt to carry social stigma such as mental health problems, commented that their church or religious community were much more accepting and supportive of their disability than society in general.

There were some differences between the South Asian respondents and the Caribbean people. Hindus, Muslims and Sikhs tended to be more formal and deferential about the role of religion in their lives than were the Caribbean and white groups. They spoke much about the trust they placed in God or Allah to determine the direction of their lives. These religious views were often in distinguishable from their way of life in general.

The importance of religion in the lives of some of the ethnic minority disabled people meant that the physical accessibility of religious ceremonies was a source of concern. This was particularly evident among South Asian disabled people. Muslims, Hindu's and Sikhs with mobility impairments recurrently described the barriers their disability caused in attending the temple and participating in worship. Worship within Hinduism, Sikhism and Islam was said to require a degree of physical mobility. One Indian woman described how Sikh temples will not allow people in wheelchairs to enter and how she had been told to sit on the floor which was impossible for her. Others commented that the Muslim ceremonies involve lots of standing and sitting

¹⁸ See the Fourth National Survey of Ethnic minorities in Britain in Modood, T. et al (1997), pp.356.

which was impossible for them to do. Many of the older people from these groups had stopped attending the temple or mosque because they could no longer do this. Some of the younger Asian people expressed significant frustration towards this situation and felt strongly that Asian religious culture needed to adapt and be more accommodating of disabled people.

Ethnicity was rarely cited as a factor in access to religious worship. However in one exceptional case an Anglo-Indian man felt he had experienced racial discrimination and prejudice among the community at the Roman Catholic church he attended. This had been in the form of comments implying Indian people were untrustworthy.

There was some evidence that gender can also affect access to religious and spiritual leaders. One Indian woman described how after years of waiting her 'guru' had visited her house. However because of rules within her culture which decreed that only men can look at or touch gurus, she had been unable to have any contact with this individual.

The white respondents were much less likely than the ethnic minority groups to cite faith communities as being important in their lives. However, people in this group who did attend church and religious ceremonies cited far fewer problems around the accessibility of services than did ethnic minority respondents. In particular, some people commented that the churches they attended were very understanding of disability. A lesbian woman who attended a gay church commented on how they did not assume all would be able to stand at certain points in the service and instead would say '*please stand as you are able*'.

Some of the lesbian and gay disabled people had faced intolerance of their sexuality within their religious community. A young lesbian woman who had been the president of the Christian Union while at university felt that the church leaders had tried to get rid of her because of her sexuality. She also said she has been 'banned' from churches because of her sexuality. She felt the Christian community were very intolerant of lesbian and gay sexuality. She described comments people had made suggesting her disability which resulted from an accident represented her 'being punished' for her sexuality. She commented that the main area of her life in which her sexuality had resulted in problems was in practising her religion and found this 'ironic' given that church communities '*are supposed to be loving and accepting*'.

In another example, a Jewish woman described the difficulty she faced in coming out as a lesbian. She felt that Judaism refused to recognise sexual diversity and coming out as a lesbian had resulted in her being rejected by both her family and her community. She felt she had been given a message that '*you can't be Jewish and be gay*'. Conversely, she also felt that her Judaism was rejected by the lesbian community. She described how lesbianism was 'very political' and shaped by feminist ideology which taught that religion was patriarchal and Judaism and Zionism were oppressive of women. Consequently she felt that within the lesbian community people were critical of her faith seeing it as '*association with the oppressor*'.

3.4.3 The disability community

Statutory day centres and local voluntary groups were an important source of social activity and support for many disabled people. The findings from this study and positive accounts of those who had become involved in local clubs or groups for disabled people confirm earlier research in suggesting that such groups can be a lifeline.¹⁹ These groups can be very empowering for disabled people, particularly those who experience the onset of disability suddenly and find this difficult to come to terms with. People described feeling like '*life wasn't worth living*' after becoming disabled. Contact and involvement with disability organisations could help people overcome this. People with all types of disability described how they had been taught that life with a disability can still be meaningful.

Contact with people with similar disabilities was also felt to be important. Some people said they had begun to feel most comfortable among disabled people. People with similar disabilities could also be a useful source of advice. A man who had experienced the sudden onset of visual impairment in his 50s described how other visually impaired people were full of tips and hints that he found invaluable, such as how to avoid confusing ingredients while cooking.

Being lesbian and gay in the disabled community

The views of lesbian and gay disabled people about how inclusive disability groups and organisations varied. Some lesbian and gay disabled people had had positive experiences within disability groups and felt the disability community was accepting of their sexuality. It was said by some that they did not think they were treated any differently than they would have been if they had been heterosexual. This tolerance was sometimes perceived as being a fairly recent development in the disability community and comments were made about the increasing commitment to diversity in recent years.

Other people described being a lesbian and gay person who represented or was active within the disability community. Generally, people reported positive experiences. Some disability organisations were mentioned as being happy to have lesbian and gay members on their committees, for example The Greater London Action on Disability (GLAD) and the British Council of Disabled People (BCoDP). Others, however, argued that disability groups sometimes marginalise the lesbian and gay community.

Gender could sometimes be an issue for those attending disability groups. For example a woman who attended a group for people with head injuries said that the fact the group was mainly attended by men made it difficult for her as a lesbian. As a result she had decided not to disclose her sexuality to the group because she felt she would '*get lots of comments about it*'.

¹⁹ Woodfield K et al (2002), pp.102.

Being from a minority ethnic group in the disabled community

The experience of being from a minority ethnic group in the disabled community received far fewer comments than those relating to the experience of being lesbian or gay in this community outlined above. Many of the ethnic minority disabled people did not have a view on this or had not given it any thought. When ethnic minority people had attended culturally mixed groups these were generally viewed very positively. One Pakistani man who had been the only Asian member of a disability group described how the people were 'nice' and he had always felt comfortable attending there.

One explanation for why being from a minority ethnic group within the disability community was not felt to be pertinent may be the extent to which ethnic minority disabled people attended culturally specific disability groups and organisations. South Asian disabled people for example, mainly attended disability groups aimed at their specific ethnic community. This type of provision was viewed as very important, particularly for older people from this community. Some people commented that if this type of provision was not available then it would be impossible to persuade elders from their community to attend.

People's experiences of these culturally specific disability groups were unanimously positive. Before attending these groups, people may not have known anyone else from their ethnic group who had the same type of disability. One Pakistani woman who concealed her disability because of the negative attitudes towards disability from the Pakistani community, spoke of how it was a relief to be able to discuss her disability freely with people who had had similar experiences. Some people felt that the people they had met at these groups had become '*like family members*' and that these groups now felt like '*a second home*'.

Other perceived benefits of meeting people from a similar cultural background were that this could provide opportunities to learn about one's own ethnic culture. This could be very empowering and make people feel more connected with their own community.

'If it weren't for the centre I would feel isolated, I would feel alone...as a black person I don't know anyone...the centre gives me a place where I can identify with other people and other people can identify with me. And I feel more at home [and] in the community. Instead of alien to the community I feel more in the community.'

(Male, 36, African, mental health impairment)

The evidence suggests that age may affect the desire to make contact and mix with people from the same ethnic background. One Caribbean woman, for example, felt this had been less important to her when she was younger because she was busy working and bringing up her family. However, this had become more important as she got older.

The gender mix of disability groups was perceived to be important by Indian and Pakistani disabled people. In particular, women often indicated that they felt more

comfortable with the idea of women only groups. Mixed gender groups appeared to be seen as inhibiting and some women commented that if men were present this would make it difficult for them to '*speak freely or make fun*'. Similarly, a Pakistani man commented that there were not any men only disability organisations in his area and if there were then he would be keen to attend these.

Some of the older Indian women spoke very positively about the day centres they attended. These were perceived to allow them to make friends and had enabled some to participate in activities which would previously have been impossible such as swimming or learning to drive. In some cases these visits to the day centre were the only times in which they left the house and had contact with the outside world. In some of these cases these day centres and the support which enabled people to access them were clearly playing an immensely valuable role in shielding people from almost complete social exclusion.

Some people did not know about any ethnicity or disability groups and said they would like to be informed about these. Ethnic minority disabled people who were involved with or worked for disability organisations sometimes argued that more work needed to be done to persuade people from their community to attend these groups. However, it was felt that the 'taboo' associated with disability in their community meant many people who could benefit from these services were reluctant to access them.

3.4.4 Voluntary work

One of the most common activities undertaken by sample members was involvement in voluntary work. This is undoubtedly an effect of the high proportion of the sample accessed through voluntary organisations. People were asked to reflect upon why they took part in voluntary activities. It was common for participants to explain that they felt they had experienced discrimination or prejudice in some areas of their lives. This had created a sense of solidarity with other people with whom they shared characteristics and a desire to work towards overcoming discrimination and prejudice. However, others explained that their involvement was primarily a means to combat isolation or to fill a space in their lives created through their lack of paid employment (the latter also being common amongst non-disabled people of retirement age and over who are no longer working).

People often volunteered to work with organisations and groups targeted at people with whom they shared characteristics. Sometimes these were very specific organisations that reflected combinations of characteristics such as an 'Asian disabled women's group', 'Caribbean centre for elderly people' or the 'Asian disability network'. More frequently however, people were involved in voluntary work which just reflected a single characteristic. Voluntary work within disability organisations and groups providing services to disabled people was fairly common. Deaf people in particular were frequently involved in organisations aiming to raise awareness of the needs of deaf people. Other examples were volunteering as a school governor at a special school for disabled people. Sometimes people worked

to represent disabled people within generic or mainstream organisations. For example disabled access committees within local authorities. A number of the lesbian and gay sample volunteered within lesbian and gay organisations such as the lesbian and gay switchboard. Other examples were organisations aimed at assisting young people in exploring their sexuality and coming out.

People less frequently worked voluntarily in organisations not connected to disability, sexuality or ethnicity. Sometimes there was again a strong link between people's own experiences and a desire to help others in similar situations. For example a lesbian woman who had been abused by her husband volunteered as a counsellor for women's aid. Other people, however, simply volunteered to carry out work or activities they enjoyed such as gardening, cooking, nursing or helping run a local church. Mention was also made of the positive effect that voluntary work could have on a person's self-esteem. Being able to help others and '*make a difference*' had given people a real sense of pride and achievement. Some of the younger people had been involved in voluntary work to get experience which they felt would be useful in trying to find paid work. There were also older people who had previously been involved in voluntary work and felt this had been valuable to them in subsequently finding paid work. It had given them experience in the workplace, and often a good reference they could use when applying for paid work. In addition, there were cases where people had ultimately been offered a paid position by the organisation they had been working for on a voluntary basis.

3.4.5 Being disabled in the lesbian and gay community

Some lesbian and gay disabled people were very critical of the lesbian and gay community which was felt to exclude disabled members in various ways. Some commented that the disability community was much more accepting of lesbian and gay people, than the lesbian and gay community was towards disabled people.

People highlighted a range of experiences to illustrate this. Very few lesbian and gay disabled people venues were felt to be fully accessible. It was felt to be a struggle to get large lesbian and gay events such as Mardi Gras to consider issues such as access. These attitudes were felt to reflect the lack of disability awareness within the lesbian and gay community.

Other people described issues they had faced in being a disabled person representing lesbian and gay groups. One woman described being very anxious and nervous about attending a lesbian and gay forum fearing she would seem very different to other members because she was a wheelchair user and was no longer working. Others spoke of expecting reactions of surprise because of the assumption that people with mobility impairments do not have a sexuality referred to above.

The lesbian and gay 'scene' was frequently referred to as excluding disabled people. The way in which it can be harder for disabled people to meet people and form relationships has been highlighted above. It is possible this is especially difficult for gay men with physical disabilities. Recurrent comments were made about the way in which the 'gay men's scene' is dominated by physical appearance and the pressure

to look good. This '*body fascism*' within the gay community was viewed as linked to low self-esteem among gay men.

'If you start off as being gay you automatically... think you are a lesser person than a straight person. You are brought up to think that being gay is not as... normal as being straight... it starts from there and you have got to keep looking wonderful all the time.'

(Male, 43, gay, white, mobility impairment).

Whatever the cause, this attitude was felt to exclude physically disabled people. Gay men with physical disabilities spoke of feeling discriminated against 'by our own community'. They described feeling awkward and conspicuous in clubs and bars which were not felt to be very welcoming to disabled gay men. Some gay men who had become disabled recently commented that they had not met anyone since the onset of their disability which was attributed to their disability.

'I think in the scene people tend to look at appearance first, and if they see someone attractive then they'll sort of go from there. When I'm on the scene people tend to look at the wheelchair and not the person sat in it. Which is frustrating. I've never picked anyone up on the scene since I've been in a wheelchair, and I've put that down to the fact that I'm in a wheelchair. It's a purely physical thing.'

(Male, 47, gay, white, mobility impairment)

Gender was a clear factor in how gay and lesbian disabled people experienced the gay community. The experience of being disabled within this community was reported to differ considerably for men and women. The lesbian community was said to be generally more accepting of disabled members. This was because lesbian women were described as using a 'political analysis of body image' which would make them resistant to traditional definitions and stereotypes of what it is to be attractive. This was felt to mean they were less likely to feel unattractive because of their disability. This was felt to be in contrast to the pressures upon disabled gay men.

3.5 Summary

The effects of disability on childhood experiences varied considerably across the sample and experiences of family life reflected a broad range from mainly positive to more negative with 'over-protectiveness' on the part of family and friends being cited as one key difficulty. Disability was reported to have specific effects for disabled people from the South Asian groups. This related to stigma perceived to be attached to disability within this community which could lead to disabled people being 'shut away' by families. In particular, women were felt to be particularly affected by this and felt to lack opportunities for education, work and marriage. Language differences between minority ethnic people born in the UK and their parents also complicated relationships.

Being disabled was felt by people from all groups to affect the experience of finding a partner and forming relationships. People from white, black and other minority ethnic groups felt that disability can '*get in the way*' of forming relationships because people '*see the disability rather than the person*'. Among people from South Asian groups, there was evidence that disability can have some very specific effects upon people's, and particularly women's chances of forming marriages and partnership.

People had received a range of help and support from their families when disability was present in later life. However, feeling dependent or a burden upon family members did cause some difficulties, as did the sudden onset of disability which was frequently reported to disrupt the balance in relationships, even if only temporarily.

The way in which people had responded to the emergence of their sexuality and the realisation that they were lesbian or gay varied. This did not appear to be linked to the presence of disability. Older lesbian and gay people had often concealed their sexuality for years, some were still concealing it for fear of the impact on older family relatives. Others who had disclosed their sexuality had received mixed responses, whilst some were supported, often there were, at the very least, temporary disruptions to family relationships. Evidence also suggests that being disabled can make it more difficult for parents and family to accept and deal with a disabled person being lesbian or gay. This can be because of parental concern and fear their child may suffer '*multiple discrimination*' due to this combination of characteristics.

Being lesbian or gay was felt to be harder for disabled people than it was for non-disabled people because of society's attitudes towards disability and sexuality. In particular, those with visible disabilities felt it was hard for society to accept the idea of lesbian and gay sexuality among disabled people.

Disabled people included in the sample were involved in a range of different types of social and leisure activities. The inaccessibility of social activities was a dominant theme in people's accounts of how their social and leisure activities were affected by having a disability.

Disabled people often reported losing friends with the onset of disability and how their opportunities to make friends and expand their social circle were affected by factors related to new, or growing barriers experienced in accessing the everyday world and the changing attitudes of friends.

People's experiences in their neighbourhood and wider community were mixed. Some spoke of living in a supportive community and had neighbours who they could call on if they needed anything. However, others had experienced harassment in the area in which they lived. In some cases the reasons underpinning these different types of harassment were clear. Sometimes, however, the characteristic at the root of these types of intolerant reactions was impossible to unravel.

As might be expected, given the ethnic mix included in the sample, people followed a range of religions which included Christianity, Judaism, Hinduism, Sikhism and Islam. Religious belief was often used as a coping mechanism in one way or another and provided a clear source of strength to people from all groups in coping with the experience of disability. The importance of religion in the lives of some of the ethnic minority disabled people meant that the physical accessibility of religious ceremonies was a source of concern. Ethnicity was rarely cited as a factor in access to religious worship. The white respondents were much less likely than the ethnic minority groups to cite faith communities as being important in their lives. However, people in this group who did attend church and religious ceremonies cited far fewer problems around the accessibility of services than did ethnic minority respondents. Some of the lesbian and gay disabled people had faced intolerance of their sexuality within their religious community.

Statutory day centres and local voluntary groups were an important source of social activity and support for many disabled people. The findings from this study and positive accounts of those who had become involved in local clubs or groups for disabled people confirm earlier research in suggesting that such groups can be a lifeline. Some problems were experienced by lesbian and gay disabled people where it was felt that such organisations were less inclusive than desired. People from minority ethnic groups tended to attend culturally specific disability groups and organisations. This type of provision was viewed as very important, particularly for older people from this community. People's experiences of these culturally specific disability groups were unanimously positive.

The lesbian and gay community was criticised for its response to disabled members. Some lesbian and gay people commented that the disability community was much more accepting of lesbian and gay people, than the lesbian and gay community was towards disabled people.

4 Experiences of education and training

This chapter explores people's experiences of compulsory and post-compulsory education. This includes decision making around education, positive and negative experiences of compulsory education within both mainstream and special schools and disabled people's views on these two different forms of schooling. It will also cover experiences in post-compulsory education and the perceived impacts of these experiences in education.

4.1 Educational qualifications

The levels of educational attainment among sample members covered a whole spectrum. This ranged from people who were very highly qualified to those who had not received any schooling. The educational qualifications people had achieved ranged from post graduate degrees to GCSE's or equivalent level vocational qualifications. The age of respondents seemed to be a factor in the likelihood of people obtaining qualifications. Far fewer of the older people in the sample had qualifications than did the younger people.

Ethnicity was also a factor affecting experiences of education. People from all of the minority ethnic groups had often not received a great deal of schooling. Gender was also relevant here and not having attended school was more common among women than men. In particular, very few of the South Asian women who had grown up in India and Pakistan had received any formal education. These older women had often not attended school or had attended 'schools' that did not provide educational qualifications but focused upon teaching and reading religious texts such as the Koran. This did not appear to be linked to disability and applied equally to those who had not become disabled until later in life. This was explained as being common among '*farming communities*', where people described how the tendency was for male children to be sent to school whilst women more frequently remained at home to help with household tasks.

4.2 Making decisions about education

Disabled people from all groups had received varying levels of support and encouragement around entering education and attending school. Parental attitudes towards education were clearly a very significant influence upon how important education was perceived to be by disabled people and the type of education people had accessed. Disability can affect the way education is viewed and the importance placed upon this in a number of ways.

Some people said their parents had taught them that education was crucial and one of the key ways in which they could try and prevent their disability limiting their lives. One African man, for example said his parents had communicated to him that his impaired mobility made education even more crucial than it would be if he were non-disabled. Because his disability made manual work unfeasible, this heightened the importance of education to enable him to secure a non-manual job.

Some parents were reported to have been concerned and very overprotective about their children attending school. This was evident among all of the ethnic groups included in the sample and was experienced by both men and women and people across the age range. It was frequently reported as relating to parents' or siblings' concerns about the disabled person's ability to cope as the Indian women below describes.

'I started school when I was 5, I was absent most of the time because my mum wasn't comfortable with me going to school at all. Because of my visual impairment she was very protective. I wasn't able to access anything probably, I couldn't see the blackboard... 'cos my eyesight was weak and she would think – I don't think she liked people teasing me. On the whole it was safety issues, she was more concerned about safety – will I be able to cross the road, will I be able to cope, will I be able to do the work etc.... She was very protective of me so she'd rather do things for me herself than have me doing them.'

(Female, 32, Indian, visual impairment)

In the South Asian group some people saw this '*protectiveness*' and desire to keep the disabled person at home as linked to the '*stigma*' reported to be associated with disability in this community which was described in **Chapter 3**. For example, some disabled Indian and Pakistani women described how school or college had been mentioned as an option for them but that they felt their families had wanted to keep them at home.

4.3 Experiences of compulsory education

The research explored people's experiences and views about the education they had undertaken. There were a number of ways in which people taking part in the interviews and group discussions felt that their disability had affected their education. These factors were felt to be relevant to both mainstream and special schools. Mainstream schools were described as providing a way in which disabled and non-

disabled children were taught together, sometimes with additional assistance for disabled children such as a special teacher. Special schools, in contrast were described as providing education care and support exclusively for children and young disabled people.²⁰

Disability was often reported to affect schooling negatively in a number of ways. Health problems or impairments caused obvious disruption to schooling. People recalled how frequent hospital appointments and treatment meant they had missed a great deal of school and had often had to cope with long periods of absence. This could mean that people had found it difficult to keep up, fell behind in work or had had to drop back a class.

Disability was particularly disruptive of a young person's schooling when this had occurred suddenly whilst people were in compulsory education. This had led to education being postponed for a number of years or even ceasing in some cases. For example, the onset of visual impairment during school years had sometimes led to people abandoning their education because it was no longer felt to be feasible to continue with this. Respondents had often made this decision themselves and there was little evidence of people being compelled to give up education against their wishes. As described by one Caribbean man who developed epilepsy '*I had to drop it ..I just thought it was too much for me, and I just couldn't concentrate*'. Other examples included the onset of disabilities such as paraplegia which had often severely interrupted schooling due to the need for medical treatment and time in coming to terms with the onset of disability.

4.3.1 Experiences of mainstream schools

Overall experiences in mainstream schools were very variable. As found by earlier research²¹ people with different disability types had often had very positive experiences in mainstream schools.

Those who had attended mainstream schools where they did not feel '*different*' to other children were often the most positive about their experiences. People frequently commented how much they had valued not being treated differently by those who taught them. Efforts made by teachers and other pupils to include disabled people in activities which may otherwise have been difficult for them such as sports activities for those with mobility impairments were greatly appreciated. Disabled people who avoided feelings of difference within mainstream schools were often those with mobility impairments. Such experiences were much less common among those with visual or hearing impairments as will be discussed below.

²⁰ The DDA 1995 (as amended by the SENDA 2001) outlawed discrimination in education from September 2002. Further and higher education institutions have a duty to make reasonable adjustments to provision where disabled students would otherwise be at a substantial disadvantage. From September 2003 this duty will include adjustments involving auxiliary aids and services.

²¹ Woodfield K et al (2002), pp.111.

As the above discussion suggests, many of the more negative experiences of mainstream schools were rooted in being made to feel different from other children. For some, the experience of being disabled at a mainstream school had been acutely difficult because of feeling '*different*' or '*the odd one out*'. People recalled feeling excluded from a wide range of activities at school. For example, fluctuating conditions such as sickle-cell anaemia could result in people not being allowed to attend field trips and other outings because teachers would not know what to do if a crisis were to occur. Sometimes people felt assumptions were made about their ability to participate in physical activity which may have been incorrect. This was expressed by one man with cerebral palsy who felt his teachers and other school and education staff tried to '*wrap me up in cotton wool*'.

Negative experiences at mainstream schools were also often related to a lack of awareness and unresponsiveness around disability. Teaching staff were often reported to have known about a disability but felt to lack awareness as to the implications of this for the type of help and support needed. Whilst there was generally felt to be much more awareness in schools about conditions such as dyslexia nowadays, some of the younger respondents felt they had not received the level of support they had needed to overcome the difficulties this created. Feeling unsupported in this way can have significant consequences for young people. For example, an Indian man felt his mounting frustration at not being given the attention necessary at school had resulted in his '*lashing out*' at a teacher which resulted in his exclusion from school.

There was also felt to be a particular lack of awareness within schools about conditions located primarily within specific minority ethnic groups such as sickle-cell anaemia. One Caribbean woman had provided leaflets for her teachers about her illness because they had not known anything about it. She described how she had to repeatedly explain to people how this affected what she was and was not able to do. She felt the responsiveness she had received on providing this information had been mixed and felt that greater awareness about this condition would have made things much easier.

Even when teachers were aware of a person's disability, the mainstream schools people attended were sometimes perceived to be unequipped to meet their needs. For example, people with visual and hearing impairments had sometimes been told to sit at the front of the class in lessons, but despite doing so remained unable to hear or see what was being communicated. Unsurprisingly, people with these types of experiences frequently felt that they had not been learning anything in this environment and as a result some had been taken out of mainstream schools to attend special ones.

Particularly difficult situations were reported when disability had gone undetected by teaching staff. Those with conditions such as dyslexia or epilepsy were often very critical of the failure of people at their school to recognise their disability. Age appears to be a significant factor in these experiences. Undiscovered dyslexia during school days was especially common among those in the older age groups. Some

gave harrowing accounts of being beaten, punished or sent out of class for being 'stupid' or 'not trying'.

Whilst many of these more extreme experiences dated back a considerable number of years, there were some reports of very negative experiences more recently. A 26 year old man who had been diagnosed with epilepsy after leaving school felt that there had been a lack of awareness and understanding about epilepsy at the school he attended. He felt angry that teachers had 'not bothered' to try and find out why his concentration and grades had become seriously affected.

'Even to this day what preys on my mind is school teachers' ignorance around recognising that a pupil might be epileptic, they find it much easier to just look at someone as an idiot that can't be bothered with school... They just thought I'd just lost interest and couldn't be bothered... it was easier for them to say 'he is lazy' and forget about me.'

(Male, 26, white, epileptic)

Sometimes those with these types of experiences had stopped attending school because conditions such as dyslexia made this too difficult. Even when people said they had enjoyed academic work some had 'given up' because they had tired of being referred to as 'stupid' or 'lazy' or because they had come to believe these labels were true. There was evidence that these types of experiences can have profound and lasting effects upon self perception and self-esteem. A number of people commented that these labels had stayed with them throughout their lives.

'My experiences of education weren't very good. I spent a lot of time sitting outside the classroom for being disruptive... when I was at school, dyslexia wasn't really recognised, they just labelled me as being thick and stupid and never tried to find out if there was any reason that I was finding it difficult to pick things up and understand them... so I was called thick and stupid, and still carry those titles around with me, even though I can intellectualise that I'm not. It's still the first place I go to really before I rationalise it.'

(Female, 52, lesbian, white, mobility impairment)

As found in the previous study²², there were some reports of other young people making the lives of disabled people difficult at school. In particular, those with hearing impairments reported suffering teasing and bullying by other children. Although bullying and teasing are known to be common experiences for many children whether disabled or not, in these instances participants reported bullying or teasing which specifically focused on their 'difference' to other non-disabled peers at school.

Another factor mentioned by disabled people which again confirms earlier work²³ was the way in which people felt their disability led to people having lesser expectations of them or thinking they were not able to learn. Some people reported

²² Woodfield K et al (2002), pp.112.

²³ Woodfield K et al (2002), pp. 114.

feeling they had not been 'pushed' at school as much as non-disabled class members.

Sometimes disabled people in mainstream schools had experienced a combination of the factors outlined above, for example, feelings of difference, feeling labelled 'stupid' and a degree of bullying or teasing from other children. The detrimental effects that this situation can have upon young people is illustrated by the case of Hannah given below:

Hannah (26) hated school. Her hearing impairment made it very difficult for her to communicate with others because it was hard for her to hear and pick up the subtleties of conversations. She described continually feeling 'left out' and feeling she was unable to mix and communicate with other children. She also felt awkward because everyone knew about her hearing impairment because the hearing aid that she wore was very large and visible. She described how other young people would treat her differently by 'looking at her ears' or 'shouting into my hearing aid'. She felt her difficulties in communicating with others led to other children and teachers labelling her as 'stupid' and stopping making an effort to involve her. As a result she felt she had become increasingly isolated and withdrawn.

(Female, 26, lesbian, white, hearing impairment)

4.3.2 Experiences of special schools

Respondents had arrived at special schools through two main routes. Some had joined special schools at the start of their compulsory education and others had joined later, after attending a mainstream school. In the latter case, transitions from mainstream to special schools were usually made because the school's facilities or teaching support were unable to meet the disabled person's needs. Some of those with visual and hearing impairments for example, had moved to special schools after failing to make progress in mainstream schools. In some cases, people had been compelled to attend special schools as a result of decisions taken by their Local Education Authority.

The key merits of attending special schools were perceived to be the availability of suitable adaptations and the experience of not feeling different and meeting others with similar experiences. Some of those who had not had access to the equipment they needed in mainstream schools felt that their learning had advanced much quicker within special schools because they were provided with what they needed. The most vociferous support for special schooling came from those in the deaf community. As found by the previous study, this group emphasised the importance of meeting other deaf people at school.²⁴ Meeting others and the realisation that there were other people with similar experiences who spoke the same language was

²⁴ Woodfield K et al (2002), pp.117.

viewed as crucial. It was even suggested that to deprive deaf people of this can have implications for wellbeing and mental health as suggested by the respondent below:

'I realised there were people like me – had the same life experiences, had the same language, and I made friends with them – I think if it wasn't for them, I might have been in a hospital or something – I felt that I could cope, having them – I know of some people who have ended up in mental institutions and hospitals and things... at that time suicide in the deaf community was quite high ...in my day, the deaf education system was bad, but grouping deaf people together was a good thing – sharing experiences and using the same communication amongst each other – that was good.'

(Male, 47, white, gay, hearing impairment)

When people had been compelled to attend a special school by their Local Education Authority this had sometimes been resented. This was particularly evident in cases where people had felt very integrated within mainstream schools and did not have a particularly strong sense of being disabled or different from other young people. The effects of this experience for some young disabled people had been profoundly negative.

'Until the age of 11 I didn't know any disabled people... the people I was with didn't treat me as disabled. Then I had to sit an exam for ... college...and I passed it but because I was disabled they wouldn't accept me...so I was forced to go to a school for disabled children, and I was bussed there every day...I was forced then to know I was disabled. I hated it there...it was like a prison camp. I hated the people because I didn't think I was disabled. I lost all my friends because I had to go to a school that was 15 miles away from the estate I was brought up on.'

(Male, 42, white, gay, mobility impairment)

The main criticisms of special schools revolved around their failure to provide disabled people with a good quality education. The schools attended by sample members were often said to be 'non-academic' and did not provide much schooling other than basic maths and English. There was felt to be focus on vocational or other activities rather than providing disabled people with an education. Instead people described being involved in various forms of physiotherapy and occupational therapy or craft work and other types of activities. In addition, some people were critical of the perceived preoccupation of teachers in these schools with discipline rather than teaching.

Even where people had attended classes teaching traditional academic subjects such as English, there sometimes appeared to have been a lack of dedicated support around this. A man with learning difficulties, for example, described how he 'didn't get on with reading' at school and consequently had left with the reading age of about 6.

As found by the previous study²⁵, bullying and teasing occurred at special schools in the same way that it did in mainstream schools. However again it was argued that the increased equality when both children are disabled mediates the impact of the bullying. As one visually impaired woman put it: *'It's a different kind of feeling altogether. You're on a par, you're on a par with each other.'*

Age was undoubtedly a key factor affecting experiences of special schools. Older people in the sample sometimes reported extremely negative experiences at special schools. This group were often very critical of the atmosphere in the institutions they had attended. One 69 year old man who attended a school for the blind described it as a *'horrific place'* dominated by the excessive use of corporal punishment. Many of these more negative experiences, however, seem to be a product of attitudes and approaches to education which existed in the UK as much as 50 or 60 years ago and have since changed.

Deaf people were often very critical of the attempts of special schools to stop them using sign language which they had learnt. One man in his late 40s for example, described how use of sign language at the school he attended had been a punishable offence. The school system had been committed to 'oralism' and focusing efforts towards teaching deaf people to speak. This was felt to have wasted time that could have been more profitably spent learning. It was generally felt that the recognition of BSL as a language was long overdue.

Some of those who attended special schools felt very strongly that the lack of commitment to educating disabled people described above had been disadvantageous in later life. Recurrent comments were made about how life may have been very different if they had been given a better education. Having attended special schools was also felt to be detrimental when seeking work. For example, a blind man who went to a school for the blind felt that this put off potential employers. There was a view that having attended a special school caused some non-disabled people to make assumptions about a disabled person's ability to integrate with non-disabled people in the workplace or other environments.

4.3.3 Specific issues expressed by black and minority ethnic disabled people

Overall, many of the experiences and issues in relation to disability and schooling raised by minority ethnic respondents mirrored those of the white group. Some of the ethnic minority disabled people had attended special schools for disabled people in other countries in which they had lived before moving to the UK. The issues raised by disabled people with these experiences were very similar to those detailed above and people had experienced a similar range of positive and negative experiences.

Respondents were asked whether their ethnicity was perceived to have affected their experiences of education in the UK in any way. Overall, this was rarely perceived

²⁵ Woodfield K et al (2002), pp.117.

to have been a factor. Some of those included in the sample commented that they had been the only black or Asian pupil at both the mainstream and special schools they attended and said this had not caused problems. Some felt strongly they had not been treated differently and had been as 'popular' as other children.

More exceptionally, there were some reports of experiences of discrimination during school days. One Caribbean woman, for example, felt herself and other black children were made to feel '*worthless*' by the headmaster at the school she attended. She saw this racism as being one of the reasons she did not obtain any qualifications.

{There was} racism in the school... My headmaster told me I'd never achieve an O level in my life because I wasn't brainy enough. Self-fulfilling prophecy. Tell a child they're naughty and they act it.... Just... the black kids in the school. We just weren't meant to achieve.'

(Female, 28, Caribbean, sickle-cell anaemia)²⁶

For obvious reasons, racial discrimination was rarely an issue for ethnic minority disabled people who attended school in their country of origin before moving to the UK. However, in more exceptional cases, this could still be an issue. One visually impaired man of Anglo-Indian origin, for example, felt he had experienced a great deal of racial prejudice from teachers in Indian schools who he felt had viewed Anglo-Indians as culpable for India's colonial past. He gave examples of incidents he saw as representing 'cruelty' at the hands of some teachers which included deliberately not reading out things which were written on the blackboard. He felt certain that it was racial discrimination rather than attitudes towards his disability which underpinned this type of treatment.

Those who had migrated to this country at an early age or who grew up in non-English speaking households sometimes mentioned language difficulties as being an issue in attending school in the UK. Language difficulties had sometimes been the only problem people had faced at school and were reported by some to be more significant or problematic than any issues faced in relation to disability. However, in other cases as highlighted by the Indian woman below, disability and language could combine to make life at mainstream school very difficult.

'If I stayed there I wouldn't have learnt anything... attendance would have got in the way because my mum was very over-protective so she wouldn't take me to school much. And not having access to things. My sight might have been less of a problem... I think language was more of a problem to begin with - You know if you can't speak English you're not going to follow [the lesson]. If you can't see on top of that it makes it even worse...'

(Female, 32, Indian, visual impairment)

²⁶ The Race Relations Act 1976 outlawed racial discrimination in education and the Race Relations (Amendment) Act 2000 placed an additional duty on all further and higher education institutions to actively promote race equality.

Ethnic minority people who attended school in their country of origin expressed some specific issues relating to the lack of facilities for disabled people in those countries. The barriers people had faced in trying to access education in countries such as India and parts of Africa were often felt to be much greater than those faced in the UK. For example, a lack of basic facilities such as the provision of wheelchairs, crutches and transport were perceived to have created insurmountable barriers to attending school for disabled people. One African woman with a mobility impairment described how her mother had physically carried her to and from school for two miles each day. Similarly, adaptations for those with visual impairment were often said to be unavailable in these countries which had meant continuing in education had become impossible for some after sudden onset of disability.

4.3.4 Sexuality

The experiences of the lesbian and gay sample in relation to disability mirrored those of other groups and these have all been reported above. Disability was often the only issue which raised problems for lesbian and gay disabled people at school. Issues relating to their sexuality were much more exceptional and this was often not viewed as having had a great deal of impact upon people's time at school. Many of the lesbian and gay sample said their sexuality had not been an issue at this stage of their lives.

Although much more exceptional, in some cases lesbian and gay sexuality was felt to have affected experiences in education. In particular, the process of becoming aware of one's sexuality can affect lesbians' and gay men's self confidence and ability to mix with other young people at school. This is often due to trying to deal with and accept feelings about sexuality as described by the respondent below:

'My outlook changed quite a lot after 14, I changed schools and we moved. I was very outgoing, had lots of friends...and I became a bit more withdrawn, a bit quieter...sexuality...was very confusing for me. I didn't really have anyone to speak to. And I alienated a few friends because I felt I was close to them, and I'd make a pass at them and that alienated them.'

(Male, 47, gay, white, mobility impairment)

In one case a bisexual man with severe learning difficulties recalled being found in a liaison with another boy by a teacher at the special school he attended. He remembered being administered corporal punishment for this. Beyond this, however the impact of his sexuality was very difficult to establish as his learning difficulties made it difficult for him to answer questions about how his sexuality had affected his time in education.

Overall, however, as mentioned above, sexuality was not reported to be a significant issue for lesbians and gay disabled people during their time at school. The lack of impact of sexuality is somewhat surprising in the light of recent research evidence which documents the occurrence of homophobic harassment and bullying in schools and the impacts of this which include poor performance, low self-esteem,

truancy²⁷ and running away.²⁸ Explanation for the infrequency of these types of experiences may be linked to the effects of age group and cultural change. In particular, age group may affect the likelihood of early awareness of lesbian and gay sexuality. Some of the older sample said they had had very little awareness of this during the time they were at school and this was felt to be linked to the much lower profile of lesbian and gay sexuality in British society in the 1950s, 60s and 70s. Consequently these lower levels of awareness may have slowed down people's recognition of this characteristic in themselves. Some people felt they had only come to understand what lesbian and gay sexuality was subsequent to leaving school and in some cases many years later.

4.4 Inclusion or exclusion – views about mainstream or special schools

People were asked in the interviews and group discussions about the merits and disadvantages of the two forms of schooling described above. Overall, there were people who argued equally strongly for each type of schooling and many of the views that were expressed mirror the findings of previous work²⁹.

Those who advocated inclusion, that is educating both disabled and non-disabled children together and not using special schools, argued that this approach is more beneficial for disabled people. It was felt that integration was important to teach disabled people how to interact with non-disabled people and to prevent them feeling that they were particularly different. There was also a view that educating disabled people in mainstream schools was beneficial for non-disabled people as it would increase awareness and understanding about disability.

The strongest advocates of special schooling were the deaf or hearing impaired. It was felt that sending deaf children to mainstream schools which do not contain any other deaf people can create problems. Children in this situation were said to be likely to feel isolated and unable to communicate, which would prevent their social and communication skills developing. The development of deaf children's communication skills was thought to be dependent upon mixing with other deaf children to some extent. In the longer term it was felt that educating deaf children in mainstream schools could leave deaf people neither belonging to the deaf or hearing community. This was vividly articulated by one respondent:

'I'm aware that some deaf children are sort of the only ones in their whole school – and I feel they are the ones that will suffer – they're being integrated, but they're the ones that are different, they get left – their social skills aren't developing...if you speak a different language, it's very cut off, it's very

²⁷ For more on this see 1997 Douglas N., Warwick I, Kemp S & Whitty G (1997) ; Rivers I (2000).

²⁸ O'Connor, W. & Molloy, D. (2001).

²⁹ Woodfield K et al (2002), pp.116.

isolating. ... I've met some of those, they can't communicate and they can't sign, because they didn't learn it – they learnt it later in life and they don't have as good skills – it takes years and years for them to catch up – and they're frightened of us, we sign too fast for them and they get left out even more because they don't belong to either.'

(Male, 47, gay, white, hearing impairment)

4.5 Post-compulsory education

Disabled people had participated in a wide variety of courses and further education subsequent to completing compulsory education and sometimes much later during their adult lives. This section considers experiences of post-compulsory education. Section 4.5.1 explores factors influencing disabled people's decisions to participate in further education. The experiences of further education reported by disabled people are discussed in Section 4.5.2. Lastly, Section 4.5.3 explores some of the positive impacts disabled people reported experiencing as a result of participating in post-compulsory education.

4.5.1 Decision making around post-compulsory education

Reasons for deciding to participate in post-compulsory education varied. Sometimes this was linked to parental influence and encouragement, in others it had seemed to be the disabled person's wish to continue learning which had driven this decision. The failure of special schools to provide a good quality education had been the motivating factor for some. Some people who had felt strongly about the lack of opportunities they had been given to gain academic qualifications felt this had made them very motivated to attend college. One man with cerebral palsy described how, after leaving his special school with no qualifications, he refused to attend a work centre for disabled people and managed to get a place at college to study business.

Younger South Asian respondents sometimes expressed very different motivations for participating in further education. Some felt their decision to undertake further study was underpinned by the wish to become free from the 'pressure' imposed by their family and community to participate in prayer and worship and follow strict rules in relation to their lifestyle. This was particularly evident among Muslim respondents as expressed by one visually impaired man:

'With our culture...you've got to pray five times a day and you've got to read the Koran every day. My mum was quite strict, if I wasn't home by 8.00 or 9.00pm she would worry. I thought the way out is to get a really decent education and also to really experience life....to go out to college.'

(Male, 27, Pakistani, visual impairment)

It is difficult to be sure if this is simply an effect of ethnicity and whether these family and cultural expectations are influenced by disability in any way. It is possible, however, that the heightened 'protectiveness' and attempts to keep disabled people at home reported among the South Asian community which were described

in **Chapter 3** may exacerbate the desire among disabled people from these communities to become more independent.

There was evidence that negative experiences at school linked to disability could significantly affect disabled people's motivation to continue in post-compulsory education. For example, Hannah who was described above had been determined to leave education when she finished school because she had hated this so much. She also felt her communication skills were so poor that she would not be able to deal with further education. Parental support and encouragement can be strong enough to overcome this, however, and Hannah had been persuaded by her parents to try college in order to see if she found this a more positive experience than she had found in mainstream school.

Age group was also a factor in the decisions people made about further education. Older respondents had sometimes not considered this because the lack of adaptations that were available at the time they had left school had been perceived to create insurmountable barriers to attending college. Again this reflects the diverse age groups represented in this sample.

People from some of the minority ethnic groups who had migrated to the UK sometimes felt accessing further education in this country could be difficult because their qualifications were not recognised. One man from the Caribbean described how he had arrived in this country and found he needed to supplement his education at night school because the qualifications he had obtained on leaving school at home were not recognised by employers.

4.5.2 Experiences of post-compulsory education

Disabled people from all groups had participated in a wide variety of courses both after completing compulsory education and throughout their adult lives. These included A levels, degree courses, Master's qualifications, vocational courses such as NVQs in business studies, accountancy and finance, BTEC qualifications in social work, photography and counselling courses. People from some of the black and minority ethnic groups had sometimes taken courses to obtain English qualifications in subjects they had already studied in their country of origin such as maths and English. Disabled people had participated in post-compulsory education at a whole range of different times in their lives. Some had gone on to do this after completing compulsory education while others had returned to this much later in life.

As with compulsory education, some disabled people had enjoyed their experiences of further education and felt they had benefited a great deal from this. The impacts of these experiences are discussed in Section 4.5.3.

Despite the benefits associated with participation in further education, negative experiences of post-compulsory education were also common. Many of the problems faced by disabled people in compulsory education which have been discussed were equally apparent in post-compulsory education. In particular, difficulties created by lack of awareness and unresponsiveness around disability

were recurrently cited and appear equally relevant to post-compulsory education. Again, those with dyslexia or learning difficulties had sometimes found tutors lacked understanding of the difficulties these disabilities created. Less well known forms of disability such as sickle-cell anaemia could also again lead to difficulties due to lack of awareness about this condition. For example, comments were made about the way in which periods of illness due to crisis received '*suspicion*' within universities and FE colleges. For example, one Caribbean woman described how tutors were often unsympathetic about her requests for essay extensions and seemed to doubt the fact she had been ill.

Lack of awareness, however, was not always perceived to be the fault of those tutors. Some disabled people felt that some responsibility for informing teachers about their disability lay with them. A man with psychosis who felt he did not get the help he needed whilst doing a City & Guilds qualification, recognised that he had not asked for assistance and his tutors did not know about his disability. The issues of concealing disability and how this is more in evidence among people with mental health problems has been discussed in **Chapter 2**.

Another problem frequently mentioned by those who had attended mainstream universities and colleges was the lack of suitable adaptations and equipment. The significance of this factor differed with age and overall younger disabled people tended to have had more access to necessary adaptations. However there were still recent examples where people had not been able to get the necessary help and equipment and had struggled because of the unavailability of adaptations. For example, people with visual impairments had sometimes been unable to gain access to large print lecture notes and adapted PCs. In other cases adaptations were provided but these were felt to be poor quality. One hearing impaired woman for example left college because the interpreter was not felt to be very good and she was repeatedly missing what the teacher was saying.

People also commented on the frustration that could be caused by the variable levels of support available in different institutions. This could cause problems for people who had moved between different colleges and universities during their academic career. One hearing impaired woman described how, after completing a course at the Open University who were '*really aware*' and had provided note takers, lip speakers and sign supported English, she had been 'horrified' on moving to another university when she was simply told to sit at the front of the class!

People who had not been provided with the support they needed in post-compulsory education had sometimes relied on friends to help them to keep up with courses. Some felt they had only managed to complete their courses because of this type of assistance and would have failed or had to leave without it.

Some people felt that different types of access needs are catered for to very different extents within educational establishments. Physical access needs were felt to be better catered for than needs for academic support. Sometimes those with multiple disabilities commented that whilst one set of their needs were well provided for, the

other were neglected. For example a woman with a mobility impairment commented that whilst there was good disabled car parking, accessible toilets and wheelchair access at the college she attended, her needs for support to overcome the obstacles to learning posed by her dyslexia were unaddressed.

Far fewer of the older disabled people had accessed post-compulsory education. Those who had sometimes felt that this had been extremely difficult. For example a deaf man talked of how present day provision such as interpreters and note takers had not been available when he went to university and he had sometimes felt like '*I was the only deaf person in London going to university*'. As a result, as was discussed in relation to compulsory education, the impact of disability upon post-compulsory education was often greater for the older people in the sample because their experiences date from a time when less help and support were available. For example a woman with a hearing impairment who then lost a great deal more hearing during her time at polytechnic following a viral infection did not return to finish her course. This was because she did not feel she could cope with trying to continue with reduced hearing and '*this was 1974 there were no support services available in those days*'

The perceived failure of special schools to provide a good quality education which was discussed in Section 4.3.2 was felt by some to have made it difficult to cope with further education. For example:

Ashok, an Indian man with a learning disability described how when he left a special school to attend college he found this '*way beyond me because it was so different to what I had been used to*'. He had failed a Maths GCSE course and had also failed an IT degree course that he had attempted from home over the Internet which had left him owing £2,000 for a student loan³⁰ which he had taken out to cover the costs of the course.

(Male, 24, Indian, learning difficulties)

In some cases people had participated in further education as a result of becoming involved with a disability group or day centre. Examples of courses disabled people were taking part in included various IT courses such as basic usage, spreadsheets and databases, and other types of classes such as woodwork, gardening, sewing and embroidery. Many were very positive about these opportunities. For example, one Indian woman whose mobility impairment had made it impossible for her to attend classes when she had lived in India said she was '*very happy*' to have been offered the chance to do a computer course at the day centre she attended in the UK.

³⁰ Ashok was uncertain about the source of this student loan (whether it was a government subsidised loan scheme or commercial loan). Current policies mean that a low-income student following a distance learning course could qualify for a £500 per year loan to assist with the costs of part-time distance learning.

Racial discrimination was noted above as a factor mentioned in relation to compulsory education and again this was also mentioned in relation to post-compulsory education by some people from minority ethnic groups. Overall this was more exceptional but in a few cases this was felt to have been a factor in people's experiences at college and university. For example, one Caribbean woman felt she had encountered racist attitudes among her tutors and that this had affected her self-confidence and the degree level she achieved.

Although, again fairly exceptional, some of the lesbian and gay disabled people also felt they had encountered discrimination in further education in relation to their sexuality. A lesbian woman who had taken a counselling course felt her sexuality had led to her being treated differently on the course.

'I was the only one who had to do a case study, and when I asked why they said 'oh well you want to see clients so you can do a case study'...I felt that I had to prove myself twice as much as everyone else...I had to prove that I could get on with a diverse...society whereas I felt that heterosexual people on the course didn't have to. It was taken for granted that they could work with everyone.'

(Female, 47, lesbian, white, mobility impairment)

4.5.3 Impacts of post-compulsory education

It is worth noting that some disabled people had felt that their experiences of post-compulsory education were extremely beneficial. In particular, some of those who had rather negative experiences in compulsory education had sometimes gone on to obtain qualifications and other positive effects from taking part in further education.

One of the main impacts of post-compulsory education for disabled people had been confidence and self-esteem. For example, those with conditions such as dyslexia which had gone undiagnosed for long periods and led to underachievement at school had sometimes had this picked up in later life and received support which enabled them successfully obtain qualifications.

'When I got to Re-start To Learning...I just thought: 'I'm so thick I might as well leave now'. To my amazement they sent me to this ...man and my first thoughts was: 'God, he won't... tolerate me being stupid'. And he said: 'Oh, you're dyslexic', and no-one had picked this up. So at the age of 36 they realised I was dyslexic and I got a lot of help, and I done psychology, women's studies, social psychology, economic and social political history...humanistic psychology, economics and two others...and I passed, and I was very pleased – very proud of myself.'

(Female, 47, lesbian, white, mobility impairment)

There was also some evidence as to the profound effects that education and the experience of meeting other students can have upon people's attitudes to aspects of their own identity such as disability, ethnicity and sexuality. These seemed to happen

in two main ways. Firstly, the experience of a new environment and meeting other people with similar characteristics and experiences was felt to be very positive. Disabled people talked about realising for the first time that there were other people like them. Similar points were made by people from the minority ethnic groups. One African woman with mental health problems, for example, spoke of meeting lots of black people for the first time at college which was felt to have been very liberating.

Secondly, meeting others with shared characteristics coupled with the experience of studying academic subjects had led some people to develop a sense of being a member of a minority or oppressed group for the first time. People frequently spoke about being exposed to new sets of ideas and perspectives. This seemed to have been quite dramatic for some people who described experiencing a type of '*awakening*' in relation to their own identity. For example, a man of mixed Indian and African origin who studied psychology followed by applied social studies described this as '*a rude awakening... I was black, I was Asian, I became politicised*'.

Consequently, going away to college can be very liberating. People from all groups expressed how their awareness and understanding of their identity was shaped by this environment. In particular lesbian and gay disabled people spoke of the value of being 'free' to explore their sexuality amongst other people with similar experiences and away from family, friends and the community in which they grew up.

Many of these impacts of education can have implications for whether people feel they have experienced discrimination and prejudice and how they respond to this. This issue will be returned to again in **Chapter 7**.

4.6 Cultural change in the availability of educational opportunities for disabled people

As noted throughout this chapter, many of the most negative accounts of mainstream, special schooling and post-compulsory education date from a different era in terms of the provision of education to disabled people. The most negative experiences are predominantly located among older respondents whose experiences in education date back, in some cases, over fifty years. These experiences are clearly a product of a very different time.

Older respondents frequently commented that the opportunities for disabled people were now very different than they were at the time they had attended school. As has been found in previous work³¹, significant progress is felt to have been made in recent years towards making education feasible for disabled people and removing barriers to this. Many referred to the major advances perceived to have been made in the development and availability of adaptations for disabled people. The increased availability of this support and various types of adaptations was commonly viewed as a positive and necessary development.

³¹ Woodfield K et al (2002), pp. 124.

In addition, attitudes towards the education of disabled people were also felt to have changed fairly significantly in recent decades. Whilst once it was felt that disabled people had been '*written off*' and the provision of education not felt to be a priority, this was felt to have now changed. This view was held particularly by the white respondents who often felt they had seen substantial change in this area in their own lifetime. Among some of the younger people within the South Asian groups there was a feeling that, within their community, there was still change that needed to occur in this area.

White respondents also commented upon a perceived drive towards integration in recent years in terms of educating disabled people within mainstream schools. There was now felt to be much more commitment towards and support for integration. Although there were some dissenting voices on this, particularly from the deaf community, older people who had had particularly negative experiences in special schools tended to view this as a positive step forward.

4.7 Summary

Levels of educational attainment among sample members covered a whole spectrum. This ranged from people who were very highly qualified to those who had not received any schooling. Ethnicity was a factor affecting experiences of education. Disabled people from all of the minority ethnic groups had often not received a great deal of schooling, both in the UK and elsewhere (for those who had migrated to the UK). Some of those in the latter group believed that their educational opportunities had been enhanced by migrating to the UK. Gender was also relevant with not having attended school more common among women than men in this sample. However, given the qualitative basis of this sample these findings are not statistically representative of the population at large.

Disabled people from all groups had received varying levels of support and encouragement around entering education and attending school. Parental attitudes towards education were a significant influence upon how important education was perceived to be by disabled people and the type of education people had accessed.

Experiences of compulsory education were similar to those already described in the previous report, both in mainstream and special schools. However, some new factors emerged as negative influences on school experiences particularly for those whose disability was located primarily within specific minority ethnic groups such as sickle-cell anaemia. In such cases people felt there was a particular lack of awareness within schools which often led to children being refused equal access to daily life in school.

Ethnicity, rather than disability was sometimes cited as the cause of negative school experiences, particularly where children had been the only, or one of few, black or Asian pupils at their school. Experiences of racism were reported, and for those who moved to the UK during their early childhood language barriers were also reported to cause difficulties, even if these proved to be transitory.

The experiences of the lesbian and gay sample in relation to disability mirrored those of other groups. Disability was often the only issue which raised problems for lesbian and gay disabled people at school. Issues relating to their sexuality were much more exceptional.

Support for mainstream or special schools was mixed. Overall, there were people who argued equally strongly for each type of schooling and many of the views that were expressed mirror the findings of previous work.

Disabled participants had participated in a wide variety of courses and further education subsequent to completing compulsory education and sometimes much later during their adult lives. Views about the accessibility and attractiveness of further education varied. For some young South Asian participants continuing education was seen as a way of ensuring a route to independence, this was also cited by people from other groups who had a strong desire to live independent lives.

In contrast, older respondents had sometimes not considered this because the lack of adaptations that were available at the time they had left school had been perceived to create insurmountable barriers to attending further education.

Despite the benefits associated with participation in further education, negative experiences of post-compulsory education were also common. Difficulties created by lack of awareness and unresponsiveness around disability were recurrently cited, as was the lack of suitable adaptations and equipment in mainstream universities and colleges. The significance of this factor differed with age and overall younger disabled people tended to describe more access to necessary adaptations. Different types of access needs were felt to be catered for to varying degrees within educational establishments. Physical access needs were felt to be better catered for than needs for academic support. Sometimes those with multiple disabilities commented that whilst one set of their needs were well provided for, the others were neglected.

Racial discrimination was also mentioned in relation to post-compulsory education by some people from minority ethnic groups. Overall this was more exceptional than different treatment on the grounds of disability. Although again fairly exceptional, some of the lesbian and gay disabled people also felt they had encountered discrimination in further education in relation to their sexuality.

Despite difficulties, post-compulsory education was seen as extremely beneficial by: helping to build confidence and self-esteem, providing opportunities to increase educational attainment, and importantly, by providing people with the chance to meet 'others like them' which was found to have profound effects on the way some disabled people perceived their personal identity.

Significant progress was felt to have been made in recent years towards making education feasible for disabled people and removing barriers to this. In addition, attitudes towards the education of disabled people were also felt to have changed fairly significantly in recent decades.

5 Experiences of work

This chapter explores disabled people's experiences of work. It focuses upon how disability has influenced people's experiences of work, and also draws out the differing roles of ethnicity, sexuality, gender and age in these experiences. There are four key sections within this chapter: attitudes to work, making decisions about employment, experiences of seeking work, experiences in the workplace, and retirement from work.

5.1 Attitudes to work

Across all the groups of disabled people interviewed, there were positive attitudes expressed towards work. These were underpinned by a number of factors.

People talked repeatedly about the sense of self worth that work gave them. Being employed was seen as very important to a person's own identity, and how they felt other people saw them. On a personal level, working gave people pride in their own abilities and allowed them to prove to themselves what they could do, rather than what they couldn't because of their disability. On a wider level it was felt that in society a great deal of emphasis is now placed on being employed, and the type of work you do, in defining your identity.

'This society is all about careers and, you know, what do you do, and your identity, and who you are.'

(Female, 27, lesbian, white, cognitive impairment)

Being employed was also seen as a means to become accepted in society, where people felt society had otherwise rejected them because of their disability. For example, one woman who had worked throughout her adult life, felt that if it hadn't been for the negative attitudes she'd experienced towards her disability in her childhood, she would not have had the same motivation to participate in employment.

'I probably wouldn't have bothered with a career or anything because I would have been accepted in society anyway, so I would take for granted my acceptance. Now I have to be accepted.'

(Female, 32, Indian, visual impairment)

Being in employment, and having their own source of income, was seen as crucial in achieving a sense of independence, specifically financial independence. In terms of age, this was a factor predominantly cited by younger disabled people who felt financially dependent on their parents or other family members.

'I don't wanna live on my parent's income... I'm not relying on no one else, and I think that is important to me.'

(Female, 19, Pakistani, learning difficulties)

'I didn't want to sponge off me brother or me sister or me dad, yeah. I want to earn me own money.'

(Male, 20, white, visual impairment)

However, it was also cited by some older disabled people who, in their current circumstances, felt dependent on a spouse or other family members.

People were motivated to work by the desire to overcome feelings of isolation. This applied particularly to people who spent much of their daily life at home, often on their own. Work was seen as an opportunity to do something interesting with their time and meet more people.

'I do want to get out there and work... I just don't want to be sitting at home, I need to go out there and socialise with people.'

(Female, 26, Caribbean, sickle-cell anaemia)

Analysis of disabled women's accounts also revealed gender as a key factor in experiencing feelings of isolation. Typically husbands or partners were at work and any children were attending school for much of the day, leaving women feeling isolated in their homes.

In exceptional cases, earning money was cited a factor motivating people to work. One example in the research of this was of a young Indian man who decided to seek work because he felt he needed to financially support his family. He had a mother, two brothers, a sister and a grandmother. He did not like the idea of his mother working to support the family, and chose to give up a degree at university to work full time. In another case, a Caribbean woman reported that when she was younger she had wanted to find work because of financial pressures at home. She felt she needed a job to support her family. These two examples suggest that age, as well as the financial situation of a person's family, are factors influencing attitudes to work. Older people with a family did not cite this as a factor motivating them to work.

5.2 Making decisions about employment

As part of the research, people in the sample were asked about the types of decisions they had made around employment, and the reasons why they had taken these decisions. There appeared to be two key decisions that people faced with regards to

employment. The first was the decision about whether or not they sought to participate in employment. Despite the universally positive attitudes expressed about work, it was clear that not all people were seeking work. For people who decided to seek work there was also the question of what type of work they sought and what type of employer they sought to work for. The evidence suggests that people's decisions about employment were influenced by certain critical factors:

Physical or mental impacts of their disability were, for some people, the decisive factor in decisions about employment. There were those who felt that the impact of their disability meant they would only be able to participate in certain types of work.

For example:

Carla had given up her previous job as a primary school teacher, having suffered a breakdown. She has been diagnosed with manic depression and now thinks she could only do a non-stressful job *'like working on the till at Tesco's'*.

(Female, 42, African, mental health impairment)

Tanya has a mobility impairment and is hoping to find a job in the housing sector. She doesn't want to be a housing officer because she feels that her mobility impairment would prevent her from being able to make home visits. She is thinking carefully about what other jobs she could do, *'it's for me to choose the job that I feel is suitable for my own needs or capabilities'*

(Female, 38, African, mobility impairment)

There were those who felt that the severity of their disability meant that they were not able to participate in employment of any kind. This reflects earlier research findings³² which showed that one third of those interviewed did not expect to work in the future:

Arwan has previously worked as a domestic cleaner. He had not been able to do the work as quickly as his employer wanted and subsequently lost the job. He thinks he was not able to do the job because of his learning difficulties. He is now no longer motivated to look for work because he feels his disability prevents him from being able to participate in employment.

(Male, 22, Pakistani, learning difficulties)

³² Woodfield K et al (2002).

However there were also people, in some cases with a severe impairment or multiple disabilities, who thought that they would be able to work if they were able to access adaptations or support. It was the perceived lack of these adaptations or support that affected decisions about seeking employment, rather than the impact of their disability. People viewed social or structural barriers as obstacles that need to be overcome to make it possible for them to work.

'Its not my condition that stops me really from doing things, its society or the workplace, for instance, not making the adaptations for me.'

(Male, 29, gay, white, epilepsy)

Attitudes of this type appeared to reflect the perceptions different people held about disability (discussed in **Chapter 2**), rather than reflecting any clear differences along the lines of ethnicity, age, gender or sexuality. Those with an understanding and a belief in the social model of disability were more likely to perceive the lack of adaptations or support as the main barrier to work, and that if this barrier was removed they would be able to participate in work. Conversely, people whose perception of disability ran more along the lines of the medical model of disability appeared more likely to conclude that they would not be able to work in the future because of the severity of their impairment or impairments. The only way they perceived that they would be able to participate in work in the future if there was an improvement in their condition.

Knowledge of the adaptations and support available for disabled people to help them participate in employment was a critical factor in the decisions some people made. For example:

Lorraine was unemployed at the time of her interview but was intending to return to work in the future. She had a mobility impairment, but did not think that this would be a barrier to her participating in employment because she was aware of the requirement that employers make reasonable adjustments, and felt that her access needs could be met by a future employer because of this.

(Female, 46, Caribbean, mobility and mental impairments)

However, Lorraine's experiences were not typical of the people interviewed, and it was clear that there were varying levels of awareness about what adaptations and support were available. Not all people were aware of the requirements that employers make reasonable adaptations in the workplace, under the DDA. There were also some misunderstandings about what the particular requirements were. For example, a person with a hearing impairment had assumed that the only type of adjustments employers were required to make were for people with a mobility impairment, and that employers would not be required to make adjustments for her impairment. There was also limited awareness of welfare to work measures including the financial support available to help disabled people move into

employment. For example, there were only two people who mentioned the Therapeutic Earnings scheme (which allows disabled people to earn up to £66 a week without affecting their benefit entitlements³³) out of all those who were interviewed. In cases where people had been aware of the adaptations or welfare to work support available it had often been an important factor influencing their views about seeking work, as Lorraine's example illustrated.

There were no clear variations in the level of awareness about adaptations and support available, between different ethnic, gender, sexuality or age groups. People had become aware of the types of adaptations and support available through a variety of sources; including from their Jobcentre, through a social worker, and from disability organisations. It was access to information from these sources that appeared to determine how aware people were of what was available. **Chapter 6** discusses in detail the issues surrounding access to these sources of information.

In an exceptional case, the perceived bureaucracy of accessing adaptations and support with certain employers had influenced decisions around employment.

'...I wanted to go into social work, but at the moment, because I've been disabled myself, there's so much red tape in social work, and all that stuff – I don't like it, with social working, especially with the government.'

(Female, 30, Pakistani, mobility impairment)

Whilst for some people, as already discussed, financial considerations had been a motivation for participating in employment, for others they acted as a deterrent to doing so. Given the great difficulties that many people had experienced in accessing benefits (see **Chapter 6**) the possibility of forfeiting these for an income from a job was perceived as a risk. If they subsequently lost or were unable to continue with the job, they faced having to reapply for their benefits again and were unaware they could be covered by the benefit linking rules³⁴ or sceptical that they work:

³³ As of April 2002 the Therapeutic Earnings scheme has been replaced by new permitted work rules, see Disability Alliance (2002) Disability Rights Handbook 27th Edition, April 2002 - April 2003, Disability Alliance, London. Information on the new scheme is available on the DWP website at: http://www.dwp.gov.uk/lifeevent/benefits/incapacity_benefit.htm#newrules.

³⁴ The 52 Week Linking Rule is available for clients who stop claiming an incapacity benefit to move into work or training for work and who subsequently reclaim the benefit within a 52 week period of leaving the benefit. The client will re-qualify for the same level of benefit without having to serve a fresh qualifying period. The 104 Week Linking Rule is available for clients who leave an incapacity benefit to move into work or training for work and who reclaim the benefit within a 104 week period. To re-qualify for the same level of benefit, without having to serve a fresh qualifying period, the client must also have claimed Disabled Person's Tax Credit, as well as an incapacity benefit*.

*Short-term higher rate or long-term rate of IB, SDA or IS with disability premium.

'I can get the job tomorrow, but I choose not to...I know there's lots of disabled people with the same story, because of the benefit...As soon as you leave it, and you apply/reapply for it, they give you the biggest hassle possible.'

(Male, 30, Indian, mobility impairment)

There were also those who felt that it would be difficult to find a job in which they could earn more than they currently received through benefits in unemployment.

'If you go to work, I think the idea is that you bring home more money than [if] you weren't going to work and the other, the other sort of – odd side, is that because of the way my benefits are, I'd have to earn quite a lot of money to make up for the benefits I'd lose.'

(Female, 42, African, mental health impairment)

Again, it is worth reiterating the low levels of awareness in the sample of the various packages of support available for those wanting to enter or return to work from benefit. One of the people who was aware of the Therapeutic Earnings scheme did indicate that hearing about the scheme had encouraged her to look for work. This supports other research³⁵ which suggests that awareness of such measures could be an important factor in overcoming financial concerns around participating in employment.

Fear of discrimination was also a factor which affected the decisions people made about employment. It was commonly felt that employers were likely to discriminate against people because of their disability, when applying for jobs.

'Yeah I've looked [for work] quite a lot, but I mean in the end I just decided what is the point, because as soon as you mention you've got a disability they don't want to know.'

(Male, 48, white, mobility impairment)

There were also people who thought they would experience discrimination in the workplace if they participated in employment. For example, one Caribbean woman who had not worked during her life felt that if she had she would have experienced prejudice from the people she worked with.

'Well it's a good thing I didn't have to go to work because I sure would be handicapped more or be ridiculed more really, you know.'

(Female, 60, Caribbean, multiple impairments)

For people with less visible forms of disability, it had often been the case that they had decided not to disclose their disability when applying for a job, directly because they thought they would be discriminated against if they did. In other cases, people had decided to only pursue employment with particular employers who they felt would not discriminate. Larger organisations, local authorities, voluntary organisations

³⁵ See for example: Corden, A and Sainsbury, R (2001); Hills, D. Child, C. Blackburn, V. and Youll, P (2001); Loumidis, J. et al (2001).

and the NHS were commonly sighted as 'good' employers who people felt would not discriminate. Across the sample it was predominantly a fear of discrimination on the grounds of disability that mediated people's decisions about employment. However, there were instances where people talked about potential discrimination on the grounds of their disability in combination with other factors, including ethnicity, age and gender. For example:

'I mean if you are going for a job, and you've got – on one side you've got – white, male, non-disabled, and on the other side you've got disabled, black and female, then you don't stand a chance.'

(Male, 28, Pakistani, visual impairment)

'Because [I'm] Asian and plus I am nearly 50 and the difficulties there are as well [relating to her disability] I think the employer, you know, sees that... there is obstacle on the pathway.'

(Female, 49, Indian, hearing impairment)

In terms of gay and lesbian disabled people, it was clear that fear of discrimination on the grounds of their sexuality had affected the type of jobs they would apply for, and decisions around whether or not they would disclose their sexuality to employers and colleagues. Local Authorities, government agencies and voluntary organisations were again cited as employers with a more 'enlightened' attitude and places where they were less likely to experience discrimination on the grounds of sexuality, either from the employer or colleagues in the workplace. Either gay and lesbian people had only sought work with these types of employers or they had decided to not disclose their sexuality in jobs where they thought they would face discrimination.

'I had to be careful depending like where you work. I couldn't tell people that I was gay in the factory... because they were kind of rough and men, men-men and women who were right northern like, like and they would rather be – a man should marry a woman, this and that. But within the civil service and working in offices it wasn't a problem... I think I was worried in case I was isolated at work or, or I got homophobic slander or whatever it was.'

(Male, 35, gay, white, mobility impairment)

The advice of family members had, in some cases, played a part in decisions people made about employment. There were people who felt that the encouragement of their parents, and the positive attitude their parents held about work, had been important in influencing them to seek work.

'My parents have been, and still are, perhaps it's an old fashioned idea about people standing on their own two feet... to get out into the world of work and make your own life, and that's what they wanted me to do.'

(Male, 51, white, mobility impairment)

This was reported by younger people in the sample when they talked about their current situation, and also by older people, looking back on their experiences as a

younger person. Parents had also influenced the type of employment people sought. For example, one person with a mobility impairment had been encouraged by his parents to concentrate on becoming qualified for office-based jobs, rather than manual work. There was some evidence indicating that the advice people received from parents about employment varied between different ethnic groups. **Chapter 3** discussed the issue of South Asian families preferring to keep disabled people at home and out of sight as an attempt to prevent or minimise the stigma brought upon their family. It appears that as part of this, younger people from these communities were less likely to be encouraged by their parents to participate in employment. Also, evidence suggested that ethnicity (combined with gender) was an issue in advice people received from a spouse. There were examples in both the Indian and Pakistani samples of women who felt they had been actively discouraged from participating in employment by a husband, on the grounds that he was providing for the family.

'I never worked here – he never – he never let me – let me work, cos – he never let me work – I wanted to work, I told him, I said 'let me go, for teaching and all that', he says 'there's no need', so I never worked.'

(Female, 63, Indian, mobility impairment)

Finally, in contrast, one young Pakistani man had been encouraged by his mother to find work because she wanted him to get married, implying that if he did not have a job it would be harder to find a wife. Unfortunately it was not clear in this example whether his ethnicity was a key factor in the advice he had received from his mother.

5.3 Experiences of seeking work

People in the sample had diverse experiences of seeking work, and taken together their experiences form a rich picture of the different issues faced by disabled people seeking work. Some people were currently in the process of seeking work. Others were in employment of some kind or were retired and had previous experiences of seeking work. People also differed in that some had experience of seeking work as a non-disabled person as well as a disabled person (where onset had been in later life), whilst others had solely experience of seeking work as a disabled person. This section highlights the barriers to entering employment that people reported, and also talks about the different forms of help they may or may not have received in seeking employment.

5.3.1 Barriers to entering employment

A key barrier, reported by people from all groups in the sample, was the perceived attitude of employers towards disability. People said that in applying for a job, employers were less likely to employ them than they were a non-disabled person because of their disability. A number of prejudicial/discriminatory attitudes of employers were reported. People felt employers were unable or unwilling to accept that, as a disabled person, they would be able to meet the requirements of the job -

irrespective of how well qualified they were, or whether the conditions of their disability actually affected their ability to do the job.

'As soon as you tick that box on the application form...there is sometimes an assumption...that disabled people couldn't possibly do the job.'

(Male, 51, white, mobility impairment)

'Even though I explained to like a number of employers that as far as they're concerned or, and I'm concerned and me doctor's concerned, I won't have a fit while I'm awake. They seem to look at that as – they read the word epilepsy and are unwilling to give me a job.'

(Male, 20, white, multiple impairments)

As was found in previous research³⁶, people felt employers were reluctant to employ disabled people because of the perceived trouble and expense of making adjustments in the workplace that would be necessary to enable them to do their job.

'I got called to several interviews and they would say 'you'd do better in another job – this isn't the job for you'. And it went on like that: 'oh, we haven't got enough room for you and your equipment.'

(Male, 45, Indian, visual impairment)

Even in cases where the necessary adjustment would be relatively minor, employers had often been reported as unwilling to carry them out. For example:

Avtar has a partial visual impairment which means he needs to be in a well-lit environment to use a computer. He previously applied for a part-time job, working as a data inputter. He was interviewed for the position and given a computer exercise to complete in a well-lit room. He completed the exercise successfully and was initially offered the job. However, the office he was going to work in was not well lit and when he said that he would need a table lamp to use his computer he was told that they could not provide this, and that he couldn't work for them.

(Male, 28, Pakistani, visual impairment)

Employers were also thought to discriminate against disabled people on the grounds that they would be taking more time off than other employees due to their disability. In some exceptional cases, disabled people thought this was a legitimate reason for employers not to employ disabled people. However, this was perceived by others as unfair and unjustified. It was not seen as their fault that they had to take time off because of their impairment. In addition, there were disabled people whose

³⁶ Woodfield K et al (2002), pp.158-162.

impairment would not require them to take regular time off from work. Disabled people in work also reported that, even in situations when they did feel ill or unwell, they would still come into work, whereas non-disabled colleagues would take time off.

Beyond direct discrimination by employers, people also reported practical barriers they had experienced in the process of applying for jobs, which they also attributed to the attitude of employers towards disability. Rehana's experiences illustrate some of these barriers:

Rehana has a visual impairment. She finds it difficult to read job advertisements in the newspaper because of the size of the text. She also finds it difficult to complete application forms for jobs because she cannot always see where to write and her handwriting is poor, because of her visual impairment. Few employers provide application forms on disk, which would allow her to use her PC, which has a screen enhancer, to complete the form. She was recently invited to be interviewed for a job. Before the interview she informed the employer that she was partially sighted. However, when she arrived she was shown to a poorly lit room. She was given written information about the interview, which was in a large font but which was too faint for her to read. She was also asked to complete an exercise on a PC as part of the interview, but there was no screen enhancer facility on the PC and she could not see to complete the exercise.

(Female, 32, Indian, visual impairment)

A lack of qualifications was another barrier that people reported to finding work. There were people in the sample who felt they had been turned down for a job because they did not have the qualifications the potential employer was looking for. Section 4.5.3 and Section 4.3.1 highlighted the negative experiences that some people had had in education. Respondents did not generally make an explicit link between these early experiences and their subsequent employability, but clearly where these experiences had impacted on their academic achievement it is possible that this had implications later in their life, when looking for work.

Although the attitude of employers to disability was the principal barrier people reported in finding employment, across the range of different ethnic, age and gender groups in the sample, employers' attitudes to ethnicity, age and gender were also cited as barriers to work.

In certain cases, people felt that the attitude of employers to ethnicity, age, gender or sexuality had been an additional barrier to them finding work. In the Caribbean and African groups there were people who felt the attitude of employers towards their disability and their ethnicity had both been barriers in finding employment.

'With the job it was difficult...[I] was finding it more difficult firstly, from being a disabled person and secondly, a black person – I was finding that to be a bit of a barrier.'

(Male, 39, African, mobility impairment)

In some cases people did not perceive one factor to be more or less important than the other. In cases where they did, disability was seen as the primary source of discrimination, with ethnicity as an additional barrier. However, people did not always find it easy to identify one aspect or the other as the primary factor, as the following quote, from a participant who was asked to reflect upon why he thought he had been turned down for a job, demonstrates :

'Because I was black. Full stop. And because I was disabled...there couldn't be any other reason. It wasn't because I hadn't the skill to do the job. So there could be no other reasons for it. It was because I was disabled and because I was black. Full stop. As I say those are the two prime reasons I can conclude.'

(Male, 58, Caribbean, mobility impairment)

Some older people in the sample felt that employers discriminated against them because of their age. Many job advertisements were seen to be phrased towards younger applicants, and employers were perceived to discount applicants of a certain age, irrespective of their potential ability to meet the requirements of the job.

'They [employers] don't want to know after you're 50.'

(Male, 54, gay, white, learning difficulties and mobility impairment).

'They'd rather take a younger person than taking someone in their mid-forties...even if the one of 45 might be more qualified than the one of 18 they'd rather take the one of eighteen, because of his age.'

(Female, 54, Indian, mobility impairment)

Again, there were people who felt they had experienced discrimination on two counts, because of their disability and their age, and again disability was perceived as the main barrier ahead of age.

There were no examples in the research of people who felt they had been discriminated against in seeking work explicitly because of their gender. However, there was one type of discrimination that was reported by women in the sample but not by men. Some women had felt that they had been actively discriminated against by potential employers because they had childcare responsibilities. It was felt that employers made the assumption that because of these responsibilities, the person would be taking more time off than other employees, and were reluctant to employ them on this basis. This was reported as a form of discrimination in its own right, and also as a factor that exacerbated discrimination on the basis of a person's disability. For example:

Martina, felt employers discriminated against her on the grounds of her disability because they were concerned about the time she would take off. She thought her childcare responsibilities were an additional factor that acted to increase these concerns. She felt employers would think that as a disabled person she would not be able to cope with the responsibilities of working and looking after her children.

(Female, 26, Caribbean, sickle-cell anaemia)

Whilst this section has talked about the different forms of discrimination people reported, it is important to note there were also people who did not feel they had experienced discrimination in seeking work, on any grounds. There were positive experiences of seeking work reported, and examples where employers had adopted a positive attitude towards disability, age and gender.

Sexuality was not raised as an issue by people in the gay and lesbian group in their experiences of finding employment. This would appear to reflect the point made earlier, that gay and lesbian people had not disclosed their sexuality to potential employers, because they felt they would be discriminated against if they did.

5.3.2 Facilitators to finding work

People reported receiving help from a range of different organisations and individuals in their experiences of seeking work. On an informal level, family and friends had often played an important role in making the person aware of a job vacancy at their place of work, *'putting a good word in for them'*, and even making a direct offer of employment. The size of the sample means it is impossible to draw quantitative conclusions about the experiences of people from the different ethnic minority groups. However, it appeared from the research that there was a higher incidence of this informal type of support amongst the white group, and the gay and lesbian group (who were also predominantly white) than there was amongst the ethnic minority groups. This is an issue that only emerged in the analysis of data following the completion of fieldwork so there was not an opportunity to explore the possible factors accounting for these variations with people within interviews.

In terms of formal help, some people had come into contact with a careers adviser whilst attending college. People were generally positive about this type of contact, but it was evident there were variations in the form it took. It ranged from simple advice about the types of work they could do in the future, to the adviser making enquiries on their behalf to potential employees. There was no clear evidence to indicate that differences in the nature of contact received were related to age, gender, ethnicity or sexuality.

The other main source of formal help people had come into contact with was through a Jobcentre (Jobcentre Plus as of this year). This included people who had come into contact with Disability Advisers, and people who were participating in the

New Deal for Disabled People scheme. People who had been in contact with a Disability Employment Adviser (DEA) reported that the main form of help they had received was advice about what type of jobs they could do, and suggestions of specific jobs they could apply for. This type of advice was generally appreciated, and there were examples of people who had found work in a job suggested to them by their Adviser. However, others did not feel the types of jobs suggested to them were appropriate to their interests. This appeared to be a particular issue for people in the sample with high educational attainment with high career aspirations who were frustrated by the perceived lack of *'professional'* jobs suggested by their Adviser.

'They try and put you into jobs that you've got no interest in at all. And then they say, 'Well what do you want to do?' 'I want to be a lawyer.' 'There's no jobs like that here. They come up very few and far between.' I said, 'I want something geared towards the legal profession, or something to help me into that.' But it's very rarely they have anything that can help me that way.'

(Female, 31, Caribbean, sickle-cell anaemia)

There were also other negative experiences reported of contact with DEAs. There were delays reported in meeting with their Adviser.

'Well I applied to see the disability officer and I had to wait two months to see him. You know two months is a long time.'

(Male, 36, gay, white, hearing impairment)

Some Jobcentre Plus facilities were criticised for being inaccessible to people with a visual impairment.

'I mean job clubs you go to job clubs, they have to be for disabled people, you can't access their computers.'

(Female, 32, Indian, visual impairment)

The support that DEAs provided in moving into work was not always felt to extend far enough. People reported wanting more practical help with finding work.

'You go down to see your disability adviser at the Jobcentre and you get all this, well you've got to sell yourself. And this is all you get out of them. They don't want to give you any physical help. All they want to do is sit behind a desk and say you've got to do this... I said, 'Well what are you here for? I would like for him to sort of instead of just saying, 'Calderdale want a social worker. There you go, apply for it.' Get in touch with Calderdale and say this person has this disability, are you prepared to even see him, let alone get him to do all the paperwork..... They're not prepared to get off their backsides, do any leg work or anything.'

(Male, 48, white, mobility impairment)

More seriously, there was an isolated case where a disabled person had been told by staff that he was never likely to get a job because of his disability, and was discouraged from coming to the Jobcentre in the future. This was despite the fact

that the person, who had a mobility impairment, felt he was capable of some kind of work. This had made him feel extremely upset, and angry at the attitude of the person he had spoken to. It was not clear in this instance whether the person he had spoken to in the Jobcentre was a DEA or another member of staff.

Aside from this isolated case, people were universally positive about the support they received through New Deal for Disabled People. They discussed a wide range of different support they had accessed through NDDP, including work placements, vocational training, and practical help with CV writing and interview skills. Participants felt that this support was very valuable in helping them find employment. They talked about the fact that they would have a good reference that they could use in future job applications, and that they could demonstrate they had experience in the workplace. Overall, they felt it had made them more confident about seeking work.

There was limited evidence to suggest that the different experiences people reported were determined by factors such as ethnicity, sexuality, gender or age. In terms of ethnicity, there was one exceptional instance of a Pakistani person who had suffered a racial attack whilst on an employment rehabilitation scheme by another participant on the scheme. There was also one Caribbean person who felt Jobcentre staff had discriminated against him in the types of jobs they suggested.

'They always think at the Jobcentre the job was not for you as a black person. With that alone you're discriminated against.'

(Male, 58, Caribbean, mobility impairment)

However, it is important to note that the above example was of a man talking about his experiences of seeking work 20 years ago. In terms of people with more recent experience of seeking work, there were no reports of racial discrimination by Jobcentre or Jobcentre Plus staff.

In terms of age, there appeared to be a perception amongst some people in the older age brackets that the NDDP scheme was designed specifically for younger people, and therefore not something that would be appropriate to their needs. This was clearly a potential barrier deterring older people from accessing the scheme.

There was also an example of an older person, aged 59, who felt he had been treated unfairly when he had become unemployed and made a claim for Jobseeker's Allowance. He had been told by staff at the Jobcentre that *'we won't push it too far, because you'll be retiring soon'*. He thought their attitude was *'the old *****'s 59...he won't be going looking for a job or anything'*.

5.4 Experiences in the workplace

One of the key areas of discussion with people in interviews was their experiences in the workplace, both in terms of how they felt they were treated by colleagues, and by their employer.

5.4.1 Relationships with colleagues

The attitude of colleagues to disability were generally positive, but there were some instances of discriminatory treatment and prejudice. As found in previous research³⁷, colleagues were often insensitive and even suspicious of the needs of disabled people, in cases where their disability was invisible rather than visible. There were also disabled people who had experienced discriminatory comments and jokes from colleagues on account of their disability, again echoing the findings of the previous research. The research for this report clearly indicates that some disabled people had also experienced discriminatory treatment by colleagues on the grounds of ethnicity, gender and more frequently sexuality. Before highlighting these it is important to note that there were also many positive experiences reported of colleagues who had not been discriminated on these or any grounds. For example:

'They treated me very well. We used to all sit together and drink tea and talk, I mean you could not tell, my dress was different or my face was different but other than that there was no difference between us. To this day if I bump into them they greet me with happiness.'

(Female, 60, Pakistani, multiple impairments)

The types of discriminatory treatment people reported took different forms. On one level, people reported racist, sexist and homophobic comments had been made to them by colleagues in the workplace. In certain cases this was described as an *'odd comment'* made by a single individual. In other cases, it was apparent that people had suffered verbal abuse over a number of years from more than one colleague. For example, there was one Caribbean woman had received racial abuse over a 20 year period, having worked as a carer. This had come from certain colleagues, and also from some of her clients. Generally the comments people received related specifically to the person's disability, race, gender or sexuality, but there were examples where an association had been made between disability and sexuality, with lesbian people being told by colleagues that their disability was a *'punishment'* for their sexuality.

The other main type of discriminatory treatment people reported, was social isolation or *'alienation'* from colleagues. The form this took was often quite subtle, but nonetheless it was clear that it had caused people some distress. Gay and lesbian people reported that their sexuality had made heterosexual colleagues behave awkwardly or in an unfriendly manner towards them, and as a consequence they had felt isolated in the workplace. One lesbian woman talked about the deathly silence that descended amongst her colleagues when she had complimented the looks of a female star of a television programme. One gay man talked about how colleagues, some of whom had also been friends, had refused to talk to him when they learnt he was gay. He felt this was because they were concerned about being seen as gay themselves.

³⁷ Woodfield K et al (2002), pp.162.

'Maybe they were worried about – if they were seen to be socialising with me then they could be tarred with the same brush.'

(Male, 47, gay, white, mobility impairment)

In terms of ethnicity and gender, a Caribbean woman reported feeling isolated because she felt she had nothing in common with her exclusively white colleagues and was uncomfortable with the perception of others that she may be a 'token' black person within her organisation.

Typically, people felt they had been treated differently by colleagues because of one particular factor, either their disability or their ethnicity, gender or sexuality, rather than a combination of factors. However, it was clear that people felt more vulnerable to discriminatory treatment by colleagues where there was more than one part of their identity that could be a target for discrimination.

5.4.2 Relationships with employers

People reported both positive and negative experiences, when talking about how they had been treated by employers. There were positive experiences of employers who had been flexible and supportive in relation to their disability, as reported in previous research³⁸. Employers had been happy to adjust working hours and allow time off when requested. They had also been willing to make adjustments in the workplace to meet their needs and, on a personal level, had adopted a supportive and understanding attitude to towards their disability. People also felt that employers would not discriminate against them in terms of career progression within the organisation. Such positive treatment was reported by people from across the different ethnic, sexuality, gender and age groups in the sample.

'Where I was working my employer was quite good, he made sure that there was a lift for me taking me to the level that I used to work from – and when the lift was out of order, he made sure there was an option of where I could work instead of climbing the stairs.'

(Male, 39, African, mobility impairment)

'I had to reach all the equipment and all these things, so they had to readjust everything, area, so and I can move around with my wheelchair because there is space I need to move around so that's what they did, they were quite conscious about everything... in fact we had a hoist in the toilet which was quite amazing. They did everything.'

(Male, 57, Indian, mobility impairment)

There were also positive experiences of how employers had treated people in relation to these different factors. For example, one Muslim Pakistani man was allowed to alter his working hours each year during the month of Ramadan, to allow him to observe his religious beliefs over this period.

³⁸ Woodfield K et al (2002), p.160.

The negative experiences of treatment by employers found in this research again echo existing evidence³⁹. Employers were criticised for pressurising employees to return to work when they had taken time off due to their disability, and for being inflexible around working hours or not being willing to make adequate adjustment in the workplace. People reported being passed over for promotion, in favour of non-disabled people often less experienced and/or qualified than them. There were also people who felt they had unfairly been made redundant, partly or wholly because they were disabled (an issue discussed in more detail in the next section). Employers were also criticised for not addressing the type of discrimination they had received from colleagues, already reported in this chapter. There was a strong sense from the data that the treatment by employers that people had experienced, good or bad, was determined by their attitude to disability, largely irrespective of other factors. However, there were certain instances where ethnicity, sexuality, or gender had been an additional factor in the discriminatory treatment they had received on account of their disability. For example:

Mary is a lesbian and has dyslexia. In a previous job she was required to produce written reports. Because of her dyslexia her spelling was not always accurate. Her secretary did not correct these mistakes when she typed up the reports but there was another secretary who was happy to correct any mistakes she had made. Her manager refused to allow her to switch secretaries and told her it was 'time for her to learn to spell'. She knew that the manager had a problem with her sexuality, and thought that this was why he had been so unreasonable.

(Female, 50, lesbian, white, multiple impairments)

Simon is Caribbean and has epilepsy. He has recently been made redundant by his employer. He had not been experiencing any difficulties meeting the requirements of his job and believes he was made redundant because his employer had a policy of not employing people with epilepsy. He was extremely disappointed that he had been made redundant and that his employer had not found him another position within the organisation. He felt that his employer would not have treated a white employee the way he had been treated.

(Male, 58, Caribbean, mobility impairment)

Aesha feels that she is not being paid a fair amount for the job she does by her current employer. She is aware that the levels of pay within her organisation are lower for disabled employees and for female employees. As a disabled woman she feels doubly discriminated against.

(Female, 50, white, mobility impairment)

³⁹ See Woodfield K et al (2002) Chapters 7 and 8.

Finally, there were exceptional cases where people had felt unfairly treated by employers on account of their sexuality, but not their disability. In the sample of gay or lesbian respondents there were people who felt they had been sacked by an employer directly because of their sexuality, and that their disability had not been an issue. For example, a lesbian woman with a hearing impairment had been sacked from her position as a medical nurse, working with people who had learning difficulties. She thought she had been sacked because her employer did not think it was 'appropriate' for a lesbian to work with people who had learning difficulties because they could respond to her and start to display more '*challenging behaviour*'. She did not feel that her hearing impairment had had any bearing on their decision to fire her.

5.5 Leaving employment

This final section looks briefly at the experiences of people who had left employment. In all but one case, people had left employment either directly or indirectly because of their disability (the exception being a man who had only become disabled after retiring at 65). Either they had taken the decision themselves to leave work through retirement, or they had been made redundant or offered early retirement by their employer. People had taken the decision to retire themselves either with the onset, or a worsening in the severity, of an impairment. In some cases this had been on the advice of a doctor, in other cases the person had just felt they could no longer keep on working. For example:

'Over the years it's got worse and worse and worse and I gave up work about three years ago - I just could not - I'm an electrician by trade, but I just could not carry on. Towards the end it became an absolute chore, because of the back.'

(Male, 63, white, mobility impairment)

People who had been made redundant or offered early retirement by their employer, had typically been declared medically unfit to work by a doctor. For example:

Derek is visually impaired and previously worked in a manual job at a factory. His impairment affected his peripheral vision. The job involved working with heavy machinery, and when his employer learnt about his impairment he was assessed by a doctor. The doctor decided that because of his impairment it was not safe for him work with heavy machinery, and he was made redundant by his employer.

(Male, 50, white, visual impairment)

There were radically different feelings expressed about retirement amongst people in the sample. For some it had been accepted, and even welcomed. For others, it had been a bitter experience and one that they looked back on with great regret. The

data suggested there were three key factors underpinning the reactions of people to retirement: financial considerations, age, and reason they had become retired.

In terms of age, the sample include people who had retired in later life (i.e. above the age of 50) and also people who had retired in their 30s or 40s. For this latter group, retirement had often come as a grave disappointment. They talked about the sense of pride and enjoyment that working had given them. The initial loss of this, and the realisation that they would possibly not be able to return to work for the rest of their life had been something that had been difficult to accept.

'I mean, I feel I'm still relatively young, I'm only 42 and to think that I will never work again maybe, is a bit hard to come to terms with.'

(African, 42, female, mental health impairment)

In contrast, there were more positive feelings reported by people who had retired later in life. The loss of the opportunity to work was not typically felt so keenly. As one person put it, he felt that when he retired at the age of 50 having worked for most of his adult life he had *'done his bit'*. However there were some exceptions to this with older respondents, even those in their seventies, reporting that they still missed the opportunity to work, because of the satisfaction and enjoyment it had brought them.

'I miss it, I've always missed my work – I love work, I'd go back tomorrow if I could...I mean I've always enjoyed work.'

(Female, 74, white, multiple impairments)

Financial considerations were also an important factor in how people felt about retirement. People had generally been much more positive about taking retirement if they had qualified for a significant pension.

'I didn't mind [retiring] cos I was getting a good pension...I think if like I'd just been terminated without a pension and I had to worry about where we were going to get the next lot of money.'

(Female, 58, lesbian, white, multiple impairments)

In many cases people welcomed the prospect of having a steady source of income from a pension, which often contrasted with the irregular earnings they had received through intermittent employment (often interrupted by disability) previously in their lives. Age appeared to be a contributory factor, because older people had generally had greater opportunity to remain with an employer for a long period of time, and qualify for a better pension. However, again, there were exceptions to this. There were some older people who had not qualified for a significant pension, and reported a range of financial concerns when they had become retired.

'They retired me medically unfit. And for the 11 ½ years I worked for them they've given me a gratuity up to now. They're giving me this gratuity. You know what this gratuity was? I think it was £1.05 pence. It's finally hit the £5 – for 11 ½ years. And when – [her employer] came to see me to tell me they are

going to retire me. I said, 'I don't want to leave work. I've got me little daughter.' 'Cos she was still at school. She was about 13 then. I said, 'How will I look after her and meself?'

(Female, 79, Caribbean, multiple impairments)

Finally, people's views about retirement were often strongly coloured by the circumstances in which they had stopped working. Where people felt their disability made it impossible for them to continue working, there was a general acceptance of what had happened.

'I was retired in '90 – '93 – '92 – no, '93 actually. I went into hospital '92 and while I was in there they came to see me and asked me what I wanted to do 'cos they knew I wasn't going back – well, I couldn't go back in any case, because I wouldn't be able to stand up so much – and so this very nice lady came to see me and said, she suggested that it might be advisable to take medical, you know, retirement on medical grounds. So I did, which pleased me really because I knew I couldn't go back.'

(Female, 74, white, multiple impairments)

However, there were people who had been made redundant by an employer when they did not feel that their impairment prevented them from working. There was a strong sense of injustice in many of these cases against employers. People appeared to accept decisions made by doctors around their ability to work, but employers were criticised for not being prepared to make adjustments in the workplace that would enable them to continue to work, and for not redeploying them in an alternative job within the organisation that they would be able to do.

'Oh terrible, terrible, because it's just I got the chance and now I'm back to square one. It's not that I can't do it because they could have put me anywhere – yeah – because there were so many places they could have made an effort to put me but they didn't.'

(Male, 57, Indian, mobility impairment)

Balanced with this there were also reports of employers who had done whatever they could to allow the person to continue working. There were those who had been offered alternative positions, and also those who had been assigned different duties within the same job, so that their impairment was not an issue.

5.6 Summary

A range of positive attitudes were expressed towards work across the sample. These related to feelings of self worth, a sense of independence, overcoming feelings of isolation, and being able to earn money.

Decisions people made about whether to work (and the type of work they wanted to do) were influenced by the physical or mental impacts of their disability, knowledge and perceptions of workplace adaptations and support available,

financial considerations, perceptions about the potential for prejudice and discrimination on the part of employers, and the advice of family members.

Fears that employers would discriminate on the grounds of disability were widespread. Ethnicity, sexuality, age and gender were seen as additional grounds on which employers might discriminate.

Family members were generally supportive around employment issues. There was, though, evidence to suggest that some younger Pakistani and Indian people had felt discouraged from working by their families.

In seeking work, the main barrier reported was the attitude of employers towards disability. Employers were felt to be prejudiced against disabled applicants in a number of ways, by being: dismissive of the abilities of disabled people, unwilling to making adaptations in the workplace, and overly concerned about the amount of time off disabled people would take.

The attitudes of some employers relating to the ethnicity, age or gender of applicants were also seen as additional barriers to finding work. In these cases, people described feeling that they had faced compounded disadvantage when seeking employment as they felt discriminated against both because of their disability and one of these additional factors.

Mixed views were reported about the assistance received in seeking work from Jobcentre and Jobcentre Plus offices. For example, Disability Advisers were sometimes criticised for not giving people enough practical support in accessing job opportunities. In contrast people were universally positive about their experiences of NDDP.

Relationships with work colleagues varied. Prejudice based on disability was commonly described. Others described how they had also encountered prejudicial treatment from colleagues on the grounds of their ethnicity, gender or sexuality. This was in the form of racist, sexist or homophobic comments, and also social isolation from colleagues.

Treatment by employers was similarly mixed. In the most positive examples employers were praised for their flexibility and supportiveness. Less positive experiences were, though, also reported. It appeared that treatment by employers was determined primarily by the attitude of the employer to disability but there were some instances where sexuality, ethnicity and gender were perceived to have been additional factors.

For those not in work at the time of interview, a range of factors had led to their situation. People had either taken the decision to stop work themselves or been made redundant or offered early retirement by their employer. People were unhappy about retirement if they felt they had been unfairly made redundant by their employer, and also if they had not qualified for a substantial pension when they stopped work. People who had been forced to retire at a younger age were also greatly disappointed by losing the opportunity to work during their adult lives.

6 Accessing support and services

This chapter discusses the views and experiences that people had of accessing a range of support and services, namely: the benefits system, housing and accommodation services, health and medical services, services for disabled people, and financial services. Access to leisure services and public transport have been previously considered in Section 3, **Chapter 3** and are not repeated here.

6.1 The benefits system

Benefit support was an important source of financial assistance for people, both in and out of employment. Within the sample there were wide-ranging views and experiences of the benefits system, in terms of attitudes towards claiming benefits, awareness of benefits, and experiences of applying for benefits. This section describes the experiences of disabled people generally, and also the particular experiences of disabled people from ethnic minorities. Based on the findings from the research there was little evidence to suggest that age, gender or sexuality were crucial factors affecting people's experiences of the benefits system in their own right. Nevertheless, there was evidence that combinations of these factors led to differing experiences of the benefit system.

6.1.1 Attitudes towards claiming benefits

Attitudes towards claiming benefits varied. Amongst the people interviewed there were generally positive attitudes towards claiming benefits for their disability, but also people who had some resistance towards claiming. People who were positive about claiming benefits talked about the fact that they felt the government, or society generally, had a responsibility to support them. They described the necessity of financial support to give them a reasonable quality of life, on a day-to-day basis. Some older people also felt that, having paid taxes over a number of years, they had effectively earned the right to receive financial support.

One reason people gave for not wanting to claim benefits was that they felt there were other people more deserving of help than them. The types of people seen as more deserving were either disabled people perceived to have more severe disabilities than them, or other non-disabled groups in society (such as widows and orphans). There were also those who had decided not to claim benefits because they did not think they needed an additional source of income. In these cases, people had an existing source of income from their own employment or the employment of a partner or spouse. Another reason people had been resistant to claiming benefits was if they did not consider themselves disabled, and as such would not consider claiming for benefits for disabled people (the issues surrounding people's perceptions of themselves as disabled are discussed in **Chapter 2**).

There were also reasons why people had been resistant to claiming benefits that related specifically to issues of ethnicity. The data suggested that there were cultural differences in the attitudes of different groups towards claiming benefits. It appeared that personal pride, and the belief it was your own responsibility, or the responsibility of your family to provide for your needs, had deterred some people from ethnic minorities from applying for benefits. In this context, receiving benefits was perceived as a form of charity. This was an issue raised by people from African, Caribbean and Pakistani communities and reflects existing findings about the reluctance to take up benefits amongst different minority ethnic communities.

'I do not like to take money and so we did not go for it... I said that I do not want charity.'

(Female, 66, Pakistani, visual impairment)

Jemma, a Caribbean woman who worked for a voluntary organisation for black disabled people also talked about how she and other black people (taken to refer to African and Caribbean people) were often too proud to apply for benefits, and that it would feel like they were begging. She felt that these attitudes were part of their culture, and that in comparison white people were happier to accept financial support.

(Female, 65, Caribbean, mobility impairment)

6.1.2 Awareness of benefits

There were varying levels of awareness amongst people of the benefits that they were eligible to apply for. This included people who had not been aware of what benefits were available to them at the time of their interview, and also people who had only become aware of what was available having been disabled for a number of years.

'I've just set up, it's taken me years to get to – to get anything – I never knew a thing, I didn't know what my entitlements were.'

(Female, 42, African, mental health impairment)

It did not appear that ethnicity, gender, age or sexuality were deciding factors in the different levels of awareness people had. What did emerge was that access to sources of information about benefit entitlements was a key factor in how aware people were. There was a general view by people from all the groups in the sample that there was a lack of information available about benefits that disabled people were entitled to. People felt it was the responsibility of the 'Department for Social Security' or GPs to make people aware of their entitlements. However it was clear that some people had not received any advice or guidance about their entitlements from these sources.

'When I came out of work I didn't know what I could claim for. At the time, yeah. I mean they don't tell you what you can claim for and what you can't claim for.'

(Male, 46, white, visual impairment)

Amongst those who had, the experience had typically not been straightforward – echoing the findings reported in previous research⁴⁰. There was also a specific issue with accessing information from the (former) Benefits Agency, relating to ethnicity. Indian and Pakistani people whose first language was not English reported difficulties understanding written information about benefit entitlements they had received from the Department for Work and Pensions (DWP). This was an issue reported by older Indian and Pakistani people, suggesting that both ethnicity and age were critical factors. However, it is important to note that this could equally be an issue for younger people from ethnic minorities whose first language is not English.

For many people in the sample it had actually been through sources other than the DWP that they had first become aware of their entitlement to benefits. People had found out by word of mouth from family or friends who were themselves disabled.

'...by speaking to someone months, months, months down the line here, who is disabled and perhaps getting a benefit, 'oh, you should be getting de-de-de, you should be getting this, or you should, you know, that's how – it's all word by mouth, really.'

(Female, 32, Caribbean, mobility impairment)

People had also become aware of what was available through voluntary organisations for disabled people. This included larger, national organisations (for example RNID) and a range of smaller, community-based groups.

One additional source of information that some people reported was the internet. It was specifically younger people in the sample who had accessed this. They had obtained information about benefit entitlements or links to voluntary organisations that had subsequently been able to help them with their benefits.

⁴⁰ Woodfield K et al (2002), pp.175.

6.1.3 Experiences of applying for benefits

The process of applying for benefits was criticised by people in the sample for being complex and time-consuming. Much of this criticism centred around the forms that people had to complete as part of the application process. These were felt to be too long and/or too complicated. They presented particular problems for people with certain disability types. People with a learning difficulty, or a mental impairment that affected how long they were able to concentrate, found it difficult to provide all the information necessary on the form. People with a visual impairment experienced additional difficulties reading, and consequently completing forms. People with a mobility impairment (e.g. arthritis) had problems with writing answers to questions on forms. There was also a deaf respondent, who felt that British Sign Language (BSL) users faced particular problems completing forms because their first language was often BSL, and not English.

There was evidence that some people from the minority ethnic groups faced additional barriers in applying for benefits. Language was again an issue for Indian and Pakistani people whose first language was not English. They experienced difficulties completing forms and in communicating their needs to Benefits Agency staff. On a broader level, some people felt there were particular barriers for people from ethnic minorities who had migrated to England at some point in their adult life. The fact that they had not been brought up in England meant that when they arrived they were typically unfamiliar with the benefits system. As a consequence they were much less likely to know the different types of benefit available and less aware of the processes necessary to claim benefits than white people who had *'grown up with'* the benefits system in this country.

'I think it [applying for benefits] is harder, yes...because white people understand – black people, they don't understand anything. You know, any forms or anything to claim something from DSS or anything – they [white people] know it more than us – and that's the difference – if you don't know, you don't get anything. They [white people] are born in it – I think – and they grows up in it – and it just like me in Jamaica, born there, grow there – I knows ins and outs which if you go there and live for 20 year, you won't know as much as I know.'

(Female, 60, Caribbean, mobility impairment)

It was also suggested that African and Caribbean people had been deterred from applying for benefits because they were not comfortable with disclosing personal information about themselves on benefit forms. This was again linked to the sense of personal pride among people in these communities.

In contrast to the barriers specifically attributed to ethnicity or disability outlined above, participants did not discuss barriers related to age, gender or sexuality when discussing use of the benefit system. However, in common with non-disabled people, respondents noted a number of other criticisms of the system. For example, people were critical of the judgements that were reached about their entitlements. There were people who felt they were entitled to receive a benefit but had had their

application rejected. There were also people who felt they were receiving a lower level of benefit than they were entitled to. People were not always clear about the reasons why they felt they had not received the benefits they thought they were entitled to, but it did not appear that ethnicity, age or gender had been an issue in this respect. There were no cases, for example, where a person felt their application for benefit had been turned down because of discrimination on the grounds of their ethnicity. In contrast, people frequently cited their disability or impairment as the source of grievances between themselves and representatives of the benefits system. People had often gone through the process of appealing against the original judgement on their entitlement, which involved the completion of further forms, a reappraisal by a doctor, and even a tribunal hearing. People reported finding this process unnecessary and unfairly demanding on their time. There was evidence that some people had been discouraged from applying for benefits directly because they had heard from other disabled people that the application process was so time-consuming and difficult.

'I might be able to claim DLA⁴¹, but I've never started on it because I know that the hassles of getting it for deaf people are even worse than for other disabled people... I've heard so many deaf people say the process is really torturous. That you complete the form – um it's almost automatically refused, and then you appeal, and you have to take it through the appeal procedures.'

(Female, 46, Lesbian, white, hearing impairment)

There were also people who felt discouraged from applying in the future because of negative experiences of the process in the past.

'You goes through a lot of trouble to get itits the system – and how difficult... this last time if I didn't get it, I wouldn't have bothered again'

(Female, 60, Caribbean, mobility impairment)

People in the sample reported receiving help or advice in applying for benefits from a range of sources. These included formal sources, such as former Benefits Agency staff, GPs, and social workers, and also more informal sources, such as family, friends and voluntary organisations for disabled people. It was clear that these sources of help and advice had often proved crucial in helping people access benefits. Not all people had been offered support by formal sources. Again, people felt there was a general lack of formal help and advice about for benefits, and that without some form of support there were difficulties in accessing benefits.

⁴¹ DLA (Disability Living Allowance) is a benefit for working-age adults and children with disabilities who need help looking after themselves and those who find it difficult to walk or get around. See Disability Rights Handbook 27th Edition, April 2002 – April 2003, Disability Alliance, London.

'I was fortunate cos at the hospital, they give you a social worker to help fill in the forms, but again, for other people in trying to access Incapacity and Attendance Allowance and things – how do you access those forms if you haven't got a support network?'

(Female, 49, lesbian, white, mental health impairment)

In terms of informal sources of help and advice, disability organisations were widely praised by people in the sample who had accessed them. As well as information about what they were entitled to, people also reported receiving practical help with completing forms.

'There was another one there [at the daycentre she attends] who talked to me about money and I told her that my husband works so how can I get any money but she said no you should be getting it and that has nothing to do with my husband. There was a white man that used to come there as well and they made an appointment and the white man came home and filled in all the forms and said that I would get some money, they will check everything and then I would get it.'

(Female, 55, Pakistani, heart condition)

In addition, family and friends had given people assistance with completing their forms. This was a particularly frequently cited source of support reported amongst the Pakistani and Indian groups. Older people in these groups whose first language was not English were often reliant on younger members of their family to complete forms on their behalf.

6.2 Health and medical services

People in the sample had many experiences and views about medical and health services they had accessed. These related to treatment they had received in a hospital environment and contact they had had with a GP. This section will first outline the experiences that were reported by people across all the groups in the sample, and then explore the role of age, gender, sexuality and ethnicity in the experiences of different groups in the sample.

In common with the findings of previous research⁴², people reported a range of positive and negative experiences of health and medical services. Negative experiences centred around long waiting times for treatment or consultation with a specialist, a lack of privacy in hospital environment, difficulty in contacting and securing an appointment with a GP, the poor state of repair of medical equipment in hospitals, and doctors not being able to devote enough time to individual cases because they were too busy. Some medical staff were perceived to be uncaring, or unnecessarily strict in their treatment of hospital patients.

⁴² Woodfield K et al (2002), pp.177-179.

There were also specific negative experiences that related to people's experiences as a disabled person. People with a mobility impairment did not generally raise access as an issue when talking about healthcare facilities but one woman with multiple impairments had found the day hospital for people with a mental health impairment she visited inaccessible for wheelchair users.

'They meet my emotional needs, but not my physical needs. Which I find very frustrating, and it makes me very angry, being a hospital...it's not wheelchair friendly, in any sense of the word really.'

(Female, 52, lesbian, white, mobility and mental health impairment)

People with a hearing impairment reported difficulties communicating with medical professionals in hospital and staff at a doctor's surgery.

'In a waiting room, waiting for my doctor, I still have to say, please, remember I'm deaf, you have to come and let me know – and sometimes they forget, they're shouting out my name and I'm waiting there, they need to come up and tell me it's my turn.... they won't give me eye contact or I can't read their writing or can't lip read them.'

(Male, 47, gay, white, hearing impairment)

People also talked about experiences where they felt that medical professionals had displayed negative attitudes towards their disability. For example, one person commented that he had heard mental health professionals in a hospital environment refer to patients as 'barking mad'. A woman with an existing mental health impairment felt hospital staff had been unsympathetic towards her when she had become mobility impaired – implying that her inability to move her legs was psychosomatic. People with a less visible disability also sometimes felt treated unfairly in healthcare surroundings. For example a woman with sickle-cell anaemia reported having to wait a long time to see a doctor at hospital, because she felt staff had thought *'you look alright, you can wait'*. GPs were also criticised by some people for not being sympathetic to the severity of their disability, and the healthcare needs they had. One man commented that he thought the attitude of his GP was *'...these blooming disabled, every three weeks they're coming to see the GP.'*

Finally, there were people who felt their impairment had not been correctly diagnosed by a GP or hospital doctor and this had either led to them receiving inappropriate treatment or no treatment at all. In exceptional cases people felt this had contributed to a worsening of their condition. Examples of these experiences are given later on in this section.

Balanced with these negative experiences were a range of positive experiences reported by people across the sample. These experiences often contrasted sharply with those reported above, for example:

'They [hospital staff] treat me very well...the nurses are always on top of my bed, they check me all the time and they are always coming to see me and ask me if I want something...they do a lot.'

(Female, 80, Pakistani, visual impairment)

'He is very good, even if I have a little problem he says don't come into the surgery and that he will come and see me himself, he is a very good doctor...I would not say that there is anything that is bad, if I have problems then the doctor sends me to the hospital...I like everything about them'

(Female, 66, Pakistani, visual impairment)

'They [hospital staff] provide a very good service and they care a lot.'

(Female, 54, Pakistani, mobility and mental health impairment)

'My doctors have been absolutely marvellous, you know they've been, they've really gone beyond the call of duty.'

(Female, 42, African, mental health impairment)

Positive experiences of this kind were expressed by people across the different ethnic groups in the sample. People who had previously lived in Africa, Pakistan and India spoke enthusiastically about the fact that hospital treatment in England was free, and that there was no difference in the treatment that rich and poor people received. There were also thought to be fewer delays to treatment to England.

'The treatment is free at the hospital...if you are poor or rich you have the same facilities, it is not that the poor person will be lying on the floor and the rich person is lying on the bed, there is nothing like that here, everybody is equal here.'

(Female, 66, Pakistani, visual impairment)

One woman talked about her father who recently had a stroke and became disabled:

'Like over here [inaudible] drugs is paid for, free of charge. But over in Africa he would have had to pay for all that. So I think it would have been a burden on him. So I think if he had a stroke in Africa it would have been much more of a problem than what he had over here...I don't think in Africa he would have had this treatment straightaway, like what you get over here.'

(Female, 36, Indian, mobility impairment)

The remainder of this section explores the influence of ethnicity, age, gender, and sexuality on experiences of health and medical services. It is important to note, however, that people did not routinely cite these factors as having influenced their experiences.

6.2.1 Ethnicity

Perhaps surprisingly, language barriers were not typically cited by people from minority ethnic groups as a major issue influencing experiences of health and medical services. For example, there were no difficulties reported communicating with health care professionals. This may in part reflect the fact that most of those interviewed from minority ethnic groups did speak English, either as their first or

second language. People for whom English was not their first language (predominantly older Pakistani and Indian) frequently reported being accompanied by a family member to visits to a GP or hospital who had translated on their behalf. Having said this, language barriers were thought to have influenced people's experiences of health and medical services in two ways. It had been an issue for younger people whose parents had not spoken English. In these cases the parents had not been able to fully understand the diagnosis that doctors had made of their child's disability. For example:

Marina has congenital spina bifida. She is one of two twins and when she was born a doctor talked to her parents about her condition. Her parents had recently arrived in England when she was born and did not speak English. They did not fully understand what the doctor had said to them about their daughter. They thought that the doctor has just said that she was 'slower' than her sister. At age eight months her mother noticed that she was not able to crawl and walk and sit up, as her twin sister was. It was only when she was two years old, when her mother was able to speak English, that she talked again to a doctor about her daughter and learnt that she had spina bifida.

(Female, 38, Pakistani, mobility impairment)

Language was also an issue for one Indian woman who had been offered, on a number of occasions, respite care in hospital to allow her husband (also her carer) to take a holiday. She was concerned that her husband should have some time away to himself but had refused the respite care because she could not speak English well, and did not think she would have been able to communicate with carer providers in the hospital. Her husband could speak English, and was normally able to translate on her behalf when she visited hospital. The example again illustrates the important role of family members in overcoming language barriers in accessing health and medical services for Indian and Pakistani people who were not able to speak English.

Another issue relating to ethnicity was the food provided to people from ethnic minorities in a hospital environment. There was criticism of the fact that Asian and Caribbean meals were not available.

'Our food wasn't looked at, the food wasn't looked at in the hospital, you had to eat what you was given and I was adamant that... a Caribbean meal should be laid on in the hospital because that's part of your identity isn't it? You know, you don't want to eat English dinners all the time.'

(Female, 46, Caribbean, mobility and visual impairment)

However, this was not a universal experience or issue reported by those who had spent time in hospital and another African woman reported that she had been provided with African meals during her stay in hospital.

Ethnicity was an issue for some people in terms of the diagnosis and treatment they received from medical staff. This was either perceived as outright discrimination, or as a reflection of a lack of awareness about a culturally specific disability. There were only exceptional instances of outright discrimination among the experiences of people from ethnic minorities. There was no discrimination reported in the contact people had with their GP. Asian people, for example, did not feel they had been treated differently by GPs who shared their same ethnicity and religious beliefs, and white GPs.

'My doctor is good, he is our own Pakistani/Muslim doctor. If I go to the white ones they are good as well. I have never thought that they are not Muslim so they do not see me well, I mean it has been okay.'

(Female, 55, Pakistani, mobility impairment)

However, discrimination was reported in the treatment people had experienced in hospital. This included a general feeling that people from ethnic minorities were treated differently by hospital staff.

'When you go to hospital the white people favour the white people more, no matter what they run around more for them.'

(Male, 74, Pakistani, mobility impairment)

There were also specific experiences of discrimination, in terms of how long people from ethnic minorities had to wait for treatment, and the appropriateness of the treatment they received. The experiences of Jared illustrate both these issues:

Jared, who is Caribbean, had an epileptic fit whilst at work and was taken to hospital. He was seen by a doctor who gave him non-prescription pain relief and told him to go home and see his GP the next day. His GP told him that he needed an x-ray, and that the hospital should have done one when he was first admitted. Jared felt that if it had been a white person, the hospital would have given him an x-ray when he was admitted and kept him in overnight. The hospital subsequently apologised for their treatment. When he did have an x-ray it revealed that he had damaged his lungs. He was referred to a specialist but it took six weeks for an appointment to be made, and over this time the condition of his lungs deteriorated further. He felt that because he was black he had not been treated as an urgent case by the specialist.

(Male, 58, Caribbean, multiple impairments)

Beyond outright discrimination, there were also people from minority ethnic groups, specifically those from the Caribbean group, who felt they had been treated differently because of a lack of awareness of their disability. Caribbean people with sickle-cell anaemia (a condition that primarily affects African and Caribbean people) felt that there was a general lack of awareness amongst medical professionals of their condition. This lack of awareness was linked to the fact that the condition generally only affected people from a certain ethnic group. It was felt that if the

condition affected white people too, there would be a much greater awareness of the condition. One woman explained that when she began to experience the symptoms of her condition as a child she had been told by a doctor that it was just growing pains, and had not initially diagnosed her with sickle-cell anaemia. A lack of awareness was also seen to be reflected in the fact that medical staff were sometimes unsympathetic to people suffering from the condition. Another woman felt she had been labelled as a *'junkie'* by medical staff at a hospital because of the strong drugs she regularly required to control the pain she experienced during sickle-cell crises.

6.2.2 Sexuality

Sexuality was an issue for some, but not all, of the gay and lesbian group in their experiences of accessing medical and health services. There were examples where lesbian women felt they had been treated differently because of their sexuality. This had happened where they had been asked about their sexual activity as part of the medical treatment they were receiving. Having disclosed their sexuality, they felt this had affected the treatment by medical health professionals they received.

'She [the nurse] was so rough, and I'm sure that was because of my sexuality...it was a really horrible experience... and it's really put – you know, it really did shake me up.'

(Female, 27, lesbian, white, cognitive impairment)

In another case a lesbian woman felt that sexuality had been an issue with medical staff and other patients, but not to the extent that it had directly affected the treatment she received.

'You can see their faces sometimes – next of kin, right, and I put [partner's name] down and they sort of look at you – what relationship is she... you get the looks... from the nurses and other patients and stuff like that. I don't really think it's affected the quality of service, I think it just sometimes affects - the mild irritation, as you say, of different people's reactions'

(Female, 49, Lesbian, white, mental impairment)

Another lesbian woman also talked about how she had been repeatedly pressurised by doctors to take contraceptive precautions despite being open about her sexuality, and adamant that she did not need them.

6.2.3 Age and gender

Age and gender were both issues that were not generally cited by people in the sample as having influenced their experiences of medical and health services. There were two cases where people felt their own age, and doctors' perceptions about age in relation to a particular medical condition, had affected their experiences. One of these was a woman who had started to suffer from osteoporosis when she was 35. Her condition had not initially been diagnosed by doctors, and she was given physiotherapeutic treatment which only served to worsen her condition. After six

months she was diagnosed with osteoporosis. She attributes the delay to the fact that osteoporosis is a medical condition typically developed in older age, and consequently doctors had not considered that she could be suffering from it because she was in her thirties. Another case was of a 51 year old man who had contracted polio when he was a child and had a mobility impairment as a consequence. He felt that medical professionals assumed that he was elderly and retired, because since polio had been eradicated in the UK some time ago, there were few people beneath a certain age who had polio. He worked full time and nurses were often surprised when he was arranging a hospital appointment that he was not able to make certain dates and times because of work commitments.

Finally, there were examples where women felt that gender, or a combination of gender and age, had been an influence on the way male medical professionals behaved towards them.

'I had this irregular heart beat and something else, so he referred me to the hospital – and this heart specialist, said, well, what do you expect in a woman of your age...and just dismissed me – so although he's not backed by his colleagues – that's the way he saw it, he decided it's just women – so yeah, I do think that some male doctors dismiss women, just because they're women'

(Female, 49, lesbian, white, mental health impairment)

'I don't know if they [doctors] discriminate, but I think they do treat you differently as a woman – they look down on you a bit more – and that might be age as well.'

(Female, 27, lesbian, white, cognitive impairment)

6.3 Services for disabled people

This section discusses the experiences people had of services for disabled people. It outlines the issues that people reported in accessing these services. The types of services people had accessed were:

- home care (assistance with cleaning, cooking, bathing, dressing, cooking) physical and environmental adaptations to home;
- meals on wheels;
- guide dogs; and
- adapted cars and scooters.

As reported in previous research⁴³ people generally felt there was a real lack of information about services for disabled people. It was thought to be difficult to

⁴³ Woodfield K et al (2002), pp. 171-172.

establish what services were available for them in their local area and how to access them.

'We don't know anyone - we don't know where, we don't know what to do, see, there's no information, is there, who to speak to if you need help.'

(Female, 20, Indian, hearing impairment)

There were examples in the sample of people who wanted some form of support but had not received any information about what they might be able to access.

Saed lives with his family. He wants to be able to cook for himself but currently finds this difficult because of the kitchen facilities in his home. He would like help with making adaptations to the kitchen to allow him to cook but neither he or his family have received any information about what services he can access.

(Male, 22, Pakistani, learning difficulties)

People in the sample had typically accessed services for disabled people through a social worker. The following quote from the son of a focus group participant (who was female, Indian, aged 56, with a mobility impairment) illustrates the importance that people attached to the role of social workers in accessing services for disabled people:

'If you have a good social worker, they could try for a lot of stuff...if you haven't, then you're just like stuck, and we know some disabled people who's basically - and I feel sorry for them - they have absolutely nothing. It's amazing, they've got really useless social workers.'

Whilst some people were happy with the services they had received, and positive about the contact they had had with a social worker, there were also negative experiences reported. There were those who felt their social worker had not been well informed about the types of service that were available for disabled people, and specifically for people with their form of disability. There were those who had found their social worker unsympathetic to their needs, and apparently reluctant to help them access support. In one exceptional case, the reverse of this was also reported. A woman had felt pressured by her social worker to apply for home help to cook and clean, which she did not think she needed.

There were also people who felt they had been neglected or ignored by their local Social Services department and had not received the help and advice they needed. Either a long time had elapsed since their last contact with their social worker, or they had not received any contact with a social worker at all. In one exceptional case, a Caribbean man suggested that this was because of discrimination on the grounds of his ethnicity. He said that he had been on the records of the social services department in his area for many years but over this time nobody had enquired about how he was getting on. *'At one time I believe a social worker was assigned to me,*

but it seems as though I'm not in existence. Otherwise, people did not raise factors such as ethnicity, age, gender or sexuality as issues in the experiences they had of social workers.

As with the benefits system, more informal sources of information and advice (namely 'disability organisations'), had often been crucial in helping people access services for disabled people. Disability organisations had given people advice about how to access services and given people the opportunity to meet others in their situation and learn about what services were potentially available to them. For example:

Kiran regularly attends a day centre for disabled Asian women and through this she came into contact with women who had got an electronic scooter through the Motability Scheme. With the support of the daycentre she has since applied for and received her own scooter through the scheme.

(Female, 51, Indian, mobility impairment)

Guptha had a number adaptations made to his flat, to make it wheelchair accessible. He had not experienced any difficulties in accessing these services, and attributes this to the fact that he knew what the necessary procedures were for doing so through contact he had had with a voluntary organisation for disabled people. He felt that if he hadn't had this kind of contact he wouldn't have known who to speak to about having the adaptations made, and would have found the whole process much harder.

(Male, 42, Indian, visual impairment)

The importance of this kind of contact is reinforced by the fact that Saed and others like him who were not aware of services available, were typically not in regular contact with a disability organisation in their area. Ethnicity did not appear to be an issue with the level or nature of contact people in the sample had with disability organisations. However, there were some specific issues for people from ethnic minorities in accessing services for disabled people.

A recurrent issue in this chapter has been the barrier that language presents in accessing services for people from ethnic minorities whose first language is not English - see earlier sections relating to the benefit system, and health and medical services. It again emerged as an issue in accessing services for disabled people. Information about services for disabled people was criticised for only being provided in English, which made it inaccessible for people from ethnic minorities who could not read English. Information provided about services was also criticised for using technical jargon, which exacerbated the language barrier for people from ethnic minorities.

There was also clear evidence to suggest there were cultural barriers to Indian and Pakistani people accessing service for disabled people. Some people from these groups were resistant to the idea of somebody from outside their family or community providing help, whether this was assistance with household tasks or personal care.

'I wouldn't like someone else in the house cleaning or stuff like that. I would rather whatever we do, we would rather do it ourselves whether we are clean or not we would rather do it ourselves.'

(Female, 16, Pakistani, learning difficulties and mobility impairment)

'I do not want white people to touch my body ... the family members should do the work. They have told me 29 times that they would give me a woman but I have told them no.'

(Male, 74, Pakistani, asthmatic)

There was also evidence that Asian people were discouraged from accessing services for disabled people because of the perceived stigma attached to disability in their community. For example, one Indian woman knew that it was possible to have adaptations made to her home but her husband did not want these made. He did not want it to become a *'disabled house'* and was concerned about what other people would think if they saw it.

There was also one quite specific issue for some Muslim Pakistanis and Indians who were visually impaired. According to certain interpretations of the Koran, Muslims are forbidden to keep a dog in their home. This was cited as a possible reason for the low take-up of guide dog services among Muslim communities.

There were Asian people who thought that people from their communities were less assertive than white people when trying to access services for disabled people. They were thought to be less aggressive when talking to service providers, less likely to complain when there was a delay in a service being provided, and less likely to reapply for a service if it was initially denied.

'What I think they need is some nagging you know, departments like that need nagging and obviously if it is an English person they keep on nagging them all the time.'

(Female, 16, Pakistani, learning difficulties and mobility impairment)

'... we have not applied again. This is the thing in our people, we just think that perhaps it is not our right and that is why we have not been able to get it, we stay quiet.'

(Female, 55 Pakistani, heart condition)

Language was thought to be a contributory factor, with those not able to speak English less able to articulate their needs to service providers.

Age was also cited as an issue, within the experiences of Pakistani and Indian people. It was suggested that younger Asians were more assertive than older people in their community, and had a greater awareness of what services were available and how to access them. Again the son of one group participant summed up these feelings:

'I think young people, if you are younger, it does make a difference, simply because younger people are more aware of their rights, you know, whatever, whatever your problem is, you're simply more aware of the processes, how to get around people... we're brought up in that culture of being able to complain, to do something.'

In contrast there were some white people who thought that people from ethnic minorities were more assertive than white people in accessing services, for example:

'The point is they [people from ethnic minorities] are more arrogant than what us whites are. There's not so many of us that stand up. We just take a lot of things for granted and carry on - which they don't. They stick to their guns and keep going.'

(Female, white, mobility impairment, did not wish to give age)

6.4 Housing services

This section explores the experiences people had of accessing housing services, either through their Local Authority or, more commonly, a Housing Association. Not everybody in the sample had experience of accessing these services (for example, those living in private rented accommodation and those who owned their own home). However for those who had, their experiences had often had a crucial bearing on their day-to-day lives. It emerged as a particularly crucial issue for people in the sample with a mobility impairment. This group had specific needs in relation to housing, where their impairment prevented them from climbing stairs and using bath, shower, toilet and kitchen facilities. The experiences people had of trying to access housing that met these needs varied considerably. For some, it had been a relatively simple, unproblematic process, and they expressed satisfaction with the service they had received.

Carl has a mobility impairment that affects his ability to walk and to climb stairs. He was previously living in private accommodation, but he found this difficult to access because there were a lot of stairs. He applied to his Local Authority and in a short space of time was provided with a ground floor flat. He found the housing providers he dealt with helpful, and was happy with accommodation they provided.

(Male, 39, African, mobility impairment)

However, there were a variety of negative experiences reported. These centred around the time it took for housing to be found, and the nature of the housing

provided. People reported waiting as long as eight months for housing to be allocated to them by a housing provider. The quality of housing provided was also criticised, and critically, housing did not always meet their needs as a disabled person.

Parveen applied to her Local Authority for a ground floor flat, informing them that she was disabled. She was offered a flat by the Local Authority but when she went to see it she found it was a first floor flat. This was not accessible to her because of her mobility impairment. She refused to take the first floor flat and it was another two months until the Local Authority was able to find her a ground floor flat. Over these two months she was forced to live in a hostel.

(Female, Asian, mobility impairment, did not wish to give age)

Kelly has experienced a number of housing problems over the last three years. After the onset of a mobility impairment she applied to a Housing Association for a wheelchair accessible flat. The flat she was provided with was in very bad condition and needed a series of repairs made to it. After a number of months the Housing Association had not made these repairs, and Lorraine felt she had to move out. The Housing Association were not able to offer her another property to move to and she spent the next three months living with her family and friends. She is now living in another Housing Association property but the kitchen is not wheelchair accessible.

(Female, 40, lesbian, white, mobility and mental health impairment)

Lorraine was living on a Housing Association estate when she became mobility impaired. She applied for a transfer to a smaller flat with no stairs but this was turned down and she was told that she would get a bed-sit. She was very angry with this and refused. The Housing Association then told her that she would have to find her own accommodation. Fortunately she managed to find someone on the estate to do a direct flat swap with.

(Female, 74, white, mobility impairment)

These negative experiences of housing services appeared to be underpinned by two factors. One of these was a **perceived shortage of suitable housing** for disabled people.

'There is a massive shortage of accessible housing that is safe for disabled people to live in.'

(Female, 40, lesbian, white, mobility and mental health impairment)

It was felt that more money should be spent on building accommodation that was purposefully designed to meet the needs of disabled people. The other factor that

people cited was **the attitude of housing providers to the needs of disabled people**. Local Authority and Housing Association staff were criticised for not taking into account the extent of the impact of disability on people's mobility, and what types of housing would meet their needs. In the example of Parveen already given in this section, despite the fact that she had asked for a ground floor flat and informed the Local Authority that she was disabled, she had still been allocated a first floor flat. When she spoke to a member of staff, their response had been *'well, first floor and ground floor, it won't make a difference.'* Another example is Anthony, a wheelchair user. He was offered a ground floor flat, but when he went to see it he found there were two steps to reach the first floor. The housing provider apologised, and admitted they had assumed that even though he was disabled he would be able to walk some distance. This lack of understanding was associated with a lack of training for housing professionals about disability issues, and the high turnover rate of staff in organisations providing housing. People also felt that if there were more disabled people employed by housing providers, this would increase awareness of disabled people's needs.

It did not appear that factors such as ethnicity were a strong influence in the experiences people in the sample had of housing services. Despite the negative comments people directed towards housing professionals, ethnicity was not seen as an issue.

'...it's the same with the housing one, whether it's a white person or a brown person. It doesn't make a difference to them, they only just do their jobs...it doesn't make any difference who you are.'

(Female, Asian, mobility impairment, did not wish to give age)

The one factor that had possibly influenced people's experiences of housing services was the assistance people received in applying for housing. It was interesting that Carl, and other people who had been positive about their experiences of housing services had typically accessed these services with the help of a social worker. It was not always clear what role social workers had played, but people, with their help, had avoided many of the problems experienced by other people in the sample. This would appear to echo the findings elsewhere in this chapter, that the intervention of a third party (be it a family member, disability organisation or social worker), has often been crucial in the experiences people had of accessing benefits and services for disabled people.

The research revealed that there were specific issues for minority ethnic groups accessing housing services. Indian and Pakistani people had, in some cases, been unhappy with the housing they had been offered when it was not in their local area. This chapter has already touched upon the importance of family and community networks for Indian and Pakistani people. Moving out of their local area would have meant losing, or at least weakening, the ties people had with this support network. Pakistani and Indian people in this situation had decided to turn down the housing that had been offered to them, and remain in their existing housing, even where it

did not meet their mobility/access needs. Another related issue, raised by some older Pakistani and Indian people was the size of the housing they had been offered. They had wanted housing large enough to accommodate their family members, some of whom they were reliant on for the care they received. Housing providers were criticised for not being able to offer housing of this size.

6.5 Financial services

This section discusses briefly the experiences people had of accessing financial services. There were only a limited number of people in the sample who talked about having accessed financial services but among these there were examples where people felt they had been discriminated against on the grounds of disability, sexuality and ethnicity.

In terms of disability, there were people who felt that applications for a mortgage or medical insurance had been turned down on the basis of their disability.⁴⁴ This treatment was perceived as being directly discriminatory. Talking about his experiences of applying for a mortgage, one man reported that he had got the impression from the contact he had with his bank that they thought the housing market was 'not for disabled people'. His application for a mortgage had been rejected, and he felt this was because the bank thought he would be unable to repay his mortgage because his disability would prevent him from working. It also appeared that fear of discrimination on the grounds of disability had deterred some from applying for a mortgage. One woman had wanted to get a mortgage but had been discouraged when she was told by a friend that banks were unwilling to grant a mortgage to people with her disability (sickle-cell anaemia).

In terms of sexuality, there was an example of a gay man who felt he had been refused a mortgage because of his and his partner's sexual orientation. When he applied the bank asked for him and his partner to take an HIV test. When they refused to do this the bank turned down their application. He felt this had been grossly discriminatory. When he applied to another bank he was given a mortgage, without experiencing any form of discrimination.

As regards ethnicity, an Indian man who is blind talked about how, when he had applied for a mortgage from his bank, it had resulted in him being wrongly accused

⁴⁴ Part III of the Disability Discrimination Act covers any organisation that provides services to the public. Service providers are required to make 'reasonable adjustments' to their services which would otherwise be impossible or unreasonably difficult for a disabled customer to use. This may mean changing a policy, providing extra help to make the service easier to use, or offering the service using alternative means. There are also special rules relevant to particular services, including insurance, which confirms unless justifiable, an insurer should not adopt a general policy or practice of only insuring disabled people or people with particular disabilities on additional or adverse terms or conditions.

of being an illegal immigrant and him having his application turned down. After applying he had been asked to provide his passport by the bank, despite the fact that he had been told that, by law, people who are registered blind are only required to provide a driver's licence to prove their residence in the UK. His passport was being processed at the time by the Home Office, and having been unable to provide it to the bank he received a letter from them alleging he was an illegal immigrant and denying him a mortgage.

Balanced against these experiences of discrimination were the experiences of people who had accessed financial services without having felt they were treated unfairly on account of their disability, or any other factor. Also, people who had felt discriminated against in accessing financial services reported that when they applied to a different financial service provider, they did not experience any of the same difficulties.

6.6 Summary

Despite the generally positive attitudes towards claiming benefits, some negative attitudes were expressed. These appeared to reflect cultural differences between ethnic groups in relation to claiming benefits.

The process of applying for benefits was perceived to be over-complex and time consuming, to the extent that some people were deterred from engaging in the process at all. Language barriers exacerbated the difficulties of the process for people from ethnic minority groups whose first language was not English.

People in the sample reported receiving help or advice in applying for benefits from a range of sources. These included formal sources, such as Benefits Agency staff, GPs, and social workers, and also more informal sources, such as family, friends and voluntary organisations for disabled people. It was clear that these sources of help and advice had often proved crucial in helping people access benefits.

In terms of informal sources of help and advice, disability organisations were widely praised by people in the sample who had accessed them. As well as information about what they were entitled to, people also reported received practical help with completing forms.

Health services were also widely praised for the support and assistance they had offered. Nevertheless, there were those who reported negative experiences. In these cases, people were critical of the service they had received and felt they had been treated differently by health professionals because of their disability, ethnicity, sexuality, age and/or gender.

The information available about services and support for disabled people was routinely criticised as lacking. This was particularly noted at a local level with people reporting being unable to ascertain what, if any, local services were available to them. Information that was provided was also criticised for only being available in English.

There were variable experiences reported of accessing services for disabled people. The role of social workers, and other support workers, was often crucial in accessing services. People did not generally feel they had been treated differently by their social worker because of factors such as ethnicity, sexuality, age or gender.

Among Indian and Pakistani participants some reported reluctance within their communities to access external support or services for disabled people, with families preferring provide support themselves.

A number of problems reported by people accessing housing services. These related to long waiting times and housing that did not meet their needs as a disabled person. Some Indian and Pakistani people had also been critical of housing if it was not large enough accommodate their families, or if it was situated outside their local communities.

Experiences of accessing financial services were limited amongst those who participated. However, where people had accessed services there were reported instances of discrimination by financial institutions on the grounds of disability, ethnicity and sexuality.

7 Exploring disadvantage

This chapter reports findings in relation towards discrimination and prejudice. This includes how discrimination and prejudice are defined and any differences in the extent to which different groups report these experiences. Views about the causes and impacts of discrimination and disadvantage will also be explored. Responses to the concept of 'multiple disadvantage' are also discussed alongside the ways in which this can occur and what this actually means for disabled people from different groups.

7.1 Experiences of discrimination

People gave very varied responses to the question of whether they had ever experienced discrimination or prejudice. There were people from all groups in the sample who did not feel they had encountered these types of experiences as a result of their disability, ethnicity, sexuality, age or gender. This is expressed in relation to ethnicity in the quote below.

'I've never actually had that feeling – because Leicester is very multicultural anyway...I've never been interviewed where I feel threatened by the colour of my skin because a lot of the places I've been to there have been a lot of like Chinese people working there, Asian people, white people, black... In Leicester especially there is a lot of multicultural faces so you know you'd never feel threatened to go to places just because of your colour skin.'

(Male, 24, Indian, learning disability)

Conversely, as has been highlighted throughout the whole of this report, other people took a very different view on this and felt they had experienced clear examples of discrimination relating to one or more characteristics. These incidents have been described in detail in the relevant chapters of this report and will not be discussed again here. These types of experiences, which related to education, employment, accessing services and a multiplicity of others areas of life, were linked to the full range of characteristics explored by this study. Overall, disability, ethnicity and sexuality were all cited with a similar amount of regularity in descriptions of discriminatory treatment and prejudicial attitudes. Gender and age were also

mentioned on occasion and examples of these are also given throughout this report. However, overall, these factors were cited as being relevant only occasionally.

7.2 Views about the nature and causes of discrimination

This section explores how people, who took part in the research, defined and discussed prejudice and discrimination. It also considers any differences in the extent to which different groups within the sample believed they had experienced discrimination and prejudice. In addition, people's views on the perceived causes and effects of discrimination and prejudice are explored.

7.2.1 Defining discrimination

The terms discrimination and prejudice were often used interchangeably. As found previously, these were often not perceived to be discrete categories.⁴⁵ However, an analysis of people's accounts revealed some evidence that these were perceived as being different. Prejudice was often referred to in terms of feelings of 'suspicion' and 'fear' that certain characteristics could arouse in some people. Discrimination was defined as anything which treats certain sections of the community differently from others because of aspects of their identity. People gave numerous examples of what this might involve, such as not getting a particular job or promotion, being spoken to in a disrespectful manner, receiving inferior service in shops, hospitals, benefit offices and so on.

Beyond this, there were thought to be different types of discrimination or different ways in which this can manifest. A distinction was sometimes made between what was described as 'overt' and 'covert' discrimination. Open or overt discrimination was used to refer to things like verbal abuse, name calling or a particular characteristic being cited as the reason for different treatment. Covert discrimination was defined as more subtle incidents of different treatment where the reason for this was not openly made clear.

Sometimes, the link between an experience and a particular characteristic was very apparent. However, at other times this was assumed. Sometimes people were certain which characteristic had underpinned negative treatment or reactions from others even where this might not have been explicitly stated:

'It is an impression, I conclude for myself. They [perpetrators] don't have to say it is because of that. I make conclusions for myself without allowing somebody to make conclusions for me. I can judge a situation for myself.'

(Male, 58, Caribbean, mobility impairment)

Others, however, believed it could be difficult to identify precisely and with certainty what was driving a particular experience or reaction. Some people commented that it was impossible to be sure about the way in which they might have been treated if

⁴⁵ Woodfield K et al (2002), pp.81.

a particular characteristic were not present. This was described by one respondent as *'the subtleties of discrimination'*. For example, an African woman with manic depression described an occasion in which she had visited a hospital voluntarily and had been sectioned by a white doctor *'You've never really got any proof that it would be different for a white person, but it feels unfair.'* A blind Indian man made a similar point in relation to trying to identify why his applications for jobs had been unsuccessful.

'Its very hard, because they don't tell you outright the true reason, but they leave you to feel whatever you want to feel, you know, and you can put it down to two or three things.'

(Male, 45, Indian, visual impairment)

Another type of discrimination which was described by one respondent as 'structural' relates to situations in which it is harder for a disabled person to do things than it is for a non-disabled person. These type of experiences were not related to conscious discrimination on the part of other people, but rather barriers that emerged for disabled people because of the way society is organised and operates.⁴⁶ The sentiment behind words of a respondent from the previous study *'The world is here for able-bodied people, it is not here for disabled people'* was echoed in discussions of this type of discrimination.⁴⁷ This category includes many of the issues around access discussed earlier in this report. For example, a woman who was a wheelchair user said she found that venues, which were not wheelchair accessible *'look as though they don't want us disabled people to come in'*. Another example of this was given by a deaf man who described how frustrating he found the fact that he was unable to use telephone banking to communicate with his bank and so had to go to the branch in person each time. He perceived an assumption of the banks that everyone can hear and use the telephone, and saw this as an excellent example of this type of discrimination.

An example of this structural discrimination was the way in which public transport was viewed as geared towards the non-disabled majority as was discussed in **Chapter 3**. This is expressed below by one wheelchair user.

'But then there's society's discrimination of having accessible buses... but you can't access them because it is a low floor. That means that a walking disabled person who can shuffle up a step can get on, but a wheelchair person can't, so I'm therefore discriminated against from going on public transport. The thing of having to book in advance to go on British Rail to get the ramp, I feel I'm being discriminated against very subtly because if I was able-bodied I wouldn't have to phone up and say can I use the train that day. So to me discrimination can take place for all these reasons.'

(Female, 47, lesbian, white, mobility impairment)

⁴⁶ This confirms earlier research which used the term 'institutional' discrimination: see, Woodfield K et al (2002), pp.82.

⁴⁷ Woodfield K et al (2002), pp.63.

7.2.2 Which groups feel they experience discrimination?

There were some differences in the extent to which different groups included in the sample perceived they were vulnerable to discrimination and prejudice. In particular there was a stark contrast between the black and South Asian groups who seemed to be almost at opposite ends of a spectrum. People from the black groups were much more likely to speak of prejudice and discrimination as being part of their experiences. Indeed for some, discrimination and prejudice seemed to be inexorably bound up with black identity. As one Caribbean woman put it *'I don't think you can be black and not feel or ever experience any form of prejudice'*. People in this group were acutely aware of the ways in which characteristics such as race can be linked to disadvantage. The prejudice and discrimination that black people have suffered throughout history was sometimes mentioned in the context of these discussions. It seems that awareness of prejudice and discrimination historically, had influenced the consciousness of people from this ethnic group.

The South Asian community was much less likely to speak of experiencing discrimination than the Caribbean, African, white and lesbian and gay groups. In particular, older Pakistani respondents often did not feel this had been a factor in their experience and sometimes seemed unfamiliar with the concept of discrimination. In stark contrast to the black group described above, the meaning of the terms prejudice and discrimination sometimes had to be explained in the interviews to older people in this group. As suggested above, the relevance of the concept of 'discrimination' may be, to some extent, dependent upon a certain level of politicisation and awareness of the ways in which discrimination can be an issue. Some of the older Pakistani and Indian people did not have a sense of this as being relevant to their lives.

This may be linked to the fact that some people in this group had very little interaction with the world outside their immediate home, family and religious community as was discussed in **Chapter 4**. Because older people from the Indian and Pakistani groups did not choose to access wider public activities and services are perhaps less likely to feel 'excluded' from these. In addition, this tendency not to perceive discrimination to be a relevant or meaningful concept, may also be linked to the influence of religious belief. The conviction that events are determined by the will of God or Allah can mean people are less likely to question or challenge their experiences or treatment by others. This was evident in the interviews when people frequently cited 'God's will' as being the reason for the things that had happened to them. This is illustrated by the words of one Pakistani woman. *'If things are refused we assume it is not our right, it is God's will, we stay quiet.'*

Age was clearly a significant factor affecting the likelihood of perceptions of discrimination within the South Asian community. The views described above were almost invariably held by older Indian and Pakistani disabled people, many of whom had migrated to this country and did not understand English. These attitudes may have implications for current debates around the existence and nature of social exclusion in relation to people from South Asian groups. However, there was some

evidence that these attitudes are changing and there are generational differences within people from this community. Younger Indian and Pakistani people were much more familiar with the discourse around discrimination. They were much more able to engage with questions about this and hold views and describe experiences.

The experiences and views around discrimination of the white people in the sample probably fall somewhere between the two sets of attitudes described above. People in this group varied considerably in the extent to which they felt they experienced discrimination in relation to their disability. Some did not feel they had encountered this in any area of their lives.

Overall, perceiving discrimination seemed linked to some extent to levels of consciousness about the rights of disabled people and the 'social' model of disability. Those people with this awareness were often involved in disability organisations through work, voluntary work or membership. Some of them were able to identify the point in their lives when they had gained this awareness and spoke of the '*transformation*' that took place in their consciousness as a result of encountering other disabled people and the disability movement. For example, a man who became an access officer for a local authority spoke of how meeting people through his job was the first time he had encountered other assertive disabled people who subscribed to the social model of disability. He believed this experience had completely changed the way he looked at the world.

The lesbian and gay group were also fairly likely to feel they had experienced discrimination and prejudice. Whilst some people were fairly conscious of having suffered discrimination and prejudice in relation to this aspect of their sexuality, overall this was more exceptional. Generally, experiences of this were more frequently mentioned to be in relation to disability than sexuality. Disability was said to have been much more closely linked with experiences of discrimination and prejudice. There were some who did not feel their sexuality had created any particular difficulty or issues. Indeed, as already noted in **Chapter 2**, some people said they did not view their sexuality as being a particularly important part of their identity.

Education and socio-economic position were also believed to be key influences on people's experiences of discrimination. These factors were thought to be strongly linked to the likelihood of being discriminated against and also people's ability to challenge this when it occurs. Some of those who did not feel they had experienced any discrimination attributed this to the fact they were '*intelligent and educated*'. In these cases, education was perceived to increase people's awareness of their rights and of what is unacceptable and to provide people with the confidence they need to challenge this. For example, one deaf woman who was a lesbian recognised she was a member of a vulnerable group yet believed that within this she was privileged. She felt that the fact she had been provided with a good education and had access to resources meant she did not have to '*live on the front line*' and did not have to encounter and deal with hostility.

7.2.3 The causes of discrimination and prejudice

A number of factors were recurrently cited as sources of prejudicial attitudes against others. Overall, the causes of prejudice in relation to disability, ethnicity and sexuality were seen to be very similar.

Ignorance and a lack of awareness were recurrently cited as causing prejudicial attitudes against disabled people, black and minority ethnic people and lesbian and gay people. As one woman put it *'I just assume somebody is ignorant... as in just do not have the fundamental information to make a proper assessment of what is going on'*.

The stigma reported to be attached to disability in the South Asian community was sometimes explained as being linked to these factors. Younger people from this group often saw these attitudes as held by others in their community because of ignorance and a lack of education about disability. This lack of understanding about disability in this community was perceived to have given rise to various misapprehensions. For example, non-disabled people were said to be worried that disability was contagious and they could 'catch' certain conditions from disabled people.

Fear was also thought to underpin discriminatory and prejudicial attitudes. Sometimes this was described as 'fear of the unknown'. It was felt that some people avoid interacting with disabled people because they are fearful of feeling unsure about what to say or what to do and so they avoid this situation rather than confronting it. Similarly, a visually impaired man who was turned down for a job believed this was because his potential employer was 'scared' he would not be able to deal with the need to make reasonable adjustments. Fear of difference was also often cited in this context, particularly in relation to prejudice against lesbians and gay men. Prejudice directed towards lesbian and gay sexuality was thought to be rooted in the perception that lesbian and gay relationships are different and so viewed as a 'threat' to society and heterosexual norms.

The specific causes of 'structural' discrimination which was discussed in Section 7.2.1 were understood as somewhat different. This type of discrimination tended to be attributed to lack of awareness about disability. This lack of awareness was felt to mean that disabled people and the needs of different groups within the disabled community are routinely not considered in the design of buildings or services.

An attitude which was only mentioned in relation to explaining racial prejudice and discrimination was self-interest and greed. This was sometimes believed to be at the root of these types of attitudes, but was not mentioned in relation to prejudicial attitudes towards disability and sexuality. People from black and minority ethnic groups sometimes stated that racism from white people was a result of resentment at the idea that jobs, houses, school places and hospital beds were being taken up by people who had migrated to this country and their families.

'When people are racist towards me and trying to stop me from being in a certain career, or putting me in a career that they don't necessarily think I should be in, it's because I don't want – some of them are thinking why should she have the opportunity when there's many white people who could have the opportunity to do this.'

(Female, 31, Caribbean, sickle-cell anaemia)

7.3 The personal effects of experiences of discrimination and prejudice

Discrimination and prejudice in relation to disability, ethnicity and sexuality were all reported to have similar types of impacts upon people who experienced them. A recurrent factor mentioned by people from all groups was the way in which discrimination and prejudice can affect self-esteem and confidence. The descriptions of these experiences in earlier chapters include a multitude of situations in which people were denied access to education, jobs, promotions, housing, services or treated differently in certain environments due to certain characteristics. People spoke of how these experiences left them 'shy and lacking in self-confidence'.

In addition, some people described how experiences of discrimination and prejudice could cause them to lower their expectations as to the type of treatment they are entitled to receive. One African woman for example spoke of the tendency among people from her community to '*withdraw and accept*' discrimination and prejudice rather than fight or challenge this.

A related consequence mentioned by some, was the way in which these experiences can prevent people from trusting others. This has obvious implications for the extent to which disabled people socialise and interact with others. An Indian woman with impaired vision described how experiencing discrimination made it hard for her to make friends as she found it difficult to trust people and was often suspicious of people's motives. This point was most frequently made by Caribbean and African disabled people. One Caribbean woman for example spoke of feeling '*cautious of white people because you don't know which white person's racist and which one's not*'. Another Caribbean woman described a similar degree of caution because of fear of racial prejudice.

'I always think the worst but I can't help it...I'm sensitive...I'm one of those person, I don't force myself onto people, you have to talk to me first before I speak to you because I am afraid of rejection. I've come up against so much barriers and rejection...I feel I'm not wanted.'

(Female, 60, Caribbean, learning disability)

Another effect of facing discrimination and prejudice was reported to be the way in which this drains energy and physical resources. This impact was mentioned as resulting from all types of discrimination. Disabled people often mentioned how 'weary' they became facing what was described in Section 7.2.1 as 'structural discrimination' or the barriers people face because of the way society is run and

operates. One man with a mobility impairment for example spoke of his frustration '*having to battle as a disabled person all the time*'. The experience of racism was also said to require an enormous amount of energy, both in the handling of the situation itself and then coping with its personal consequences. These findings confirm previous research among minority ethnic groups in Britain which found the experience of encountering racism recurrently reported as 'tiring'.⁴⁸

Feelings of depression were also considered to be a consequence of experiences of discrimination and prejudice. People recurrently described how they had been 'upset' or 'hurt' after these types of experiences. One Indian woman described '*feeling badly inside*'. This type of reaction was particularly associated with overt forms of prejudice such as name calling and verbal abuse. However, these types of feelings were also reported as resulting from experiences where types of structural or covert discrimination prevented people from being given opportunities or accessing services. As one Caribbean woman put it '*It just makes me feel hurt and that I can't do certain things when really and truly I can.*'

Some people said they had become much more defensive and 'aggressive' as a result of experiences of discrimination and prejudice. This was most common among those who had suffered the worst experiences of discrimination and prejudice. For example, older white respondents who had had extremely negative experiences in special schools or in employment sometimes felt these experiences had left them liable to become very aggressive in situations where they perceived prejudice. Although much more exceptional, there were some examples where this had involved physical aggression and people had become violent in response to experiences of discrimination and prejudice. A young Pakistani man who had received verbal abuse from another boy at school reported responding by '*beating him up*'.

The impacts of some of the more extreme cases of discrimination and prejudice had been far more severe. For example a woman who used a wheelchair, who had been subject to ongoing abuse from young people on the estate in which she lived, viewed the results of this experience as affecting every area of her life.

'It's had a very bad effect on my health and mental health the harassment that I've experienced. It has... given me a tremendous amount of stress and the fall out has affected every area of my life, from the financial to the emotional, every area of my life has been devastated with all this. For... ten years... the major thing in my life was housing and not work because the housing problems took over more and more of my life and my energy... and that is what is stopping me having a life, including a working life.'

(Female, 40, lesbian, white, mobility impairment)

⁴⁸ Fenton, S. & Karlsen, S. (2002).

7.4 Multiple disadvantage?

People were asked in the interviews for their views on the concept of '*multiple disadvantage*'. This included whether they thought this was a valid concept, if it was perceived as relevant to their experiences and how this manifested itself and affected their lives.

Responses to these questions varied. There were some that said this idea was not relevant to their lives. Some people did not feel they had encountered discrimination or prejudice related to any aspect of their identity. Others believed that only one aspect of their identity had ever created issues or problems. For example, a deaf gay man who had experienced numerous barriers in searching for work linked to his hearing impairment, thought his sexuality had not ever created any particular difficulty. He did not see his sexuality as a comparable issue.

The concept of multiple disadvantages was questioned by some people. There were those for whom this idea had no resonance and who disagreed with the idea that people might be inevitably disadvantaged by different aspects of their identity. It was said that experiences are a result of the personality of individuals rather than their race, gender, disability or sexuality. For example, some people felt that the greatest determinant of how their disability was treated by others was their own attitude to this.

There were others, however, who clearly found that the concept of '*multiple disadvantage*' had salience to their lives. As with perceptions of discrimination generally, black and lesbian and gay people were much more likely than South Asian people to perceive this as relevant. This was illustrated through the frequent references by people from these groups to themselves as belonging to '*a number of oppressed groups*'. Gender was also a factor here and women from these two groups often also emphasised this aspect of their identity as adding to this combined '*oppression*'.

As suggested by the previous study⁴⁹, on some occasions people had a clear sense of which characteristic was linked to experiences of discrimination or prejudice. People gave examples of numerous incidents in education, at work or in the social world, which were believed to be entirely a result of their disability, ethnicity or sexuality. For example as mentioned earlier, disability was often the only issue which raised problems for lesbian and gay disabled people at school and sexuality was often not thought to have been an issue at this stage. Alternatively, when entering work, disability could cease to be an issue, but people might then encounter intolerance directed towards their sexuality. When people felt they had experienced examples of discrimination linked to different characteristics, they were sometimes able to compare these. For example, some of the Caribbean and African sample commented

⁴⁹ Woodfield K et al (2002), pp.91.

that the discrimination or prejudice they had received in relation to having mental health problems had been much worse than any incidents relating to their ethnicity.

However, for others, the characteristic at the root of these types of intolerant reactions were impossible to unpack. As discussed earlier in this report, it seemed in some cases harassment and abuse were linked to certain combinations of characteristics. People sometimes described this in terms of encountering '*double prejudice*' which related to more than one aspect of their identity.

Ultimately, the issue of whether incidents are linked to one or more characteristic is academic. What is important is that one 'combined effect' of certain combinations of characteristics is the increased possibility of encountering discrimination or prejudice as a result of more than one characteristic which may encounter prejudicial attitudes. This increased likelihood of encountering discrimination and prejudice for certain groups is a cause for concern in the view of the various negative impacts these experiences can have.

Moreover, certain characteristics were *in themselves* also believed to be linked to low self-esteem and self-confidence irrespective of their relationship to experiences of discrimination and prejudice. For example, this report has highlighted the numerous ways in which disability can affect self-esteem, such as through the impacts this can have upon self perception, social activity and social interaction. There was also clear evidence of this in relation to the way that being lesbian or gay can affect self esteem. Illustration of this is provided by the respondent below:

'If you start off as being gay you automatically... think you are a lesser person than a straight person. You are brought up to think that being gay is not as... normal as being straight... it starts from there...'

(Male, 43, gay, white, mobility impairment)

The possession of more than one characteristic which can negatively affect self-esteem is another way in which certain combinations of characteristics can create 'multiple disadvantage'. The combined effects in this area appear to be multiple pressures upon self-identity and self-esteem.

At the same time, being disabled, black or Asian, lesbian or gay was felt to make life more of a '*struggle*'. This was expressed repeatedly in the research. For example, people often commented that disabled people continually '*need to be more assertive*' in a multitude of situations. This assertion was thought to be necessary in all areas of life, for example, education, seeking employment and experiences in work, accessing services and so on. Disabled people were said to constantly face the need to disclose their disability and then assert their needs and capabilities to people such as teachers, employers, friends, service providers, etc. For example, in terms of looking for work, disabled people were said to need to be able to overcome employers' doubts about their ability to do a job and demonstrate how, with the necessary adaptations, they could fulfil required tasks. More broadly, one disabled woman for example, believed that it would have been useful to receive counselling

when she was younger in order to *'raise my awareness of what I was dealing with and what I could do to help myself'*. A similar point is made by the respondent below in relation to the deaf community, and this is reflective of the views of people with other types of disability.

'I think you have to be assertive, not all deaf people are, they'll sort of put up with it, they're not willing to stand up, but - I think deaf people need training, to know how to stand their ground on things, know their rights, know what is acceptable and what's not, they can't just assume that hearing people are right and be passive and get upset and hide themselves away...it does get tiring, sometimes you need a bit of a break, when you can't be bothered facing something or other again, you avoid it, sometimes that happens... but sometimes you have to brace yourself and go in there and keep going.'

(Male, 47, gay, white, hearing impairment)

There was evidence of similar effects in relation to ethnicity and sexuality. Dealing with racism or homophobia for example, was said to require a great deal of assertiveness in challenging this and preventing it from happening or continuing.

Certain combinations of characteristics, then, appear to increase the possibility that people will encounter discrimination and prejudice and can place multiple pressures upon self-esteem. The significance of this would appear to lie in the fact that this pressure upon self-esteem and self-identity must make it much more difficult for people to produce the very assertiveness which is said to be needed by disabled people. It is perhaps this situation and these factors which are central to explaining what the concept of 'multiple disadvantage' means for different groups of disabled people.

7.4.1 Gender

Overall gender was much less frequently referred to as being relevant to explaining experiences of discrimination. However, there were some occasions in which women found their gender had been a factor, which disadvantaged them. For example, one woman said she felt that being deaf was harder for her because she was female than it would have been had she been male. She said she was 'patronised' being a deaf woman and thought that if she were male she would have *'more gravitas'*.

A gender dimension was also associated with the point made above about the need for disabled people to be more assertive. The view was expressed that it is much easier for men to be assertive in the way disability can necessitate than it is for disabled women. This is because there is felt to be a degree of 'social pressure' which mitigates against women developing this self-assertion. It was thought that whilst it is socially acceptable for men to be assertive, if women were to demonstrate this trait they would be viewed negatively as *'a stropmy cow'*.

As discussed earlier in this report (Section 3.2.1), gender was reported to be a strong influence on experiences within the South Asian community. South Asian women, in particular, believed that the restrictions relating to gender within their community were significantly exacerbated by their disability.

'Gender and the Asian community, we know that's an ongoing problem. Women are treated as second class historically in the Asian community. It's only nowadays that you see Asian women doing more productive roles in society. And if you're an Asian disabled woman I think that's twice the hammer on the head, to be honest with you. I think change needs to come from within the Asian community first... I don't think that's going to happen overnight.'

(Male 33, Indian, mobility impairment)

Or another way of putting this was that the issues relating to disability and ethnicity were significantly emphasised by gender.

'I think there's definitely a strong point there, that if a person is disabled, you have a set of problems. In addition to that, if you're ethnic – OK – your problems get doubled – right – you can't help it. In addition to that if you're a woman from an ethnic background who is disabled, bloody hell, you've had it!'

(Male, 45, Indian, visual impairment)

Disabled women from these South Asian groups were thus believed to experience a degree of 'multiple disadvantage' within their own community. Indeed, some women from these groups commented that the discrimination they suffered within their own community surpassed anything they had encountered in the wider society.

7.4.2 Age

The role of age in experiences of discrimination received mixed views. One perspective was that age increases the vulnerability of disabled people and this can make them a target for crime such as theft and mugging. Disabled people were thought to be particularly vulnerable to becoming victims of crime, a risk which was perceived to increase with age.

Among the Indian and Pakistani groups there was some conflicting evidence about the role of age as a source of disadvantage or discrimination. Some believed that disabled people's experiences could improve with age because in the South Asian culture age is equated with experience and respect. However, this did not always seem evident in the experiences of some of the older people from this group. There was a clear sense among some of feeling a burden to family and of no longer being of any use. Some of those who had experienced late onset of disability showed clear signs of distress when being asked how their current quality of life compared with what they had experienced when they were younger.

7.4.3 Other factors

More exceptionally, people in the sample highlighted other characteristics, which they believed created greater issues in their lives than their disability, ethnicity, sexuality, gender or age. One woman for example commented that the fact she was working class had been one of the biggest impacts on her experiences in education and employment. She felt that this characteristic had caused her to struggle to a much greater degree than anything she had experienced relating to the fact that she was disabled or a lesbian.

In other cases people described how other factors could combine with disability to cause difficulty. Socio-economic position and income level was a key factor here. For example, the experience of being a disabled person was believed to exacerbate the problems generally associated with surviving on a minimal income.

'If you're blind - you also need to make up for it with support - increasingly, some of that support is technical. That equipment over there, I can put a book in and turn it into speech and read it without having to look for it in Braille. In other words, I can go to Smiths and buy a book and read it, and for the first time in my life - I've only had that equipment for about three years - it's now at a cost that somebody like me can just about afford. Somebody like me, I mean somebody on an occupational pension, but (for) the blind person who's not working, it might as well not exist - he can only read about it, he can only hear about it.'

(Male, 69, white, visual impairment)

Another final characteristic which was mentioned particularly by some of the Caribbean and African women was the effects of being a female parent where doubts were sometimes raised by employers because of caring commitments. As had been discussed in **Chapter 4** this was viewed as sometimes being an issue in seeking work and when in employment.

7.5 Summary

People differed as to whether or not they believed they had experienced discrimination or prejudice. Across all groups were people who reported discrimination as well as those who did not. Overall, disability, ethnicity and sexuality were all cited with a similar amount of regularity in descriptions of discriminatory treatment and prejudicial attitudes. Gender and age were also mentioned on occasion, however, overall these factors were cited as being relevant much more occasionally.

The terms discrimination and prejudice were often used interchangeably. As found previously these were often not perceived to be discrete categories. Discrimination was defined as anything which treats certain sections of the community differently than others because of aspects of their identity. A distinction was made between 'overt', 'covert' and 'structural discrimination'.

A number of factors were recurrently cited as sources of prejudicial attitudes against others. Overall the causes of prejudice in relation to disability, ethnicity and sexuality were all thought to be very similar. Ignorance or a lack of awareness were prime factors, fear was also believed to underpin discriminatory and prejudicial attitudes.

It was not always easy for people to ascribe the links between an experience of discrimination or prejudice and specific aspects of their personal characteristics. In some cases, the links were made overt by those perpetrating the different treatment, on other occasions *'the subtleties of discrimination'* meant disabled people had to make assumptions about why they had experienced different treatment.

The extent to which different groups included in the sample considered that they were vulnerable to discrimination and prejudice varied. People from the black groups were much more likely to speak of prejudice and discrimination as being part of their experiences. The South Asian community was much less likely to speak of experiencing discrimination than the black, African, white and lesbian and gay groups. Also within this group, older people spoke less commonly of experiencing discrimination. The lesbian and gay group were also fairly likely to feel they had experienced discrimination and prejudice. Whilst some people were fairly conscious of having suffered discrimination and prejudice in relation to this aspect of their sexuality, overall this was more exceptional. Generally experiences of this were more frequently stated in relation to disability than sexuality.

The tendency to perceive or acknowledge discrimination seemed linked to levels of consciousness about the rights of disabled people and the 'social model' of disability.

Education and socio-economic position were considered as key influences on people's experiences of discrimination. These factors, along with age and gender, were believed to be strongly linked to the likelihood of being discriminated against and also people's ability to challenge this when it occurs. These personal characteristics were seen by some to be just as important in heightening or lessening vulnerability to discrimination and disadvantage as disability, ethnicity and sexuality.

Discrimination and prejudice in relation to disability, ethnicity and sexuality were all reported to have similar types of impacts upon people who experienced them. Impacts included: lowered self-esteem and confidence; lowered expectations as to the type of treatment you are entitled to receive; decreased trust in others with resulting impacts on people's willingness to socialise and interact; and, finally, debilitating effects on physical and mental health.

The concept of *'multiple disadvantage'* received mixed responses. Some people did not feel they had encountered discrimination or prejudice related to any aspect of their identity. Others thought that only one aspect of their identity had ever created issues or problems. There were those for whom this idea had no resonance and who

disagreed with the idea that people might be inevitably disadvantaged by different aspects of their identity. Others, though, believed the concept had salience to their lives. As with perceptions of discrimination generally, black groups and the lesbian and gay group were much more likely than South Asian groups to perceive this as relevant.

Certain combinations of characteristics appear to increase the possibility that people will encounter discrimination and prejudice which can place multiple pressures upon self-esteem. The significance of this would appear to lie in the fact that this pressure upon self-esteem and self-identity must make it much more difficult for people to produce the very assertiveness which is said to be needed by disabled people.

8 Strategies for the future

This chapter will explore disabled people's views about progress made towards securing equal rights in this country in recent decades. This will be followed by exploration of attitudes towards current government policy and initiatives in relation to the disabled community. In the light of this, the views of disabled people about current areas of policy and practice considered to need prioritising will be discussed. The chapter will finish with some concluding thoughts about the value of placing the concept of multiple disadvantage on the policy agenda.

8.1 Changing attitudes in society towards disability, ethnicity, age and gender

This report has referred to the significant amount of change which was believed to have occurred in British society in recent decades. Participants believed that a great deal of progress had been made in relation to the position of disabled people in society and that the opportunities for disabled people had substantially increased.

In particular, as earlier chapters have highlighted, many of the worst experiences in relation to education, employment and other areas of life, date from a different era in terms of the rights and treatment of disabled people. The most negative accounts were provided by older respondents whose experiences date back in some cases over 50 years ago. These experiences are clearly a product of a very different time and provide powerful refutation to a bygone age. This is probably largely a consequence of the lack of disability awareness in schools and amongst employers up until recent years. The extent to which people perceived significant change, highlights the progress believed to have been made in these areas.

As a result, the experience of growing up black or Asian or lesbian or gay in this country was considered to be very different now to how it had been 30 or 40 years ago. The older lesbians and gay men in the sample gave accounts of growing up unaware of lesbian and gay sexuality and failing to recognise this or felt able to deal with this. It was thought that the greater awareness about lesbian and gay sexuality in the present day made these experiences less likely. This seemed substantiated by accounts of the younger lesbians and gay men included in the sample who had often

been conscious of their sexuality for some time and did not appear to have acted to suppress or deny this in the same way. This appears linked to cultural change in British society and the growth in profile and acceptance of lesbian and gay sexuality which has occurred in recent decades.

Nevertheless, there was a widespread belief that considerable barriers still remain in relation to the position of disabled people in society. As this report has highlighted throughout, people from all groups believed that a great deal of prejudice and discrimination still remains against disabled people, black and minority ethnic groups and lesbians and gay men. Obstacles which relate to gender and age were cited less frequently and generally viewed as less significant than those caused by these other factors.

There was a perception among members of the sample that the disabled community, the minority ethnic community and the lesbian and gay community are all engaged to some extent in separate struggles for equality. Some people commented that progress in some areas had been faster than others. Views were expressed on the comparative positions of disabled people, lesbians and gay men and people from ethnic minorities on the road to equality. One view was that the rights of lesbians and gay men were some distance behind those of other groups. This perspective tended to be voiced by those who thought that being lesbian or gay had had more of an 'impact' upon their lives than other characteristics. Some lesbian and gay people felt that the erosion of prejudice and discrimination was less advanced in relation to this area of their lives than other areas. This is illustrated by the views of the woman below.

'I'm more in touch with the sexuality side of my life than disability. That's what stops me marrying my partners, that's the one that stops a lot of my legal rights, whereas the disability side of my life is something where I have more awareness about what I'm entitled to... There are more people fighting against my rights as a gay person than a disabled person.'

(Female, 25, lesbian, white, hearing impairment)

There was a consensus that change would continue to occur over time. However, some commented that there was still a long way to go. Some disabled people were certain they were unlikely to experience the removal of all obstacles to access and equality in their lifetime.

8.2 Views about current policy and provision for disabled people

This section explores views on current government policy and provision in relation to disabled people. It will consider views about the levels of support and help that are available to disabled people, attitudes towards employment-related schemes for disabled people and the Disability Discrimination Act.

The extent to which people were aware of current policy initiatives or had views in this area varied greatly. Unsurprisingly, disabled people who were involved in disability-related charities and organisations often had the most informed views about current policy in relation to disabled people. Others, however, had very little awareness of the nature of government policy in these areas and sometimes did not think that anything was being done to help disabled people. Again, as in relation to the discussion about discrimination in Section 7.1.2, older people from the South Asian groups were least likely to be aware of current policy initiatives and have strong views on this. People from this group often expressed the view that they and people from their community '*did not know about such things*'. Comments from this group tended to be much narrower in scope and related to specific benefits or types of assistance they had been able or unable to access.

8.2.1 Views about levels of support and help available to disabled people

People were asked for their views about the levels of support and assistance available to disabled people. Among those with some awareness of policy and provision aimed at disabled people a recurrent criticism was that this was inconsistent. Current provision for disabled people was perceived to be 'patchy'. People perceived that the services people received were often determined by what was available in the area in which they lived rather than by people's needs. Respondents gave numerous examples of being denied much needed types of help or support which were said to be available to disabled people in other areas, for example, electric wheelchairs, handrails and home help and care. This was said to be unfair and it was argued that disabled people should be able to gain access to the same types of help and support. It was thought to be 'wrong' that the quality of provision someone received was determined by the area in which they lived.

In addition, another area of inconsistency that people highlighted was the level of support and help available to people with different types of disability. Provision for some disability groups was considered to be much better than that for others. In particular, people with mental health problems often felt that there was less help available to them than there was for people with other types of disability such as those who were wheelchair users. For example, one area which received criticism was the lack of supported housing or residential care available. One man was very critical of the way that 'half-way houses' offering support to those leaving hospital or psychiatric wards had all been closed in his area and this type of assistance was no longer available.

8.2.2 Employment-related schemes for disabled people

The idea of specific support and targeted programmes to assist disabled people to start or return to work was strongly supported by all groups in the sample. Indeed, assistance to enable disabled people to enter work was considered to be one of the most powerful ways to improve the quality of life of disabled people. In particular, some of the younger people from the South Asian groups believed this was very

important because disabled people from their community who were able to find work would achieve financial independence from their families. In addition, the presence of disabled people in the labour force was argued to be valuable in changing attitudes towards disability in wider society.

Some people in the sample were entirely unaware of schemes such as New Deal for Disabled People (NDDP) and were surprised that this type of provision existed. A degree of frustration was expressed about the fact that more had not been done to make them aware of programmes which might be extremely beneficial.

There was also evidence of a large amount of misunderstanding about the requirements of NDDP. Some people, for example, thought that they were not eligible to participate in this '*because it was only for young people*'. As a result of discussing the programme in the interviews, a number of people said they planned to visit their local Jobcentre to find out more about the scheme and how they could take part.

As **Chapter 5** has discussed, people were often very positive about the support and new skills they had acquired as a result of participating in NDDP. Some criticisms were however voiced about the perceived lack of support available on completing the programme. Some people felt frustrated by the fact that despite gaining new skills through NDDP, they had been unable to find work after finishing the programme. Whilst this difficulty in finding work was often attributed to factors such as discrimination, it was sometimes believed that more support could be provided by the programme to help participants move into work.

Another, more exceptional, criticism of NDDP was made by a disabled African woman who had experience of the programme as an employer. She felt that the lack of support for employers provided by the programme made it very difficult for small business to take on disabled employees.

'I used to have a nursery... I joined the New Deal... and people with disability were having to come to me, and I personally, as a disabled person, am turning them away as well, because of ...the financial status... in order to allow somebody with disability to come and work for me I need to adapt my property, and if the money is not there then ...I'm not able to provide for them because I'm private, there are no grants for - at the time there were no grants for sole traders or - you know, there's nothing like that, ... There should be - in order for them to be equal opportunity employers ... then they won't discriminate against people who have disabilities. I have done it - even though with a disability, I have had to discriminate, you know.'

(Female, 38, African, mobility impairment)

8.2.3 The Disability Discrimination Act

Views about this legislation in this study very closely echo views outlined in the previous study. Overall this legislation was welcomed and the work of the Disability Rights Commission in representing the rights of disabled people received favourable

comments. This said, however, the legislation was considered weak and a '*tokenistic gesture*' and a number of people commented that it should '*be given more teeth*'. Despite limited awareness of how DDA legislation can be enforced, people commonly stated that the government should be doing more to provide financial and practical backing to ensure that bodies such as the DRC can enforce the DDA legislation. In particular, the legislation was perceived to be ineffective in one of its main objectives of ensuring that employers provided disabled people with the necessary adaptations in the workplace. Other aspects of the legislation, such as the regulations in relation to access on public transport, also came under criticism. The perception that only new models of buses and trains need comply with access requirements was seen as evidence that the legislation was ineffective. One visually impaired man commented that if one of his friends in a wheelchair wanted to get on a bus he would have to wait 26 years which was the current life span of the models of bus used in the area in which he lived!⁵⁰

8.3 Ways forward and strategies for the future

This section considers disabled people's views about priorities for policy and legislation. In the interviews and group discussions people were asked for their views about government policy and legislation and for suggestions about what needs to change.

Substantial differences were apparent in the extent to which the different groups included in the sample engaged with these questions. In particular the white group and lesbian and gay group often had much to say on these issues. Another group with particularly strong views, as mentioned above, were those people who worked in disability organisations or were active in the disability community. For example, issues such as access for disabled people or raising awareness of disability were sometimes areas in which people had worked or campaigned. Again, older people from the South Asian community often had little to say on this. There was a sense from some in this group that their preoccupations were becoming less focused upon life and more upon death and what lay beyond. The influence of religious belief was often predominant in responses to questions about the future. This perspective is reflected in the words of an elderly Pakistani man who had suffered a stroke. '*The*

⁵⁰ Where a disabled person considers they have been discriminated against, they can raise their complaint directly with the employer or service provider to see whether the issue can be satisfactorily resolved. If this is not successful, when the complaint is about access to services they may bring civil proceedings in the county court. In employment situations, they may make a formal complaint to an employment tribunal. Disabled people, employers or service-providers wanting more information about their rights and duties under the DDA should contact the Disability Rights Commission (DRC) on their Public Helpline 08457-622-633. The DRC's role includes assisting disabled people to secure their rights and arranging legal advice or help where appropriate. Their website can be found at <http://www.drc-gb.org>

time to think was before, but there is no time to think now, it is time to remember Allah and worship.'

8.3.1 Legislative change

Views about the rights of disabled people largely mirrored those reported in the previous study⁵¹. People from all groups stated that disabled people should have the same rights as non-disabled people in order to secure equality of opportunity. Some argued that specific changes to legislation needed to occur to ensure this. It was believed that the rights of disabled people should be more forcibly enshrined in legislation and new legislation should be introduced to help secure equal opportunities for disabled people. For example, among the deaf people included in the research, the need for recognition of BSL as an official language was recurrently emphasised as long overdue.

Another suggested improvement was in relation to taxation laws for disabled people. Whilst initiatives such as the Disabled Person's Tax Credit were received positively by those who were aware of this, it was felt that more could be done in this area. Disabled people were thought to incur additional costs as a result of their disability and believed the state should do more to off-set these by providing additional tax relief to disabled people. One African woman with a mobility impairment suggested that there should be a specific tax code for disabled people which entitled them to a reduced level of taxation.

The lesbian and gay sample highlighted a number of areas of legislation which were considered to be priorities for change. These confirm the findings of research conducted in 1995 in relation to this issue; suggesting that not a great deal has changed in views on this topic in the succeeding years.⁵² The right to nominate same-sex partners as next of kin was particularly emphasised as a priority by those with chronic or degenerative illnesses. This issue was thought to have implications in a range of areas. One of these was hospital access. For example, a lesbian woman who was terminally ill with lung cancer was very distressed by the possibility that her daughter, who would be defined by law as her next of kin, might be able to circumvent her partner's wishes in relation to her own care. Other issues which were mentioned related to the execution of wills and a deceased person's estate. The woman in the previous example was equally concerned, and angry, about the fact that her partner would not be given the same status in the event of her death, as would a partner in a heterosexual marriage. An additional issue raised in the context of these discussions was the entitlement of same-sex partners to pension rights. Finally, the repeal of section 28 was another issue often mentioned by the lesbian and gay sample as being a matter of legislative priority.

The need for legislative change was mentioned very infrequently by people from the minority ethnic sample. It is difficult to say why this was with any certainty. It is

⁵¹ Woodfield K et al (2002), pp.188.

⁵² Snape, D, Thompson, K & Chetwynd, M (1995).

possible, however that this is linked to the lack of awareness about legislation and policy in relation to disabled people evident among older people from the South Asian community which was mentioned above.

8.3.2 Raising awareness

Strong support was given to the idea that society needs to change if disabled people are to have equal social rights. As found by the previous study, one of the most frequently mentioned areas in which it was felt that there needed to be social change, were levels of awareness about disability among non-disabled people.⁵³ Among all groups in the study there was a common emphasis on improved awareness and understanding and the need for a renewed drive to create this. This awareness, they thought, ought to include providing understanding about different disability types and what it means to be disabled. It was also felt that public awareness needed to be raised around certain types of disability felt to be relatively unknown or misunderstood. The disabilities frequently mentioned in this context were epilepsy, dyslexia, mental health problems and sickle-cell anaemia.

The importance of focusing on the young was thought by some to be the most effective way of changing attitudes. Children were believed to learn prejudicial attitudes from others, rather than possess these innately. So it was thought that teaching young people about disability at an early age might prevent the development of negative and discriminatory attitudes. As mentioned in **Chapter 4**, educating disabled children in mainstream schools was cited as one way of teaching non-disabled children about disability. In addition, those with hearing impairments thought that BSL should be taught in schools as a way of raising awareness about deaf people among the non-disabled population.

Some people believed very strongly that all those involved in delivering services should receive disability awareness training and be made to understand the perspectives of people with different types of disability. This was considered likely to have a positive effect in eroding 'structural discrimination' and preventing the establishment of services, systems and procedures that unwittingly excluded disabled people. The respondent below, who had a visual impairment, illustrates this point in describing his attempts to raise awareness about blind people.

'I ... put a blindfold on them and I give them a piece of paper and say: 'Can you read that, please?'... and I say: 'Well, you know, that's the experience a blind person has every time he finds a printed piece of material through his letterbox, and we would like... you to do different things for us, we'd like you to put your material on floppy disks, 'cos a lot of us have computers now, we'd like you to provide some Braille stuff for us.'

(Male, 69, white, visual impairment)

⁵³ Woodfield K et al (2002), pp. 202.

It was also believed that awareness needed to be increased in wider society about the discrimination and disadvantage that people with different types of disability can encounter. This was viewed as important in changing attitudes and increasing public understanding about the objectives of facilities, services, and initiatives aimed disabled people. Non-disabled people were sometimes perceived as resentful of these type of facilities seeing them as 'special treatment' and failing to understand that the aim of this type of treatment was simply to create equality of opportunity. As one woman put it *'you need to get the message across that disabled people just want to be the same as everyone else.'*

Some of the younger people from the South Asian community thought the most effective way of helping disabled people within their community was attempting to change attitudes towards disability. It was felt that this required a long-term plan to increase understanding and work to reduce the stigma attached to disability.

'If you're trying to make a difference to the Asian or black and ethnic minority communities as regards disability, look at changing the attitudes rather than just... – just giving them benefits. That's highly important. Change the attitudes of that community towards disability. It's a tough task, but that needs to be done before you're going to make any positive long-term change.'

(Male, 22, Pakistani, mobility impairment)

Similar points were also raised in relation to raising awareness about the types of discrimination people who were lesbian and gay or from black and minority ethnic groups can encounter. A greater public understanding about the disadvantage that can be linked to different characteristics was thought necessary to augment policy and legislative change in these areas.

8.3.3 Increased funding in order to provide necessary adaptations and support for disabled people

The importance of funding to improve access was recurrently emphasised. A multitude of examples were provided of the types of access and adaptations perceived to be necessary for disabled people and which it was thought should be routinely provided. For example, it was felt that ramps on public transport should be automatically provided by different types of transport providers and that these types of adaptations should not have to be requested specifically. Other examples were the provision of more disabled toilets and better wheelchair access in shops and public buildings. Visually impaired people emphasised the importance of brightly coloured railings and signs which were tactile as well as visual. Alternatively, deaf people stressed the necessity of visual stimuli in accompaniment to sound, such as fitting fire alarms in public spaces with flashing lights. It was felt that structural barriers, such as poor physical access to public transport, could and should be overcome with additional and sustained expenditure from government and other institutions.

The types of personal adaptations and support mentioned above were known to be available to disabled people, but, provision was felt to be inconsistent and said to

need to be more comprehensive. Consistency in provision was viewed as essential to prevent transitions in life such as moving jobs, or moving on to a different university from causing a disruption in the accessibility of vital support.⁵⁴ For example, deaf people often emphasised the necessity of note taking help in education because of the difficulty in lip reading and note taking at the same time. However the variability of this provision across educational institutions was considered to be a significant barrier to learning for this group.

One of the most significant obstacles to these sorts of provisions was viewed to be a lack of funding. It was consistently stated that disabled people were denied the adaptations they needed largely because of their cost. For example, a deaf man who worked for a disability charity felt that BSL interpreters were often not available to deaf people because these types of organisations could not afford to provide them. Consequently, there was a strong view that funding should be put in place to ensure that disabled people had access to the adaptations they needed in education, work or other areas of their lives.

The wider availability of independent living support was also cited by some. This was generally perceived to be very valuable as has been discussed in **Chapter 6**. Some disabled people expressed the wish for a greater degree of this type of support. In cases where people were currently provided with support from family members, people sometimes expressed a preference for reducing the level of support received from their family.

Beyond this, people felt that there needed to be a recognition that providing disabled people with the necessary adaptations and equal opportunities although expensive, is ultimately worthwhile if a longer-term view is taken. People who worked for disability organisations often had a professional perspective on these issues as well as a personal one and this could give rise to strong views. One of these related to the need to take a longer-term perspective. This was thought to have implications for funding. As put by one man *'don't just put money into 3 year grants, look at sustainability for the organisation. Look at the long-term effect on that community'*. A similar point was made by the following respondent in relation to visually impaired people, although the sentiment was echoed by people with other disability types.

'And what Government needs to understand is this isn't gonna be done on the cheap – [it] is going to cost money initially to provide integrated education with support services, to provide support for individual blind people, so that they can purchase the equipment, so that they can employ readers – they need to pay people to read material to them... they need to provide that money... [But] our argument is there's a tremendous saving in the long-term because... more and more blind people are going to be at work ... so not only do they pay tax,

⁵⁴ Research recently commissioned by DWP on 'The provision of support and services to disabled people' is currently looking specifically at these issues.

but they're not living on benefit. So we believe that it is morally right to support them, ... but it is also economically prudent to support them 'cos it's going to save money in the long-term. But it is a long-term... and long-term spending of money isn't usually very popular with voters, people want instant results.'

(Male, 69, white, visual impairment)

8.3.4 Integration of disability into the mainstream

Another issue which is linked to the point made above about raising awareness, is the importance of disability issues being seen as a mainstream rather than a specific issue. It was felt that issues relating to disability should be considered as a matter of course in the formulation of policy, provision of services and in other areas, rather than viewed as being a separate or side issue. So for example, there was strong support for the idea that architects and those who design buildings be compelled to consider access issues at the early stages of design and planning as a matter of course.⁵⁵

Disabled people in the white groups often were opposed to disabled people being catered for exclusively by specific services as this was thought to allow mainstream organisations to avoid doing anything about disability, due to the assumption disabled people were already catered for. For example, some contended that disabled people should be able to access training opportunities in the same way as other people and argued strongly against the idea of special training schemes for disabled people.

The media was perceived to have a strong role to play in this area by helping to 'normalise' disability and make it more of a mainstream issue through regular inclusion of disabled people. This issue was explored in the previous study⁵⁶. For example, recurrent comments were made about the infrequency with which disabled people were included in television programmes such as soap operas.

8.3.5 Consult and listen to disabled people

One frequent source of frustration mentioned by disabled people was the tendency for non-disabled people to make assumptions about their needs and capabilities without asking disabled people themselves. This was perceived to happen on various different levels within society. At an individual level, people recurrently

⁵⁵ Part M of the Building Regulations in England and Wales require reasonable provisions to be made for disabled people to be able to gain access to and to use most new buildings and extensions to buildings, other than dwellings, which include a ground floor. An amended Part M will be designed to supplement the final phase of Part III of the DDA which comes into force on 1 October 2004, and requires service providers to tackle the physical features of their premises which would otherwise make access impossible or unreasonably difficult for disabled customers.

⁵⁶ See Woodfield K et al (2002), pp. 41.

highlighted the frustrations associated in situations where teachers, employers, social workers etc made decisions about what they could do or what they needed without asking. This was perceived to be patronising as expressed by a Caribbean woman talking about the attitude of her employer:

'They make decisions for you based on the fact that they think they know what you can cope with and what you can't cope with. It must be based on some kind of stereotype, because I haven't forwarded that information for them to make that decision for me, you know, without consulting me...and the stereotype or typical [view] is that we haven't got the abilities or capabilities to the full potential of somebody who's able bodied. So therefore we're treated differently, like children so to speak'

(Female, 65, Caribbean, heart condition)

These types of attitudes and behaviour were also perceived to happen on a much broader level in terms of the formulation of organisational and public policy. People from all groups called for the heightened involvement and consultation of disabled people in the formulation of all levels and types of policy.

'There's some very good sighted people pontificating about blind issues – [but] always try to have it supported and backed by people with the experience of being blind - the blind themselves - it is we really who know. I wouldn't pontificate about what wheelchair-users need, as I don't know. That's my message to policy-makers - listen to us - listen to us.'

(Male, 69, white, visual impairment)

8.3.6 Involve disabled people in delivering services

A closely related point was made repeatedly by people from all groups who objected to the low numbers of disabled people involved in delivering both disability and mainstream services. This was viewed as a significant missed opportunity. Involving disabled people in delivering services was thought to be a particularly effective way to ensure better treatment and understanding of disabled service users. Some people made the point that this was entirely logical in that *'no one but a disabled person can fully understand how the environment disables them'*. Involving disabled people in designing and delivering services was suggested as one way of overcoming the 'structural' discrimination existing in society.

In particular, disability charities and organisations came under vociferous criticism for their failure to include disabled people among their staff and management. A significant amount of frustration was expressed around this issue for two main reasons. Firstly, as mentioned above, it was felt that the perspectives of disabled people were best appreciated and understood by disabled people themselves. There was a view that many of the non-disabled heads of the large disability organisations *'know nothing of what they are talking about'*. Consequently, the employment of disabled people by disability charities was thought to make sense on the grounds of efficacy. Secondly, disability charities and organisations were also felt to have a role

to play in providing a model of what good practice in relation to employing disabled people would look like.

[Disability organisation]... do employ some blind people... I want to be fair, but if a prospective employer found out that they only employ 7%, that only 7% of their employees are blind, I think they'd be entitled to say: 'If you can't employ any more blind people, why should you expect us to do so?' And that I think is another barrier. Their argument against employing more blind people is: 'We employ the best people for the job'. And I say to them if you're saying that you can only find 7% of such a large workforce, you really are talking nonsense - there must be more than that - and if there isn't, then we really need to get extremely worried.'

(Male, 69, white, visual impairment)

8.3.7 Recognise the diversity of disabled people

This point was thought to have a number of implications for policy and the delivery of services. Firstly, in relation to the point above, it was said that it was important to involve a diverse range of disabled people in delivering disability services etc. It was felt that access officers and the people staffing disability services were always 'white and English' and that they needed to reflect the diversity of the disabled population. This was considered to be crucial in increasing the take-up of disability services by people from black and minority ethnic groups.

People argued that effectively recognising the diversity of disabled people might include providing specific or targeted services. This point was made particularly by ethnic minority disabled people who sometimes differed substantially from white respondents in their preference for specific services. These include, for example, disability centres or groups aimed at people from a specific ethnic group and ethnic matching in the provision of independent living support and home helps as has been discussed in **Chapter 6**. The importance of providing specific disability services was highlighted earlier in this report in **Chapter 3**. It was thought that providing targeted and specific services can make disability organisations and services more accessible to some groups. For example, it was suggested that older people from South Asian groups were more likely to use culturally specific services and would not attend mixed race disability groups.

The wider availability of these type of services may increase the numbers of people able to benefit from the positive impacts these experiences are reported to provide. It is important to remember that the majority of this sample was drawn from disability organisations and so predominantly includes disabled people who were in contact with these type of organisations. Undoubtedly there must be a group of disabled people not in touch with these services whose experiences are largely unreflected in this study and who could benefit from this type of service. Some sample members who worked within specific disability groups had a great deal to say about the effects these services can have upon the quality of life of disabled people.

There was also thought to be a need for attempts to remove the obstacles in accessing services reported as faced by people from black and minority ethnic groups. The way in which fear of discrimination, language barriers and cultural differences can create barriers have been discussed in **Chapter 6**. These issues were felt to require initiatives designed to increase awareness of available services among black and minority ethnic groups and erode barriers to take-up of these services.

In addition, there was a view that there is a tendency for all disabled people to be grouped together in policy terms. This was said to be inappropriate because the disabled community contains the same degree of diversity as the general population. The assumption that because people share the characteristic of disability, they share other similarities was resented by disabled people.

A far more exceptional view was expressed by some older African and Caribbean disabled people who had migrated to the UK who said that as they had become older they felt an increasing desire to move back to their country of origin. They would like government assistance to enable them to return. This feeling was prompted by changes in circumstance when people's children and families had become independent or moved away or where their disability had become more severe or prolonged. For example, a handful of disabled people with mobility impairments and conditions such as arthritis and rheumatism often felt the warmer climate in Africa and the Caribbean would lessen the pain they experienced and improve quality of life. Often in these cases financial obstacles and a lack of resources were perceived as the main obstacle to leaving the UK.

8.4 Conclusions - placing the concept of multiple disadvantage on the policy agenda

This report has highlighted that the concept of 'multiple disadvantage' is meaningful to many disabled people from different groups, although there are some for whom this concept had no salience. Section 7.4 explored what this actually means for people's lives and concluded that for some, the reality of multiple disadvantage is a situation of multiple pressures on self-esteem, within a context of possessing more than one characteristic deemed to make life more of a 'struggle' and create the need for constant self-assertion. Obviously these two conflicting pressures are self-reinforcing. Low self-esteem undermines the ability of disabled people, black and south Asian people and lesbians and gay men to demand equal treatment, highlight ways in which services are not accessible, convince potential employers of their capabilities and so on. Whilst on the other hand, failure to assert one's entitlement to equal treatment and successfully challenge discrimination and prejudice can exacerbate already low self-esteem.

The compounded degree of disadvantage experienced by some people in this study unarguably confirms the decision to place multiple disadvantage upon the policy agenda. However, as this report has shown, experiences of disadvantage and discrimination are by no means inevitable for people with certain combinations of

characteristics. There were people included in this study for whom this concept had no relevance and who did not feel that any aspects of their identity had created problems in any areas of their lives. Moreover, neither should the concept of disadvantage be viewed as static or fixed. The nature of the interactions people make and the reactions they experience can change over the life course as a result of a whole range of factors.

The question of who it is within certain groups who experience these combined effects is of course crucial. **Chapter 7** has thrown some light on this, and the evidence in this research suggests that disabled people, particularly from the Caribbean and African and lesbian and gay groups, had been most affected. Among these groups, older people tended to have had the worst experiences.⁵⁷ Among the South Asian disabled people conversely, the idea of disadvantage was unfamiliar and not thought to be relevant to older respondents, although younger groups were more likely to engage with this and perceive it as being relevant to their lives. However, a much more important factor in differentiating those who had experienced disadvantage from those who had not, which cuts across all of the groups included in the study was education levels and socio economic position. Those who had not received opportunities to gain a good schooling, qualifications, develop careers and were on a low income, were more likely to perceive disadvantage in their past and current experiences. Moreover, this was considered to be self-perpetuating in that early experiences of disadvantage in relation to school or work can determine life chances and limit opportunities for progression and change.

The findings from this research has provided overwhelming evidence about the ways in which disability, ethnicity and sexuality can be linked to experiences, which are on one hand more difficult and challenging, while on the other can erode self-esteem. **Chapter 7** has discussed the way in which disabled people were perceived to constantly need to be more assertive in all areas of their lives. An effective policy response to this situation, perhaps requires a two pronged approach. The first of these relates to the need to change society in order to reduce the structural barriers that disabled people, black and minority ethnic people, and lesbian and gay people encounter. This also needs to be underpinned by challenging attitudes and raising awareness to reduce the possibility people will encounter more overt forms of prejudice and discrimination. The message and suggestions for 'ways forward' discussed in the previous section can all be seen as contributing to these objectives in different ways.

Secondly, the need to help and support disabled people themselves should not be neglected. One of the most poignant elements of this study perceptible to all who conducted the interviews, was a strong sense of wasted potential among disabled

⁵⁷ Although as has been explained this is less to do with the effects of age than the fact that many of these experiences date back a considerable period of time to an era when the opportunities for disabled people were far more restricted.

people with a great deal to offer and contribute to society. This is obviously due to the denial of opportunities, but is also because people did not always recognise incidents of discrimination, or feel they could challenge these. Consequently, it could also be argued that an equally important policy focus should be upon ways of working with disabled people to empower them and equip them for situations in which they need to assert their rights, challenge prejudice and demand equal treatment. This was recurrently emphasised and is vividly articulated by the respondent below in relation to the visually impaired, but the sentiment is applicable to all groups.

'The blind person needs human support... and if he has these supports he can then go to a prospective employer and show how he can do this job with this support....So that...an employer says to you - now I applied for a job as a computer operator: 'You can't read the screen, how on earth can you operate a computer?' 'Look, it is possible today to have equipment that turns speech into', etc, etc, etc, and if you can go along with some portable equipment to the interview and say: 'Look, I happen to have this here actually', and demonstrate, that is the sort of thing, and you need then, you need blind people - and I think this applies to so many disabilities - to go round talking to prospective employers and showing them what blind people can do.'

(Male, 69, white, visual impairment)

The potential impacts of this type of assertiveness should not be underestimated and this can also contribute to changing attitudes in wider society.

The question of how these pressures upon self-esteem can be overcome and awareness, confidence and self-assertion fostered, was not explored in any detail in this study. This said however, sometimes people did provide some insight into the ways in which this might occur. One disabled woman, for example, suggested that it would have been useful to receive counselling when she was younger in order to *'raise my awareness of what I was dealing with and what I could do to help myself'*. These types of support are not just relevant to disability and could also be of value in relation to ethnicity and sexuality. A Caribbean woman with sickle-cell anaemia, recalled how she had been provided with a black role model through a mentoring scheme at university. She felt this had been significant in raising her confidence and awareness of the ways in which other black people were successful and thought this type of initiative could be very positive for other young black people. These are of course, only tentative suggestions and the question of how this can be achieved might be a question for future research. What is more certain is that change in this area has the potential to contribute powerfully to the government's stated objectives of securing equality of opportunity for all.

8.5 Summary

Participants believed that a great deal of progress had been made in relation to the position of disabled people in society and that the opportunities for disabled people had substantially increased. The experience of growing up black or Asian or lesbian

or gay in this country was also considered to be very different now to how it had been 30 or 40 years ago. However, people from all groups believed that a great deal of prejudice and discrimination still remains against disabled people, black and minority ethnic groups and lesbians and gay men. Obstacles which relate to gender and age were cited less frequently and generally viewed as less significant than those caused by these other factors.

The extent to which people were aware of current policy initiatives or had views in this area varied greatly. Older people from the South Asian groups were least likely to be aware of current policy initiatives and have strong views on this.

Among those with some awareness of policy and provision aimed at disabled people, a recurrent criticism was that this was inconsistent. The services people received were often perceived to be determined by what was available in the area in which they lived rather than by people's needs. In addition, another area of inconsistency that people highlighted was the level of support and help available to people with different types of disability.

Some people in the sample were entirely unaware of schemes such as New Deal for Disabled People (NDDP) and were surprised that this type of provision existed. A degree of frustration was expressed about the fact that more had not been done to make them aware of programmes which might be extremely beneficial. There was also evidence of a large amount of misunderstanding about the requirements of NDDP. Despite these reservations, those who had awareness of the scheme, or who participated in the scheme were overwhelmingly positive about its impact.

Overall the DDA was welcomed and the work of the Disability Rights Commission in representing the rights of disabled people received favourable comments. This said, however, legislation was perceived to be weak and a number of people commented that it should '*be given more teeth*'. Those who held this view also felt that the rights of disabled people were not forcibly enshrined in legislation and that new legislation should be introduced to help secure equal opportunities for disabled people. In contrast, others felt existing legislation was sufficient to ensure equal opportunities.

Strong support was given to the idea that society needs to change if disabled people are to have equal social rights. It was seen as vital to raise levels of awareness about disability among non-disabled people in order to bring about social change. Similar points were also raised in relation to raising awareness about the types of discrimination people who were lesbian and gay or from black and minority ethnic groups can encounter. Wider public understanding about the disadvantage that can be linked to different characteristics was believed to be necessary to augment policy and legislative change in these areas.

The importance of funding to provide adaptations and support for disabled people was recurrently emphasised. It was consistently argued that disabled people were denied the adaptations they needed largely because of the cost of these.

It was also thought that issues relating to disability should be considered as a matter of course in the formulation of policy, provision of services and in other areas rather than viewed as being a separate or side issue.

People from all groups called for the heightened involvement and consultation of disabled people in the formulation of all levels and types of policy. There were also calls to involve disabled people in delivery of services.

Existing services provided for disabled people were criticised for not recognising the diversity of disabled people. Recognising the diversity of disabled people might mean the provision of specific or targeted services. This point was made particularly by ethnic minority disabled people who sometimes differed substantially from white respondents in their preference for specific services.

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Appendix A

Sample profile tables

Table A.1 African group

Characteristics	Male (2)	Female (4)	Total (6)
Age			
16-29	-	-	
30-49	2	2	4
50-59 (females)	-	1	1
50-64 (males)	-	-	-
60+ (females)	-	1	1
65+ (males)	-	-	-
Current activity			
Paid employment	1	1	2
Voluntary work	-	-	-
In education/training	-	-	-
Not working due to ill health	-	2	2
Unemployed but looking for work	1	1	2
Retired	-	-	-
Qualifications			
None	-	-	-
GCSE/equivalent	-	-	-
A level	1	-	1
Vocational qualification	1	-	1
Degree	-	2	2
Other	-	2	2

Continued

Table A.1 Continued

Characteristics	Male (2)	Female (4)	Total (6)
Living circumstances			
Renting from LA/HA	2	-	2
Renting privately	-	-	-
Home owner	-	3	3
Living with family or friends	-	-	-
Living in supported accommodation	-	1	1
Disability type			
Single impairment	2	3	5
Multiple impairments	-	1	1
Main/only disability			
Mobility	1	3	4
Visual	-	-	-
Hearing	-	-	-
Mental	1	1	2
Learning	-	-	-
Other	-	-	-
Onset of main disability			
Less than a year	-	-	-
1-5 years	-	2	2
6-10 years	-	-	-
Over 10 years	1	1	2
Life	1	1	2

Table A.2 Caribbean group

Characteristics	Male (2)	Female (9)	Total (11)
Age			
16-29	-	2	2
30-49	1	3	4
50-59 (females)	-	1	1
50-64 (males)	1	-	1
60+ (females)	-	3	3
65+ (males)	-	-	-
			Continued

Table A.2 Continued

Characteristics	Male (2)	Female (9)	Total (11)
Current activity			
Paid employment	-	3	3
Voluntary work	-	-	-
In education/training	-	-	-
Not working due to ill health	2	4	6
Unemployed but looking for work	-	-	-
Retired	-	2	2
Qualifications			
None	-	1	1
GCSE/equivalent	1	1	2
A level	-	-	-
Vocational qualification	1	2	3
Degree	-	1	1
Other	-	4	4
Living circumstances			
Renting from LA/HA	1	6	7
Renting privately	-	-	-
Home owner	1	2	3
Living with family or friends	-	1	1
Living in supported accommodation	-	-	-
Disability type			
Single impairment	2	3	5
Multiple impairments	-	6	6
Main/only disability			
Mobility	1	3	4
Visual	-	-	-
Hearing	-	1	1
Mental	1	-	1
Learning	-	1	1
Other	-	4	4
Onset of main disability			
Less than a year	-	-	-
1-5 years	-	1	1
6-10 years	-	1	1
Over 10 years	2	3	5
Life	-	4	4

Table A.3 Indian group

Characteristics	Male (9)	Female (8)	Total (17)
Age			
16-29	1	-	1
30-49	5	4	9
50-59 (females)	-	2	2
50-64 (males)	1	-	1
60+ (females)	-	1	1
65+ (males)	2	1	3
Current activity			
Paid employment	4	2	6
Voluntary work	1	-	1
In education/training	-	-	-
Not working due to ill health	2	5	7
Unemployed but looking for work	1	-	1
Retired	1	1	2
Qualifications			
None	1	3	4
GCSE/equivalent	1	-	1
A level	1	-	1
Vocational qualification	3	1	4
Degree	1	2	3
Other	2	2	4
Living circumstances			
Renting from LA/HA	1	-	1
Renting privately	-	-	-
Home owner	5	5	10
Living with family or friends	2	3	5
Living in supported accommodation	1	-	1
Disability type			
Single impairment	6	5	11
Multiple impairments	3	3	6
Main/only disability			
Mobility	3	3	6
Visual	3	2	5
Hearing	-	1	1
Mental	-	-	-
Learning	2	-	2
Other	1	2	3

Continued

Table A.3 Continued

Characteristics	Male (9)	Female (8)	Total (17)
Onset of main disability			
Less than a year	-	-	-
1-5 years	2	1	3
6-10 years	-	1	1
Over 10 years	3	2	5
Life	4	4	8

Table A.4 Pakistani group

Characteristics	Male (6)	Female (8)	Total (14)
Age			
16-29	3	2	5
30-49	-	2	2
50-59 (females)	-	1	1
50-64 (males)	-	-	-
60+ (females)	-	3	3
65+ (males)	3	-	3
Current activity			
Paid employment	1	-	1
Voluntary work	-	2	2
In education/training	2	2	4
Not working due to ill health	1	3	4
Unemployed but looking for work	-	-	-
Retired	2	1	3
Qualifications			
None	2	5	7
GCSE/equivalent	1	1	2
A level	-	1	1
Vocational qualification	1	1	2
Degree	1	-	1
Other	1	-	1
Living circumstances			
Renting from LA/HA	1	1	2
Renting privately	1	-	1
Home owner	2	2	4
Living with family or friends	2	5	7
Living in supported accommodation	-	-	-

Continued

Table A.4 Continued

Characteristics	Male (6)	Female (8)	Total (14)
Disability type			
Single impairment	2	3	5
Multiple impairments	4	5	9
Main/only disability			
Mobility	2	4	6
Visual	1	2	3
Hearing	-	-	-
Mental	-	-	-
Learning	2	2	4
Other	1	-	1
Onset of main disability			
Less than a year	-	-	-
1-5 years	1	1	2
6-10 years	-	2	2
Over 10 years	2	3	5
Life	3	2	5

Table A.5 Gay/lesbian group

Characteristics	Male (5)	Female (8)	Total (13)
Age			
16-29	-	2	2
30-49	4	4	8
50-59 (females)	-	2	2
50-64 (males)	1	-	1
60+ (females)	-	-	-
65+ (males)	-	-	-
Current activity			
Paid employment	1	3	4
Voluntary work	-	-	-
In education/training	-	-	-
Not working due to ill health	2	5	7
Unemployed but looking for work	1	-	1
Retired	1	-	1

Continued

Table A.5 Continued

Characteristics	Male (5)	Female (8)	Total (13)
Qualifications			
None	1	-	1
GCSE/equivalent	1	-	1
A level	-	-	-
Vocational qualification	1	4	5
Degree	2	4	6
Other	-	-	-
Living circumstances			
Renting from LA/HA	3	2	5
Renting privately	-	1	1
Home owner	1	4	5
Living with family or friends	1	1	2
Living in supported accommodation	-	-	-
Disability type			
Single impairment	3	3	6
Multiple impairments	2	5	7
Main/only disability			
Mobility	2	3	5
Visual	-	-	-
Hearing	2	2	4
Mental	-	2	2
Learning	1	-	1
Other	-	1	1
Onset of main disability			
Less than a year	-	-	-
1-5 years	-	3	3
6-10 years	1	2	3
Over 10 years	1	1	2
Life	3	2	5

Table A.6 White group

Characteristics	Male (9)	Female (2)	Total (11)
Age			
16-29	1		1
30-49	-	1	1
50-59 (females)	-	-	-
50-64 (males)	5	-	5
60+ (females)	-	-	-
65+ (males)	3	1	4
Current activity			
Paid employment	2	1	3
Voluntary work	-	-	-
In education/training	1	-	1
Not working due to ill health	4	-	4
Unemployed but looking for work	-	-	-
Retired	2	1	3
Qualifications			
None	4	1	5
GCSE/equivalent	-	-	-
A level	-	-	-
Vocational qualification	2	1	3
Degree	3	-	3
Other	-	-	-
Living circumstances			
Renting from LA/HA	3	1	4
Renting privately	1	-	1
Home owner	3	1	4
Living with family or friends	2	-	2
Living in supported accommodation	-	-	-
Disability type			
Single impairment	6	1	7
Multiple impairments	3	1	4
Main/only disability			
Mobility	3	2	5
Visual	3	-	3
Hearing	-	-	-
Mental	1	-	1
Learning	-	-	-
Other	2	-	2

Continued

Table A.6 Continued

Characteristics	Male (9)	Female (2)	Total (11)
Onset of main disability			
Less than a year	-	-	-
1-5 years	-	-	-
6-10 years	1	2	3
Over 10 years	5	-	5
Life	3	-	3

Table A.7 Other group (1x Turkish, 1 x Iranian)

Characteristics	Male (0)	Female (2)	Total (2)
Age			
16-29	-	1	1
30-49	-	1	1
50-59 (females)	-	-	-
50-64 (males)	-	-	-
60+ (females)	-	-	-
65+ (males)	-	-	-
Current activity			
Paid employment	-	-	-
Voluntary work	-	-	-
In education/training	-	1	1
Not working due to ill health	-	1	1
Unemployed but looking for work	-	-	-
Retired	-	-	-
Qualifications			
None	-	-	-
GCSE/equivalent	-	1	1
A level	-	-	-
Vocational qualification	-	1	1
Degree	-	-	-
Other	-	-	-
Living circumstances			
Renting from LA/HA	-	-	-
Renting privately	-	-	-
Home owner	-	-	-
Living with family or friends	-	2	2
Living in supported accommodation	-	-	-

Continued

Table A.7 Continued

Characteristics	Male (0)	Female (2)	Total (2)
Disability type			
Single impairment	-	-	-
Multiple impairments	-	2	2
Main/only disability			
Mobility	-	2	2
Visual	-	-	-
Hearing	-	-	-
Mental	-	-	-
Learning	-	-	-
Other	-	-	-
Onset of main disability			
Less than a year	-	-	-
1-5 years	-	-	-
6-10 years	-	-	-
Over 10 years	-	1	1
Life	-	1	1

Table A.8 Group participants

Characteristics	Group 1	Group 2	Group 3	Group 4	Group 5	Total
Gender						
Male	4	3	2	5	3	17
Female	-	2	3	5	3	13
Age						
16-29	1	-	-	2	-	3
30-49	2	3	3	4	1	13
50-59 (females)	-	2	2	-	1	5
50-64 (males)	1	-	-	2	1	4
60+ (females)	-	-	-	2	2	4
65+ (males)	-	-	-	-	1	1
Current activity						
Paid employment	3	-	1	-	-	4
Voluntary work	-	-	1	-	-	1
In education/training	-	1	-	-	-	1
Not working due to ill health	-	4	3	10	4	21

Continued

Table A.8 Continued

Characteristics	Group 1	Group 2	Group 3	Group 4	Group 5	Total
Unemployed but looking for work	-	-	-	-	-	-
Retired	1	-	-	-	2	3
Qualifications						
None	-	-	-	5	1	6
GCSE/equivalent	1	2	1	5	-	9
A level	-	-	1	-	-	1
Vocational qualification	-	1	-	-	3	4
Degree	3	-	-	-	-	3
Other	-	2	3	-	2	7
Living circumstances						
Renting from LA/HA	2	5	5	5	4	21
Renting privately	1	-	-	-	-	1
Home owner	1	-	-	2	2	5
Living with family or friends	-	-	-	3	-	3
Living in supported accommodation	-	-	-	-	-	-
Disability type						
Single impairment	3	4	3	7	3	20
Multiple impairments	1	1	2	3	3	10
Main/only disability						
Mobility	4	-	5	8	4	21
Visual	-	-	-	1	-	1
Hearing	-	-	-	-	-	-
Mental	-	5	-	-	-	5
Learning	-	-	-	1	-	1
Other	-	-	-	-	2	2
Onset of main disability						
Less than a year	-	-	-	-	-	-
1-5 years	1	1	-	1	-	3
6-10 years	-	1	-	3	4	8
Over 10 years	2	3	1	2	2	10
Life	1	-	4	1	-	6

Appendix B

Recruitment documents

Example recruitment letter

[Date]

Dear [Name]

Exploring diversity in disability

We are asking for your help with a study looking at the issues facing black and minority ethnic disabled people. The study, funded by the government's Department for Work and Pensions, is being carried out by a group of researchers from the *National Centre for Social Research*.

The study wants to find out more about the experiences and views of black and minority ethnic disabled people. We want to include people from different ethnic groups, and different types of disability. To help us do this, we are asking for a little bit of information from everybody. Attached is an information sheet that we would like you to fill in. When you have completed the sheet, it is important that you return it to us in the pre-paid envelope provided. Unfortunately, we may not be able to include everyone who fills in a form. In the next few weeks we will make a decision on who we are going to interview and get back in touch with you to let you know.

Interviews will last for between an hour and an hour and a half. We can interview you at your home, or wherever is most convenient. Everyone who takes part will get £15 as a token of thanks for their help, and all the information they give will be completely confidential.

We hope that you will be able to take part. If you have any questions or would like to talk to one of us about the study, please feel free to ring us here at the *National Centre* on 020 7250 1886. You are welcome to reverse the charges.

Yours sincerely,

Sue Arthur, Tim Knight, Kandy Woodfield

Research team

Screening questionnaire

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1. What was your age last birthday?

ENTER AGE IN YEARS

2. Please tell us your gender

Male

Female

3. Please describe your ethnic background

White UK

Indian

White Irish

Chinese

Bangladeshi

Black Caribbean

Pakistani

Black African

Other, please write here _____

4. What is the nature of your disability, impairment or health condition?

Mobility Impairment Learning disability

Visual Impairment Mental health

Hearing Impairment

Something that affects your heart, circulation, blood pressure or breathing

Other, please write here _____

PLEASE TURN OVER TO THE OTHER SIDE OF THIS QUESTIONNAIRE

5. How long have you had this disability, impairment or health condition?

- | | | | |
|------------------|--------------------------|----------------|--------------------------|
| Less than a year | <input type="checkbox"/> | Over 10 years | <input type="checkbox"/> |
| 1-5 years | <input type="checkbox"/> | All of my life | <input type="checkbox"/> |
| 6-10 years | <input type="checkbox"/> | | |

6. Which of the following describes your main activities at present?

- | | | | |
|---|--------------------------|--|--------------------------|
| In paid employment | <input type="checkbox"/> | In education/training | <input type="checkbox"/> |
| Not working due to ill-health or disability | <input type="checkbox"/> | Not working because of caring responsibilities | <input type="checkbox"/> |
| Unemployed but looking for work | <input type="checkbox"/> | Retired | <input type="checkbox"/> |
- Other, please write here _____

7. If you have experience of employment, can you tell us your current or most recent job title? Please write here _____**8. What qualifications do you have?**

- | | | | |
|---|--------------------------|------------------------------------|--------------------------|
| GCSE/O level | <input type="checkbox"/> | A level | <input type="checkbox"/> |
| NVQ/GNVQ/BTEC (or other vocational qualification) | <input type="checkbox"/> | Degree – graduate or post-graduate | <input type="checkbox"/> |

Other (professional qualifications for example), please write here _____

9. Do you currently:

Rent your house/flat/room from your local authority or housing association

Rent your house/flat/room from a private landlord

Own your own house

Live with family or friends

Live in supported accommodation

Have another kind of living arrangement, please write here _____

Can you please tell us your full name, address, telephone number and/or email address where we can contact you

Name: _____

Address: _____

Tel no: _____

Email: _____

Can you please let us know your preferred means of communication, for example: Braille, tape, telephone or large print (please specify size)

Will you require any specific support to take part in the research, for example: a sign language interpreter, a non-English speaking interviewer (please specify language) or someone to accompany you during the interview

THANK YOU VERY MUCH FOR YOUR TIME

The information you have given is completely confidential

Appendix C

Topic guides

P.6037 EXPLORING DIVERSITY IN DISABILITY

Topic Guide for depth interviews

Research objectives

- to explore respondent's life experiences and the role that disability and ethnicity/gender/age/sexuality play within those experiences
- to identify and explore perceptions and attitudes towards disability, within the context of ethnicity/gender/age/sexuality
- to investigate respondent's views and experiences of discrimination and prejudice

1. Introduction

- Introduce self, the study and the National Centre
- Explain about confidentiality, tape recording and length of interview
- Explain need to recap some areas covered by recruiter/recruitment questionnaire but in more detail
- Check respondent is comfortable with length of interview, the way the interview will be conducted where third party facilitation is being used, if rest breaks will be needed or if there is anything else that can be done to make it easier for them

Important: Throughout **Sections 2-6** explore the role of disability/impairment in the respondent's view and experiences but only within the context of what the respondent has said to you about when, where and if disability/impairment was a factor. Where it is mentioned it should be probed thoroughly and where it isn't it should be explored later through the use of Sections 7-10

Important: Throughout **Sections 2-10** you should explore the experience/role/impact of migration *where appropriate*.

2. Current personal circumstances

- Age, household/family composition/living arrangements
- Household income, both from earnings and benefits
- Current experiences of daily life
 - Whether working/seeking work/doing voluntary work/in education/other
 - Hobbies and interests
- How would they describe their ethnicity
- Nature of disability/impairment/illness (briefly only)
 - Onset, duration, changes over time, effect on daily life

3. Experiences of childhood and education

If onset of disability/impairment after childhood explore this area only briefly

- Childhood and family background
 - Where lived/family composition
 - Experience of family life (emotional, economic, stability)
 - Key factors affecting family life when a child
- Experience of education and school life (discuss individually different schools attended)
 - Where attended school/type of school (ie. Mainstream/integrated/special)
 - Relationships with other students
 - Treatment by teachers
 - Experiences of school/key memories
 - Factors affecting experience of school
- Forming friendships/the social world
 - Important friendships and relationships growing up
 - Nature of friendship network (local or school friends/friends from other activities)
 - Factors affecting friendship and social life
 - Other leisure activities
- Access to the social world
 - Access to transport/leisure activities/services
- Other factors affecting childhood

- Self-image as child and when growing up
 - How felt about themselves
 - How feel others saw them
 - Feelings of belonging/belonging to 'what'

4. Transitions into adulthood and employment

If onset of disability/impairment after retirement age explore this area only briefly

- Experiences of leaving school
 - Age left school/qualifications gained
 - Plans for the future (i.e. further education/work)
 - Nature and impact of careers advice
 - Factors affecting decisions made about future
- Family circumstances
 - Experiences of leaving home (if appropriate) and factor precipitating leaving
 - Forging new relationships/family formation/having children
 - Relationship breakdowns and separations
 - Feelings about any changes to family circumstances
- Further education
 - Aspirations for FE/HE and experiences of FE/HE
 - Factors affecting experiences
 - Qualifications gained
 - Barriers and facilitators to further education
- Employment and working life
 - Employment aspirations
 - Perceptions of employability
 - Experiences of seeking work
 - Experiences of work (exploring different jobs where appropriate)
 - Factors affecting type of work or nature of work (i.e. part or full time/self-employment)
 - Relationships with other employees
 - Treatment by employers
 - Barriers and facilitators to work
 - Experiences of claiming benefit, changes over time

Where appropriate - please explore changes to above over time (*i.e. as respondent has grown older*)

- Experiences of changing friendships and new friendship circles

For those who are retired:

- ***Perceptions of retired life style***
- ***Experiences of ageism***
- ***Activities since retirement e.g. work, volunteering etc.***
- ***Experience of support for overcoming barriers***

5. Use of services/informal support systems

Explore use of services after onset of disability/impairment

- Access to, and use of, services
 - Different types of services used (e.g. health, home/residential care, support, advice, counselling, transport, financial services etc.)
 - Experiences of using services (positive/negative aspects)
 - Experience of, and differences between, formal and informal (i.e. community or family based) support systems
 - How became aware of services
 - Awareness of other services available
 - Barriers and facilitators to accessing services
 - Suggested changes to services

6. Self-image

- Self-image and personal values
 - Changes to self-image over time, factors accounting for changes
 - Changes to values over time, reasons for changes (*e.g. you have described various different areas of your life to me, which do you value the most? why?*)
 - How others see them, changes and reasons for changes
 - The impact of how others see them

Explain that now you would like to talk more specifically about disability within the context of what respondent has already described about their life and the impact or not of their impairment on their life

7. Images and perceptions of disability

Important: Probe respondent about role of ethnicity, gender, age, and/or sexuality in perceptions and images of disability

- Perceptions of disability, how define what disability means both to them and to other disabled people
- If respondent has not already provided this information, ask about:
 - Onset, duration, changes over time, effect on daily life of disability/impairment
- Images of disability (self)
 - Self image and perceptions
 - Perceptions of other disabled people/types of disability
 - Positive/negative ways in which image of self has affected life (e.g. in decision-making, activities undertaken, choices made)

Important: Explore different images of disability among non-disabled people of:

- a) same ethnicity, gender, age, and/or sexuality as respondent
 - b) different ethnicity, gender, age, and/or sexuality to respondent
- Images of disability (others)
 - Views about non-disabled people's perceptions of disability
 - Positive/negative ways these perceptions have affected their life (e.g. different treatment)
 - Perceptions of media representations of disabled people
 - Changes over time in images and perceptions
 - Experiences of different communities/different cultures (exploring different cultural or religious communities, different worlds, ie. work/family, different countries)

8. Perceptions and experiences of discrimination

- Perceptions of discrimination, what form/s it takes
 - Views about causes/sources of discrimination in different contexts;
 - views about which groups, if any, discriminate
 - Views about discrimination relating to disability
 - Views about discrimination relating to ethnicity, age, gender, sexuality

- Experiences of exclusion, discrimination or being treated differently
 - Explore experiences in different spheres of life (family/education/social/work and seeking work/access to services)
 - Where less/heightened discrimination and why
 - The impact of discrimination
 - Views about, and experiences of, changes to nature and degree of discrimination over time
- Personal perspectives about multiple discrimination
 - Views about whether they feel they experience multiple discrimination
 - Nature of multiple discrimination experienced
 - Combinations of factors (disability and ethnicity, disability and age, disability and gender, disability and sexuality) that are seen to be basis for multiple disadvantage
 - Differences between ‘single’ discrimination and multiple discrimination
- Overcoming discrimination/exclusion
 - Who responsible: explore self, government, society, others
 - Awareness and experience of practical/financial support available to overcome discrimination (whether community based, government agency etc.)
 - Key areas/issues requiring attention
 - Suggestions and ideas for promoting inclusion, reducing discrimination and enabling disabled people to reach full potential
- Awareness and experience of government campaigns/national policy changes such as See the Person/NDDP/Jobcentre +
 - Views about the value of/need for such campaigns to address discrimination or prejudice

9. Awareness of and views about rights, support and campaigns for disabled people

Important: Throughout section probe for how they feel their personal characteristics (eg ethnicity, gender, age, sexuality) make a difference to their rights or support available

- Awareness of the legal and civil rights of disabled people
 - Views about the comparative rights of disabled and non-disabled people
 - Views about the type of rights disabled people need/want
- Awareness of practical/financial support available to disabled people
 - Experiences of different forms of support incl. govt agencies
 - Views about the impact and value of different forms of support

- Awareness of disability rights campaigns, e.g. campaigns for access
 - Experiences of disability rights campaigning
 - Views about the value and impact of disability campaigns
- Awareness of disability organisations
 - Experiences of joining/using disability organisations
 - Views about the value and impact of disability organisations
- Awareness of national policy changes, explore
 - The DDA, NDDP, Disabled Person's Tax Credit
 - Views about their role, value and perceived impact

Explore respondent's views on rights, support and campaigns for non-disabled people who have same ethnicity, gender, age, and/or sexuality as them

10. The future

- Aspirations, expectations for the future
 - Aspirations for self (e.g. physical, emotional, practical and employment)
 - Aspirations relating to family, friends and other relationships
 - Social or leisure activities
 - Support and help
 - Other expectations
- What might stop them/what would help them achieve aspirations
- Any other suggestions for what should be done/messages for policy makers

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Topic Guide for group discussions

Research objectives

- to explore respondent's life experiences and the role that disability and ethnicity/gender/age/sexuality play within these
- to identify and explore perceptions and attitudes towards disability, within the context of ethnicity/gender/age/sexuality
- to investigate respondent's views and experiences of discrimination and prejudice

1. Introduction

- Introduce self, the study and the National Centre

A study to explore people's experiences and attitudes towards disability and how experiences might be affected by other characteristics such as age, gender, ethnicity and sexuality

- Explain about confidentiality, tape recording and length of discussion

Begin by asking group to discuss how discussion will work particularly where third party facilitators are present and how participants would like others to communicate in order to participate fully. Is there anything else that can be done to make it easier for them?

2. Group introductions

Brief round table introductions

- Age & ethnicity
- Household/family composition/living arrangements
- Current activity: whether working/parenting/in education/other
- Onset of disability, duration, changes over time, effect on daily life of disability/impairment

3. Images and perceptions of disability

Important: Probe about role of ethnicity, gender, age, and/or sexuality in perceptions and images of disability

- Perceptions of disability
 - How define what disability means to themselves
 - Different meanings associated with different types of disability
 - Perceptions of other disabled people/types of disability

- Images of disability (self)
 - Self image and perceptions
 - Positive/negative ways in which image of self has affected life (e.g. in decision making, activities undertaken, choices made)
- Images of disability (others)
 - Views about non-disabled people's perceptions of disability
 - How have these perceptions of others affected their life (e.g. positive/negative effects e.g. different treatment)
 - Perceptions of media representations of disabled people
 - Changes over time in images and perceptions
 - Experiences of different communities/different cultures (exploring different cultural or religious communities, different worlds, ie. work/family, different countries)

4. Life experiences

Important: explore how disability, ethnicity, sexuality, gender and age may have affected experiences either negatively – (experiences of exclusion, discrimination or being treated differently) or positively any experiences affected by more than one of these factors?

- Home
- Experience of education and school life
- Social (forming friendships, leisure and cultural activities)
- Employment and working life (e.g. as applicants, workers, colleagues & employers)
- Access to, and use of, services

Where appropriate - please explore changes to above as respondent has grown older

For those who are retired:

- **Perceptions of retired life style**
- **Experiences of ageism**
- Any other aspects of life (not discussed) which has been affected by disability ethnicity, sexuality, gender and age
 - Are any of these characteristics more or less likely to affect experiences

5. Perceptions and experiences of discrimination

- Views on policy makers' concern about the possibility of 'double discrimination'
 - Is this relevant, sensible, misplaced?
- Perceptions of discrimination, what form/s it takes
 - Views about causes/sources of discrimination in different contexts;
 - Views about which groups discriminate
 - Factors perceived to underpin different treatment
 - Views about discrimination relating to disability (vs discrimination relating to ethnicity, age, gender, sexuality)
- Areas of life where less/heightened discrimination and why
- Views about, and experiences of, changes to nature and degree of discrimination over time
- Views about how/if discrimination or exclusion differ for people with different forms of impairment
- The impact of discrimination
 - On their lives (positive/negative effects of different treatment)
 - On society
 - Do different types of discrimination have different impacts
- Personal perspectives about **multiple discrimination**
 - Views about whether they feel they experience multiple discrimination
 - Nature of multiple discrimination experienced
 - Combinations of factors (disability and ethnicity, disability and age, disability and gender, disability and sexuality) that are seen to be basis for multiple disadvantage
 - Differences between 'single' discrimination and multiple discrimination
- Overcoming discrimination/exclusion
 - Who responsible: explore self, government, society, others
 - Awareness and experience of practical/financial support available to overcome discrimination (whether community based, government agency etc.)
 - Key areas/issues requiring attention
 - Suggestions and ideas for promoting inclusion, reducing discrimination and enabling disabled people to reach full potential

6. Awareness of and views about rights, support and campaigns for disabled people

- Awareness of the legal and civil rights of disabled people
 - Views about the comparative rights of disabled and non-disabled people
 - Views about the type of rights disabled people need/want
- Awareness of government campaigns/policy (e.g. See the Person/NDDP/Jobcentre +)
- Awareness of disability rights campaigns, e.g. campaigns for access
 - Views about the effectiveness and value of/need for such campaigns to address discrimination or prejudice
 - Views about the value and impact of disability campaigns
- Awareness of disability organisations
 - Experiences of joining/using disability organisations
 - Views about the value and impact of disability organisations (*for them personally and society as a whole*)
- Awareness of practical/financial support available to disabled people
 - Experiences of different forms of support incl. govt agencies
 - Views about the impact and value of different forms of support
- Awareness of national policy changes, explore
 - The DDA, NDDP, Disabled Person's Tax Credit
 - Views about their role, value and perceived impact

Explore/compare views on rights, support and campaigns for non-disabled people who have same ethnicity, gender, age, and/or sexuality as them

7. The future

Final closing questions to bring discussion to an end

- Suggestions for DfEE about role government can play in supporting disabled people
- What would an ideal world be like for disabled people and how could it be brought about

Appendix D

Analytical framework

1. Background

Socio demographic characteristics & disability what & when

- 1.1 Household income
- 1.2 Household composition
- 1.3 Family details
- 1.4 Summary of key activities
- 1.5 Religious belief & affiliation
- 1.6 Summary of only/main disability
- 1.7 Details of any other disabilities/health conditions
- 1.8 Other

2. Experience, definitions and perceptions of disability

- 2.1 Experience of disability
- 2.2 Attitude to own disability
- 2.3 Impact of disability on family relations
- 2.4 Definitions of disability
- 2.5 Self perception in relation to disability
- 2.6 Issues in relation to different disability types
- 2.7 Non-disabled people's perceptions of disability

2.8 Images of disability

2.9 Other

3. Early Life & Education (Disability & Ethnicity)

3.1 Views of own ethnicity

3.2 Details & impact of migration

3.3 Experiences of growing up/early family life

3.4 Transitions to adulthood

3.5 Partnerships/family formation

3.6 Experiences of compulsory education

3.7 Experiences of post-compulsory education

3.8 Other

3. Early Life & Education (Disability & Sexuality)

3.1 Experiences of growing up/early family life

3.2 Transitions to adulthood

3.3 Sexuality emergence and own response

3.4 Coming out

3.5 Partnerships/family formation

3.6 Experiences of compulsory education

3.7 Experiences of post-compulsory education

3.8 Other

4. Employment & social life (Disability & Ethnicity)

4.1 Motivation, attitudes & decision making around work

4.2 Experiences of seeking work

4.3 Details & Experiences of work

4.4 Decision making around retirement or giving up work

4.5 Voluntary work

4.6 Experiences of the social world – friends, hobbies, leisure activities

4.7 Other

4. Employment & social life (Disability & Sexuality)

- 4.1 Motivation, attitudes & decision making around work
- 4.2 Experiences of seeking work
- 4.3 Help received to find work
- 4.4 Details and experiences of in work
- 4.5 Decision making around retirement or giving up work
- 4.6 Voluntary work
- 4.7 Experiences of the social world – friends, hobbies, leisure activities
- 4.8 Other

5. Accessing Services (Disability & Ethnicity)

- 5.1 Claiming benefits
- 5.2 Housing services
- 5.3 Health & medical services
- 5.4 Services & assistance for disabled people
- 5.5 Experiences of disability organisations
- 5.6 Minority ethnic community/support groups
- 5.7 Financial services
- 5.8 Other

5. Accessing Services (Disability & Sexuality)

- 5.1 Claiming benefits
- 5.2 Housing services
- 5.3 Health & medical services
- 5.4 Services & assistance for disabled people
- 5.5 Experiences of disability organisations
- 5.6 Lesbian and gay organisations / support groups
- 5.7 Financial services
- 5.8 Other

6. Prejudice, Discrimination & social exclusion

- 6.1 Views about discrimination
- 6.2 Experiences of discrimination
- 6.3 Impacts of discrimination
- 6.4 Views about the idea of multiple discrimination
- 6.5 Nature of multiple discrimination
- 6.6 Suggestions for ways of overcoming
- 6.7 Other

7. Ways forward

- 7.1 Views about rights of disabled people
- 7.2 Awareness and views about support available
- 7.3 Awareness and views about disability rights campaigns
- 7.4 Views about government policy in relation to disabled people
- 7.5 Ways forward – own life & generally
- 7.6 Interpretative column
- 7.7 Other

Other research reports available

<i>No.</i>	<i>Title</i>	<i>ISBN</i>	<i>Price</i>
1.	Thirty Families: Their living standards in unemployment	0 11 761683 4	£6.65
2.	Disability, Household Income & Expenditure	0 11 761755 5	£5.65
3.	Housing Benefit Reviews	0 11 761821 7	£16.50
4.	Social Security & Community Care: The case of the Invalid Care Allowance	0 11 761820 9	£9.70
5.	The Attendance Allowance Medical Examination: Monitoring consumer views	0 11 761819 5	£5.50
6.	Lone Parent Families in the UK	0 11 761868 3	£15.00
7.	Incomes In and Out of Work	0 11 761910 8	£17.20
8.	Working the Social Fund	0 11 761952 3	£9.00
9.	Evaluating the Social Fund	0 11 761953 1	£22.00
10.	Benefits Agency National Customer Survey 1991	0 11 761956 6	£16.00
11.	Customer Perceptions of Resettlement Units	0 11 761976 6	£13.75
12.	Survey of Admissions to London Resettlement Units	0 11 761977 9	£8.00
13.	Researching the Disability Working Allowance Self Assessment Form	0 11 761834 9	£7.25
14.	Child Support Unit National Client Survey 1992	0 11 762060 2	£15.00

15.	Preparing for Council Tax Benefit	0 11 762061 0	£5.65
16.	Contributions Agency Customer Satisfaction Survey 1992	0 11 762064 5	£18.00
17.	Employers' Choice of Pension Schemes: Report of a qualitative study	0 11 762073 4	£5.00
18.	GPs and IVB: A qualitative study of the role of GPs in the award of Invalidation Benefit	0 11 762077 7	£12.00
19.	Invalidation Benefit: A survey of recipients	0 11 762087 4	£10.75
20.	Invalidation Benefit: A longitudinal survey of new recipients	0 11 762088 2	£19.95
21.	Support for Children: A comparison of arrangements in fifteen countries	0 11 762089 0	£22.95
22.	Pension Choices: A survey on personal pensions in comparison with other pension options	0 11 762091 2	£18.95
23.	Crossing National Frontiers	0 11 762131 5	£17.75
24.	Statutory Sick Pay	0 11 762147 1	£23.75
25.	Lone Parents and Work	0 11 762147 X	£12.95
26.	The Effects of Benefit on Housing Decisions	0 11 762157 9	£18.50
27.	Making a Claim for Disability Benefits	0 11 762162 5	£12.95
28.	Contributions Agency Customer Satisfaction Survey 1993	0 11 762220 6	£20.00
29.	Child Support Agency National Client Satisfaction Survey 1993	0 11 762224 9	£33.00
30.	Lone Mothers	0 11 762228 1	£16.75
31.	Educating Employers	0 11 762249 4	£8.50
32.	Employers and Family Credit	0 11 762272 9	£13.50
33.	Direct Payments from Income Support	0 11 762290 7	£16.50
34.	Incomes and Living Standards of Older People	0 11 762299 0	£24.95
35.	Choosing Advice on Benefits	0 11 762316 4	£13.95
36.	First-time Customers	0 11 762317 2	£25.00

37.	Contributions Agency National Client Satisfaction Survey 1994	0 11 762339 3	£21.00
38.	Managing Money in Later Life	0 11 762340 7	£22.00
39.	Child Support Agency National Client Satisfaction Survey 1994	0 11 762341 5	£35.00
40.	Changes in Lone Parenthood	0 11 7632349 0	£20.00
41.	Evaluation of Disability Living Allowance and Attendance Allowance	0 11 762351 2	£40.00
42.	War Pensions Agency Customer Satisfaction Survey 1994	0 11 762358 X	£18.00
43.	Paying for Rented Housing	0 11 762370 9	£19.00
44.	Resettlement Agency Customer Satisfaction Survey 1994	0 11 762371 7	£16.00
45.	Changing Lives and the Role of Income Support	0 11 762405 5	£20.00
46.	Social Assistance in OECD Countries: Synthesis Report	0 11 762407 1	£22.00
47.	Social Assistance in OECD Countries: Country Report	0 11 762408 X	£47.00
48.	Leaving Family Credit	0 11 762411 X	£18.00
49.	Women and Pensions	0 11 762422 5	£35.00
50.	Pensions and Divorce	0 11 762423 5	£25.00
51.	Child Support Agency Client Satisfaction Survey 1995	0 11 762424 1	£22.00
52.	Take Up of Second Adult Rebate	0 11 762390 3	£17.00
53.	Moving off Income Support	0 11 762394 6	£26.00
54.	Disability, Benefits and Employment	0 11 762398 9	£30.00
55.	Housing Benefit and Service Charges	0 11 762399 7	£25.00
56.	Confidentiality: The public view	0 11 762434 9	£25.00
57.	Helping Disabled Workers	0 11 762440 3	£25.00
58.	Employers' Pension Provision 1994	0 11 762443 8	£30.00
59.	Delivering Social Security: A cross-national study	0 11 762447 0	£35.00

60.	A Comparative Study of Housing Allowances	0 11 762448 9	£26.00
61.	Lone Parents, Work and Benefits	0 11 762450 0	£25.00
62.	Unemployment and Jobseeking	0 11 762452 7	£30.00
63.	Exploring Customer Satisfaction	0 11 762468 3	£20.00
64.	Social Security Fraud: The role of penalties	0 11 762471 3	£30.00
65.	Customer Contact with the Benefits Agency	0 11 762533 7	£30.00
66.	Pension Scheme Inquiries and Disputes	0 11 762534 5	£30.00
67.	Maternity Rights and Benefits in Britain	0 11 762536 1	£35.00
68.	Claimants' Perceptions of the Claim Process	0 11 762541 8	£23.00
69.	Delivering Benefits to Unemployed People	0 11 762553 1	£27.00
70.	Delivering Benefits to Unemployed 16–17 year olds	0 11 762557 4	£20.00
71.	Stepping–Stones to Employment	0 11 762568 X	£27.00
72.	Dynamics of Retirement	0 11 762571 X	£36.00
73.	Unemployment and Jobseeking before Jobseeker's Allowance	0 11 762576 0	£34.00
74.	Customer views on Service Delivery in the Child Support Agency	0 11 762583 3	£27.00
75.	Experiences of Occupational Pension Scheme Wind–Up	0 11 762584 1	£27.00
76.	Recruiting Long–Term Unemployed People	0 11 762585 X	£27.00
77.	What Happens to Lone Parents	0 11 762598 3	£31.00
78.	Lone Parents Lives	0 11 762598 1	£34.00
79.	Moving into Work: Bridging Housing Costs	0 11 762599 X	£33.00
80.	Lone Parents on the Margins of Work	1 84123 000 6	£26.00
81.	The Role of Pension Scheme Trustees	1 84123 001 4	£28.00
82.	Pension Scheme Investment Policies	1 84123 002 2	£28.00
83.	Pensions and Retirement Planning	1 84123 003 0	£28.00

84.	Self-Employed People and National Insurance Contributions	1 84123 004 9	£28.00
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