

Towards joined up lives
Disabled and deaf Londoners' experience
of housing, employment and post-16 education
from a Social Model perspective

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March 2006

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Mayor's foreword

When I launched the report "Another Planet" I was shocked by disabled and Deaf people's real experiences of discrimination and disadvantage. I said at my first Disability Capital conference that such disablism was completely unacceptable in our city and I made a commitment to find out more about the root causes of the disadvantage faced by disabled and Deaf people. I therefore commissioned "Towards joined up lives" in order to fill this gap in our knowledge.

"Towards joined up lives" provides a vivid account of the experiences of disabled and Deaf Londoners. Although I believe that we have made considerable progress over the last two years in starting to remove the barriers to equality, this new research shows that we still have much to do. I am committed to implementing recommendations arising from this report for the GLA group so that we can begin a real and irreversible improvement in the life chances of disabled and Deaf Londoners. Publishing this research is the beginning of a collaborative effort towards implementing the recommendations. I will over the coming year work in partnership with government, local authorities, employers and further and higher education providers to find solutions to the issues highlighted by this report.



David Morris foreword

One of the areas highlighted by the Another Planet survey was that, to a large extent, available research did not reflect disabled and Deaf people's true experience of discrimination. The vast majority of available material categorises people from a medical or individual perspective and does not look at barriers leading to disadvantage and discrimination. Such material explains our experiences of discrimination by our impairment, and so misses the extent and reality of disablism.

"Towards joined up lives" was commissioned specifically to examine the lived experience of disabled and Deaf Londoners from a Social Model perspective. This research has also forged a new partnership between disabled people's research organisations and a mainstream research organisation. This partnership was brought together in recognition that organisations of disabled people often do not have the necessary capacity to deliver large-scale research projects and that mainstream research organisations often do not have a working understanding of Social Model methodology.

"Towards joined up lives" aims to look at three fundamental areas of life: education, employment and housing. These three areas are intrinsically linked and disadvantage in one area will affect the ability of individuals to achieve their potential in the other two. The report sets out a range of barriers, which need to be removed if the vision of a society whereby everybody can achieve full citizenship and develop their potential is to become a reality.

Many of the findings of the report may not surprise disabled and Deaf Londoners, but there will be some surprises for a wider readership. Lack of access to information and communication support, inappropriate services, discriminatory attitudes and harassment, lack of support and advocacy resources, inflexible and bureaucratic systems, a severe shortage of accessible housing; all of these things have been barriers for many of us for years. However, I believe we have a major opportunity within the current context of changing legislation and attitude, to start removing these barriers systematically and make London a place where all of our life chances are equal.



Executive summary

“Towards joined up lives”, is a qualitative research study commissioned by the Greater London Authority on the experiences of disabled Londoners in housing, post-16 education, and employment.

This study follows the social model of disability. It sets out to capture the views and experiences of disabled Londoners themselves and describes the barriers they face in their homes, in employment and in post-16 education.

Altogether 123 Londoners took part in the research, which began in December 2004 with fieldwork being completed by May 2005. There were 12 focus groups involving 76 people and 47 in-depth interviews.

The research included people with varied experiences of disabling barriers and took account of other aspects of diversity such as sex, ethnicity and age.

The main findings

Key cross-cutting themes (Chapter 4)

- The three research areas of housing, employment and post-16 education are closely linked, and problems in one – in particular in housing – will have a negative effect on the others.
- Easily accessible, comprehensive, accurate and timely information is vital to disabled people achieving success across the three areas.
- Problems in acquiring information in respect of benefits and support together with a lack of accessible formats, bureaucracy, and unclear guidelines were common across all three areas.
- Disabled people experience discrimination, harassment and lack of awareness and understanding, not only from the general public but also from professionals who come into contact with them on a regular basis.
- Services for disabled people across the city are inconsistent and not coordinated. In some cases neglect by statutory services can lead to isolation and social exclusion.
- People with hidden impairments experienced a serious lack of understanding, and consequently had their rights undermined.
- Participants perceived no evidence of a proactive approach to promoting disability rights, such as raising awareness, enforcing the law and committing sufficient resources.
- London was generally felt to be more physically accessible than other cities, but the people were perceived to be less friendly and helpful.

Key Issues In Housing (Chapter 5)

- Delays, cost and poor quality of adaptations to housing and problems with maintenance.
- A serious shortage of accessible housing, a resultant lack of choice and inappropriate housing provision.
- Support and advice services for disabled people are inadequate and not joined up.
- Lack of information about housing options and rights. Information difficult to get and often provided in inaccessible formats.
- Not knowing where to go for information, advice or support.
- Financial issues, including the benefits system and its excessive bureaucracy. Financial support for disabled people is complex and difficult to access, which can lead to hardship and a lack of choice.
- Poor housing services from local authorities; some discriminatory practice.
- Harassment by neighbours, lack of personal security and poor police and local authority responses.

Key Issues In Employment (Chapter 6)

- The benefits system, or people's understanding of it, was seen as a major obstacle preventing people seeking and remaining in work.

- Access to Work was strongly praised as a useful scheme which enabled people to work, but knowledge of it was limited.
- Jobcentre Plus and Disability Employment Advisers were very strongly criticised for lacking in understanding of disability issues.
- Attitudes and lack of awareness on the part of both employers and colleagues were also major barriers.
- Employers were perceived as being unwilling to introduce greater flexibility of working practices, to commit resources to make work places accessible, or to invest in equipment.
- Other means of support for employment, such as apprenticeships or positive action programmes, were seen as important.
- Employers and other agencies were seen to be ignorant of, or deliberately ignore, their obligations under the Disability Discrimination Act.
- Voluntary work was very important for many disabled people in this research but could also have drawbacks in terms of lack of access support and financial implications.

Key Issues In Education (Chapter 7)

- The risk of losing benefits and/or amassing debts while studying was a deterrent for disabled people's pursuit of education.
- Inconsistency in levels of access promoted and advertised by different educational establishments.
- Inconsistency in levels of support, equipment and other access when studying. Delays in getting equipment were a problem.
- Lack of understanding of access needs and lack of prompt response to them.
- Unhelpful and even hostile staff attitudes, and sometimes insensitivity and lack of understanding from students, particularly in relation to hidden impairment.
- Flexibility of hours, length of courses and response to variations in health were important issues for many students.
- Lack of physical access compounded by unresponsive policies.
- Disabled students experiencing discrimination found it hard to combat.
- Participants with experience of post-16 education generally had better things to say about it than either housing or employment.

Conclusions (Chapter 8)

The experiences related by participants in this research were mainly negative. They faced barriers of attitude, physical access, organisation and information in all three areas, which led to a lack of choice and real options.

Statutory responses in general were inadequate; for example, responses to neighbourhood harassment and to requests for adaptation were strongly criticised. Housing problems in particular had a knock-on effect on other areas of life.

There were also some positive comments, mainly on Access to Work and in the field of education. However, the research indicates that in all three areas, appropriate responses and services rely too often on the knowledge, understanding and commitment of individuals.

Recommendations

Involving disabled people and challenging disablism

1. The GLA should make sure that its Disability Equality Scheme and Equalities Toolkit incorporate actions appropriate to the recommendations contained in this report.
2. The GLA should consider the establishment of a resource to build the capacity of organisations across London run by disabled people.
3. The GLA and GLA group should resource and develop the structure of Independent Advisory Groups of disabled people to inform the effective integration of disability issues into mayoral strategies and service provision.
4. The GLA group should develop a strategy to promote and raise awareness of disability issues across London stakeholders, building on Disability Capital.
5. The GLA should develop a disability equality leadership programme for its mayoral advisers, directors and board members
6. The GLA should review the accessibility of City Hall, including the availability of parking spaces.
7. GLA and Metropolitan Police Authority (MPA) should work together with the police and local authorities to ensure that all staff are better able to assist disabled people who are being harassed, and that incidents of hate crime against disabled people are properly recorded and monitored.
8. The discrimination law review should look at ways of making disability legislation more effective, and of making it easier for disabled people to take legal action.
9. Disability Equality training should be provided to all staff responsible for reception and service delivery, in the fields of post-16 education, housing and employment. This training must cover the full range of barriers experienced by disabled and Deaf people, including those experienced by people with hidden impairments, long-term illness and variable health.

Information, advice and support

10. The GLA should consider establishing a centralised and centrally funded accessible communications unit to ensure that all the information produced by the GLA group (internal and external) is accessible.
11. The GLA group should look at the possibilities of more effective information provision about services available across the city through its Information and Communications Technology (ICT) strategy and using the London portal.
12. The GLA with the Office for Disability Issues and other stakeholders should explore the possibility of establishing cross-departmental, cross-agency one-stop shops in each borough, using expertise of statutory and voluntary sectors; that would provide information, advice and advocacy.

Housing

13. The serious shortage of accessible housing in London, which is highlighted by this research, needs to be addressed.
14. The London Plan 2004 contains targets that 10% of all new housing should be built to wheelchair accessible standards and 100% of all new homes should be built to lifetime home standards. A system needs to be developed to monitor the delivery of these targets.
15. There is a need to provide better information, advice, support and more choice to disabled people about accessible housing options and to make sure that adapted housing is let to disabled people wherever possible.
16. Government departments, local authorities and housing associations should implement the strategic recommendations coming out of 'Reviewing the disabled facilities grant programme' (ODPM and DH) Oct 2005.
17. Social landlords need to improve the information available to disabled people about the adaptations service in their area, how the system operates for people living in different tenures, and where they can go to for advice.
18. Social care provision including direct payments need to take account of all disabled people's legitimate independent living needs for such things as small repairs, shopping and going out socially.

Employment

19. The GLA group should develop an effective plan to ensure that it meets its targets in the employment of disabled staff.

20. The GLA group should establish a comprehensive list of accredited disability equality trainers and training organisations as a procurement tool and develop a training tool based on the social model.
21. The LDA should promote disability equality among employers through Diversity Works for London and ensure employers are aware of their legal obligations and of the availability of schemes such as Access to Work.
22. The LDA should consider ways in which incentives to employers (e.g. local award schemes) might be used to encourage the employment of disabled people.
23. The GLA group should investigate how positive action programmes such as work experience and mentoring schemes might be used to encourage the recruitment and retention of disabled people in London.
24. The Olympics and Paralympics strategies should incorporate a programme of sustainable job creation, with equality of opportunity for disabled people.
25. The government (DWP) should promote Access to work much more effectively, so that all employers and all disabled people know about it.
26. The government should actively disseminate information to disabled people about changes to benefit rules and programmes available, which ease the transition from benefit to work, with contact details for independent advice about these rules.
27. The government should implement well-designed training for personal advisers in Job Centres about disability, rights and benefits.

Education

28. Institutions, especially those in higher education, should consider ways to recruit more disabled, especially academic staff.
29. Institutions should audit the accessibility of the learning environment and plan improvements into their regular maintenance programmes through their disability equality schemes.
30. All institutions in further, adult and higher education should have the capacity to run flexible courses (in time &/or place) for disabled students, when needed.
31. All institutions should take a strategic approach to providing proper standards of equipment in reasonable time, as required by legislation.

32. Each institution should identify an appropriate person to whom disabled students can make complaints without fear of reprisal.
33. Government should provide sufficient resources to colleges and universities to enable them to meet the needs of disabled students more effectively.

Research gaps

- More needs to be known about the needs of disabled people who are isolated, including those who come to the attention of neither the statutory nor the voluntary agencies.
- The financial situation of disabled students and potential students needs more research. How do financial factors affect their participation? The issues will differ in higher and further education.
- Research is needed on disabled people's experiences of volunteering: What lessons can be learnt from their experiences? How can disabled volunteers progress into paid employment or maintain a good quality of life while volunteering?
- There is a lack of quantitative work which uses the social model perspective.

Implementation

The GLA and GLA group, in partnership with stakeholders, will draw up an action plan and work to implement these recommendations. The plan and working party will take account of comments made by the Advisory Group during the course of the project.

1 Introduction

This is a GLA commissioned report into the views of disabled Londoners, aged 16 and over, on housing, post-16 education and employment. It is based on the responses of 123 participants who took part in focus groups or interviews between February and May 2005. The research study was designed and carried out within a Social Model framework. As a result it seeks to identify barriers to participation by disabled people.

A significant number of people have been involved in the research and the production of this report. The research team would like to thank all those involved, and in particular the participants, the Advisory Group and the GLA project team.

This chapter describes what the researchers were asked to do, how the research was carried out, and the people involved. It also explains what some of the terms the report uses mean within the Social Model framework. Finally it explains the structure of the report.

What the researchers were asked to do

The Greater London Authority (GLA) commissioned a partnership of Equal Ability Limited, Future Inclusion Limited, and Ionann Management Consultants Limited to conduct a research study on the experiences of disabled people aged 16 and over in the Greater London area, in housing, employment and post-16 education.

The aim of the research was to explore the issues which disabled people themselves consider to be important, to expand the GLA's knowledge in the three areas of housing, employment and post-16 education, and to produce high-quality research which can influence those in a position to bring about positive changes and improvements for London's disabled people.

The original invitation to tender envisaged a quantitative approach drawing on the 2002 London Household Survey. After further consideration of practicalities and research needs, the GLA invited bidders to provide a revised tender and pricing schedule to meet a new, more qualitative research specification.

This was therefore to be a more focused piece of qualitative research which would try to capture the views of disabled Londoners themselves describing the barriers they faced in housing, in employment and in post-16 education. It was to be carried out using focus groups and in-depth interviews.

The primary source of participants was to be the 1,320 households in the 2002 GLA London Household Survey which contained disabled people who had expressed a willingness to be contacted for further research.

How the research was carried out

The research process, summarised here, is detailed in Appendix B - Methodology.

This section describes the main stages of the research. There were challenges, both expected and unexpected, particularly about building a sample of participants, and about conduct of the focus groups and interviews. Future research may benefit from lessons learned during the course of this study. There is more about this in Appendix B – Methodology.

Research Stages

The project began in December 2004. The research work occurred in 3 stages:

- Preliminary Stage - review of relevant literature, design of mailings to potential participants, and selection of participants (December 2004 to March 2005);
- Fieldwork Stage – interviews and focus groups (February 2005 to May 2005);
- Analysis and Report Stage - analysis of the findings, drawing conclusions, making recommendations and preparation of this report (May 2005 to November 2005).

Preliminary Stage

Work here included:

- Considering GLA literature reviews on housing, employment, and post-16 education and other relevant literature highlighted by the Advisory Group, in order to identify areas to be covered in the research (listed in Appendix E). Chapter 2 gives a summary of this material to provide context for this report.
- Drafting and sending out a letter of invitation to be sent to appropriate households in the London Household Survey. This letter was used later for potential participants from other sources. The letter invited people to take part in their preferred way (interview or focus group) and asked them what access provision they needed to participate effectively.
- Conducting telephone interviews with 20 London-based disability organisations, mostly of disabled people. They were selected for their relevance to the research areas. These organisations proved to be a very useful way of reaching people, for example, by providing other contacts such as people attending a drop-in centre. The aims of the telephone interviews were:
 - To let the organisations know that the research was taking place so that their members could provide input if they wanted to.
 - To invite their comments and views on barriers, knowledge gaps and key issues in the three study areas. These comments were helpful in framing the interview and focus group questions.
 - To ask them (in appropriate cases) to suggest or nominate potential focus group participants and interviewees, from amongst their members and service users.

Selecting participants.

The original plan had been to invite about one third of the appropriate London Household Survey participants to take part. Early responses were low so it was decided to continue and in the end an invitation was sent to all of the appropriate households on the list. In view of the limited response to the invitation, other avenues were explored. Letters or emails were sent to about 250 people on the GLA's Disability Capital data base. Potential participants identified through the telephone interviews above were also contacted. Even so, as the fieldwork progressed it became evident that a more proactive approach was needed. A "snowballing" approach was used to make further contacts with potential participants through existing participants and through relevant voluntary and other organisations. (Please see Appendix B - Methodology for more details.)

Fieldwork Stage

In this stage, a number of focus groups and interviews were held. The focus groups took place at a number of different venues, but mainly at City Hall.

All focus groups were facilitated by two members of the research team, one of whom took detailed notes. All interviews which were conducted in people's homes were also conducted by two team members. Interviews at drop-in centres and public places were conducted by one team member.

Detailed notes were taken of all focus groups and interviews, in part to be able to illustrate this report with participants' own comments.

A structured set of questions was prepared for the focus groups and interviews, which is provided in Appendix C - Questions.

Focus groups Altogether 12 focus groups were held, involving 76 people in total. Nine of these were at City Hall. Numbers attending each focus group varied from 4 to 15 people. Problems that participants experienced with the venues and the impact this had on attendance are explored in Appendix B - Methodology. Focus groups lasted for three hours and people were paid £25 plus expenses for giving up their time to attend.

Interviews In all, 42 people have been interviewed. Some interviews were conducted by telephone. People who were interviewed were paid £10. Communication support was available if required.

Email 5 people responded to interview questions by email.

Analysis and Report Stage

In writing this report, we have tried as much as possible to let the participants' voices be heard. The quotes throughout the report come directly from participants, but are presented anonymously to preserve confidentiality. The quotes use the language of the participants and we have not changed language to reflect important distinctions between disability and impairment.

Notes of interviews and focus groups were read by all team members. Key recurring themes were drawn out. These were grouped into themes that related just to one research area, and themes that cut across or linked two, or all three, areas. Greater emphasis has been given in the report to issues that were mentioned more often by participants and were of the most importance to them as barriers to equality.

Based on the key recurring themes, the research team, in discussion with the Advisory Group and the GLA Project Team, drew a number of conclusions.

From those conclusions, recommendations have emerged. The research was undertaken during a time when disability is at the forefront of government thinking, and when new legal responsibilities are being imposed on those providing housing, employment and post-16 education. These issues, and the background established through the GLA literature reviews, are set out in the context chapter. The recommendations have been made within this framework.

The people involved

"Towards joined up lives" was managed by a GLA project team, informed by an Advisory Group, and carried out by the research partnership as described below.

The GLA Project Team

The project was managed by a GLA project team.

Advisory Group

An Advisory Group of disabled and non-disabled people was established by the GLA to provide a source of advice and expertise from people with particular knowledge of the issues. The Advisory Group provided input at all stages of the research. Its members are listed in Appendix A.

The Research Partnership

The partnership created for this research comprises:

- Equal Ability Limited
- Future Inclusion Limited
- Ionann Management Consultants Limited

All three partners had a range of research experience. For this project, Ionann Management Consultants undertook the fieldwork and the majority of the analysis and report writing. Equal Ability and Future Inclusion provided expertise on disability and researching within a Social Model.

Participants

123 Deaf and disabled Londoners participated in the research, sharing their experience in the three research areas and providing views on the changes needed. The participants' characteristics, including the disabling barriers they face, were recorded to enable an understanding of the spread of participants involved. Details of the monitoring results are in Chapter 3.

The Structure of the Report

This report is arranged as follows:

Chapter 2 draws on the literature reviews conducted by the GLA and other relevant sources to provide a context for the research.

Chapter 3 analyses the monitoring information provided by the research participants using an approach based on the Social Model.

Chapter 4 looks at underlying common themes and links which are found across all three research areas and also highlights the issues for London.

Chapter 5 details the findings in the housing area.

Chapter 6 details the findings in the employment area.

Chapter 7 details the findings in the post-16 education area.

Chapter 8 sets out the conclusions and recommendations.

There are a number of Appendices, covering the Advisory Group membership, methodology, focus group and interview questions, monitoring form, documents of interest, abbreviations and definitions.

Note

All the issues identified in the report reflect the real experiences of disabled Londoners. Even if only one person raises an issue, it is important to recognise that it is a barrier to their equal participation, and so is no less valuable to the research. However, as far as possible, participants' points have been ordered so that those expressed by the largest numbers of people are presented first.

2 Context

This chapter describes the general context within which this research was undertaken. The legal framework is followed by an introduction to the Social Model of Disability, and related issues of language and definition. Next, there is a review by the GLA of relevant research, starting with the evidence for discrimination and barriers, and moving on to the three topic areas. Finally, there is a summary of recent policy developments relating to the delivery of services to disabled and Deaf people.

Legal framework

The research took place against a changing background of legislation affecting all three research areas. In 1995, the Disability Discrimination Act (DDA) became law, providing disabled people with a level of protection against discrimination for the first time. Since then the DDA has been added to and strengthened, primarily by the Disability Rights Commission Act 1999, the Special Educational Needs and Disability Act 2001 and the Disability Discrimination Act 2005.

From the outset the DDA has provided most disabled people with protection against discrimination in job recruitment and employment. Initially not all employers were covered by the law but all are now covered with the exception of the Armed Services. This part of the legislation only requires action to be taken for a particular disabled employee, or jobseeker. There is no requirement to anticipate the possible future access needs of a workforce.

Disabled people have significant rights not to be discriminated against in access to goods, facilities and services. These have been introduced in stages, the final one relating to the duty to make physical adjustments (changes) being introduced in October 2004. These duties require a level of anticipation of the access needs of disabled people to ensure they can access services. However, in transport and in two of the areas covered by this research - housing and post 16 education – there is still no comprehensive protection against discrimination.

New duties were introduced into the DDA in 2001 for further and higher education institutions, which only came fully into effect in September 2005, after the fieldwork for this research was completed. Institutions must now not discriminate against disabled people, and must make reasonable adjustments (changes) to ensure disabled students and would be students are not put at a substantial disadvantage. This protection does not extend to graduates.

In housing, since 1996 disabled people have had the right not to be unjustifiably discriminated against when renting or purchasing a home. This right only currently extends to direct discrimination – a landlord saying, for instance, they will not take any visually impaired tenants. There are significant problems in enforcing this however, as the duty does not currently require

landlords to undertake, or in the case of physical changes, even allow, reasonable adjustments. This will be required by the end of 2006.

With changes introduced by the Disability Discrimination Act 2005 the definition of disability now covers most people who experience disability discrimination including people diagnosed with HIV or multiple sclerosis, and more people with cancer.

Perhaps most importantly, for the areas of this research in the future, the 2005 Act introduced into the DDA a positive duty to promote disability equality in the public sector, to be met from 2006. This means that public authorities will have to anticipate disabled people's access needs, and will need to ensure that those to whom they delegate their responsibilities, for instance through contracting, take disability equality into account.

Social Model of Disability

The research is based on the Social Model of Disability and aims to identify the barriers to participation in mainstream provision in the three research areas. It also identifies issues that are consistent themes across the lives of disabled people.

From the outset, the GLA stressed the importance of this piece of research being 'Social Model' based. The Social Model of Disability states that people with impairments are disabled by physical and social barriers. The Social Model draws a distinction between impairment and disability:

"Impairment is the functional limitation within the individual caused by physical, mental or sensory impairment.

"Disability is the loss or limitation of opportunities to take part in the normal life of the community on an equal level with others due to physical and social barriers." (Barnes 1991)

The research was done within a social policy context in which a Social Model approach has recently been incorporated for the first time. As the Prime Minister's Strategy Unit outlines in the report "Improving the Life Chances of Disabled People":

"disability should be distinguished from impairment and ill health... disability is defined as: disadvantage experienced by an individual resulting from barriers to independent living or educational, employment or other opportunities that impact on people with impairments and/or ill health."

The Social Model was developed by disabled people in opposition to what came to be known as the Medical Model of disability. The key difference between these two models is the location of the 'problem'. In the medical model, disabled people are unable to participate in society as a direct result of their impairment. Impairment causes disability. So it is, effectively, a disabled person's personal tragedy that their level of participation is limited. Within a Social Model approach, the 'problem' of disability results from social structures and attitudes, rather than from a person's impairment or medical condition. This approach has been developed by the civil rights movement of disabled people, which has increasingly influenced a rights-based view of equality for disabled people that has now extended to government thinking.

In the words of Professor Colin Barnes:

"the traditional individualistic medical view of disability... explains the difficulties faced by disabled people in their daily lives as individually based functional limitations. Increasingly in recent years disabled people have come to recognise that the term "disability" represents a complex system of social restrictions imposed on people with impairments by a highly discriminatory society."

(Barnes 1991)

The incorporation of the Social Model of Disability into mainstream policy is perhaps the most important development in the policy context for disabled people since the introduction of the Disability Discrimination Act in 1995. This signals a move away from paternalistic approaches to disabled people. Historically, this paternalism has resulted in the provision of services and benefits that have imposed dependency on disabled people, rather than enabling their active participation as equal citizens. Government has clearly recognised that:

"Disabled people's experience of Government support and services needs to change. Too often disabled people feel that they are fighting a system which is fragmented, complex and bureaucratic and which does not put the needs of disabled people at the heart of service provision."

(Prime Minister's Strategy Unit 2005)

The Social Model is no longer a fringe concept, but clearly now at the heart of policy development.

The Social Model and language

"The language that people use reflects what they think and can influence how they deal with situations. If they behave as if the problem is with the individual, they will take a different approach than if they regard the problem as being

with the attitudes, systems and practices that create disabling barriers.”

(Clark & Marsh 2002)

Persuading people to use the right language – that is language that properly reflects the lived experience of disabled people within a Social Model context – has been key to promoting the rights of disabled people.

Amongst those campaigning against any form of discrimination, the power of language has been understood as a driver of discriminatory attitudes. Challenging racism and sexism, for example, has involved challenging racist and sexist language. In the same way, disabled people have challenged disablist language that places the cause of the problem of disability on the individual. In the same way that racist language has rightly become taboo within our diverse communities, disablist language is increasingly being understood as unacceptable, and part of the problem.

Words such as “handicapped”, “retarded”, “crippled”, “the disabled”, “normal” and “wheelchair bound” reflect the individualistic medical approach rejected by the disabled people’s movement and can be very offensive. Other language, commonly still in use, such as “people with disabilities”, “special”, “vulnerable adult” and “care” can be disablist and is never appropriate within a Social Model approach.

This report uses the term “disabled people” to refer to all of those people with impairments and long-term medical conditions, regardless of cause, who are disabled by social restrictions. Professor Michael Oliver talks about:

“restrictions [that] occur as a consequence of inaccessible built environments, the inability of the general population to use sign language, the lack of... (accessible)... reading material... or hostile public attitudes to people with non-visible (impairments)” (Michael Oliver 1990, quoted in Barnes 1991)

It is important to understand that this approach describes how restriction leads to disadvantage and does not necessarily mean that people will self-define as disabled. For example, many people expressed their experience to the researchers in other ways and did not appear to self-define as disabled in the political and policy sense of the word. However, they still face discrimination and disadvantage – disability – because of their impairment. Often people with impairments do not identify as disabled people because of the fear of discrimination, because of stigma and because of negative social stereotyping. This is particularly the case with people who acquire impairments at any age, and older disabled people.

This report uses language appropriate to a Social Model approach. However, much of the literature uses Medical Model language, as did a number of the participants, and the report reflects their words where applicable. For example, work undertaken for the Department for Work and Pensions by the National Centre for Social Research referred to in this chapter uses the terms 'severely impaired' and 'less severe impairments' (2002) In this context, it is Medical Model usage of the terms.

The Social Model and research

The majority of research work around disability is based on the medical model. The literature reviews received from the GLA highlight this – the issues for disabled people arising from the research are analysed on a mixture of Social Model and impairment lines. Because people are used to medical model based research, they believe that knowing the 'impairment makeup' of research participants tells them something about disabled people's experiences. However, this is largely an illusion. The needs of disabled people are not clearly differentiated on impairment lines. For example, both someone with a hearing impairment whose first language is British Sign Language (BSL), and someone with a learning difficulty may need clear signage with pictograms, whereas two people with visual impairments may need information provided differently from each other – a pensioner with no sight who learnt Braille at an early age as opposed to a pensioner who lost their sight late in life and has not had the opportunity or physical ability to learn Braille. People with identical impairments may experience very different barriers as a result of other aspects of their personality or personal situation. For instance, someone who becomes incontinent may have sufficient personal income to buy their own continence supplies, whereas someone on limited income cannot avoid the barriers created by having to use an ineffective, rationed, continence service for their supplies.

For this research, monitoring of participants was on a Social Model basis. In order to do this, the research team had to focus on the barriers that disabled people encountered in the research areas. However, because the research covered housing, education and employment, it was difficult to focus in on specific barriers without the monitoring form becoming overly long and complex. So the monitoring form (see Appendix D) was designed to identify the main type(s) of barrier that the participant faced in everyday life. Participants were asked about the following type of barrier:

- Physical access to buildings, streets, and transport vehicles
- Access to the written word
- Access to pictures and images
- Access to speech or conversation
- Access to other sounds

- People's attitudes to them because of their impairment, medical condition or disability (we chose to use all three terms for impairment, because different people would understand different terminology.)
- Stressful situations

They were also offered an 'other barriers' option to capture any specific barriers that might have been missed. This is a fairly high level approach to capturing the barriers experienced by disabled people, and in further research it would be appropriate to 'drill down' further to relate the barriers to specific situations being investigated.

There was some debate within the partnership as to whether the form should also include questions on impairment. However, we felt that such an approach would be inconsistent with a Social Model approach to the research. The implication of this is that it will be difficult accurately to compare this research with preceding research which has been medical model based.

The benefits of undertaking research from a Social Model perspective, both for disabled people and for organisations, cannot be stressed too strongly. By focusing on the barriers disabled people face, knowledge is gained of changes organisations need to make, in terms of things they can do and things that should benefit a range of different people. There is more commonality between the access needs of people with different impairments or medical conditions than Medical Model structured research can draw out. From an organisational perspective this helps to understand the changes that will provide the widest benefit. And, as one participant pointed out, you don't even recognise disability if things are designed properly from the outset.

Review of previous research

This review looks first at the general themes of discrimination, barriers and costs, before dealing with the three research areas.

There has been little research from a purely Social Model perspective ('Disabled People in Britain and Discrimination' being an exception). However, there has been a significant amount of research from an individualistic medical approach into the three research areas, housing, employment and post-16 education.

The Evidence for Discrimination

In 1991, a ground-breaking study of discrimination was published by the British Council of Disabled People (BCODP). This book by Professor Colin Barnes, "Disabled People in Britain and Discrimination – a Case for Anti-Discrimination Legislation", for the first time set out the evidence and case for comprehensive anti-discrimination legislation. The book brought together details of the widespread and systematic discrimination faced by disabled people. It is

acknowledged as the foundation stone for the eventual introduction of the Disability Discrimination Act in 1995.

“Disabled People in Britain” used existing statistical material and re-evaluated it within a Social Model context. For the first time, it demonstrated categorically the levels of discrimination and disadvantage faced by disabled people in the UK. It established that disabled people live in poverty, are less likely to be employed or have educational qualifications, are less likely to have access to appropriate and accessible housing, face inaccessible transport and built environment and are less likely to be represented in public life.

In 2003 the Greater London Authority published the result of its survey of the experiences of disabled and Deaf Londoners “Another Planet?” This identified the key issues for disabled people and formed the basis of the high level priorities for action contained in the GLA’s Disability Equality Scheme. The survey report concludes that in 1991:

“BCODP undertook research into the experience of institutionalised discrimination of disabled people. 12 years on much has changed, particularly in the field of legislation. However a lot of the experience of disabled people has not. Disabled Londoners routinely face discrimination in all areas of their lives”.

“Another Planet” presents a snapshot of the everyday lives of disabled and Deaf Londoners. Many of the examples given were common to the majority of participants, some are very personal, some are disturbing.

This was not a random sample, being a largely internet-based survey and therefore self-selecting, but there were some startling figures. For example, half the participants said they had experienced hate crime, abuse or bullying because they were a disabled person. More than three quarters said they face discrimination.

Barriers: multiple and linked

Research shows that disabled people face multiple barriers, which tend to be linked across many areas of their lives. Breaking those links to remove the barriers must be an efficient use of resources.

The London Health Commission report in 2003 found that disabled people fared worse on all the factors affecting health for which information was available. These were unemployment, housing conditions, some types of crime, air quality and road casualties.

Hendey and Pascall (2002) studied the success of young disabled people in transferring to an independent adult life, in terms of housing, employment, a

social life and citizenship. They found that doing well in all four areas was uncommon. Few had a job as well as independent housing, especially if they needed personal assistance, and those who did relied heavily on parents rather than other support.

Another common theme in the literature is the costs incurred as a result of impairment. Recent research for the Joseph Rowntree Foundation by Smith et al (2004) demonstrates the high costs of living for disabled people, especially those needing personal assistance.

Although Disability Living Allowance contributes towards the costs, take-up remains low and it only covers about half the additional costs incurred by people with some impairments. At the same time, local authority charges for personal support services have become more common (e.g. Hendey and Pascall 2002). The result is that disabled people remain among the poorest in society.

Housing

Lack of information about the housing needs of disabled people.

Only a limited amount of data is routinely collected by local authorities about disabled people's housing needs and their access to appropriate housing provision. An unpublished review of the literature confirms that the needs of disabled people for adaptations, appropriate housing and support are often not being met. Unsuitable housing in turn raises barriers to employment, friendship and family networks (Twomey 2004).

Relatively few disabled people are home owners or private renters. In the owner occupied market, there is a lack of knowledge of the issues affecting disabled people; the literature emphasises this as a housing barrier. However, not enough is known about the extent of disabled people's exclusion from the owner occupied market or their experience of the private rented sector. (Twomey 2004)

Research on housing allocations and Disability Facilities Grant (DFG)

Some recent government research has helped to fill in some of the gaps in our knowledge about the impact of changes in policy and practice in housing allocations processes and Disability Facilities Grant (DFG):

1. In the social rented sector, a government evaluation of 27 pilot Choice-based Letting Schemes (a new method of allocating housing which is gradually being introduced by all local authorities) found that the development of support for "vulnerable" groups was an area of weakness. Some groups experienced difficulties with the bidding processes. Information was not always provided in accessible formats. (ODPM May 2004)

2. The government has recently carried out a review of the disabled facilities grant (DFG) which funds adaptations for disabled people (*ODPM & DH Oct. 2005*). This review results from a growing concern about: The DFG means test, observed inequity between housing tenures, long waiting lists and increasing demand for adaptations.

Some of the main problems found in the research are as follows:

- The Test of Resources excludes some people in great need, especially among families with disabled children and adults of working age.
- In 2003-4, 47% of all housing authorities had insufficient capital to meet valid DFG applications.
- There is, in some areas, a serious shortage of community occupational therapists to carry out DFG assessments.
- Delays, with serious consequences, may be caused by the wait for occupational therapist assessments (average 97 working days). They may also be caused when the local authority capital budget for adaptations is already fully committed; when applicants are unable to raise their contributions as assessed by the test of resources; when the maximum grant is too low to meet the costs of the work needed, or by a shortage of builders to carry out the work.
- There are inequalities between tenures. Private tenants are in a weak position; tenants of housing associations suffer from divided responsibility for funding; council tenants cannot share in the DFG ring-fenced allocation.
- Information to service users and potential service users is on the whole extremely poor, for fear of uncovering need that cannot be met.
- There is a grave shortage of housing stock suitable for rehousing as an alternative to adaptation for disabled households in any tenure. For families, a wait of three years or more would be likely in 70% of local authorities.

The research makes a number of immediate recommendations for DFG and addresses strategic and other key issues at a national, regional and local level, which would improve the operation of the system. These include abolishing the means test for families and for grants of less than £4,000.

In January 2006, guidelines were published on minor adaptations for housing association tenants (*College of Occupational Therapists, Housing Corporation, ODPM, DH*). Tenants often need these adaptations quickly but they are given low priority. The new guide suggests which items may be safely fitted without an assessment visit by an occupational therapist; this should help to remove one of the main causes of delay.

Addressing the need for more accessible housing in London

The London Plan (*GLA Feb 2004*) has addressed the shortage of accessible housing by setting a target that 10% of all new homes should be built to

wheelchair accessible standards and 100% of all new homes should be built to lifetime home standards. This should produce a minimum of 23,000 new wheelchair accessible homes over the next 10 years. The need for this level of provision is backed up by the results of the London and Sub-regional Strategy Support Studies (*GLA July 2005*); for example, 41,057 households say that they need to move to alternative housing with specialist adaptations.

The GLA also commissioned a 'feasibility study' for the London area (*April 2004*), which included the results of a survey of local authorities, housing associations and local organisations of disabled people. The first stage of the study demonstrates:

- a shortage of accessible housing in London
- a lack of information held by social landlords about the accessible housing that does exist
- long waiting times for adaptations
- huge problems with re-housing, delays in assessment, lack of flexibility and choice and too little information about possible housing options e.g. shared ownership, accessible housing
- lack of support for disabled people in finding a suitable property
- the need for a London Accessible Housing Register (AHR) to provide information to disabled people about accessible housing options
- the importance of linking such a register to good support, advice and advocacy services for disabled people.

The second stage of the feasibility study explored the scope for setting up a London-wide Accessible Housing Register linked to housing advice and support services for disabled people. This concluded that a pan-London AHR should be developed, which is integrated into the development of pan-London choice based lettings and mobility (*GLA Nov 2004*). This is now being taken forward by the 'Capital Moves' project supported by the Mayor, the Association of London Government, the Housing Corporation and the London Housing Federation, which aims to set up a pan-London choice based lettings and mobility scheme incorporating a London AHR by 2007.

Research on housing advice in London has found that housing advice services provided to disabled people in London are often of poor quality and inadequately resourced. Not enough is known about the overall provision of advice and whether or not it meets the needs of particular client groups. What is clear from the body of evidence is that advice for disabled people needs to be person centred and to deal with all the person's needs rather than the fragmented advice that many disabled people receive at present.

(*GLA & Shelter Dec. 2004*)

In London, as in the UK, disabled people tend to be in the social rented sector. In the London Household Survey (GLA 2002), half of all households having a person with a long-term illness or disability rented their accommodation from a social landlord, compared with 27% of all households.

Employment

Many studies have implicitly asked what it is about disabled people that accounts for their lack of employment. There has also been a focus on the attitudes of employers.

The Social Model directs attention towards the social arrangements and public policies that have the effect of excluding disabled people from the labour market. It also takes account of what disabled people themselves think.

Although “Towards joined up lives” concentrates on employment, there are alternatives which some disabled people find more appropriate, like political involvement, artistic expression or voluntary work.

Highlights from the literature include the following points:

- disability is a normal part of life. In London, one person in six of working age has a disability which limits their work &/or daily activities (GLA Sept. 2005, using figures from the Annual Population Survey).
- transitions constitute a key point at which disabled people encounter discontinuity in service provision, for example into paid work, from paid work or from one job to another (Disability Rights Task Force 1999; National Centre for Social Research for DWP 2004).

About one third of disabled people without work want to work – a significantly higher proportion than of non-disabled people. In 2001/02, about half of disabled Londoners of working age were economically active, compared to three quarters of all Londoners of working age (Annual Local Area Labour Force Survey 2001/02, GLA 2003). The unemployment rate for disabled people was 11%, compared with 6.7% for all (the percentages are based on those in work or actively seeking it).

Many people acquire impairments while already in employment. Each year about 3% of those in work become ‘limited in daily activities’, of whom about half subsequently report an ongoing impairment, and 17% of whom lose their jobs within one year. There is greater movement in and out of the labour market for disabled people than for the general population (Burchart 2000). Improving retention would therefore have a significant effect on the employment rate of disabled people overall.

For people out of work but on benefits there can be a poverty trap, and this is particularly acute for disabled people. A recent report for the Rowntree Foundation, based on detailed budgets, comments that

“when disabled people start work and stop receiving Income Support, they may cease to be eligible for a number of passported benefits, including free prescriptions. Potentially, this could increase the amount of unmet costs by a significant amount.”

For example, *“for a person with high-medium needs, an income consisting of the average wage and Disability Living Allowance (DLA) would still not meet their needs. Even when PA costs are excluded, and higher-rate care and mobility DLA is received, a person with high-medium needs would face unmet costs of over £80 per week.”* (Smith et al for Rowntree Foundation, 2005)

While there are public funds such as Access to Work (AtW) and the Independent Living Fund, it is not clear how effective or accessible they are in practice – and there is some evidence that Access to Work is not well known either by disabled people or by employers. A report on Access to Work by the Disability Employment Coalition in 2004 states that ‘Seventy-four per cent of employers have not heard of AtW despite the fact that ‘for every £1 the Treasury spends on AtW, it recoups on average £1.48 in tax and NI contributions’.

Stanley and Regan (2003) stress the importance of issues of security and risk, not just financial gain, to disabled people entering work from benefit. The risks associated with moving into employment are especially high for disabled people if they are on benefits. The casualisation of work (e.g. out-sourcing, temporary and part-time contracts) can lead to less flexibility to respond to the access needs of disabled employees, for example through loss of legal protection. At the same time, disabled people live in a more volatile labour market than most (Christie & Mensah-Coker 1999; Burchart 2000). Disabled people are particularly worried about the effect on long-term benefit receipt of moving into and out of employment (Howard 2004). For example, to receive Incapacity Benefit, a disabled person must be ‘incapable of work’ but, at the same time, they must prove to an employer that they are able and willing to work. This is a significant dilemma. (Stanley and Regan 2003). Disabled people fear having their Incapacity Benefit threatened if they consider employment (Work and Pensions Committee 2003). In order to be confident enough to move into employment, they need to be sure it will last, or if not, that the transition back onto benefits will be smooth.

Government concern over expenditure on benefits can put pressure on disabled people to negotiate these risks and poverty traps. However, the Green Paper on welfare reform (Jan. 2006) proposes a number of reforms which would make it easier for disabled and ill people to enter work. For example, people on incapacity benefits would receive comprehensive return-to-work help.

“Towards joined up lives” shows that there are also some misconceptions amongst participants about benefits and employment and what the current rules are (below p.79). This reflects the lack of easily accessible and reliable information about benefits and employment.

In Jobcentres, the role of Personal Advisor is crucial (*Stanley and Regan 2003*). However, recent research found that, with some exceptions, clients were dissatisfied with staff. They mentioned lack of knowledge of disability issues, lack of basic politeness and respect for individuals, plus lack of privacy, the need to repeat details and long waits. (*Dowson et al 2003*).

There is considerable evidence of prejudice and discrimination against disabled people, both in recruitment and at work. DWP research in 2002 showed almost a quarter of disabled people saying they had experienced discrimination, and in two fifths of cases this was from employers or managers. The commonest form of discrimination was the assumption during the job application process that the disabled person did not have the ability to do the job. In employment, about 16% were treated differently by colleagues, 16% reported dismissal because of their disability, and 15% said they were not allowed suitable time off for treatment. Specific forms of prejudice included negative comments, assumptions about abilities, being patronised and being treated offensively. (*National Centre for Social Research for DWP 2002*)

There is little detailed evidence of disabled people’s experiences at work. The DWP in 2002 found that a third of disabled people felt their impairment made it harder to get and to keep work, over a fifth said it worsened their chances of promotion, and 11% believed they earned less than non-disabled people. Research participants who were “severely impaired” experienced greater difficulties at work than those with “less severe impairments”. The qualities in employers that are valued by disabled people include supportiveness, openness and flexibility, e.g. adjusting working hours, providing equipment. (*National Centre for Social Research for DWP 2002*)

Post-16 Education

This project concentrates on further, higher and adult and community education (ACE). These areas are less well researched than housing or employment. Gaps in research include the finances of disabled students, especially in FE, and extra-curricular life in HE.

Disabled people are under-represented in all three sectors. A survey of disabled young people aged 16–24 by the Disability Rights Commission (DRC) found that, of those who had not gone on to FE or HE, nearly one third had been discouraged because of their impairment. For example, they were worried about support, transport or accommodation. *(Wilson 2004)*

Further education

In 2003, there were more than 650,000 FE students in London, of whom 43,500 (8.2 per cent) were known to have a disability &/or learning difficulty *(figures supplied to GLA by London Central Learning and Skills Council)*. A number of studies have shown that disclosure of an impairment or illness can be a problem for students. There are several reasons for this, including not seeing themselves as disabled, fear of discrimination, worry that the information will go to the wrong people and lack of knowledge of support options.

Research from the learner perspective contrasts the experiences of mainstream students with those on separate courses. Students in the mainstream are mostly satisfied with the quality of learning and support, although they are sometimes below the level of their aspirations. Students on separate courses (usually people with learning difficulties) often lack clear goals; many want to work but have few effective routes into employment. *(Anderson et al. 2003)*

Research on social life shows that non-disabled students often identify benefits of working alongside non-disabled peers *(Ash 1997)*. Some mainstream students have an active social life at college but others feel isolated. Most students on separate courses are away from college life and often unaware of its existence. *(Anderson et al 2003)*

In FE, fear of bullying by mainstream students is common among students with learning difficulties on separate courses. On the other hand, bullying can lead school pupils to request transfer to separate education *(Gray 2002; Wilson 2004)*.

Students identify physical access as one of the main barriers to participation and have useful things to say about it. From the colleges' point of view, there needs to be more clarity on 'reasonableness' of adjustments and on Learning and Skills Council funding *(LSDA 2004)*.

Disability legislation is meant to make equality part of normal provision. However, staff in FE tend to see implementation of the law as an addition to their usual workloads.

Transitions to and from FE

Research suggests that transitions are more complex and difficult for disabled people (Maynard 2000). There is a lack of coordinated support at the transition stage from school to college. Transition from FE to HE is generally better managed, but there is a need for more communication between the sectors (Anderson et al 2003; Sanderson 2001).

Adult and Community Education

ACE is potentially important for disabled people. The Learning and Skills Development Agency (LSDA) have found that it can often be a crucial first step; it provides a setting where disabled students can try things out safely. The more informal nature of ACE allows room for innovative design. (LSDA 2004)

Several studies have recommended more opportunities for non-vocational study in FE, but this is relevant for ACE as well. All groups could benefit, but especially students with learning difficulties and older learners, who often join for social and leisure reasons. (Anderson et al 2003; Simons 1998; Farmakopoulou and Watson 2003; Barnes, Mercer & Shakespeare 1999)

Higher education

In 2003/04, there were more than 370,000 HE students in London, of whom about 4.4 per cent were disabled (figures derived from data supplied by HESA). According to UCAS (the Universities and Colleges Admissions Service), a significant number of students do not declare a disability; the main reason may be that they fear non-admission.

Research on institutions suggests that disability has generally been seen as an add-on in the programme of widening participation in HE. Recently, the DRC has found signs of progress, but also a need for much more consistent provision and awareness. The baseline provision includes lecture notes in advance, intranet provision, and assistance in the library and laboratory (NFER 2003).

Researchers have found that staff regard access to buildings and aids as the main barrier, and these are also crucial for students; however, the students give more weight than staff to attitudes, which if anything concern them still more than the physical aspects. (Tinklin, Wilson & Riddell 2004; Shevlin, Kenny & McNeela 2004)

Two themes occur repeatedly in research involving disabled students in HE:

1. Disclosure. The official policy is to encourage early disclosure of an impairment/illness. However, when students do disclose, the information is not always well handled. Some students say they want to control when and where they give information about their impairment. (*Fuller, Bradley & Healey 2004; Borland & James 1999*)
2. Provision of lecture notes is appreciated by many disabled students but lecturers can be reluctant to provide them. Well-prepared handouts and notes posted online are just two examples of good practice benefiting everyone, disabled and non-disabled. (*Healey, quoted in THES, 20/8/2004*)

The developing Government framework

The report “Towards joined up lives” is published at a time when there are significant and potentially life-changing opportunities for disabled people in the UK. However, there are a number of challenges in exploiting these opportunities to the full. Government has recently published a suite of policy initiatives that could, if effectively implemented, radically change the way in which services are delivered (2005). These are principally the Prime Minister’s Strategy Unit report “Improving the Life Chances of Disabled People”, the Green Paper “Independence, Wellbeing and Choice” and the DWP five-year strategy “Opportunity and security throughout life”, which proposes changes to the benefits system.

“Improving the Life Chances of Disabled People”

In February 2005 Maria Eagle, then Minister for Disabled People, launched the Prime Minister’s Strategy Unit report “Improving the Life Chances of Disabled People” at the offices of the National Centre for Independent Living, a national organisation of disabled people. The report sets out a radical vision for improving opportunity for disabled people:

“By 2025, disabled people in Britain should have full opportunities and choices to improve their quality of life and will be respected and included as equal members of society.”

The report identifies a wide range of barriers faced by disabled people:

Attitudinal barriers, for example among employers, health professionals and service providers, and among disabled people themselves;

Policy barriers, resulting from policy design and delivery, which do not take disabled people into account;

Physical barriers, for example through the design of the built environment, transport systems and so on;

Empowerment barriers, as a result of which disabled people are not listened to, consulted or involved.

The Government justifies its intervention on the basis of social justice, benefits to the economy and value for money. It sets out a centrepiece for the strategy in the promotion of independent living, providing disabled people with choice, empowerment and freedom. The overall aim of the strategy is to allocate resources and deliver services in ways that:

- personalise responses to need;
- enable people to have choice and to be empowered over responses to need; and
- support disabled people to help themselves.

One of the key recommendations is the direct involvement of disabled people, primarily through local centres for independent living, which are thought to be well-placed to provide advice and information, advocacy support and practical assistance in managing individualised budgets. The report also recommends:

- Establishing an Office for Disability Issues headed up by the Minister for Disabled People;
- Establishing a National Forum for Organisations of Disabled People;
- Improvement to the availability of independent advocacy;
- Easier access to advice and information;
- Consideration of the adoption of updated Lifetime Homes standards and improvements to the use of accessible properties and disabled facilities grants;
- Increased local authority accountability for making sure that all aspects of disabled people's transport needs are taken into account;
- Introducing individual budgets for disabled people which coordinate services to which they are entitled, giving greater choice over the mix of support either through direct payments or direct service provision;
- Improving advice services available to disabled people, and addressing existing problems with suitable housing and transport;
- Improving support for families with young disabled children by making child care and early education accessible, meeting additional needs of families with disabled children and ensuring services are centred on disabled children and their families, not on processes and funding streams;
- Putting in place mechanisms for effective planning for the transition to adulthood and giving young disabled people access to more transparent and appropriate opportunities and choices; and
- Improving support and incentives for disabled people obtaining and remaining in employment, including reform of benefits, more effective work focused training and the improvement of the Access to Work scheme and other in-work support.

“Independence, Well-being and Choice”

In March 2005, the Government (*Department of Health*) published a Green Paper setting out proposals for the future direction of “social care for all adults of all age groups in England”. The paper establishes “the principle that everyone in society has got a positive contribution to make to that society and that they should have a right to have control over their own lives”. It sets out “an ambitious programme for the next 10–15 years of services, which will be person-centred, proactive and seamless. The lives of people who use social care will be transformed by giving them more control and choice.”

The key proposals contained within the report include:

- wider use of direct payments and the piloting of individual budgets
- greater focus on preventative services
- a strong strategic and leadership role for local government
- encouraging the development of new and exciting models of service delivery
- harnessing technology to deliver the right outcomes.

The Government White Paper “Our health, our care, our say: a new direction for community services” published in February 2006 confirms the vision outlined in the Green Paper “Independence, wellbeing and choice” of “high quality support meeting people’s aspirations for independence and greater control over their lives making services flexible and responsive to individual needs.”

The measures in the White Paper are designed to ensure that

- People will be helped in their goal to remain healthy and independent.
- People will have real choices and greater access in both health and social care.
- Far more services will be delivered – safely and effectively – in the community or at home.
- Services will be integrated, built round the needs of individuals and not service providers, promoting independence and choice.
- Long-standing inequalities in access and care will be tackled.

A new deal for welfare: empowering people to work

This Government Green paper published in January 2006 sets out a “modern vision of full employment” with an aspiration for an employment rate of 80%. It acknowledges that many disabled people are able to and want to work.

The proposals in the Green paper are underpinned with the principle that, with an increase in help and support, there should no longer be an automatic assumption that just because someone is ill or a disabled person they are incapable of doing any sort of work. It asserts that action is needed on a whole range of fronts if government is to encourage and support people to overcome the multiple barriers to working that they face. The main proposals are

- Replace Incapacity Benefit (and Income Support paid on the grounds of incapacity) with a new 'employment and support allowance' for new claimants by 2008. This will have an enhanced employment support component for those people undertaking mandatory work-focused interviews and later work-related activity.
- Those who cannot engage in any activity because of the "severity of their condition" (though they will be given help and support to find work should they wish) will receive an enhanced support component.
- Introduce mandatory work-focused interviews supported by a mandatory action plan of return to work activity for new and existing claimants. There will be benefit sanctions for those who do not comply. These sanctions would reduce the benefit paid in "slices", ultimately to the level of Jobseeker's Allowance.
- Revise the medical assessment (personal capability assessment), focusing upon ability and support needs (capability and capacity) rather than incapacity.
- Provide in-work support to ensure people continue working - with a Return to Work Credit to ensure people really are better off in work.
- Simplify Statutory Sick Pay (SSP) to enable employers to better manage sickness and to address the flow of people from SSP to incapacity benefits.
- Change the rules for Jobseeker's Allowance and increase contact with lone parents to limit the flow of people from other benefits to incapacity benefits.
- Take steps to increase their awareness of the opportunities on offer, for example through providing information at medical examination centres when claimants attend a review.
- Place employment advisers in GP surgeries.
- Financial incentives for local authorities to engage with the private and voluntary sectors to establish local back-to-work schemes, for people claiming benefit on the basis of incapacity.

3 Participants in the research

This chapter presents information about the participants in the research, using the monitoring approach discussed in Chapter 2. The monitoring form is in Appendix D. The data provided by participants is analysed on the social identity of and barriers experienced by the participants.

Sources of participants

196 people expressed an interest in participating in this research. 50 of these came from responses to a mailing to 1,320 households in the London Household Survey. 91 came from responses to contacting a further 250 people on the Disability Capital list. 1 person responded through both the London Household Survey and Disability Capital. The remaining people came from the “snowballing” impact of referrals from disability organisations (25 people), actual participants referring other people as potential participants (20 people), and a teacher referring their students (9 people).

In the end, 123 of the 196 people expressing an interest actually participated in the research. Not all 196 participated due to various factors. A variety of dates, times and focus group venues was offered to the potential participants, but these did not suit everyone, and the project timescales and budget did not permit greater flexibility.

Of these 123 participants, 19 came exclusively from the London Household Survey; 45 came exclusively from Disability Capital; 1 came as an overlap in both these sources; 31 came from referrals by various organisations contacted; 18 came from referrals by people who attended a focus group; and 9 came from their teacher’s referral.

Of 123 total participants:

- 76 people took part in focus groups;
- 42 people were interviewed, either in person or by telephone;
- 5 people requested, received and responded to questions via email.

Monitoring forms were completed by 117 of the 123 participants; 6 people did not complete the forms at the end of their session, or failed to post or email them back later.

Monitoring Results

Social Identity

Gender

The 117 monitoring forms received were from:

- 52 men (44%),
- 64 women (55%)
- 1 transgender participant.

Age

The 117 monitoring forms received were from participants ranging in age from 21 to 87. The researchers are aware that some nine participants who did not complete monitoring forms were in a younger age range – 17 to 18.

Table 1: Age of participants

<i>Age Band</i>	<i>Number</i>	<i>Per cent</i>
20-29	6	5
30-39	15	13
40-49	30	26
50-59	17	14
60-69	10	8
70-79	6	5
80-89	3	3
Age not given	30	26
Total	117	100

Ethnic Origin

Minority ethnic groups accounted for 29% of the 117 participants who completed monitoring forms – a good reflection of London's overall population.

Table 2: Ethnic origin of participants

<i>Ethnic origin</i>	<i>Number</i>	<i>Per cent</i>
Asian or Asian British	4	3.4
Black or Black British	19	16.2
Mixed ethnic origin	3	2.6
Other minority origin	8	6.8
White	81	69.3
Not answered	2	1.7
Total	117	100

The 8 participants who placed themselves in the "Other" group (in Table 2 above) provided the following 12 different self-definitions of "Other":

All; Australian; Caribbean; Celtic; Greek; Human; Irish/Sri Lankan; Japanese; North African; Scottish; White Irish

Sexual Orientation

For the 117 participants who completed monitoring forms, reported sexual orientation was as follows:

- 75 % (85 people) – heterosexual
- 19 % (22 people) – no choice selected (see participant comments below)
- 3 % (4 people) – gay
- 3 % (3 people) – bi-sexual
- 3 % (3 people) – lesbian

This question produced the highest number of non-responses.

Of the 22 participants who didn't select any pre-defined choice, two wrote the following comments:

"Does it matter?"

"Ethnic origin, sexual preferences, and age is a waste of space on this form.

More constructive questions."

Religion or Faith

For the 117 participants who completed monitoring forms, 54 (46%) did not state a preference. Other religions/faiths are shown in the table below:

<i>Religion/Faith Preference</i>	<i>No.</i>	<i>%</i>
Totals	117	100
Breakdown of Total:		
None stated	54	46
Church of England	17	14
Roman Catholic	10	8
Christian	7	6
Muslim	7	6
Atheist	3	3
Hindu	2	2
Humanist	2	2
Others (15): each cited only once	15	13

Barriers

Barriers – ranked

As described above, people were asked to pick the three biggest barriers that prevented them from doing what they wanted to do. They were asked to rank them with “1” for the biggest barrier, “2” for the second biggest and “3” for the third. Some people just ticked three boxes without ranking them, or put “1” for each choice. Not everyone picked three areas. Finally not everyone completed this section.

Table 4: Barriers - all Participant ranking of barriers

Barrier	1st choice		2nd Choice		3rd Choice		4th/lower	
	no	%	no	%	no	%	no	%
Physical Access to buildings, streets, transport	51	44	8	7	14	2	1	>1
Access to written word	11	9	8	7	2	2	4	3
Access to pictures and images	-	-	3	3	2	2	1	>1
Access to speech or conversation	8	7	4	3	5	5	1	>1
Access to other sounds	-	-	4	4	-	-	4	4
People’s attitudes to you	30	26	35	30	20	17	1	>1
Stressful situations	6	5	27	23	27	23	3	3

Totals do not add to 100% due to possible multiple answers from each participant.

Adding up the numbers of everyone who chose each barrier, the most difficult barriers for most people were:

People’s attitudes to you	86 people (74%)
Physical access	74 people (63%)
Stressful situations	63 people (54%)
Access to written word	25 people (21%)
Access to speech or conversation	18 people (15%)
Access to other sounds	8 people (7%)
Access to pictures and images	6 people (5%)

(Note that because people declared more than one barrier, the numbers add up to more than 100%.)

This underlines the points made repeatedly by participants in this research about the importance of people’s attitudes, physical access and stress across the three areas.

Barriers – other

Participants were invited to write in any other barriers they experienced. These were:

- A system that has failed me on many levels
- Access in general to services, decision makers
- Accessing information to find help for myself
- Physical access to theatres, leisure centres
- Ban strobe lights in streets and public places
- Barrier 1: lack of appropriate help because of lack of understanding of my illness (ME)
- Barrier 2: employment
- Barrier 3: education
- Being treated as not fully human/stupid
- Belief that everyone can access information on email/web sites/texts
- Harassment
- Lack of information
- Pain, inaccurate information re physical access
- Parking in central London
- People in authority who will not accept my problems since retirement
- Public transport - train stations and tubes
- Reclusive periods
- Travelling, having to stand

Other Factors about Participants

Monitoring was undertaken to endeavour to ensure a spread of different characteristics of social identity that reproduced London's population as a whole. The use of monitoring by barrier, rather than impairment, reflected the Social Model approach to the research, although as London statistics have been previously collated on impairment, direct comparison was not possible here.

The monitoring form did not ask for details of people's current housing or employment status, nor about their experience of education. The aim of the research was mainly on getting participants' views and experiences of all three areas, regardless of their current status. In retrospect including some questions about this on the monitoring form might have provided useful information. However, space issues on the form might not have permitted this.

By definition, participants will be those who were confident enough to put themselves forward to speak with the researchers. In the case of focus group participants, they will also have been confident enough – and had the means and support – to travel to the venue. Disabled people who experience extreme social exclusion may not be present amongst the participants. However, tackling the issues raised by those people who did take part will push back the

boundaries of exclusion and can only benefit those who were unable, or unwilling to take part, or who are too excluded to have been reached during the research process.

In focus groups and interviews, participants were asked about their current accommodation. The large majority lived in local authority property, a small number lived in specialist accommodation provided by a disability organisation and a smaller group were in owner occupation. Only three people mentioned privately rented property.

The majority were not at present in work. Those who were tended either to have funding through the Access to Work scheme, or to have employers with a strong understanding of disability equality. Focus groups were held both during the day and during the early evening to give working disabled people an opportunity to participate, but it appears that the numbers of participants in work does not reflect the number of disabled people who work. Because of the logistical difficulties of getting permission from employers, the researchers did not go to workplaces to interview disabled people, or conduct focus groups, whereas focus groups were held in educational establishments. This may have had an impact on the sample.

To summarise, the sample probably included a relatively low number of disabled people who were

- isolated
- in employment,

and a relatively high number who were

- in the social rented sector
- students.

4 Findings across all three research areas

“I want to be independent but it’s a constant fight to get things done that you want to get done.”

“It makes it that much more difficult to go into work or college as you’re fighting just to live in your own home.”

Key Issues

- The three research areas of housing, employment and post-16 education are closely linked, and problems in one – in particular in housing – will have a negative effect on the others.
- Easily accessible, comprehensive, accurate and timely information is vital to disabled people achieving success across the three areas.
- Problems in acquiring information in respect of benefits and support together with a lack of accessible formats, bureaucracy, and unclear guidelines were common across all three areas.
- Disabled people experience discrimination, harassment and lack of awareness and understanding, not only from the general public but also from professionals who come into contact with them on a regular basis.
- Services for disabled people across the city are inconsistent and not coordinated. In some cases neglect by statutory services can lead to isolation and social exclusion.
- People with hidden impairments experienced a serious lack of understanding, and consequently had their rights undermined.
- Participants perceived no evidence of a proactive approach to promoting disability rights, such as raising awareness, enforcing the law and committing sufficient resources.
- London was generally felt to be more physically accessible than other cities, but the people were perceived to be less friendly and helpful.

No one’s life falls into neat pigeon-holes. Housing, employment and post-16 education are part of the actual or potential tapestry of life for any adult and as such are generally interwoven. Disabled people may find that their ability to operate effectively in one of these areas is affected by their situation in another. For example, the personal resources, such as energy and time, absorbed by living in unsuitable housing or fighting discrimination in other areas, can have a negative impact on someone’s capacity to work or study. Or

someone may have had limited access to education and not be able to achieve the qualifications they need to get appropriate or satisfying work.

This chapter draws out some underlying themes and issues which emerged in all three areas as being major barriers for disabled people. It includes points made about London in particular and suggestions that participants made about what the GLA should do.

In this and the three following chapters, participants' own words have been used. Sometimes participants use words or express things in ways that demonstrate a lack of information and knowledge of what is available. The researchers have not changed their words to be 'correct'.

Cross-cutting Links and Themes

Participants highlighted some of the practical issues that link the three areas within disabled people's lives.

Most often mentioned issues

Accessible and affordable housing and links to other areas

Accessible and affordable housing is a prerequisite for access to employment and education. Lack of appropriate housing and long delays in the provision of adaptations were barriers which were mentioned by a majority of participants. Linked to this was the risk of losing one's home if it became impossible to work.

"I was thinking about getting back into education but until my housing situation is sorted out I don't have the energy to be fighting in both areas."

One participant wanted to do a degree:

"but if your housing is not right, how can you give your attention to education and employment?"

Similarly, unsafe and unsuitable housing meant that some people could not get back into work if they wanted to after a period of not working.

Several participants mentioned the links between all three topic areas:

"These three areas are interlinked and are dependent on each other and not independent as managers and politicians would like to think. By fixing one area it will have a positive effect on the other areas."

"If you link the three areas together you find there is a problem with all of them. They reflect the key features of society. If you can't get into one of them you're not seen in my view as part of society."

Information

The lack of comprehensive, consistent and accessible information was the strongest theme to emerge in all three areas. Information was crucial so that people were informed of their rights and entitlements, and of services that were available to overcome the barriers in each area.

People who attended focus groups found the exchange of information about what is available to be very useful indeed. There was a wide variation of knowledge across the participants.

“Information is the most important thing you can get if you become disabled through illness or accident. At that vulnerable stage you need information then about what is available.”

People often found out things by accident as happened in the focus groups when participants exchanged information about services they had accessed. There seemed to be no systematic way of letting people know what was available across the board. Each piece of information had to be looked for in a different place and was provided by a different source. There was no linking or coordination of information.

“No one checks that you know about all the other services. For example when you get Disabled Living Allowance they don’t tell you what else you can apply for.”

People felt excluded in relation to obtaining information. One participant commented:

“You have to be a member of a special club to get the information. This should not be the way, everyone should have access to information very easily with no complications.”

Sometimes people had come by important information by chance. One man knew the procedure (in relation to housing) because he had spoken to a woman in a meeting who told him what to do.

One agency might say one thing, and another agency would say another thing. There seemed to be no national or local umbrella or overall responsibility for coordinating and providing information. As one participant said:

“even the professionals don’t know where to direct you – no-one knows”.

Many people said there was a need for a one-stop information service which crossed departmental and agency boundaries.

It was suggested that anyone who applied for any particular benefit should automatically be sent information about all other services. A proactive approach should be taken by statutory agencies, not leaving people to work things out over a number of years. Several participants suggested that a Directory of Services in London which was maintained by the GLA and into which all local councils, CABx, voluntary agencies and so on could link would help to disseminate the information and to ensure some consistency.

One participant used her local library a lot, where there was information about specialist housing associations and equipment. She felt that if she was not a literate library user she would not have found this information.

Some participants felt that information should be available at hospitals and in surgeries:

“when you first become aware that your health is declining, you need to have all entitlements made known then.”

Another participant who rang her local council disability call centre was told they could not give her the information: “get your carer to do it”.

Poor information dissemination led to frequent misconceptions about what is available. An important theme linked to information is that many disabled participants in this research were not being properly informed about available services, or were being denied access through being given misinformation, for example about benefits, by staff in the agencies concerned.

Problems with information were demonstrated throughout the research with participants sometimes showing misunderstanding and misconceptions about systems and procedures, support and benefits. Such misconceptions were apparently trivial, but in some instances they had a serious impact, preventing participants from doing what they wanted to – for example, misconceptions about benefit implications prevented people seeking work.

Participants also stressed the need for information to be available in a range of accessible formats. While the internet was a valuable tool, not everyone had access and many web sites were not formatted or presented appropriately and were not accessible.

On the other hand, some good practice was reported: for example

“[My] Council has a magazine that updates you on what is going on in the borough and all their literature is available on tape, they cater well for blind people. There is a leaflet called What If? which directs you to contacts in social

services, dentist, advice centres etc. They cover everything and it's available in many formats, they take into consideration people with different disabilities."

"The disabled forum was good. If I wanted to know something about services for disabled people in the council, they had the leaflets and knowledge under one roof. There is a huge booklet provided by the council with information for disabled people, including contact numbers, services, who does what. This should be standard practice for all councils."

Benefits and Support

A large number of participants described the problems they faced in obtaining the range of benefits available. These were common problems in all three areas. These are described in more detail in each section.

The first barrier related to information as mentioned above: how to find out what might be available, who would be eligible and how to claim. As above, this was an area in which more clear and consistent information was needed.

The next commonly experienced barrier related to the stress of dealing with a massive amount of bureaucracy and red tape. It could be difficult for some people to attend offices in order to make claims. The forms were not always accessible and there was often no one available to provide assistance. Staff showed little understanding of disability issues. The approach of the agency's staff added to the barriers created. Participants felt that they were constantly being asked to provide repeat information about themselves.

"My Occupational Therapist changed all the time, so I've been explaining my situation over and over again; all they have to do is keep a file in a central place"

Delays were also a common experience reported by a majority of participants.

Participants mentioned the inability of the system to respond flexibly to changing circumstances, for example, moving in and out of work, or taking up studying. Many people, rightly or wrongly, were afraid that if they did try to work or pursue a course of study, they might lose current benefits and not be able easily to reclaim them if need be. For several people who had succeeded in obtaining certain benefits, the specific use to which they were supposed to put those benefits seemed to them to be artificial – people's finances are not neatly compartmentalised. As one participant said:

"It's like the Disability Living Allowance – a person who will need a car to get to work or education to be an active part of society may not do so because she needs the money to live, to eat."

Attitudes and Assumptions

"It's taken years just for the basics to be accepted, like not using nasty names to describe disabled people."

"People don't look at you and see how you can be an asset. They see you as a problem, hassle, not as a person."

"It's hard to be positive about being disabled as usually being seen as disabled is a negative thing, Usually you are regarded as silly, sexless and worthless."

People's attitudes and assumptions about disability and disabled people's capabilities was a clear barrier in housing, employment and post-16 education. This could be particularly damaging when the assumptions were being made by people in positions of decision making power.

"People like you – assuming all blind people the same, assuming they must all know each other!"

"People see us as devalued."

Even within a disabled person's immediate circle and those who could be expected to support them attitudes could be disabling:

"My parents refused to recognise my disability and the medical profession discounted my condition."

Discrimination

"Disabled people suffer triple discrimination. You have to have extra determination to succeed. You suffer instant unconscious reactions and discrimination. People's attitudes – some people over-compensate. On the one hand some people are willing to help because you are disabled. On the other hand some one else might resent you – their body language shows. For disabled people body language is even more important – we are sensitive to little cues about disability."

People's responses to disabled people ranged from outright discrimination to insensitivity and lack of knowledge and understanding. These responses presented serious obstacles in all three areas.

A young disc jockey with learning difficulties described what he and his friends experienced when they tried to go to mainstream clubs and music venues. They were usually turned away by the bouncers in a rude and dismissive manner, even though the venues are licensed by the local authority and the staff should

have had some training. He felt he and young people like him were unfairly excluded from social and leisure activities because of their impairment.

Gatekeepers

Related to attitudes, many contributors felt that the gatekeepers to services and benefits, such as Occupational Therapists in housing, Disability Employment Advisors and other job brokers in employment, and college staff in education, presented an additional barrier. They often had poor understanding and a lack of training, compounded by condescending or rude attitudes. As a result, disabled people could be denied access to the services they needed, or the opportunity to work:

“The [job broker] said that I had to apply for jobs in writing, which I explained to them because of my disability I can’t do. They informed me that I had the wrong type of disability to make most of their services”

One Size Fits All ... Badly!

This was another point made emphatically in relation to all three areas. Disabled people are as diverse as everyone else and will have a range of access and other requirements. Putting in ramps and installing lifts only addresses a small number of barriers for some disabled people. People with different impairments experience different barriers and so require different solutions and approaches. These positive changes are often of benefit to everyone.

Points made by some participants

Harassment and Intimidation

A good number of participants mentioned harassment from neighbours and people outside their homes. This is discussed in more detail in Chapter 5 under housing. Harassment at home (from neighbours or other tenants in a communal building) was the main problem reported, but these concerns also arose about employment (bullying and harassment from colleagues) and in education less often.

It was a serious concern that police and local authorities did not always respond appropriately to incidents at people’s homes. This suggests the need for more training for police and housing managers in particular.

Hidden Impairments

Participants discussed the difficulties that people faced when they did not obviously have an impairment or medical condition – “you don’t look ill” – from work colleagues, or in housing, or on public transport. People failed to understand why something might be a barrier. For example, someone who used a bike to aid mobility but could not carry it up stairs found that people did not believe that they could do one but not the other. Others needed to be able to

sit when using public transport but this was not understood by other passengers. Many people said they were tempted to use a stick sometimes just to send a message to people.

“I hate labels and stereotypes but sometimes you need to label yourself to get any consideration. When using public transport I sometimes carry a walking stick to ensure that I get a seat. People are only helpful when they see obvious disability. It makes it then very hard for those of us with hidden disabilities.”

“People’s attitudes to me are not positive as I have a hidden disability. I can get very anxious and hyper at times, and people think I am being abusive and nasty. I cannot help it and they do not understand that this is a form of disability. People need to be made a lot more aware of the different kinds of problems.”

Inconsistent Support

Inconsistency in services provided by local authorities, housing providers and educational institutions was mentioned by a large majority of participants. There was no apparent way of checking the quality of what was delivered and provided. One participant said that there should be an audit of all services for disabled people, to see to what extent the services met acceptable standards.

On the other hand, a good number of participants spoke more positively about the role of independent disability organisations at local level, and the work of voluntary sector organisations which ran drop in and information services. They were often seen as more useful than public sector providers, and provided support, social contacts and information to a consistently higher standard. Participants suggested that a network of independent support and drop in centres should be promoted and resourced.

Neglect by statutory services, isolation

As a result of poor or inconsistent services some disabled people could not leave their homes and were isolated and unsupported, literally out of sight and out of mind. For several participants the failure of statutory services to meet their needs was an additional barrier to getting other services. There was no one to help with small repairs or shopping for example. The failure of statutory services to identify and meet the needs of disabled people in the community leads to isolation.

Several participants spoke of feelings of isolation because they could not leave home much and they lived alone. This was vividly illustrated by the

case of two brothers who had been largely confined to their home for about 20 years until a new social worker was assigned to them who put them in contact with an organisation which provided training and education.

Points raised by a small number of participants

The Law: enforcement and campaigning

While some participants noted that legislation had brought about improvements, a much greater number felt that it was “toothless” and that it was not enforced rigorously enough. The Disability Rights Commission (DRC) was also seen as ineffective in terms of enforcement. Some participants suggested that there was a need for an independent and well funded body, perhaps comprising all the disability organisations, which could lobby for improvements and implementation of policy. Such an independent body could also allocate funding to promote disability rights and services.

Responsibility and Resources

Participants said they felt there was a lack of will and real commitment to change from national and local government, and from employers and housing providers. One problem was that at the top – at government level – a single department with overall responsibility for disability had not yet been established. This meant policy was fragmented.

Linked to this was a shortage of resources at national and local level, and again, a fragmentation of the sources of funding for services.

Promotion and Awareness

“Society needs to be exposed to real disabled people, to positive images of us, different races, impairments, sexualities. Many people only know about people with physical disabilities and are not aware of other disabilities. People need to be educated.”

Many people spoke of the need to take a more proactive and high profile approach to promoting disability rights and thereby raise awareness and bring about a change in people’s attitudes and in the overall culture and ethos of society.

“You don’t see any positive images of disabled people in the media or in our schools. Disability education needs to be on the top of the media and public’s agenda.”

Participants said there should be posters on bus stops and in supermarkets, on buses and in tubes, all places where people would see them clearly and start to become more aware of disability issues.

One participant pointed to the publicity campaign relating to London's Olympic bid and asked why a similar campaign could not be launched on disability rights.

"We should be doing things in London in relation to disability issues and awareness before we try and get the Olympics in London."

In a closely related point many participants highlighted the need to educate and raise people's awareness of disability issues. This crossed all three areas. In addition to the general public, it was essential that staff providing access to services received disability equality training. This also applied to the police and local authority community safety departments, as there is evidence in this research of a poor response to the harassment of disabled people (see chapter 5).

Issues for London.

Is London different?

While not all could comment on this topic, a good number of participants had either previously lived outside London or had family and friends who they visited in other parts of the country so they did feel able to comment.

Participants were asked whether they saw any differences between London and other parts of the country:

"I think these problems exist wherever you are but as London is a big city, it should be doing more to be in line with other European countries. I think living in London as a disabled person has its pros and cons but generally I think as a disabled person I'm better off in London, as transport is more reliable and possible, and there are more volunteer organisations and facilities."

On the positive side, people generally felt that transport was improving in London and was probably better than in other areas, particularly rural areas with infrequent bus services.

"Even though transport is dire, it's getting better and more reliable [in London] compared to other areas."

"London seems to be better than other cities in terms of transport and it is increasing but not quickly enough. The attitudes of some bus drivers is ridiculous and so unhelpful at times. They are always in a rush keeping to timetables and there is a risk of injury to passengers trying to get off the bus before the driver accelerates off. These are not only concerns for disabled people, but for elderly people, parents with children – actually everyone."

Some participants felt there were more facilities in London, but that:

“the problem is that London is so big you need some form of comprehensive directory of all the services available for disabled people.”

“I think London is so different depending on what borough you live in, or where you work or go to college. People’s attitudes and beliefs towards the treatment of disabled people can vary from one street to another. So to ask if London is different is very complex. I think we may have more access to information and services, but whether or not the level is high and professional is another thing.”

“London is probably the most accessible city in England. [...] 90% of the time London is way ahead of everyone else.”

However several people also felt that Londoners’ attitudes are “nastier”, people were rude, stressed and always in a hurry. They were less likely to help or to be aware of disability issues. Outside London, people were more approachable and flexible.

“I think people in London have a less caring attitude to anyone who is different. They generally are unfriendly and keep themselves to themselves unless you are in a close situation like work. In the North, where I have lived for a while, people are more genuine and helpful, but services aren’t as good, whereas in London services are good, but some people aren’t as considerate.”

Housing was felt to be very hard in London, because of the shortage of suitable accommodation and the fragmented system for allocating housing across the boroughs and between local authorities and housing associations.

The GLA

Participants made suggestions as to the role of the GLA in promoting disability rights.

The points below reflect perceptions and understanding of participants themselves and may not reflect work already underway in the GLA. In some cases what they suggest is not within the remit of the GLA (for example monitoring compliance with legislation). In other cases, the GLA is already working on these issues, for example housing.

Points raised included:

- The GLA should have a cross-London role in monitoring and enforcing compliance with legislation.

- The GLA should actively promote consistency of services across the boroughs and play a coordinating role.
- The GLA would be ideally placed to collate and disseminate comprehensive information about disability entitlements and services.
- The GLA should strongly encourage boroughs to think about the design of all new houses.
- The GLA should act as a watchdog for disability rights in London.
- The GLA could stage a Disability Showroom to promote good practice and provide a central resource area.

Chapter 5 Housing

“To feel equal and independent I need housing which removes barriers.”

Key Issues

- Delays, cost and poor quality of adaptations to housing and problems with maintenance.
- A serious shortage of accessible housing, a resultant lack of choice and inappropriate housing provision.
- Support and advice services for disabled people are inadequate and not joined up.
- Lack of information about housing options and rights. Information difficult to get and often provided in inaccessible formats.
- Not knowing where to go for information, advice or support.
- Financial issues including the benefits system and its excessive bureaucracy. Financial support for disabled people is complex and difficult to access, which can lead to hardship and lack of choice.
- Poor housing services from local authorities; some discriminatory practice.
- Harassment by neighbours, lack of personal security and poor police and local authority responses.

It would seem that very few of the participants were in owner occupation or private rented accommodation. Where it is possible to tell, most of the comments made by participants relate to local authority provision, and to a lesser extent housing association accommodation.

Most often mentioned issues

Adaptations and maintenance

Of all the topics covered in this research, adaptations was probably the one that provoked the most anger and the highest number of complaints, particularly of local authority housing and social service departments. This was an extremely strong theme for the majority of participants.

“Any adaptations that I’ve needed I’ve had to push for them and threaten going to the Ombudsman before they have done anything. I can only get anything done by complaining and threatening legal action. If I was a quiet person I would be living in the ghetto struggling to live in my own home.”

Participants spoke about very long delays in getting adaptations carried out – even minor ones. One person waited 18 months for a shower to be fitted. The housing association used its own contractor who was not informed about the person’s impairment and what type of shower would be required. The end result was not appropriate and in the process the heating system broke down, meaning another week of waiting for it to be repaired.

Some participants had found that the choices they were given for adaptations were inappropriate, limited or even non-existent.

“As I did not agree with Adaptations, I told them to leave the property. There was no room for discussion on behalf of the Occupational Therapist (OT). It was her way or the highway, which puts me in a dangerous position as I am not living in a house that is suitably adapted for a blind person. The scary thing is that not all people are as vocal as me so will get much worse deals.”

The need to ask for consent from private landlords in order to make basic adaptations was mentioned:

“I felt I had to go down on bended knee.”

Several participants complained about the amount of bureaucracy involved in getting adaptations and the number of forms to be filled for even simple jobs.

“My Council is not forthcoming in adapting properties. There is so much red tape, form filling and politics. You feel you are begging with your bowl to get things done. It makes me extremely angry. I had to threaten to go to the press.”

“The OT informs you of the equipment or adaptations you may need but whether or not you get them is another thing, as it always comes down to cost and lack of budgets. Five years ago you would immediately get the things you needed to partake in life fully but now there is so much red tape and services aren’t known by the public.”

Participants found they had to pay for adaptations, especially if they were in employment.

“If you work you have to pay for adaptations made to your house.”

Owner-occupiers in this sample had to meet a large proportion of costs for adaptations, and mostly had to get the work done themselves. They had mixed views on the helpfulness of local councils. (It is in fact the case that a ‘Test of resources’ is currently applied for Disability Facilities Grant (DFG), although this

is currently under review by ODPM. The means test for families with disabled children was abolished on 31st December 2005}.

The cost of adaptations meant in some cases that it could be cheaper for participants to do it themselves. One person was visited by an occupational therapist who assessed a need for handrails for the front steps: she was asked to pay £60. Her son did it for her instead and it cost £12.00.

One man noted that shops selling specialist disability equipment were often very expensive. It could be much cheaper to go to B&Q and do one's own adaptations to equipment – but this meant having someone who could help with this process.

One participant said:

“I’m quite independent and have learnt to adapt as time has gone by. I’m now totally blind and don’t ask the council for anything. I do it all myself or get family to help; if not you find out that you are paying more for the works being done by the council than employing someone independent.”

Another participant suggested the need for a "handyperson" service in each borough to be used for simple DIY jobs.

Two people made the point that adaptations, once made, should be kept for the benefit of future disabled occupiers.

“My council say they need to re-house me in sheltered accommodation but are going to take out all the adaptations in my current home, which is such a waste of money. It should be given to another disabled person, as it’s an excellent house but is just too big for me on my own.”

Delays in getting simple repairs and maintenance jobs done were common experiences for many participants. Sometimes that could leave people without essential services.

“I do not know where to go for help and advice. When I am in trouble, the warden does not help [living in council “disabled friendly” housing]. For example when I need a light bulb changed I have to call the council and sometimes have to wait for two weeks before someone can come by. I wish the council would make light fittings adjustable so that I can at least do simple things myself. I depend on neighbours a lot.”

Some people also reported poor management of properties and their estate. One local authority had devolved its property to tenant

management companies, which were not well run and led to poor estate maintenance. Delays in repairing lifts were fairly routine.

A much smaller group of people did point up more positive experiences:

“My council has been brilliant with adaptations such as lowering worktops and cupboards, widening doors. The bathroom and shower are well modified.”

“The Housing Association comes within days and measures up for any adaptations needed. The longest wait has been six weeks. These quick responses help disabled people. They are now more disability aware. There should be a template for other associations in regard of disability needs.”

Shortage of accessible housing, lack of choice and inappropriate provision

The evidence from participants suggested that there was a shortage of suitable accommodation in general in London for disabled people. The amount of money spent on social housing was a fraction of what is needed. There was not enough accessible housing. Disabled people’s needs were not taken into account in some regeneration schemes or even much new building.

“I was living in a hotel for three years as there were not enough accessible properties. I then was offered a one bedroom flat where my wheelchair was unable to turn around in the flat but they said I had to take it and that they would make the adaptations. It took two years to make the adaptations. In the meantime I got married and had a son. I’ve asked them to re-house us into a larger property but they say nothing is available.”

“So they allocate you poor housing that is not suitable for your needs – a blind person, top floor of tower block, with lifts that don’t really work. It builds up and makes me depressed.”

One participant had just bought a flat after some time in private rented accommodation. It was very light and warm, in a quiet street, and newly built with good design features. However it was on the first floor, with fourteen stairs, which was a real consideration for her. No ground floor flats were available. She had to make a compromise because the other aspects were so good and take a risk that she could continue to manage the stairs.

One female participant lived in a three storey house but could not easily get to the top floor where the bathroom was. She had to take two painkillers, “wait for a while” and then try to climb the stairs.

Participants also mentioned a lack of choice as to private, owner occupied, Housing Association or Council accommodation.

“It’s the Council or nothing, those are the options I’ve been given.”

Because the availability of accessible housing is extremely limited, and people have little choice in where they can live, participants found that they could be housed away from family and friends, who formed their support networks. This could leave them feeling very isolated. One participant said that if it wasn’t for family and friends she wouldn’t be able to do half the things she did – she would feel isolated without them. Another said:

“My main problem is isolation. If there is a problem there is no one around to help me.”

Isolation could in turn deprive people of information and reduce their chances of employment or education, as became apparent in some of the interviews.

The research indicated that more purpose built housing was needed, and several people mentioned Lifetime Homes, which would suit the needs of everyone over time from babies to disabled people to elderly people. Participants felt architects who design housing should receive mandatory training in disability issues.

“Properties need to be built around disabled people. Make them more enjoyable to live in. Changes will not only benefit disabled people but also the community.”

On the other hand, it was also essential not to take a “one-size-fits-all” approach. Disabled people did not all have the same requirements in terms of access and adaptation.

“I have recently been offered and accepted a special needs flat. It took a long time to design and adapt the flat to my needs. After going through with this procedure I found that nothing was right as it was designed to suit the needs of someone else! It is quite frustrating because there is hardly any consultation, no updates, feedback or reference to my condition in anything that the system does for you.”

“I moved into a property that was specifically designed for disabled people. They built the toilet with a fire door which was very heavy, so one time I was stuck in my bathroom for just over seven hours. All the rooms had phones except for the bathroom. I felt scared and like I had no control. The children let me out on return from school.”

“In their mind a lift is a lift.”

The research indicated that young disabled people in particular may need supported housing. They may get frustrated living at home and parents too may need help and support.

Information, advice and support

This was a serious concern for a large number of participants who reported great difficulties in determining what support was available, what their entitlements were, and what options, if any, might be available.

Participants found it difficult to determine what housing provision they were eligible for. It was felt that people who were aware of their rights found it easier to secure the type of housing they needed. Some participants suggested a directory or register of adapted homes in London and a system for applying for housing across boroughs.

Face to face or personal advice was more appropriate for some people – particularly older people, one participant suggested. Many said that it was best if information was given by a specialist advisor who knew of the full range of entitlements and services.

Some participants felt that drop-in centres, where people could discuss

housing options across London, would be useful. If someone was linked to a disability organisation, it was easier to find out about housing - otherwise “you wouldn’t know where to go”. Local organisations of disabled people often provided better support than local authority social services departments. It was also felt to be important that carers have information about services.

Some participants had gained information through unusual routes. Builders touting for work had informed one person about a government grant scheme.

It was important that information was available in appropriate formats. This covered both general information about housing and specific information to individuals from housing associations, landlords or local authorities. One person said that however many times she reminded her housing association about her visual impairment, they would forget and send her unreadable letters.

Some people with internet access found this useful but several participants pointed out that this is not suitable or available for everyone. Assumptions were made that everyone has access to the internet. Many official web sites are not developed to take into account access issues – they are inaccessible to some software packages that some disabled people need to use.

"I have looked at my council's web site and find that they don't have any packages to support my needs as a blind person when trying to access information. I feel upset and continuously discriminated against, I truly feel like a second class citizen. They think the packages are accessible but they rarely are. Why don't they investigate the most used packages and then install the suggested package."

Financial and Benefit Issues

"I feel confused by the system. If I want something I need to fill out a form that runs to fifty pages."

This was a major concern for the majority of participants. The system for getting Housing Benefit and Disability Living Allowance was felt to be bureaucratic, full of red tape, took a long time and was often seen as unfair and open to different interpretations. There was a sense that people needed to know their rights, and the loopholes, in order to get anywhere.

Participants experienced problems of assessment for housing benefit and financial support, with a poor standard of assessment by doctors. It could be distressing to hear a series of unknown doctors discussing one's impairment. It was felt that people should be able to use their own doctors and consultants for assessments.

One participant had understood that someone who is already on Incapacity Benefit is not eligible for a Community Care Grant, which could mean much more support. (This is not necessarily true, although receipt of Community Care Grant does depend on a person's financial circumstances.) Another believed that the Council Tax discount was only available if a person could prove how much of their house was adapted. (This is not quite accurate, although the house does have either to have additional space for a permanent wheelchair user, or adapted rooms – and a claim may be verified by a local authority officer.)

One local authority was reported to have begun to charge for home care services which had previously been free. As a result, one participant now had rent arrears of £6,000 because the rent money had been used to pay for other services.

The adaptations grant process was found to be complex and lengthy:

"The grant [for adaptations] from the council is means tested and I had to contribute an amount, which I think is fair, but it took a long time as it had to go to the grants panel, then I had to complete a form with all my information and income. At the end of this process I was told that the job would cost

£11,000. I think I should have been given a price from the outset. There should have been something available that showed in bands how much you could get off if you had an income or savings of £0-7,000 and £7,100-14,000 etc. This was a waste of time and I got the works done much cheaper."

This point also raises issues of choice for disabled people about the amount of adaptation they want, and what they can afford. If local authority funding was accepted this could mean the person had no choice about what was done.

There was often a complete lack of knowledge of issues relating to the needs of disabled people in local authority housing benefits offices. Frequently there was no one who could provide the specialist advice which was needed.

Benefit forms were often not available in the right formats and there was no assistance with firstly locating the right forms and then completing them.

"The paperwork when claiming benefits can be overwhelming especially when you are dyslexic and not all councils or housing associations clearly signpost where you can get help completing forms. This should be standard practice throughout London."

Participants also felt that no one asked them early enough for information about their financial situation that would directly affect the support they could get, and so they built up expectations that could not be fulfilled.

"We should be means tested from the offset instead of bringing builders, surveyors and OTs [Occupational Therapists] into the equation"

Participants mentioned the lack of financial advice for disabled people in private sector housing.

"I am owner occupier and my health is collapsing, so I need to sell my house. I can't afford to pay the mortgage. I called the council and explained; they replied I would have to be out on the streets before they could do anything. If I rent privately the cost will be more than my mortgage. I'm trying to plan for the future but they don't want that."

In relation to private rented accommodation, a participant was being charged more rent for a ground floor flat, which was discriminatory.

It could be hard to share with non-disabled flat mates, and to cope with other people living in close proximity. But this had financial implications: living alone is more expensive in London than flat sharing, particularly for young people.

Local Authority Allocation Policies

Many participants were strongly critical of housing services from local authorities in relation to allocation and transfer policies and how they were applied. They also mentioned lack of consistency and variations from one local authority to the next.

Some participants experienced delays in getting transfers to, or offers of suitable properties.

"I currently live in a three bedroom council house with my bathroom upstairs and for the last eighteen months I've been living in my sitting room downstairs as I can't physically access upstairs. I asked my housing officer if I could get a transfer and I was told there was no need for that as I could wash in the sink."

Some participants were offered unsuitable or inappropriate properties that did not match their requirements. There was a lack of choice and real options.

"I was given a basement flat which sounds good but it had three steps to get to my door which is totally impractical as I am a wheelchair user. I am lucky in that I can walk a few steps but it does take it out of me. Sometimes I wonder if they even think when they are allocating properties. I think they just want to get rid of you as soon as possible."

Participants found that there was a problem of provision for people with access needs that did not entail adapting their physical environment. People had little flexibility or understanding of the issues involved.

"My consultant said that if I'm moved to a property closer to my hospital and in a more positive environment away from the noise from my neighbours, these are all changes that will help to bring me out of this mental illness. However you try and explain that to the housing department with a letter from your consultant and they still have no clue as it doesn't fit within a box... Basically I don't have the right type of disability, mental health issues don't count."

Another instance of this type of barrier faced by several participants was noise from neighbours. This was mentioned by participants with a range of impairments, including learning difficulties, physical impairment and those with conditions which required periods of quiet rest. As with harassment, it was rare that they got a helpful response from authorities, nor was this taken into account in allocating property.

Some participants said they were assigned one bedroom properties inappropriately.

“The assumption is that disabled people do not have partners or friends or PAs. We should be offered properties with two bedrooms depending on requirements and not have the power taken away from us.”

Disabled visitors should also be taken into account:

“If you’re disabled it’s likely you will have some disabled friends so the property needs to be accessible even if you don’t have that impairment.”

One person mentioned the bidding scheme used in Choice Based Lettings Schemes, which they felt potentially could be useful. However, they felt it was important for the properties to be described accurately in terms of access, and adapted housing should be ring-fenced as available only for disabled people, given how few suitable properties there were.

Local Authority Staff

Staff who have little or no understanding or knowledge of the barriers faced by disabled people were mentioned frequently by participants. Little training appeared to be given. There was a perception of constant turnover of staff with no time for expertise to be developed. Lack of understanding could make things worse.

“They put all disabilities into one pot”.

Several participants suggested that staff in local authorities and other housing providers should be given disability equality training.

“Staff need to be educated about disabled people and be given courtesy courses, as it makes me really annoyed, to the point where sometimes I really would prefer to go thousands of pounds into arrears than to go down to the offices and sort out my claim, that they have messed up.”

Participants felt each office should have at least two people trained in British Sign Language (BSL) and information available in Braille, and designated and trained officers should be available in each authority who would have the skills to place people in the right type of housing. It was suggested each council should have someone with experience of disability to help people with neighbours, repairs, adaptations, everything, instead of people “being given the run around”.

“Each office should have someone who is trained not to patronise us or to make things worse”.

“I was given a flat on a first floor that was not easily accessible to me and was informed I was lucky I had been given a flat at all. It’s like we’re given handouts and should be happy even if there are safety issues.”

As well as untrained staff, many participants reported housing staff who made assumptions about disability and applied stereotypical views about people’s requirements and capacities.

“Employees at the council in terms of benefits and housing always make comments of ‘what have you got to be depressed about, a pretty young woman like you’. They are so oblivious about the whole issue, it’s like they expect me just to snap out of things.”

Points made by several participants

Harassment and personal security

As identified in Chapter 4, experiences of harassment by neighbours and being placed in housing situations that made people feel vulnerable, were mentioned by a large number of participants. Issues mentioned included:

- Harassment by other tenants in the same building (in some cases drunk)
- Harassment and verbal abuse from neighbours
- Anti-social behaviour from groups of young people
- Lack of action by police and local authorities.

A woman who was taunted repeatedly by children and young people contacted the police. They recommended a fence, but her housing association would not agree to it.

Another participant said:

“I do not like to use the corner shop as the path leading to the shop is downhill and awkward. The kids who hang around there make fun of me.”

Participants described a lack of personal security as ‘vulnerability’. Some participants did not express concern about their own personal security, but considered that other disabled people might be more ‘vulnerable’.

One woman participant reported feeling particularly vulnerable from drunk male tenants in her building. She hid her stick so they did not think she was even more vulnerable. Her housing association’s response was always to move her, rather than the male tenants. For this reason she was now on the top floor despite having a mobility impairment. She felt that it was more dangerous for disabled women as they were more vulnerable.

A retired interviewee said that he felt vulnerable from attack when at home alone with his wife now that the children had left home. It was a four bed room house which they owned, in a cul de sac, where most other residents were out at work all day. A new development had been built behind and the area had changed from a quiet one to a very busy one full of people they did not know. They could not afford a security system and were hoping to move. Social Services could not assist with the security system. It was proving difficult to find a self-contained ground floor flat.

A good experience was reported by one man who had been burgled three times, who said that the community safety team had installed CCTV and an alarm system which made him feel much safer.

In all but one case reported during this research, responses from the police, local authorities or other housing providers had been extremely poor. In the case of the police, they demonstrated no disability awareness and were completely insensitive to disabled people experiencing harassment.

“I have problems with my neighbours, they leave rubbish outside my house and know I’m disabled and can easily hurt myself. It’s like living near Steptoe and Son. I’ve complained to the council but they haven’t done anything. I don’t know who else to complain to as I can’t speak to my neighbours as they are not the type of people you can speak with. They block my entrance to my flat and I use a wheelchair, which is really awkward as I have to get out of it to get into my house, it takes a lot of energy out of me.”

“I called the police as there was group of youths driving up and down my road very late in the evening, beeping their horns and making noise. I explained to the police officer that I was blind and then he asked me if I could describe what the youths were wearing, their ethnicity and even their mopeds’ registration numbers. This is a classic example, no one really listens.”

Gatekeepers

Contacts with social services and with occupational therapists were mentioned as unhelpful by a smaller number of participants and they were sometimes regarded as gatekeepers to the system. Problems here included staff turnover, new and unfamiliar staff, and having to explain the same things again and again. Staff were sometimes patronising and often ineffective.

“I had to go through six social workers before I was offered a property and that was on the sixth floor. Even though I don’t use a wheelchair my legs aren’t good and getting worse. I think they thought I should just be grateful and I was.”

“Occupational therapists have too much control on deciding what adaptations are suitable for you and whether or not you really need them. This takes all the power away from us and treats us like infants. Who else is more qualified to say what I need than me? The OT’s job should be to assist us in recognising what changes to our homes would make living more comfortable and practical.”

Points made by a small number of participants

Housing Associations

A few participants reported some problems with housing association policies, but this was to a much lesser extent than complaints about local authority services. Housing associations were more likely to be commended than criticised.

Difficulties reported with housing associations concerned letters and information being sent in unsuitable formats despite repeated requests; and, as with local authorities, not being able to offer suitable properties to meet someone’s access requirements; and being slow to respond to requests for transfers.

Going out

A few people mentioned the occasional need for support to go swimming, or to the theatre, with there being no obvious source, or resources, through which to get this.

Positive comments

Positive comments were in the minority, but there were enough to give an idea of what people liked. A few praised fast efficient services for suitable housing, adaptations or repairs.

“{council is}...quick in making adaptations and lining you up for appropriate housing.”

Somewhat more experienced good support and information. Probably the most common type of praise was that the participant knew where to go or who to contact for information and support; knowing where to start made a big difference. Compliments were also made to helpful staff and those who visited or checked to see how things were going.

“Some councils are very good and publicise a form filling service very effectively, which all residents are aware of and many take up who have difficulties.”

“I am independent but any time I need help there is someone on call within the complex {sheltered housing for blind people}.”

“They are always trying to improve my situation and leave me to get on with things but they are always available on the phone and are very easy to contact”

Illustration

The following extracts from an interview illustrate many of the points made in this chapter, with examples of good and bad practice. Note that the housing was unsuitable for this individual, although the block was built for disabled people.

HOUSING STORY (from an interview)

- *I am not happy with my housing situation; when I was offered the property I was originally in a bed sit and was just happy to get out. Once I had moved into my 1 bedroom flat that was on the third floor in a block specifically for disabled people, I was very happy. I didn't mind that I had to climb the stairs when the lifts were not working because it was such an improvement to what I had previously*
- *However my situation has changed, I should be moved. I am going to give birth in 2 weeks and I am a VIP {visually impaired person}. I'm going to find it very difficult to get up and down the stairs with my baby, when the lifts don't work*
- *I have no garden for my guide dog or child to play*
- *My social worker is very supportive and has written my housing office a letter saying that I should be moved but they said there is nothing they can do until I have given birth. In one way I can understand that but for me it will be extremely difficult trying to move with a child, trying to get used to my new environment. Ideally I should be offered a new property much earlier. It will be very hard and crowded living in a 1 bed, with 2 adults, 1 baby, 1 dog and no garden*
- *Information is really hard to get and its always assumed that everyone has a computer*
- *I asked my Housing Officer to help complete a form and she replied that they could not help instead my social worker helped me to complete the forms. Next time I've been told that my Housing officer has to help but I'm not really sure who can help me with what*
- *No information/leaflets are available in Braille*

6 Employment

“The world of work is an unforgiving structure. There is a great stigma to being unemployed.”

“I believe there is a big untapped source of talent.”

Key Issues

- The benefits system, or people’s understanding of it, was seen as a major obstacle preventing people seeking and remaining in work.
- Access to Work was strongly praised as a useful scheme which enabled people to work, but knowledge of it was limited.
- Jobcentre Plus and Disability Employment Advisers were very strongly criticised for lacking in understanding of disability issues.
- Attitudes and lack of awareness on the part of both employers and colleagues were also major barriers.
- Employers were perceived as being unwilling to introduce greater flexibility of working practices, to commit resources to make work places accessible, or to invest in equipment.
- Other means of support for employment, such as apprenticeships or positive action programmes, were seen as important.
- Employers and other agencies were seen to be ignorant of, or deliberately ignore, their obligations under the Disability Discrimination Act.
- Voluntary work was very important for many disabled people in this research but could also have drawbacks in terms of lack of access support and financial implications.

Except where noted, this discussion of employment is focused on those who are doing or are seeking paid, not volunteer work. Since it appeared that many participants in this sample had limited experience of current paid work, there is significant focus on gaining work, and on perceptions of work and employers’ attitudes and practices.

While many participants expressed a desire to work if it became possible, a smaller number felt that it would always be impossible for them and it was not worth trying.

Points made by a majority of participants

Benefits System

This was seen as a major barrier to employment by most participants. There was a lack of knowledge of the benefits system and how many hours work people could do without losing benefit. It was hard to get information. The system was seen as unfair because some benefits were means-tested and there was no access to crisis loans.

Bureaucracy and red tape were also frequently mentioned as barriers. If people came off benefits and started work, it could be very difficult to get benefits started again if the job did not work out, and this was seen as a major disincentive given the stress involved in securing benefits in the first place. This had been experienced by a good number of people, with others saying it was a deterrent although they had not tried to obtain work. People were also afraid of ending up in a worse financial position because of the costs of going to work – travel, personal assistants etc – which might mean they were better off on benefits. Thus many participants felt they were caught in a poverty trap.

“I told them that I could not write and needed to make an appointment for someone in the Jobcentre Plus to complete my forms. They booked me in for an appointment in two weeks’ time. On my arrival I was told that they don’t help claimants to complete forms. I was referred everywhere but somewhere, so can you imagine if I was to get a job then leave - the amount of problems involved in that? It’s frightening to imagine. It would be too much to cope with and make me extremely ill.”

“I am a qualified youth worker and I had to work full time to afford to pay for my carer. I was better off when I was not working. We need to be given more flexibility and support when trying to work. My benefits get cut because I’m working more hours but my carer’s duties remain the same. I’m going around in circles.”

“The government gives with one hand and takes with the other. I need breathing apparatus for a couple of hours a day. I was informed that if I go back to work they will take it away from me as I will be working, not because I’m being paid, but because I am active. They are keeping us down and not wanting us to be independent, trying to keep us in our places.”

One participant spoke about applying for a Freedom Pass. She was told she had to go to the office in person, even though she had problems walking for any distance. The nearest bus stop was 200 yards from the social services office. If someone can walk more than 100 yards, they are not eligible anyway - catch 22.

Some comments made by participants showed a lack of knowledge of their benefits position.

“Benefits stop as soon as you get a job, support stops immediately. DLA is taken away because I now have a job. But I’m still disabled and I need my carer paid for.”

This shows a lack of knowledge/understanding as Disability Living Allowance is not means-tested and is retained when in work. It also underlines the responsibility of statutory agencies to ensure accurate and thorough information is easily available to all.

“Sometimes you have a job opportunity but it’s a gamble. If you find the job isn’t suitable and you have to leave, the support of benefits will not be there, so there will be no money at all coming in.”

Again there is now a linking rule that allows people to go straight back on the same benefits in most cases but this did not appear well known to several of our participants.

Some participants would have liked to work part-time, but part-time work did not pay enough to live on and people would be stuck in the poverty trap.

Access to Work

“I would not have had any jobs if Access to Work was not available, as they provided me with a PA, adapted chair and keyboard. It makes a major difference and makes it possible for me to work and get an income.”

Any of the participants who had used Access to Work were extremely positive about its value. Without it they would not have been able to work. Not many participants had experience of this scheme, however, and it is clear that few people are fully aware of what it can do. This emerged in focus groups: whenever anyone talked about the scheme others in the group were very interested and said that they did not know about it. Even those who had heard of it did not always have accurate information about it.

Because people were unaware of Access to Work, several people expressed concern about a lack of support should they get a job. For example one woman who needed help to go to the toilet felt that lack of support meant that employment was not an option for her. However, funding for this type of support is likely to be available through Access to Work.

Some participants commented that employers themselves were not always aware of Access to Work.

The only criticism of this scheme was that some people reported delays in getting the right equipment but after this it worked very well.

“I think the government is reluctant to make this well known as it may cost them too much money.”

Jobcentre Plus

In complete contrast, no one said anything positive about the services at Jobcentres and, in particular, Disability Employment Advisers were strongly criticised. They seemed very unaware of disability issues and poorly or not trained. Several examples were given of being offered inappropriate work. These included offering a driving job to someone with a visual impairment; offering jobs involving lifting to people with mobility impairments; and offering low level jobs, based on the assumption that disabled people were not capable of much more than shelf-stacking.

In addition, most participants who had experienced them reported rudeness and poor treatment, not being offered anywhere to sit, not being provided with materials in different formats, and being put off – told to come back on another day.

“Most Disability Advisers in Jobcentres need more training on disability issues, legislation, and advice, as they tend to give inaccurate advice and you find that you end up telling them about initiatives that are available. I called up Access to Work myself as she did not know what she was doing. Most disability advisers are overworked, unqualified and have no training or awareness of disability issues and the schemes that are available.”

“Inside the Jobcentre they take no notice of people’s disability. I had a stick and needed to sit down to try and access the computer, but I was told to get up as it was a health and safety risk.”

“More disabled advisers should be employed in Jobcentres to build better relations. Many of them just don’t know what to do. Sometimes there are difficulties communicating. And they don’t even consider alternative forms of communication like writing things down.”

“Perhaps they should be put on commission as an incentive to get more disabled people into work. They need to try and turn the negatives into positives.”

Attitudes to disabled people in work

In relation to employment, it is clear that there are significant barriers resulting from the attitudes of employers and colleagues in the workplace. Both employers and colleagues made wrong assumptions about disabled people and their capability, and showed a lack of awareness of disability issues.

“People have trouble understanding my disability. This is unfair. As a result I don’t expect to be employed by anyone.”

“I’m a musician and there is a different culture, you need to be persistent and keep your head together. When I speak to people on the phone about my work, they seem very interested, but when they see me in person, the interest is lost. Sometimes I win bands around, other times I don’t. People in the arts and entertainment are not aware of disabled people and our skills.”

Participants felt there should be a focus on their potential not their impairment. Employers should focus on what people can do, not what they can’t do.

Some people said too that they were often offered part-time work as the employer would assume they were not capable of full-time work.

“Part-time work is usually what I get offered, as the employer assumes that I will be too tired, or not be as reliable, this is so frustrating. People are always taking the decision out of disabled people’s hands and doing what they think is right. What is good for one person is not good for another.”

(Other people mentioned the benefits of part-time work – p. 87 below).

Participants felt that employers assume disabled people are stupid and/or have no qualifications. They also believed that people assume disabled people are second class citizens when it comes to work. Several participants reported that despite being well qualified, they could only get work which was perceived as menial or low status. They felt undervalued and underpaid.

It is clear that there is an element of fear in employing or working with disabled people.

“I’m not a scary person but for some strange reason people are generally scared of the unknown and disabled people are unknown – that has to change especially in the job market.”

“In the work environment I would like to be treated as a person, not as a curiosity.”

People with mental health issues experience significant discrimination even in workplaces where the issue should be fully understood, as shown in the following illustration.

This example shows how prejudice can have a long-term impact on disabled people.

EMPLOYMENT STORY 1

"I used to work for a hospital in the area of mental health. I became depressed and was hospitalised due to the severity of the depression. When I returned to work I was told 'We think it would be tidier if you left'. I was very angry and disillusioned as I thought my bosses would have been more sympathetic in understanding my plight. However this was not the case, they were very dismissive and not helpful at all.

If I was not a strong person that could have been the final nail in my coffin but I had the support from the hospital where I was being seen

My employers just wanted me out, a nice quick and clean process where there were no loose strings. I think if I had lost the use of my legs they would have been more understanding, I don't know why they were not supportive.

Because of this situation I now have to access mental health care services on the other side of London, as I used to work for my local mental health care services and I know they would not treat me fairly. I would like to go back to work but there is so much stigma attached to mental health issues that I doubt very much I would be seen as a reliable candidate."

Ageism was said by some participants to be an additional factor which worked against disabled people.

"I am very hard to employ, as I'm 50 years of age with little or no training. In my younger days I did building and carpentry work but it's impossible for me to go back into that area. I need to change my direction of work and would like to work in IT or computers. However I need to go back to University so that I can have more skills and qualifications in my pocket but realistically what are my chances? I have my age, lack of qualifications or training and my disability which people will see as obstacles and not see what other benefits I can bring to a company."

"I applied for 150 jobs and got only three interviews. During interviews questions are asked and I give proper answers but the panel does not look convinced. Maybe young managers don't want older people to work for them. I

am not interested in knowing how many ramps have been put up for me – I just need the opportunity and certainty of re-training to get employed.”

Working environment

In addition to attitudes, barriers to work exist in the working environment – employers’ policies and the physical environment. Flexibility in the design and implementation of policy and in providing adjustments is not only a legal requirement, but participants noted its importance to them in getting and keeping work.

“I’ve literally jumped through hoops at interviews, and taken tests, and still not got the job. Once I was even asked if I was sure I wanted to take the test, once they realised I was blind. When I had to take an aptitude test I explained to the person running the interview process that I would need someone to read me the questions. They were really reluctant and not helpful at all. Disabled people don’t fit into the white face, black suit environment. We’re just given excuse after excuse. I’m always being told, things are quiet, or to call back in one week.”

Lack of flexibility was a major obstacle, which deterred people from seeking work. Some participants also pointed out that if someone developed an impairment while in a job, flexibility was required to overcome the barriers preventing continued work.

There was a need to recognise that sometimes people can work a lot, other times not so much. Flexibility of hours and working patterns was essential to allow for variations in health. Local authority employers were seen by some as being more flexible than the private sector. It was felt essential for employers and colleagues to allow some flexibility to respond to changing health, or to travel or other difficulties.

Some participants reported that employers were punitive and inflexible about time-keeping. Not everyone can manage public transport, particularly the tube and especially at rush hours when it is crowded, rushed, and hard to get seats. It was important for employers to recognise this and to provide cover first thing in the morning if someone was late and not book meetings at 9 am.

Employers often had no overall strategy for managing disability at work. Several participants reported bullying and harassment at work based on their impairment, and lack of action to deal with this by employers.

“They teased me and made me look small. The support of family, friends and the union has got me through.”

There are also problems in relation to physical access, access to information, and provision of equipment.

“Accessibility in offices is an obstacle: for example, can I access the toilet? No – the doors are too heavy, or they’re on a level without a lift. These are all concerns that we as disabled people think about when thinking about accessing employment. It adds up to a lot of stress which may lead to depression. It makes you think is it really worth it?”

Access to places of work and access to the right equipment were the key areas of concern here.

One participant said she had been invited for a job interview but access was not available – she could not attend and did not get the job.

Participants felt that most employers did not want the cost and bother of taking on disabled staff and meeting their requirements. “They want an easy ride, desk, chair, computer.” They did not want to commit resources to providing equipment and making adaptations.

“Resources are a great issue. Live in a capitalist society and a company will find an able bodied person more financially viable despite the fact that a disabled person may have more qualifications.”

As in the other areas, participants mentioned the difficulties of getting information in accessible formats.

“There are a range of web sites that can give you information about jobs. But if you’re blind how do you get access to specialist equipment?”

Specialist equipment is needed by some visually impaired people to access the internet, and is expensive to obtain unless you are already in work or formal education.

A small number of people mentioned problems caused when a new line manager was appointed, or when the overall management of the workplace changed. Because positive mainstream employment practices were not well established, too much depended on individuals and their attitudes, as the following story shows.

EMPLOYMENT STORY 2

"I was forced out of my job about three years ago. I used to look after children when they were sick. They would come to my office and I would see how they were and take relevant action. However a new headmistress was appointed and she decided that when children were ill I should go to the place that each child was situated. Meaning I was up and down the entire school and 99% of the time on my feet. I explained to her that I was disabled and that this would be impractical and very uncomfortable for me and she totally disregarded my concerns.

I had to lodge a complaint to my union, which I really did not want to do, but I had no choice. In the end I won but she never spoke to me again and would ignore me all the time. I had to leave as the situation became really awkward and I began to feel like a leper.

Most colleagues were supportive as I had known them for a long time, we would regularly go to the pub for drinks and my disability was not a problem. However with a new change in leadership also came a change in not accepting difference

Employers need to be more aware and flexible and realise that just because they want all employees to run in the sports day its not always going to happen but we may be able to assist and be just as valuable doing something else."

Again,

"I worked part time as caterer and lost my job when new management came in because I was disabled. Other staff who were also disabled or black lost jobs too. The new management didn't even speak with us; he just gave us our marching orders. The previous management was very understanding and appreciated our differences and the skills that we had to offer."

One person was on a second written warning from the employer because of lateness even though the employer knew about her impairment when they took her on and at first showed understanding. However after a new manager arrived, this changed completely. It had depended on an understanding manager.

Points made by some participants

Other support in and into employment

One focus group suggested that a targeted apprenticeship scheme should be available for disabled people, which would allow people to show their abilities and to see whether or not a particular type of work was right for them.

In addition to the apprenticeship scheme, several participants also suggested that employers should offer more mentoring and shadowing programmes. Support workers for people returning to work could be helpful particularly at the beginning. Employers needed to demonstrate a commitment to providing a supportive working environment and reducing stress.

Some people felt that part-time work and job sharing schemes should be more widely available for disabled people. It could be hard to work full-time for some people because of their health or impairment. (Other people mentioned the disadvantages of part-time work, p.81 above).

It was suggested that more consideration be given to positive action schemes to open up employment opportunities to disabled people. Several student participants suggested that employers should offer and advertise work placements in universities and colleges so that disabled students could not only get a range of experience but also see which employers showed a commitment to disability equality.

“More large employers should offer work placement schemes for disabled people. Then you’ll really see which employers are truly trying to attract disabled people into their labour force. These placements would make other staff and employees aware of disability issues and show that we can work just as effectively as non-disabled staff. Also it will help the disabled person to see if it is an organisation they want to work for without having the strings attached to permanent employment.”

Understanding legal and statutory obligations

There was limited understanding among employers and colleagues about their obligations in relation to disability and, in particular, a lack of understanding of employers’ legal responsibilities under the Disability Discrimination legislation.

While some participants acknowledged that the DDA had given people more rights and brought about some improvements, they also felt that there was a problem over the definition of “reasonable” within the legislation. As it stood the term was too vague and therefore easy to use to find loopholes. Nor was the legislation enforced rigorously enough. Several participants suggested that employers who did not comply with legislation should be penalised.

“HR departments just pass the buck. You have to keep fighting to get what you want.”

There were several instances of participants experiencing problems with employment that are covered by the DDA, but they either were not aware of or had chosen not to use the legislation to address the problems. For example one

woman was qualified for an IT position but was unable to take it up because it entailed moving equipment. It is quite likely that this would have been covered by the requirement to make reasonable adjustments to the job tasks.

One participant with dyslexia reported that his employer offered to teach him to write which, although well intended, was quite inappropriate.

Awareness amongst those supposed to help disabled people into work was also considered to be inadequate. Job clubs failed to provide information to people in appropriate formats, despite being asked. Recruitment agencies, for example, told one participant that because she was blind they could not get her a job. One participant with learning difficulties felt he experienced a lot of discrimination from employment agencies. He has more potential employment opportunities now that he attends a drop-in centre where he can access training opportunities in IT and study media and production at a local college. Previously he had tried building work in the family business but epilepsy limited what he could do.

Participants felt that employers often paid lip service to employing disabled people.

“There are too many empty statements “trying to actively employ disabled people”. These are just put in adverts or on office walls for looks purposes only”

“Lots of organisations have the 2-tick scheme but I think most of it is just for show”

Some participants felt that disability equality policies existed on paper only. They were not promoted and not implemented.

“Employers need disability equality training NOT disability awareness. Their mindset needs changing. Disabled people have the skills to successfully do the job but we are never taken seriously. Employers are not keeping to legislation, they are being very tokenistic and trying to tick the right boxes.”

On the other hand, there were a couple of examples of employers who clearly understood their obligations. For one participant working in a council, from the start the council demonstrated it was an equal opportunity employer. The original job specification had called for copy typing but the Council was still happy to accept her application when she pointed out she could not manage this. Previous potential employers had told her she “looked too blind”. Now, 90% of her work is audio typing and the council “finds ways to accommodate” the rest of the work. The work was varied and interesting and the flexitime

scheme allowed her to work at the times that were best for her. The job provided friends and a social life.

For another participant:

“My employer is fantastic. They have gone out of their way to make my working life as adaptable as possible”.

As well as an occupational health adviser in the work place who ensured the right seating and equipment, the organisation provided a computer and fast broadband connection in her home so that on days when travel is not possible, she can work from home. In her previous employment the fax machine and copiers were a long way off and up stairs. No accommodation was made for this on her bad days. People did not understand that “it’s my legs that don’t work not my brain!”

Disabled People’s response to discrimination in work

Some participants felt that working would not be possible given their impairment.

“There was no way I could have continued to work as I was very exhausted and still get very tired very quickly. I told my employers that I had MS and they were very good with giving me time off, working flexible hours. They said that they would have given me any support so that I could stay and do my job but I knew it was not possible and my illness was getting worse as the months went on. But their attitude made me feel like an important and vital part of the organisation.”

For others, the barriers such as the benefits system and people’s attitudes are too stressful to make it worthwhile.

“It’s not fun telling people about your pains and discomforts on a daily basis. You just end up saying I’m fine. Your family just about gets it because they live with you on a daily basis. Employers are not as understanding or aware.”

Repeated rejection is a deterrent. Many people in this research were involved in voluntary work. And, as some people also pointed out, not having suitable housing and adaptations is a barrier to seeking both employment and education.

Several participants commented that they had gained qualifications in order to compete with non-disabled people but that they had then been perceived as over-qualified by employers.

It was reported that often people tried hard to hide the fact they were a disabled person particularly when starting a new job.

One person was offered the option of working from home for two days a week but did not want to seem to be getting special treatment in case this provoked a reaction from her colleagues.

A participant who had experienced discrimination on mental health grounds recognised how important her own resilience was in combating discrimination (Employment Story 1 above).

Even when faced with blatant discrimination, disabled people may not want to pursue a claim (Employment Story 2 above).

The majority of participants would have liked to work, if the barriers they faced could be removed. As well as providing income, employment also provided a means of meeting people and making friends.

The following story is an example of a participant overcoming barriers and moving towards independent living, with examples of good and bad practice. The system itself contributed little to her employment success, except that she received good educational support.

EMPLOYMENT STORY 3

“My experience with the OT (occupational therapist) was not very positive. I was advised not to take up the job, which I thought was very degrading. I was asked questions like “Can you pick up this kettle” – I came away feeling worthless.

“I feel fully supported in my current job (full-time) by my colleagues and manager. Sometimes individuals can stop and stare at you, which I find silly and offensive. Managers are generally very supportive but it comes down to the individual person at the end of it. The worse is when people make assumptions and there have been situations in the workplace where I have been made to look/feel stupid.

“I have not experienced discrimination when looking for employment because I don’t hold back. I am supported by my parents and I seek to better my life. It is all a personal effort. Once in the job I have felt uneasy sometimes due to ignorance. I wish I did not have to explain myself all the time to colleagues. Ideal situation for me would be to get support and acceptance in the work environment – the room I work in.”

This person is currently living with her parents and is on the council list to get a place of her own. She has just finished a course and felt very supported at college – got good placements as well.

Voluntary Work

"I do lots of volunteer work as any paid employment will leave me worse off financially and health wise. I can chose the days and times I would like to work. I am treated like a person who happens to be disabled and given the respect that I deserve. Ideally I would like to work part time in local government but I can't chance things not working out. The mass of red tape when trying to return onto benefits would be enormous."

Many participants in this research said that they were involved in various forms of voluntary work. Much of this was work for disabled people's organisations at local level, such as local disability alliances, or support networks for particular impairments. Others worked with refugees and asylum seekers and in CABx for example. Some participants said it was only disability organisations and voluntary organisations which enabled disabled people to contribute to society as they wished. Some participants undertook the equivalent of more than a working week being involved in a whole range of different voluntary work.

In the main, people spoke positively about these experiences. Several people said they did voluntary work because it was a way to demonstrate potential and capability and to counter the negative experiences of paid employment. It was good for self-confidence and self-esteem.

"I'd rather do voluntary work because there is less pressure and you go in when you feel well enough to."

On the other hand others felt the pressure of not wanting to let voluntary agencies down if they were not able to attend.

One participant with a visual impairment was doing voluntary work with a CAB and using its learning pack for training purposes. Initially he was not cleared to advise as he could not make eye contact with clients! There was also a tendency to push him to see more clients than he could cope with.

No access or support help was available for people doing voluntary work in the way it is for people in paid employment.

For some people it was not an adequate substitute for paid work.

"I tried to get a job but the only thing I was offered was unpaid volunteer work. I'm wanting to contribute but I'm just not being given the chance. I don't want to be on benefits forever but I can't see any other way. If I do too much volunteer work I'll lose some of my benefits, so right now I'm in a lose-lose situation."

Points made by a small number of participants

Self-employment

"I am self employed, a freelance journalist. I can never guarantee what my health will be like tomorrow so this job is the best for me."

A very small number of participants said that they were self-employed. The main problems here were that there was no financial help for days when people could not work. A larger number of people expressed interest in being self-employed but said there was a lack of information about how to go about it.

One participant with learning difficulties has a production business. He attends a drop-in centre run by a voluntary organisation, which gives him use of computers and provides support to develop his business. He has produced records and a soundtrack for a film to be shown at City Hall, all using computer technology. He is a part time disc jockey, sometimes paid, sometimes producing music at fund-raising events for people with learning disabilities.

Working from Home

A small number of participants worked from home, by arrangement with their employers. This could be beneficial because it avoided barriers in getting to work and barriers in the work-place. However, it could also be isolating. Also there were no natural time boundaries as in a work-place, which meant it could be hard to switch off.

Development and Promotion

A small number of participants discussed development and promotion. It could be a problem when work-based training courses were not provided in accessible formats or venues, with appropriate training materials.

One person felt he had not been promoted simply because of his impairment. But he added:

"In some cases you think, forget the promotion, thank god you've got a job."

Access to information

Being in employment enabled one participant to gain information about provision that might not have been easily available to others. She worked in a large local authority and so she had become aware of Access to Work, help with housing adaptations and other services from which she now benefited. If she did not work where she did she felt she would not be aware of these schemes and would not benefit.

Positive comments

The employment rate of participants in this project was probably lower than that of disabled people in general, which means that the findings in this chapter should be interpreted with caution.

There were a few examples of unalloyed good employment practice:

“Changing entire career due to support offered and rights available.”

Such experiences appear to be exceptional. Positive comments were in the minority, and usually related to Access to Work or voluntary work. Attitudes towards disabled people tended to vary with the individual manager or colleague, which brought an element of uncertainty into their careers.

7 Post-16 education

“Disabled people should use mainstream education but the resources, skills and support need to be available. Attitudes need to change towards us but this will only be done if awareness is improved and integration is promoted.”

Key Issues

- The risk of losing benefits and/or amassing debts while studying was a deterrent for disabled people’s pursuit of education.
- Inconsistency in levels of access promoted and advertised by different educational establishments.
- Inconsistency in levels of support, equipment and other access when studying. Delays in getting equipment were a problem.
- Lack of understanding of access needs and lack of prompt response to them.
- Unhelpful and even hostile staff attitudes, and sometimes insensitivity and lack of understanding from students, particularly in relation to hidden impairment.
- Flexibility of hours, length of courses and response to variations in health were important issues for many students.
- Lack of physical access compounded by unresponsive policies.
- Disabled students experiencing discrimination found it hard to combat.
- Participants with experience of post-16 education generally had better things to say about it than either housing or employment.

This chapter covers the experiences of those participants who were undertaking or had recently undertaken some form of education or training. Participants were asked to describe only recent or current education. These responses cover those studying in further education and in higher education (a smaller number). Where possible an indication is given of what sector is being referred to as the organisation and funding of the two sectors is different.

Because this research did not monitor on the basis of employment or education status, it is not always possible to know whether a student was in further or higher education other than through points emerging in focus groups and interviews.

Some of the participants who contributed to this section were found through the overall process for the research. To ensure a wider reflection of all sectors,

two focus groups, each with four students, were held at a London university. In addition nine Deaf students attended a focus group after being invited by their teacher from a further education college. Several participants were attending a college which offers separate courses for people with certain impairments.

In general the research found those undertaking education at the moment tended to be older students. Many of the students in this sample had experienced quite a long and difficult process to get the education they wanted.

“I grew up in an era when disabled people were taught separately and had a separate, more basic curriculum. Not a lot was expected from me and when my parents found out I could read and write they were pleased enough. So this put me at a disadvantage and like many other disabled people I have had to spend longer at college to do my A levels to improve my skills and equip myself with the right tools to go to University.” (higher education student)

Those participants who took part in a focus group at an educational establishment mentioned the barriers they had overcome and still had to overcome. Participants in other focus groups said that although they would like more education, they felt it was not possible for them and not worth trying.

Points mentioned by a majority of participants

Student finances

Financial obstacles were clearly a major deterrent for many people. Many mentioned problems of finance in relation to education. Where people were receiving benefits they were reluctant to risk losing whatever arrangements were already in place. There was doubt as to whether fees would be paid or not and whether grants would be available.

Given the barriers to employment, some participants felt that they could not risk taking out student loans which they might not be able to repay. At post graduate level there were no concessionary fees. Reduced fees would help disabled people to study and learn new skills to help them to find more suitable work.

“When I was studying at University I was on the higher rate of the Disability Living Allowance. However now I have left I have gone back down to the lower rate. It’s a huge drop and leaves me with little or no money. It’s so hard to make ends meet. I want to get a job but I lost my confidence after I had my second child. I really want to show my children that I’m doing my bit.”

“I am learning Braille at my local town hall and it is very good. There were problems initially. It was difficult to get these lessons and they cost. It took

Social Services and the RNIB from 1999 to 2003 to get me this course. I have to pay for this myself. I wanted to do a computer course as well but could not afford it. I was not on the right kind of benefit to do that course for free.”

One person mentioned the Disabled Students’ Allowance which had provided £3,000 for the purchase of equipment.

Support for learning

Support of various kinds so that participants felt they had equal access to the learning experience was very important, and some participants did receive it.

“I’m going to the college in October and this is only really possible because they are giving me relevant support. This whole experience for me is possible because I will be given a PA, tape recorder, a copy of notes. All the tools to be able to contribute to the course.”

“Adult education courses at colleges are brilliant; they asked me what type of support or communication needs I required. They are laterally thinking and as a result many disabled people go to [this] College, as they have found the right format for success. They are aware, and act on the needs of disabled students, working together and not separately.” (further education student)

However, there was a great deal of inconsistency in what was offered, what was promoted and advertised, and what was actually delivered by educational institutions. Some students mentioned problems of finding out what was available in terms of courses. Support, access and financial help were also mentioned frequently. Institutions needed to do much more to make people aware of what they offered and to positively welcome disabled students. Local authorities were also inconsistent in their knowledge of what was available for disabled people and their ability to provide information about education, as well as their provisions for providing equipment needed.

Access to a range of disability support during studying was mentioned by many participants as being crucial. It was suggested that there should always be a disability adviser available in person or on the phone who could make arrangements for support for students and be a source of general advice and encouragement. In the further education sector, support was said to vary from college to college and there was a lack of consistency. (Although support is not consistent in the sector, quite often the disability adviser is called something else, like ‘Learning support adviser’, and participants may not be always be aware of this). Students in the higher education sector seemed to be more aware of the disability support service in universities. (All universities now have some kind of disability support office). However disability advisers were perceived to be over-worked – “staff are bogged down”.

"I tried to go to mainstream university but had to drop out because of the lack of support, it all got far too much for me. One adviser was very helpful, I think it was because she was blind, but they could not get my equipment and I just couldn't keep up with the lectures with no support."

In contrast, one participant noted that that her college has two disabled advisers who are "brilliant" and were seen as very helpful.

Several participants mentioned the need to have a "buddy" or mentoring system. One participant suggested that there should be disabled student support groups at each university.

Many students also perceived a lack of resources in educational institutions, which undermined efforts to include disabled people. There was often a strong focus on saving money. In one example, a college employed a generic counsellor rather than a specialist Deaf teacher. This was also reflected in the provision of equipment and access.

Smaller colleges and institutions were less likely to have good arrangements in place.

After the financial concerns mentioned earlier, getting the right equipment provided was the biggest area of concern for the majority of students, with most complaints focusing on poor standards and long delays in getting the equipment which was needed. It was suggested by some higher education students that the assessment of needs should be done at the very start of the course and should be repeated, as requirements did change over time.

The barriers to equality of learning experience that people reported included:

- Not being able to see OHPs and displays, with the material not provided in other formats.
- No magnifier in the library
- Not being able to access books and library materials
- Lack of ergonomic keyboards
- Poorly designed and inaccessible web sites. It was important for web sites to be suitable for disabled people, as it sent a message about the institution's commitment to disability equality.
- Getting the right equipment - it could be a "post code lottery" depending on each local authority's policy.
- Limited access to note-takers and interpreters
- Interpreters who could not always keep up with tutors, specially those who had not been given any guidance on working with interpreters
- Failure to provide handouts and materials in advance and in different formats
- Getting personal assistants through the institution's security procedures, as sometimes security staff did not understand the role of the assistant.

Even when a course was supposed to take disabled people into account, that did not always happen.

"[My] college had a computer course which catered for disabled people, but no one wanted to help me as I did not have a disability that the course catered for, I was too much work. It was too much effort, so they isolated me from the group. All they had to do was to install the JAWS package [a speaking computer package]."

A fairly frequent comment was that students would provide information about their requirements on access forms, but that nothing further happened. No action was taken to meet the requirements.

"Sometimes you tell people about your problem but it is never followed up. I guess that is part of the fight."

Attitudes

"Because of your needs you feel you are considered troublesome."

The ways in which students were treated by staff and other students was clearly very important. Many participants reported unhelpful and insensitive staff who seemed not to want to deal with disabled people. Discriminatory behaviour towards disabled students from other students was another factor. A group of Deaf students reported that they were laughed at and teased by other students.

Some participants suggested that disability equality training should be provided for both staff and students.

Several participants mentioned that assumptions about capability would be made by staff, who would decide what they thought someone could or could not achieve, without discussing this with the student or allowing them to show their abilities.

"I was taking a community care course and as soon as they realised I was disabled they took me off the course. They said that I did not have the aptitude to pass the course. So I left, I was very upset. I could have done the course, if they'd helped me. They weren't friendly and maybe it's better that I left."

Examples were given of patronising attitudes, for instance from library staff when they were asked to help.

One student reported that she missed a lecture and asked her tutor for the handout for that session, to be told "Do you expect me to re-arrange the class just for you?"

Sometimes, a policy that appears positive can be perceived by others as a potential barrier. The requirement to disclose impairment is one such policy. One person said:

“When you hand in work you have to submit your condition so that the marker knows. This is a positive thing as it makes the tutors aware.”

However it was suggested that this could also be negative, because some tutors might see it is a ploy for getting extra marks.

Disability support staff were sometimes seen as marginalised and not well supported, and in one case said to be “terrorised” by the academic head of department. Some students reported that it was expected that they should have personal assistants, as they were perceived as not being able to manage without support and the institution did not see it as their role to provide assistance.

Some tutors tried to put disabled students off or encouraged them to look for alternatives.

“Some teachers think that disabled students should not be in college.”

One participant was undertaking information technology training. The centre was not accessible to disabled students, for example, having only 15 inch screens. The tutor did not want him to read things in large print and said “you should not come here if you have a disability”. Yet he had been referred by the Disability Employment Adviser. It was a “bitter experience” and he did not use the Disability Employment Adviser again. “They provide nothing anyway.”

However participants also reported good experiences, though this was to a lesser extent:

“I am the only disabled person on the course and I am treated really well by my fellow colleagues. I think at first people were a bit unsure and did not know how to approach me but as the course went on they realised I’m no different to them. That is why it is so important that colleges are mainstreamed to get away from the stigma attached to disabled people.” (further education)

“I did a computer course a while ago and the college was very supportive. The tutors were very good and never singled me out for my disability. It was a very positive experience.” (further education)

“I don’t feel that people treat me differently because I’m disabled. I feel generally quite well treated by other students and staff.” (higher education)

One participant who wants to do a PhD acted as a mentor to an undergraduate student who came to her own home. She could put everything into it as she did not have to travel.

Flexibility of the learning environment

This was an important issue for many students. As with employment, there was a need for flexibility of hours and the overall length of courses.

Flexibility was needed to take account of variations in health and extra time that people might require. One person said it had taken her seven years to do a masters degree, because of obstacles and bouts of illness. She had had a “bitter battle” with some universities while others had been more helpful and flexible when illness recurred.

“Open University degrees are very good, the support was exceptionally good, but it took me eight years to complete. But it was at a pace I could handle without feeling that I was lagging behind other students. However you miss out of the whole socialising experience, going to the student union bar and so on.”

There was also a need for flexibility in teaching methods. For example the Open University was mentioned as more suitable for some people but it still required some facilities and help at home with equipment. It was suggested that more use could be made of information technology and on-line teaching. Short online “taster” courses might be provided so that people could see if particular topics were right for them.

Assessment methods were not raised to any great extent by participants, other than the need to be allowed more time to complete coursework.

As with employment, a small number of students faced transport barriers in getting to their college, and sometimes found that staff did not understand the impact of this and were not prepared to be flexible.

“When I am late at college my tutor does not take into consideration that I have a very difficult journey into the college because of the transport system. When I try and explain her response is ‘So you want to get out’.”

Accessibility

Unsuitable and inaccessible buildings were reported by a majority of participants in both sectors. Old college and university buildings were hard and expensive to convert and were sometimes even listed buildings which it was believed could not be altered.

Lack of lifts, lifts which were too small, or not always in operation, was a common comment.

"[My] college has a lift so that it is accessible for disabled students and staff. But on Saturdays the lift is not in operation. The course I wanted to study was on a Saturday. Monday to Friday we welcome diversity but on Saturdays we are not accessible."

Also, lack of wheelchair access and long distances between classes in different buildings caused participants difficulty.

"As well as worrying about studies, disabled students face extra problems such as mobility around campuses, specially those that are really big. We need to plan ahead more. Will they let me know when they are cancelling a lecture? Will the lecturer look at me so I can lip read?"

Problems with exam or assessment centres were also common. One further education student reported that she had been given a grant for training but when she attended the exam centre, it was not accessible, though it claimed that it was. There were five flights of stairs and no lift, unsuitable chairs and no room to rest her leg in a stretched position.

Another participant reported:

"I was doing a nursery nurse course and all was going well. I was doing well in the course but when I had to take my exams it was upstairs in a building with no lifts. I asked if they could bring the paper down and I could take it in another room, but they said no because there were not enough adjudicators. So my chance of having a career went out of the window, with my dream of owning my own home. I never tried again, they took all my hope away on that day. They should have been more flexible."

One further education participant did a year-long counselling course, which she paid for herself, as well as paying her own travel costs. The café at the institution was not accessible so she took her own sandwiches. Then the accessible toilet was demolished. There was no "buddy" system, no note taker and not much support. At the end of the course she was told she could not counsel people. This experience was so stressful that she could not consider paid employment.

A student in higher education reported an experience of the barriers faced at her previous further education college which led her to conclude that access to study was a question of "survival of the fittest". The college had had no access, the lift was always broken, and she had to go a very long way round in order to

attend a class which she found distressing. The teachers tried to put her off and suggested she seek alternative colleges.

Points made by some participants

Dyslexia and other hidden impairments

This was mentioned by several participants in relation to both further and higher education. Several reported that dyslexia had not been spotted until they reached further or higher education. While some participants reported good assistance and equipment being provided, it often took a long time for arrangements to be made. Other students mentioned problems getting support when their impairment was not apparent.

One student with dyslexia who had been provided with a laptop reported jealousy from other students who could not see why they should not also get laptops.

There could be pressure not to disclose dyslexia but to struggle on, because of the fear of being considered stupid or incapable by teaching staff. One participant was told she should leave the course because “if you’re dyslexic you can’t learn new languages”.

“It wasn’t until I was a year into the degree that I found out I was dyslexic, because I was struggling with some work and was advised by my lecturer to get help and go to student support and an English workshop. I was given an assessment and it turned out that I was dyslexic. I felt I should have been given more information about what support and equipment I could have been given such as voice recognition equipment. My changing needs are not taken into consideration but this is a problem with my local education authority not the University.” (higher education)

EDUCATION STORY

"I found a course that interested me in the Floodlight book and went to college. I wanted to do my A levels and HND to give me a greater chance of getting onto a fine art degree. There were a few other disabled people on the courses that I took and no one left because we all had great one-to-one support throughout the whole duration of the course.

"I applied to University last year and they saw my portfolio and were impressed but said that they thought I would not cope with the written essay, which made me very upset and angry. They obviously liked my work but did not want to give me a chance.

"I am now studying a GCSE in English at Tower Hamlets, which will allow me access to the degree courses. My tutor suggested that I have an assessment and we found out that I was dyslexic. I have great support from Tower Hamlets. I have tape recording facilities and more time with essay writing. My teachers are very supportive and are helping me to develop my writing skills

"This makes things more clear about why I was struggling and now I have this information, I can get the necessary support at Universities. I am not scared about reapplying to Universities, as they will now give me the necessary support to help assist me through my course

"I think if I was not a very determined person I would not have done as much in education as it has been very hard and sometimes frustrating. I'm lucky that I have a talent for art.

"I think too that Universities should give disabled people more help and be more understanding when we are applying for courses and not to judge us because we are different. Before I applied I knew I had learning disabilities but I also knew I could do well on the degree course as I had done really well on my HND and A levels. However the difference was that the colleges gave me a fair chance

"Universities should at least offer foundation courses for students with learning disabilities to prepare them for the work in the main degree courses and if the student does not think they can get through the degree course with the necessary support then they know that they were given a fair chance to succeed. If not you begin to feel neglected."

[Extracts from an interview.]

Points made by a few participants

Disability Discrimination Act

As in the other areas, there were mixed views on this. While several saw it as helpful and starting to make real changes happen in post-16 education, others felt that it was “toothless” and was not properly enforced.

Commitment to Stated Policy

Some participants in further education questioned whether institutions were really as committed to disability equality as their promotional materials stated. It was felt that once people had enrolled so that the organisation would receive the funding, the staff lost interest in whether the students were able to complete their courses. This was also reflected in a lack of consultation with disabled students.

“Some colleges are full of broken promises and do not fulfil what is written in their prospectuses. I just ended up stressed and depressed from my college experience.”

“Once you’re enrolled into the course, the college gets the money so they don’t really care. They make no real attempt to keep you on the course.”

(This type of situation could only arise in further education, where funding for disabled students is received and administered by the colleges. In higher education, support funding is paid to the student through Disabled Students’ Allowances).

Some participants described a more positive experience:

“All the colleges that I was interested in had the facility of having the prospectus on audio tape cassettes, which showed me that they were actively trying to attract more disabled people into their college. It also makes you think that their support and advice services would also be at a high standard. In my case at [my present] college my whole experience is very positive.”

(further education student)

Disabled people’s response to discrimination

Other factors were self-confidence and the determination to succeed on the part of disabled people themselves. Sometimes the themes of personal confidence and external barriers were combined in the same comment:

“Disabled people who are educated in ‘special schools’ have the odds stacked against them and need to work so hard. It’s not only intellectual but also the way they view themselves that they have to battle.”

A few participants lacked confidence in their own abilities. More often, they were deterred from education by external barriers and all the battles they felt would be needed for success:

“Being disabled you have to fight to achieve; most disabled people going into further or higher education are very determined people. You have to have certain mind set to apply and go through University as disabled people.”

In several instances, participants were speaking for other disabled people, not necessarily themselves.

In relation to assessment, one participant expressed fear of reprisal by tutors:

“I’ve wanted to complain about a lecture but I’m scared that they will give me a bad mark, so choose not to say anything”

Disabled Teaching Staff

A small number of participants mentioned the importance of having more disabled staff in educational institutions, both because they might be more likely to understand the barriers faced by disabled students and to provide positive role models for potential future students.

“It makes sense for teachers to either be disabled, have some lived experience of disability or good training on disability.”

“There need to be more disabled teachers and lecturers but if they are not getting support as students, they will not make it through the system to be role models for disabled children and young people.”

As noted in the section on Employment, many disabled people do not disclose impairments which may not be apparent; and participants were likely to mean visibly disabled teaching staff, or staff who openly acknowledged their impairment.

Other Diversity Aspects

Only one participant mentioned a link to other areas of diversity in relation to education.

“As a black person, we are not taught about the contributions that black people have made to the UK but as a black woman who is disabled, we are non existent in the history books. This makes me feel like I’m not valued, that I don’t mean anything, as if I have no real significance in the make up of things.”

Positive comments

On balance, the comments were negative in education too, but there were many more favourable reactions than in either housing or employment. In a number of interviews, education was the only area in which the interviewee had anything positive to relate. The experience was sometimes valued for itself, and not just as a step towards employment.

- “Did a computer course a while ago and the college was very supportive. The tutors were very good and never singled me out for my disability. A very positive experience.”
- Goes to college where he does pottery. Is very interested in the area and found out about the course through a teacher.

Some participants emphasised specialist knowledge (e.g. in relation to dyslexia or visual impairment). More often, they referred to good practical support and non-discriminatory attitudes from staff and students.

8 Conclusions and recommendations

Conclusions

As noted in Chapter 2, Context, many of the findings of this small piece of qualitative research are consistent with findings of earlier research, as identified by the three GLA literature reviews. Major areas of similarity between this and earlier research could be briefly summarised as follows:

- There is low owner occupation among disabled people, with fewer living in private rented accommodation
- Many disabled people experience harassment
- There is a high level of unemployment among disabled people along with a strong desire to work if possible
- Neither employers nor the system of benefits are responsive to change and transition;
- Starting work is perceived by many people to be a risk in terms of losing benefits entitlements
- Jobcentre Plus and other job agencies were seen as providing a very poor service
- Access To Work is appreciated as a service but very poorly understood, both by employers and disabled people
- Disabled students are not always provided with timely and adequate support and equipment so that they can complete their studies.

All of these points clearly emerged in the responses from participants. However there were also some additional points covered which do not clearly emerge from the literature, or where disabled people themselves put more emphasis.

Monitoring form barriers

The monitoring form showed that the greatest barriers faced by our participants were seen as people's attitudes, physical barriers and stressful situations.

Certainly the question of attitudes – from the general public, from gatekeepers to the system, from neighbours, and from potential colleagues and employers – is a strong theme to emerge from this research.

Problems of physical access were common across participants in all three sectors. Inaccessible and inappropriate living accommodation caused very fundamental problems for many participants. This in turn has an impact on employment and education options.

Many participants identified stressful situations as a barrier. However, it seemed to emerge from the research that stress is linked with dealing with the barriers and obstacles presented on a day to day basis, not just situations that are stressful in themselves.

Lack of information to support empowerment

One of the strongest themes to emerge from the research, is information. Information is key. There is a serious level of misinformation among disabled people – many participants' comments demonstrate a lack of accurate information. Participants were not being properly informed about available services or were misinformed about issues such as benefits. In addition, it is clear that participants were unaware of the extent of their rights, including the provisions of the Disability Discrimination Act, and how to enforce them effectively. Changes in policy and particularly programmes available do not appear to be getting through to those who should be benefiting from them. Across all three research areas, participants reported the difficulty of getting reliable information about options in formats which were accessible to them. They reported having to go to many different sources for information about provisions. Cross-cutting and consistent information was simply not available for many, though a small number did report good practice.

The benefits system has changed in relation to moving in and out of work, but the perceptions of participants were that it could be extremely risky to consider trying out work or education in case this meant a loss of financial support which could be very difficult to reinstate. Government attempts to improve the job prospects of disabled people through changes to the benefits system and improvements to Access to Work are having little impact because disabled people are unaware of them. Access to Work is over 10 years old, but many participants did not know it was available, despite the fact that those who did use it had found it to be a good service.

There are still genuine barriers in parts of the financial support system intended to empower disabled people. Even so, many participants did not have the information that would enable them to choose how they wanted to live, or to move out of their current situation without fear of jeopardising their financial security. Disabled people face a lack of choice and real options, in all three research areas, which is made worse by the imbalance of power between the gatekeepers to the system and disabled people themselves. A shift of culture will be required to bring about a rebalancing of power, to give disabled people the tools with which to dismantle the barriers, which prevent them living their lives in the way they wish. Disabled people are tax-payers and deserve public services and information delivered by trained and competent staff.

Attitudes

Attitudes from ignorance through to hostility ran through most areas of discussion. Related to this was a tendency to stereotype disabled people and not to recognise their diversity and their potential. At best, such attitudes resulted in a lack of action, for example on the part of employers or education providers. At worst, many participants experienced harassment and direct

discrimination. This was particularly evident in housing, where harassment from neighbours and others in the local community caused participants significant distress.

Several participants suggested that there was a need for much more robust promotion of disability rights and raising awareness among the public as well as service providers.

Poor statutory responses

In all three research areas, there was evidence of a poor response from statutory authorities and a lack of proactivity.

In housing, local authorities failed to respond to the needs of disabled people to develop or retain social networks and to live in a place where they felt secure. This was compounded by the poor response of police to threats to disabled people's security. In addition, there were widespread problems reported by many participants about getting adaptations done in their homes. As well as facing long delays and excessive bureaucracy, participants also reported a lack of choice about what was done. This could mean very expensive adaptations were proposed, which did not really meet the person's requirements and which would add to problems and poverty and debt. Several participants mentioned that in the end it was both quicker and cheaper for them to get the work done themselves, if they could.

In employment, those who are supposed to support disabled people into and in work, particularly Jobcentre Plus, were criticised for a lack of understanding and for their low expectations of disabled people.

In education, institutions promised more to prospective students than, in the event, they delivered.

Resources

Across the piece, a lack of, or inappropriate use of, resources was a recurring theme. In housing, participants highlighted the significant shortage of accessible housing in London. In employment, employers were seen as not being willing to commit resources or time to adaptations to the workplace or equipment. In education, resources were sometimes inappropriately allocated, with generic provision substituted for specific requirements.

Lack of understanding of access needs

In all three research areas, participants' access needs were not being met. In many cases, this was a result of a lack of communication which led to a lack of understanding across the organisation. In education, for example, the admissions staff might have known about and acknowledged a student's access

needs, but the tutors did not understand and therefore did not meet them. Across all three areas, participants commented on a need for flexibility that often was not available.

Good practice

Participants identified a few examples of good practice. However, there is no common understanding against which these can be measured. In any event, good practice needs to be shared across all boroughs, employers and other service providers so that disabled Londoners receive a consistent, satisfactory service in all three areas.

The research indicates that, all too often, positive practices rely on the knowledge, understanding and commitment of individuals. Disability equality and rights are not yet embedded into organisational structures.

Interconnectedness

This research has also underlined how closely linked the three areas of housing, employment and education are. Any improvements need to take this into account and tackle barriers across the three sectors rather than in a piecemeal fashion. However as some participants pointed out, despite there being a Minister for Disabled People, there is as yet no single government department responsible for disability which means services, accountability and resources are fragmented and poorly if at all coordinated. The establishment of the Office for Disability Issues provides the opportunity to address this and to make a real difference to disabled people's lives.

Research Issues

Appendix B reports in detail on the methodology used for this report and any lessons which can be drawn on for future research.

A clear gap in this research was its ability to explore unmet need in more detail. Inevitably, people who are trapped and isolated in their own homes so that they do not come to the attention of either statutory or voluntary agencies are absent from this research. The problems of isolation were highlighted by those who had experienced them in the past, but were no longer in that position. Isolation is a serious issue for disabled people, however, and future research could estimate the extent of such isolation.

The barriers faced by owner occupiers, those in private rented accommodation and people who are or would like to be self employed are other areas which did not emerge from the present research and where in future more research might be useful.

Previous research has demonstrated significant barriers for disabled people from black and minority ethnic communities. The participants in this research, despite its having a level of black and minority ethnic participants that reflected the population of London (29%), did not highlight these additional barriers. In consequence, research targeted at the barriers faced by black and minority ethnic disabled Londoners would also be an area worthy of further study.

Further research on what constitutes good practice and how to disseminate it would also be useful.

Recommendations

Involving disabled people and challenging disablism

1. The GLA should make sure that its Disability Equality Scheme and Equalities Toolkit incorporate actions appropriate to the recommendations contained in this report.
2. The GLA should consider the establishment of a resource to build the capacity of organisations across London run by disabled people.
3. The GLA and GLA group should resource and develop the structure of Independent Advisory Groups of disabled people to inform the effective integration of disability issues into mayoral strategies and service provision.
4. The GLA group should develop a strategy to promote and raise awareness of disability issues across London stakeholders, building on Disability Capital.
5. The GLA should develop a disability equality leadership programme for its mayoral advisers, directors and board members
6. The GLA should review the accessibility of City Hall, including the availability of parking spaces.
7. GLA and Metropolitan Police Authority (MPA) should work together with the police and local authorities to ensure that all staff are better able to assist disabled people who are being harassed, and that incidents of hate crime against disabled people are properly recorded and monitored.
8. The discrimination law review should look at ways of making disability legislation more effective, and of making it easier for disabled people to take legal action.
9. Disability Equality training should be provided to all staff responsible for reception and service delivery, in the fields of post-16 education, housing and employment. This training must cover the full range of barriers experienced by

disabled and Deaf people, including those experienced by people with hidden impairments, long-term illness and variable health.

Information, advice and support

10. The GLA should consider establishing a centralised and centrally funded accessible communications unit to ensure that all the information produced by the GLA group (internal and external) is accessible.
11. The GLA group should look at the possibilities of more effective information provision about services available across the city through its Information and Communications Technology (ICT) strategy and using the London portal.
12. The GLA with the Office for Disability Issues and other stakeholders should explore the possibility of establishing cross-departmental, cross-agency one-stop shops in each borough, using expertise of statutory and voluntary sectors; that would provide information, advice and advocacy.

Housing

13. The serious shortage of accessible housing in London, which is highlighted by this research, needs to be addressed.
14. The London Plan 2004 contains targets that 10% of all new housing should be built to wheelchair accessible standards and 100% of all new homes should be built to lifetime home standards. A system needs to be developed to monitor the delivery of these targets.
15. There is a need to provide better information, advice, support and more choice to disabled people about accessible housing options and to make sure that adapted housing is let to disabled people wherever possible.
16. Government departments, local authorities and housing associations should implement the strategic recommendations coming out of 'Reviewing the disabled facilities grant programme' (ODPM and DH) Oct 2005.
17. Social landlords need to improve the information available to disabled people about the adaptations service in their area, how the system operates for people living in different tenures, and where they can go to for advice.
18. Social care provision including direct payments need to take account of all disabled people's legitimate independent living needs for such things as small repairs, shopping and going out socially.

Employment

19. The GLA group should develop an effective plan to ensure that it meets its targets in the employment of disabled staff.
20. The GLA group should establish a comprehensive list of accredited disability equality trainers and training organisations as a procurement tool and develop a training tool based on the social model.
21. The LDA should promote disability equality among employers through Diversity Works for London and ensure employers are aware of their legal obligations and of the availability of schemes such as Access to Work.
22. The LDA should consider ways in which incentives to employers (e.g. local award schemes) might be used to encourage the employment of disabled people.
23. The GLA group should investigate how positive action programmes such as work experience and mentoring schemes might be used to encourage the recruitment and retention of disabled people in London.
24. The Olympics and Paralympics strategies should incorporate a programme of sustainable job creation, with equality of opportunity for disabled people.
25. The government (DWP) should promote Access to work much more effectively, so that all employers and all disabled people know about it.
26. The government should actively disseminate information to disabled people about changes to benefit rules and programmes available, which ease the transition from benefit to work, with contact details for independent advice about these rules.
27. The government should implement well-designed training for personal advisers in Job Centres about disability, rights and benefits.

Education

28. Institutions, especially those in higher education, should consider ways to recruit more disabled, especially academic staff.
29. Institutions should audit the accessibility of the learning environment and plan improvements into their regular maintenance programmes through their disability equality schemes.
30. All institutions in further, adult and higher education should have the capacity to run flexible courses (in time &/or place) for disabled students, when needed.

31. All institutions should take a strategic approach to providing proper standards of equipment in reasonable time, as required by legislation.
32. Each institution should identify an appropriate person to whom disabled students can make complaints without fear of reprisal.
33. Government should provide sufficient resources to colleges and universities to enable them to meet the needs of disabled students more effectively.

Research gaps

- More needs to be known about the needs of disabled people who are isolated, including those who come to the attention of neither the statutory nor the voluntary agencies.
- The financial situation of disabled students and potential students needs more research. How do financial factors affect their participation? The issues will differ in higher and further education.
- Research is needed on disabled people's experiences of volunteering: What lessons can be learnt from their experiences? How can disabled volunteers progress into paid employment or maintain a good quality of life while volunteering?
- There is a lack of quantitative work which uses the social model perspective.

Implementation

The GLA and GLA group, in partnership with stakeholders, will draw up an action plan and work to implement these recommendations. The plan and working party will take account of comments made by the Advisory Group during the course of the project.

Appendix A: Advisory group members

'Towards joined up lives': Advisory Group Members

External Members

<i>Person</i>	<i>Organisation</i>	<i>Position</i>
Ossie Stuart (chair)	Freelance disability consultant and trainer	Greater London Action on Disability [GLAD]
Jacqueline Runnalls	London Borough of Waltham Forest	Occupational therapist
Reyhana Malek	Habinteg Housing Association (specialises in accessible housing)	Research Manager
Richard Rieser	Disability Equality in Education	Director
Jennifer Dyer	National Bureau for Students with Disabilities [SKILL]	Policy Director
Lynda Griffin	Bexley College.	Programme area leader for students with learning difficulties.
Nicholas Russell	Trade Union Disability Alliance [TUDA]	Representative
Paul Drake	Employers' Forum on Disability	Information and Policy Manager
Breda Twomey	Disability Rights Commission	Research Officer

'Towards joined up lives': Advisory Group and Project Team – GLA group London Development Authority [LDA]

<i>Person</i>	<i>Organisation</i>	<i>Position</i>
Elaine Smith	LDA	Skills and employment manager – equalities
Julie Fleck	GLA/LDA	Principal Advisor, Access and Inclusion.
Frances McAndrew	LDA	Equalities and Diversity Manager.

Greater London Authority [GLA]

<i>Person</i>	<i>Organisation</i>	<i>Position</i>
Mark Watts	Mayor's Office	Chair, Disability Policy Group; Senior Policy Advisor
Robin Barer	Social Inclusion Team	Project Leader; Senior Policy Officer
David Morris	Equalities team	Senior Policy Project Manager
David Haralambidis	London Stakeholders	Coordinator Disability
Isabel Robertson	Housing and Homelessness Team	Senior Policy Officer
Sue McIntosh	Social Inclusion Team.	Senior Policy Officer
Grant Pettitt	Health Policy Team.	Senior Policy Officer
Simi Awosika	GLA	Administrative Officer
Muge Dindjer	GLA	Social Policy Manager.

'Towards joined up lives': Advisory Group Members**Research Team**

<i>Person</i>	<i>Organisation</i>	<i>Position</i>
Dianna Yach	Ionann Management Consultants Limited	President
Anne Dunn	Ionann	Head of Research
Deisha Watson	Ionann	Senior Researcher
Andrew Cleary	Ionann	Researcher
Neena Samota	Ionann	Researcher
Amit Sharma	Ionann	Researcher
Eric Smellie	Ionann	Researcher
Sue Maynard Campbell	Equal Ability Limited	Managing Director
Alice Maynard	Future Inclusion Limited	Managing Director

Appendix B: Methodology and lessons for future research

A brief outline methodology is provided in Chapter 1 of the main report. These more detailed comments are intended to complement that section of the report and to assist any future research in this field.

The research work fell into three main stages:

- Preliminary
- Fieldwork
- Analysis and report

This appendix follows these stages. Also included is information about the research partnership, the role of the GLA and Advisory Group and brief observations on Social Model Research.

Preliminary Stage

1. Participants involved

London Household Survey

The original brief for this research envisaged using the London Household Survey (LHS) of 2002 as a basis for a quantitative piece of research which would involve calling at the relevant households and conducting interviews held in participants' homes. The 2002 survey had produced a data base of 1,320 households which both contained disabled people and expressed a willingness to be contacted for further research. The revised invitation to tender also proposed to use the LHS as a basis for a smaller, more qualitative piece of work which would use focus groups and personal interviews.

As a first step a letter of invitation to take part was sent to one-third of the households in the LHS data base. The invitation offered a choice of participation in focus groups or personal interviews. A form was enclosed so that people could specify any transport, dietary, access or support requirements. People could reply by whichever method suited them – post, fax, telephone or email.

As the initial response was very poor, and given time pressures to begin the field work, it was quickly decided to send the invitation to all households on the LHS data base. This did provide more responses but the return rate from this source remained poor. Of the 196 people who finally expressed interest in taking part, only 50 came from the LHS.

In discussion with members of the GLA project management group, it emerged that other research using the LHS data base had proved much more successful. However this research had not been in a potentially sensitive area such as disability and it had involved house to house visits to follow up an initial introductory letter. It seems likely that personal visits to each address are a better use of this type of database.

Disability Capital

A further mailing was then sent to about 250 people on the GLA Disability Capital data base. This produced a better response: 91 of the 196 people who expressed interest came from this source. These were people who had either attended a GLA conference on disability or who had completed a questionnaire on the GLA web site. They could therefore be described as 'activists' to some degree or other.

There was discussion throughout the project between the GLA project management team and the research team as to the balance to be achieved in the sample between 'activists' and 'ordinary' disabled Londoners. It was clearly desirable to try to reach people with hidden impairments, especially those who might not take part in conferences and other consultations and whose voices are too often completely unheard. This is an issue highlighted in this research. There is clearly a need to continue to conduct research which will include this group of people to a much greater extent than was possible in this research project.

On the other hand, it was felt in the team that just because someone might be perceived as an 'activist' this did not make their views and experiences any less valid.

Attempts were made throughout the project to reach more 'ordinary' disabled Londoners. See below.

Snowballing Methods

In order to try to achieve a more diverse and broadly based sample – and also to improve on numbers – two forms of what is often called the 'snowball' approach were adopted.

Firstly, participants themselves often suggested others who should be contacted. This was a useful way of reaching people who might not have been otherwise reached. However the risk here was that this resulted in more Disability Capital participants being reached, or that it reached people with the same impairment. It had been decided at an early stage and in discussion at the first Advisory Committee meeting that the research should take a cross-impairment approach and that focus groups should not be held for any one

specific group of people. For example participants often belonged to local support groups for their own impairment and the snowball method could result in several people from one group coming forward.

The second method was to build on the initial contacts made with disability organisations at the start of the research. These telephone interviews had been conducted at the start of the research. About 20 different organisations were contacted. There were two purposes: to explain the research and to ask the organisations to suggest any issues which they felt should be explored; and for relevant organisations, to see whether any of their service users might be willing to take part.

The team went back to some of these contacts who had been particularly helpful and also made some new organisational contacts. Unfortunately the new contacts were made towards the end of the field work and there was not enough time to conduct discussions and then interviews with disabled people. The assistance of three organisations in particular was crucial to this study's success reaching certain groups not included in previous research: Habinteg Housing Association and Aylesbury Day Centre in Southwark, which enabled the team to reach people with a range of impairments; and Elfrida, a drop-in centre for people with learning difficulties. This was done because our monitoring of participants indicated that this group was not being reached by the main research approach and therefore risked being unnecessarily excluded.

Having made these contacts, the team then attended regular drop in, social and support sessions at the invitation of the organisation concerned. In our view, it would have been desirable to adapt this approach at an earlier stage and to use it much more as a main source of reaching people. This method has the potential of reaching many more 'ordinary' disabled Londoners who might not be taking part in other forms of research or consultation. It also takes the research to them in places which are familiar and comfortable, rather than making demands on participants' time and resources and asking them to travel to venues which may be difficult. From a very practical point of view, it is cost effective and makes good use of research time. Personal visits in people's homes always require two researchers (see below) and involve time in setting dates and time, plus travel. A team of researchers can attend one drop in session and conduct a good number of one-to-one interviews with people without too much disruption to their lives. It also offers the scope to collect examples of good practice at local level and for staff at local level to raise any practical access issues which might not be apparent at policy level. This method however may not reach people who remain isolated and unseen, nor would it reach disabled people who choose not to attend clubs and organisations (often working disabled people), and it would therefore not be enough on its own.

We recommend that greater use is made of the network of local voluntary sector organisations which run drop-in and similar sessions for their service users in future research.

Targeting Statutory Organisations

Because post-16 education was a key issue for this research and because not all participants had recent or current experience of this, the team approached London Metropolitan University which agreed to host two student focus groups. This was a useful method with which to reach a target group and it was also a cross impairment approach. With more time, the team would have liked to conduct similar sessions at a further education college and also to have visited Westminster Kingsway College of which several participants spoke highly.

We also suggest that future research explore the possibility of attending local Jobcentre Plus offices, hospital/health care institutions, CABx, housing offices etc. to try to include people who use these services.

2. Communication & Logistics

In the end it was only possible to include 123 of the 196 people who expressed interest in taking part. The main reasons for this were:

Communication Problems

Where potential participants had provided telephone numbers or email addresses, it was relatively easy to make contact to offer a choice of dates for focus groups or interviews. Because dates were set for focus groups and there was not a long time available to get back to people, this tended to exclude people whose preference was for communication by letter. Although the team went back to every person who had expressed an interest, time constraints meant that not everyone was able to be included in time.

It is important that people have the option of replying in whatever form is best for them and time should be allowed for this.

Logistics

When people were contacted, the team offered a choice of focus groups on existing dates at City Hall, focus groups in their own area if this could be arranged, a telephone interview or a personal interview in their own home. At the beginning, more people were willing to attend focus groups but as time went on, more people opted for interviews in their own homes. This took time to arrange in terms of finding two interviewers who would be available at a time convenient for the person.

If personal interviews in people's homes are used in future research, a good lead-in time is required.

Future Sampling

Based on this experience, we would not recommend using the LHS as a main source of participants unless it is used to arrange house to house visits to follow up an initial contact letter. The most productive method in our experience is by taking the research out to places where disabled people are – drop in centres, etc – and by targeting specific groups and venues.

3. Organisational Issues

Venues

City Hall was used as a venue for the majority of focus groups. This offered the advantage of large meeting rooms with plenty of space for wheelchairs and other support; the rooms are equipped with induction loops; and catering can be easily provided. For this research it also offered a distinct financial benefit as there was no cost involved in room hire.

However, there were also problems with using City Hall.

People arriving in cars or taxis had to enter and leave City Hall through the loading bay. This does not send a positive message to disabled people about access – quite the contrary. There were many complaints about this from participants who were not then in the best frame of mind for a focus group. The loading bay was the biggest cause of complaint in the entire research.

The team and participants were totally reliant on security staff to collect people from the loading bay and to return them there afterwards. We would like to offer our warm thanks and praise for City Hall staff who were a great help on this. However it was inevitable that there were sometimes delays, particularly if several people arrived in a short space of time. Participants complained of having to wait for some time before they were collected and they then arrived late despite having left their homes in good time.

Finally the loading bay does not seem to have any signage on the road to let people know it is the way in to City Hall. The team would order transport for participants which failed to arrive because taxi drivers could not find the loading bay. On one occasion team members and two participants waited after the evening focus group for 45 minutes for taxis to arrive. It was only after one of the research team actually walked through the loading bay to the barrier that one of the taxis was located.

While most participants found the meeting rooms adequate, some commented on lack of windows which opened directly to the outside (the windows opened onto the cafeteria area) and others found City Hall difficult overall because of the greyness of the décor and lack of colour or other visual signs and décor.

Many participants commented that they would have preferred to attend a focus group held locally and that they had had to spend some time travelling into central London.

An important lesson for the future is not to hold focus groups which either start or end during London's rush hours. For several participants travelling on public transport in the rush hour was an obstacle to participation. City Hall focus groups were held from 2 to 5 pm in the afternoons and from 6 to 9 pm in the evenings.

Other obstacles to attending and therefore being able to participate included people's own changing health from day to day. For some people who had arranged to attend, on the actual day their health meant this proved impossible. The weather was another hazard. Focus groups planned to take place in Willesden did not materialise because it snowed that day, making travel particularly hazardous.

An important reason for using City Hall was financial. However we did find that it was possible to find local venues which catered specifically for disabled people and which were available at extremely good rates because they tended to be community venues intended for this kind of event.

We recommend for the future that focus groups are held in suitable local venues in order to maximise the number of people who can participate.

Safety Issues

The team discussed issues of safety in relation to conducting personal interviews in people's homes. It was decided that, to make sure the person felt comfortable and safe allowing researchers into their homes, two people would always be sent and they would be a mixed male/female team. As well as notes being taken, home interviews would be taped (with the person's consent) to ensure a record of what took place during the interview. This approach also took into account the safety of the research team, particularly for evening interviews. We believe it was important to take this approach to safeguard all concerned but it does of course have cost and logistical implications.

People's Preferences

As mentioned earlier, as the field work went on, more and more people opted for face to face interviews rather than phone interviews or to attend focus groups. It would be interesting to review whether this is more of an issue for disabled people who may find it difficult to get out of their homes, and also to consider the implications for the results. Are those attending focus groups more likely to be mobile, or to be an 'activist'? Are those requesting home interviews

more likely to be isolated and less mobile? If so, should their experiences be weighted differently? These preferences also have cost and time implications.

Monitoring Form

This is discussed in chapter 3 under research issues in relation to the Social Model approach. It is standard practice to ask participants to complete some basic monitoring information and it is important that this is kept as short as possible to avoid taking up too much of people's time, and to avoid it turning into a questionnaire in its own right.

However in this case some questions which might be considered in future research are:

- Should disabled people be asked to specify their impairment as well as to identify the barriers they face? If so, what is the aim of this question and who is the potential user of the information? Does it risk medicalising the approach and does it dilute the Social Model?
- Were the barriers listed the right barriers? Should there be others?
- Given that this research wanted to explore issues of housing, employment and post-16 education, should the monitoring form have asked people to say what kind of accommodation they were in, their employment status and whether they were participating in any form of education? Again if this was asked, what would the purpose of the question be?
- The main aim of the monitoring form was to try to identify whether the research included a good representation of London's population. How could the form used this time be improved to meet this aim?

Payment

The initial tender from the team specified that as well as paying travel and support costs as required by participants, people attending focus groups would be paid £25 in recognition that they had given up time to attend and to underline that their views were considered of value. In the early stages of contacting different organisations it was pointed out that this was potentially discriminatory to those who preferred interviews, who would not be paid. After discussion in the team it was agreed that people who were interviewed would be paid £10. While focus groups lasted for three hours, interviews lasted for no more than one hour and also did not involve any travel time for the participant.

The experience in this research was that participants were very pleased to receive the payment; some had not expected it and were happily surprised. A few participants did not want the payment themselves but asked for it to be

sent to their disability organisation. We did not get a sense that payment at this level had any adverse impact on who was willing to take part and therefore the results.

We recommend that similar payments be made in any future research.

Fieldwork Stage

1. The questions

As explained in chapter 1, the questions used for focus groups and interviews were derived mainly from the three GLA literature reviews and to a lesser extent from points made in the initial interviews. It was decided not to ask people directly about employment, education or housing status. As mentioned earlier, this is perhaps something that could have been included on the monitoring form. The reason for not asking this directly was that the team wanted to probe people's views and experiences rather than clarify current status.

Our experience with the questions in practice was that they worked well in prompting people to talk about their experiences. Not all questions applied to everyone, particularly in interviews, and the team was flexible to allow participants to express other points which the questions did not evoke. There were no serious problems with any of the questions.

2. Cross-Impairment approach

It was decided at an early stage that single-impairment focus groups should not be held. This seemed to have worked very well with most groups being attended by a diverse range of people who enjoyed sharing views and experiences. Where it was felt that some groups of people might not be taking part (notably, as far as the team could tell, learning disability, people with HIV/AIDS) it was decided to try to redress this by using targeted interviews.

We recommend the cross impairment approach for future research in combination with targeted interviews.

3. Timing

Before the field work there had been some debate about how long the focus groups should be. Focus groups normally last for two hours. It was decided to allow three hours so that there could be frequent breaks as needed and to allow time for any interpretation or other support, and to ensure no one felt rushed or pressured into giving their views more quickly than they might have wished. Against this there was a concern that three hours was a long time to ask of people.

The experience of this research was that three hours worked very well. Most groups took at least two breaks, roughly once an hour. People really used the time well; they had a lot to say and the main problem was that people were still talking animatedly after three hours – some people could have taken longer.

The one hour allowed for interviews also worked very well and was appropriate. Not everyone needed a full hour.

4. Approach of the participants

On the whole the focus groups were very lively, extremely interesting, and had a very good atmosphere. Participants enjoyed meeting each other, and the team, and there was a very positive sharing of information, as mentioned in the report. People made contacts and extended their networks which they said would be useful for them in the future.

One focus group was attended by three people who knew each other and who were determined to attack the GLA through the focus group. They also verbally attacked the researchers who were conducting the group and made derogatory comments about other members within the group. The remaining participants supported the team and helped to move the discussion on but this was one occasion which was quite distressing for all concerned. Fortunately this was a one-off.

5. Researchers

As mentioned in chapter 1, all focus groups were facilitated by two team members, one of whom took detailed notes. Interviews in people's homes were conducted with two team members; interviews in drop in centres and public venues were conducted by one person. Team members gave all participants their contact details in case they wanted to add to anything at a later date.

Analysis and Report

This is discussed in chapter 1. Detailed notes of all focus groups and interviews were taken. Focus group notes recorded the main points agreed by all present and where of potential interest, any additional points made by individuals. A count of individuals making each point was not part of the focus group approach. Therefore the analysis is based on mentions of issues either by a group or an individual. This is a standard qualitative approach.

The points made were grouped into key issues and a count made of number of mentions of each issue. In the main report the issues mentioned by the most people are set out first. Very little, if any, relevant material was left out.

The Research Partnership

The GLA had been keen to provide opportunities for partnerships of different types of consultancy to work together and tender for this research. This was a very positive approach which we believe helps to widen the range of smaller organisations which might be able to tender for this work. Very often procurement processes tend to be structured in a way that makes it difficult for smaller organisations or individual researchers to be able to meet all the tender requirements and we welcome the GLA approach to this research as one which widens opportunities.

We feel on balance that the partnership between the three organisations has worked well but future projects should allow more time for consultation at each stage.

The field work was conducted by a team of non-disabled people and the advice and consultation role of Future Inclusion and Equal Ability was therefore even more essential. The team very much welcomed the training provided by these two organisations and feel that such training is essential both for non-disabled researchers and for disabled researchers in order to broaden their understanding of people with different disability equality issues than their own.

The field work team was itself very diverse in terms of age and ethnicity, and fairly evenly balanced in terms of gender. The team had extensive experience of working on diversity particularly in terms of race and gender, and had a strong commitment to inclusive and ethical research which was a good foundation on which to build skill development in the Social Model of Disability.

Several participants spoke to team members about non-disabled researchers doing this research. These were usually positive discussions, with participants welcoming the involvement of non-disabled researchers. No adverse comments on this were received. For their part the team members were appreciative of any constructive feedback they received.

Role of GLA and Advisory group

The team appreciated the GLA project officers' help throughout the project. Feedback from the Advisory group was also very useful.

In retrospect, we would recommend that, in any future research, more time, and therefore budget, is allowed for building relationships and consultation within the partnership, and building rapport with project managers and advisory groups. However, it is crucial always to be careful to maintain the impartiality of independent researchers.

Social Model Research

Implications of taking the Social Model approach are discussed more fully in chapter 3.

It was noted and welcomed by some participants that the research was being conducted on a Social Model basis. The field work team felt that not making a medical approach the starting point, and not asking people to define themselves in terms of their impairment, was very liberating. It seemed to open doors rather than close them.

Because so much research is based on the medical model, and policy making is also geared towards responding to different impairments, there was always a constant 'pull' back to the medical approach, which was very well illustrated in the debate over the monitoring form. There is a natural desire, it seems, to want to know which sort of people said what. In drafting, this 'pull' has the effect of sometimes risking a drift back towards defining issues according to needs and impairments rather than rights and barriers.

Scope and Limits of Research

The research was designed to explore the experiences, views, concerns and aspirations of disabled people in the areas of housing, post-16 education and employment. A qualitative approach based on the Social Model was followed using focus groups and in-depth interviews.

The research included people with different experience of disabling barriers and took account of other aspects of diversity such as sex, ethnicity, sexual orientation, faith and age.

The study focused on what disabled Londoners told the research team about their experiences, rather than the findings of previous research. However the context section and the conclusions attempt to link the findings with other studies and policy reports as appropriate.

Literature reviews were outside the scope of the research study. However, a chapter on the context for the study has been included which draws on literature reviews compiled by the GLA. Direct comparisons between previous research studies and the present study were not possible given that previous research was informed primarily by a Medical rather than a Social Model approach.

We recommend that further quantitative research is conducted which is based on the Social model, which could explore some of the issues raised in this small study from a social model perspective.

Appendix C: Questions for Focus Groups and Interviews

Note: this appendix is the format for focus groups. For interviews, the same questions were used, varied according to the individual concerned. For example if they had no recent employment or education experience, a general open question about this was asked instead.

Points For Focus Groups

Introductory points

Introductions and background about the research and its aims. Timing, refreshments, and confidentiality.

1. Are there any questions or concerns about this focus group and what will happen with the results?

Getting started

2. Could each person say their first name, for the benefit of everyone else, and say briefly why they wanted to come to one of our focus groups – what are they hoping may happen as a result?

Housing

3. What sort of housing do you live in now? (eg local authority, private rented, owner occupied etc) Is this the sort of housing you want, or not?
4. Could you say three things that would give you the kind of housing you would really like? Three improvements, three things you'd really like.
5. What are the barriers to getting these things? Do you face discrimination as a disabled person? What form does this take?
6. Are there problems with getting financial support for the housing you need? Are there problems with systems of assessment – financial or access?
7. What about information – how easy or hard is it to get the information you need about options? What is the best way for you for information to be provided – for example, internet, phone, one to one contact?
8. Do you have access to the advice and support you need to be able to make your own decisions about housing?
9. How much do housing problems affect employment and education?

10. What happens if your situation changes – your health improves or gets worse for example, or you want to change jobs, or move in with different people, or be nearer family or friends?
11. Any other points just on housing?

Employment

12. What is your current position? E.g. are you working, employed, self employed, not employed, studying, doing something else?
13. What would you like to be doing? Eg would you want to have a job, or be self employed, or doing something else?
14. What is stopping you doing what you want to do in terms of employment? Eg benefits system, opportunity, discrimination, attitudes, transport, housing, other
15. What experiences have you had of working in the past?
16. What about government schemes, New Deal, Access to Work, Job Centre Plus, other things? Have they helped?
17. How does the benefits system work for you if you are working or not working?
18. What happens if your situation changes – to your benefits or anything else? How flexible are employers? How flexible is the benefits system and other means of support?
19. When you get a job, what about keeping it? What sort of support or advice would help? What should employers be thinking about doing? And colleagues?
20. How does employment relate to housing and education in your own situation and past experience?
21. If you had a wish list of three things which would help you with employment what would the three things be?

Education after 16

22. In general, how would you assess the education that you were given?
23. What was wrong? What would you have liked instead? Was anything good about it?

24. Are you involved in any kind of education now? Eg adult ed, training for work, studying further, anything?
25. If you are, what problems have you experienced in getting the education you want? Why do these occur?
26. Is there more education that you would like to be have now? What is this?
27. What stops you getting the education you need? Is discrimination a problem?
28. What would help you to reach your aims and goals for education?
29. If you move into education have you had any problems with benefits and other financial support like grants?
30. What should educational institutions be doing to make it possible for you to take a full part? For example, the way they teach, they way they provide information, anything else?
31. Any other points on education?

Linking it all up

It's a bit artificial separating these three areas so some final questions covering all of them.

32. How do you see these three key areas linking together – and what stops these links being made for you? (for example, local authorities structures not making the links, bureaucracy etc).
33. Is there something different about London that makes any of these things better or worse?
34. We have focused on practicalities – jobs, money, homes. What about your social life – family, friends, relationships? Are these affected by some of the barriers you have mentioned so far? And if they are, what could help?

Conclusions

35. Have we missed anything? Anything you really feel should be said?

Appendix D: Monitoring form

Are you: Male Female Transgender

How old are you?

Ethnic origin (Please tick the group which best describes your ethnic origin)

- Asian or Asian British Black or Black British White
 Mixed ethnic origin Chinese

Other group please say which

Are you:

- Lesbian Gay Bisexual Heterosexual

If you have a religion or faith, could you say what it is?

What are the biggest barriers for you in doing what you want to do?

Please put '1' for the biggest barrier, and '2' and '3' for up to two other barriers:

- Physical access to buildings, streets, and transport vehicles
 - Access to the written word
 - Access to pictures and images
 - Access to speech or conversation
 - Access to other sounds
 - People's attitudes to you because of your impairment, medical condition or disability
 - Stressful situations
 - Other barriers – please tell us
-
-
-
-
-
-
-
-
-
-

Thank you for completing this form. The information is used only to ensure we include a diverse range of Londoners in this research.

Appendix E: Bibliography

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Appendix F: Abbreviations

Abbreviation	Meaning
ACE	Adult and Community Education
AHR	Accessible Housing Register
ALG	Association of London Government
AtW	Access to Work
BCODP	British Council of Disabled People
BSL	British Sign Language
CAB(x)	Citizens' Advice Bureau(x)
DDA	Disability Discrimination Act 1995 as amended
DFG	Disability Facilities Grant
DIY	Do-it-Yourself
DLA	Disability Living Allowance
DH	Department of Health
DRC	Disability Rights Commission
DWP	Department for Works and Pensions
FE	Further Education
GCSE	General Certificate of Secondary Education
GLA	Greater London Authority
GP	General Practitioner
HA	Housing association
HE	Higher Education
HND	Higher National Diploma
ICT	Information and Communications Technology
JAWS	a speaking computer package
JC	Job Centre
LA	Local authority
LDA	London Development Agency
LHS-2002	London Housing Survey 2002
LSDA	Learning and Skills Development Agency
MPA	Metropolitan Police Authority
NFER	National Foundation for Educational Research
NHS	National Health Service
ODPM	Office of the Deputy Prime Minister
OHPs	Over head projections
Ots	Occupational Therapists
PA	Personal Assistant
PCA	Personal Capability Assessment
RNIB	Royal National Institute for the Blind
SSP	Statutory Sick Pay
THES	Times Higher Educational Supplement
TUC	Trade Union Congress
UCAS	Universities and Colleges Admissions Service
UK	United Kingdom
VIP	Visually Impaired Person

Appendix G: Definitions

Social Model:

From a social model perspective, people are disabled, not by their impairment, but by the environmental and social barriers that prevent them participating fully as members of society. There is a focus on the removal of barriers, and providing 'different but equal' treatment to enable all people to participate.

Medical Model:

From a medical model perspective, people are disabled by their impairment and the absence or reduction of functionality that it causes. There is a focus on medical intervention – disability is something the person is burdened with, which should be cured so they may become as 'normal' as possible.

Impairment:

An impairment is a (usually permanent) medical condition that results in an absence or reduction of function, whether physical, sensory, emotional or intellectual.

Disability:

Disability is caused, not by a person's impairment, but by barriers in their physical and social environment – buildings, transport, information provision, people's attitudes etc.

Disabled person:

A disabled person is someone who is disabled by the barriers that they meet in their physical or social environment.

Lifetime Home:

A Lifetime Home is any home which is designed to incorporate 16 essential features that make it accessible or adaptable for any stage in a person's life. Life stages include things like having small children and needing room for pushchairs, temporary or permanent impairment, or ageing. A Lifetime Home is not necessarily built to wheelchair standard, although it can be adapted to accommodate a wheelchair. Wheelchair standard homes can accommodate a wheelchair user without adaptation specifically for the wheelchair. See www.lifetimehomes.org.uk for more information.

Independent Living:

Independent Living is about disabled people controlling their own lives, and choosing where and how they want to live. It is not about disabled people doing everything for themselves, but about them deciding, as the experts on their wants and needs, how to run their lives.

Separate courses (education):

A course or class specifically provided for and only open to disabled students, sometimes called 'segregated provision'.

Deaf and deaf:

“'deaf' written in lower case denotes the medical condition of hearing loss. Upper case 'Deaf' is the political and social term of belonging to the Deaf community. It is used in the same way other nationalities and groups would be spelt with upper case letters, e.g. Spanish or Muslim.” (Deaf and Creative, University of Wolverhampton)

Advocacy:

“Independent Advocacy is no more than making sure that people who are at risk of being excluded are not also on their own. As far as possible, advocacy helps people to get their point across, speak up for themselves, get organised. But sometimes some people just need someone else on their side.”
(Independent Advocacy: a guide for commissioners – The Scottish Executive).
Advocacy can be provided by paid workers or volunteers (peer or citizen advocates), or through support to enable self advocacy.

Access to Work:

This is one of the JobcentrePlus programmes to support disabled people in and into work. Grant funding is provided to cover costs that arise “because of an individual's disability”. These costs can be for items such as equipment, personal support, additional travel costs, and communication support.

Other formats and languages

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Chinese

如果需要您母語版本的此文件，
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Vietnamese

Nếu bạn muốn có bản tài liệu này bằng ngôn ngữ của mình, hãy liên hệ theo số điện thoại hoặc địa chỉ dưới đây.

Greek

Αν θέλετε να αποκτήσετε αντίγραφο του παρόντος εγγράφου στη δική σας γλώσσα, παρακαλείστε να επικοινωνήσετε τηλεφωνικά στον αριθμό αυτό ή ταχυδρομικά στην παρακάτω διεύθυνση.

Turkish

Bu belgenin kendi dilinizde hazırlanmış bir nüshasını edinmek için, lütfen aşağıdaki telefon numarasını arayınız veya adrese başvurunuz.

Punjabi

ਜੇ ਤੁਹਾਨੂੰ ਇਸ ਦਸਤਾਵੇਜ਼ ਦੀ ਕਾਪੀ ਤੁਹਾਡੀ ਆਪਣੀ ਭਾਸ਼ਾ ਵਿਚ ਚਾਹੀਦੀ ਹੈ, ਤਾਂ ਹੇਠ ਲਿਖੇ ਨੰਬਰ 'ਤੇ ਫ਼ੋਨ ਕਰੋ ਜਾਂ ਹੇਠ ਲਿਖੇ ਪਤੇ 'ਤੇ ਰਾਬਤਾ ਕਰੋ:

Hindi

यदि आप इस दस्तावेज की प्रति अपनी भाषा में चाहते हैं, तो कृपया निम्नलिखित नंबर पर फोन करें अथवा नीचे दिये गये पते पर संपर्क करें

Bengali

আপনি যদি আপনার ভাষায় এই দলিলের প্রতিলিপি (কপি) চান, তা হলে নীচের ফোন নম্বরে বা ঠিকানায় অনুগ্রহ করে যোগাযোগ করুন।

Urdu

اگر آپ اس دستاویز کی نقل اپنی زبان میں چاہتے ہیں، تو براہ کرم نیچے دئے گئے نمبر پر فون کریں یا دینے گئے پتے پر رابطہ کریں

Arabic

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Gujarati

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