Liverpool Central Primary Care Trust

Accessible Health Information:

Project Report

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Executive summary

This report details the findings of a one-year project on the accessibility to disabled people of information provided by the National Health Service. Part III section 21 of the Disability Discrimination Act (1995), which came into effect in October 1999, specifically requires service providers, such as the health service, to make 'reasonable adjustments' in order to ensure that any information provided is accessible. The findings presented here indicate that this law is currently not being complied with.

The term 'health information' is defined here as any information that is provided for patients and the public by the National Health Service and / or other related bodies. In order to make this information accessible, the health service should provide documents in large print, large print with pictures and symbols, Braille, computer disc, website, audiotape and videotape with plain, spoken language, audio description and British Sign Language. Availability of alternative formats should be well publicised and electronic healthcare records should be used to record people's individual access requirements. Plain English should be used at all times, together with a 14-point sans serif font. Websites must conform to the W3C Web Accessibility Initiative guidelines. Prescription notes, medication labels and accompanying information should also be made accessible. All National Health Service premises and family doctors should have a textphone, and waiting rooms should have a system for informing patients of when it is their turn that is audible, visual and tactile. Everyone who has contact with patients or strategic responsibility for service provision must have Disability Equality Training. Finally there should be a central agency implementing a co-ordinated approach to producing accessible health information. A more detailed list of recommendations is included at the end of the report.

The first two chapters make the case for providing accessible health information and examine previous work in this area. Chapters 3 to 4 relate the experiences and opinions of disabled people in Merseyside who took part in the consultation. Chapter 5 examines accessibility of information within the cervical screening programme. Chapters 6 and 7 suggest two possible ways forward involving electronic healthcare records and disability equality training. Finally chapter 8 summarises the recommendations that have been made throughout the report.

This report makes the following recommendations:

1. Alternative Formats
a. Patient information should always be designed and printed professionally, in accordance with the NHS Identity Guidelines, which in turn should be updated with the findings of this report
b. The following formats should be available:
  i. Large print
  ii. Large print with pictures and symbols
  iii. Braille
  iv. Computer disc containing the file in plain text format
  v. Accessible website
  vi. Audiotape
  vii. Videotape with plain, spoken language, audio description and British Sign Language.
a. Phone calls and face-to-face meetings should be available alternatives to written communication.

2. Plain Written English
a. Keep sentences short – 15 to 20 words
b. Only one main point should be made in a sentence
c. Write active, positive sentences
d. Avoid abstract thought, figurative language and metaphors
e. Be direct to the reader – use I, we, you
f. Try to make writing sound like speech
g. Use everyday words
h. Be consistent and repeat words
i. Don't use jargon, acronyms or abbreviations
j. Explain complex ideas
k. Give reader the chance to comment on the information

3. Typeface and Font Size
a. A sans-serif font should always be used - Adobe Frutiger for professionally printed material and Ariel for documents produced in-house
b. Block capitals, italics and underlining should never be used. Bold type can be used instead
c. Standard print should use a font size of no less than size 14-point
d. Large print should be at least of size 20-point
e. Systems should to flexible enough for different fonts and sizes to be used whenever required

4. Signage
    f. All signage should adhere to the NHS Identity Guidelines: Capital Build Projects, which should be updated in accordance with the Royal National Institute for the Blind's See It Right guidelines

5. Layout
    g. Use matt paper that weighs over 90 grams per square metre (gsm), and make sure that the folding would not stop the document being scanned.

    h. The right-hand margin should not be justified

    i. Lines should be neither too long nor too short - 65 characters maximum

    j. Text should not be placed in columns

    k. Avoid reverse type - white writing on a coloured background

    l. Use good quality matt paper and either a cream or tinted background to avoid glare

    m. Do not break up words with a hyphen at the end of a line

    n. Never let sentences run onto the next page

    o. Break up the text into small paragraphs that succinctly make a point

    p. Use bullet points to make the main points clear

    q. Sections must be denoted with clear headings and colour coding

    r. The leading (the space between each line) should be approximately 1.5 times the font size

    s. Pictures should be large, illustrate a point and placed a sufficient distance away from the text

    t. Illustrations used should not be patronising

    u. Symbols should be used only to indicate the sort of information given, not as a replacement for text

    v. Columns of text should have sufficient space left between them

    w. Use generous amounts of space on forms for people to fill in a response

    x. Use a consistent layout for different ranges of leaflets

6. Access to Alternative Formats
    y. Availability of alternative formats should be clearly displayed in large print on the front cover of all leaflets

    z. Alternative formats should be available in hospitals, waiting rooms, libraries and other public buildings

    aa. An accessible catalogue should be produced listing every leaflet and the formats that it is available in

    bb. Electronic Healthcare Records should be used to record people's information access needs

7. Websites

a. Sites must conform to the W3C Web Accessibility Initiative guidelines – this can be check using the W3C validator (www.w3.validator.org) and the Bobby automated checker (www.cast.org/bobby)

b. All images and sound clips should be accompanied with alternative textual descriptions

c. Video clips should be captioned or an alternative transcription should be provided

d. There should be a good contrast between the foreground and background colours

e. Links should always be clearly identifiable by means other than colour alone, for example underlining

f. Do not rely on video, Flash movies and Java applets to convey information - always provide a way to skip them and an alternative textual description

g. Portable Document Format (PDF) files should be created using Adobe Acrobat (version 5) and the accessibility option should be enabled

h. There should be a mechanism to change the colour scheme, font typeface and size to suit individual needs

i. A text-only option should be available

j. Frames and tables should be either avoided, or tags should be used to indicate the order in which the text should be read

k. Important information should be available as an on-line signed video clip

8. Prescriptions and Medication

a. Large clear print should be used on prescription notes

b. The reverse side and repeat prescription forms should be redesigned to make them accessible

c. A system where a prescription and a patient's exemption details are passed directly to their chemist of choice by the practice would eliminate the need for prescription notes altogether

d. The 'speaking medication label' should be available in the United Kingdom

e. The information that comes with medication should be accessible

9. Appointments

a. All National Health Service premises and family doctors should have a textphone

b. The NHS UK website directory of family doctors in accessible buildings should be publicised better
c. The system in the waiting room for informing patients of when their appointment is due should be audible, visual and tactile
d. Doctors should come and escort patients to their room in order to show people where to go and strengthen the doctor-patient relationship

10. Face-to-face Communication

e. Everyone who has contact with patients or strategic responsibility for service provision must have Disability Equality Training
f. Disability Equality Training provided by the health service should have accreditation from the British Council of Disabled People, once their scheme comes into operation in March 2003
g. Other methods of education should also be used, including posters and displays, items in regularly circulated newsletters, videotape material, integration with induction training, and periods of disability equality training during other training programmes
h. There should be a dedicated sign language interpretation service for local health services that would ensure that interpreters were readily available for appointments and emergencies
i. Interpreters should be at least of level 3 registered trainee standard
j. Services that require confidentiality, such as counselling, should have trained workers who can sign to a high standard
k. Deaf people who have sign language as a first or preferred language should be proactively recruited and trained by the health service, to increase its number of workers who sign
l. Everyone who has contact with patients should learn at least basic British Sign Language

11. The Cervical Screening Service

a. Awareness should be raised within the programme that impairment is not a valid reason for denying a disabled woman a smear test and removing her from the recall list
b. Everyone who works within the programme, including general practitioners, nurses and receptionists, should receive Disability Equality Training
c. All letters sent out should use plain language and Ariel font size 14
d. There should be a system for recording women's preferred method of communication, in order to appropriately and confidentially inform women who cannot read the standard letters

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e. The three standard NHS leaflets should use plain language and be produced alternative formats.
f. Simple information on colposcopy procedures should also be produced in alternative formats

12. General
a. There should be a central agency implementing a co-ordinated approach to producing health information
b. Disabled people should be actively included in writing health information, especially information about specific impairments
c. Every Trust should have a worker responsible for disability equality issues
d. Emancipatory research techniques should be used in research involving disabled people
e. The Disability Discrimination Act (1995) should be effectively enforced to ensure that service providers comply with the law and provide accessible information

Contents

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1 Introduction

1.1   The importance of access to health information

As our society develops and new discoveries are constantly made, we become increasingly reliant on information in order to participate. Information is fundamental to any decision, and indeed has been described as 'the fourth right of citizenship'. Lack of information is disabling, and just as discriminatory as 'a narrow door or a flight of stairs' (Derbyshire Country Council Social Services Department, 1986 – cited in Barnes, 1991, page 135). As the old cliché says, "knowledge is power", and disabled people who lack access to information will therefore be excluded and disadvantaged in terms of making informed choices and influencing decision-making.

Health information enables people to make decisions that affect their entire lives, and a lack of this information can have a direct effect on people's health and recovery (Shah et al, 2002). French (1994) concluded that: "there is room for improvement in the attitudes of health professionals towards disabled people." With this in mind, it is a matter of concern that the medical profession, general practitioners especially, still have a lot of control over disabled people's lives. This is not only the case in matters related to health, but also access to other non-medical aspects of disabled people's lives, such as welfare benefits, personal assistance, enabling equipment, education, employment, day services, building adaptations, travel discount cards, adoption, etc. Disabled women interviewed by Begum (1996) "expressed concern about the extent to which doctors could shape their lives and opportunities." Whilst this unsatisfactory system of 'gatekeeping' still exists, it is very important that the health service and its employees are able to communicate effectively with all disabled people, regardless of the nature of their impairment.

The term 'health information' is defined here as any information that is provided for patients and the public by the National Health Service and / or other related bodies. Therefore the aim of this project work was to investigate how the National Health Service can make information accessible to all disabled people. Ideally this involves producing information that can be directly accessed by disabled people, rather than them having to rely on somebody else. For example:

a) Information about how to make appointments.
b) Face to face information provided to a patient by a doctor or nurse in the course of a consultation.
c) Information that is currently provided in the form of leaflets and letters (e.g. letter of invitation to cervical screening programme, leaflets included with letter and results letters).
d) Telephone advice services.
e) Information provided by telephone on an ad hoc basis.
f) Information about how to change appointments and the means of changing them.
g) Information provided at specific venues such as clinics and waiting rooms.
h) Information that is currently provided by means of posters and notices.
i) Directional signs in premises.
j) Information in waiting areas about when it is a patient's turn to be seen.

1.2   Who are disabled people?

Traditionally it was thought that a disabled person's medical condition was the root cause of their exclusion from society (Oliver, 1998). Doctors and other professionals have power over disabled people's lives, forcing them into segregated schools, day centres and residential homes. This social exclusion led to inadequate policies and legislation, inappropriate attitudes, a poor stereotyped media image and inaccessible buildings and information. In the mid-seventies a new way of thinking about disability, called the social model of disability or the 'barriers' approach, emerged from the disabled people's civil rights movement (Union of Physically Impaired Against Segregation, 1976; Oliver, 1983). This stated that disabled people are those people who experience barriers within society related to their impairment. It makes the following definitions:

- Impairment is a limitation to the function of people's minds, bodies, or senses.
- Disability is the disadvantage or restriction of activity caused by a society that excludes people with impairments.

This exclusion occurs because of environmental and cultural barriers such as: a segregated education system; inaccessible working environments; inadequate welfare benefits; discriminatory health and social support services; inaccessible transport, housing and public

buildings; lack of recognition of alternative forms of communication; and negative media portrayals.

The term "disabled people" can include people who:
- are Deaf or hard of hearing
- have visual impairments
- have mental health issues
- have learning difficulties
- have physical impairments
- have restricted growth
- are HIV positive or have AIDS.

However it is up to the individual to self define. By working to this approach, the focus is shifted from trying to cure individual impairments, to removing disabling barriers from society.

Information has been included as one of the seven fundamental needs for putting the social model of disability into practice and removing the barriers to independent living (Derbyshire Coalition of Disabled People, 1988; Davis, 1990). The 'Disabled Peoples' Rights and Freedoms Bill' proposed by the Rights Now coalition as a replacement for the Disability Discrimination Act specifically calls for "access to health information" (British Council of Disabled People, 2002). A substantial number of people experience barriers to information and communication in Great Britain. For example it is estimated that there are (Gregory, 1996):

- 7.3 million people with literacy difficulties
- 8.7 million people who are deaf or hard of hearing
- 1.7 million people with a visual impairment, unable to read standard print with ease
- 1 million people with a learning difficulty
- 6 million people with mental health issues

Obviously some people will be in more than one of the above groups.

In 1996 Liverpool Health Authority adopted the social model of disability (Liverpool Health Authority, 1996), and incorporated it into its equal opportunities policy; this policy has now been passed on to the new Primary Care Trusts. From the social model perspective, the National Health Service needs to make changes to the ways in which it communicates with all patients, in order to remove the barriers to

disabled people accessing information and services. This is also a requirement under the Disability Discrimination Act 1995.

1.3   The Legislation

Section 9 of The Disabled Person's Act (1986) obliged the then Department of Health and Social Services to give disabled people information appropriate to their needs. Barnes (1991, page 137) relates how this law was largely ignored and such information provision was left to under-funded voluntary sector organisations. The Disability Discrimination Act (1995) supersedes the 1986 act and requires providers of services to take reasonable measures to make their services accessible. Part III section 21 of the act, which came into affect in October 1999, specifically requires service providers to make "reasonable adjustment" to any "practice, policy or procedure which makes it impossible or unreasonably difficult for disabled persons to make use of a service" (HMSO, 1999a; HMSO, 1999b). In terms of the provision of information, this legislation requires alternative formats to be provided ensure that disabled people have access. Of course there may well be a difference of opinion between the service provider and the service user as to what constitutes a "reasonable adjustment". However with respect to accessible information, the code of practice recommends the provision of an "auxiliary aid or service" and gives examples where the service provider is legally obliged to supply alternative formats. The National Health Service is not exempt from this requirement (Department of Health, 2001b; Carter and Markham, 2001), and is therefore now required by law to ensure that information and services are accessible.

Examples of how this can be achieved are:

i) People with visual impairments should be offered large clear print, computer disc, audiotape, Braille or an accessible website, and other services should be available such as readers, telephone services, tactile building signs, spoken announcements, audio-description services and assistance with guiding.

ii) People who are Deaf or hard of hearing should be offered written information, subtitled videos, videos with British Sign Language, accessible web-sites, and pictures with plain English text. Other services should be offered such as facilities for taking and exchanging written notes, speech-to-text transcription services, induction loop systems, textphones, telephone amplifiers, teletext displays, audio-visual telephones, audio-visual fire alarms and qualified sign language interpreters or lipspeakers.

iii) A person with a learning difficulty may require the provision of information in large clear print, plain language, with colour coding, symbols and illustrations.

Obviously the same person, for example a Deaf person with a learning difficulty, will face a variety of barriers and therefore require a variety of solutions.

It is worth noting that many of these adjustments would benefit not just disabled people but the general public at large. Some of the above formats are already available but this project demonstrates that many disabled people still receive information from the National Health Service in a format that they are unable to access independently. This practice breaks the law, and can compromise the patients' right to confidentiality. For example, if the result of cervical screening is sent to a woman with a visual impairment by letter she will have to ask someone else to read it to her and therefore the disclosure of her result is not confidential.

Even when information in alternative formats is produced, it is not always made available to all of the people who require it. It is quite common to see details of how to order literature in various formats at the back of a publication. However these details are themselves often printed in an inaccessible format, thus further preventing disabled people from independently accessing that information.

2 Previous Research

Many papers and reports have been written about the information access requirements of disabled people; some have directly addressed access to the National Health Service and health information (Ubido et al, 1995; Royal National Institute for the Blind, 1998a; Band, 1998). However most of the work done in this area focuses on the needs of one particular impairment group in isolation, sometimes to the detriment of other groups. Very little of the literature on provision of health information in general takes account of alternative methods of accessing information and communication. For example, Carter et al (1998) make the point that sign language is not usually included in any discussion about interpretation services in the NHS.

Kempson (1987) showed that at times of stress, such as a visit to the family doctor, people forget quite a large proportion of the information that is given to them verbally. Therefore there is a need to reinforce the doctor's information in other ways, either through the provision of accessible printed / recorded information or through the provision of support services within the hospital or clinic to which people can turn following the consultation (Moore, 2000). Edwards et al (2002) observe that patients generally require more information about their own health than is currently provided; favouring information about levels of risk presented visually in diagrams and graphs.

Deyo (2001) states that the printed material in doctors' offices is often inadequate. "Patients often find that it is too simple or too technical; excludes discussion of treatments they are interested in; and offers too little information of treatment efficacy, self management and prevention." Coulter et al (1999), after evaluating the standard of patient information, concluded that information materials "must contain relevant, research-based data in a form that is acceptable and useful to patients… Many information materials adopt a patronising tone…" They advocate the involvement of multidisciplinary teams (which include patients) in developing and testing the materials.

2.1   People with a Visual Impairment

Tinker et al (1993) found that some older people have difficulty with "leaflets and posters as information mechanisms" because of the print size, as did Cawthra (1999). Deaton (1993) found that when a sample of visually impaired people were presented with a list of 10 health issues, over 90% said that there were barriers to them accessing information on

every issue. Many commented that health information was available only in formats inaccessible to them. People were angry that the information they received was often cut down or censored, although a minority also expressed the view that too much information is just as bad as too little. The majority admitted that obtaining confidential information was a big problem, and some were resigned to the fact that they will never be able to obtain private information confidentially. A survey carried out by the Royal National Institute for the Blind (1995) found that 85% of the visually impaired people interviewed experienced barriers when reading their mail, and 93% wanted all of their information to be sent in a format they could access. A subsequent survey (Royal National Institute for the Blind, 1999) found that 95% of the general public support the right of people with a visual impairment to accessible information.

The 'Ill Informed' report from the Royal National Institute for the Blind (1998a) found that most people with a visual impairment are currently unable to access the majority of information relating to healthcare, service provision and complaints procedures. They surveyed 326 National Health Service trusts and found a low average level of provision of alternative formats. Out of all of their publications, only 8% were available on audiotape, 4% in Braille, 25% in large print, 2% on computer disc and 7% via a telephone call. It is not stated how large the type is for large print. They recommend that people should be able to have personal correspondence, appointments letters, general health information leaflets, medication labels and hospital information in their preferred format. They call for policies to be developed to ensure that the information access requirements of visually impaired people are recorded, and for local groups of visually impaired people to be consulted over the development of health information services. They wanted all staff to receive training about the Disability Discrimination Act (1995) and the needs of visually impaired people. A later report stated that nearly 90% of visually impaired people who access health services independently regard the provision of information in accessible formats as "poor or very poor," and 40% of respondents singled out better access to health information as "their number one concern" (Royal National Institute for the Blind, 1998b). They later advocate establishing benchmarks and resource-based standards for general information provision (Moore, 2000).

The Royal National Institute for the Blind (2001) also produces general guidelines on making information accessible to people with a visual impairment. The 'See It Right' pack covers the following areas:

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- **Clear print:** Use a type size of 12 or preferably 14 point and avoid highly stylised fonts. Avoid using block capitals, italics and underlining. The leading (i.e. the spacing between the lines of text) should be 1.5 times more than the text size. Numbers should be written as words. Lines should contain no more than 60-70 characters and must be horizontal. Text should not be justified and columns of text should have sufficient space left between them. Allow a generous amount of space on forms for people to fill in their response. If pictures are used then put a frame around them, avoid fitting text around images and never put text over the top of an image. Use matt paper that weighs over 90 grams per square metre (gsm), and make sure that the folding would not stop the document being scanned.
- **Large print:** Use a type size of between 16 and 22 point, and check that the text contrasts clearly with the background (even when black and white are reversed).
- **Handwriting:** Where handwriting is absolutely necessary, use a felt tipped pen with a slightly thicker line.
- **Audiotapes:** Should not contain background noise, but should contain a contents list, be easily indexed and labelled in both large print and Braille.
- **Videotapes:** Should have audio descriptions of facial expressions, actions, scenery.
- **Braille:** This format is recommended for product and service information, when that information needs to be reviewed and remembered.
- **Signs:** Should be non-reflective and should contrast with its background (door / wall colour, etcetera…). Similarly the letters should contrast with the background colour. A border should be placed around a sign – a sign 300mm by 80mm is recommended to have a 15mm border (increase proportionally for larger signs. Characters should be embossed with a depth of 1mm-1.5mm, and Braille should also be used. Characters should be between 15mm and 50mm high. The spacing between characters should be increased by 20-30%, and between words by around 25%.
- **Electronic text:** Ideally a text-only file should be used. This information can be distributed via floppy disc, CD-ROM or over the internet.

- **Websites:** All images and sound clips should be accompanied with alternative textual descriptions. Video clips should be captioned or an alternative transcription should be provided. There should be a good contrast between the foreground and background colours. Links should always be clearly identifiable by means other than colour alone (i.e. underlined). Do not rely on video, Flash movies and Java applets to convey information.   Always provide a way of skipping them and an alternative textual description. Use the W3C guidelines and check the pages using the W3C validator (www.w3.validator.org) and the Bobby automated program (www.cast.org/bobby) for checking accessibility.
- **Deafblind people:** Suggests the reduction of background noise on the telephone, the use of textphones and specialist interpreters.

SURFACE (2002) found that documents created with the Adobe Acrobat application in Portable Document Format (PDF) have not been easily accessible to users of assistive technology (such as screen readers) in the past. Publishers and authors prefer this format because it retains document layout and formatting across a range of platforms. There are services available on the web that can extract text from such files and convert it into either a plain text file or a web page. However only the text portions of the original document can be retrieved and much document formatting will be lost. In the latest version of Adobe Acrobat (version 5), it is possible to create accessible documents by enabling the use of tags, which can be used to reformat the document into a different layout. However this is a step that must be actively taken, as the documents will not automatically be accessible. The report suggests making documents available in other electronic formats, such as plain text, Hyper-Text Mark-up Language (HTML), Rich Text Format (RTF) or Microsoft Word. Such file formats retain their original layout, but are readable with screen reader software. The same document held on all of these formats could be held on one compact disc.

Recommendations:
- **Use matt paper that weighs over 90 grams per square metre (gsm), and make sure that the folding would not stop the document being scanned**
- **Websites must conform to the W3C Web Accessibility Initiative guidelines – this can be check using the W3C**

validator (www.w3.validator.org) and the Bobby automated checker (www.cast.org/bobby).

- **All website images and sound clips should be accompanied with alternative textual descriptions.**
- **Website video clips should be captioned or an alternative transcription should be provided.**
- **There should be a good contrast between the foreground and background colours on a web-page**
- **Links should always be clearly identifiable by means other than colour alone, such as underlining**
- **Do not rely on video, Flash movies and Java applets to convey information on a website. Always provide a way of skipping them and an alternative textual description.**
- **Portable Document Format (PDF) files should be created using Adobe Acrobat (version 5) and the accessibility option should be enabled.**

2.2   People who are Deaf or Hard of Hearing

"The lack of skilled professionals who have both an awareness of Deaf culture and competence to communicate with Deaf clients remains a tremendous barrier" (Steinburg, 1991). Equal access to health services for all people would also involve the provision of sign language interpreting services (McCay, 1988), an issue usually neglected in the provision of interpreters by the health service (Carter et al, 1998). Mohay et al (1991) warn against medical practitioners relying on a patient's family for sign language interpretation, advocating the use of professional interpretation services.

Wright (1993) recommends named nurses who would learn British Sign Language and be on call to communicate with Deaf people. In America, Kimmel (1989) reports on a hospital that contracted on-call interpreters and increased Deaf people's satisfaction with the service, since interpreters no longer needed to be specifically requested. A similar scheme for contracting interpreters has been successfully run by the health service in Liverpool for the past few years. Sims (1989) and McEntee (1993) go further and call for Deaf people to be proactively recruited and trained in nursing in America, and Montgomery (1981) also cites examples of nurses and therapists learning sign language. However there are far more people who use American Sign Language compared with British Sign Language, so what may be practical in America may not necessarily be practical here.

A report on the access needs of Deaf women recommended a flashing light / number system in all waiting areas, marked records, reduced background noise, longer consultation times, Deaf awareness training, textphones (Minicom) in practices and hospitals, an on-call 24 hour sign language interpretation service, clear health information leaflets and videos aimed specifically at Deaf people (Ubido et al, 1995). Both this report and Whitehouse et al (1995) highlighted the need for counsellors who use sign language and are aware of cultural issues around deafness, because of the importance of confidentiality with such services. The latter report, which looked at the needs of Deaf substance abusers, also found a need for written and audiovisual materials aim specifically at people who are Deaf or hard of hearing. Likewise DiPietro et al (1981) and Mohay et al (1991) found that people who have been Deaf from birth have a lack of understanding of medical terminology and conditions, although how much understanding the general public has of medical terms is also debatable. Devlin (1992) and Kelsall (1993) cites examples from Manchester where a parenting video was made with sign language communication, some midwives learned British Sign Language, and hospitals installed minicoms. Finally the importance of health information about deafness that comes from the perspective of Deaf people cannot be overstated. Jonah Eleweke and Rodda (2000) found that contributing factors to parents selecting a communication mode to use with their Deaf children were the influence of information provided to parents and the parents' perceptions of assistive technology.

2.3   People with a Learning Difficulty

Band (1998) carried out research for Mencap on the health needs of people with learning difficulties, but interviewed only supporters. The report described the quality of health information as inadequate. It recommends the need for information in accessible formats, and the provision of "proper" health information. McCray and Carter (1999) highlight examining alternative forms of communication used to give and receive information.   Mencap's later general guide on making information accessible makes many practical suggestions (Mencap, 2000).

2.4   Disabled People who Experience Multiple Oppression

Disabled people from Black and racial minorities face further communication and information barriers. A conference report by the Greater London Association of Disabled People (1991) on race and disability called for information in other languages to be available in alternative formats. Eleven years later Shah et al (2002) again

reinforced the fact that information systems should be flexible enough to produce information in different languages in alternative formats. They also found that disabled people from Black and racial minorities often helped each other disseminate health information. They recommended that Black-led user groups should be encouraged and supported to spread information, and that there should be a review of the accessibility of complaints procedures. Deaton (1993) acknowledged that the barriers to accessing information should not be treated as a fringe issue. Begum (1995) recommended the following points for communicating with Black disabled people:

- Establish a pool of community language and sign language interpreters
- Provide training and guidelines on working with interpreters
- Use face-to face communication to communicate with Black disabled people wherever possible, rather than relying on printed information
- Check what forms of sign language are being used by Deaf people who are Black or from racial minorities.
- Translate information into other languages on audiotapes, since many people cannot read community languages

Begum (1996) found that disabled women encounter a number of information access barriers when visiting the doctor, such as doctors who appear "aloof and silent" with people with a visual impairment, inaccessible print, lack of qualified sign language interpreters in primary care teams, lack of confidentiality in information disclosure and the use of medical jargon. One woman was quoted as saying "The doctor writes to me in print the whole time. I've told them before that if they're going to write to me would they ring me and tell me as well. The Gas Board manage to do it, so I don't see why the doctor can't." Disabled women also identified various attitudinal barriers that "result in restrictions on their access to information and health care." For example, there were cases when doctors did not talk directly to the disabled woman, preferred to disclose information to people who accompany the disabled woman, and focused on the impairment rather than the reason for the visit. The disabled women who had had positive experiences of visiting their local practice emphasised the doctor's attitude and the effect this had on both the service given and on how the women feel about themselves. The conclusions call for physically accessible surgeries, patient held records, equal opportunities training for all staff, up-to-date accessible information, and a named individual with responsibility for disability issues.

Lomas`s (1998) research into Deaf women accessing the health service was the only reference found on about this topic. It recommends ongoing Deaf awareness training for all health service employees, and basic sign language training for front-line staff. All interpreters used by the health service should be at least of level 3 registered trainee standard, and the responsibility for booking interpreters should be with the health service. The report raised the need for Deaf counsellors and health information workers who could communicate confidentially in sign language. The most popular request from Deaf women was for health information in British Sign Language on video.

Recommendations:
- **There should be a dedicated sign language interpretation service for local health services that would ensure that interpreters were readily available for appointments and emergencies.**
- **Interpreters should be at least of level 3 registered trainee standard.**
- **Services that require confidentiality, such as counselling, should have trained workers who can sign to a high standard.**
- **Deaf people who have sign language as a first or preferred language should be proactively recruited and trained by the health service, to increase its number of workers who sign.**
- **Everyone who has contact with patients should learn at least basic British Sign Language.**

2.5   Other Research on Information Access for Disabled People

A variety of literature provides general guidance on producing accessible information (Plain English Campaign, 1993; Gregory, 1996; National Information Forum, 1996; Basic Skills Agency, 1996; Townsley et al, 1997; Mencap, 2000; Leat, 2000; Royal National Institute for the Blind, 2001). The following points are made on writing clearly:

- Keep sentences short – 15 to 20 words maximum
- Only one main point should be made in a sentence.
- Write active, positive sentences
- Get rid of unnecessary words
- Avoid abstract thought, figurative language and metaphors
- Be direct to the reader – use I, we, you
- Write numbers as numerical figures and not words

- Try to make writing sound like speech
- Use everyday words with an informal tone
- Be consistent and repeat words
- Don't use jargon, acronyms or abbreviations
- Explain complex ideas
- Give reader the chance to comment on the information

They also gave the following advice on design and layout:

- Use plenty of space around the text
- Use a clear, sans serif font
- Use a font size of 12 or more
- Never use block capitals
- Lines should be neither too long nor too short (65 characters maximum)
- Include illustrations or easily recognizable symbols
- The right margin should not be justified, as this can create large spaces in between words, making it difficult to follow a line of text
- Text should not be placed in columns, as again this makes a line difficult to follow
- Avoid reverse type (i.e. white writing on a coloured background)
- Use good quality matt paper to avoid glare and writing on the reverse side showing through
- Do not break up words with a hyphen at the end of a line
- Never let sentences run onto the next page
- Break up the text into small paragraphs that succinctly make a point
- Make the main points clear by using bullet points
- Use clear section headings
- Try to use a consistent layout for different publications

Research by the National Information Forum (2001) consulted with relatively few disabled people with impairments that are typically experience barriers to information access. Concentrating largely on people with physical rather than sensory and intellectual impairments, the resulting recommendations do not suggest the provisions of different alternative formats. Most of the people interviewed (85%) said they relied on their doctor for health information, and only 23% had heard of NHS Direct. The Royal College of Physicians (1998) charter on disabled people using hospitals called for hospital trusts to provide both standard health information in accessible formats, and information on specific

facilities provided for disabled people. The charter also recommends marking disabled patients' medical records with the name of their impairment, but only with the prior consent of the patient. In order to improve face-to-face communication, the report recommends the provision of disability equality training for all staff, based on the social model of disability and delivered by disabled trainers. As it is unlikely that formal training sessions will directly involve more than a small proportion of the staff, alternative methods such as posters and displays, items in regularly circulated newsletters, videotape material, integration with induction training, and periods of disability equality training during other training programmes are also recommended by the charter.

French (1994) also advocates that health workers receive high quality disability equality training delivered by disabled people, that they understand the meaning of disability as disabled people define it, and that they are informed about the important role disabled people have played in the development of services. The literature search conducted in French`s report indicates that attitudes of health workers (specifically doctors and occupational therapists) towards disabled people deteriorate as their training progresses, and that more personal contact with disabled people improves attitudes.

Recommendations:
- **Keep sentences short – 15 to 20 words**
- **Only one main point should be made in a sentence.**
- **Write active, positive sentences**
- **Avoid abstract thought, figurative language and metaphors**
- **Be direct to the reader – use I, we, you**
- **Try to make writing sound like speech**
- **Use everyday words**
- **Be consistent and repeat words**
- **Don't use jargon, acronyms or abbreviations**
- **Explain complex ideas**
- **Give reader the chance to comment on the information**
- **The right-hand margin should not be justified**
- **Lines should be neither too long nor too short - 65 characters maximum**
- **Text should not be placed in columns**
- **Avoid reverse type - white writing on a coloured background**
- **Use good quality matt paper and either a cream or tinted background to avoid glare**

- **Do not break up words with a hyphen at the end of a line**
- **Never let sentences run onto the next page**
- **Break up the text into small paragraphs that succinctly make a point**
- **Use bullet points to make the main points clear**
- **Sections must be denoted with clear headings and colour coding**

2.6   Discussion

Most of the researchers and publishers fail to follow their own advice and therefore do not make any attempt to present their research findings and recommendations in an accessible format. The fact that the authors and publishers have chosen to ignore their own findings detracts from the recommendations that are being made. This paradox of not practising what has been recommended can maybe be explained by the fact that much of the work was commissioned and funded by organisations **for** disabled people, such as Mencap and the Royal National Institute for the Blind. These organisations are mostly run and controlled by non-disabled people and are not representative of the views of disabled people (Drake, 1996). Hevey (1992, page 22) states: "the 'disability' charities have created a hegemony, a near totality, in which their voice is accepted as the voice of disabled people. Within the disability industry, however, disabled people are actually the last in line." This was demonstrated in a recent survey on the employment of disabled people (Hermeston, 2001), which listed the percentage of disabled workers in organisations such as Mencap ("at least 3%") and Royal National Institute for the Blind ("7.7%"). By writing reports that are inaccessible to their supposed beneficiaries, they raise the question for whose benefit were they written?

Much of this work also takes into account the view of 'carers', since such organisations typically include, and are often controlled by, self-proclaimed carers. However carers` views and agendas can often be radically different to those of disabled people. By treating these two distinct groups as one and ignoring the unequal power relationships that often exist between them, the views of the beneficiaries (disabled people) about the barriers that they personally experience are not necessarily given priority over the views of non-disabled people. Barnes (1991, page 146) notes that the recent emergence of a strong and articulate 'carers' movement' adds a further dimension to the discrimination faced by disabled people. Morris (1993, page 23) comments that the currently fashionable focus on unpaid carers provides

an obstacle to disabled people being seen as citizens in their own right. This is especially true of research with people with learning difficulties, as it is generally assumed that this group of people are unable to communicate for themselves.

For example, although Langan et al (1994) note Morris' comment, they go on to write a whole paper on people with learning difficulties accessing primary care services based solely on interviews with carers. Similarly Coopers and Lybrand (1988) wrote a whole report for the then Department of Health and Social Security on the "information needs of disabled people, their carers and service providers" without recommending the provision of alternative formats, thus calling into question whose needs were being prioritised? Whilst it is probably easier for non-disabled researchers to talk to other non-disabled people about the needs of disabled people, this approach denies the importance of first-hand experience and often fails to identify social barriers. For example, a recent Patient's Forum report on involving "hard to reach groups" within National Service Frameworks stated that "it is important to have both patient and carer perspectives" and went on to consult with only non-representative organizations **for** disabled people and carers' organisations (Hogg, 2002). Because of this the work reflects the medical model of disability, portraying aspects of specific impairments as barriers, and therefore does not adequately report the barriers that disabled people themselves perceive. Another barrier to consultation created by Hogg (2002) was the lack of questionnaires in alternative formats. Bewley and Glendinning (1994, pages 27-28) found this to be a regular occurrence with consultations involving disabled people.

The practice of publishing work on accessible information in inaccessible formats goes against the principles of emancipatory research, which require researchers to make their findings available for the benefit of the disabled people's civil rights movement. Stone and Priestley (1997) state that research should be undertaken only "where it will be of practical benefit to the self-empowerment of disabled people and / or the removal OF disabling barriers." In addition, Barnes (2001) sets emancipatory research above other methodologies partly "because of the high priority placed in dissemination by researchers who adhere to this perspective." By denying access to the supposed beneficiaries of their work, other authors and organisations mentioned above are effectively barring those people from commenting on or criticising their work. It also draws the researchers motives into question, since they are denying disabled people the opportunity of self-empowerment and information that they could use to remove their disabling barriers.

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Most of the previous research either concentrates on just one specific impairment in isolation, or individually addresses impairments in turn. By not using the social model of disability and concentrating on identifying how barriers can be removed, the recommendations become narrowly focused and may even conflict with one another. For example, one piece of work calls for visual alert systems in practice waiting rooms for the benefit of Deaf people, whilst another wants audio alert systems for people with visual impairments. A barrier removal approach, which does not concentrate on people's impairments, would have correctly identified the alert system as the barrier and suggested a device with audio, visual and tactile components. Similarly Mencap (2000) recommends writing numbers as numerical figures and not words since figures are more recognisable, whereas Royal National Institute for the Blind (2001) recommend the reverse as people with a visual impairment "can easily misread 3, 5 and 8 and, in certain typefaces, 0 and 6 too." Again adopting a barrier removal approach would suggest the use of numerical figures in a distinguishable typeface, or both numbers and words as on cheques.

Recommendation:
- **Emancipatory research techniques should always be used in research involving disabled people**

3 Getting the ideas and opinions of Local Disabled People

Local organisations of / for disabled people and day centres were asked to advertise for disabled people to participate in this project, and advertisements were placed in various local publications aimed at disabled people. Approximately 130 disabled people participated who were members, staff or users of the following organisations: Action for Blind People, Liverpool Voluntary Society for the Blind, Ideas in Motion Creative Writing Group, North West Disability Arts Forum, Liverpool Mental Health Consortium, The Moving On With Learning (MOWL) Project, The Joint Forum, Liverpool Scope, Merseyside Society for Deaf People, and Henshaws Society for Blind People. Every person was consulted about the following health information leaflets and asked for their comments:

Liverpool Health Authority
- How to make a complaint on Liverpool's NHS services (old version)
- How to make a complaint on Liverpool's NHS services (new version)
- Get the right treatment! (Liverpool and Sefton Health Authority A5 leaflet)
- Summary of the Liverpool Health Authority Annual Report 1999-2000
- A new service for Deaf people in Liverpool (A4 poster)

Department of Health
- The Patients' Charter and You (A5 booklet)
- Your Guide to the NHS (standard version)
- Your Guide to the NHS (audiotape version)
- Your Guide to the NHS (version for people with learning difficulties)

In addition some people also commented on the leaflet "Your Baby has Down's Syndrome – a Guide for Parents" by the Down's Syndrome Association.

3.1 Alternative Formats

There are a whole variety of formats that can be used to convey information, many of which would be of benefit to non-disabled people as

well. The provision of information should be made as flexible as possible, since people may have more than one impairments and therefore may require a combination of formats. It is also worth noting that some disabled people may not have English as their first language, so the information systems should be flexible so that information in other languages can be presented in alternative formats too.

Everyone thought that the leaflets used "too much jargon", that "abbreviations such as G.P." should not be used and that there were "too many words used" (i.e. the language should be succinct). Complex language that uses unnecessary words and a formal tone should be avoided. Medical jargon such as "gynaecological", "paediatric" and "renal" should be either avoided or explained using simple language. Abbreviations like "H.A.Z.", "M.R.I." and "P.C.T." should not be used. Familiar, common words should be used, and the tone should be informal. All of these issues particularly cause barriers for people with learning difficulties, people who are Deaf or hard of hearing and people with dyslexia. It was commonly agreed that all health information leaflets should use plain, clear language that is readily understandable to everyone. The Plain English Campaign publishes a guide called 'How to write medical information in plain English' (see appendix).

The language used to refer to disabled people should be consistent with the social model of disability, avoiding such terms as "people with disabilities", "the handicapped" and "people with special needs." Similarly the health service should use the terms adopted by those groups of people themselves. For example the National Health Service consistently uses the term "people with learning disabilities" to refer to people with learning difficulties, even though this group has long rejected the term because it sounds "too medical".

It was particularly difficult to talk to people with learning difficulties. This was because many of them attend institutions such as 'day-care centres', which have been shown to be "highly segregative", "organised around notions of 'care' rather than user participation" and "paternalistic" (Barnes, 1991, page 56). Therefore a consultation day was organised in conjunction with people with learning difficulties who use day centres where they could put forward their views (see chapter 4).

Those people who could access written information preferred large, clear print that used plain language, colour coding, illustrations and photographs. Symbols should be used sparingly – documents that use a symbol to represent every written word can be highly ambiguous

and only accessible to a few people. Many people praised local projects that work with people with learning difficulties to produce health information in a format that is accessible to them, thus benefiting both the participants and the health service. Groups from Liverpool People First and the United Response Oakfield Day Centre have produced leaflets in conjunction with health workers such as "Having a Smear Test" and "Your Medical Records."

One leaflet in particular, "Your Guide to the NHS" was criticised by one group for using real photographs in the standard edition and "childish cartoons" in the version for people with learning difficulties. This same document was also unpopular for inserting sections labelled "Notes for Carers" (i.e. unpaid people who provide assistance) throughout which used complicated language and undermined the idea of providing information for people with learning difficulties. Overall information conveyed both visually and audibly is preferable to written information. This could be provided either on audiotape with an accompanying booklet, so that the page numbers referred to on the tape match the page numbers in the booklet. This would be accessible to a large proportion of the population; the National Information Forum (1996) found that 67% of people under the age of 60 owned a tape recorder and many others have access to one. Alternatively videotape or Digital Versatile Disc (DVD) could be used to convey information. This need not be expensive, just someone talking into a video camera with accompanying subtitles. To ensure good quality it may be best to use someone with training in drama or public speaking. One group decided that their ideal format would be a short video using plain language and "real people" as opposed to cartoon illustrations.

The main criticism of the leaflets from people who are Deaf or hard of hearing was that none of the information was of any use to people who do not read. English is not the first language of many Deaf people who use British Sign Language (BSL), although it is often assumed by health professionals that Deaf people read English fluently. Therefore videos made by Deaf people using British Sign Language are needed. Ideally two types of videos are needed: one using plain, spoken language with subtitles and another in BSL made by Deaf people, though if resources will not stretch to two videos then one would suffice. This would be produced in British Sign Language using Deaf actors, with a voice-over in English or any other spoken language and subtitles. This would be the most accessible video format possible. A local company run by Deaf people makes accessible videos in sign language (see appendix).

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Approximately 50 people with a visual impairment were interviewed. They preferred a number of different formats, including large clear print, Braille, computer disc, audiotape, accessible websites, telephone services, tactile building signs, and spoken announcements. Electronic media such as computer discs or accessible websites in accordance with the W3C Web Accessibility Initiative guidelines (located at http://www.w3.org/WAI) are also popular, as this enables people to convert directly the information into formats that are accessible to them. For example, by using a computer the information could be put into a specific font size preferred by that person or fed into speech output software. People felt it important that the computer floppy or compact disc used the plain text file format (denoted by the suffix ".txt"), so that additional software (such as Microsoft Word or Adobe Acrobat Reader) is not necessary for access. However older people with a visual impairment commented that these formats only worked "for the younger generation", as they "typically do not have access to a computer and many people with a visual impairment would not be able to afford one." Even where computers are available in public places such as libraries, they typically are not equipped with the software necessary to make them accessible to people with a visual impairment.

It should not always be assumed that people with a visual impairment always prefer tape. Although Braille is used by only a small percentage of people with a visual impairment, Braille readers often prefer it as they find it quicker to find what they are looking for and dislike using audiotape. Therefore both formats should be provided as alternatives. People also commented that too often there was a reliance on responding in writing, when a phone call would be a better method of response for them. Indeed some Mental Health Survivors disliked leaflets and other forms of written communication, preferring face-to-face contact and phone calls instead.

Recommendation:
The following formats should be available:
    a. **Large print**
    b. **Large print with pictures and symbols**
    c. **Braille**
    d. **Computer disc containing the file in plain text format**
    e. **Accessible website (see text for explanation of "accessible")**
    f. **Audiotape**

g. **Videotape with plain, spoken language, audio description and British Sign Language**

3.2   Typeface and Font Size

Most of the people with a visual impairment whom we interviewed were unable to access any of the leaflets that we showed them, as the size of font used was too small. Many cited other types of health literature and information that are inaccessible to them because of the size of the writing, such as appointment letters, hospital signs, prescriptions and repeat prescription forms, hospital appointment slips, labels on medication bottles and the literature that comes with people's medication. One woman went for a women's health check-up at a G.P. practice and had to reply verbally to the questions on the form in front of the whole waiting room because the form used by the practice was inaccessible to her.

The consensus of people interviewed was that standard print should use a font size of no less than 14-point, and large print should be at least 20-point. The text should not be crowded. Block capitals, italics and underlining should never be used (bold text can be used to provide emphasis). Many people with visual impairments and / or learning difficulties who could read preferred large print, but found variation in the size used. At the moment the National Health Service Identity Guidelines (Department of Health, 2001a) recommend the use of a size of at least 12-point as standard and 14-point for large print, clearly at odds with the views expressed here.

The identity guidelines also specify the Adobe Frutiger font as the standard typeface for printed material, and the Arial font for letters, forms, internal documents, etc. Most people thought it was important that a sans-serif font is always used, as serifs (i.e. flourishes on the ends of letters) can distort the shape of the character. One person with a visual impairment said that their screen reader software made mistakes when reading text in Arial font and preferred the Times New Roman serif font. Therefore it should be recognised that this format will be suitable for the majority but not everyone, and that systems should to flexible enough for different fonts and sizes to be used when required.

Many people commented that they often received information in a serif font, which would indicate that the National Health Service Identity Guidelines are currently being ignored by some parts of the service, even though they are meant to be obligatory rather than optional. The

Department of Health produced the guidelines in order to professionalise design and ensure a consistent approach to the provision of information. If a document is produced for the health service, it is essential that it be professionally produced with a designer who will incorporate the text and images in a way that is clear, professional and consistent with other messages coming from the National Health Service. Therefore it is important that patient information is always professionally designed and printed in accordance with the identity guidelines.

People said that poor signage in buildings is a barrier to them not finding their way. People with a visual impairment said that the only accessible signs in the Royal Liverpool University Hospital were within the Eye Clinic. The directions to that part of the hospital are not accessible so it is difficult to find. Similarly people said that the nameplates on doctors' doors are always inaccessible, using writing that is too small, inaccessible colour schemes and no Braille. Poor signage is a particular barrier for people who may be lacking self-confidence.

Again it seems that the National Health Service Identity Guidelines for capital build projects (Department of Health, 2001a) are not always being used, since they contain clear regulations on the format to be used in signage. This specifies the use of the Adobe Frutiger sans-serif font and an acceptable colour contrast of 'NHS Blue' (Pantone® 300) on white. The guidelines specify a widely accessible format, although they need to be updated in accordance with the Royal National Institute for the Blind's See It Right guidelines so that they include Braille and specify a minimum ratio of text to sign size. So again it is more likely that the barriers are caused by these guidelines being ignored. Also the guidelines only apply to property owned by the National Health Service, so other property used by the service will be exempt.

Recommendations:
- **A sans-serif font should always be used (Adobe Frutiger for professionally printed material and Ariel for documents produced in-house).**
- **Block capitals, italics and underlining should never be used. Bold type can be used instead.**
- **Standard print should use a font size of no less than size 14-point**
- **Large print should be at least of size 20-point**
- **Systems should to flexible enough for different fonts and sizes to be used whenever required.**

- **Patient information should always be designed and printed professionally, in accordance with the NHS Identity Guidelines.**
- **All signage should adhere to the NHS Identity Guidelines: Capital Build Projects, which should be updated in accordance with the Royal National Institute for the Blind's See It Right guidelines**

3.3   Layout

Many people preferred the larger A4 format of leaflets, such as the version of "Your Guide to the NHS" for people with learning difficulties, as these used larger font sizes and bigger pictures. Although increasing the size of the words had an impact on accessibility, increasing the leading (the space in between the lines) by approximately 1.5 times the font size also helped to make the text appear clearer and less cluttered for visually impaired people and those with dyslexia.

The contrast between the colour of the paper (or background colour) and the colour of the text is important for accessibility. The people with a visual impairment that we spoke to preferred the sharp contrast of black on white or vice versa. Under no circumstances should text be placed over a patterned background or picture, and all backgrounds used should be one solid colour. Similarly the text and background colours should never be different shades of the same colour. However people with dyslexia tended to dislike a sharp colour contrast as this tended to produce a shimmering effect, preferring variety of pastel coloured backgrounds. A good compromise of black writing on cream coloured paper was suggested for letters, which should also work well for people with a visual impairment. Similarly it was found that a 5% background tint of the main colour in order to slightly soften the contrast and remove the glare can work just as well. Indeed this can sometimes work better than black on white, depending on the nature of the visual impairment.

Many people agreed that the leaflets did not use enough pictures and symbols. However people with visual impairments said that if pictures must be used, they should be well spaced away from the body of text. In the Health Authority Annual Report where attempts had been made to represent information in the form of graphs, pie charts and tables, the results were not readily accessible to many disabled people. As already mentioned, one group of people with learning difficulties preferred the use of photographs to cartoon illustrations. If there are

issues around getting consent to use photographs, there is a national archive of medical and health related photography on the World Wide Web. If illustrations are used, they need to be made uncluttered and clear. Sometimes the point of the illustration can be lost because there is too much other information. Therefore illustrations should be used only to illustrate a point and depict what the text is saying (i.e. not merely decorative and not used instead of text) and should never be patronising. The 'Change Picture Bank' CD-ROM contains some health related illustrations that may be freely used, and is preferable to using clip-art. Symbols should be used sparingly to illustrate the type of information given (i.e. an envelope symbol to indicate an address or a telephone symbol to indicate a phone number). They should never be used to illustrate every word on a page - if lots of symbols are used then the meaning can be ambiguous.

Some people with a visual impairment said that they would prefer one simple large picture that illustrated a point, as opposed to a detailed group of smaller pictures that were difficult to see. Many people liked the colour coding for different sections used in version of "Your Guide to the NHS" for people with learning difficulties, which used the National Health Service colour palette for maximum contrast. However it should be noted that this method of indexing should not be relied upon, as some people will not be able to see the colours. For large documents such as the Liverpool Health Authority Annual Report, an index at the back and a glossary of terms might enable people to find what they are looking for with ease.

Recommendations:
- **The leading (the space between each line) should be approximately 1.5 times the font size**
- **Pictures should be large, illustrate a point and placed a sufficient distance away from the text.**
- **Illustrations used should not be patronising.**
- **Symbols should be used only to indicate the sort of information given, not as a replacement for text.**
- **Columns of text should have sufficient space left between them.**
- **Allow a generous amount of space on forms for people to fill in their response.**
- **Try to use a consistent layout for different ranges of leaflets.**

3.4   Availability

A common response from people working within the National Health Service when questioned about alternative formats is that there is never much of a demand. However if the people who require alternative formats are unaware of their availability, or for that matter unaware of the existence of the information in the first place, then it follows that demand will not be high. Even when information in alternative formats exists, their availability is typically advertised in places that are inaccessible to the people who require them. The offer of alternative formats should be clearly displayed in large print on the front cover of all printed materials, and not at the back in small writing. One person complained that alternative formats have not been sent even when they have been asked for, perhaps suggesting that they were never actually available or that processes have not been developed to ensure that they are distributed.

Few Deaf people had ever had previous access to the materials that we showed them. Even the service for Deaf people was unknown to most of those whom we interviewed at the Merseyside Society for Deaf People. Many people with a visual impairment said that they do not read health information leaflets because they either did not know what they were about or never received any.

Someone suggested making a catalogue of all of the health information leaflets on tape, so that people could find out what is available to them. Where information was advertised as being available in other formats, people with access to the Internet said that they would prefer to access the material online rather than wait for the large print copy to arrive. However this would require the web address to be printed in large print on the standard leaflet. Many people wanted large print versions of leaflets to be available in hospitals, practice waiting rooms, libraries, etc. The advantage of using libraries is that resources such as CCTV machines, magnifier equipment and computers are often available there. Other people suggested that CCTV machines should be given to people with a visual impairment for free by the state as part of the provision of mobility and communication aids, to enable them to access more written information. Although these are not available at the moment, in some cases "Easy Readers" are available which can convert an ordinary television set into a CCTV machine. These machines could be made available in health centres and hospitals, where people usually get leaflets.

Everyone said that they would be happy for the health authority to retain information about their access needs on record if this meant they

received information in the format of their choice automatically. This applies to both general information and personal letters, and could be achieved by recording access needs on people's Electronic Healthcare Records (see section 5). In addition, Liverpool Voluntary Society for the Blind (see Appendix) holds a register of people with a visual impairment who live in the city. Knowsley Social Services keep a separate register for their area. These registers could possibly be used to enable the health service to communicate more effectively if people's consent could be obtained.

Recommendations:
- **Availability of alternative formats should be clearly displayed in large print on the front cover of all leaflets.**
- **Alternative formats should be available in hospitals, waiting rooms, libraries and other public buildings.**
- **An accessible catalogue should be produced listing every leaflet and the formats that it is available in.**

3.5   Electronic Formats

Very few of the people that we spoke to had ever looked at the Liverpool Health Service website, or even knew that it existed. None of the examples of health information leaflets advertised the web address of the site, although the "Get the Right Treatment" leaflet has the www.merseyhealth.com address which has a link to the health authority website. The people with learning difficulties that we consulted preferred websites with lots of pictures, with every link having an accompanying symbol. However people with a visual impairment preferred the use of as few pictures as possible. One method of overcoming this paradox would be to provide a text-only version of the site as well as a graphical version. Various people also made the following points:

- All pictures and symbols should be accompanied by an additional text description (using "ALT" tags in the source code of the web-page), so that screen reader software can identify them.
- There should be a mechanism for the user to change the colour scheme / contrast, typeface and text size to suit their individual needs.
- The use of frames and tables make it difficult to predict which section the screen reader will read first. Ideally the page should be structured so that the screen reader would read its actual content before the web site's logo and main links. So frames

and tables should be either avoided, or tags should be used to indicate the order in which the text should be read out.

- There should be "home" links at the top and bottom of each page that make it possible to return to the front page. At the bottom of each page should be a "back to the top" link which returns the reader to the top of the current page, as this is a good way of notifying readers that the end of the current page's content has been reached.
- The provision of written information in the English language is a barrier to Deaf people whose first or preferred language is British Sign Language. Therefore important information should be available as an on-line signed video clip

Recommendations:
- **There should be a mechanism to change the colour scheme, font typeface and size on a website to suit individual needs.**
- **A text-only option should be available.**
- **Frames and tables should be either avoided, or tags should be used to indicate the order in which the text should be read.**
- **Important information should be available as an on-line signed video clip**

3.6   Prescriptions and Medication

People agreed that prescriptions are now better since they are no longer hand written, however the type and size of print still makes them inaccessible to people with a visual impairment. Many disabled people have to tick a box on the inaccessible reverse side of the prescription note in order to get free prescriptions. One person with a learning difficulty complained that he is never asked to sign or tick the back of the prescription, as it is always assumed that he is unable to. Another person takes their personal assistant who shows them where to tick / sign. Chemists are not consistent as some ask to see a benefit book and others don't; however some disabled people have their benefit paid by direct debit and do not have a book.

Many people with a visual impairment complained that the repeat prescription forms are inaccessible, again because of font size and type, and that it can take up to three days to get a repeat prescription. This agrees with work done by Begum (1996), where the disabled women interviewed said that their number one reason for visiting their doctor was to get a repeat prescription. If the forms were accessible in the first place then a proportion of those visits would be unnecessary and some

of the doctor's time would be freed. A scheme is being piloted at Brownlow Group Practice in Liverpool city centre which would allow patients to view their medication details and order repeat prescriptions over the World Wide Web. This could be of great benefit if the website was made accessible, especially if it could be extended so that people could also make appointments via the worldwide web too. This would also enable Deaf people to by-pass using the telephone. There was widespread agreement that all chemists should be able to deliver medication to people's homes. If all practices were able to send prescriptions directly to the chemist, together with details of any payment exemptions, then the barriers associated with prescription notes could be eliminated completely.

There was a lot of concern about access to the information on medication labels, as mistakes with the dosage could be fatal. Somebody commented, "The instructions and dosage on the pill bottle label can vary between the doctors and chemist." Somebody spoke of the chemist suddenly giving them tablets that contained double their regular dosage and neglecting to tell the person that they should only take one pill instead of two. Some people wanted a simply Braille system to be used for medication. Another person was aware of a medication label available in America that incorporates a microchip and miniature speaker that can record and play back the dosage. Another barrier to taking medication is that the information supplied is typically in very small, inaccessible writing. Some attempt has been made in Liverpool to address this with the 'Well Informed' series of leaflets on medication typically prescribed by mental health services, which can be photocopied and distributed to patients. An improvement on the standard provision, these leaflets however still require further work to make them accessible and make them available on the World Wide Web.

Recommendations:
- **Large clear print should be used on prescription notes**
- **The reverse side and repeat prescription forms should be redesigned to make them accessible**
- **A system where a prescription and a patient's exemption details are passed directly to their chemist of choice by the practice would eliminate the need for prescription notes altogether**
- **The 'speaking medication label' should be available in the United Kingdom**

- **The information that comes with medication should be accessible**

3.7   Appointments

The most common method of making an appointment was over the phone. Most practices had a fax machine, but none of the people interviewed knew of a surgery with a textphone (e.g. minicom). Some Deaf people got around this by using the Typetalk service, which enables people with textphones to communicate with people without access to a textphone through an intermediary. Other Deaf people said that they made appointments through faxes or by visiting in person.

A very common complaint was that people could not get appointments soon enough, with some people waiting up to 2-6 week for an appointment with the head of a practice. Also some people said it would be much better if the G.P. could visit them at home. Disabled people in employment who use other community health services such as physiotherapy, occupational therapy and chiropody commented that it was impossible to get an appointment out of office hours. Some wheelchair users said that many G.P. and dentists' surgeries do not have physical access, and information on which practices are accessible is not readily available. This tallies with research done by Begum (1996), who found that physical access was a major factor (62%) amongst the disabled women interviewed when asked how they selected which practice to register with. One woman was advised to "go round looking at surgeries" until she found a suitable one. Since practices have specific catchment areas, it is possible that a person's local practice will not be an accessible one. In theory this situation should be remedied by 2004 when the Disability Discrimination Act (1995) regulations on physical access to public buildings come into effect, but in practice is unlikely that all health premises will be accessible by then. However in the meantime the on-line NHS UK website (www.nhs.uk) which lists accessible general practices should be better publicised as nobody that was interviewed knew of its existence.

It seems that many places have great difficulty with letting disabled people, especially those with sensory impairments, know when it is their turn to be seen. One person with a visual impairment spoke of being "forgotten" and having "to wait in the waiting room for one and a half hours to see the doctor." Other people spoke of often missing their names when they were called out and then having to wait a long time, or not being informed which doctor they were going to see. A Cheshire

survey from 1995 found that 76% of the women who participated had problems in the waiting room when attending hospital or their doctor's surgery (Ubido et al, 1995). Various systems for alerting people when their appointment is due were mentioned, including announcements on a tannoy / speaker, a patient's name and room number being called out or printed on a screen, numbered tickets, colour coded tickets, a flashing light and audible alarm, and the doctor or receptionist escorting the person to the correct room. What is required is an alert system that is visual, tactile and audible, coupled with a personal escort.

People with mental health issues described sitting and waiting for an appointment as being "intimidating", even when they are on time. Again they spoke of preferring the doctor to come out and escort the patient to their room, as this helps to break down barriers between the doctor and the patient. One person with a learning difficulty said they were segregated from the other patients and "put in a separate room", which they did not like.

Recommendations:
- **All National Health Service premises and family doctors should have a textphone**
- **The NHS UK website directory of family doctors in accessible buildings should be publicised better**
- **The system in the waiting room for informing patients of when their appointment is due should be audible, visual and tactile**
- **Doctors should come and escort patients to their room in order to show people where to go and strengthen the doctor-patient relationship**

3.8   Face-to-face Communication

Everybody interviewed thought that the attitudes of health service staff towards disabled people were a major barrier to accessing information, and bad attitudes resulted in disabled people not being given the choices about their health management to which they had a right. Most disabled people saw receptionists as "gatekeepers" or "guard-dogs", who created a barrier to them accessing that service. This was attributed to their poor attitudes towards disabled people. Ironically enough, many people with a visual impairment cited the Eye Clinic at the Royal Liverpool University Hospital as the worst example of staff attitude. This is corroborated by Lomas (1997, page 12) who conducted a survey with 30 visually impaired people in Liverpool, finding that information provision and

communication was so poor that "most had no understanding of their eye condition or services available."

People with mental health needs spoke of receptionists talking slowly to them and having "no respect for confidentiality." Deaf people said that they thought receptionists should be able to use sign language, and that very often they cannot see the receptionists' faces in order to lip-read. Factors such as the counter being too high or glass in between the receptionist and the person can also cause communication problems for disabled people.

The majority of the comments about doctors concerned their "authoritarian" attitudes towards disabled people and reliance on "stereotypes". Many people said that their doctor tended to focus on their impairment (or guide dog) instead of the ailment that they wanted looking at. Traditionally the medical profession has seen disability as their domain (Oliver, 1998), focusing on treating and 'curing' specific impairments. It is not without reason that the traditional model of disability, which asserts that an individual's impairment are the cause of the 'problem', is commonly known as the medical model of disability. Here is a selection of comments on the attitudes of doctors:

- "The doctor just talks down to you like you're a child, and wants to get you out as quickly as possible."
- "He does not explain what's wrong with me, as he's sometimes too busy to talk. I feel rushed."
- "The doctor talks to my carers and not to me. He patronises me. He pauses after each word. I'm sat there like a lemon!"
- "The doctor asked if he could touch my tummy. I said no but he did it anyway. I would have preferred a woman doctor."
- "Doctors can blame your illness on the weather. Sometimes they don't tell you the truth."

People who are Deaf or hard of hearing cited access to British Sign Language interpreters and the lack of health service staff who can sign as a huge barrier to them accessing non-written information. One person said that "all doctors should be able to sign, and children should never have to act as interpreters for their parents at the doctors'." Another person said, "Doctors have poor body language appear to be scared of Deaf people." Others wanted more staff to be able to sign, such as counsellors and sexual health workers (whose services are meant to be confidential). People who lip-read said doctors are sometimes not aware of this and hide their lips from view. Another

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spoke of a doctor whose first language was not English, who refused to repeat himself even though the person could not hear what the doctor was saying. Most Deaf people said they usually resorted to communicating via pen and paper with their doctors. A survey in Cheshire from 1995 reported that only 7% of the 134 women interviewed said that they usually fully understood what the doctor said to them when they visit on their own (Ubido et al, 1995). This could maybe be addressed with longer consultation periods for Deaf people.

Many disabled people spoke of the problem of doctors only talking to the person accompanying them and not to them. People generally preferred to see the same doctor, as this meant they could build up a relationship and overcome some of the barriers created by the doctor's attitude. Many thought doctors prefer looking at a printed page to talking, making it very difficult to make eye contact. The people with mental health needs commented that doctors are loath to recommend services outside of the health service, such as alternative medicines and services provided by the voluntary sector. Instead "they always look for medical solution, and are more likely to give you a prescription." They also found doctors who never emerge from their offices very intimidating.

Everyone interviewed thought that attitudes could be greatly improved by all National Health Service staff that either have contact with patients or have strategic responsibility for service provision to undergo training as part of their mainstream training programme. Indeed many people thought that Disability Equality Training should be compulsory. Independent disabled consultants active within the disabled people's civil rights movement should deliver such courses, since contact with disabled people is an important ingredient in bringing about positive changes in attitude (French, 1994). The social model of disability and the concept of the removal of barriers within society should be central to the programme. Other suggested topics were: the history of disability and the disabled people's civil rights movement, examples of the societal barriers disabled people experience in society, the use of words, images and stereotypes around disabled people, charitable versus civil rights perspectives, and the Disability Discrimination Act (1995). The training should end with the drawing up of an action plan for barrier removal with respect to the participant's workplace and role.

It was strongly felt that non-disabled trainers should not be used for two reasons. Firstly an element of the training experience is the opportunity for participants to talk with disabled people and to have their preconceptions and stereotypes challenged. In addition, in the past non-

disabled trainers have delivered courses on 'Disability Awareness Training'. These have focussed on issues around impairment and used simulation exercises, instead of addressing the environment and societal barriers. French (1992) suggests "simulation exercises fail to simulate impairment correctly, and address neither the coping strategies and skills disabled people develop in living with impairment, nor the cumulative social and psychological effect of encountering social and physical barriers over a lifetime." She goes on to say that "there is little evidence to suggest that simulation exercises bring about a positive attitude change", and that many disabled people find this practice offensive as what is being simulated is merely the acquisition of an impairment for a short period of time.

A few disabled people also wanted staff to undergo impairment-specific training such as Deaf Equality Action Training (currently run locally by the Merseyside Society for Deaf People – see appendix) and Visual Impairment Awareness Training (currently run by a number of local organisations). However others thought that these courses stigmatised individual impairment groups and very often used simulation exercises. French (1992), commenting on a Visual Impairment Awareness course for architects, said "they only attempted to 'understand' one type of impairment when presumably they should be planning for all disabled people simultaneously…. Unless a broad view is taken of disability it is highly likely that any adaptations architects make will further disable people with dissimilar impairments." Therefore as Liverpool Health Authority has adopted the social model of disability, impairment-specific training would seem to go against this policy and individualise disability instead of addressing the barriers within society that exclude disabled people.

Recommendations:
- **Everyone who has contact with patients or strategic responsibility for service provision must have Disability Equality Training**
- **There should be a dedicated sign language interpretation service for local health services that would ensure that interpreters were readily available for appointments and emergencies.**
- **Everyone who has contact with patients should learn at least basic British Sign Language.**

3.9   Case Study 1: The Complaints Procedure Leaflet

Many people commented on the accessibility the leaflet "How to Make a Comment or Complaint" produced for Liverpool Health Authority. Although the front cover advertises its availability in seven other languages (but not British Sign Language), there is no mention of availability in alternative formats. Most disabled people had never heard of the complaints procedure and had never seen the leaflet before, suggesting that it needs to be advertised more effectively. There is also nothing on the leaflet to say whether the information is accessible via the Liverpool Health Authority website, despite the inclusion of a picture of a disabled woman using a laptop computer (presumably to either access the complaints procedure or make a complaint). Although information about making a complaint is available on the web, the phrasing is different and more information is given in the leaflet.

A common comment was that the language used in the leaflet was very formal and complicated. A person with a learning difficulty commented that they "didn't know what the word complaint means." The size of the writing is far too small and the colour scheme of blue on white is not very clear. The pictures used to illustrate the leaflet show a person on the phone with their head in their hands looking exasperated, surely not a very positive image to give! Some people found the number of different people to contact for complaints involving different trusts and practices confusing, preferring a system where one main contact is given who could then refer the person on to the correct department in the correct organisation. Only one textphone number is given at the very end of the document (i.e. not in connection to any of the complaint managers). The textphone advertised is situated in the health authority reception, and no indication is given of how a complaint communicated by textphone would be dealt with in terms of satisfaction or confidentiality. Some disabled people said they would prefer to make their complaint in person rather than using the phone. Other people commented that the leaflet should give some idea of what should be expected of the service, so that they could judge for themselves whether to make a complaint or not.

3.10 Case Study 2: Your Baby has Down's Syndrome – a Guide for Parents

A few disabled people, including some people with Down's syndrome were also shown this publication by the Down's Syndrome Association. The small print size and complicated language makes this leaflet inaccessible to many disabled people. The only alternative format available is a web page, however this is not indicated on the printed leaflet.

Disabled people disliked the negative tone of the introduction, which contains the headings 'sorrow', 'anger', 'shock' and 'guilt'. It was felt that the booklet should start with something celebratory, congratulating the reader on becoming parents, and then follow this up by addressing potential concerns. The terms 'mental handicap' and 'learning disability' are used, even though these are offensive to many people with learning difficulties (People First, 1992). Many of the health problems and suggested activities listed could equally apply to any other baby, and their inclusion here further stigmatises by implying this is 'specialist' information. The section "What does the future hold for our child?" occupies mere half of a page in a 24-page booklet, and does not include any input from people with Down's syndrome themselves. The general emphasis on 'problems' associated with the child and disruption to the rest of the family is rooted in the medical model of disability, which views the disabled person as the problem. The list of contacts lists medical practitioners, state services and their own organisations, omitting citizen advocacy organisations and organisations of disabled people. There are personal accounts from parents, brothers, sisters and grandparents, but again nothing from people with Down's syndrome themselves. It was thought that the more detailed medical information in the appendices on congenital heart defects and genetics would only cause more anguish, and that such information should be put in a separate leaflet and made available on request. Finally the association's membership categories list adults with Down's syndrome last, below parents, 'carers' and grandparents, thus reflecting their true priorities. Many of these problems could have been avoided, had disabled people been actively involved in writing the leaflet.

This was seen as a very important leaflet, since due to the United Kingdom's antenatal screening programme for Down's syndrome, the information it contains could quite conceivably influence whether an abortion takes place or not, so it is vital that it is based on accurate and realistic information. In 1999, 1,813 abortions occurred in England and Wales due to evidence that the child would be disabled (The Stationary Office, 1999), with 329 attributable to Down's syndrome. Due to the law, which allows abortion to take place any time up to birth, 4 of these occurred outside the 24-week gestation period which is the latest time that an abortion can be undertaken if the foetus is not deemed to be disabled. What cannot be determined is how many of those abortions would not have taken place if it were not for inaccurate stereotypes and inadequate health information, such as this leaflet.

Recommendation:

- **Disabled people should be actively included in writing health information, especially information about specific impairments.**

3.11   Conclusions

The disabled people that we spoke to highlighted many important issues that have serious implications for the National Health Service. Some people wanted to see a shift in the culture of the organisation, as "patients are not necessarily seen as customers and not offered choices." Significantly disabled people highlighted numerous instances where they were unable to access information from the health service, despite the relevant legislation having been in place since October 1999. This indicates that part 3 section 21 of the Disability Discrimination Act (1995) has not been effective so far at ensuring the provision of accessible information by service providers such as the National Health Service.

Recommendation:

- **The Disability Discrimination Act (1995) should be effectively enforced to ensure that service providers comply with the law and provide accessible information.**

4 The 'Shaping Your Health Service' Day

4.1   Aims

As already mentioned, it is particularly difficult to consult with disabled people who attend day centres. Many such institutions are "highly segregative", "organised around notions of 'care' rather than user participation" and "paternalistic" (Barnes, 1991, page 56). Therefore a day was organised in conjunction with people with learning difficulties who use day centres where they could put forward their views.

4.2   Planning

The planning group consisted of the project officer, a "Learning Disability" Nurse, service users from 3 local day centres and a member of staff from each of 4 local day centres. Service users were encouraged to take part in decision-making concerning the event. Most of the day centre staff attended in order to support their service users, however some came on their own and seemed loath to involve their service users in the planning process.

The group agreed the following timetable:

10.30 am   Tea / Coffee and signing in
11.00   Introduction
11.15   Workshops
12.15 pm   Lunch
1.20   Presentations:
- Laurence Clark - Civil Rights for Disabled People
- Oakfield Day Centre - Health Records Leaflet
- Liverpool Mental Health Consortium - Breaking Down the Barriers Day
- Liverpool People First Women's Health Group

2.10 Feedback from morning workshops
2.45 Dr. Joyce Carter, Consultant in Public Health - The Health Service's Commitment to Disability Equality
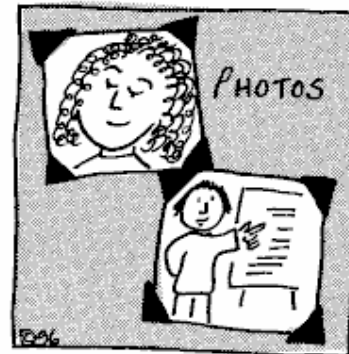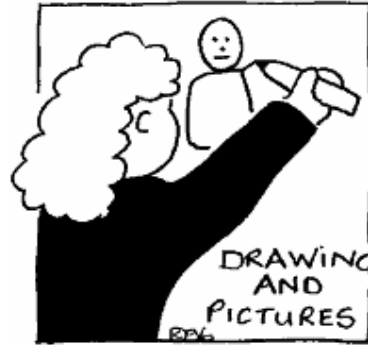3.00 Finish

However on the day many of people attending were ordered by the day centre staff to leave before the 3 o'clock finish in order to catch their transport, despite those centres having been involved in the planning of the day. If statutory bodies are going to effectively consult with people who use day services, then the service must be flexible enough to allow adequate time for that consultation to take place.

4.3   Results

Overleaf are the conclusions from the day, presented in the same format that they were distributed to the participants (i.e. large print with picture from the Change Picturebank compact disc). It is worth noting that other disabled people also made many of the same points that are suggested here in the previous section, however it was still important that this traditionally excluded group of people were included.
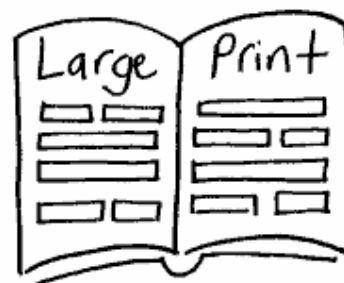
Pictures:

*
* Leaflets should use more colour
* There needs to be pictures to help people who cannot read
* We want more pictures and fewer words, as they tell us more
* There should be fewer pictures on each page, but they should be large and clear
*
* Pictures should connect with the text to enable people to make sense of the information
* Some people prefer the use of photographs, as cartoons feel childish
* Other people preferred cartoons, as the meaning is clearer

Format:

*
* Prefer bigger A4 format
* Words should be bigger and clearer, in large print
* Leaflets contain too much writing
* Too much information can

be "boring and naff"

-
- Information should also be available in: Braille, audiotapes and videotapes with signed and spoken language
- Audiotapes should state page numbers so that people can look at the pictures in the leaflets and listen to the tape at the same time

Language:
- Too much medical jargon is used
-
- No abbreviations – "most people would say doctor, not G.P."
- It is difficult to get sign language interpreters for appointments
- There are barriers to Deaf people making appointments
- There is a language barrier when English is not the first language of a member of the medical staff

Family doctor's practices:
- Doctors should listen to people, take notice and explain things to them rather than to their parent or support worker

- There should be trained patient advocates available
- Buildings should be easy to get into
-
- Reception staff do not know how to treat people with learning difficulties
- It should be easy for people to know when it is their turn to be seen
- People wait too long to see a doctor
- The writing on the back of prescriptions is too small
- There should be equality training for support workers, patient advocates, receptionists and medical staff

Finally…
- People with learning difficulties should be involved with writing health leaflets and planning services

5 The Cervical Screening Programme

5.1   Introduction

The cervical screening programme was examined in detail with a view to identifying barriers that prevent local disabled women from accessing information about the service. Milburn and MacAskill (1994) highlight the "vital" need for readily understandable information on cervical screening, and Baird (1997) found that women's levels of anxiety about the smear test could be made worse by a lack of understanding of the purpose of the test. Slater (2000) concluded that women are often inadequately informed about cervical screening and are not in a position to provide valid consent. Therefore it is important that information about the test is made accessible to everyone, including disabled women.

This research had the following aims:

- To consult local disabled women and health service employees about current health information and service provision within the cervical screening programme.

- To describe existing information about cervical screening in primary care, community clinics drop-in centres, and in the hospitals to which women are referred if they need further investigation of treatment following an abnormal smear.

- To identify barriers to all stages of the cervical screening programme amongst disabled women in terms of information.

- To identify impairment-specific barriers for people with physical impairments, sensory impairments and learning difficulties in terms of them finding out about cervical screening services and making use of them at all stages.

- To suggest changes to the current provision of information to improve access, based on the views of local disabled women.

5.2   Background

There is evidence to suggest that the prevalence of cervical cancer can be reduced amongst all women through access to the screening

programme. Cervical screening is estimated to prevent between 1,100 and 3,900 cases of invasive cancer each year in the United Kingdom (Brown, 1998, page 14). Nationally 85% of eligible women have been screened in the last 5 years (Brown, 1998, page 2), although locally in Liverpool only 75% of women access the service. Specific coverage data does not exist for disabled women in general, but coverage for disabled women with learning difficulties has been estimated in various studies. Mencap estimated that only 3% receive the smear test nationally (Band, 1998). Other research carried out with a sample of 52 women with learning difficulties found that 40% had received the test at some point in their lives, and 23% had received the test more than once (Broughton and Thomson, 2000). In specific populations, research has estimated varying coverage for women with learning difficulties over the previous 5-year period:

- 8% in Sefton Health Authority (Newnes, 1999)
- 13% in Southampton and South West Hants Health Authority (Stein and Allen, 1999)
- 19% in Brent and Harrow Health Authority (Hall et al, 1998)
- 24% in Exeter Community and Health NHS Trust (Pearson et al, 1998)

Of the 43 women in Exeter who had had their recall postponed for non-medical reasons, GPs gave the following reasons for postponement (Pearson et al, 1998):

- "Smear not required" (13 women)
- "Disabled / mentally challenged" (8 women)
- "Learning disabilities" (5 women)
- "Down's syndrome" (3 women)
- "Not sexually active" (2 women)
- No reason given (12 women)

Therefore out of 43 women denied access to the service, only the 2 who had not been sexually active had been barred for a valid reason. These findings reflect the ignorance of disabled people within health professionals.

Many factors can influence uptake of the service. Majeed et al (1994) demonstrated that variables such as access for women from racial minorities, overcrowding, not owning a car, and unemployment have a negative correlation with the numbers of women accessing the

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service. These are all factors that significantly impact on the lives of disabled women. In addition other factors have a positive association, namely the presence of a female doctor and whether the woman had given birth within the last 5 years.

Some research has been conducted into access to the cervical screening services for people with learning difficulties. But relatively little has been undertaken on access for other disabled women, despite this issue being highlighted in more general research on access to health services. One woman with visual impairment told Deaton (1993): "information on the menopause and breast and cervical cancer is hard to come by." Lomas (1998) found that one of the most frequent replies from Deaf women being asked: "what would you like to happen to have better services and information?" was: "more information about breast cancer and smear tests." Begum (1996) found that 37% of the women that she interviewed visited their doctor for a cervical / breast screening test. One of her interviewees related the following story about her female doctor: "I have difficulty with cervical smear tests and other gynaecological matters as I cannot use an examination couch, and she is reluctant to treat me at home. She does usually agree that I have the smear test done at home but I rather had to plead and justify the reasons I need this. My cervical smear test was due recently. This time my GP has refused to do the test at home and doesn't know where I can get it done. I await an answer from her."

More research into access for women with learning difficulties has been undertaken, possibly because of recent Department of Health guidance (Lindsay, 1998). This noted that: "concerns are often raised about the inclusion of people with learning disabilities in routine programmes, particularly when consent and co-operation are an issue. The staff of screening services, such as those for breast and cervical screening, require training on the special needs and problems of people with learning disabilities." However it should be noted that the often-used term "special needs" is both misleading and offensive to many disabled people (Reiser and Mason, 1990, page 88), since essentially the need of disabled women in this context is the same as the need of other women – i.e. to have the test. What should be addressed is the removal of social, attitudinal and physical barriers, which prevent disabled women from receiving the test.

Typically research with people with learning difficulties still follows the medical model of disability and locates the 'problem' with the individual. For example, Aspray et al (1999) state that "cognititive

difficulties may prevent some of these patients appreciating the benefits of screening, and even those with more independence may be unaware of available medical services." This point of view ignores the health service's legal responsibility to inform women with learning difficulties via accessible methods. Hall et al (1998) advocate focused initiatives for reaching women with learning difficulties in institutions, including educational programmes, the involvement of 'carers' and female doctors skilled and flexible enough to administer the test in any position offered.

Some 'carers' expressed the view that women with learning difficulties are less likely to have a smear test due to assumptions that they are sexually inactive (Langan et al, 1994). However this assumption is not always true since some people with learning difficulties have partners and are sexually active. In addition, it has been shown that people with learning difficulties are at an increased risk of sexual abuse (Brown et al, 1995; McCarthy, 1999). Research shows that incidence of abuse amongst disabled people is as much as 4 times higher that among the non-disabled population. People with learning difficulties are at the highest risk of abuse. The majority of survivors of abuse are women, but men are also at risk. Such abuse is often not reported, remaining known only to the abuser and the victim, and very few cases reach the courts (Mencap, 2002). Therefore it cannot be safely assumed that women with learning difficulties are sexually inactive, and this must be established by communicating with the women.

Although it can be difficult to establish a sexual history, it should always be attempted just as with any woman receiving the test. Haire et al (1992) state that the same person can give a different impression on different days as to whether they are sexually active, and that this information is often considered too intrusive to record. However they go on to say that the problem of consent cannot be used to as an excuse to exclude some women from the screening programme. Since then a lot of research has been carried out around informed consent from people with learning difficulties (Hart, 1998; Fovargue, 2000), and guidance has been written for gaining consent for screening tests (Nottingham, 1999; NHS Cancer Screening Programmes, 2000). Therefore the process of giving consent should be conducted over a period of time whilst the woman is educated about the reasons for and practicalities of the smear test.

Broughton and Thomson (2000) found that 75% of the women with learning difficulties that they interviewed did not understand the purpose

of the cervical smear test, thus highlighting the need for accessible information. Factors contributing to a positive experience for the woman include: an extended preparation time in order be familiarised with the environment and understand the procedure, a woman administering the test to avoid embarrassment, and relaxation techniques to reduce anxiety. The authors call for more information on the importance of the procedure and its relevance to them, and advocate the involvement of "specialist learning disability nurses." A similar need for appropriate health information was identified in Sefton (Newnes, 1999), and led to the development of a series of accessible health information leaflets around cervical and breast screening. These were developed by women with learning difficulties at Liverpool People First, in conjunction with a 'Learning Disability Nurse'.

5.3   Methodology

Both health service workers and disabled women with a wide range of impairments were interviewed. Semi-structured, one-to-one interviews were conducted with 13 health service employees from the following professions:

- Co-ordinator of the local cervical screening programme
- Consultant Gynaecology Oncologist
- Consultant in Genito-Urinary Medicine
- Central Operations (Merseyside) Screening Services Manager
- Co-ordinator of Screening Quality Assurance
- Hospital Colposcopy Nurse
- Hospital Colposcopy Registrar
- Hospital Disability Advisor
- Hospital Cervical Screening Nurse
- Drop-In Clinic Cervical Screening Nurse
- General Practitioner
- Practice Nurse
- Senior Practice Receptionist

The discussions with health service employees covered the following areas:

- Number of disabled women they have referred / given smear tests to.
- Circumstances in which a smear test would be refused to a disabled woman.

- Accessibility of the information which they use
- Location and physical accessibility
- Barriers to having smear test

Semi-structured focus sessions facilitated by a disabled woman were held with groups of disabled women, contacted via local organisations of disabled people. Disabled women who did not wish to participate in group discussions, took part in a one-to-one semi-structured interviews with the disabled woman researcher. All of the women were shown a selection of invitation and results letters from local practices, hospitals and the health authority. They were also shown a number of leaflets produced by the national screening programme, hospitals, privately companies and other organisations. The discussions were focused around the following topics:

- Whether they are aware of what a smear test is
- Whether they have experienced a smear test
- Accessibility of the information given
- Location and physical accessibility
- Barriers to having smear test

In total 27 disabled women took part in the research.

5.4   Results

5.4.1 Uptake

All health service workers were asked to estimate how many disabled women accessed their service in the previous 12 months. Generally they recalled that approximately 1% of their patients were disabled women, although drop-in and domiciliary service staff seemed to recall seeing more disabled women than general practices and hospital staff. None of the places conducted equal opportunities monitoring to ensure that disabled women were accessing their service.

Health service workers offered various reasons for disabled women not accessing their service, including:

- "Disabled women are not targeted"
- "Assumptions are made about disabled people not having sex"
- "Parent speaks on their behalf"
- "Can't come independently"

- "No sign language interpreter"
- "Disabled people are perceived differently by the public"
- "Unable to assume an appropriate physical position"
- "Lack of education about cervical screening"
- "Disabled people have different health needs"
- "Physical issues"
- "Not being registered with a GP"
- "Medical staff making assumptions"
- "Feelings of fear, embarrassment, and other factors that affect all women"
- "The word 'abnormal' is scary"
- "Lack of accessible transport"
- "Need to be allotted more appointment time and suitable equipment"
- "Protected or ill-informed by carers"
- "Disabled people are not considered a priority"

It was also noted that some impairments are hidden; therefore staff are probably encountering more disabled women that they realise.

When asked if there were any circumstances in which a smear test would be refused to a disabled woman, a difference of opinion emerged. Some staff said that they would administer the test regardless of whether the woman was a virgin or not, since it may not be possible to verbally establish a sexual history. However other people said that it was a waste of time to give the test to a virgin and put her through the ordeal unnecessarily. Therefore there is a need to ensure consistency across the service.

5.4.2 Invitation Letters

Most disabled women commented that the letters sent by the Central Operations (Merseyside) department were typically not printed on headed paper. This meant that they would not necessarily know where the letter had come from. Therefore it would not be prioritised as important in terms of both getting assistance to read the letter if the information could not be accessed independently, and acting on the information accordingly. One person commented that if a letter looks mass-produced then they would be less likely to read it.

It is worth noting that Central Operations (Merseyside) sends invitation letters only to women who are registered with a local practice. However Begum (1996), whilst researching relationships between

disabled women and general practitioners, found that only 94% were registered with one. This discrepancy could be due to disabled women who are resident in long-term institutions not registering with a local practice (Cancer Screening Programmes, 2000), especially if the institutions are privately run. Doctors may remove a disabled woman from the recall list for not other reason than the fact that they had an impairment. It was recalled by a health service employee that one family doctor had written: "cease recall – has Down's syndrome" on a patient's recall form. Therefore it is important to ensure that disabled women are not excluded from the invitation and recall system.

All of the disabled women thought that the size of the text on all of the letters was too small. This was a particular issue for women with either a visual impairment or a learning difficulty (including dyslexia). The consensus was that size 14 point should be used as a standard. Nobody who required letters to be written in large print received this format. People who used large print preferred sizes ranging from 16 to 24 point.

Some of the disabled women, most notably people with a visual impairment or dyslexia, expressed a preference for a sans-serif font such as Arial: "I prefer a plain font… something like Ariel font size 20 is large enough for me to see." Letters produced on dot matrix printers were the most difficult to read.

People often commented that there was little contrast between the "grey writing and white background". This is a particular issue for visually impaired people. People with dyslexia preferred pastel coloured backgrounds. None of the women had ever been asked if they wanted to receive information in formats such as Braille, large print or audiotape. Some would prefer to be informed via a phone call rather than through the mail. None of the letters would be independently accessible to people who could not read English. All of the disabled women and the health services employees agreed that recording access needs would ensure that appropriate communication methods would be used. Someone commented: "once you've asked for an alternative format you should get it automatically rather than having to keep asking for it. Telephone reminders when hospital appointments are due would also be appreciated."

Only one of the clinics that participated attempted to record information about the nature of people's individual impairments. Their patient records included the fields "blind", "partially sighted", "deaf",

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"walking" and "other", with an additional field to record what "other" might be. However different people with the same impairment may have different information access requirements. For example visually impaired people may require Braille, large print or a telephone call. Therefore it would be much more effective to record people's preferred method of communication.

Some disabled women felt that references to cervical cancer in the invitation letters increased their fear. Some also felt that the letters should offer a definite date and time for an appointment, as the suggestion that they themselves make one is easy to ignore. The tone of the general invitation letter from the Central Operations department was thought to be too formal and impersonal. The more personal style of letters from family doctor's surgeries would make them more likely to take up the appointment. However there is not always consistency between the methods used by practices to follow up the initial reminder letter. Some doctors followed up with a second letter, others approached women when they went for other, unrelated appointments, and some did nothing at all.

None of them received literature that directed them to a named contact that could address specific fears relating to their impairment. Someone said: "when I've asked there hasn't been anyone in particular to talk to about it." This was particularly an issue for people with a physical impairment. It was also thought that the literature should identify which places have best physical access and accessible equipment.

5.4.3 Printed Leaflets

In general many of the disabled women experienced barriers when accessing information on this area. One woman said she obtained basic information and advice by "listening to what other women said and guesswork". Another woman said: "I know all of this anyway as I pick it up in women's magazines."

On the 3 standard National Health Service leaflets "Your Smear Test", "What your abnormal result means" and "The colposcopy examination" a sans serif font was used, however the size of the text was too small for many of the women. The contrast between foreground and background worked well for people with dyslexia because of the pastel shades, but proved a barrier to people with a visual impairment. The leaflets use a lot of words with no pictures or illustrations to back up the text. They use abbreviations such as "G.P." and "CIN", and medical

jargon such as "dyskaryosis", "cervical intra-epithelial neoplasia", "biopsy" and "colposcopy" throughout. Although these terms may be explained the first time they are used, the meaning will not be readily apparent to many people when they are used subsequently. There is nothing on any of the leaflets to indicate whether they are available in alternative formats.

None of the disabled women interviewed had ever seen the National Health Service leaflet for people with learning difficulties, "Having a Smear Test". Likewise nobody had ever had the opportunity of a prior visit to allay fears, as described in those leaflets. The women liked having illustrations as well as words, but the pictures were thought to be patronising and not illustrative of the text. The size of print was good (14 point), although people with visual impairments pointed out that this did not constitute 'large print'. The language is clear, but the phrase "down below" was thought to be patronising and ambiguous. Again there was no indication of the information being available in alternative formats, nor is there any information on follow-up treatments available in this format.

The leaflet "A guide to cervical cancer" produced by the company Durex was liked because it was considered to be "less medical", avoiding jargon and medical terms. Although larger than the standard National Health Service leaflets, the size of print was still too small for people with a visual impairment. The content focuses more on general issues around sexual health, at the same time promoting their brand of condoms. No mention is made of the information being available in alternative formats.

The women were also shown in-house information leaflets and sheets from various local hospitals. The fact sheets on colposcopy from the Royal Liverpool University Hospital had good, clear print and contrast. Presenting the information in bullet points aided readability, and using a 14-point font size meant that more people with visual impairments could access them. More general information about preparing for the examination is given, so the tone feels less medical. Some people commented that it would be better to have the contact details and directions at the beginning, so that they were readily apparent in an emergency.

The leaflets on follow-up treatments from the Liverpool Women's Hospital used a clear, sans serif font, however the text was too small. Someone commented that the emboldened headings stood out much

better than the actual text. People liked the bulleted, question-and-answer style of writing. Terminology such as "cold coagulation" and "loop excision", the titles of the 2 leaflets, were very off-putting to many people. It was also commented that an A5 format would be preferable to A6, as this would allow an increase in font size.

The information on colposcopy from University Hospital Aintree was produced on a word processor in a 10-point serif font. The women found this document too wordy, so they were unable to quickly access any specific information that they may require. Again the contact details and directions should be in a more prominent position, however having a named nurse as a contact was definitely preferable.

Finally none of the information produced by the hospitals was accompanied with any pictures or illustrations, nor were any leaflets available in alternative formats. One visually impaired woman, who had undergone treatment and was not able to access any of the hospital information, had had the procedure adequately explained to her beforehand. However she still would have preferred to have that information in a format that she could have taken away with her.

Everyone preferred the booklet "Having a smear test", produced by the Liverpool People First Women's Group in conjunction with the local health service and Merseyside Health Action Zone. The language and pictures were said to be clear and not at all patronising, the amount of information was appropriate and "not overwhelming", and the size of print (20 point) constituted "large print". The pictures all related to the text and sought to inform people about what to expect. The only criticisms were the lack of alternative formats, and the fact that information of follow-up treatments was not included (although additional leaflets covering those areas have now been produced).

5.4.4 Appointments

Wheelchair users commented that often the receptionist's desks are too high. This means that they cannot make eye contact, have to shout, are often ignored, and can obstruct part of the waiting area in small receptions. Some disabled women found the attitudes of receptionists to be a barrier, describing them as "patronising", "obstructive", "inflexible" and "guard dogs". Someone commented: "the reception staff are like the Hitler Youth." Reception desks with glass screens can be a barrier for Deaf women, since they stop sound travelling and any glare can obstruct someone who is lip reading.

Telephone access proved to be a barrier for some women. Deaf women found that general practices do not often have a textphone facility, a fact corroborated by the interviews with health service workers. Also one woman who had a hearing impairment commented that she is only able to access a phone with an amplifier when she is either at home or at work, and so could not make an appointment from a public telephone.

The disabled women had experienced various systems for alerting a patient to when it is their turn to be seen, such as people's names being called and flashing signs. Someone commented: "they call you out and you don't even know where they're calling you from." None of the disabled women had any objections to their access needs being recorded, so that a surgery could alert people appropriately. Everyone agreed that a system that is audible, visual and tactile would be the solution. Waiting times were also an issue for some women: "Where I am at the moment you wait around a lot which means I'm in a great deal of pain."

The issue of signage was more of a barrier in hospitals. Women commented that signs are typically at the wrong height and were too small. None of the hospitals signs encountered were either tactile or used Braille. Where arrows were used, it was not always clear which direction they were indicating.

5.4.5 The Smear Test

The disabled women associated cervical screening with feelings of fear, anxiety, embarrassment, and discomfort. However these reactions to smear tests are typical of women in general (Milburn and MacAskill,1994; Yu and Rymer, 1998). Therefore this work concentrated on the additional barriers faced by disabled women, over and above the barriers that all women encounter when having the test.

Women with a physical impairment said they had experienced some physical barriers. None of them had been to a practice where the height of the couch was adjustable. The size of the treatment rooms was also a barrier to wheelchair users. One woman said: "I take my partner with me so I'm calmer." However, some preferred to put up with poor access if they had a good experience with the practice staff: "I prefer to put up with the poor access to get a friendlier, more helpful good experience." Another woman with a hearing impairment spoke of the importance of face-to-face communication: "I find it difficult in a

consultation when the doctor or nurse is not face to face with me as I need to lip read. I challenge this now, but I never used to."

The most common barrier experienced by disabled women, regardless of their impairment, was the attitudes of the health service workers. Many prefer to speak to the person accompanying the disabled woman, whether they are a partner, parent, personal assistant or simply a friend who is there to lend moral support. As one woman said: "if I go with a carer, the nurse or doctor will talk to them rather than me… If they talk to the carer, how does the carer know about the situation you're in?" All of the women preferred to be spoken to directly, rather than through an intermediary.

Some disabled women felt that they were not always listened to, particularly those with a physical impairment. One woman, who had previously had several positive experiences of having a smear test at a particular practice, anticipated that the experience would be equally positive at a different one. However when she explained how the procedure had been carried out before, a method that was both comfortable for her and practical for the doctor, they ignored her request. She related: "I've got no control over my legs… They said they were finding it hard… I had already explained that I needed two members of staff to hold my legs, not just one… They said they would have to send me to Broadgreen Hospital. I had to make another appointment and take more time off work. When I went to the hospital they couldn't understand why I was sent there. They had no problems as there were two members of staff present - as I had asked for." Another woman summed up this attitude by saying: "they've seen you for 30 seconds and they think they know what you can and can't do."

Other women spoke of being perceived as a problem because the procedure will take more time for reasons related to their impairment. One woman said: "my physical needs are not particularly complex. I just preferably need someone to go a little bit slower and give me 30 seconds longer to get on the bed. They are almost physically pushing you to hurry up. It's not really necessary to have that sort of attitude, it just makes the whole thing quite stressful."

Some disabled women talked about health service staff making assumptions about the level of assistance required. Some people had assistance forced upon them when it was not required, and others were never offered it although it was required. One woman related a scenario where both her and her mother had unrelated appointments at a practice

at the same time. As it was convenient, the mother offered her daughter a lift. When the daughter's appointment for a smear test was due, the receptionist shouted out: "Mrs. X, will you get your daughter ready for her smear test now." This caused a good deal of anger and embarrassment unnecessarily, since she did not need any assistance anyway. In addition, this also constituted a breach in confidentiality.

In contrast, others stated that they were not offered assistance because their impairment is not always visible: "I just find their attitude is really insensitive because you can't tell by looking at somebody if they've got a problem… From a physical point of view, because I look quite well, they don't seem to understand that there's anything wrong with me, even if they see me with a walking stick."

A few women expressed dissatisfaction at the health service worker's attitudes towards their impairment. For example, one woman stated: "I've been for one smear test which was a nightmare. As part of my impairment I jump a lot because of muscle spasms. The nurse was really funny with me, asking 'what are you jumping for?' I had explained before. I told her at the end 'I didn't appreciate your tone of voice'... she didn't respond. It put me off from going again; it was my first time as well which made it worse… I feel on reflection that the practice nurse was shocked because I had an impairment. I don't know whether this was because of the stereotypes about disabled people being asexual..."

Although most of the experiences related were negative, there were also a few positive ones. One woman commenting on doctors and nurses said: "there are some good ones but they are few and far between." Another woman, who had previously had several bad experiences, stated how she had now found a doctor who made her feel comfortable and inspired confidence. She said: "the staff were great, they explained every step to me before they did anything." This meant that she was able to relax and felt no pain or discomfort. In comparison with previous experiences, she described this one as "absolutely fantastic" and is now less fearful of future smear tests. The Practice Nurse interviewed said that she found that it helped to use a wall chart of the female reproductive system when explaining the procedure to women with a learning difficulty.

Of the women who had less than satisfactory experiences, many thought that training for the staff would have improved attitudes. Someone commented: "Some sort of disability equality training maybe would have helped."

5.4.6 Getting the Results

Many of the barriers to accessing the letters containing the results of the test were identical to the barriers associated with the invitation letters. However because the information about test results contained in these letters is highly confidential, it was felt by all of the disabled women that it is imperative that this information is conveyed via methods that are accessible.   Some women commented that there is plenty of room to make the print larger. Again concern was raised over headed paper not being used, as this led to confusion over where the results had come from. Many women again expressed a preference for alternative methods of communication, in particular telephone calls.

Another concern was the language used around test results. Women with a learning difficulty or dyslexia found medical jargon such as "CIN" difficult to read, and doubted its necessity. The terms 'normal' and 'abnormal' result were highlighted as being particularly misleading in the light of an explanation of what they actually meant. One standard letter from a GP, informing a patient that they had an abnormal result, categorically stated that the patient did not have cervical cancer. Women thought that this again was very misleading. These findings are in agreement with general research on women's understanding of cervical screening test results (Kavanagh et al, 1997; Marteau at al, 2001).

5.4.7 Follow-up Investigations / Treatments

Of the 27 women interviewed, only 4 had had personal experience of the follow-up procedures. None of them had received information on the procedures beforehand that they had been able to access. Nobody liked any of the leaflets, and as before there was a distinct lack of information in alternative formats. Someone commented: "I had no information about the colposcopy examination before I had it done. If I had known what would happen I don't think I would had had it done." Another woman was given a leaflet that she was unable to read prior to her colposcopy examination. She found the whole experience "disgusting", since in effect she did not receive any information or verbal explanation. In contrast, another woman in the same situation was at least able to rely on medical staff explaining each stage of the process: "the doctor at the time told me everything that was going on and why it was going on." However verbally delivered information cannot be taken away by the patient and reviewed later on.

These accounts highlight a distinct need for one accessible NHS leaflet on follow-up procedures, which can be made available in alternative formats.

One woman with a visual impairment also suggested a free telephone help-line, with an option to select from a menu a particular aspect that they required more information on.

Whatever the method, it is not acceptable to allow women to undergo these procedures without first being adequately informed. One woman commented: "it was horrible… very painful… I hope I don't have to have it done again. That's why I dread having smear tests, in case I have to have it done again." Experiences like this one may be able to be avoided if women are adequately informed beforehand.

5.5   Conclusions

This research has highlighted many of the barriers that disabled women face when accessing the cervical screening programme in Great Britain.

Recommendations:

- **Awareness should be raised within the programme that impairment is not a valid reason for denying a disabled woman a smear test and removing her from the recall list.**
- **Everyone who works within the programme, including general practitioners, nurses and receptionists, should receive Disability Equality Training.**
- **All letters sent out should use plain language and be printed in Ariel font size 14.**
- **There should be a system for recording women's preferred method of communication, in order to appropriately inform women who cannot read the standard letters.**
- **There should be a named contact, who can discuss issues related to impairment. Moreover, every Trust should have a worker responsible for disability equality issues**
- **The three standard NHS leaflets should use plain language and be produced in the following formats:**
    1. **Large print**
    2. **Large print with pictures and symbols**
    3. **Braille**

4. **Computer disc containing the file in plain text format**
5. **Accessible website**
6. **Audiotape**
7. **Videotape with plain, spoken language and audio description.**
8. **Videotape with British Sign Language.**

- **Simple information on colposcopy procedures should also be produced in the formats listed above.**
- **All practices and hospitals should have a textphone, and staff should be trained how to use it.**
- **The system in the waiting room for informing patients of when it is their turn to be seen should be audible, visual and tactile.**

6 Electronic Healthcare Records

A major problem with using accessible methods of communication and providing information in an accessible format is knowing which of the formats identified previously is required by a specific individual. Research carried out with Deaf people recommends 'marking' their medical records (Ubido et al, 1995). The Royal National Institute for the Deaf currently advocates the use of Electronic Healthcare Records to achieve this (Loosemore-Reppen, 2001). A survey carried out by the Royal National Institute for the Blind (1995) found that 95% of people with a visual impairment thought that companies should keep a record of their customers' preference for accessible information format. In addition, the research carried out in section 3.4 indicates that disabled people would not mind having their access needs recorded if it meant that they received accessible information. Therefore it should be possible to always send appropriate information in a format that meets an individual patient's needs if disabled people's access requirements are recorded in the Electronic Healthcare Records system currently under development.

The introduction of Electronic Healthcare Records will allow patients to access their own medical records. Quite apart from the benefits for accessible health information, this will also hopefully make health professionals finally think more carefully about the terms that they use to describe people, since their patients will now be able to read their own notes. Disabled people long ago rejected the terminology created by the medical profession, which had negative and oppressive associations, and adopted their own. If patients are to be given access to their records then a large amount of Disability Equality Training is called for first, in order to eliminate such discriminatory words and attitudes.

The many advantages of using Electronic Healthcare Records and locating a large amount of diverse information about an individual patient in one place have been much discussed. However as far as we can see, the needs of disabled people have yet to be addressed. The Disability Discrimination Act (1995) wisely abolished the system set in place by the Disabled Persons (Employment) Act 1944, which required local registers of disabled people to be kept (Oliver and Barnes, 1998, pages 131-132). This was intended to ensure that disabled people could find work in 'reserved occupations', however it was never properly enforced and only 10 employers were prosecuted under it in 52 years. It is not suggested that Electronic Healthcare Records should be used in a similar way to

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record whether or not a person is disabled, nor their specific impairment. Such a practice would have no practical value with respect to accessing health information, since two people with the same impairment may have very different access requirements. Moreover the labelling of disabled people in this way could facilitate further acts of discrimination.

An acceptable alternative would be the inclusion of every patient's information access needs on their individual Electronic Patient Record. This would enable almost every section of health service with access to these records to know the appropriate format to use for communication. A further advantage would be that patients themselves could specify and update their access needs through the World Wide Web. If all health service employees had access to the general information on the patient's Electronic Healthcare Records, a disabled person would only need to specify their access requirements once.

From this is follows that the already largely automated process of communication with patients could be altered in order to ensure that an appropriate format is always used and people are not just being treated as 'troublesome exceptions'. Where large clear print has been requested, the software could look up the correct font type and size automatically. Where Braille has been specified, the print out could be redirected to a Braille embosser. Where the patient has a learning difficulty and requires simplified information using plain English, an alternative version of the letter / literature could be automatically sent. Where literature on computer disc or audio or videotape is necessary, this fact could be flagged to the computer operator who could then make the appropriate arrangements. Such measures would ensure that disabled patients would always be able to independently access any information from the health service.

The advantages of Electronic Healthcare Records go wider still. Whilst it is hoped that both the health service and other statutory bodies will take notice of other aspects of the Disability Discrimination Act and move towards accessible buildings and transport, the specification of physical access needs on Electronic Healthcare Records could still be of benefit when booking appointments. Moreover it is not only disabled people who have difficulty accessing health information. People who require information in different languages could be accommodated in the same way. Versions of letters and leaflets in different languages could be automatically generated whenever specified by the patient's record. In addition if everyone is given the option of saying that they prefer information in a specific format, this would allow people who do not read

the opportunity to ask for information on audio-tape without having to declare that they do not read every time they encounter a health worker.

Electronic Healthcare Records are scheduled to go live in Liverpool in 2004, and nationally in 2010. If the needs of previously excluded groups, in particularly disabled people, are not addressed during the development stage then the opportunity to get it right from the start will be lost.

Recommendation:
- **Electronic Healthcare Records should be used to record people's information access needs**

7 Disability Equality Training

7.1   Previous Provision

It is important that we have a have a co-ordinated approach to training across all of the local trusts. As previously mentioned, the adoption of the social model of disability should be shaping the working practices of all health service employees when they come into contact with disabled people. However in practice the majority of employees do not understand the social model or its implications for their work. In addition, the implications of the Disability Discrimination Act (1995) for the Health Service continue to grow, covering employment and service provision. Individuals also have responsibilities to act in a non-discriminatory way, and if they do not understand what these responsibilities are then there could be legal implications for both the individual and the employing trust.

In the past some Liverpool Health Authority staff had received training on disability issues. This has ranged from full Disability Equality Training for the members of the Disability Discrimination Act Implementation Group to impairment-specific awareness training for a number of staff, including Hamilton House reception staff. This training has been organised on an ad hoc basis, was of variable standard and was not available to the vast majority of staff. In addition a national distance learning training scheme by the Grassroots organisation called "Welcoming Patients with Disabilities" has also been sporadically offered locally. Although widely used, this scheme has impairment-specific content, does not follow the social model of disability (as can be seen from the title) and test people's knowledge of trivia, rather than their grasp of concepts.

7.2   Content

The current Disability Equality Training strategy for Liverpool Primary Care Trusts will provide a standardised training package for employees. It was partly based on the literature search and the views expressed by local disabled people during the consultation stage of this work. The course will be brought in line with the British Council of Disabled People's accredited training programme when it is launched next year (see appendix for contact details).

The training is aimed at three key target groups: people undergoing induction training; people who come into regular contact with

disabled people or who have some strategic responsibility for services; and general health service staff. Although local National Health Service trusts (other than primary care trusts) are not directly included in the strategy, it states that they will be encouraged to provide training in line with the proposal in order to maintain a uniform approach. The strategy proposes that following people undertake training:

- Directors of the Primary Care Trusts and Strategic Health Authority
- Reception staff
- Any people who are responsible for strategic development, such as commissioning or corporate affairs managers
- Human Resources employees
- Primary Care Trust board members and staff
- General Practitioners, practice managers, and practice nurses
- People responsible for dealing with complaints
- People responsible for staff training.

The course lasts for one and a half days and is presented by independent disabled consultants active in the disabled people's civil rights movement. The first one-day session covers the following areas:

- The medical and social models of disability
- The history of disability
- The disabled people's movement, its history and its achievements
- Some of the barriers disabled people experience in both society and health service specifically
- The importance of words, images and stereotypes
- Charity versus civil rights views of disability
- The Disability Discrimination Act and its implications for the National Health Service
- Other relevant legislation such as the Human Rights Act and Special Education Needs and Disability Act

At the end of the day the participants draw up individual action plans to help them apply the issues they have covered to their work. The second half-day session examines how the action plan is working and explores ways to address any problems that may have been encountered.

7.3   The Pilot

The project ran a pilot training course covering the areas previously listed, delivered by a local independent disabled consultant active in the civil rights movement. It was attended by 15 health service workers from a number of different professions, including a Primary Care Group Chief Executive, development managers, office managers, practice nurses, receptionists and project officers. Although every effort was made to get general practitioners to attend, including the securing of post-graduate education accreditation, this did not prove possible.

Action plans included aims such as improving access to paper information, installing fire alarms that are both audible and visual, installing a sanitary vending machine in the accessible toilet and contacting disabled people to find out what changes they would require. All of the feedback received was very positive – here is a representative sample of quotes:

- "I found all of the training both enjoyable and useful."
- "The video was informative – I found it very uncomfortable to watch."
- "Very action focused – resulted in changes in practice."
- "Learnt that changes can be made, even if they are small."
- "Learnt never to judge by appearance."

In the final session the group discussed and made the following recommendations:

- A certificate of attendance should be given to those who completed the course / action planning.
- The follow-up session is vital.
- The course should be rolled out to all staff.
- There is a need for co-ordination across different trusts.
- Examples of action plans should be made available when advertising the course, so that people can see what can be done with little cost.
- It is important that all staff are kept up-to-date on the law.
- The PROPEL primary care training programme needs to run this course.

7.4   On-line Training

Many health service workers are unable to attend training sessions, as this would means an interruption to the service that they are providing. Therefore a training package that can be delivered over the World Wide

Web is currently being developed by this project, in partnership with Connect at the University of Liverpool. This will enable participants to take the course over a number of weeks. The finished product will include text, sounds, images and video clips. Issues will be discussed by on-line notice boards, with a moderator steering the debate.

It was felt that all such training should involve participants coming into contact with a 'politicised' disabled person. Therefore in order to pass, people will have to attend a seminar taken by an independent disabled consultant active in the disabled people's civil rights movement.

7.5   Conclusions

Previous research has shown that disability equality training can have a positive affect on people's attitudes towards disabled people (French, 1992). What is now needed is resources to make the training available to the majority of local health service staff, and the integration of the course into the mainstream equality and health service training programmes.

In March 2003 the British Council of Disabled People are launching a scheme for accrediting disability equality training. In order to ensure consistency, the National Health Service should seek accreditation from this organisation.

Recommendations:
- **Everyone who has contact with patients or strategic responsibility for service provision must have Disability Equality Training.**
- **Disability Equality Training provided by the health service should have accreditation from the British Council of Disabled People, once its scheme comes into operation in March 2003.**
- **Other methods of education should also be used, including posters and displays, items in regularly circulated newsletters, videotape material, integration with induction training, and periods of disability equality training during other training programmes.**

8 Recommendations

This report has highlighted many ways in which the National Health Service is currently not complying with the Disability Discrimination Act regarding the accessibility of its information.

Based on the views expressed by local disabled people and the literature search, here are the necessary steps that need to be taken to ensure that health information is made accessible.   The numbers in brackets indicate which section the recommendation is from:

1) Alternative Formats
   a. Patient information should always be designed and printed professionally, in accordance with the NHS Identity Guidelines, which in turn should be updated with the findings of this report (3.2)
   b. The following formats should be available:
      i. Large print
      ii. Large print with pictures and symbols
      iii. Braille
      iv. Computer disc containing the file in plain text format
      v. Accessible website
      vi. Audiotape
      vii. Videotape with plain, spoken language, audio description and British Sign Language (3.1).
   a. Phone calls and face-to-face meetings should be available alternatives to written communication (3.1).

2. Plain Written English
   a. Keep sentences short – 15 to 20 words (2.5)
   b. Only one main point should be made in a sentence (2.5)
   c. Write active, positive sentences (2.5)
   d. Avoid abstract thought, figurative language and metaphors (2.5)
   e. Be direct to the reader – use I, we, you (2.5)
   f. Try to make writing sound like speech (2.5)
   g. Use everyday words (2.5)
   h. Be consistent and repeat words (2.5)
   i. Don't use jargon, acronyms or abbreviations (2.5)
   j. Explain complex ideas (2.5)
   k. Give reader the chance to comment on the information (2.5)

3. Typeface and Font Size
    a. A sans-serif font should always be used - Adobe Frutiger for professionally printed material and Ariel for documents produced in-house (3.2)
    b. Block capitals, italics and underlining should never be used. **Bold** type can be used instead (3.2)
    c. Standard print should use a font size of no less than size 14-point (3.2)
    d. Large print should be at least of size 20-point (3.2)
    e. Systems should to flexible enough for different fonts and sizes to be used whenever required (3.2)

4. Signage
    a. All signage should adhere to the NHS Identity Guidelines: Capital Build Projects, which should be updated in accordance with the Royal National Institute for the Blind's See It Right guidelines (3.2)

5. Layout
    a. Use matt paper that weighs over 90 grams per square metre (gsm), and make sure that the folding would not stop the document being scanned (2.1).
    b. The right-hand margin should not be justified (2.5)
    c. Lines should be neither too long nor too short - 65 characters maximum (2.5)
    d. Text should not be placed in columns (2.5)
    e. Avoid reverse type - white writing on a coloured background (2.5)
    f. Use good quality matt paper and either a cream or tinted background to avoid glare (2.5)
    g. Do not break up words with a hyphen at the end of a line (2.5)
    h. Never let sentences run onto the next page (2.5)
    i. Break up the text into small paragraphs that succinctly make a point (2.5)
    j. Use bullet points to make the main points clear (2.5)
    k. Sections must be denoted with clear headings and colour coding (2.5)
    l. The leading (the space between each line) should be approximately 1.5 times the font size (3.3)
    m. Pictures should be large, illustrate a point and placed a sufficient distance away from the text (3.3)
    n. Illustrations used should not be patronising (3.3)

o. Symbols should be used only to indicate the sort of information given, not as a replacement for text (3.3)
p. Columns of text should have sufficient space left between them (3.3)
q. Use generous amounts of space on forms for people to fill in a response (3.3)
r. Use a consistent layout for different ranges of leaflets (3.3)

6. Access to Alternative Formats
a. Availability of alternative formats should be clearly displayed in large print on the front cover of all leaflets (3.4)
b. Alternative formats should be available in hospitals, waiting rooms, libraries and other public buildings (3.4)
c. An accessible catalogue should be produced listing every leaflet and the formats that it is available in (3.4)
d. Electronic Healthcare Records should be used to record people's information access needs (6)

7. Websites
a. Sites must conform to the W3C Web Accessibility Initiative guidelines – this can be check using the W3C validator (www.w3.validator.org) and the Bobby automated checker (www.cast.org/bobby) (2.1)
b. All images and sound clips should be accompanied with alternative textual descriptions (2.1)
c. Video clips should be captioned or an alternative transcription should be provided (2.1)
d. There should be a good contrast between the foreground and background colours (2.1)
e. Links should always be clearly identifiable by means other than colour alone, for example underlining (2.1)
f. Do not rely on video, Flash movies and Java applets to convey information - always provide a way to skip them and an alternative textual description (2.1)
g. Portable Document Format (PDF) files should be created using Adobe Acrobat (version 5) and the accessibility option should be enabled (2.1)
h. There should be a mechanism to change the colour scheme, font typeface and size to suit individual needs (3.5)
i. A text-only option should be available (3.5)
j. Frames and tables should be either avoided, or tags should be used to indicate the order in which the text should be read (3.5)

k. Important information should be available as an on-line signed video clip (3.5)

8. Prescriptions and Medication
a) Large clear print should be used on prescription notes (3.6)
b) The reverse side and repeat prescription forms should be redesigned to make them accessible (3.6)
c) A system where a prescription and a patient's exemption details are passed directly to their chemist of choice by the practice would eliminate the need for prescription notes altogether (3.6)
d) The 'speaking medication label' should be available in the United Kingdom (3.6)
e) The information that comes with medication should be accessible (3.6)

9. Appointments
a) All National Health Service premises and family doctors should have a textphone (3.7)
b) The NHS UK website directory of family doctors in accessible buildings should be publicised better (3.7)
c) The system in the waiting room for informing patients of when their appointment is due should be audible, visual and tactile (3.7)
d) Doctors should come and escort patients to their room in order to show people where to go and strengthen the doctor-patient relationship (3.7)

10. Face-to-face Communication
a) Everyone who has contact with patients or strategic responsibility for service provision must have Disability Equality Training (3.8 / 7)
b) Disability Equality Training provided by the health service should have accreditation from the British Council of Disabled People, once their scheme comes into operation in March 2003 (7)
c) Other methods of education should also be used, including posters and displays, items in regularly circulated newsletters, videotape material, integration with induction training, and periods of disability equality training during other training programmes (7)
d) There should be a dedicated sign language interpretation service for local health services that would ensure that

interpreters were readily available for appointments and emergencies (2.4 / 3.8)

e) Interpreters should be at least of level 3 registered trainee standard (2.4)

f) Services that require confidentiality, such as counselling, should have trained workers who can sign to a high standard (2.4)

g) Deaf people who have sign language as a first or preferred language should be proactively recruited and trained by the health service, to increase its number of workers who sign (2.4)

h) Everyone who has contact with patients should learn at least basic British Sign Language (2.4 / 3.8)

11. The Cervical Screening Service

a) Awareness should be raised within the programme that impairment is not a valid reason for denying a disabled woman a smear test and removing her from the recall list (5)

b) Everyone who works within the programme, including general practitioners, nurses and receptionists, should receive Disability Equality Training (5)

c) All letters sent out should use plain language and Ariel font size 14 (5)

d) There should be a system for recording women's preferred method of communication, in order to appropriately and confidentially inform women who cannot read the standard letters (5)

e) The three standard NHS leaflets should use plain language and be produced alternative formats. (5)

f) Simple information on colposcopy procedures should also be produced in alternative formats (5)

12. General

a) There should be a central agency implementing a co-ordinated approach to producing health information (2.1)

b) Disabled people should be actively included in writing health information, especially information about specific impairments (3.10)

c) Every Trust should have a worker responsible for disability equality issues (5)

d) Emancipatory research techniques should be used in research involving disabled people (2.6)

e) The Disability Discrimination Act (1995) should be effectively enforced to ensure that service providers comply with the law and provide accessible information (3.11)

9 Appendix: Useful Contacts

9.1   National Organisations

The British Council of Disabled People
This is the national umbrella organisation of organisations of disabled people and individual disabled people. It also encompasses the National Centre for Independent Living, promoting services that allow disabled people to take control of their own lives.

They can be contacted at general@bcodp.org.uk, or on 01332 295551 (voice), 01332 295580 (fax) or 01332 295581 (text).

The Disability Rights Commission
An independent organisation set up by the government to help secure civil rights for Disabled People. It provides advice and information on many issues, including the Disability Discrimination Act, as well as supporting individuals to secure their rights by giving legal advice. They have a help-line number: 08457 622 633 (voice), 08457 778 878 (fax) or 08457 622 644 (text). They also have a website, which provides lots of information on disabled people's civil rights: www.drc-gb.gov.uk.

The Plain English Campaign
The Plain English Campaign is an independent pressure group fighting for public information to be written in plain English. 'Public information' means anything people have to read to get by in their daily lives. 'Plain English' is language that the intended audience can understand and act upon from a single reading. They publish a free guide called 'How to write medical information in plain English'. They can be contacted on 01663 744409. The address of their website is www.plainenglish.co.uk.

9.2   Local Organisations

Merseyside Coalition of Inclusive Living (MCIL)
MCIL is a newly formed local organization who work to the social model of disability by promoting inclusion and self-determination and working to overcome the barriers of discrimination and segregation. They promote disabled people's civil rights by seeking to consult with, and advise local decision makers and service providers in addressing the needs of disabled residents and service users. For further information please contact Patrick Barwise on 0151 225 6015 (voice).

Liverpool Association of Disabled People (LAD)
LAD is a local organisation run and controlled by disabled people. They provide information and advice on disability issues, particularly welfare benefits. They also perform building access audits. They can be contacted on 0151 263 8366 (voice) or 0151 260 3187 (text).

Merseyside Society for Deaf People
An organisation providing information and support for Deaf people in Merseyside. They also run Deaf Equality Action Training Courses. Contact: 0151 228 0888 (voice and text).

Liverpool Voluntary Society for the Blind
An organisation that provides information, support and training to blind and partially sighted people in Liverpool. As part of their service they keep a register of people with a visual impairment, to whom they send a taped newsletter quarterly. Contact Jim Moran on 0151 221 0888 or at lvsb@lvsb.freeserve.co.uk

In Vision Productions
A local company run by Deaf people, which make BSL videos. Contact Barry Kirwan at bkirwan@btinternet.com

10 References

Aspray,T.J. Francis,R.M. Tyrer,S.P. and Quilliam,S.J. (1999) Patients with learning disability in the community. **British Medical Journal,** 318: 476-477.

Baird,A. (1997) Anxiety and the cervical smear test. **Primary Health Care**, 7(2), 26-29.

Band,R. (1998) **The NHS – health for all?: people with learning disabilities and healthcare.** London: Mencap.

Barnes,C. (1991) **Disabled people in Britain and discrimination.** Third edition, London: Hurst and Company.

Barnes,C. (1994) **From national to local: an evaluation of the effectiveness of national disablement information providers' services to local disablement information providers.** University of Leeds Centre for Disability Studies Research Archive: http://www.leeds.ac.uk/disability-studies/archiveuk/index.

Barnes,C. (2001) **Emancipatory disability research: project or process?** University of Leeds Centre for Disability Studies Research Archive: http://www.leeds.ac.uk/disability-studies/archiveuk/index.

Basic Skills Agency (1996) **Making reading easier.** London: Basic Skills Agency.

Begum, N. (1995) **Beyond samosas and reggae: a guide to developing services for Black disabled people.** London: King's Fund Publishing.

Begum, N. (1996) Doctor, doctor… disabled women's experiences of general practitioners. In: **Encounters with Strangers** (Morris, J. ed.), London: The Women's Press, 167-193.

Beresford,P. and Wallcraft,J. (1997) Psychiatric system survivors and emancipatory research: issues, overlaps and differences, in Barnes,C. and Mercer,G. (eds.) **Doing disability research.** Leeds: The Disability Press.

Bewley,C. and Glendinning,C. (1994) **Involving disabled people in community care planning.** York: Joseph Rowntree Foundation.

British Council of Disabled People (2002) **The Disabled Peoples' Rights and Freedoms Bill.** http://www.bcodp.org.uk/campaigns/rightsfreedomsbill.html, Derby: British Council of Disabled People.

Broughton,S. and Thomson,K. (2000) Women with learning disabilities: risk behaviours and experiences of the cervical smear test. **Journal of Advanced Nursing**, 32(4): 905-912.

Brown,H. Stien,J and Turk,V. (1995) The sexual abuse of adults with learning disabilities: report of a second two–year incidence survey. **Mental Handicap Research**, 8(1): 3-24.

Brown,J. (1998) **The Performance of the NHS Cervical Screening Programme in England**. London: The Stationary Office.

Carter, J.M. and Hare-Cockburn, K. (1998) Breaking down language barriers. Sign here, please. **British Medical Journal** 317: 816.

Carter J.M. and Markham N. (2001) Disability discrimination. **British Medical Journal** 323:178-179.

Cawthra, L. (1999) Older people's health information needs. **Health Libraries Review** 16: 97-105.

Coopers and Lybrand (1988) **The information needs of disabled people, their carers and service providers.** London: Department of Health and Social Services.

Corker,M. (2002) Deafness / Disability – problematising notions of identity, culture and structure, in Ridell,S. and Watson,N. (eds.) **Disability, Culture and Identity,** London: Pearson.

Coulter,A. Entwistle,V. and Gilbert,D. (1999) Sharing decisions with patients: is the information good enough? **British Medical Journal** 318: 318-322.

Davis, K. (1990) **Activating the social model of disability: the emergence of the 'seven needs'.** Derbyshire: Derbyshire Coalition of Disabled People.

Deaton, H. (1993) **Out of sight, out of reach, out of bounds: access to information for visually disabled people,** (Turner, M. ed.) London: Greater London Association of Disabled People.

Department of Health (2001a) **The NHS Identity Guidelines.**
London: Department of Health.

Department of Health (2001b) **Working in Partnership to
Implement Section 21 of the Disability Discrimination Act 1995
Across the National Health Service.**
http://www.doh.gov.uk/dda/section21dda.htm

Derbyshire Coalition of Disabled People (1988) **The seven needs
and the social model of disability.** Derbyshire Coalition of Disabled
People: http://www.dcil.org.uk/Papers/SevenNeeds.html.

Devlin, R. (1992) Breaking the sound barrier. **Nursing Times** 88(46),
26-27.

Deyo,R.A. (2001) A key medical decision maker: the patient. **British
Medical Journal** 323: 466-467.

DiPietro,L.J. Knight,C.H. Sams,J.S. (1981) Health care delivery for
deaf patients: the providers role. **American Annals of the Deaf** 126:
106-112.

Drake,R.F. (1996) Charities, authority and disabled people: a
qualitative study. **Disability, Handicap and Society** 11(1): 5-23.

Edwards,A. Elwyn,G. and Mulley,A. (2002) Explaining risk: turning
numerical data into meaningful pictures. **British Medical Journal**
324: 827-830.

Fovargue,S. Keywood,K. and Flynn,M. (2000) Learning disability:
participation in health care decision–making by adults with learning
disabilities. **Mental Health Care**, 31(10): 341-344.

French,S. (1992) Simulation exercises in disability awareness
training: a critique. **Disability, Handicap and Society** 7(3): 257-266.

French,S. (1994) Attitudes of health professionals towards disabled
people. **Physiotherapy** 80(10): 687-693.

Gregory, W. (1996) **The informability manual: making information
more accessible in light of the Disability Discrimination Act.**
London: HMSO.

Greater London Association of Disabled People (1991) **Race and disability: a dialogue for action.** London: Greater London Association of Disabled People.

Haire,A.R. Bambrick,M. and Jones,J. (1992) Cervical screening for women with a mental handicap. **The British Journal of Family Planning,** 17: 120–121.

Hall, P., Ward, E., Djuretic, T., Laing-Morton, T., Guy, M., Gill, M., Whitmore, J. (1999). Cervical screening for women with learning disability. **British Medical Journal,** 318: 536.

Hart,S.L. (1999) Meaningful choices: consent to treatment in general health care settings for people with learning disabilities. **Journal of Learning Disabilities for Nursing, Health and Social Care** 3(1): 20–26.

Hermeston,R. (2001) Charities must try harder. **Disability Now,** July 2001.

Hevey,D. (1992) **The creatures time forgot.** London: Routledge.

HMSO (1999a) **Disability Discrimination Act 1995 (c. 50).** London: HMSO.

HMSO (1999b) **Disability Discrimination Act 1995. Code of practice. Rights of access. Goods, facilities, services and premises**. London: HMSO.

Hogg,C. (2002) **National Service Frameworks: Involving patients and the public.** London: The Patients' Forum.

Jonah Eleweke,C. and Rodda,M. (2000) Factors contributing to parents' selection of a communication mode to use with their deaf children, **American Annals of the Deaf** 145(4), 375-383.

Kavanagh,A.M. and Broom,D.H. (1997) Women's understanding of abnormal cervical smear test results: a qualitative interview study. **British Medical Journal,** 314(7091): 1388.

Kelsall,J. (1993) Giving midwifery care for the deaf in the 1990s. **Midwives Chronicle and Nursing Notes**, March 1993: 80-82.

Kempson, E. (1987) **Informing health consumers: a review of consumer health information needs and services.** London: College of Health.

Kimmel, B. (1989) Providing equal access for deaf clients. **JONA** 19(3): 26-28.

Langan,J. Whitfield,M. and Russell,O. (1994) Paid and unpaid carers: their role and satisfaction with primary health care for people with learning difficulties. **Health and Social Care** 2: 357-365.

Leat,M. (2000) **Seeing the light: a rough guide to making information easier to understand.** Surrey: Surrey Users Network.

Leshin,L. (1997) **Trisomy 21: the story of down syndrome.** http://www.ds-health.com/trisomy.htm

Lindsey,M. (1998) **Signposts for success in commissioning and providing health services for people with learning disabilities**. Leeds: NHS Executive.

Liverpool Health Authority (1996) **Liverpool's Annual Public Health Report 1996**. Liverpool Health Authority.

Lomas,G. (1997) **Closing the gap: linking health and social care for visually impaired people.** London: Royal National Institute for the Blind, on behalf of the Visual Handicap Group.

Lomas,M. (1998) **Access to Health Services: Falling on Deaf Ears?** Manchester: Association of Greater Manchester Authorities.

Loosemore-Reppen,G. (2001) **Response to the London Health Commission: tackling health inequalities.** London: Royal National Institute for the Deaf.

Majeed,F.A. Cook,D.G. Anderson,H.R. Hilton,S. Bunn,S and Stones,C. (1994) Using Patient and general practice characteristics to explain variations in cervical smear uptake rates. **British Medical Journal,** 308: 1272–1276.

Marteau,T.M. Senior,V and Sasieni,P. (2001) Women's understanding of a 'normal smear test result': experimental questionnaire based study. **British Medical Journal,** 322(7285): 526-528.

McCarthy,M. (1999) **Sexuality and women with learning disabilities.** London: Jessica Kingsley Publishers.

McCay, V. (1988) Rights of deaf hospital patients. **American Annals of the Deaf** 133(4): 253.

McCray,J. and Carter,S. (1999**)** Access unrestricted. **Nursing times,** 95(23): 47-49.

McEntee, M.K. (1993) Accessibility of mental health services and crisis intervention to the deaf. **American Annals of the Deaf** 138(1): 26-30.

Mencap (2000) **Am I making myself clear?** London: Mencap.

Mencap (2002) **Behind closed doors: preventing sexual abuse against adults with a learning disability.** London: Mencap.

Milburn,K. and MacAskill,S. (1994) Cervical Screening: continuing concerns in the 1990's. **Health Education Journal** 53: 201-213.

Mohay,H. and Kleinig,D. (1991) Providing medical care for deaf patients. **Medical Journal of Australia** 155: 498-499.

Montgomery, G. (1981) Audiocentric attitudes: a barrier to understanding deaf people. **Nursing** 28: 1231-1234.

Moore,N. (1995) **Access to information: a review of the provision of disability information.** London: Policy Studies Institute.

Moore,N. (2000) **The information needs of visually impaired people: a review of research for the RNIB.** London: Royal National Institute for the Blind.

National Information Forum (1996) **How to provide information well: a good practical guide.** London: National Information Forum.

National Information Forum (2001) **Face to face: an inquiry into the unmet information needs of disabled people.** London: National Information Forum.

Newnes,J. (1999) **What are they going to smear?** Sefton: Sefton Health Authority.

NHS Cancer Screening Programmes (2000) **Good practice in breast and cervical screening for women with learning disabilities.** Sheffield: NHS Cancer Screening Programmes.

Nottingham,J. (1999) Women must be given fully informed information about cervical screening. **British Medical Journal,** 318(7197): 1555.

Oliver M. (1983) **Social work with disabled people.** Tavistock: Macmillan Press.

Oliver M. (1998) Theories of disability in health practice and research. **British Medical Journal** 317:1446-1449.

Oliver M. and Barnes C. (1998) **Disabled people and social policy: from exclusion to inclusion.** Addison Wesley Longman.

Pearson,V. Davis,C. Ruoff, C. and Dyer,J. (1998) Only one quarter of women with learning disability in Exeter have cervical screening. **British Medical Journal,** 316: 1979.

People First (1992) **These look just as sickening to people with learning difficulties.** London: People First.

Plain English Campaign (1993) **The plain English a to z guide of alternative words.** Whaley Bridge: Plain English Campaign.

Royal College of Physicians (1998) **Disabled people using hospitals: a charter and guidelines.** London: Royal College of Physicians.

Royal National Institute for the Blind (1995) **Blindness: the daily challenge.** London: Royal National Institute for the Blind.

Royal National Institute for the Blind (1998a) **Ill informed: the provision of accessible health and medical information.** London: Royal National Institute for the Blind.

Royal National Institute for the Blind (1998b) **Within reason: access to services for blind and partially sighted people.** London: Royal National Institute for the Blind.

Royal National Institute for the Blind (1999) **Get the message.** London: Royal National Institute for the Blind.

Royal National Institute for the Blind (2001) **See it right.** London: Royal National Institute for the Blind.

Shah,S. and Priestley,M. (2002) **Better services, better health: the healthcare experiences of black and minority ethnic disabled people.** Leeds Involvement Project.

Sims, J. (1989) Breaking the silence. **Nursing Times** 85(24), 16-17.

Slater,D.N. (2000) Are women sufficiently well informed to provide valid consent for the cervical smear test? **Cytopathology,** 11: 166-170.

Stein,K and Allen,N. (1999) Cross sectional survey of cervical cancer screening in women with learning disability. **British Medical Journal,** 318: 641.

Steinburg, A. (1991) Issues in providing mental health services to hearing impaired persons. **Hospitals and Community Psychiatry** 42(4): 380-389.

Stone,E. and Priestley,M. (1997) Parasites, pawns and partners: disability research and the role of non-disabled researchers. **British Journal of Sociology**, 47(4): 699-716.

SURFACE (2002) **Liverpool Health Authority communication and information accessibility audit: stage one report.** Salford: Salford University Research Focus on Accessible Environments (SURFACE).

Tinker,A. McCreadie,C. and Salvage,A. (1993) **The information needs of elderly people - an exploratory study.** London: Age Concern Institute of Gerontology.

The Stationary Office (1999) **Abortion statistics for England and Wales.** London: The Stationary Office.

Townsley,R. and Gyde,K. (1997) **Plain facts: information about research for people with learning difficulties.** Bristol: Doveton Press.

Todd,M. Tomlinson,C. and Baker,M. (1996) **Providing a service for all: a training guide.** Edinburgh: Scottish Tourist Board.

Union of Physically Impaired Against Segregation (1976) **Fundamental Principles of Disability**. London: Union of Physically Impaired Against Segregation.

Ubido,J. Huntington,J. and Warburton,D. (1995) **Cheshire deaf women's health survey.** Cheshire: Cheshire Deaf Society.

Whitehouse,A. Sherman,R. and Kozlowski,K. (1991) The needs of deaf substance abusers in Illinois. **American Journal of Drug Abuse** 17: 103-113.

Willetts, G. (1997) **Services for people with visual impairments in Luton – a review report for the social services department.** London: Royal National Institute for the Blind.

Wright, D. (1993) Deaf people's perceptions of communication with nurses. **Journal of Nursing** 2(11): 567-571.

Yu, C.K.H. and Rymer,J. (1998) Women's attitudes to and awareness of smear testing and cervical cancer. **The British Journal of Family Planning,** 23: 127-133.