

Resource Disability Portfolio Guide

1

Disability in Context



Use **Guide 1** to gain understanding about how disabled people place themselves within society and to learn what factors influence their choice of services.

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The Portfolio is published as a result of collaboration with a working party, which includes specialist consultants, and aims to support the elimination of discrimination in service provision. The views expressed in these guides are not necessarily those of Resource.

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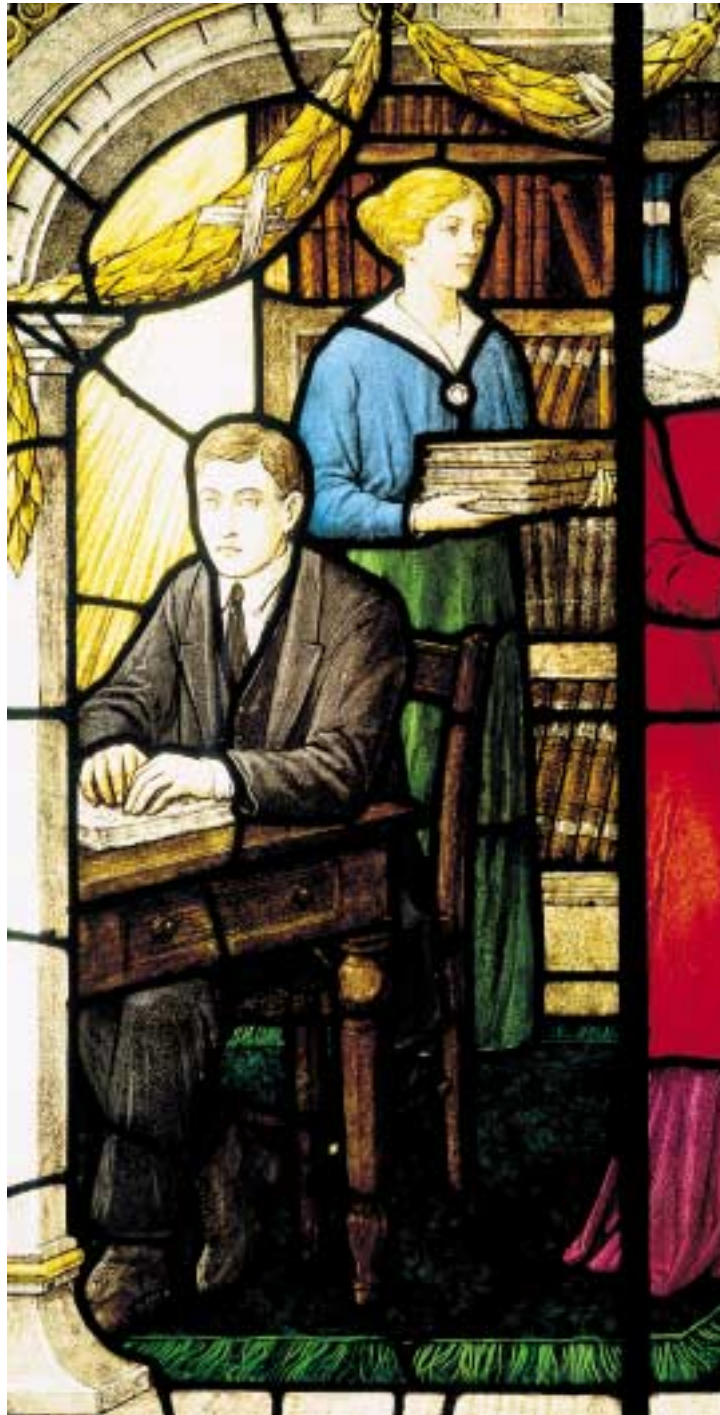
A disabled artist's view: *Great Britain from a Wheelchair*,
Tony Heaton, 1995.

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Over a long period, up to recent times, the accepted way to view disability was as a state deserving of benevolence and pity. The new view of disabled people is as valuable citizens with equal rights, who make their own life decisions and choices.

Early 20th Century stained glass, National Library for the Blind. © NLB





Introduction

The identity of disabled people has undergone dramatic change over recent decades. How they view themselves affects how they behave, and how you view them affects how you serve them.

Over a long period, up to recent times, the accepted way to view disability was as a state deserving of benevolence and pity. In this context, it was not common to provide equal access to services or to offer real choice to disabled users. The deserving receiver was expected to be grateful, pleased and apologetic, and had no choice unless their physical, intellectual or sensory needs were minor.

Change began in 1981, when the International Year of Disabled People focused attention on the topic and made some disabled people more aware of their own numbers. The doctrine of equal opportunities focused on an obligation not to discriminate, because it wasn't fair. This approach was harder in relation to disabled people, since to meet their needs was seen as expensive and difficult by comparison to a non-discriminatory attitude towards other groups. Equal opportunities for disabled people were viewed as a drain on resources, resulting in disabled people being less equal than others.

In the years leading up to 1995, the notion of disability rights developed. This idea took strength from what was happening in America and elsewhere, and defined disabled people as people with something to contribute, who had the right to both give to and take from society. This idea was the foundation for a high profile disability movement and was an influential force for change, leading to the implementation of the Disability Discrimination Act (DDA) 1995, and later to the creation of the Disability Rights Commission (DRC), to enforce the Act.

Today, society is subject to many cultural influences. Each of the three attitudes described above is still present, both among service providers and disabled people themselves. Change is slow, but it doesn't go backwards. The new view of disabled people as valuable citizens with equal rights, who make their own life decisions and choices, continues to gain ground and shows disabled people as part of society and influential on its progress.

Disabled people can contribute on all levels – by saying what they want from services, working for organisations, suggesting change, passing on recommendations, swelling visitor numbers. The culture of social inclusion recognises that disabled people exist, meets their needs and creates a space where they can contribute.

1 Who disabled people are

As a starting point, many people ask “How many are there?” Statistics are risky, because they can be made to say almost anything. It is, however, fair to say that disability is present in more ways, and in different proportions, than many people realise.

Disability is more prevalent than most people believe because so many circumstances and conditions can lead to a temporary or permanent state of disability. It is hard to ask the right question to get a definition, because people are influenced by factors such as embarrassment, pride and political opinion when they identify as disabled. (See p.21 about self-definition).

Based on questions asked in the census, there are currently estimated to be 8.6 million disabled people in Britain (15 per cent). This includes over 6.8 million of working age (Labour Force Survey spring 2002).

Of disabled people, around 5 per cent use a wheelchair (in other words, 95 per cent do not). Of the 5 per cent, many do not use a wheelchair ‘full-time’ but only for occasional or long-distance use. The erroneous perception that a wheelchair user is the only ‘real’ disabled person has been reinforced by the adoption of the wheelchair badge as a symbol for disability.

The total UK adult population with any hearing impairment is 8.6 million (15 per cent) according to the Royal National Institute for Deaf People (RNID). This includes approximately 50,000–70,000 British Sign Language users.

According to the Royal National Institute for the Blind (RNIB) and Office for Population Censuses and Surveys (OPCS), there are 1.7 million people with a visual impairment. Over 90 per cent have some sight.

According to Deafblind UK, 23,000 people are deafblind but many more people, especially if they are over 65, have some degree of both sight and hearing loss.

The number of adults and children in the UK with learning disabilities is estimated at 1.2 million (2 per cent) according to Mencap.

People experiencing mental health issues at any one time total one in seven (14 per cent) according to Mind. This is based on figures from the OPCS, and from the Audit Commission.

Help the Aged gives the figure of 9 million people over the age of 65, or 15.7 per cent of the population. This influences the perception of disability statistics, because of the strong relationship between age and actual disability. 34 per cent of those aged 50 plus have a disability, compared with 10 per cent among 16–24 year-olds.

None of the above are necessarily mutually exclusive and many people have more than one impairment.

Characterising disability

It is important to look at what characterises the experience of being disabled, because this can create the conditions which categorise people socially and economically. Disability can arise for all kinds of reasons, and can lead to deprivation in various ways.

Disabled people are twice as likely as others to have no qualifications – education is not as consistently available, and is often at a lower academic standard than for others, while further and higher education, vocational training and work experience

can all be harder to access (Labour Force Survey spring 2002). Employment is an area of huge disadvantage. Disabled people are around five times as likely as non-disabled people to be out of work. People who become disabled while they are working have a one in six chance of losing their job while one third of all disabled people who find work are out of a job within a year (Labour Force Survey spring 2002).

Losing the opportunity to work, and being disadvantaged in job-seeking, can lead to low income and benefit dependency. Having said this, many disabled people find ways to fit their working lives around disability and, when adequately supported, generate income for themselves and economic benefit to society.

Disabled people exist in all roles, and their family or social position is a powerful argument in the business case for providing better services. A disabled parent, child, friend or partner may influence the choices non-disabled people make. The spending power of disabled people in the UK is estimated at £45–50 billion.

2 Rights for disabled people

Disabled people have long been campaigning for comprehensive and enforceable civil rights, arguing that previous legislation had failed to deliver as intended. The 1944 Disabled Persons (Employment) Act aimed to ensure that employers employed a certain number of disabled people. It asked disabled people to register to demonstrate eligibility for employment.

However, although many disabled people registered, few employers were prosecuted for failing to meet their obligations. The system became unenforceable, the concept 'registered disabled' being all that remained of the idea. Registration ceased in 1995 when the Disability Discrimination Act (DDA) came into force, and should no longer be used as a proof of eligibility for concessions.

One other legacy from this legislation was the conviction among campaigners that legislation without enforcement would be toothless. This formed part of the case leading to the establishment of the Disability Rights Commission (DRC) (see below).

The DDA was enacted in 1995, with an implementation programme which extends to 2004. For the first time in UK legislation, it introduces measures aimed at ending discrimination. It establishes the right of access to goods, services and facilities and puts an anticipatory duty on service providers to know the needs of disabled people and how they can be met.

The DDA does not provide full civil rights, but it was significantly strengthened by the creation of the DRC – with similar enforcement powers to those of other commissions. The DRC also plays an advisory role and has the power to initiate enquiries into the DDA's implementation.

Some disabled individuals have embraced the idea that they have rights, but are not well-informed about how far these rights extend, or in what situations they are applicable. One reason for informing yourself about the DDA is to be able to judge when you are asked to do something which the law does not require.

Your duties under the law

The Disability Discrimination Act (DDA) covers the areas of employment, access to goods, facilities and services and the management of land and property.

Since December 1996 it has been unlawful for employers to treat disabled people less favourably than other people for a reason related to their disability. Employers have had to make reasonable adjustments so that disabled people are not disadvantaged.

Since October 1999 it has become unlawful for service providers to refuse to serve someone for a reason related to disability, to offer a service on different terms, or to provide a service of a lower standard. Service providers have to make reasonable adjustments so that disabled people can access their services. They have to review policies, practices and procedures and, where a physical barrier exists, they have to provide a reasonable alternative to make service available.

From 2004 service providers will have to make changes to physical features so that disabled people can use their services. (For more information on the DDA see Guide 5.)

Changing legislation

Within the disability movement, overseas examples are seen as indicators of the changes to come in Britain. The momentum for civil rights of disabled people in the UK was in part inspired by disability legislation in the US (Americans with Disabilities Act). The US developed this legislation in the aftermath of the Vietnam war, to support the social inclusion of veterans. Australia also now has the Australians with Disabilities Act and, in a ground-breaking case, their courts found the Olympic Games of Sydney guilty of denying blind people access to its website.

European policy will have impact on the development of disability rights in the UK. The European Employment Directive 2000/78/EC (2000), means that provision under the DDA will extend to all employers from 2004. The European Disability Forum and the Disability Rights Commission call for a European Union Directive on rights of access to goods to be passed in 2003. The Council of Europe is considering recognition of sign language as a minority language, as the Greater London Authority has done.

Discrimination claims not recognised by UK courts could be appealed in European Courts under the Human Rights Act. The European Union Treaty Article 13, which recognises the need to combat discrimination against disabled people, provides stimulus for a campaign for full civil rights of disabled people.

The idea of 'community'

One of the difficulties experienced when trying to make contact with disabled people is the perception that there is a single disability community.

Unlike many other minority communities (including Deaf culture) there is no real disability community. Discrete communities do exist, because of activists and people from impairment groups who may choose to socialise together, but the world of disability is varied and non-homogenous.

Disabled people have experiences in common but many do not choose to share these as a cultural dimension. Disabled people may also gravitate towards certain services through necessity (health and social services, occupational therapy, employment services or benefits) but it is wrong to see these as natural or chosen identities.

Instead, it should be assumed that disabled people are present in all roles and social situations. They may have cultural identities based on ethnicity, social background, religion, interest or regional identity. A disabled person is as likely to be a member of a historical society, a researcher in a reference library or a student on a fine art course as they are to come to a touch tour, sign interpreted talk or community consultation.

The term 'the disability community' could be used as a form of wording in a project description, but the very definition itself does not identify this target group.

3 How disabled people view themselves

By the associations disabled people choose, they position themselves in the world of disability. Any disabled person could belong to one or more of the spheres described below, perhaps at different times finding different areas more in sympathy with their feelings on a particular issue.

Politics and rights

A comparatively recent phenomenon is the birth of disability politics. The disability movement has a number of faces: the face of protest and demonstration – activists who block transport and demonstrate in city centres; or the network of Disability Arts, where creative means are used to express identity.

There can be conflict between disabled people who have differing views on the role of charities and fundraising, some showing active antipathy to ideas of charity and benevolence.

The rights movement has also given rise to the idea that organisations serving disabled people should be disabled-led – their board, management and staff predominantly disabled people. Linking these organisations is the British Council of Disabled People (BCODP), which represents only those organisations who have more than 50 per cent control in the hands of disabled people.

There are other national organisations such as the Royal Association for Disability and Rehabilitation (RADAR) and the Trade Union Disability Alliance (TUDA), who focus on the reinforcement of rights. The provision of information and services is one of the main roles of national disability organisations.

Every town, district or region has its coalitions, access groups or other disability organisations. These vary in their philosophies and mission, some championing disability rights in various contexts. Every disabled person has experienced a shift in their perception of what they are entitled to, as a result of the changing culture in Britain. They are now more likely to see themselves as customers with the opportunity to choose what they want to do. This could show as higher numbers of disabled customers choosing to visit in families or pairs, or as people being more assertive when they find facilities lacking.

Companionship and support

Disabled people vary in shades of opinion, just as everyone does. There are many organisations which bring disabled people together for peer support or companionship. Impairment-specific groups (like stroke clubs or societies for visually impaired people) may be social gatherings, and other groups exist for fundraising and carer support.

Some of these organisations may have a developing role as advocates, or are perhaps becoming disabled-led, but many have little to do with protest, focusing instead on the day-to-day experience of a specific illness or condition.

Deaf culture

The Deaf community is a cultural and linguistic minority, which includes people who were born Deaf, or were deafened before beginning to speak, who may have Deaf parents and whose first language is British Sign Language (BSL). People who identify in this way do not consider themselves to be disabled, but as members of a specific community, describing themselves as Deaf with a capital 'D'.

A shared history (one of exclusion by the hearing world) and language, together with education for many at the same schools, creates a strong bond between members of this community. They will travel long distances to meet other Deaf people and often form lifelong relationships within the Deaf community.

Use of the services provided in museums, libraries and archives has not traditionally been part of the culture of Deaf people, who have tended until recently to use Deaf clubs and organisations as their main information and culture resource. This has begun to change, with efforts by Deaf people to educate others about their culture, more awareness among hearing people, better access to education, more interpreter support and wider use of technology.

Fewer young people now use Deaf clubs, often preferring to meet in pubs and sporting venues. Increasingly, they have expectations that a range of other services should be accessible to them.

For more information about Deaf culture, make contact with the British Deaf Association (BDA). A report on Deaf audiences in museums has recently been published by London-based consultancy Deafworks (see p.27).

British Sign Language

British Sign Language (BSL) is the first or preferred language of 50,000–70,000 people in the UK, and is more widely used than Welsh or Gaelic. A campaign for official government recognition of BSL continues. It is recognised by the Greater London Authority as a minority language. Since this is the first or preferred language of Deaf people, written English interpretations may be of limited value, and other visual interpretations more useful.

Both Deaf children and hearing children of Deaf parents have the potential to be bilingual in BSL and English. Deaf people in other cultural and ethnic groups will have their own Sign Languages.

BSL is a true language with its own grammar and syntax and is now one of the most popular subjects in adult education. Its continued vibrancy is a testament to the efforts of Deaf people to preserve and publicise their own language over the years since it was banned from use in educational settings in 1888. The Deaf community holds the view that this ban effectively oppressed them for most of the next century.

Social/medical models

Two opposing models of disability have been identified by the disability movement.

The 'medical model', now considered outmoded, identifies disability as an illness or condition affecting an individual, and with the onus of dealing with the consequences on that individual. It locates blame or responsibility around the person with the disability, leaving them to manage solutions.

The newer 'social model' identifies barriers within society which create disability for individuals. The barriers can be physical, organisational and attitudinal. The responsibility for solving or removing barriers is shared by all those involved in any situation or interaction. Resource and other national bodies including the Arts Council have adopted the social model.

A simple example, often quoted, is that the medical model would say a person is unable to climb stairs because they have a disability which means they have to use a wheelchair, while the social model would say that a wheelchair user is disabled by the flight of stairs which bars their entry to the building.

Defining disability

Defining disability is an issue which has taxed those who draft legislation, and which has a knock-on effect on everyone's expectations of disabled people.

There are times when there is a need to define disabled people – the 1991 census, for example, contained a question about long term illness or disability, designed to quantify the number of disabled people in society. Previous laws (see under Rights for Disabled People on p.11) introduced 'registration' as a way of certifying people as disabled, so that they would qualify for employment advantages.

While there are occasions when it is necessary to establish whether a person is disabled, there is seldom a need to find out how. It should be enough for people to answer a simple yes or no question, and not give further details or the name of an impairment. Before asking about disability in your customers, you need to be clear why you need to know.

Equal opportunities monitoring forms can ask about disability, preferably by saying "Are you disabled? Yes/No." The reason for this is to ascertain whether the opportunity (for employment, say) is being made fairly available. On other occasions, you may ask for proof of disability, in order to be sure that people are eligible for concessions (registration as proof no longer exists).

In service provision terms, however, the only significant reason for asking the question is to find out what people need. Asking a question like "Do you have any access needs?" should be enough. This approach uses the social model of examining possible barriers, rather than the medical model of naming syndromes and impairments.

Self-definition as a choice

In reality, there are many more people who are disabled than who call themselves disabled. There are many reasons for people choosing not to call themselves disabled – they may have acquired disability late in life, and have already defined it in negative terms, making them slow to accept the definition. People who acquire impairments linked with ageing are likely to fall into this category. The 'culture' of disability will be meaningless to this group, and they are unlikely to respond to messages targeted at disabled people.

Other people who do not identify as disabled are those who strive to be fully integrated, influenced by a social history when it was hard to integrate without 'keeping up with' others. For these people, there was no perceived advantage to taking on the definition of disability, and plenty of disadvantages (discrimination often followed if you identified yourself as a disabled person).

However people define themselves, they have a right to their choice. You may perceive that people have a disability, an impairment or a need, but you may not insist on their calling it by the name that you choose. The social model is particularly useful here, because it enables you to remove barriers, without having to point at people who need the improved access.

4 Everyday experiences

However disabled people define themselves, they are influenced by experiences which do not necessarily form part of everyone's lives. All the social and economic factors outlined above contribute to their experiences, which in turn shape their expectations.

Institutional culture

Day centres, residential homes and sheltered workplaces are aspects of life experienced by many disabled people. While it is a benefit and a necessity to enable disabled people to be supported and to reduce isolation, institutional culture creates certain types of behaviour. This can include being passive and uncomplaining (for example, saying that everything is fine when it isn't) and being shy about making choices between different experiences.

Physical access

It is impossible to discuss disability without touching on this subject. Later Guides will look at ways in which physical barriers can be obviated, or their impact reduced. But service providers should also consider how the existence of physical barriers has shaped the expectations of disabled people, making them distrustful of experiences, say, in older buildings.

Representation

This issue is becoming more significant. Do your displays and materials indicate an expectation that disabled people will be among your customers? Often disabled people are implicitly made to feel 'other'. A good example is when, in a library, all material about disability appears under the category 'health' and never under search words such as 'arts' and 'politics'.

Education

This is another area where disabled people have different experiences. In special school education, qualifications may not be ranked highly, while social and survival skills may only be exercised within a small peer group, rather than in wider society. This can lead to job applicants being poorly qualified and having to repeat time after leaving school to gain exam passes. In mainstream education, students may struggle to gain all the support they need, which can make it harder for them to keep up with lessons and also lead to poor qualifications.

British Sign Language was banned from use in educational settings in 1888. For most of the next century this ban persisted and resulted in Deaf young people leaving school with reading ages of less than eight years and no qualifications – the result of not using a natural language and of the weight given to the teaching of speech. Until very recently Deaf people were also barred from entering the teaching profession even to teach Deaf children.

Gaining information

This can be harder for disabled people for many reasons (see Guide 6, Inclusive Information, for guidance on information provision). Gatekeepers, who could be care workers, disability agencies or teachers, may have their own perspective or role restrictions. Where limited perspectives exist in gatekeepers, disabled people don't get the information which is sent to them. Predicting these obstacles could help you understand the ways in which information can get blocked.

Conclusion

There are many ways to meet the needs of disabled people. One of the aims of this portfolio is to shift the focus from intransigent and expensive building adaptation issues to changes of behaviour, routine, policy and attitude by all the organisation's staff and volunteers. By doing this, as well as by paying attention to manageable physical issues, you can improve the experience of disabled visitors and employees.

This Guide shows how changed attitudes and better knowledge could enable organisations to recognise, analyse and remove the barriers which disabled people face in their everyday lives. The portfolio is intended to be your guide in this changed way of thinking. You can expect future Guides to be full of advice as well as explanation, giving the information you need to develop inclusive services and practices. They are based on best available information from a variety of sources, presenting the information in a way relevant to your practice. The selection of topics was based on information you said you needed to improve your service to disabled people during the Resource survey on access for disabled people in 2001.

Further information

British Council of Disabled People (BCODP)

Tel: 01332 295551

Textphone: 01322 295581

Email: general@bcodp.org.uk

www.bcodp.org.uk

British Deaf Association

Tel/textphone: 020 7588 3529

Email: helpline@bda.org.uk

www.bda.org.uk

Deafblind UK

Tel/textphone: 01733 358100

www.deafblind.org.uk

Disability Arts Forum London

Tel: 020 7916 4202

Textphone: 020 7691 4201

www.ldaf.net

Disability Rights Commission

Tel: 08457 622633

Textphone: 08457 622644

Email: enquiry@drc-gb.org

www.drc-gb.org

European Disability Forum

Email: info@edf-feph.org

www.edf-feph.org

Government site

Email: Enquiry-disability@dwp.gsi.gov.uk

www.disability.gov.uk

Help the Aged

Tel: 020 7278 1114

www.helptheaged.org.uk

Mencap

Tel: 020 7454 0454

www.mencap.org.uk

Mind

Tel: 020 8519 2122

www.mind.org.uk

National Disability Arts Forum

Tel: 0191 261 1628

Textphone: 0191 261 2237

www.ndaf.org

Resource

Tel: 020 7273 1444

www.resource.gov.uk/action/learnacc/00access.asp

Royal Association for Disability and Rehabilitation (RADAR)

Tel: 020 7250 3222

Textphone: 020 7250 4119

www.radar.org.uk

Royal National Institute of the Blind (RNIB)

Tel: 020 7388 1266

www.rnib.org.uk

Royal National Institute for Deaf People

Tel: 0808 808 0123

Textphone: 0808 808 9000

www.rnid.org.uk

Trade Union Disability Alliance

Fax: 01273 704875

tudamail@aol.com

Deaf Culture websites

www.bbc.co.uk/seehear

www.deaflinks.info

www.deafclub.co.uk

Publications

*Buried in the Footnotes: the absence of disabled people
in the collective imagery of our past*

Annie Delin, in *Museums, Society, Inequality*, Ed Richard Sandell,
Routledge 2002.

*Access for deaf people to museums and galleries: a review
of good practice in London*

Deafworks 2001

Tel: 020 7689 0033

Textphone: 020 7689 1048

www.deafworks.co.uk

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- 3 Training for Equality
- 4 Audits
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- 6 Inclusive Information
- 7 Using Technology
- 8 Access on a Shoestring
- 9 Accessible Environments
- 10 Outreach and Partnerships
- 11 Consulting Disabled People
- 12 Employment at Every Level

The **Disability Portfolio** is a collection of 12 guides on how best to meet the needs of disabled people as users and staff in museums, archives and libraries. It gives invaluable advice, information and guidance to help overcome barriers and follow good practice.

The Portfolio is available in 12 point clear print or 15 point large print formats, braille, audio cassette and on the website. Please contact 020 7273 1458 or info@resource.gov.uk

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