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## **Rights and Responsibilities:**

The Disability Discrimination Act (1995) and Adults with Learning Disabilities

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#### In memoriam

This report is dedicated to the late Rachel Sherratt, who contributed to this study and was a committed advocate for the rights of people with learning disabilities.

## Acknowledgements

We are grateful to the Baily Thomas Trust for funding this research. Our sincere thanks go to everyone who took part in focus groups and interviews, for giving up their valuable time and sharing their views and experiences. We benefited greatly from the advice and guidance of our Project Advisory Group:

- John Clarke, Frances Cullen and Mark McGroarty (self-advocates, Quality Action Group, Stirling)
- Helen Eastman, Advocacy Worker, Quality Action Group, Stirling
- Jane Mackenzie (Corporate Policy Officer, Disability Equality, Glasgow City Council)
- Professor Alan Roulstone (De Montfort University, Leicester)
- Lisa Shine (former Policy Officer, Disability Rights Commission Scotland) member of the group in 2007
- Martin Hayward, (Policy Team Leader, Equality and Human Right Commission), who joined us in 2008
- Lynn Welsh (Head of Legal Affairs, Disability Rights Commission Scotland, then Head of Strategic Litigation Scotland, Equality and Human Rights Commission)

Mark Shrimpton (formerly Assistant Director, Legal and Operations Team, Disability Rights Commission) kindly assisted with access for the case studies.

June Watson worked part-time on the study from January-May 2007: we are grateful for her contribution. Mark McGroarty, Frances Cullen and John Clarke cofacilitated focus groups with people with learning disabilities, supported by Rachel Sherratt. Dot Kirkham provided transcribing services, Archie Williams designed the accessible summary while Alexis Merry provided administrative support.

## A note on terminology

We asked members of the Quality Action Group if we should refer to 'people with learning disabilities', 'people with learning difficulties' or some other term in this report. The group advised that either term is acceptable. We decided to use 'people with learning disabilities' as that term is most widely used in the UK. However we apologise if this causes offence to anyone.

Because the study is broadly based on the social model of disability, we refer to 'disabled people' rather than 'people with disabilities' and to 'impairments' rather than 'disabilities'.

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#### 1.0 EXECUTIVE SUMMARY

#### 1.1 Introduction

The purpose of this research is to examine Part III (access to goods, facilities and services) of the Disability Discrimination Act (DDA) 1995 in relation to people with learning disabilities. Very little previous research has been done on this topic. The study aims, firstly, to explore how far people with learning disabilities, family carers and service providers are aware of their rights and responsibilities under the Act; secondly, to examine what legal action has been taken by people with learning disabilities and thirdly, to identify any barriers associated with the Act and how these might be overcome.

To address these aims, a literature search was conducted, five focus groups were carried out with people with learning disabilities and three with family carers. Interviews took place with six disability organisations and 14 service providers, such as a leading supermarket, sports club, telephone company and GP umbrella organisation. Two legal case studies were also conducted.

## 1.2 Knowledge and awareness of the DDA 1995

Knowledge of the DDA and awareness of rights and responsibilities was low among most people with learning disabilities, family carers and service providers. There were also some misunderstandings of the Act. Organisations of and for people with learning disabilities were better informed, some acting as a source of advice and information for other agencies.

However, some service providers had a strategic awareness of their responsibilities and at least two service provision 'umbrella organisations' played an important role in cascading information and advice to members or linked agencies. A bowling alley and a museum umbrella organisation, for example, had taken practical steps to promote inclusive accessible services.

## 1.3 Understanding discrimination

People with learning disabilities tended to understand discrimination in terms of unfair treatment. Many felt a strong sense of injustice about the lack of respect, and in some cases harassment, which they experienced on a regular basis. They wanted to be treated with the *same* respect, enjoy the *same* rights and opportunities and be able to use the *same* facilities as everyone else. This requires certain *differences* or adjustments in the way services are delivered. Family carers were more likely to equate discrimination with poor standards of care in health and social care services. Some felt *they* were discriminated against.

Disability organisations and service providers between them identified six types of unfair treatment (not all of which are 'illegal') – prejudiced attitudes and behaviour

towards people with learning disabilities, making assumptions about or decisions on behalf of a person, inaccessible information, lack of assistance in shops and other services, prevention of access to services and low awareness or understanding of people with learning disabilities. Overall, most service providers were relatively unaware of what constitutes discrimination against people with learning disabilities. They recognised that lack of access to services was discriminatory but had limited understanding of how to facilitate it.

## 1.4 The provision of goods, facilities and services

When asked about their experiences of using services, people with learning disabilities said they generally found services, such as shops, cafes and sports centres, reasonably helpful. A few staff were singled out for particular praise. Some people always used the same services, such as a pub or taxi company, where they were well known and well treated. However, this reduced their choice of services.

At the same time, there were reports of people being treated with a lack of courtesy and respect. Problems had been experienced with staff attitudes, the attitudes and behaviour of other customers, inflexible application of rules (especially by some banks), inaccessible information and facilities and insufficient support for communication.

The reasonable adjustments made by service providers were heavily skewed towards facilitating physical access. Most services offered only one or two adjustments for people with learning disabilities. These included producing information in accessible formats, providing assistance (for example, the supermarket could provide a personal shopper), accommodating service delivery to individual requirements (for instance, the bowling alley helped with scoring and finding balls of the correct weight), providing 'special' opportunities (although some of these were segregated activities) and promoting positive attitudes. A few organisations were conducting research to better inform their work.

## 1.5 Experiences of discrimination

When asked if they had ever been treated unfairly in services, several participants with learning disabilities recounted personal experiences of what they considered to be direct discrimination by service providers. These included being refused service in a pub, being prevented from using a swimming pool and a bank threatening to withdraw loan facilities, which had been operating smoothly for 12 years, when it discovered the borrower had a mild learning disability. Most people had not actively challenged such incidents. However, a few individuals, who tended to be those active in disability organisations, had protested. Family carers were unlikely to complain, believing it would be ineffectual or could even lead to withdrawal of support. The emotional impact of being unfairly treated should not be under-estimated.

Very few cases involving people with learning disabilities under Part III of the Act have gone to court or mediation in the UK, and none in Scotland. Suggested reasons for this included lack of advocacy support, a failure on the part of some advice agencies to identify disability discrimination and the fact that individuals are responsible for taking cases to court, a time consuming and costly process. Acting as a witness in court is likely to be intimidating for a person with learning disabilities while the legal requirement to 'prove' the presence of impairment by satisfying a medical definition of disability does not help.

The two legal cases studied, one settled in court and one by mediation, were supported by the Disability Rights Commission (DRC) and either an advocate or an MP. Both were won by the claimants. Each case was slow to progress, requiring considerable perseverance on the part of the claimants. In the court case, the claimant believed the experience was unlikely to have much impact on the defendant's (a tattooist) attitude towards disabled people or equality issues. In the mediation case, there was evidence that the defendant (a local council) acted on advice about improving accessibility for people with learning disabilities.

#### 1.6 Conclusions and recommendations

The findings show an urgent need for wide scale information provision, education and consciousness-raising, along with stronger enforcement and penalties to improve compliance. Legislative changes are also required, along with more advisory and better legal support for people with learning disabilities. A range of recommendations are made, targeted at government, Equality and Human Rights Commission (EHRC), service providers including businesses, local authorities and the voluntary sector as well as organisations of and for people with learning disabilities.

The definition of disability within the DDA should be amended to one broadly based on the social model of disability and cases brought forward under Part III of the Act should go to tribunals rather than court.

Two campaigns are recommended: firstly, a major public awareness campaign, funded and organised by Government, promoting positive attitudes towards people with learning disabilities; secondly, an initiative targeted at service providers, led by the Equalities and Human Rights Commission, focusing on ways to improve access for people with learning disabilities, highlighting both the benefits to business of the 'disability pound' and the relatively low costs involved. Disability organisations should have a key role in these campaigns but this should be complementary to, not a substitute for, the efforts of other responsible agencies.

Statutory and voluntary organisations working with people with learning disabilities and /or family carers should actively educate people about their rights under the Act.

A Disabled People's Advocacy Service should be set up, funded by Government but run by the voluntary sector, to promote access to services, particularly legal services.

Enforcement strategies regarding DDA compliance should become part of the work of mainstream inspection agencies. There should be stronger penalties for offenders, for example, removal of confidentiality clauses governing out of court settlements.

#### 2.0 INTRODUCTION

This study is about the Disability Discrimination Act (DDA 1995 (HMSO 1995), particularly the rights it gives to people with learning disabilities and the responsibilities it places on service providers. The focus is on Part III of the Act which deals with access to goods, facilities and services. The research, completed in March 2008, was funded by the Baily Thomas Trust and conducted at the University of Strathclyde. In 2005, a meeting took place with the Quality Action Group (QAG), a self-advocacy group in Stirling, to discuss research priorities. One member identified discrimination and unfair treatment as key issues in the day to day lives of people with learning disabilities — thus, the idea for this study. The QAG was closely involved in the research. Three members received training in research skills, co-facilitated the focus groups with people with learning disabilities and, with support from the QAG Advocacy Worker, sat on the Project Advisory Group.

The Introduction to this report sets out the policy and research context and the study's aims and methods. Next we present the research findings in three main sections - knowledge and awareness of the DDA 1995 and understanding discrimination, the provision of goods, facilities and services, and experiences of discrimination, including two legal case studies. The report ends by drawing out conclusions and recommendations for policy and practice.

In addition to this report, an accessible booklet and a podcast and CD of that booklet will be available.

## 2.1 The Policy Context

It is well known that people with learning disabilities face discrimination and unfair treatment in many areas of their lives. The DDA 1995 set out rights for disabled people in five areas - access to goods, facilities and services, buying or renting land or property, employment, education and transport. Within the Act, an individual is defined as disabled 'if he has a physical or mental impairment which has a substantial and long-term adverse effect on his ability to carry out normal day-to-day activities' (DDA 1995, Part I:S1). 'Discrimination' occurs when a disabled person is treated less favourably than others because of impairment and this treatment cannot be justified, or when an organisation fails to make a 'reasonable adjustment' to accommodate a disabled person and that failure cannot be justified. 'Reasonable adjustments' comprise a series of duties falling into three areas: first, changing practices, policies and procedures; secondly, providing auxiliary aids and services and, thirdly, overcoming a physical feature by removing, altering or avoiding it, or by providing the service through alternative means (DRC, 2002). 'Justified discrimination' may be permissible in limited circumstances on health and safety grounds but only if the service provider 'reasonably' believes that such treatment is necessary.

Section 19 (1), Part III (Goods, Facilities and Services) of the DDA 1995 states:

It is unlawful for a provider of services to discriminate against a disabled person –

(a) in refusing to provide, or deliberately not providing, to the disabled person any service which he provides, or is prepared to provide, to members of the public'

## Section 20 (1) further states that:

- (1) ... a provider of services discriminates against a disabled person if -
- (a) for a reason which relates to the disabled person's disability, he treats him less favourably than he treats or would treat others to whom that reason does not or would not apply; and
- (b) he cannot show that the treatment in question is justified.

Less favourable treatment by the service provider can only be justified if 'it is reasonable, in all the circumstances of the case, for him to hold that opinion' (Section 20 (3)). This would include as outlined in Section 20 (4):

- (a) ... the treatment is necessary in order not to endanger the health or safety of any person (which may include that of the disabled person);
- (b) ... the disabled person is incapable of entering into an enforceable agreement, or of giving informed consent, and for that reason the treatment is reasonable in that case;

The DDA 1995 has been added to by later legislation. There are two instruments which may be of particular significance for people with learning disabilities. The Disability Discrimination Act 1995 (Amendment) Regulations Act 2003 outlawed harassment of disabled people, meaning unwanted conduct directed at an individual because of their impairment,

which has the purpose or effect of - (a) violating the disabled person's dignity, or (b) creating an intimidating, hostile, degrading, humiliating or offensive environment for him (Part II, S3b).

The Disability Discrimination Act 2005 introduced the Disability Equality Duty, requiring all public sector authorities to actively promote disability equality. This Act sets out a general duty, whereby public bodies must have due regard to the need to eliminate harassment, promote positive attitudes towards disabled people, encourage participation by disabled people in public life, promote equality of opportunity and take steps to meet disabled people's needs, even if this requires Rights and Responsibilities:

'more favourable' treatment. In addition, from December 2006, most public authorities have a specific duty to provide a Disability Equality Scheme.

In 2000 the Disability Rights Commission (DRC) was set up to prevent discrimination and secure rights for disabled people. Its activities included giving information and advice to disabled people, employers and service providers, supporting legal cases to test the limits of law and providing an independent conciliation service. The latter was a 'confidential and fully accessible free dispute resolution service for those who might otherwise bring litigation under Parts III and IV of the DDA' (DRC 2007). The DRC published a series of guidance relating to the legislation, including several about the provision of goods, facilities and services (DRC, 2002, 2004, 2006a and 2007). In October 2007, the DRC's responsibilities passed to the Equality and Human Rights Commission (EHRC).

#### 2.2 The Research Context

Very little research has been carried out about the implications or impact of the DDA on people with learning disabilities. There has been a good deal of research about other aspects of the Act, particularly relating to employment, and several studies about Part III, but the latter have mainly focused on people with physical and/or sensory impairments. There is some evidence that 'disability' is commonly equated with physical impairment (Grewal et al, 2002) and that 'adjustments' have been largely limited to physical adaptations (Stoneham 2006, Leverton 2006, Meager et al 2002) with many providers wrongly assuming their services are then fully accessible to all customers (Stuart, Watson and Williams 2002). Meager et al (2002) found that service providers are often unaware of having disabled customers and lack any systematic means of identifying them. This is likely to be particularly true of people with invisible impairments including many forms of learning disability.

A number of commentators have critiqued aspects of the DDA. It has been argued that the medical model underlying the definition of disability, and the need for individuals going to court to 'prove' they have an impairment, is detrimental to achieving disability equality (Woodhams and Corby 2003). These authors identify several problems relating to the requirement for medical evidence, including differences between legal and managerial definitions, the focus on negative aspects of disability and the particular difficulties for people with invisible impairments. Under the DDA, the onus falls on individual disabled people to take up cases of alleged discrimination, a process which, apart from being costly, time-consuming and stressful (Gooding, 2000), is likely to pose particular difficulties for those with learning disabilities. Recent legislation allowing for 'special measures' to support the evidence of vulnerable witnesses in criminal and civil proceedings may help. Findings of a pilot project supporting people with learning disabilities to

<sup>&</sup>lt;sup>1</sup> See The Vulnerable Witnesses (Scotland) Act 2004

give evidence or act as witnesses in court in England (in cases of abuse) are reported by Fareed (2006).

The DRC supported some people to take cases to court, by paying fees and providing legal advice, a function continued by the EHRC, although Roulstone (2003) was critical of the DRC's decision to set a limit on the number of cases it would represent at 75 per annum, which could be construed as quota justice. Such quota justice may fail to respond to repeat or multiple discrimination as limited funding has led to examplar cases of novel forms or contexts for discrimination. Few cases involving individuals with learning disabilities have gone to court. Leverton (2002) examines the 53 known Part III claims issued up to 1 February 2001, noting that this number included only four people with learning disabilities (see p36. of this report for information about recent numbers).

## 2.3 Study Aims and Methods

The study was approved by the University of Strathclyde Ethics Committee. Its aims were:

- to explore knowledge and awareness of the Disability Discrimination Act 1995 among people with learning disabilities and service providers with responsibilities under the Act
- 2. to identify what action people with learning disabilities have taken (with support) in relation to mediation and litigation under Part III of the Act, and with what outcomes
- 3. to identify any particular barriers associated with the legislation or its implementation relating to people with learning disabilities and the provision of goods, facilities and services, and how these might be overcome
- 4. to make policy and practice proposals for improving awareness and implementation of the Act.

A literature search, focus groups, interviews and case studies were used to explore these aims.

Five focus groups were carried out with people with learning disabilities and, to include the experiences of people with profound multiple impairment, three focus groups were carried out with family carers. Focus groups explored people's awareness of their rights under the DDA and what action people had taken, or would consider taking, if they thought they were being treated unfairly by service providers. Between three and seven people took part in each group and sometimes supporters were also present.

The focus groups were arranged through organisations in Central Scotland, some with a UK, some with a Scottish-wide and others with a local remit. These were a self-advocacy organisation of people with learning disabilities, two information and campaigning organisations for people with learning disabilities, a tenants' group, a

social club and three agencies providing support for carers of disabled people, one specifically people with profound multiple impairment. Self advocates from the Quality Action Group co-facilitated the focus groups with people with learning disabilities. Accessible information sheets and consent forms were sent to each organisation in advance.

Semi-structured interviews were carried out with six disability organisations and 14 service providers. Of the 20 interviews, four were telephone interviews and 16 were carried out in person. Interviews were intended to explore first, how far social, recreational and retail organisations were aware of, and responding to, their responsibilities to people with learning disabilities under the DDA and, secondly, to identify any barriers in the process and how these might be tackled. An information sheet and consent form was sent to each agency, inviting nomination of a senior manager as a key informant. These respondents were all based in Scotland, although several represented UK wide organisations.

Disability organisations and service providers were selected on the basis of the *type* of facilities which participants in focus groups said they used or wished to use and on advice from the Project Advisory Group. Organisations involved in the study are listed below.

## Disability Organisations

- Four organisations of or for people with learning disabilities, including one for people with learning disabilities from black and ethnic minority backgrounds
- Two organisations of or for disabled people.

#### Service Providers

- Bowling Alley
- Telephone Company
- Supermarket
- Museum
- Job Seeking Service
- Legal Service
- Athletics Club
- Culture and Sport Organisation
- City Council Department of Planning and Regeneration
- Tourist Body (umbrella organisation)
- Hotel and Pub Body (umbrella organisation)
- General Practitioner (umbrella organisation)
- Sporting Body (umbrella organisation)
- Museum Body (umbrella organisation).

Interviews were also used to investigate two legal cases involving people with learning disabilities who had taken incidents of discrimination under Part III of the Act to mediation or court. Participants were recruited through the DRC Conciliation Rights and Responsibilities:

and Mediation Unit and the Legal Team. Both incidents had occurred in England and had been taken to court or mediation in England. (No such cases have gone to court in Scotland). For the first case study a group interview or discussion took place with the claimant, her mother, support workers and advocate. For the second, an interview was carried out with the claimant's 'litigation friend<sup>2</sup>'. Data were collected about the incidents and circumstances of discrimination, the process and events leading up to the court hearing or mediation, the court hearing or mediation meeting and the outcomes of each case.

With respondents' agreement, all interviews and focus groups were audio-taped. Data were then fully transcribed and analysed using an inductive approach.

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<sup>&</sup>lt;sup>2</sup> A litigation friend conducts legal proceedings on behalf of a person judged unable to do so, due to age or incapacity. S/he must act fairly and competently, in that person's interest, and have no personal interest in the claim.

#### 3.0 RESEARCH FINDINGS

## 3.1 Section One: Knowledge and Awareness of the DDA 1995

## People with learning disabilities

Most participants with learning disabilities said they had heard of the DDA 1995 although few knew much about it. Some were aware of the general principles or intentions of the Act, describing it as promoting rights and equality for people with learning disabilities. A few people had some familiarity with the Disability Equality Duty (although no-one referred to it as such) since reference was made to tackling issues such as name-calling, harassment and social exclusion. One participant with learning disabilities rightly said that this was intended to not take away from the Act but strengthen the Act:

We can [get] help from that Act and we're human beings like other people, no' dogs.

We've got to be treated equally, not, not just, we don't want to be treated differently from everybody else.

Similarly, an organisation for people with learning disabilities found that its members were often aware of the essence of the Act and its intention but not its name.

A few participants who had heard of the Act were misinformed, or misunderstood, aspects of it. A couple of participants in one group were not aware that an Act is law; that is, that it carries the force of law. They understood that laws have to be obeyed and that breaking the law is an offence which can be punished. However, they did not realise the legal significance of the term 'Act' which led to a belief that the DDA had no statutory force and thus, no prospect of being effective in changing service providers' behaviour or securing people's rights. Indeed, one of these people argued that discriminating against people with learning disabilities should be made illegal. One participant thought the DDA only applied to Scotland while another did not think the rights bestowed by the Act applied to her 'personally'. Participants in one group pointed out that a person with learning disabilities would need support and perhaps training to take up a case of alleged discrimination, although they were not sure who would offer such support nor whether legal aid would be available. One group suggested there should be an Easy Read version for people with learning disabilities – which there was, at that DRC time. website (see the http://83.137.212.42/sitearchive/DRC/easyread/index.html information on the EHRC website). Participants had heard about the Act through

<sup>&</sup>lt;sup>3</sup> One person suggested support might come from a 'named person' under the Mental Health (Care and Treatment)(Scotland) Act 2003, but this would not be relevant as the role of a named person is to represent an individual's interests in respect of mental health care and treatment.

various sources – at 'meetings', conferences, college, self-advocacy groups and voluntary organisations.

Another indication of a low level of awareness about their rights among people with learning disabilities is the fact that the DRC Helpline received very few calls about services, goods and facilities from this group. An organisation for people with learning disabilities and the DRC legal service suggested that training about rights often failed to reach people with learning disabilities because many are not connected to organisations of or for disabled people nor organisations of or for people with learning disabilities:

Organisations that are clued up will not always be working with people with learning disabilities.

#### Family carers

Carers appeared less well informed about the Act than participants with learning disabilities. Most admitted knowing little or nothing about it. Although they had been given information through carers' organisations and local authorities, the Act itself was an 'enormous document', hard to navigate, and they were fully occupied caring:

We don't have time to sit and read through all these things, we're carers...and at night when you've maybe got an hour to yourself you're so exhausted or tired that it's like reading gobbledygook.

Carers more familiar with the Act believed its main focus was on improving access to buildings and public spaces and thus more likely to benefit people with physical impairment rather than the majority of those with learning disabilities.

#### **Disability Organisations**

Not surprisingly, organisations of and for people with learning disabilities tended to know more about implications of the Act for people with learning disabilities than other disability organisations, and some were a source of information and advice for other agencies. They could offer training to service providers and advice to people with learning disabilities who wished to pursue an incident of unfair treatment, for example, by making a complaint to the company (but not by supporting people to take cases to court).

Organisations of and for people with learning disabilities were particularly knowledgeable about service providers' responsibilities under the Act. For example, one participant commented that the 1995 Act focused on physical access while the 2005 Act emphasised issues of more relevance to people with learning disabilities and those with mental health needs. He explained, for example, that the new 2005 Act had extended the earlier one:

There is a lot about public transport operators [in the new Act]. [They] have got to try and treat disabled people fairly and let them have seats, do not brush them off. Plus public transport staff have got to treat people nicely and not shout and a taxi driver's got to not pretend that the ramp's not working. ... it's to do with behavioural things like how public transport drivers and staff are behaving towards people with disabilities.

Of the two organisations for disabled people, one had a good level of knowledge about meeting responsibilities for people with learning disabilities and the other was less knowledgeable but highlighted that access to information was a key issue:

We don't specifically concentrate on people with learning difficulties. When we are challenging access we try and take into account everybody's needs so we try and promote the view that not everybody's the same and there are groups of people with learning difficulties that are members of panels but we don't specifically go out and highlight issues pertaining to them.

#### Service Providers

Most service providers reported that, not having read the Act, they knew very little about it:

In terms of what the Act actually says, I don't know if I could tell you.

They relied instead on policy documents, codes of practice and other forms of guidance to provide them with information about implementing and understanding the DDA. Most had found out about the DDA 1995, and subsequent Acts or amendments, through information provided by, for example, their organisation's human resource department or email bulletins (particularly from the DRC) which they subscribed to. A small number of individuals reported actively seeking advice about their responsibilities under the Act, most commonly by searching the internet. Reference was also made to legal advice sought in order to ensure that their organisation would not be in breach of the Act.

A number of service providers stated that training and consultation would be useful to help them find out more about the Act and their responsibilities. A few had engaged in these activities but generally consultation groups did not include people with learning disabilities. More often physical access issues were the focus of training and consultation.

We explored the flow of information in a little more detail for two sectors (Museum and Sports industries). It emerged that in the former, the museum umbrella organisation was viewed as a key resource, keeping museums up to date with new

information, practice ideas and changes to disability legislation relevant to particular services. The access manager from the museum umbrella organisation indicated that there was a database of members whom she could reach by email very quickly. The access manager also stated that she dealt with many queries about intellectual access which she responded to individually. The sports industry had a different approach. It was not the sports body that was responsible for passing information about disability to sports clubs but the athletics club. Queries were directed to the athletics club staff. Staff also ran a training programme about issues relating to people with a range of impairments, including learning disabilities, across all Scottish local authorities.

Limited time and financial resources prevented several service providers from seeking information or attending training. Examples included removal of government funding for GP training which made it *extremely difficult to organise a day training on DDA* and insufficient time to go through the wealth of information that organisations regularly received from different interest groups.

Thus, service providers had varying levels of knowledge and understanding of the Act and of their responsibilities to people with learning disabilities. All the organisations were aware of their duties in relation to physical access mainly for wheelchair users, though some reference was made to access for people with visual and hearing impairments. In some cases service providers' knowledge of the Act was limited to physical access. For example, the hotel and pub industry representative admitted that the industry's understanding of the Act was largely:

At the level of understanding wheelchair access and the problems that's going to cause for people who don't have it, whether they should have it and the costs involved in the implementation.

The GP participant stated that it was the responsibility of practice managers to make sure that surgeries complied:

Obviously we're aware of it, we have the basic knowledge of most GPs but we have management staff who basically have the responsibility from the point of functioning as a business and their job is to make sure we comply.

This view concurred with that of the Legal Service participant who believed service providers were aware of physical access issues mainly because of DRC's extensive campaign on this issue. She commented that they were less likely to know about issues affecting people with learning disabilities, in part because it was unlikely that there would be any recourse for service providers who did not improve services for people with learning disabilities.

[Service providers] just don't think about it. Very few of them will actively go out of their way to be hostile but they don't think about it particularly. They don't care about it particularly. And I think possibly those who do think about it, [think] it's not a group who ... would necessarily enforce their rights.

One role of a new member of staff at City Planning and Regeneration was to ensure that race and disability equalities were:

central and integrated to everything that is done in delivery of services or goods into [the] public [sector] and to try to influence the private sector to be a good provider of services.

This respondent admitted that, prior to starting the post, he had thought the DDA only applied to employment. Since taking up the job, he had attended disability awareness training and Disability Advisory Group meetings through which he had become aware of issues relating to *mobility and poor vision* and understood that access issues also applied to people with learning disabilities but that *spotting them or identifying them is far more difficult*. The City Planning and Regeneration participant indicated that he was part of a team which was very knowledgeable about equality issues. It appears that on the one hand this service provider promoted equality issues by organising disability equality training for staff but on the other hand appointed a person with little or no experience of disability to a role where such experience was likely to be very helpful.

Other service providers had a more strategic awareness of their responsibilities under the 1995/2005 Acts. This included the tourist body and sporting umbrella agencies' representatives. They saw the purpose of these Acts in terms of establishing rights for disabled people. The tourist body commented:

[The legislation is about] establishing rights for people with a disability to equal treatment and it's a move towards outlawing discrimination which is really quite a change of emphasis. It's based on rights rather than provisions if [an organisation] can get round to it. It has changed the status of the legislative approach quite considerably. I think there is a real issue for our industry as a whole that that message has still got to get through.

One of the sporting body participants believed that *equitable delivery of sport* was essential in order to meet the national sporting strategy to 'increase participation and improve performance'. However, they were not aware of practical approaches that could be used to meet these strategic objectives. The sporting body had a facilities department which one representative saw as more knowledgeable about practice implications for disabled people, including those with learning disabilities, an area she felt was outwith her expertise.

A few service providers knew a little about meeting the needs of individuals with learning disabilities. They were generally aware of the intention of the Act at strategic level, and in addition could identify some reasonable adjustments that could improve access for people with learning disabilities. This included the Supermarket, Tourist Body, Telephone Company, Museum and Museum umbrella body.

Services for disabled people were aware of their responsibilities to people with learning disabilities under the Act. This included the DRC Legal Service, Sports Club, the Job Seeking Service and the organisation for Black and minority ethnic people. The mainstream Job Seeking service, for example, assisted prospective employees and employers with help and support to enable disabled people to work in their premises.

We do have an access to work team. So if someone is starting work and they need help and support in the workplace that's the route they would take the employer to get whatever it is, something to enhance the screen, a chair. We've got a work psychologist as part of our team, so if a customer was unsure about what kind of work they were able to do, we can get a work psychologist's assessment done for that person.

Two other participants were very well informed and aware of their responsibilities towards people with learning disabilities. These individuals, from the Bowling Alley and Museum umbrella organisation, strived to promote integrated, accessible services. The deputy manager for the Bowling Alley suggested that the Act was intended to ensure that everyone has [access to] the best facilities in the centre, that they can all use the facilities the same as everybody else. She stated that the Disability Act doesn't just cover wheelchair users, it's also other special needs people [sic] in terms of understanding what problems they face. By way of example, she raised the issue of emergency evacuation:

I was checking a meeting about our fire risk assessment and what to do in the event of an emergency evacuation. That made me think again, are we paying enough attention to people in the groups, they may be confused by the loud noise, they're unaware that something has gone on and start to panic.

It was personal interest, not company strategy, which motivated the deputy manager to develop an accessible service for people with learning disabilities. Having observed that relationships between staff and customers with learning disabilities were poor, she developed staff training courses about disability, capitalising on her previous experience of working with people with learning disabilities. However, she thought staff were not aware that this training was connected to the DDA (indicating it had not been part of the course).

The access department of the Museum umbrella organisation focused on addressing discrimination issues (in all areas) to improve access to museums. Within this access department the participant was employed to specifically explore ways in which to promote intellectual access. This participant was very aware of both the 1995 and 2005 Acts, had worked with people with learning disabilities and understood the implications of the Act for them.

It is about not just making the collections there for them but also for them to be part of it.

These results suggest that unless a service is specifically for disabled people then service providers are not likely to be well informed about the Act. Some organisations were aware of the intention of the Act but their knowledge about how to implement this was limited. Few organisations actively sought to provide a service which was easily accessible to people with learning disabilities.

## 3.1.1 Understanding Discrimination

#### Service Users

Participants with learning disabilities were asked if they were familiar with the term 'discrimination', while carers were asked what they understood by that word. Some of those with learning disabilities were unsure what it meant. Both those with learning disabilities and carers tended to describe discrimination in general terms, referring to people's human or civil rights, and the fact that people with learning disabilities are part of the community and should be included. Some talked about the need for buildings and transport to be physically accessible. In fact, when asked about discrimination in a general sense, all participants were, again, much more likely to refer to the unequal treatment of people with physical and sensory impairments, and particularly wheelchair users, rather than people with learning disabilities.

Several participants with learning disabilities pointed out that some actions or responses, which might at first glance be considered discriminatory, were not necessarily so – if those responses were applied to everyone for a good reason and not solely to people with learning disabilities because they had an impairment. For example, a shop assistant would not be able to help an individual when she was busy with other customers. The issue of being treated in the same – or different – ways to other people was a recurring theme. A couple of participants also talked about *why* discrimination might occur – unfamiliarity with people with learning disabilities who, until relatively recently, have not been particularly visible in the community, and a fear of difference:

I don't know if it's a kind o' a threat that we're different...but because it hasnae been a kind o' a norm that you get different people going into a pub or even a restaurant...there just seemed to be this 'because I'm different, we're going to treat you different'...you get people that maybe need support for feeding or to help them to drink or whatever and they [other customers] might find that very offensive but they have a right to be there... It doesn't matter what disability a person has, everybody's got a right to have access wherever they've got to go.

Similar points were made by carers who referred to the 'fear', 'stigma' and lack of understanding surrounding people with learning disabilities, coupled with the historical legacy of having been 'hidden away' in the past.

## Disability Organisations and Service Providers

Most service providers knew little about discrimination issues for people with learning disabilities, though some were able to offer one or two examples. Not surprisingly, disability organisations, particularly those of or for people with learning disabilities, were well informed. Between them, disability organisations identified six types of unfair treatment, outlined below. (Although they saw these as 'discrimination' it should be added that not all the examples given fall under the legal definition of this term). Some are discussed in more detail in Section III, 'Experiences of Discrimination'.

Prejudiced attitudes and behaviour towards people with learning disabilities Examples of negative attitudes and behaviour from organisations of people with learning difficulties included rude staff and customers.

Bus drivers and ticket people being rude, hostile, not letting people on the bus, sending people off the bus before their stop. Not sitting beside somebody in a bus.

The organisation for people with learning disabilities from a black and minority ethnic background stated that their members faced double discrimination. They faced racial discrimination in addition to disability discrimination.

A number of service providers identified poor attitudes as discriminatory. For example, the hotel and pub industry representative commented:

I think the discrimination, it's not whether you adhere to the law, it's a frame of mind and it's an attitude and that to me has always been more important than whether you've got a ramp. It's how people are treated, that to me is the point.

However, this participant did not appear to recognise that fair treatment should also include physical access for those who require it.

# Making assumptions and decisions on behalf of someone with learning disabilities

Organisations of people with learning disabilities stated that service providers and members of the general public made assumptions about people with learning disabilities. For example, one woman said that shop assistants had assumed that she was unable to select the correct size of clothing when she was in fact looking for a gift:

I know that people look at me if I'm actually looking at the size that I'm not and the reason that sometimes I look at the size I'm not is ... Christmas presents and they'll say she cannae be that size, I've heard them, she's no' that size, what's she looking for?

The tourist body believed that making assumptions and decisions was discriminatory:

I think that more widespread discrimination is less in your face, it's where there is just the assumption that people with learning disabilities are not customers that are going to be taking decisions or are working with us in their own right and that's again back to speaking to the carer rather than the person.

## Poor provision of information

Menus are so fancy people don't understand what's on the menu.

Poor provision of information was identified as a form of discrimination by service providers and disability organisations. The former generally understood accessible information to mean larger font sizes. Disability organisations and the DRC Legal Service participant identified more complex issues. For example, one organisation for people with learning disabilities stated that complaint forms and contracts were discriminatory because they were written in language which was inaccessible to people with learning disabilities. As a result, people may sign contracts which they do not fully understand.

#### Lack of assistance

Disability organisations considered poor assistance to be discriminatory. This occurred in a range of organisations including shops and leisure centres and was not limited to mainstream services. One participant spoke of an incident where she had experienced poor service at an event for disabled people.

Everybody had gone through [the door] and I was the last one to go through ... and 'oh, this is not for the like of you, this is for disabled people' and I looked at her and said, 'I beg your pardon?' ... She knew she'd put her foot in it when she said it ... I mean it doesn't take much to ... just have a bit of courtesy just in case you might put your foot in it at some point.

#### Prevention of access to services

I think people are being discriminated when people say you can't do things and yes, [probably with more support you could.]

(Organisation of people with learning difficulties)

Disability organisations identified a range of mainstream services that people with learning disabilities had difficulty accessing, including financial services:

They don't even have a credit card. How many of them have got their own house? How many have got the mortgage?

Service providers often mentioned 'prevention' of service as discrimination. The tourist service was able to identify an example of discrimination where people with learning disabilities were not allowed to use the activity.

An activity provider...refused to allow people with Down's Syndrome to take part in the activity when it was really quite unreasonable. They were quite aware of their abilities and it was a safe environment but it was just definitely prejudice...we got involved because there was a complaint from the group organiser and we did eventually resolve it with an apology.

There is a distinction in the examples provided between deliberate denial of a service, as in the above example, and *failure to provide a reasonable service* where the service was inaccessible to individuals.

A concrete example of the latter was offered by the Bowling Alley. Despite striving to provide an integrated service, during the interview it occurred to this participant that a waiting service for drinks was not offered to groups of people with learning disabilities but was offered to other groups:

... just thinking of it, they probably don't get lane host attention because the lane host does bring drinks, and I could probably guarantee that they don't get offered that service. ... The regulars would be quite happy to shout about it if they didn't get it, whereas this group may not know they can or maybe it would occur to them that they could and they should be just as valued as anyone else.

Another example emerged from discussions with the GP who raised the issue of problems providing vaccinations, cervical smear tests and other preventative measures to people with learning disabilities. He commented on the lower than average uptake of smear tests among women with learning disabilities. The GP

did not cite this as an example of discrimination but related it more to individual characteristics:

Recently I was trying to give someone the flu vaccination who's got a learning disability and they became quite aggressive. That was particularly difficult so that's someone who ended up not getting it. And obviously trying to do a cervical smear on someone, that's just almost impossible or is impossible because it would be an assault almost to do it. So it's a difficult problem with some patients.

A recent inquiry into health inequalities by the DRC (2006b:1) found that that people with learning disabilities and those with mental ill-health did not have 'full and proper access to the primary health care services they need to promote their health and well-being.' However, a perception that because services are *available* to all, they are equally *accessible* to all seemed to be held by several respondents.

## Low awareness or understanding of people with learning disabilities

Disability organisations suggested that a lack of understanding of people with learning disabilities was discriminatory and led to unfair treatment, for example, if somebody makes a noise that everybody on a bus can hear, people would laugh at it. Poor understanding posed additional problems for people with learning disabilities from a Black and minority ethnic background. They faced lack of cultural awareness as well as lack of understanding in relation to their impairment.

Some disability organisations thought that people with learning disabilities often accepted poor behaviour and attitudes from service providers without comment and, indeed, came to expect this behaviour. If organisations obtain little or no feedback about unacceptable service and behaviours, this undoubtedly perpetuates discrimination:

Some people just accept what they get. It needs other people to tell them that it's not right. I think that it takes a lot of time for some people to say that they didn't like something. I think some people accept it.

It is fair to say that most (not all) organisations, other than those for and of people with learning disabilities and disabled people, are relatively unaware of what constitutes discrimination against people with learning disabilities. There seems to be wide recognition that preventing access to services is discriminatory but further findings, discussed in the next two sections, suggest that individuals are not likely to understand how to reduce discrimination in order that services can be accessed. The in depth understanding of organisations of people with learning disabilities suggests that they have a key role, as they are currently carrying out in other areas, in educating service providers about discrimination against people with learning disabilities.

# 3.2 SECTION TWO: THE PROVISION OF GOODS, FACILITIES AND SERVICES

## 3.2.1 Experiences of Using Services

#### Service Users

Participants were asked what services and facilities, such as shops, cafes and sports centres, they made use of, what they liked or disliked about these places and how helpful the staff were. This prompted a good deal of discussion with wide ranging experiences reported.

#### Staff attitudes

Participants with learning disabilities and carers described staff in many services as 'all right', 'okay' or 'generally helpful'. Carers with adult sons or daughters had seen improvements over the years; for example, shops were much more helpful nowadays. A few service providers were singled out for praise. For example, one man visiting a local leisure centre had been shown round by an attendant who explained how to access the changing room lockers. Another person having difficulty with his mobile phone took it to a shop where the assistant explained how it worked and then made sure the person could operate it himself. Participants had seen other people with learning disabilities hand over their purses to shop staff, so the latter could count out the money due. In some cases, staff had explained to the individual how the different coins added up. In contrast, there were other reports of shop staff expressing irritation at being asked to count out money, as if it were too much effort and, more generally, being impatient and disrespectful - 'cheeky', 'whispering about you when you're leaving', 'treating you like a child' and, in a sports centre, 'really stroppy' when one person took a while to count out his money. A number of participants with learning disabilities frequented services, for example a particular pub or taxi service, where they were 'regulars' and knew the staff well. They could rely on being treated fairly in these services, but their choice of services was considerably reduced.

#### Public attitudes

A number of participants with learning disabilities reported incidents where other customers using services had shown impatience or disrespectful attitudes towards them. This included being told to 'hurry up' while taking time over a transaction, being asked where their 'carers' were and being called offensive names in a pub. In the latter incident, the assistant manager had apparently told the offenders that their behaviour was unacceptable and that they were barred from the pub until they learnt to respect other people. Particular frustration was voiced by parents whose children had invisible impairments, such as autism, leading to what could be seen as 'bad' or strange behaviour and provoking open disapproval and censure from some members of the public. Similar incidents have of course been reported elsewhere (eg: Ryan 2005).

#### Inflexible rules

An inflexible approach to applying rules and regulations, without exploring options that might be more appropriate for people with learning disabilities, caused difficulties for some participants. For example, when one woman married and changed her name, her bank would not change the name on her account until she produced a passport, driving licence and bills in her own name - documents she did not possess. On making enquires at another bank, she was told she could open an account with her marriage certificate, a recent bank statement and a letter regarding Disability Living Allowance which showed her married name. Her supporter, present in the focus group, said:

It seemed [the first] Bank weren't prepared to just say 'well, we'll make an appointment so we would come in and meet you' and [not] 'you don't have this bill, that bill or this passport or that, so therefore we're not going to even talk to you'...[The second] Bank was able to deal with their rules in a way that was kind of face-to-face, human, understood the situation but [the other] just seemed not to be prepared to give any time at all.

#### Inaccessible facilities and information

Premises and environments which are physically inaccessible provoked a lot of discussion in most groups, for example, unsuitable toilets, lack of ramps, missing or broken lifts and pavements with high kerbs. Although most participants with learning disabilities were not personally affected by these types of barriers, they were aware of the difficulties presented for other people with learning disabilities who also had physical and sensory impairments, and for disabled people more broadly. Physical access was a particular issue for carers of people with profound multiple impairment (described by one parent as 'often bottom of the agenda') who talked at length about the difficulties of organising outings. They often phoned ahead to check what facilities were available and whether particular arrangements could be put in place if needed:

It's a lot of work and a lot of planning and sometimes you get there and you're maybe assured there's a disabled toilet but the standard of the disabled toilet, we find it's no' suitable for a change of clothes, a change of nappy or anything like that.

Lack of accessible transport was another problem discouraging carers from taking their sons and daughters out and about as much as they wanted. Inaccessible transport (covered in Part V of the Act) is clearly a significant barrier to using goods, facilities and services. At a more general level, carers were concerned about the paucity of social and recreational opportunities available to their sons and daughters. Facilities were limited both in numbers and inclusiveness:

It's not my son's disability that creates the problems. We deal with them. It's the other side of the coin: it's getting people to understand where we're coming from and what his needs are and that is the big battle.

Echoing the findings of many other studies, (eg: Morris 1999, Tarleton 2004) the importance of providing information in accessible formats was highlighted by most groups. Participants with learning disabilities had found that bus timetables were printed in too small a font: in one area, large print timetables had to be specially requested and took two weeks to arrive in the post. One city provided electronic information at bus stops: this was welcomed in principle but use of a 24 hour clock was confusing for some people. The audio timetables available in another town were considered most helpful. There was criticism of the small print often used in café menus, especially when counter staff in one establishment had said they did not have time to read the menu to customers. Information leaflets in general were often printed in too small a font while posters and notices were not usually displayed at a level accessible to wheelchair users. Carers also reported poor signage in many services, for example, train stations, GP surgeries and, interestingly, crematoriums. It was recommended that more pictures should be used in public signs. However, verbal or pictorial information alone was not always sufficient: sometimes people needed to be shown things. For instance, being given 'complicated directions' about where to find a particular item in a large supermarket could be confusing: people preferred to be taken to the appropriate aisle or shelf.

Another issue raised by participants with learning disabilities was the difficulty some people experienced understanding information provided by banks, building societies and mortgage lenders, which often included unfamiliar words. It was suggested that some companies encouraged people to borrow money without explaining the implications or risk of ending up in debt.

#### Communication

Many of the points raised above relate to the need for clear and courteous communication. Carers raised a number of specific problems in this area, including the frequent absence of sign language interpretation at hospital clinics, even when requested in advance, and the shortness of the standard GP appointment, since six minutes did not allow time for their relative to be meaningfully involved in the discussion. A difference of view emerged among carers about the desirability of medical practitioners directly consulting their (sometimes adult) son or daughter. One parent found it frustrating that her GP sought information from her daughter which she (the mother) did not think the young woman able to articulate. Other parents however supported that practice, pointing out that people with learning disabilities had fought long and hard to have their own voices heard.

## 3.2.2 Providing Services (Making Reasonable Adjustments)

In reading this section, it is worth bearing in mind that the reasonable adjustments, if any, offered by service providers to meet their responsibilities to people with learning disabilities give an indication of how the Act is interpreted, and the level of importance accorded it, within an organisation.

## Disability Organisations and Service Providers

Organisations of people with learning disabilities outlined the level of service and type of reasonable adjustments they would welcome. Good services were helpful and proactive in offering advice, assistance and opportunities without waiting to be asked. A number of service providers stated they had made reasonable adjustments in order to meet their responsibilities to people with learning disabilities under the DDA but perhaps only the four (Job Seeking Service, Bowling Alley, Museum umbrella organisation and Sports Club) identified earlier as knowledgeable about the Act provided such an inclusive level of service. For example, the Job Seeking service had a range of packages, sources of funding, unlimited length of time to work with individuals and employer contacts who could assist helping individuals find work, or decide if work was a suitable option.

#### Accessible Information

Organisations for and of people with learning disabilities were positive about the availability of Easy Read documents and spoken information provided by the DRC on the internet:

It's a lot of stuff that the DRC has in the office for people to look at and it's accessible as well and the website's going to be very accessible in the next week or two. ... They're going to [put] the booklets they have onto the website and there's going to be people speaking and they'll have different formats for people who can't read ... Any difficult words, there'll be a drop down arrow with a dotted line under and it tells you what it means.

Some service providers focused on providing accessible information as the main method they used to meet their responsibilities. In the tourist service, for example, the quality assurance department *looks in particular at the information that visitor attractions provide to achieve standards of readability.* The organisation also encouraged the use of larger font sizes for wall displays but found that this was not always adhered to:

We have increased the print size for wall displays and we've lowered the positioning, as far as possible, but every time I go into a [centre] now I notice things up on the wall are still there on A4 with 12 point type, that is still an issue there and we are struggling a bit to achieve where we want to be there.

The medical service representative commented that practice leaflets were sent out to all patients and that these leaflets contained information about accessing services. He also thought that carers would need to help people read the leaflets - which suggests they may not be easy to read.

They send out practice leaflets with information of services, carers could help them read it. They explain what to do if there are access issues.

#### Assistance and Accommodation

A number of service providers indicated that they offered some assistance to customers with learning disabilities. The supermarket offered a shopping assistance service to any member of the public who required it. A member of staff is made available to take customers around the store if they wish help with their shopping. At the Bowling Alley the correct weight of bowling balls is set out for people with learning disabilities and lane hosts help with scoring. Staff are encouraged to assist customers with learning disabilities and are happy to do so. Price reductions were also offered.

The Museum consulted with groups in advance of their attendance at the establishment in order that the excursion could be tailored to their interests and requirements. GPs were happy to provide double appointments for anybody who would benefit from a longer consultation period and to visit people in their own homes if they were not able to visit the practice.

The job seeking service assisted people with learning disabilities, and other disabled people, to find employment or voluntary work. They involved the individual, family members, if desired, and the employer in discussions about suitable hours and responsibilities. They were able to provide financial or material assistance to help individuals begin employment.

#### **Providing Opportunities**

The tourist service identified one tourist operative who worked closely with people with learning disabilities by fundraising to help provide them with opportunities to participate in outdoor activities. The Museum umbrella organisation was able to offer a small amount of funding to museums who applied to enable them deliver a project that provided access for people with learning disabilities. Similarly, the athletics club offered people with learning disabilities the opportunity to participate in sporting activities. This organisation reported that in their experience people with learning disabilities often preferred to play sports with other people with learning disabilities because they did not have to worry about negative attitudes or their performance. (It is not clear if people using the club's facilities had expressed this view: this reason is sometimes given to 'justify' segregated provision).

## **Developing Positive Attitudes**

The tourist service commented that some tourist operators have attended training about developing positive attitudes to people with learning disabilities, including understanding that many are independent individuals who do not need support. A database containing information about customers with learning disabilities was created at the Bowling Alley to avoid them having to show a letter proving they had an impairment and were therefore entitled to a discount.

#### Research

Three organisations (the museum, tourist and sport umbrella organisations) thought it was important to carry out research in order to discover examples of good practice and barriers to meeting responsibilities to people with learning disabilities. The sporting organisation was carrying out a literature review to obtain information and the museum umbrella agency conducted a survey of museums to find out what work was being done to improve intellectual access to museum collections. The tourist service was considering different marketing strategies in order to encourage a wide spectrum of visitors, including people with learning disabilities, to visit tourist attractions.

Most service providers offered just one or two adjustments for people with learning disabilities. As the tourist representative commented:

As an organisation [tourism operators are] not as far down the road towards complete compliance as they would be comfortable with, so many tourism operators are at risk of falling foul of the Act.

The hotel and pub representative commented that he was not sure what a reasonable adjustment would be 'because it's never really occurred to me'.

The GP assumed that the medical service was accessible to people with learning disabilities and hoped they were 'ahead of the game' in meeting responsibilities under the DDA 1995 because they had a responsibility to offer services to all patients. He thought this despite making the following comment:

I'm not aware of anything we've particularly done but we're not getting anything back that there's an issue.

Overall, there were few examples of service providers attempting to achieve the overall inclusion that organisations of people with learning disabilities identified as good service provision.

#### 3.3 SECTION THREE: EXPERIENCES OF DISCRIMINATION

## 3.3.1 Discussion of Vignettes about Discrimination

To seek views about concrete examples of discrimination and help stimulate discussion about their own experiences, four of the groups with learning disabilities were asked to discuss some vignettes. (These were not used with one group which, due to prolonged discussion, was already over-running). Each vignette was written in big print and accompanied by illustrations. A copy was given to each participant and the facilitator also read out the text, followed by three questions. The first vignette recounted a real incident taken to court (and won) under Part III of the DDA 1995. The vignettes presented the following scenarios (which were considered in turn):

Vignette 1: Jane and George are a married couple. They enjoy going for a drink to their local pub. The last time they went to the pub they were asked to leave after they had one drink. The landlady did not say why. They left but now miss going to the pub and want to know why the landlady asked them to leave.

Vignette 2: A group of 12 people with learning disabilities go to the local 10 pin bowling. They don't know how to work the scores. This means they don't know who is winning. They ask one of the staff to help them. She says she doesn't have time to explain the scores to them. They ask someone else but they do not help either. They leave feeling fed up.

Vignette 3: A young woman with learning disabilities has a bank account. She goes to the cash machine to get money out but becomes confused and the machine keeps her card. She goes into her bank and tries to explain what had happened. There is quite a queue and the teller asked her to come back later. She needs money urgently and gets upset but leaves the bank.

The questions following each vignette were:

- What should [the people with learning disabilities] do next?
- Do you think the [service providers] acted correctly?
- Is this action against the law?

It was very striking how closely these scenarios echoed incidents which participants themselves had experienced: they readily identified with the protagonists in the vignettes. (For example, one person said "why should we be banned after just having one drink?") The exercise elicited a continuum of responses, ranging from reluctant acceptance of the situation at one end to direct challenge and a proposed consciousness raising campaign at the other. In the middle ground were defence of the protagonists' (i.e. people with learning disabilities') actions and an apparent need to establish that they were not at fault. One person who thought the protagonists had little choice but to accept the

situation (a minority view) recommended they should avoid that particular service in future for fear of similar experiences:

Jane and George should choose another pub...even if it's travelling further away.

I'd stay out o' the pub and just tell people it's no' worth going intae that pub because she just throws people oot.

Other 'non-confrontational' actions recommended were, in the bowling alley, to ask other customers for help with scoring and, in the bank, to take along a carer.

Several participants pointed out that staff may be particularly busy at certain times, or services short staffed, and it was necessary to wait one's turn before being attended to. Thus, it was suggested that the bowling group should find out if the staff were genuinely too busy to deal with them *at present* and would be willing to help later, or if the rebuff was 'for no good reason'. It was recognised that there may be valid reasons for asking customers to leave a pub if, for instance, they did not have enough money to pay for their drinks or were 'misbehaving' in some way – so long as these rules were applied equally to everyone. The reasonable nature of participants' comments struck a contrast with the unreasonable attitudes of service providers in the vignettes and encountered by some individuals in real life.

However, there was also a feeling among some participants that the protagonists in the vignettes needed to defend themselves and prove their innocence of any wrong-doing:

You should actually ask is there something we have offended you with or have we upset you because usually how good you are. We're no' drunk after one drink...

This comment may reflect some people's sense of relative powerlessness, of having to justify themselves even when they have done nothing wrong.

However, other participants thought the service providers' actions should be challenged and that, rather than the protagonists having to defend themselves, the onus should be put back on the staff to explain or change their attitude: the bowling group should ask the attendant "What's your problem?" Several people thought an appeal to a higher authority was needed, such as demanding to see the manager, returning the next day with a supporter 'to make sure the story's no' being turned about' or seeking the support of a self-advocacy group and perhaps making a group protest, since there was power in numbers. An interesting difference of opinion arose about the value of having a dedicated staff member to deal with disabled customers. One person thought there should be an 'identified' staff member who could 'understand'. A similar point was made by a carer (during a different discussion) who advocated a 'named person...specially trained' to deal

with people with learning disabilities; another proposed 'a designated service for people with a disability'. A different view was that being responsive to people with learning disabilities should not be the responsibility of one worker, but of all.

One participant with learning disabilities went further. He proposed that the protagonists should take control of the situation by mounting a rights-based campaign with the aim of educating service providers, such as the bowling alley, bank and pub, about their responsibilities:

Tell them to come to a meeting and have a place booked where you can have the meeting and just explain what it's like being disabled and having learning disabilities and get other people to come along who are disabled and have learning disabilities and say, look it's in your best interest...this is what we think should be done and then give them your ideas and let them go away, hopefully with a leaflet or two or whatever, and it would actually explain the whole situation as they already listened to and they can take intae consideration the ideas and hopefully through that in the future they'll be able to have better facilities and better staff.

There were mixed views about whether the service providers in the vignettes had acted illegally and on the whole people were not sure if they had or not. However most participants agreed that the services providers had acted in an uncivilised and disrespectful way, one commenting 'It's against our law, never mind anybody else's.'

#### 3.3.2 Personal experiences of discrimination and unfair treatment

#### Reported incidents

Many participants with learning disabilities recounted personal experiences of what they considered unfair treatment by service providers. We do not know if these incidents would be judged unlawful if they were taken to court but they bear striking similarities to the vignettes described above. The first of one of which, as already mentioned, was based on a case won by a couple with learning disabilities who had been asked to leave a pub after one drink. Two of the study participants had been treated in exactly this way on one occasion while a third person had experienced this on several occasions. One woman said:

There was people went to a pub in Leith after, after the disco and we went in and they said that you were allowed one drink and you had to leave and I was trying to challenge it, why had we got tae, got asked to leave and they were saying we don't need to give reasons. One man had gone along to his local swimming baths, only to be told he could not use the pool: the reason was apparently unclear. Another person had been paying off two bank loans for 12 years. Following some minor change, the bank asked her to complete a new form with her personal details:

Now because I said in the details that I have a mild disability they said oh well we cannie give you a loan because you have a disability, it has to go up to the higher office and I said but why? I said you know and I'm sayin' to mysel' but just because I have a disability. I've paid every month or whatever you know, I've never been, never had any problems.

Problems with banks have been reported elsewhere (Livingstone, 2007). Both participants with learning disabilities and carers reported difficulties with bus drivers. One man described an occasion when a bus driver refused to accept his disabled person's bus pass on the grounds that he was not (in the driver's opinion) entitled to it.

Various incidents were reported where people had witnessed, or been informed of, unfair treatment shown to other people with learning disabilities. For example, one participant told how his wife had gone to a lunch club for older people at a local community centre, accompanied by a support worker. Another social worker had rung the club in advance and been told that the lady would be made to feel welcome. Her husband recounted:

A member of staff from the community centre who was running the club had actually said what is it you're wanting, why are you here and it was explained why and she said, oh you cannie be here, this isnie for you and then when they tried to explain about the staff member phoning up and finding out about the club and told that she can come along and all that kind of thing they didnie seem to be too happy about it and basically said, oh well you can just sit there then, but made her feel as though she really shouldnie be there.

## Participants' responses to unfair treatment

The emotional impact of being unfairly treated should not be under-estimated. Not surprisingly, given that these incidents generally occurred in public places, several participants described feeling 'embarrassed' and 'degraded'. Others were 'angry', 'upset', 'unhappy' or 'sad'. There was a strong sense of injustice at being treated differently from other people simply because, as participants saw it, they had a learning disability. This did not mean their right to access services or facilities should be any different from that of other people, nor did it justify being treated in a different, or lesser, way.

Nevertheless, it seemed that most people had not actively challenged the perceived discrimination: individuals who already occupy a position of relative powerlessness were being placed in a humiliating position and may have felt they had little choice but to accept it and go away. This is interesting, given that only a minority of participants had suggested the protagonists in the vignettes should accept the situation and leave. However, some examples of challenge and resistance were reported. The woman asked to leave a pub after one drink had challenged this at the time and later, with support, wrote a letter of complaint to the establishment. The woman made to feel unwelcome at the lunch club had reportedly 'let rip':

[She] gave them a mouthful and some of it wasn't very pleasant, to let them know what she thought. She says I'm part of this community. My face doesn't fit, I'm no' welcome but my face doesnie have to fit...I should be made to feel welcome like the next person.

The man whose bus pass was not accepted had staged a spontaneous sit-down protest, refusing to get up off the bus floor until his pass was accepted:

Everyone had tae get off the bus because they couldnie wait and hours later someone phoned the polis and the polis car come doon and he says what are you sitting there for? I says well the bus driver is refusing tae serve me...so the polis man say you wouldnie mind getting up and he says to the driver, the boy's quite right you cannie throw him off the bus...he's got the right to be on this bus because he's disabled.

#### Carers' experiences of discrimination and unfair treatment

Carers' accounts of unfair treatment were rather different, tending to focus on a perceived poor standard of care, particularly within health and social services, which some saw as discrimination. The most disturbing example was of a young man with profound needs attending a short term care unit. Due to a catalogue of errors, his mother reported.

He'd had no drinks, he had no food, he had the wrong medication and he hadn't been shaved for a week.

This example raises the interesting question of whether a segregated service (ie: used only by disabled people) which provides a poor service to all its users, could be guilty of discrimination under the Act. Advice given to our Project Advisory Group by the legal representative indicated this would depend on whether the reason for poor treatment related to impairment, whether it was unreasonably difficult for an individual to use the service and whether people with particular types of impairment are treated less favourably than others: for example, in this case,

was the young man with profound multiple impairment being treated less than people with mild learning disabilities using the same service?

As already reported, it was not uncommon for carers to encounter inaccessible or unsuitable toilets, lack of accessible transport and an absence of communication support. One parent appeared to speak for many when she said:

People have a right to have care; they shouldn't be short-changed; they should have the best of care; they should have people who are dealing with them capable of dealing with them and I think more than anything we should be listened to.

Some carers felt that *they* were discriminated against: services could withhold support, thus denying carers some relief, and/or they could obstruct carers' best efforts to provide the 'right' care for their relatives. For example, one mother had been refused planning permission to build an extension to her house, which would allow her son to live more independently of his parents but avoid a move to supported accommodation, which she opposed. She commented:

I think the discrimination's against us because I'm only trying to do the right thing for my son for his future and for this time of life for me to stand back and have a little bit of rest and time for me.

A recent landmark ruling in the European Court of Justice is relevant here. Sharon Coleman, a legal secretary, was forced to resign because her employer said she was taking too much time off work to look after her disabled son. The ECJ found in her favour and, subject to confirmation of that opinion by a UK panel of judges later this year (2008), protection from discrimination under the DDA will extend to carers and other close associates of disabled people. At present, however, it is not clear if this will apply only in the workplace or more broadly (Carvel 2008).

Despite their negative experiences of using services, carers were reluctant to complain. They lacked the time and energy to do so; complaints made in the past had been ignored or come to nothing and there was a fear of losing what support they had - 'being held to ransom' as one person said. Thus it seems unlikely that these particular carers would consider taking forward any incidents of perceived discrimination. The carers' support worker who took part in one focus group had offered to take up certain incidents with the DRC but

They [carers] would just say you know, I just don't have the energy for that. I really feel I need to concentrate all my energy on what I've to do today.

## 3.3.3 Cases Going to Mediation or Court

#### The National Picture

Data collected for this study refer to cases which went to mediation or court with support from the DRC. Here, we explain how this process worked. Since October 2007, a similar service has been offered by the EHRC. The law itself has not changed.

As noted in the Introduction, the DRC offered a confidential dispute resolution service, through an independent agency, for people who might otherwise have taken cases to court under Parts III or IV of the Act. Because litigation is costly, time consuming and potentially confrontational, conciliation is seen as a less stressful option. Complaints (which by law must be lodged within six months of the alleged discrimination occurring) were first referred to the DRC's Conciliation Management Unit (CMU). A Conciliation Caseworker assessed if there was a legal basis for the complaint and, if so, whether it was suitable for conciliation. Conciliation involves a single meeting, facilitated by a qualified conciliator, in which both parties are encouraged to resolve their dispute without compromising the legal rights of the disabled person. If this is not successful, or if the defendant refuses conciliation, the claimant can proceed to a court case.

As already noted, in the UK few cases of discrimination against people with learning disabilities under Part III of the Act have been taken to court or to mediation. During the period September 2005 to March 2007 five cases, all in England, were referred to the DRC's Casework Service for **consideration** as possible court cases (CMU, personal communication, 2007). Four of these cases related to less favourable treatment and one to a failure to make reasonable adjustments. Of the five cases, three reached a full and final settlement and for one there was no settlement. No data were available about the outcome of the fifth case. Questions can however be asked about the limits of conciliation as a suitable response to blatant, repeat or aggravated discrimination or where harassment (section 55 of the DDA) is in evidence. Whilst a valuable option in responding to less serious cases, the overuse of conciliation approaches could deny sufficient redress in serious cases where settlements would have a positive educational role in incentivising better service provider practices.

Part III of the Act is relatively little used by people with learning disabilities in comparison to other areas such as employment and education. For example, during the same period 10 education cases were referred to the DRC Conciliation Management Unit (CMU). Five of these reached full and final settlement, for two there was no settlement while data are not available about the other three (CMU, personal communication, 2007). Part III cases are also fewer amongst disabled people generally, not just people with learning disabilities, with *no Part III cases at all in Scotland*:

There have been I think in total six cases in court in seven years at all on Part III and I think outside the Commission there's maybe been one other case ever. So that's it, there's [only] one case a year ever on Part III (legal representative).

In line with these comments, we found information in the public domain about seven cases of discrimination against adults with learning disabilities under Part III (DRC undated). Three involved less favourable treatment in pubs, three involved less favourable treatment and unwillingness to make reasonable adjustments in banks and one case was about less favourable treatment in a tattoo shop.

In one of the pub cases, one defendant asked the claimant to leave because she was 'behaving inappropriately'. The claimant's companion, who was with her at the time, supported the claim suggesting that the individual had not been acting inappropriately. In another incident, 24 people with learning disabilities were told that, because the 'regulars' had been unhappy with them being in the pub on a previous occasion, they were only allowed to have one drink and must then leave the premises without making use of the Karaoke machine. In the third pub case, a landlady refused to allow two individuals with learning disabilities into her pub. She followed this up with a letter stating that they, and seemingly all people with learning disabilities, would be refused entry at all times. One of the pub cases was settled out of court, the other was withdrawn and the outcome of the third is unknown.

The three bank cases related to internet access to accounts by third parties who had power of attorney. The banks refused to allow access, or stopped third party access to the accounts for security reasons. In each case the banks said they would have preferred face to face transactions within branches. Two cases were settled out of court and one was withdrawn. The tattoo case, as will be shown below, was taken to court and won by the claimant.

The legal representative highlighted several reasons that she felt contributed to limited use of Part III. The first pertains in particular to Scotland, where there is little legal interest in or legal provision for social justice matters:

There are no law centres, lawyers aren't interested in it ..., don't see it as something that'll pay, don't know anything about it and would find a lot of the clients irksome in a way that they can't be bothered to deal with. Basically there's very little social justice infrastructure in Scotland. There are hundreds of law centres in England, there are six in Scotland and they're all based in Glasgow.

Secondly, there is little advocacy support for individuals with learning disabilities who wish to take a case to court:

I would actually find it incredibly difficult in Scotland to find advocacy support if somebody was coming to me on their own but you do need that kind of backup. It's not just about the legal stuff, somebody else needs to be doing some support.

A third reason suggested for limited use of Part III was that advisory services, such as Citizens Advice Bureaus, did not recognise disability discrimination in cases brought to them, nor were they able to provide financial assistance or advocacy support to allow individuals to take cases to court:

[Despite] in-depth training on Part III for the last two years, [Citizens Advice Bureaus] still say they never see a disability discrimination case ever ... they don't seem to be able to pick up on it and they don't offer court representation. It may be possible they would write a letter complaining on somebody's behalf but they wouldn't take it as a discrimination case going through court.

Finally, the court process was thought to be *very expensive*, *very time consuming* and *very off-putting*. Two issues were identified as intimidating aspects of the court process. One was that in order to establish that an individual was disabled, their impairment would be openly discussed in court:

You've got to be willing to go into a court publicly, have your disability discussed in some detail, have us get medical reports that confirm that you have a learning disability and all the negative connotations [associated with that].

In addition, the individual would have to take the case to court in his/her own right and not as part of a group. They would be required to stand as a witness on their own.

In some cases you have to ask is it worth it for the individual ... because you can't do it in a group action way. Mr Bloggs has got to do it. Will they be good witnesses at the end of the day? That's what the court demands of you, you're going to have to stand in a witness box and be cross examined and if it gets to that point, very few people want to do that.

# 3.3.4 Legal Case Studies

In order to explore the experience, process and outcomes of taking action against a service provider, we examined two discrimination cases in detail. The first case was the incident which occurred in a tattoo business. This case was taken to court. The second case involved an incident at a sporting venue, which was eventually resolved through mediation. The legislation guiding these judgements was outlined in the Introduction.

# Case Study One: The Tattoo Parlour

Case Details: September 2005

During a family holiday, Ms A decided she would like a tattoo. Unfortunately a flight of stairs prevented Ms A, who uses a wheelchair, accessing one tattoo parlour but staff directed her to another tattoo shop. Here, Ms A chose a tattoo but her father was told by the tattooist 'We don't do people like that.'

It was explained to the tattooist that Ms A was over 18 and could legally have a tattoo, and indeed had some already, but the tattooist started to argue and shout. He phoned a second man, purportedly his father<sup>4</sup>, at which point Ms A and her family left the premises. The second man arrived and shouted after Ms A and her family as they walked down the street away from the tattoo shop.

#### **Emotions**

This incident was very hurtful to Ms A and her family, especially as the tattooist had addressed Ms A's father, instead of Ms A. Speaking to Ms A, her mother commented:

He spoke to your Dad didn't he, he went in the shop and just totally ignored you, that was really horrible, it made me feel sick afterwards, so I think you [Ms A] must have felt ten times worse than what we felt like the rest of the day. It's a real insult to you [Ms A], isn't it.

Being shouted at by the tattooist and the other man was embarrassing and somewhat frightening and this, coupled with a threat to call the police, prompted the family to phone Ms A's advocate:

The [second man that came] said we disgusted him and shouted at us while we were in the street, shouting away down the street and it was a Saturday afternoon in [town] so it was really busy and everybody's looking round at us wondering what the heck we were doing, why we were disgusting and he was going to get the police on us, shouting he'd get the police and that's when we phoned [Ms A's advocate].

## Seeking Advice and Taking Action

The police were never called but Ms A's advocate advised the family to get some details from the tattooist: his name, and the name and address of the company.

<sup>&</sup>lt;sup>4</sup> The tattooist said this man was his father. Ms A's family suspected he was not the father but the shop owner Rights and Responsibilities:

The tattooist refused to provide these details. The advocate also suggested the family write down everything they could remember about the incident.

When Ms A returned home from holiday the advocate suggested she write to the tattoo company. She received no reply, and neither did the advocate who had also written, so Ms A decided to contact the DRC. The DRC received no response to their requests for conciliation and after a few months a summons to court was sent to the tattooist. He responded, through a lawyer, that Ms A lacked the capacity to make a judgement and that he wouldn't be able to give [Ms A] a tattoo because of her condition, now she already has [a tattoo] (Advocate).

May 2007 - The Court Hearing
The judge stated (in the judgement) the main issue of the case:

...this Claimant has disabilities which are clearly apparent and the issue that arises is whether her treatment amounted to disability discrimination in breach of the Disability Discrimination Act 1995.

As the defendant had claimed that Ms A did not have the capacity to make her own decisions she had to prove in court that she was able to make decisions which her family thought was a really horrible thing to do, particularly as the tattooist had not attempted to communicate with Ms A.

They said when they saw [Ms A] in the shop they didn't think she was capable of making decisions but they never spoke to [Ms A].

(Ms A's mother)

The judge spent time talking to Ms A, getting to know her and how the Talker she used to communicate worked. The family and Ms A were pleased because the judge was prepared to give [Ms A] time to answer. This also allowed the defendant to see Ms A communicating. The judge was satisfied that Ms A was able to give instructions to her lawyers and did not need the assistance of a 'litigation friend' (Judgement). The defendant also claimed that for health and safety reasons he could not have given Ms A a tattoo: however, Ms A already had a tattoo therefore this reason did not stand in court.

To Ms A the defendant did not appear to have taken the case seriously. She reported that he had attended the hearing with a family member, rather than an advocate or lawyer, that he smelt of alcohol, that both and he and his companion wore 'scruffy clothes' and, in Ms A's view, appeared bored and yawned throughout the proceedings. Perhaps most significantly, the defendant did not provide any evidence or ask any questions at the hearing:

[The defendant] offered no evidence in response and the only attempt to justify this treatment is contained in the Defence, prepared by a solicitor, which raises health and safety issues and questions Ms A's capacity to give consent. It also seeks to deny the Claimant's version of events and suggests that [Miss A's] father was abusive and made communication impossible. (Judgement)

The judge concluded that the defendant:

... ignored the legal claim when first intimated, created a smokescreen in his defence and pursued the matter to a hearing at which no serious attempt was made to present a defence. This is despite offers to resolve the matter by conciliation through the Disability Rights Commission. (Judgement)

The judge recognised that although the defendant may have had little experience with disabled people, a more appropriate response would have been for the tattooist to suggest he was not confident about giving Ms A a tattoo. The final judgement was that:

A declaration of disability discrimination is appropriate (Judgement)

#### ... with a proviso that:

... a copy of this Judgement be sent to the local newspapers in the hope that through publicity any remaining prejudice against disabled people may be outlawed in [the local area]. (Judgement)

#### Changed Attitudes

Ms A did not think that the defendant had been aware that he was discriminating when he refused to give her a tattoo but nor did she believe that the court hearing would change his attitude towards disabled people. Her mother felt that if Ms A were to go back to get a tattoo she would still be refused, only now the tattooist would say he was sorry, that he wasn't confident. There was some concern that some service providers would now think of reasons in advance for refusing a service.

## Case Study Two: The Sports Event

In this case, some details have been changed to protect identities.

## Case Details: September 2004

Mr B went to his local sports venue, run by the local council, to buy two tickets for an upcoming event. While purchasing the tickets, he discovered that there was no charge for his since he would be accompanying his wife, who used a wheelchair, as her carer. Mr B then asked for two further tickets, one for his brother and his carer. Mr B assumed that his brother, who had severe learning disabilities, would also be entitled to a free carer's ticket.

The ticket sales person informed Mr B that his brother was not entitled to a free carer's ticket as the disabled access policy only applied to wheelchair users. Mr B remarked that the venue's access policy should be changed to include people with learning disabilities.

## September 2004: Raising the Discrimination Issue

Mr B's response to a local council survey brought the ticket incident to the attention of the local MP, who wrote to Mr B stating that the issue would be addressed immediately.

#### October 2004

Mr B received a letter from the manager of the sports venue which stated that the council would review the contents of your letter regarding discrimination between different disabilities groups and as soon as we have a formalised policy identifying any changes to the [sports venue] we will contact you.

#### November 2004

A month later, with no further contact about amending the sports venue's access policy, the MP contacted a senior council official. The latter replied, commenting that difficulties had arisen and the council *may need to wait for the completion of some national reviews* before developing a new access policy. The official highlighted the health and safety element of the access policy for wheelchair users and emphasised that the council would need to consider the implications of extending the policy to the carer of Mr B's brother:

The background to this [policy] was that the accompanying person could assist in evacuating the person in case of a fire alarm or emergency. Mr B has requested that this offer be extended to the person who accompanies his brother although he is not in a wheelchair and the implications of this need to be taken into account in conjunction with other aspects that have been identified and could lead to a revised policy.

The letter further stated that the sports venue staff had contacted two organisations for people with learning disabilities for advice in relation to access requirements.

# December 2004: Involving the Disability Rights Commission

Mr B was frustrated by the lack of developments and searched the internet for information about possible action he and his brother could take. He learned about the DRC's casework service and a few weeks after contacting the DRC a caseworker (responsible for assessing suitability for court action) was assigned.

## January 2004

The case worker wrote to the sports venue, asking about the ticket incident and informing the venue of the DRC's conciliation service. Following a response from the sports venue, the caseworker suggested to Mr B that it would not be possible to demonstrate that his brother had received less favourable treatment, and that they would not be able to show that the sports venue was discriminating by offering wheelchairs users a free carer concession.

Disagreeing, Mr B responded to the case worker that the same health and safety reasons outlined for wheelchair users applied to people with severe learning disabilities. They too would need support in the event of an emergency and therefore were being discriminated against by not being offered a free carer's ticket. He argued:

... if you left someone with severe or profound learning difficulties on their own in a [sports venue] and an emergency evacuation was necessary, there was a fire ..., then they too would need support and in the absence of that support they would not only be putting themselves in danger, but because of their actions or inactions, they might be putting other people in danger too.

Mr B believed that if he had agreed with the case worker that it could not be shown that his brother had received less favourable treatment, the case worker would have closed the case and the sports venue policy may never have changed.

## February 2005: Filing a Court Action

The DRC changed their mind and decided to pursue the case so Mr B, by now his brother's litigation friend, and his brother filed a court action against the council which was responsible for the sports venue. Mr B commented that through the court hearing, we were hoping to effect a change throughout the country on this one. I was surprised, maybe shocked, at the time to realise that nobody had ever taken any venue to court before for such a reason.

#### March 2005

The council stated that they would defend their action (that is, their access policy) and in their defence statement claimed that the council access policy could not be inverted and characterised as a policy of <u>not</u> allowing free entry to anyone except the companions of wheelchair users. The defence statement also claimed that the access policy did not constitute a breach of the DDA 1995, denying that:

... the practice of issuing tickets to those accompanying wheelchair users had any effect at all on the ability of the Claimant to attend the [sports venue], let alone that it made it "impossible or unreasonably difficult" for him to attend.

March 2005 – July 2005: Preparation and Evidence
During preliminary hearings a number of issues pertinent to the outcome of the case arose:

## 1. Health and Safety

The local fire brigade issued a statement commenting that people with severe learning disabilities should be accompanied by carers.

... it is considered a person with learning disabilities would be unaware of the emergency procedures and therefore unable to follow the fire safety guidance provided by the staff. ... If a member of the public due to no fault of their own was unable to respond to the fire safety guidance provided by the staff there is the potential that this may compromise the safety of others. ... The potential problems as explained would be alleviated if [venues] encouraged the policy that clients with severe learning difficulties were accompanied by a carer.

## 2. Ability to Pay

The sports venue (local council) assumed that the claimant's family paid for the claimant's tickets to sports events and presumed therefore that a concession was not required. Mr B thought this was tantamount to means testing, which suggested that if the family could afford tickets the venue should not be obliged to provide a free carer's ticket.

3. Advice from Organisations for People with Learning Disabilities
An organisation for people with learning disabilities suggested there should be no charge for carers' tickets. It argued that service providers do not charge for the use of other reasonable adjustments such as ramps or sign language interpreters, so why charge for carers.

#### 4. Business Interests

The venue was never at full capacity; at most it was 92% full. This meant that the carer was not taking the place of a fee paying customer and therefore did not compromise the business interests of the venue.

## July 2006: Mediation

The DRC met with the claimants to suggest approaching the defendants for mediation rather than taking the case to court. Mr B was disappointed and maintained the opinion that they had a clear case of discrimination. The DRC indicated that if the court case was won by the council this would send the wrong message to other venues.

#### October 2006

Present at mediation were the Claimants (Mr B and his brother), the DRC and council legal teams and the independent conciliator. Despite his request, Mr B commented that the Council refused to allow one of the organisations for people with learning disabilities, which the sports venue was alleged to have sought advice from, to attend mediation. No written evidence was produced that the sports venue had sought such advice from the organisation.

Mr B further explained that the sports venue claimed to have written to the DRC requesting more information about conciliation but had not received a reply. The DRC told Mr B they had not received such a letter, a copy of which was not produced as evidence.

Mr B thought that the sports venue probably had not mentioned to colleagues within the local council that conciliation had been offered. He found the Council representatives to be generally positive about making changes and listening to suggestions made by the DRC. Mr B and his brother considered that they may have pursued conciliation if they had been aware of this option. (Following mediation a representative at the Council contacted Mr B to inform him that procedures for notifying the Council of such information had changed).

The outcome of mediation was that the council would develop an access policy which would be sent out for public consultation. Mr B was positive about this outcome stating that the Council seemed to have taken on board the advice offered at mediation and were positive about changing their access policy to include people with learning disabilities. In addition, free carer tickets for the Claimant would be available with immediate effect.

## April 2007: The Sport Venue's New Access Policy

The sports venue had approached a number of other similar venues in order to initiate a collaborative process to develop a new access policy which all venues could adopt. The ensuing draft policy was made available for public consultation.

Mr B and his brother were sent a copy of the new draft access policy for comment. Mr B was very pleased with it, commenting that it was a role model for all other ... venues in the country to follow.

#### **Conclusions**

The process of reaching court or mediation was lengthy in both cases. A shared characteristic of the claimants was perseverance in the face of little development. Claimants, with the support of an advocate (Case 1) and MP (Case 2), approached the defendants on a number of occasions without much success before pursuing legal avenues. During this time claimants constantly endured reminders of the incident and the emotional upheaval it had caused.

The two cases highlighted different reasons which may contribute to a case going to court. In the tattoo case, the defendant's attitude was the main reason that he ended up in court. He ignored letters and requests for conciliation, and did not react until he was summoned to court. He continued to appear disinterested at court. In the second case, the sports venue and council were slow to react to requests to change their access policy largely because of bureaucratic procedures. They responded in writing but without committing any time scales for developing the policy and without indicating the procedures through which this might happen. It seems likely that without the perseverance of the claimant and the DRC that the incident and development of the access policy would not have been given priority. Without mediation, it seems likely the council would have adopted a less collaborative approach to revising its access policy.

Although the outcome of both cases was in favour of the claimants, it seems that the process had different effects on the two defendants. In the tattoo case, the claimant felt that the defendant had not changed his attitude towards disabled people and would not change his behaviour, apart from perhaps being less rude when refusing to give someone a tattoo. The claimant involved in the sports venue case felt that the defendant was interested in the advice offered and made good use of it when developing the new access policy. In these two cases - by no means a representative sample and therefore not one from which we could generalise - the outcome of mediation was, overall, more satisfactory than that of the court case. However, had the sports venue case gone to court, as Mr B wanted, it would have served as an example to other councils. As it is, information about this case is not in the public domain (and that is why we have changed certain details about it).

#### 4.0 CONCLUSIONS AND RECOMMENDATIONS

## 4.1 Conclusions

This research has shown that, overall, there is limited knowledge of the rights of people with learning disabilities under the DDA 1995, while awareness of the implications of Part III, again for people with learning disabilities, is very low. This was true of most service providers involved in the study, ranging from representatives of medical services to the licensed retail trade, family carers and the majority of people with learning disabilities. Some service users were misinformed, or misunderstood, aspects of the legislation. However, there were exceptions. Disability organisations, especially those of and for people with learning disabilities, were generally well informed, but there was little evidence of any, other than the DRC, having resource to support claims under the Act. A few service providers had made it their business to find out about the Act. Umbrella organisations can play an important role in cascading information to other bodies and providing a strategic lead, as illustrated by the Museum and the Sports umbrella agencies. On the other hand, good practice may be driven by one individual's personal interest, as in the case of the Bowling Alley, and thus prove isolated or short-term.

People with learning disabilities saw discrimination in terms of unfair treatment and most had direct personal experience of it. This ranged from specific acts that were clearly illegal, such as being refused a service on grounds of impairment to a widespread lack of respect and courtesy. Some respondents related this to lack of familiarity with and understanding of people with learning disabilities. The recent spate of 'hate crimes', including murders, against people with learning disabilities can partly be seen as an extreme expression of this. A recurring theme was that people want to be treated with the same respect, enjoy the same rights and opportunities, and be able to use the same facilities as everyone else. This requires certain differences, or adjustments, in the way services are delivered. Carers tended to have a different and arguably narrower perception of discrimination, equating it with a poor standard of care in health and social services. However, barriers relating to physical access and transport also affected those caring for people with profound multiple impairment. A recent ruling by the European Court of Justice may extend rights under all or parts of the DDA to carers.

Limited knowledge of the law among most service providers was matched by limited understanding of discrimination against people with learning disabilities, although again there were exceptions. Reasonable adjustments were heavily skewed towards facilitating physical access, echoing earlier findings that many organisations understand disability in terms of physical and perhaps sensory impairment, with a focus on wheelchair users (Stuart et al 2002). Some providers seemed to think they were meeting their responsibilities to people with learning disabilities because they had made one reasonable adjustment such as producing

accessible documents or even, in a couple of cases, because they did not actively prevent individuals from using their services. It was also suggested that lack of negative feedback from people with learning disabilities indicated that services were satisfactory, a view revealing some complacency and little understanding of the factors militating against people with learning disabilities challenging services. Service providers generally at best made one or two reasonable adjustments: very few recognised the need for an integrated service that made people feel welcome and treated the same as everyone else. The services that tended to do better were those catering specifically for disabled people. While their good practice is to be commended, it does not further the inclusion of people with learning disabilities in mainstream facilities. There was a view that some service providers were not interested in finding out about their legal responsibilities, partly due to a lack of awareness of people with learning disabilities as customers but sometimes because they did not think they would be sanctioned for discriminating against this group.

On the whole, people with learning disabilities found services reasonably helpful and highlighted some examples of good practice. The research identified two ways in which people were prevented from accessing services. One resulted from failure to make reasonable adjustments, which could prevent someone using a service or receiving a partial or less satisfactory service. The second was when a service provider deliberately refused to serve an individual or allow them to enter or use a facility. Examples of failure to make reasonable adjustments were commonly reported by people with learning disabilities and family carers, and the number of reported instances of outright refusal was significant. Given the small number of people with learning disabilities involved in this study, this gives some idea of the level and frequency of unfair treatment experienced by individuals with this label on a day-to-day basis. This is not a new finding, although we are not aware of any previous studies which have looked at the issue in the light of Part III of the DDA.

Nearly all the participants with learning disabilities expressed a strong sense of injustice about unfair treatment. When asked to consider the vignettes, the majority thought the protagonists should complain about the unfair treatment. In recounting their real life experiences however, it seems the majority were unlikely to complain, believing it would not achieve anything. This perception reflects the relative powerlessness of people with learning disabilities in terms of economic, social and political capital. However, some activists linked to self-advocacy organisations had strong views about their rights and a few had resisted or protested against unfair treatment. Carers were generally reluctant to complain, fearing this might result in removal of services.

Very few Part III cases involving people with learning disabilities have gone to mediation or court in the UK and none in Scotland. This is a matter for serious concern. A number of reasons were suggested. These were, in Scotland, a poorly developed 'social justice' infrastructure and, across the UK, lack of advocacy support, a failure in advisory services to identify disability discrimination and the

fact that individuals are responsible for taking cases to court - a lengthy, costly and stressful process. Certain provisions within the DDA also militate against it – the need to provide evidence in court (or at a pre-trial hearing) 'proving' that an individual falls within a medical definition of disability which, for people with learning disabilities, could mean listening to evidence about their IQ levels and reported inabilities. In addition, the requirement to show that one is unable to 'carry out normal day-to-day activities' in order to establish rights within anti-discrimination legislation is something of a nonsense. In addition, the DRC limited the number of court cases it would support to 75 per year. (In the second case study, the DRC declined to take the sports venue to court and Mr B had to settle for mediation). While there can be strategic reasons for avoiding court, as well as protective ones for individuals with learning disabilities, it could be argued that more serious cases should not be heard through mediation. This points to the need for an alternative route to justice, as discussed below.

# 4.2 Recommendations for Policy and Practice

The findings show an urgent need for wide scale information provision, education and consciousness-raising, along with stronger enforcement and penalties to improve compliance. Legislative changes are also required, along with more advisory and better legal support for people with learning disabilities. In this section, we identify recommendations (arising from the conclusions and discussion with the Research Advisory Group) aimed at specific bodies.

## Recommendations for Government

- The medical definition of disability in the DDA 1995 should be changed to one broadly based on the social model of disability, thus more closely reflecting the spirit and intention of the Act. The DRC (2006c) issued a consultation document canvassing views on a change to the law to provide:
  - a. protection against discrimination on the grounds of impairment, regardless of level or type of impairment and b. entitlements to the removal of disabling barriers p.14

Such a definition would avoid the need to prove that the impairment has a long term, substantial effect on the individual's daily life.

- The law should identify examples of reasonable adjustments to improve access for people with learning disabilities, such as producing information in accessible formats, which services must provide.
- Part III legal cases should, like those brought forward under the Education and Employment provisions of the Act, go to tribunals rather than courts.
   This would be a less daunting and more accessible route to justice for people with learning disabilities. Tribunal staff receive training in equality

issues and are able to build up expertise in this area. They take a more holistic view than courts and can, for example, instruct service providers and their employees to undertake disability equality training.

- Government should sponsor a major public information and awareness campaign to promote positive attitudes towards people with learning disabilities. The Scottish Executive recently ran a high profile campaign, entitled See Me?, to educate and improve attitudes towards people with mental health difficulties, including television advertisements and notices on billboards and buses. This could serve as a model for a similar campaign about people with learning disabilities.
- A Disabled People's Advocacy Service should be set up, contracted out to the voluntary sector, to promote access to services generally and to legal services in particular. With bases in England, Scotland, Wales and Northern Ireland, it would provide information, advice, advocacy and support. Such a service would cater for all disabled people but must fully include those with learning disabilities.
- Government should fund organisations of and for disabled people to deliver disability equality training, and training about the implications of the Act, to service providers as part of an initiative spearheaded by the EHRC (see also below).
- Enforcement strategies are needed to ensure that service providers are meeting their responsibilities under Part III of the Act. This role should be undertaken by mainstream inspection agencies so that disability equality becomes embedded within organisational culture, in the same way that Health and Safety already is.
- There should be stronger penalties for those who do not comply with the law. For example, where cases are settled out of court, confidentiality clauses should not be allowed. A number of large settlements have been made south of the border which have not been made public (personal communication, EHRC). Fear of adverse publicity is likely to improve compliance.

# Recommendations for the Equalities and Human Rights Commission

 A campaign should be targeted at service providers and the business community on the types of adjustments needed to facilitate access for people with learning disabilities. It should emphasise that such adjustments are often relatively small and not expensive. The initiative should also highlight the power of the 'disability pound', making companies and services aware that it is in their business interest to offer a good service to people with learning disabilities. Although separate figures are not available for people with learning disabilities, there are 10 million disabled people in the UK with a spending power of £80 billion (Employers' Forum on Disability, undated). See below for further recommendations on this point. With government funding, organisations of and for disabled people should be closely involved in this initiative.

# Recommendations for service providers, including the business community, local authorities and the voluntary sector

- Leading umbrella organisations, such as the Confederation for British Industry and the Employers' Forum on Disability, should work closely with the EHRC on the above campaign, cascading information to member companies. The Employers' Forum on Disability (undated) has already identified a number of arguments for promoting the disability pound: access to a profitable market, improved reputation with disabled customers, their friends and family, improved customer service for all and the growing number of customers interested in corporate social responsibility.
- Similarly, umbrella organisations in specific areas of provision have an important role to play in transmitting these messages to members and related companies, along with information about legislation and advice on meeting statutory duties.
- These agencies should also take a stronger lead in encouraging compliance. The tourist body in the study was considering whether this should be a criterion for registration. An example which could be followed is that of Scope which collaborated with architects' and surveyors' organisations to conduct audits of physical access, awarding a kite mark to agencies meeting required standards.
- Service providers should consult with their customers with learning disabilities and the voluntary sector, including organisations of people with learning disabilities, regarding the current accessibility of their facilities and how this could be improved. Public bodies are already required to consult with disabled people as part of the Disability Equality Duty but may overlook those with learning disabilities.
- All new staff should receive disability equality training as part of their induction.
- Services should ensure information is provided in a variety of accessible formats, such as Easy Read leaflets.
- Statutory and voluntary organisations working with people with learning disabilities and/or family carers should actively promote and educate people

about the Act. This could be done by making written, audio and visual information available (such as that provided by EHRC or the useful Mencap (2004) leaflet) and organising workshops.

# Recommendations for organisations of and for disabled people

• Disability organisations, particularly those of or for people with learning disabilities, should have a key role in the public awareness campaign promoting positive attitudes towards people with learning disabilities, and the information campaign directed at service providers, recommended above. These organisations are uniquely placed to do so through their personal experience of discrimination which they can communicate to others with more authority and authenticity than non-disabled people. However, the number and capacity of such organisations is limited and their contribution must be an addition to, and not a substitute for, the efforts of other bodies with responsibilities in this field.

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## **6.0 REPORT INFORMATION**

# This report is available in other formats

An accessible summary in booklet form is available for people with learning disabilities – *Rights and Responsibilities: Fair treatment for people with learning disabilities.* This report, the booklet and a podcast of the booklet will be available at <a href="http://www.strath.ac.uk/eps/centresdivisions/aerc/disability/">http://www.strath.ac.uk/eps/centresdivisions/aerc/disability/</a> A CD Rom summary will also be available. For further information, please contact kirsten.stalker@strath.ac.uk or phone 0141 950 3135.