

DISABILITY: PROGRESS MADE AND PROGRESS STILL REQUIRED

HOW ACCESSIBILITY HAS ENABLED ME TO ADAPT TO A SIGHTED WORLD AND WHAT FURTHER SHOULD BE DONE IN THIS FIELD.

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I thought I would begin by looking back at what things were like 30, 40 or even nearly 50 years ago when I first stepped out into the world from my special school for the blind, and compare them with what they are like today—to see how far they have come, how much they have changed and what the primary agents of change have been. After that we'll be able to consider what remains to be done to provide better accessibility for disabled people. I think we will find that things have changed quite a bit, particularly in the way we conceptualize and think about disability, but I think we may also find that the situation on the ground is not as transformed as we might like, and that there has not always been a transformation in practice to match the change in thinking.

When I went to university in the early 1960s, the systems for dealing with disabled students were at best informal, but more often non-existent. So far as I was concerned, you could get books in braille—not yet on tape—if they happened to exist in the limited collection held by the Royal National Institute of Blind People (RNIB), or otherwise you recruited your own readers from the girls' colleges—it's remarkable how much better at reading girls were always thought to be! The university set aside a special room in the library for blind students to work with their reader, and permitted them to take out books that other students couldn't. But apart from that they pretty much left blind students to get on with it. The tutor might provide a bit of extra advice about reading, but the idea of the library or the college having their own braille or scanning facilities to provide blind students with independent access to books, reading lists, handouts—all that sort of thing—was unheard of. For exams, they put blind students in rooms by themselves, with nothing more than an invigilator, the paper in braille and a bit of extra time.

This was both good and bad. As a blind person, the onus was pretty much placed on you to find ways of accessing a sighted world, which felt little obligation to accommodate itself to your needs. There was a good deal of advice about how

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to do it from those who had done it before—of whom there were quite a few in the rather narrow and privileged part of the blind world where I came from—which I'm sure helped to foster my spirit of independence. Just how well less robust and more vulnerable spirits would fare in such a system is open to question. On the plus side, they did let you in—there was quite a tradition of blind people going to Oxford from the school I went to—and I encountered very little prejudice while I was there. In fact I made a lot of good friends who treated me normally as one of themselves. It was one of the vices of blind education at that time that it was pretty much Oxford for the high-flyers or nothing. The idea of sending a wider range of people to a wider range of institutions did not come till later. That was of course the situation of blind students of whom, as I say, there were quite a number. I don't think I ever encountered a deaf or a disabled student, and there were certainly no adjustments that would make it likely that I would. As I say, there were no systems—only minimal, but perfectly commonsense *ad hoc* adaptations for those who were motivated to get in.

We jump forward ten years or so to the University of Leeds, where I taught as a Law lecturer. My colleagues and I did quite a bit there to get the “disability in higher education” ball rolling. We founded the Association of Blind and Partially Sighted Teachers and Students and contributed to an influential report by the National Innovation Centre on disabled students in higher education; Lord Snowdon's Working Party on Integration; and the actions which ultimately led to the founding of Skill (the National Bureau for Handicapped Students, now Students with Disabilities) in 1974. We lobbied hard and successfully for reader and other employment support for blind professionals (the forerunner of Access to Work), improved financial and other support from the RNIB for visually impaired students, and institutionalized policies and systems of support for disabled staff and students in Britain's colleges and universities. A trail-blazing example of the last of these which set a pattern for subsequent initiatives elsewhere was the so-called Declaration of Intent adopted by the University of Leeds in 1973. Some time after that the University designated a member of staff as Adviser to Handicapped Students, but before you run away with the idea that Leeds was so far ahead of its time, I should tell you that this was a position occupied on a purely voluntary basis on top of existing academic duties.

When I set up the Disability Resource Team within the Greater London Council (GLC) in 1984, I identified three dimensions or principles in terms of which access, or the accessibility of society for disabled people, should be judged—integration, or as it would now be termed inclusion; participation—the extent to which disabled people are able to have a say in policy and provision for disabled people; and non-discrimination. In the rest of this talk I will say something about where we are on each of these now—what progress has been made and what still remains to be done.

Speaking generally, there has been what is often called a paradigm shift in thinking about disability. The provision of accessible surroundings for disabled people is now seen as a matter of rights and reasonable adjustments rather than welfare, services or support—almost not of provision at all, but of inclusion in a

diverse society. Services are generally mainstreamed rather than specialized. The accent is now on educating disabled children in mainstream schools if at all possible. The European Union (EU) has also undergone a complete transformation in philosophy and policy towards disability in the last ten years: where before it was all a question of specialist help and support, now the accent is firmly on removing social barriers, mainstreaming and combating discrimination, and participation and consultation.²

In Britain we now have the Disability Discrimination Act (DDA) 1995,³ which has applied to employment and refusal of service since the end of 1996, and has required changes to practices, policies and procedures since 1999 and to physical features of premises since 2004.⁴ The Disability Rights Commission (DRC) was established in 2000⁵ and the DDA was extended to education by the Special Educational Needs and Disability Act (SENDA) in 2001.⁶ In addition, all employers, with the sole exception of the armed forces, are now subject to regulation by the European Directive on Employment and Occupation.⁷ Finally, the Disability Discrimination Act 2005 has introduced further positive changes to the DDA with comprehensive health coverage for people with cancer, human immunodeficiency virus (HIV) and Multiple Sclerosis (MS) from the point of diagnosis; new transport and housing rights; coverage of public functions and the introduction of the Public Sector Disability Equality Duty since December 2006.⁸

What does this amount to in practice? Before it was merged into the Commission for Equality and Human Rights (CEHR, now EHRC), the DRC dealt

² See B. Hepple, M. Coussey, and T. Choudhury, *Equality: A New Framework, Report of the Independent Review of the Enforcement of UK Anti-Discrimination Legislation*, ¶ 1.33 (Oxford: Hart Publishing, 2000).

³ See C. O'Conneide, *Age Discrimination and Irish Equality Law*, in E. O'Dell (ed.), *Older People in Modern Ireland: Essays on Law and Policy* (2006); C. Gooding, *The Disability Discrimination Act 1995: An Overview*, in J. Cooper, *Law, Rights and Disability*, 139-163, 139 (2000).

⁴ See Bell, David N.F. and Heitmueller, Axel, *The Disability Discrimination Act in the UK: Helping or Hindering Employment Amongst the Disabled?*, (Jan. 2005). IZA Discussion Paper No. 1476, available at SSRN: <http://ssrn.com/abstract=659164> (last visited June 9, 2008).

⁵ See C. Gooding, *The Disability Discrimination Act 1995: An Overview*, in J. Cooper, *Law, Rights and Disability*, 139-163, 139 (2000).

⁶ *Id.*

⁷ See M. Bell, *A Patchwork of Protection: The New Anti-Discrimination Law Framework*, 67(3) MLR 465-477, at 467-475 (2004).

⁸ See Petersen, Carole J., *The Right to Equality in the Public Sector: An Assessment of Post-Colonial Hong Kong*,

32 H.K. L.J., No. 1, p. 103 (2002).

with about 100,000 enquiries a year.⁹ At least 40,000 people have brought cases of discrimination before an Employment Tribunal, but nevertheless, as far as I can make out, only about 2000 of them (3%) were successful.¹⁰ This figure would look better if cases where the application was withdrawn or the case settled were removed from the total, but the success rate is still very low. Markedly fewer claimants have found it possible to take goods and services cases to the County Court. In its short seven-year life, the DRC supported cases which have by and large resulted in positive clarifications of the law.¹¹ The Government will now pay for special equipment and support required by the disabled to perform their jobs. It will also meet the extra expenses they have as students. From my own experience, much more information is made available in an accessible form. Though only about 5% of publications are available in Braille, much more ephemeral material is now produced in that format, such as bank statements, utility bills and consultation documents. In addition, Information and Communication Technologies (ICT) afford access to email and the internet, though internet access can still be a problem. Today, when I go to a meeting (in a subsidized taxi), I can read the papers beforehand in Braille and when I go to the theatre, I can listen to a commentary about what is happening, known as audio description. None of this was the case when I was starting out.

So there has been progress. But it has been much too slow. When a World Tonight Special on the radio recently followed a wheelchair user round Aylesbury for the day, they found that only one of the five outlets he wanted to visit could be considered “accessible” for disabled people. There is something of a puzzle here. Things have indeed improved, but yet in many ways apparently got no better. At a recent conference, a speaker from Norway pointed out how blind people today enjoyed better education, social protection, free access to technology and free transport to work, yet scarcely more than 30% of those eligible were gainfully employed. Much the same is true of Britain.

How might we explain this? Rising standards and expectations are a possibility. Things are better than they were, but not much nearer to what we would like them to be when we look at our much better-off sighted neighbor. Another possibility is that laws and policies have improved, but implementation

⁹ See S. Nott, *Securing Mainstreaming in a Hostile Political Environment* 8(1) INT’L. J. DISCR. & L. 121 (2005).

¹⁰ See J. Rubery et al., *The Ups and Downs of European Gender Equality Policy*, 35 Ind. Rel. J. 603, (2004). See also, F. Mackay and K. Bilton, *Learning From Experience: Lessons in Mainstreaming Equal Opportunities*, (2003).

¹¹ See K. Wells, *The Impact of the Framework Equality Directive on UK Disability Discrimination Law*, 32(4) I.L.J. 253-273, at 256-257 (2003).

still lags far behind. A third related possibility is that attitudes and what we say about disability, have improved, but what we do about it has not. It is probably a bit of all three.

In any case, so far as the formal legislative position is concerned, gaps still remain: there is still no anti-discrimination legislation to protect volunteers or disabled people on ships or planes, and there is still no protection against unreasonable discrimination against members of the armed services with an impairment or health condition.

The DRC has argued that the definition of disability under the DDA needs to be replaced so that anyone who has or is perceived to have an impairment (of whatever type or degree) is protected from discrimination.¹² Such a change would be to place emphasis on whether a person had been discriminated against rather than whether he was sufficiently disabled. It is possible to worry that this could “open the floodgates” as lawyers say, to all sorts of unmeritorious cases and take the focus off the central cases of disability which most need protecting. But it doesn't seem to have had this effect in other countries which have adopted such a definition. Nevertheless, the DDA's definition of disability appears to be one of the main obstacles to successful claims under the DDA.

The recent Discrimination Law Review proposed that there should be a single objective justification defense in cases of disability discrimination, namely that the conduct in question is a proportionate means of achieving a legitimate aim. Moreover, the DLR argued that there should be a single (lower) threshold at which the duty to make reasonable adjustments is triggered, namely, if the failure to make such an adjustment puts the disabled person at a substantial disadvantage, that is to say, any disadvantage which is more than just minor or trivial.¹³ In addition, disabled people in rental or leasehold property should be allowed, where reasonable, to require landlords to make an adjustment to physical features of the common parts of residential let premises to improve access, at their own expense (unless the landlord chooses to pay).

Under EU law people should also be protected against discrimination on grounds of an association with a disabled person, and it is now generally agreed that people should be protected against discrimination on the ground that they are perceived as a disabled person. But most importantly, there needs to be a European directive to combat disability discrimination in areas other than employment. This would cover all fields of EU competence, and therefore help to break down discriminatory barriers in areas such as education, social protection,

¹² *Equalities Review, Fairness and Freedom: The Final Report of the Equalities Review* (Feb. 2007), available at <http://www.theequalitiesreview.org.uk/publications.aspx>.

¹³ *Id.* See also, Owen Fiss, *Against Settlement*, 93 YALE L.J. 1073 (1984).

public health and access to goods and services and telecommunications. But most importantly, it needs to cover manufactured goods which are not covered under the rules of the Single Market.

Let me finish by saying something about what still needs to be done in the United Kingdom (UK) in light of the recently adopted United Nations Convention on the Rights of Disabled Persons (UN Convention).¹⁴ The UK government may well conclude that the UK is ahead of most other states in anti-discrimination legislation, and they may well be right to do so. But I would not want them to conclude that they can safely rest on their laurels and carry on as if it was business as usual. I believe that there are clear areas where the UN Convention calls for governments to provide services or take action over and above what is to be found in current UK legislation or practice.¹⁵ It also seems that despite the increased emphasis on rights in UK legislation in recent years,¹⁶ in certain areas there has been deterioration in the level of support needed to ensure that these rights can be fully enjoyed, notably in the field of social care.

Let me give three examples of where UN Convention requirements are not properly being complied with for visually impaired people in the UK at the present time. Article 26 on habilitation and rehabilitation requires States Parties to take effective and appropriate measures to enable persons with disabilities to attain and maintain maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life.¹⁷ However, recent research by the Guide Dogs for the Blind Association found that 20% of those surveyed had not received any form of needs assessment; only 56%

¹⁴ Quinn, G., & Degener, T., *Human rights and disability: The current use and future potential of United Nations human rights instruments in the context of disability*, Geneva, Office of the High Commission for Human Rights (2002), available at <http://193.194.138.190/disability/study.htm> (last visited June 9, 2008).

¹⁵ See J. Clarke and S. Speeden, *Then and Now: Change for the Better?*, (2001); N. O'Brien, *The GB Disability Rights Commission and Strategic Law Enforcement: Transcending the Common Law Mind*, in A. Lawson and C. Gooding, *Disability Rights in Europe*, 249-263 (2005).

¹⁶ See B. Hale, *The Quest for Equal Treatment*, Public Law 571-585, at 575 (2005); A. McColgan, *Discrimination Law* (2nd ed.), 271-280 (2005).

¹⁷ See *Draft Articles for a Comprehensive and Integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities*, available at <http://www.un.org/esa/socdev/enable/rights/ahcwgreportax1.htm> (last visited June 9, 2008). See also, M. Bell, *The Right to Equality and Non-Discrimination*, in T. Hervey and J. Kenner (eds.), *Economic and Social Rights under the EU Charter of Fundamental Rights. A Legal Perspective*, 91-110 (2003); M. Bell, *Anti-discrimination Law and the European Union*, (2002); M. Bell and L. Waddington, *Reflecting on Inequalities in European Equality Law*, 28 EUR. L. REV. 349-369 (2003).

of those who had had their needs assessed were offered services based on the assessment; and only 37% had received training in mobility.¹⁸

Again, the “Equipped for Living” report produced last year by the Improving Lives Coalition, a consortium of voluntary sector bodies concerned with improving social services for visually impaired people found, based on a survey of 500 people in England and Wales, that blind and partially sighted people were receiving very little in the way of equipment to help with independent living. For example, computer equipment using large text, speech or braille was only available to 14% of people, and four out of five of them had to buy it for themselves.¹⁹ This small selection of data from these two surveys illustrates the extremely poor state of rehabilitation services for blind and partially sighted people in the UK today.

Article 21 on freedom of expression and opinion and access to information says that States Parties should provide information intended for the general public to persons with disabilities in accessible formats and technologies appropriate to different kinds of disabilities, in a timely manner and without additional cost.²⁰ Yet in the area of health services alone, a recent survey of blind and partially sighted people in the UK showed that 95% of respondents had never received health advice leaflets or information from their local surgery in their preferred format; 96% had never received letters from their general practitioner, results of tests or other correspondence in their preferred format; and 95% had never received medicines labeled in large print.²¹

Again, Article 9 on accessibility says that States Parties shall, amongst other things, take appropriate measures to ensure to persons with disabilities access, on an equal basis with others, to transportation.²² Yet still almost no buses in the UK currently have on-board announcements of the route, destination or next stop. And according to the Guide Dogs research mentioned

¹⁸ See, *Guidance Note on Disability and Development*, European Commission, (July 2004), available at: http://ec.europa.eu/development/body/publications/descript/pub7_17_en.cfm (last visited June 9, 2008).

¹⁹ *Id.*

²⁰ See Waddington, Lisa, *A New Era in Human Rights Protection in the European Community: The Implications the United Nations’ Convention on the Rights of Persons with Disabilities for the European Community*, Maastricht Faculty of Law Working Paper No. 2007-4 (April 2007), available at SSRN: <http://ssrn.com/abstract=1026581> (last visited June 9, 2008)..

²¹ *Id.*

²² *Id.* See also, N. Bamforth, *Conceptions of Anti-discrimination Law*, 24(4) O.J.L.S. 693 (2004).

earlier, only 39% of blind and partially sighted people travelled by bus and 11% by train.²³ The UN Convention will be the first human rights treaty to be ratified by the EU. It therefore involves obligations not just for the UK, but for the EU as well in areas where it has competence. Non-discrimination and equality are two of the primary underlying principles in the UN Convention and are at the heart of many of its specific articles, such as those on accessibility.²⁴ Given that the EU now has competence to address disability discrimination pursuant to Article 13 of the Amsterdam treaty, and has already done so with regard to discrimination in employment, it should now take the next step and adopt a general disability directive covering all the areas falling within its competence, including access to goods and services, transportation and manufactured goods.²⁵ The last of these is particularly important since under Single Market legislation it cannot be addressed by national legislation.²⁶

To conclude, the UN Convention should be welcomed, but we should welcome it with our eyes open. Many of the rights in it are as long as a piece of string. Phrases like “as far as possible”, “to the greatest extent possible” and “all appropriate measures” abound. I commend the initiative of the European Blind Union (EBU) to spell out in detail the meaning of the various rights for blind and partially sighted people and I hope that the government will enter into discussion with our UK affiliates to clearly define the scope of such rights for people with disabilities.

²³ *Id.*

²⁴ *Id.*

²⁵ *Id.*

²⁶ *Id.* See also, Anna Lawson, *The United Nations Convention on the Rights of Persons with Disabilities: New Era or False Dawn?*, 34 SYRACUSE J. OF INT'L L. & COM. 563, at § IV (590-616) (2007).