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*Creating opportunities with disabled people*  
**LEONARD CHESHIRE** 

# Fair Treatment?



## A Survey of Disability Access Policies in Primary Care Trusts

## Summary

This report demonstrates the enormous gap between Government expectations about challenging health inequalities and discrimination against disabled people, on the one hand, and reality, on the other. Disabled people face significantly greater difficulties in accessing primary health care services than the general population. Many of these difficulties arise from inadequate communication, inflexible service delivery patterns and inappropriate attitudes about disabled people's abilities. We show that Primary Care Trusts (PCTs) who have responsibility for the local delivery of health services are failing many disabled people and, worryingly, have no plans to address this.

For example:

- Only half of those PCT's surveyed had consulted disabled people about issues relating to disability access to their services
- 90% of PCT's do not provide mandatory disability equality training for their staff
- Only 9% of PCT's identified the attitudes and behaviour of staff as a priority.

We call on the Government to make the provision by all PCT's of disability equality training for their staff a mandatory requirement. This relatively simple and cost-effective measure will equip staff with the knowledge to provide more effective services to disabled people.

### Jo Campion

Jo Campion is the Parliamentary Officer at Leonard Cheshire. Her experience in the political field has included working with the House of Commons Library and conducted research examining the relationship between MPs and their constituents. She has co-authored a number of House of Commons Library Research Papers.

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## 1 Background and Research Aims

**1.1** In 2002, Leonard Cheshire's Social Exclusion Report 'Inclusive Citizenship: Social equality for Disabled People' highlighted disabled people's exclusion from essential primary health care services<sup>[1]</sup>. Their degree of exclusion from doctors' surgeries, dental practices, opticians and pharmacies compared to that of the general population was marked. The report found that:

- 12% of wheelchair users found doctors' surgeries inaccessible, whilst 60% of profoundly deaf people found them so.
- Four times more disabled participants than was the case in the general population found dental practices inaccessible.
- 21% of disabled people found access to accident and emergency units inadequate. This is over 50% higher than for the general population.

**1.2** As a follow-up to this research, Leonard Cheshire surveyed all 302 Primary Care Trusts (PCTs) in England<sup>[2]</sup>. The research, based on the replies of the 70 PCTs who responded, investigated the policy and practice of PCTs, the training provided for primary care staff within their organisations and the level and nature of consultation with disabled users of their services. The research aims were to:

- Establish the current level of involvement of Primary Care Trusts in resolving problems of inadequate access for disabled people.
- Establish what level of understanding Primary Care Trusts had about the problems faced by disabled people when accessing primary care services.
- Establish the availability and status of disability equality training for primary care staff.
- Find out the level of disabled people's involvement in plans to resolve issues about accessibility and whether consultation with local disability organisations had taken place.

## 2 Discussion of the findings

### Priority given to Disability

■ 6% of Primary Care Trusts say it is not part of their policy or practice to assess disability access to services within their Trust.

**2.1** The response rate for the questionnaire was only 23%. This in itself could be seen as a reflection of the low level of priority given by Primary Care Trusts to disabled people. Our concern is that the 232 Primary Care Trusts who did not respond to our questionnaire may not even have a policy on disability access, there being a strong likelihood that they are placing disability so low on their agenda that their responses would have made even more disappointing reading.

**2.2** The questionnaire asked the Trusts about their policy and practice and what their services are doing to resolve any disability access issues (see Appendix A). In 1999 a number of Health Service Circulars were distributed to all NHS services and bodies stating their responsibilities under the Disability Discrimination Act 1995<sup>[3]</sup>. It is worrying to note that of the 70 Primary Care Trusts that responded, 6% have not incorporated these responsibilities into their policy and practice.

**2.3** Some Primary Care Trusts forwarded our questionnaire to local disability groups or, if they had one, their Disability Trust Advisor. In these cases, comments were made on the lack of priority given to disability by their Primary Care Trusts when faced with other demands on their time and money.

*"It is exceptionally hard to get Primary Care Trusts interested in services for people with physical and sensory disabilities, because those people are not a priority... it feels [like] Primary Care Trusts are only interested in cancer, coronary heart disease and elderly people."*

Disability spokesperson working with a Primary Care Trust, November 2002

[1] For a copy of this report please contact Leonard Cheshire's External Policy Unit, contact details at end of this report

[2] Questionnaires were sent to all 302 PCTs in England. Further information on how this research was conducted and a copy of the questionnaire are available on request.

[3] HSC 1999/156 and HSC 1999/093

## Access and the Disability Discrimination Act

Of the Primary Care Trusts that are currently working to resolve access issues:

- 89% listed physical access considerations as one of their main priorities.
- 20% identified communication considerations as one of their main priorities.
- Only 9% identified attitude or behaviour of staff as one of their priorities.

**2.4** The questionnaire asked the Primary Care Trusts to give details of the main disability related issues that had been identified as problems by their services and how they had prioritised these issues<sup>[4]</sup>. The majority listed physical access problems such as ramps, lifts, automatic doors and parking facilities as their main concern. One fifth considered communication issues such as induction loops and clear signage a priority, whilst fewer than one tenth identified the attitudes and behaviour of staff or staff training as a concern.

**2.5** From October 2004 all primary care services will be completely covered by the Disability Discrimination Act 1995. Our research suggests that almost all the Primary Care Trusts who responded were aware of the physical changes and requirements that this demands. However, a number of Primary Care Trusts expressed reservation over whether their services would meet the October deadline, stating lack of funding and services being situated in old buildings as major concerns. Leonard Cheshire's previous research showed that physical access was a particular problem in dental surgeries<sup>[5]</sup>. A number of Primary Care Trusts echoed this concern and commented that the dental practices within their Trusts were not commonly sited in purpose built locations and most were not entitled to Health Service funding to make physical changes.

## Availability of Disability Equality Training

- 90% of Primary Care Trusts do not provide mandatory disability equality training to practice staff.
- 37% of Primary Care Trusts provide some form of voluntary disability equality training to practice staff.
- 50% do not provide training or do not know whether they provide training of any kind.

**2.6** Only 9% of Trusts identified the behaviour and attitude of staff in their services towards disabled service users as a priority. This low number is also reflected in the responses to question 4, which show the proportion of Primary Care Trusts currently providing disability equality training for staff within their services<sup>[6]</sup>. A number of additional comments were also made in some questionnaires that voluntary training sessions were not well attended.

**2.7** In February 1999 research was carried out by the NHS Executive and a number of disability groups. Disabled people were questioned about their experiences of using primary and secondary health care and 'the most significant barrier cited by the majority of disabled people was that of inappropriate staff attitudes and behaviours'<sup>[7]</sup>. This was common to users with all disabilities and was highlighted throughout the research. A number of recommendations were made and all staff in direct contact with patients were to have received disability equality training by October 1999. The training was to be on-going for new staff. Leonard Cheshire's research strongly suggests that this has not been carried out and such training is being given low priority by Primary Care Trusts. Since the 1999 report there appears to have been no further guidance from the NHS Executive. Although a training workbook was produced in conjunction with Grass Roots plc, unexpectedly low numbers have been ordered by primary care services over the last three years<sup>[8]</sup>. One advisor to a Primary Care

[4] Q3. 'What, if any, are the main issues that have been identified by the services in your Trust relating to disabled access? Please give details.'

[5] Heaven et al, 2002

[6] Q4a. Does your Trust provide practice staff with disability equality training? (including any externally commissioned training). Q4b. If yes, is this mandatory or voluntary?

[7] HSC 1999/156, p.2

[8] Welcoming Patients with Disabilities, 1999

Trust who managed to get private funding for the workbook to be provided for local health care staff said:

*“There is very little support and guidance from the NHS Executive or Strategic HA to enable DDA compliance beyond the physical environment.”*

Karen Shook, Trust Advisor  
Disability Equality and User Involvement

Another Trust Advisor commented that:

*“lip service is paid to the improvements in access and the provision of Disability Awareness Training and knowledge of the DDA.”*

Disability spokesperson working with a Primary Care Trust,  
November 2002

## Consultation with Disabled Individuals/ Organisations

- 46% of Primary Care Trusts had not consulted disabled users or did not know whether they had consulted disabled users when trying to identify the problems of disability access within their Trusts.
- 53% of Primary Care Trusts had not consulted disabled users or did not know whether they had consulted disabled users when trying to identify solutions to the problems of disability access within their Trusts.
- Despite more than half of the Primary Care Trusts stating they had consulted disabled users to find solutions to disability access problems, only 26% listed information about those solutions.

**2.8** Around half of the Primary Care Trusts responding to the questionnaire have not yet consulted disabled individuals or local disability groups when trying to identify either the problems of disabled access to services or their solutions<sup>[9]</sup>. Consultation with disabled people is obviously crucial when trying to resolve the problems they face when using health services. Often the perception of the problems disabled

people face are very different from the reality, and so advice from those affected can be extremely useful. This lack of attention to disabled people's views may have contributed to the strong emphasis given by Primary Care Trusts to physical access rather than to the behaviour and attitude of staff, which previous research has proven is what disabled people consider to be the major barrier to access. One Primary Care Trust advisor said that, although her Trust had consulted disabled people in her area, those people had left the consultation feeling that it had not been meaningful and had not been conducted appropriately.

## 3 Recommendations

**3.1** In the *Tackling Health Inequalities – 2002 Cross-Cutting Review* the Government acknowledged that disabled people were at particular risk from both social exclusion and inadequate healthcare access. It stated that tackling health inequalities was a top priority for the Government and ‘that those in greatest need of public services often have the lowest levels of use and the poorest access... reflecting a lack of responsiveness to the needs of users, poor transport, discrimination and poor knowledge and access to information’<sup>[10]</sup>. Two years earlier, the Government published its NHS Plan and explicitly vowed to challenge discrimination against disabled people and other minority groups in the delivery of health services<sup>[11]</sup>. Clearly, this research shows that this vision has yet to be translated into reality for many disabled people who face immense barriers in accessing primary health care services in 2003.

**3.2** Previous research has reported that disabled people consider the attitude and behaviour of staff as the most important barrier to adequate access to health services and thus disability equality training is vital if primary care services are to be fully accessible and adequate for disabled people's needs. This research suggests the approach that Primary Care Trusts

[9] Q5. Have you consulted disabled users of primary care services in order to identify any problems of disability access? Q6. Have you consulted disabled users of primary care services in order to find solutions to any problems of disability access? Q6a. If yes, please give details of the most popular solutions suggested.

[10] DoH & HM Treasury, 2002, p.7 & p.50

[11] The NHS Plan – A plan for investment, a plan for reform, CM 4818-I, 2000

are taking with the issue of disability access lacks structure and uniformity. Some Primary Care Trusts provide training, have consulted users and have incorporated the issue of access into their policy and practice. Others have taken a less active stance and are falling well behind on both their legal requirements under the Disability Discrimination Act 1995 and the recommendations from the NHS Executive and the Department of Health. The key recommendations identified below will help resolve these inconsistencies by setting uniform standards that must be adhered to and providing service users with clear lines of redress if their access needs are not being met.

- The new Strategic Health Authorities and Primary Care Trusts should be required to ensure that all front line primary care staff have attended disability equality training within two years and that all new staff are trained as part of their induction process. Strategic Health Authorities should regularly monitor this.
- The Department of Health should carry out a full review of disabled people's access to primary health services and set targets for improvements. These targets should be monitored every two years and, where necessary, remedial actions taken.
- Primary Care Trusts should be required to conduct meaningful consultation with local disabled people when tackling the problems of inadequate access. This could be achieved either through the appointment of a disability advisor or by establishing formal mechanisms of consultation with local disability groups.

## 4 Conclusion

- Although 93% of Trusts consider it part of their policy and practice to resolve problems of disabled access within their Trust, half have not consulted disabled people about either the problems or the solutions and only 10% provide mandatory disability equality training to their practice staff.

In conclusion, this report indicates that little progress is being made in this area and that the needs of disabled people are not being given high enough priority by the majority of Primary Care Trusts. This is unacceptable and conflicts with Government health and social inclusion policies. Negative attitudes about disabled people and low expectations of their abilities can be easily and cost-effectively addressed through training. Therefore, if reducing health inequalities and increasing social inclusion are to be real commitments of the Government, health care providers must be required to deliver disability equality training to all frontline staff.

## 5 Considerations for Further Research

This report has investigated the role of Primary Care Trusts and disability. Further research on the role of the new Strategic Health Authorities and their work to resolve the problems of inadequate disabled access would be helpful.

## 6 References

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- Working in partnership to implement Section 21 of the Disability Discrimination Act 1995, HSC 1999/156 (1999), Department of Health: London

## 7 Appendix A

**Table 1 – Primary Care Trusts and Disabled Access**

Questions	% of Primary Care Trusts answering Yes	% of Primary Care Trusts answering No	% of Primary Care Trusts answering Don't Know
1. Is it part of your policy and practice to ask services within your Trust to assess their disabled access?	93%	6%	0%
2. Are any of the services in your Trust currently working to resolve disabled access issues?	93%	3%	3%
4. Does your Trust provide practice staff with disability equality training (including any externally commissioned training)	50%	34%	13%
5. Have you consulted disabled users of primary care services in order to identify any problems of disability access?	54%	30%	14%
6. Have you consulted disabled users of primary care services in order to find solutions to any problems of disability access?	47%	37%	14%