bridging the gap:
improving access to primary healthcare services for disabled people
About the Scottish Consumer Council

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- carrying out research into consumer issues and concerns;
- informing key policy and decision-makers about consumer concerns and issues;
- influencing key policy and decision-making processes;
- informing and raising awareness among consumers.

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These are:

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Can consumers actually get the goods or services they need or want?

CHOICE
Can consumers affect the way the goods and services are provided through their own choice?

INFORMATION
Do consumers have the information they need, presented in the way they want, to make informed choices?

REDRESS
If something goes wrong, can it be put right?

SAFETY
Are standards as high as they can reasonably be?

FAIRNESS
Are consumers subject to arbitrary discrimination for reasons unconnected with their characteristics as consumers?

REPRESENTATION
If consumers cannot affect what is provided through their own choices, are there other effective means for their views to be represented?

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Chairman’s preface

The needs of disabled people are increasingly recognised by service providers, not least because of the impact of the Disability Discrimination Act. Last year we decided to find out how primary healthcare providers were responding to the challenges of making services accessible. We wanted to find the best examples of practice in Scotland, and to find out what had been the drivers which had led to successful changes in practice.

Our results are somewhat disappointing. The responses to our survey of service providers did not uncover very many examples of what we considered good practice. Six of the best of these form the basis of this report. They varied in scope and focus, and all had achieved positive improvements for disabled people. Nonetheless, there were still areas which could have been better. For example, in some of the projects involving new premises or the refurbishment of older premises there was limited evidence of involvement of, or consultation with, disabled people, with service providers often relying on the building regulations to keep them right on aspects related to the physical accessibility of buildings.

However, there are aspects of all these six case studies which do highlight the things which can make a difference to disabled people. This can range from things which make individual consultations with a particular care provider better, to things which contribute to the involvement of disabled people in the planning processes going on at NHS board level.

I hope that primary care providers across Scotland will find this report helpful as they think about how to ensure that their services do not discriminate against a significant percentage of Scottish patients.

Graeme Millar
CHAIRMAN
Acknowledgements

We would like to thank the staff and disabled people who we spoke to about the six case studies.

This research was overseen by the Health and Social Care Committee of the Scottish Consumer Council. At the time, the members of the committee were John Hanlon (chair), Liz Breckenridge, Isabelle Low, Mukami McCrum, Helen Tyrrell, John Wright, Graeme Millar (ex officio), Heather Brash (ex officio) and Martyn Evans (ex officio).

The interviews with staff and disabled people were conducted by Carole Millar of Carole Millar Research, assisted by Anna Ritchie, Researcher at the Scottish Consumer Council. Anna Ritchie also carried out the survey and analysed the results.

The report is based on a fuller report of the focus group work by Carole Millar Research which can be viewed on the Scottish Consumer Council website.

A short report and checklist for primary healthcare providers is also being produced. This can also be accessed through the Scottish Consumer Council website.
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1 Introduction

During 2004 the Scottish Consumer Council carried out research to explore how well primary healthcare services have responded to the needs of disabled people, in the light of the requirements of the Disability Discrimination Act 1995, and a range of policy initiatives from the Scottish Executive Health Department. This short summary report highlights the key findings of this research and provides some useful checklists for primary healthcare providers who want to improve the service they are providing. A full report of the research can be found on the SCC website. A much shorter practical summary of the research is also being produced, aimed at primary healthcare providers, Community Health Partnerships and NHS boards.

1.1 Why we carried out this research

Following discussions with the Disability Rights Commission and the Scottish Executive Health Department, we decided it would be useful to carry out some research which could be used to encourage service providers to improve and extend access to primary healthcare services for disabled people. To do this, we would focus on existing examples of good practice and explore, with service providers and with disabled people, the factors which have contributed to this good practice in the NHS.

1.2 What we did

Phase 1

We carried out a short literature review to identify some of the key themes, and the areas in which there was already evidence about the experience of disabled people, and the barriers which they faced in accessing primary healthcare services.

Phase 2

The second phase of the research aimed to identify examples of good practice. A short survey was sent out to the following people:

- disability advisers in NHS boards
- primary care trusts
- LHCC general managers
- NHS Education Scotland
- professional bodies
- organisations of and for disabled people
- disabled people.
The survey asked if they knew of any particular initiatives or examples of working practice which had been undertaken either specifically to address disability discrimination, or which they considered had improved the accessibility of primary care services to disabled people.

We were particularly interested in the following things:

- whether the service provided accessible information
- whether the premises were accessible
- were staff attitudes good
- whether the service was flexible enough to respond to individual needs
- whether staff communicated effectively with disabled people
- what support there was for patients and staff.

**Phase 3**

We identified seven examples to explore in more detail. To do this, we interviewed NHS staff involved in the initiative to obtain more information and details, and to establish:

- the factors which led to the initiative
- how it was implemented
- the extent to which disabled people were involved in its planning and design
- how staff had benefited from the initiative
- whether there was any disability equality policy or statement in use
- what the initiative cost and where the budget for this came from.

In each case study, we tried wherever possible to hold focus groups with relevant groups of disabled people living in the area to explore the extent to which they believed the project or initiative had improved their access to services. Where it was not possible for patients to participate in a focus group, individual interviews with patients were undertaken.

### 1.3 Being clear about what we mean - definitions

**Primary healthcare services**

We limited the research to primary healthcare services, which include services provided in the community by doctors, dentists, pharmacists, opticians and other health professionals such as physiotherapists and chiropodists, to whom members of the public can refer themselves directly. We did not include accident and emergency services.

We did this for various reasons. Primary care health services are the first point of contact with the health service for service users, and the current policy within the NHS is that ‘if it can be done in primary care then it should be done in primary care’¹. The vast majority of patient experience of the NHS is in the local community in primary healthcare settings, and so any improvements to access in this area will be of benefit to considerable numbers of people.

In addition, there are particular difficulties in encouraging improvements in accessibility in the primary care sector as the majority of staff providing the services are independent contractors and not NHS employees. They therefore bear most of the cost associated with making improvements, for example to their premises, although there are sometimes funds available from the NHS to support this.

**Access**

We have used a definition of access which includes three elements: accessibility, availability and acceptability.\(^2\) This makes it possible to consider the following aspects of access under these headings:

| Accessibility          | • Geography and location  
|                        | • Transport               
|                        | • Physical barriers       
|                        | • Cost                    |
| Availability           | • Appointment systems and waiting times 
|                        | • Opening hours           |
| Acceptability          | • Communication           
|                        | • Language or culture     
|                        | • Privacy and confidentiality 
|                        | • Attitudes               |

**Disabled people**

For the purposes of the research we have included all those covered by the Disability Discrimination Act 1995. The Act defines a disabled person as someone with ‘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’.

**Good practice**

In deciding whether something could be described as good practice for the purposes of our research we considered it had to:

- be in a primary care setting
- aim to be of significant benefit to disabled people – by addressing a clearly identified barrier
- address one of the aspects of access described above
- have been implemented and not just in the planning stage
- demonstrate an awareness of the importance of improving access for disabled people
- have been of benefit to disabled people

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2 Setting the context: the policy background

One in five people in Britain (approximately ten million) have some kind of disability. Scotland has almost one million adults covered by the Disability Discrimination Act (DDA). Disabled people generally find accessing goods and services more inconvenient than non-disabled people. Access to health services, particularly hospital out-patient departments, has been shown to be a particular problem.3

2.1 Disability Discrimination Act 1995

The DDA makes it unlawful for those who provide goods, facilities and services to discriminate against disabled people by treating disabled people less favourably for a reason related to their impairment, without justification. Employers and service providers have a duty to make reasonable adjustments for disabled people. This applies to the NHS as much as to any other service provider. It may involve providing ‘an auxiliary aid or service’ such as information in large print, changing a policy or practice – for example, approaching a deaf person directly when it’s their turn to see the doctor, or finding an alternative way to provide a service, for example providing the service at home.4

From October 2004, organisations and businesses which provide goods or services to the public are required to remove, alter, or provide reasonable means to avoid physical features that make it impossible or difficult for disabled people to use a service.

To achieve implementation of the DDA in the NHS, all staff should not only know their responsibilities under the DDA, but they should also understand the social model of disability.

2.2 Scottish Executive Health Department guidance and policy

Equality and diversity

The Scottish Executive Health Department issued guidance entitled Equality for disabled people in Scotland in August 1999 on access to services for disabled patients. While the focus of the guidance is on hospitals, the content is equally applicable to other parts of the health service. It recommends that NHS organisations should have a local strategy on access to services for disabled people and designate a member of staff as a disability services adviser. The guidance focuses on communication with disabled people, improved awareness of disability and its impact in particular situations, physical access, and changes in procedures and routine practices which may be needed to make services more accessible for disabled people.

The Scottish Executive Health Department (SEHD) is currently carrying out work leading towards developing a generic equality policy for the NHS in Scotland, known as Fair for All. The Minister for Health and Community Care recently announced a new partnership between the NHS in Scotland and the Disability Rights Commission to ensure equity of access to healthcare.

3 Scottish Household Survey, quoted in Disability Rights Commission, Disability in Scotland 2002: key facts and figures, DRC, Edinburgh, 2002
Accessible and responsive services

The health plan Our National Health published in 2000 set out the core aims of the NHS in Scotland and stated that:

*Extending access, reducing waiting and improving the way the NHS responds to the needs of patients must be a key priority for every part of the NHS.*

*Our National Health* sets out a range of ways in which the NHS will make its services accessible to disabled people. These include monitoring the training and awareness of NHS staff about existing good practice on disability issues, improving physical access to health services, meetings and offices by carrying out an audit of all NHS premises, and ensuring that the NHS complies with the Disability Discrimination Act.

The NHS in Scotland is giving a high priority to patient focus and public involvement, through a range of initiatives associated with the *Patient Focus and Public Involvement* framework. The commitment to patient-centred services should be apparent at every level within the health service.

NHS Quality Improvement Scotland (NHS QIS) has been established to improve the quality of healthcare in Scotland by setting standards and monitoring performance and by providing advice, guidance and support to the NHS. Its generic clinical governance standards include a focus on access to services, communication with patients, involvement of patients and the public, and patient information.

The recent NHS QIS report *Safe and Effective Patient Care* found that NHS organisations in Scotland are generally reactive rather than proactive, responding to problems rather than anticipating and potentially avoiding them. It also found that very few NHS organisations were routinely involving patients in decisions about their care and in the development of services and policies, and that communication with patients is an issue that gives rise to concern. It is likely that their involvement of and communication with disabled patients will be, at best, in line with practice in general, but potentially not even up to that standard, as it is inherently more complex.

### 2.3 Conclusion

At the present time there are significant drivers requiring the NHS in general to address the extent to which it is meeting the needs of disabled people in the way it plans and provides services. These drivers are legislative (Disability Discrimination Act 1995), regulatory (NHS QIS), and as a result of policies such as that contained in the White Paper on health, *Partnership for Care*, and *Fair for All*, as well as the requirements of Best Value and Community Planning which are likely to impact on health policy.

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3 Research findings

3.1 Responses

Surveys were sent to 105 primary healthcare providers, with 33 responses returned. Surveys were sent to 274 disabled people and organisations for, and of, disabled people and 46 responses were received. The responses received from primary care providers offered some examples of good practice. Seven of the 33 offered no examples at all. The responses from disabled people contained very few examples of good practice, with many respondents describing the problems they experienced in accessing services. None of the case studies chosen to explore in more depth were nominated by disabled people. This negative feedback was echoed in the focus groups with disabled people, who very often talked about problems and negative experiences as opposed to what had improved.

3.2 Identifying case studies for further exploration

We aimed to explore eight examples of good practice. Ideally, we wanted to cover a range of primary care settings, for example GP surgeries, dentists, pharmacies etc, and to find examples which were addressing the needs of people with a range of types of impairment.

After examining the responses, we decided to add initiatives which were happening on an NHS board-wide basis, using a particular process like a disability working group or a disability adviser, to explore the impact this could have in primary care settings.

Our short list included the following:

- a dental practice which brought together several small practices on one site, and undertook extensive work to convert a building for this purpose, seeking to improve accessibility (Oban);
- a health centre which had developed and extended its premises (Glasgow);
- a new multi-agency centre containing both NHS and other community services (West Lothian);
- a disability adviser who was appointed to tackle disabled access across one NHS board area (Forth Valley);
- a disability advisory working group which brought together disabled people and service providers at primary care trust level (Ayrshire and Arran);
- work in a range of healthcare settings to improve communication, particularly with people with learning difficulties, through the use of symbols (East Lothian); and
- a GP practice which was aiming to meet the needs of deaf and hard of hearing patients (Shetland).

nine out of the 46 responses were from people who work for an organisation of, or for, disabled people and did not have an impairment.
We were unable to take forward any work in Shetland, and so the research is based on the six remaining initiatives listed above.

The lessons which we believe can be drawn from these six initiatives are set out below. However, the difficulty of identifying examples of good practice does suggest to us that there is still a substantial gap between policy intentions and legislative requirements and the reality of the experience of disabled people throughout Scotland.

The six examples which we chose to explore in greater detail all have positive aspects, and demonstrate that there are many people who are taking seriously the importance of improving access for disabled people. Nonetheless, we were disappointed not to find more examples of good practice.

In the following chapters we describe the key drivers for change, the factors which promote change, the things which continue to make change difficult, and the patient experience. Our conclusions are set out in Chapter 8. Appendix 1 contains a checklist of do’s and don’ts for primary care providers, based on our research findings. Appendix 2 provides more detail about the six case studies.

A summarised version of this report and checklist for primary healthcare providers is also being produced and distributed to GP surgeries, dental surgeries and pharmacists.
4 Key drivers for change

The key drivers for change in the six initiatives were as follows:

- Building regulations – a move to refurbished or new premises was recognised as an opportunity to improve access for disabled people.
- Disability Discrimination Act – the DDA was seen as influential in pushing access for disabled people up the agenda and its greater priority meant that there was the possibility of funding to support improvements.
- The lobbying from disabled people and their organisations helped to keep disabled access on the agenda.
- Currently, service providers appeared to be more likely to drive change than disabled people at a local level.

4.1 Building regulations

In three of our case studies, it was a move to different premises or a major refurbishment of an old building which provided the opportunity to make major changes to improve physical access. The requirements of current building regulations means that in terms of physical accessibility, any new building should be fully accessible.

Recognising the importance of the opportunities that such upgrading brings, the Disability Awareness Working Group (DAWG) in Ayrshire and Arran has representation from the NHS board’s estates department on their group. The Disability Adviser in Forth Valley also works very closely with the estate department in that area. Both would be consulted about any new builds in their area.

Where changes were driven primarily by building regulations, this was not necessarily coupled with any consultation with disabled people to explore whether the service provider should go beyond what building regulations required. The project manager for the Strathbrock Centre did conduct an audit, using a local disability organisation, ten months before the centre opened. At the Oban dental practice there was no consultation although the needs of disabled people were taken seriously.

One of the hazards of relying on building regulations is that these change, and the Strathbrock centre found that while the width of doors met the regulations at the start of their project, by the time it was built these had changed, and the doors were now thought to be too narrow. Involving disabled people can highlight the need to go beyond the building regulations in order to meet people’s needs.
4.2 Legislation

Disability issues have been given greater prominence by the DDA. The general feeling was that while the DDA had initially been seen as threatening and a challenge, it was now viewed more positively.

The work on the Oban dental practice was carried out 12 years ago, and so was not in any way driven by legislative change.
5 Doing it better – factors which promote change

Our research suggests that there are several things which are likely to promote change in practice. These are as follows

- Effective partnership working
- Consultation with disabled people
- Awareness of the needs of disabled people
- Effective use of resources
- Flexibility
- Support for staff
- A learning culture – evaluation and feedback

5.1 Effective partnership working

- This allows changes which individual practitioners could not achieve alone. This was the case with three of the case studies, where services had come together in new or refurbished premises.
- Solutions can be found in a collaborative way. For example, the DAWG in Ayrshire and Arran brought together a wide range of people to tackle problems in a creative and collaborative way. Similarly, the disability adviser in Forth Valley aimed to work across sectors and agencies to develop improvements in services.
- It allows good practice developed in health services to be shared with other public services, and vice versa. Several of our case studies involved local authorities as well as NHS staff (DAWG, Strathbrock and the Forth Valley disability adviser). The East Lothian Inclusive Communication project hopes to extend its work to local authority settings.
- It was however pointed out that the more partners there are, the more complex it becomes to reach decisions (eg the Strathbrock centre, where 12 partner agencies were involved all with an equal voice).

5.2 Consultation with disabled people

- Consultation with disabled people was recognised by health boards as very valuable although it required considerable effort to set up. In Ayrshire and Arran the existence of DAWG meant that consultation at health board level had become routine, and very much the norm. Some health service staff used DAWG to make contact with more local disability groups or access panels, thus promoting local consultation.
- Local initiatives sometimes lacked a structure and, as a result, consultation was not always as thorough as it could be in health board-wide initiatives.
• Comprehensively consulting disabled people can involve large numbers, which some service providers might find daunting. The aim should be to find a way of involving a wide range of disability groups so that people feel their interests are being represented, as well as having appropriate representation from staff departments and senior management.
• Even where service providers had a commitment to consultation with patients and members of the public (as in Strathbrock), they had not always succeeded in facilitating effective consultation with disabled people in their area.
• More work is required to encourage disabled people to sit on generic patient groups or forums.
• In at least one of our case studies (Oban) the service provider was unaware of any disability group being in existence at the time of the premises conversion which could have assisted with consultation.

5.3 Awareness of the needs of disabled people

• More needs to be done to improve attitude and awareness amongst health service providers.
• Training was seen as the main means of achieving this.
• Disabled people would like to see disability awareness training included within core training and prior to registration, and not as being optional. The DAWG is actively developing ways of including disability awareness in other training programmes. In Forth Valley disability training is now built into the induction of all new NHS staff. In the Strathbrock centre, all staff moving into the new building undertook disability awareness training. The café in the centre is run by Capability Scotland, with training places for young disabled people, which is considered to reinforce the awareness of those working in the centre.
• Despite a willingness and interest in training, time and resources represent a barrier to more training being undertaken.

5.4 Effective use of resources

• Money and resources will always be limited, so setting priorities to ensure that any funding is spent to best effect is important. This might be ensured via an access audit or a needs analysis. The input from the disabled community is also important in setting priorities. In Forth Valley an audit was undertaken in areas with the greatest numbers of patients.
• When viewed across an entire health board area the number of improvements required can be overwhelming. There is therefore a need to take one step at a time, constantly prioritising to ensure money spent makes the greatest improvement for the greatest numbers of people.
5.5 Flexibility

- Providers tended to see themselves as flexible in their approach and were generally keen to help anyone who needed it, although there was not always a way of identifying who needed help. Annotating health records to alert staff to that need is one means, as is encouraging people to ask for help. The dental practice in Oban made efforts to ensure that disabled people would receive help in getting up their ramp, as people in a wheelchair were likely to need assistance. The Strathbrock Centre is beginning to use text messages to communicate with some patients with a hearing impairment.

5.6 Support for staff

- Ongoing support for staff as well as training was seen as important if improvements were to be maintained and staff to be confident in their relationship with disabled patients. This was something which is considered to be a particular advantage of having a disability adviser operating at NHS board level.
- It is important that all staff are supportive of any initiatives and this may involve some work to communicate the importance of the initiative to staff directly involved. This was the experience of the East Lothian Inclusive Communication project.
- Support from senior management was also seen as essential. In Ayrshire and Arran a board director sits on DAWG, and until recently there was also a non-executive director present. This helped with communication from community level to senior management.

5.7 A learning culture – evaluation and feedback

- None of the examples in this study had received any formal evaluation although most recognised the value of getting feedback from disabled people to identify which improvements had been most effective and to identify any further barriers. In Forth Valley the disability adviser looks at the levels of use of services such as BSL interpreters as one indicator of the success of particular initiatives. They also monitor the level of referrals from staff, who may be gaining in confidence in communicating with disabled people and dealing with difficulties without referring to the disability adviser. In the Strathbrock centre they are using opinion meters in the building which contain an on-screen questionnaire which will be able to be used to assess the feedback from different groups, including disabled people.
6  The continuing challenge -
barriers to change

Although the intention of the research was to focus on good practice and the drivers behind it, it inevitably uncovered many of the barriers which continue to prevent change from happening. These fall under the following headings:

- Funding
- Staff resources
- Legacy of the NHS estate
- Staff attitudes
- Focus on physical disability
- Lack of consultation of disabled people
- Conflicting needs of different groups

6.1  Funding

- The cost of improvements by independent contractors, for example dentists, is borne by those contractors rather than the NHS.
- Grants that are available sometimes come with unattractive conditions.
- Funds to make NHS estates fully accessible are limited and are competing with other health priorities. The Rutherglen centre had much less money available to improve accessibility than they would have liked.
- Where funds are limited, more work may be done in low cost areas, which will nonetheless have benefits for disabled people, for example changes in car parks, lowering kerbs, installing ramps and rails, and improved signposting.
- Accessing funds at the right time is not always possible – sometimes it is difficult to build in consultation with disabled people as funds have to be spent within a set time frame.
- There may be a lack of knowledge about how to put forward a robust proposal for funding.
- Improvements to properties are less likely to happen if a move to new premises is imminent or expected within a few years.

6.2  Staff resources

- It is difficult for staff working in primary care to get time off to attend training.
- It is not a good use of resources for all staff to receive specialist training which they would not use enough to keep their skills up to date. Forth Valley would prefer to train key front line staff such as receptionists rather than attempting to train all staff. Similarly they recognised that it did not make sense to train all staff in the use of British Sign Language, because it took a lot of time to train and needs to be kept up to date by regular use.
• The impact of producing information in a range of formats needs to be assessed to calculate how much should be done. The dentist in Oban felt it would be unreasonable to expect him to communicate to one patient in Braille. This is an issue which will be faced by many small practices.

### 6.3 Legacy of the NHS estate

• Many premises within the NHS estate would either be very costly or impossible to make fully accessible. One estates manager indicated that £2-3m would be needed, but that his budget was only £200,000.
• One solution suggested by DAWG was for dentists, for example, to make sessional use of accessible premises.

### 6.4 Staff attitudes

• The attitude of staff remains a significant barrier, with some staff unwilling to provide a more flexible service to compensate for the physical barriers.
• The way to tackle this would be for more training to be provided for staff.
• Patients are often reluctant to ask for help. To get around this, DAWG have developed a poster saying ‘If you need help, just ask’ to encourage those who have a hidden disability to seek help.

### 6.5 Focus on physical disability

• There is a tendency to focus on improving access for physically disabled people. Disabilities such as learning disability or mental health problems receive much less attention.
• Access to information receives less attention than physical access.

### 6.6 Lack of consultation of disabled people

• There remains a lack of consultation particularly at a local level where there are less likely to be structures in place to facilitate it. There was little evidence of consultation with disabled people, except in Forth Valley and Ayrshire and Arran, where this was something which underpinned the work of the disability adviser and DAWG.

### 6.7 Conflicting needs of different groups

• Conflicts can arise between meeting the needs of different groups of people. In Oban, patients pointed out that bumps placed outside a building to help people with a visual impairment had to be removed as those in wheelchairs found it very difficult to get into the building.
• The requirements of disabled people sometimes conflicted with what was required to comply with health and safety regulations, for example heavy fire doors which were hard for people in a wheelchair to open.
7 The patient experience – the impact of good practice on patients

We aimed to explore how far the six initiatives had made a difference to patients.

Key Findings

- Low awareness of improvements
- Patients’ perceptions
- The diverse needs of disabled people
- Patient involvement

7.1 Low awareness of improvements

- Patients catered for within refurbished buildings tended to see access as being good.
- The awareness of improvements, apart from those areas where a specific refurbishment had been undertaken, was not high. The sheer scale of the improvements required, combined with the fragmented nature of some improvements, resulted in many patients being unaware of any change.
- Improvements that had been made tended to get taken for granted very quickly while attention shifted to those things that still needed to be improved.
- Some changes, such as the use of symbols, represented an improvement in access, and were appreciated.

7.2 Patients’ perceptions

- Despite asking patients to describe the good aspects of provision, there was a tendency to focus on aspects of service that still required improvement.
- Patients recognised the cost and resource implications of making improvements to services.
- Patients’ perceptions of staff attitude were generally favourable, with disability awareness thought to be increasing. However, some did feel that further disability awareness training would benefit even the most well-meaning of staff.
- Patients saw provision of information for disabled people as receiving notably less attention than physical access and asserted that this is an issue that requires to be addressed.
7.3 The diverse needs of disabled people

- Patients agreed that it was difficult to meet the demands of all because of the diverse and sometimes conflicting needs of disabled people.
- A few would not like heavy handed enforcement of disability discrimination measures in case attitudes towards disabled people, which are currently seen as good, worsen.

7.4 Patient involvement

- Patients liked the idea of being able to have a say in the way services were provided and to have the opportunity to explain their views. They would like to be involved and consulted to a greater extent than they currently are, even if it was as infrequently as once a year.
8 Conclusions

This research does show that access to primary healthcare services for disabled people is being tackled by some service providers in a range of ways. However, the difficulty of identifying examples of good practice suggests there is still a substantial gap between policy intentions and legislative requirements, and the reality of the experience of disabled people throughout Scotland.

The six examples which we chose to explore in greater detail all have positive aspects, and some demonstrate the potential of particular approaches, for example the impact which a disability adviser can have across a health board area, or the way in which new or refurbished premises can significantly improve access to services. They all demonstrate a desire to make services better for disabled people, and also show how challenging this can be.

Some of the initiatives which we looked at were not primarily driven by the recognition that services must be made more accessible for disabled people, but simply by the requirement of building projects to meet current building regulations. Not all the service providers had consulted or involved disabled people to any great extent. There was limited emphasis on the importance of disability equality training which disabled people consider to be of central importance. Finally, there was little evidence that disabled people themselves had noticed much real improvement in their experience of primary healthcare services.

Our research suggests that service providers need to give greater thought to how they consult with disabled people, and to plan this in a strategic way. This is more likely to be successful where there is a dedicated resource available to support and enable such work. A disability adviser based in an NHS board can contribute to this.

It is equally important not to think that disabled people need special arrangements to be involved or consulted. More work is needed to encourage disabled people to sit on generic patient groups or forums. The new Community Health Partnerships (CHPs) will be a new forum in which it will be important to hear the voice of disabled people, and CHPs should ensure that disabled people are represented on the Public Partnership Forums which they will be obliged to set up by April 2006.

It is also important to remember that a great deal of the care which is provided in primary care settings is carried out on a one-to-one basis. The quality of the interaction between the health professional and the disabled individual will be very important in determining how satisfied disabled people feel with the care and treatment they have received. While much will depend on the awareness and training of individual health professionals, it is likely that disability advisers working at board or CHP level can help to raise the awareness of service providers, and support the kind of training which will make the difference to disabled people.
Staff training in disability equality continues to be crucially important to the experience of disabled people when they use services, and primary care providers need to make sure that the people who need such training are getting it.

The two appendices which follow attempt to draw some positive lessons out of this research, suggesting ways in which primary care providers can begin to tackle the many barriers which still exist in primary healthcare services for disabled people.
Appendix One
Checklist for primary care providers

<table>
<thead>
<tr>
<th>Do</th>
<th>Don’t</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Work out what you need to do</strong></td>
<td></td>
</tr>
<tr>
<td>Carry out a needs assessment or disability audit to find out what needs to be done</td>
<td>Ignore the DDA</td>
</tr>
<tr>
<td><strong>Consult with disabled people</strong></td>
<td></td>
</tr>
<tr>
<td>Consult with your disabled patients – find out if there is a local disability group or access group and make links with it</td>
<td>Do nothing because it’s all too complicated – take one step at a time</td>
</tr>
<tr>
<td><strong>Find out what other help is available</strong></td>
<td></td>
</tr>
<tr>
<td>If your NHS board does not have a disability adviser or disability working group, encourage the board to consider appointing an adviser and setting up a disability group or forum at board or CHP level</td>
<td>Assume that if it meets the building regulations, that is all you need to do. Often small additional changes can produce significant benefit for disabled people.</td>
</tr>
<tr>
<td>Find out if there is a disability group or forum connected with your local authority which you could use for consultation</td>
<td>Assume that there is nothing you can do – even if you have inaccessible premises, think of alternative ways of providing a service</td>
</tr>
<tr>
<td>Find out about possible sources of funding – ask the disability adviser at your NHS board</td>
<td>Assume that you know what is most important in improving access – ask disabled people</td>
</tr>
<tr>
<td>Think about getting together with other partners to tackle disability issues together – for example, it may be more cost effective to produce accessible information at CHP level than in an individual practice</td>
<td></td>
</tr>
<tr>
<td><strong>Remember the needs of different groups</strong></td>
<td>Ignore the competing concerns of different groups – get them together to discuss how to proceed</td>
</tr>
<tr>
<td>------------------------------------------</td>
<td>--------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td></td>
<td>Focus on physical barriers – making improvements in communication can make a real difference for some disabled people</td>
</tr>
<tr>
<td><strong>Remember the range of solutions</strong></td>
<td></td>
</tr>
<tr>
<td>Think about how you provide information for disabled people – Scottish Accessible Information Forum (SAIF) guidelines should help with this</td>
<td>Forget about the importance of making information accessible</td>
</tr>
<tr>
<td>Think about alternative ways of providing a service, for example making sessional use of accessible premises</td>
<td></td>
</tr>
<tr>
<td><strong>Communication</strong></td>
<td></td>
</tr>
<tr>
<td>Check whether patients need any help with communication</td>
<td></td>
</tr>
<tr>
<td>Check that your patients have understood what you have said to them</td>
<td></td>
</tr>
<tr>
<td><strong>Keep the process going</strong></td>
<td></td>
</tr>
<tr>
<td>Encourage an ongoing process of improving access – there is always more which you can do</td>
<td></td>
</tr>
<tr>
<td><strong>Training</strong></td>
<td></td>
</tr>
<tr>
<td>Arrange for your staff to have disability equality training – this is particularly important for reception and other front line staff</td>
<td>Think that you have to train all staff – focus on key front line staff for disability awareness training</td>
</tr>
<tr>
<td><strong>Feedback</strong></td>
<td></td>
</tr>
<tr>
<td>Tell people what you have done – people need to be reminded that things are better than they used to be</td>
<td></td>
</tr>
<tr>
<td>Find out what disabled people think about your services – think about how you will get feedback</td>
<td></td>
</tr>
</tbody>
</table>
Appendix Two
Examples of good practice – summary findings

Ayrshire and Arran Disability Awareness Working Group (DAWG)

This group was set up in 1999 to encourage an inclusive approach within the primary care trust. It has a wide membership, including representatives of local disability forums in Ayrshire and Arran, local access panels, the local health council, local authorities, the NHS board and the Scottish Accessible Information Forum.

<table>
<thead>
<tr>
<th>Good points</th>
<th>Limitations</th>
<th>Achievements</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disabled people and providers sit round the table on a regular basis</td>
<td>Independent contractors (eg GPs) are not involved</td>
<td>Action audits have led to improvements eg in colour contrasts in premises, installation of disability aids such as grab rails, improved signage.</td>
</tr>
<tr>
<td>Disabled people represent local groups of disabled people</td>
<td>Most effective in relation to large building projects.</td>
<td>Involved at planning stage in refurbishments.</td>
</tr>
<tr>
<td>Any issue can be raised</td>
<td>People with learning disabilities not included to date</td>
<td>Have tackled abuse of disabled parking bays</td>
</tr>
<tr>
<td>New projects routinely brought to group</td>
<td></td>
<td>Developed a poster saying ‘If you need help, just ask’ to encourage people who have a hidden disability</td>
</tr>
<tr>
<td>Local authority represented as well as NHS board</td>
<td></td>
<td>Consultation about patient information</td>
</tr>
<tr>
<td>Raises awareness of disability</td>
<td></td>
<td>Working on including disability awareness in training programmes</td>
</tr>
</tbody>
</table>
Forth Valley Disability Adviser

Despite the SEHD guidance in 1999 that NHS boards should have a disability adviser, at the time of our research it was only in Forth Valley that this was being taken forward in a proactive way, although it is expected that other boards will be appointing disability advisers in the near future.

<table>
<thead>
<tr>
<th>Good points</th>
<th>Limitations</th>
<th>Achievements</th>
</tr>
</thead>
<tbody>
<tr>
<td>Covers primary and acute care across entire NHS board area</td>
<td>Disabled people not always aware of changes in practice</td>
<td>Disability group set up with representatives of staff and patients</td>
</tr>
<tr>
<td>Works closely with estates department</td>
<td></td>
<td>Strategic planning group set up with representation from local authorities</td>
</tr>
<tr>
<td>Co-terminosity with local authority boundaries</td>
<td></td>
<td>Disability training built into induction for all new NHS staff, including GP staff such as receptionists</td>
</tr>
<tr>
<td>Adviser is at centre of disability network</td>
<td></td>
<td>Training in specific areas carried out</td>
</tr>
<tr>
<td>Input into design of new build and refurbishments</td>
<td></td>
<td>Developed an audit tool</td>
</tr>
<tr>
<td>Strong initial focus on sensory impairment</td>
<td></td>
<td>Developed tape for GP practices describing services available</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Disability equality policy drafted</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Guidelines produced for each care area about what to do if someone comes in who has a particular disability</td>
</tr>
</tbody>
</table>
Oban dental practice

Before the development of these refurbished premises, the dental practices which are now housed were all up a flight of stairs in the town centre. The partners have been committed to making the practice as accessible as possible to disabled people.

<table>
<thead>
<tr>
<th>Good points</th>
<th>Limitations</th>
<th>Achievements</th>
</tr>
</thead>
<tbody>
<tr>
<td>Commitment by practice staff to improving access</td>
<td>Cost of refurbishment means practice no longer offers NHS treatment except to patients who are exempt from charges</td>
<td>Dentists can treat patients in wheelchairs</td>
</tr>
<tr>
<td>Flexible staff encouraged to respond to individual patient needs</td>
<td>Physical access not perfect – eg the ramp up to the building is quite steep</td>
<td>Wide doors, reduced threshold at doors, contrasting door colours</td>
</tr>
<tr>
<td>Dental provision no longer up stairs</td>
<td>No disability equality awareness training</td>
<td></td>
</tr>
</tbody>
</table>

Strathbrock Partnership Centre

This is a flagship development which is often cited as an example of the future of health service premises.

<table>
<thead>
<tr>
<th>Good points</th>
<th>Limitations</th>
<th>Achievements</th>
</tr>
</thead>
<tbody>
<tr>
<td>Different agencies in same premises, including social work, housing, mental health resource centre, council information services, carers centre, pharmacy, community health services, three GP practices and café</td>
<td></td>
<td>Local disability organisation ‘road tested’ the new building and as a result some changes were made, for example induction loops at every desk.</td>
</tr>
<tr>
<td>Single point of access to services</td>
<td>Automatic doors installed as a result of feedback from centre users</td>
<td></td>
</tr>
<tr>
<td>Single point of access to information about services</td>
<td>All staff trained in disability awareness before starting work in new centre</td>
<td></td>
</tr>
<tr>
<td>Shared use of resources</td>
<td>Young disabled people employed in the café which is run by Capability Scotland</td>
<td></td>
</tr>
<tr>
<td>Service user involvement built in</td>
<td>Using text messages to communicate with people with a hearing impairment</td>
<td></td>
</tr>
<tr>
<td>Emphasis on primary care</td>
<td>Using opinion meters to get feedback on service users’ experience of the centre</td>
<td></td>
</tr>
<tr>
<td>Centre has developed links with disabled organisations and groups</td>
<td>Taking steps to make disabled parking bays legally enforceable</td>
<td></td>
</tr>
</tbody>
</table>
**Rutherglen Primary Care Centre**

This is an example of a refurbishment of old and restricted premises. The centre is built around a bright and spacious mall with a new build on one side and refurbished premises on the other. Three of the practices own their premises, while the remaining three rent from the NHS.

<table>
<thead>
<tr>
<th>Good points</th>
<th>Limitations</th>
<th>Achievements</th>
</tr>
</thead>
<tbody>
<tr>
<td>Symbols developed in consultation with people with communication difficulties</td>
<td>The use of symbols has to be learned by both staff and patients</td>
<td>Staff training in use of symbols raised awareness of needs of disabled people</td>
</tr>
<tr>
<td>Aims to help a wide range of people including those with a learning disability, people who have had a stroke and people with dementia</td>
<td>Not everyone would agree that the use of symbols is the best way to improve communication with people with learning disabilities</td>
<td>Simple text information leaflets with use of symbols developed for each clinic.</td>
</tr>
<tr>
<td>Helps reduce anxiety on part of patients</td>
<td></td>
<td>Improved signage</td>
</tr>
<tr>
<td>Project raises awareness of staff as a result of the use of symbols in signage</td>
<td></td>
<td>Appointment cards which use symbols and contain photo of health professional</td>
</tr>
<tr>
<td>Consultation with patients and clinicians through public involvement worker</td>
<td></td>
<td>Symbolised instructions for taking medicine</td>
</tr>
</tbody>
</table>
East Lothian Inclusive Communication project

This project focuses on people with communication difficulties, and aims to make use of symbols to improve communication. The symbols have been developed from the Bonnington Symbols system. These symbols are being used in a hospital out-patient department in East Lothian. While an out-patient department is not strictly primary care, learning disability clinics are held which could equally take place in a health centre, and there is a degree of direct access. A parallel use of symbols is being piloted across GP practices and health centres in North Edinburgh Local Health Care Co-operative through the East Lothian Inclusive Communication in Health project.

<table>
<thead>
<tr>
<th>Good points</th>
<th>Limitations</th>
<th>Achievements</th>
</tr>
</thead>
<tbody>
<tr>
<td>Complies with current building regulations</td>
<td>Commitment to community involvement, but no regular involvement of disabled people</td>
<td>Front line staff getting disability training</td>
</tr>
<tr>
<td>Wider range of services provided locally, so less need for travel</td>
<td>Medical staff have not yet undertaken any disability training</td>
<td>Automatic doors</td>
</tr>
<tr>
<td>Consultation with physical disability team at Greater Glasgow Health Board fed into planning</td>
<td></td>
<td>Lowered reception desks</td>
</tr>
</tbody>
</table>

Consultation with physical disability team at Greater Glasgow Health Board fed into planning

Talking lift

Staff awareness training carried out