

## ENABLING INFORMATION

A Report on improving access and raising standards  
in information services for disabled people  
and their carers in Scotland

FINAL REPORT OF THE SCOTTISH WORKING GROUP ON INFORMATION  
SERVICES FOR PEOPLE WITH DISABILITIES

MARCH 1995

## THE ESTABLISHMENT OF THE WORKING GROUP

In February 1994 the Social Work Services Group of the Scottish Office Home and Health Department convened a meeting to discuss how to take forward the results of the Scottish Office survey, Survey of Information Services for People with Disabilities, which was carried out in June 1992. The meeting included representatives from the Scottish Office, the Benefits Agency and the Association of Directors of Social Work, as well as from the voluntary sector, and organisations of disabled people. It was agreed that a short life working group should be set up and that SWSG would convene the first meeting, although its role was to be a facilitator rather than having any control over the group. It was agreed at this meeting that the needs of children, those with a sensory impairment, ethnic minority groups, and people living in rural areas should be covered. The meeting agreed on the bodies which would be invited to send representatives to the group.

The members of the group were:

|                   |   |
|-------------------|---|
| Ann Foster        | Scottish Consumer Council, chairman   |
| Liz Beedie        | Edinburgh Disability Benefit Centre   |
| David Dunsmuir    | Disability Scotland (from September 1994)   |
| Gillian Fyfe      | Scottish Consumer Council (until July 1994)   |
| Alan Hyslop       | Common Services Agency, Health Systems Division   |
| Jackie Heaney     | Strathclyde Forum on Disability (until September 1994)                                      |
| Dougie Herd       | Lothian Coalition of Disabled People  |
| Mike McCarron     | Association of Directors of Social Work   |
| Andrew McNaughton | Scottish Office Home and Health Department, Social Work Services Group (from October 1994)  |
| Bill Moore        | Social Work Services Group, Scottish Office Home and Health Department (until October 1994) |
| Liz Nicholson     | Citizens Advice Scotland  |
| Lawrence Nugent   | Strathclyde Forum on Disability (from September 1994)                                       |
| Janet Thomas      | Disability Scotland (until September 1994)  |
| Shirley Young     | Children in Scotland  |

The support staff were:

|                |            |
|----------------|------------|
| Liz Macdonald  | Researcher |
| Margaret Regan | Secretary  |

The first meeting of the Working Group was held on 16 March 1994. At this meeting the remit of the group was agreed as follows:

- to consider how the provision of information for people with disabilities and their carers at national and local levels might be improved in the light of the experience and initiatives of existing information services in Scotland, the

findings of the Scottish Office survey, the experience of the National Disability Project (NDIP) in England and other initiatives and experience generally; and

- to produce a report by March 1995 for the consideration of the Secretary of State with concrete proposals, including rough estimates of costs for implementing provision in Scotland.

## EXECUTIVE SUMMARY

### **Introduction**

The Working Group was set up by the Scottish Office to consider how the provision of information for people with disabilities and their carers in Scotland might be improved. The group took account of the experience of existing information services in Scotland, the experience of the National Disability Information Project in England, and of developments elsewhere.

### **The existing pattern of provision**

Responses to the Working Group's statement indicated the following features in the present situation:

- wide variation in the provision of information services at local level throughout different parts of Scotland, and in the extent to which and the manner in which local authorities attempt to meet their statutory duty to provide information to disabled people;
- poor relationships amongst information providers at national and at local level, and between national and local level;
- concern about the quality of information available, and of the services providing that information;
- a need for more cooperation between agencies in the statutory sector, and between the statutory and the independent sectors;
- a desire for a central clearing house to distribute national information to local information services and to service providers, and to be an authoritative source of Scottish information; and
- a concern that too much time and effort is spent on collecting information and not enough on disseminating it and publicising the services available.

### **Proposals for improvement**

The Working Group bases its recommendations on certain propositions:

Disabled people need the same kind of information as everyone else, but often find it more difficult to access that information because of

- physical barriers;

- information not being in a form or a language in which they can understand it; and
- attitudinal barriers.

In addition disabled people need information and advice about disability benefits and other rights, aids and equipment for work or for daily living, about self help and support groups, and about independent living.

Disabled people and their carers tend to look locally for the information and advice they need.

In addition the Working Group accepts various principles which it thinks should underlie any improvement to existing provision:

Services should be designed so as to meet the needs of users, whether they are disabled people, their carers or professionals.

Disabled people must wherever possible be actively involved in the provision and management of such services.

The Working Group believes that the most significant way in which improvements can be made in getting information to those who need it is to improve the dissemination of information at local level, in such a way as to

make information and advice from generalist agencies more accessible, by improving the physical accessibility of general sources of information and advice, and by making it possible to produce information in a range of formats and appropriate languages;

improve the provision of specific disability information, with particular reference to the availability of resource centres for aids and equipment;

improve the awareness of disability among service providers of all types;

improve collaboration, multi-agency working, and networking at local level; and

ensure that national standards for the dissemination of information and advice are met by any organisation which receives funding from central ,or local government to provide this service.

## **Recommendations**

The Working Group recommends that, in order to achieve the improvements in the delivery of information and advice to disabled people and their carers at local level described above, the following steps should be taken:

Local authorities should be required to set up a strategy group to prepare a strategy for information and advice services in their areas. The strategy group should include representatives from the independent and statutory sectors, and involve disabled people.

The provision of national disability information to local service providers should be streamlined and improved in such a way as to meet the needs of those service providers and other users.

The development of standards for use in this area should be the responsibility of an advisory body which should be composed of disabled people, carers, and their representatives, together with people with other appropriate experience. This advisory body should also be responsible for the overview of the operation of information services for disabled people at national level.

With a view to streamlining the provision of national information to local services, a Scottish national disability information service should be established under the auspices of the advisory body.

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### PART 1 BACKGROUND

#### 1 INFORMATION AND WHY IT IS IMPORTANT

1.1 In 1977 the National Consumer Council described the right to information and advice as an irrevocable right of citizenship (1). Information empowers citizens in three ways:

- by enabling them to participate in the democratic process, for example by electing an MP or member of a school board;
- by enabling them to claim their rights and entitlements as citizens and as consumers; and
- by enabling them to take responsibility for the quality of their own life.

1.2 This right has been increasingly recognised both in legislation and in the development of information and advice services in the voluntary sector, with these services receiving funding from local authorities, central government and health boards.

One feature of this development has been the creation alongside general information and advice agencies, such as citizens advice bureaux, of more specialised services, either dealing with a particular kind of advice, eg consumer advice or housing advice, or to meet the needs of a particular group. The setting up of a working group on the delivery of information as part of the International Year of Disabled People recognised a distinct need for information services for disabled people. This group became the National Information Forum which works for the improvement of information for disabled people. Disablement Information and Advice Lines (DIALs) began to develop in the 1980s.

1.3 Local authorities and health boards have in recent years been required by legislation to provide information about their services to certain categories of people, including disabled people. They must also provide information about other relevant services of which they are aware.

1.4 In 1991 the government launched the Citizen's Charter initiative to make public services more answerable to consumers. The right to comprehensive and accurate information about services is an important element of the Citizen's Charter. As part of the Citizen's Charter initiative the Central Office of Information produced The Informability Guide in 1994 to promote good practice in ensuring that information is accessible to as wide an audience as possible, including people with literacy problems, sensory impairment or learning difficulties. The guide looks at different categories of impairment and describes the various media which can best be used to provide information. The Guide encourages information providers to consider accessibility at the start of every information project. The government also published in 1994 The Citizen's Charter and People with Disabilities, a checklist, to be used together with the

Informability Guide. The checklist considers each of the 6 charter principles (setting standards; information and openness; choice and consultation; courtesy and helpfulness; putting things right; value for money) and the particular considerations which might apply in relation to disabled people.

1.5 Disabled people need information about all the same sorts of things as other people.

"It is essential to remember that disabled people need much the same amount and type of information as everyone else. They too are consumers, employers, parents, drivers, holiday-makers. The common attitude that disabled people need only be addressed when the message relates to health or social service matters is clearly wrong, and patronising"(2)

In addition there is information which can be called "disability information" which may be information about disability benefits, about independent living, about the services available for disabled people, about aids and equipment, self help groups, or the effects of a disabling condition.

1.6 It is important to differentiate between information, advice and advocacy, and to distinguish situations in which each is required, and to be specific about the level of service being offered.

"Information only becomes useful - and enabling - when it is selected for appropriateness and presented in a form the recipient can understand. Packaged like this it is called something else - advice". (3)

Not all agencies provide the same type of service, and there is clearly a need for a variety of levels of information and advice. Libraries may well have an important role to play in improving information services, but they do not offer advice.

Many organisations offer information and advice, from the Benefits Agency, through service providers in the statutory sector, to citizens advice bureaux and community based information and advice projects. Sometimes it is important that independent information and advice is available, for instance if someone wants to appeal against a decision by a service provider in the statutory sector.

If barriers to services remain despite relevant information and advice having been given, there may also be a need for further support in the form of advocacy. In addition some people will have a particular need for advocacy, including children, those with learning disabilities and, in some circumstances, people from ethnic minority groups. Highland Community Care Forum has set up a Highlands Advocacy Project after finding that disabled people in Highland Region are "disempowered and disenfranchised". Individual advocacy was considered as the first step to empowering people to speak about their needs.

Some agencies which offer information and advice are unable to offer advocacy, for example the Benefits Agency.

1.7 As well as disabled people and their carers, whose position is described in the following section, various categories of service providers need disability information to do their jobs properly. These include, for example, housing, education, and welfare rights officers.

## **1.8 Conclusion**

The importance of information has been increasingly accepted. At central government level this is reflected in the Citizen's Charter initiative. At local level there is a statutory obligation to provide information to certain categories of service user. Within the voluntary sector there has been a steady growth and development of information and advice agencies, some of them catering specifically for the needs of disabled people. While there is undoubtedly a great deal of information being produced, whether about community facilities, residential homes, schools, hospitals or benefits, it is less clear whether people are receiving the information they need, when they need it, and in a form in which they can understand it. The more information is produced, the more important it becomes that people know where to find that information, and where to get advice about its implications for them. It is also important to be clear that information and advice are a means to an end. It may sometimes be a difficult decision how to allocate funds between direct service provision and information about services, but this should not be used as an excuse for poor or inadequate information.

## 2 DISABILITY AND ITS CONSEQUENCES

### 2.1 The definition of disability

There is still debate about the definition of disability. The traditional view of disability has been that it is a personal experience described in terms of functional loss. There has been an over-reliance on this traditional medical model, which views the disabled person as someone needing medical help and support from social services.

An alternative view of disability has emerged, known as the social model, which defines disability in terms of the barriers which a person experiences in gaining access to goods, services, rights and entitlements. Disability is the "loss of or limitation of opportunities to take part in the normal life of the community on an equal level with others due to physical or social barriers" (4). The responsibility for removing these barriers rests with society rather than with the individual. The range of people who experience such barriers will include those whose mobility is impaired, people with sensory impairment, those with learning disabilities, those with mental illness, many elderly people, as well as people with conditions such as HIV, MS, ME or epilepsy who may not define themselves as "disabled" but who may face many of the same barriers as disabled people, whether physical or created by prejudice or ignorance. All these people need help to overcome these barriers.

The definition of disability has consequences for the type of information which disabled people are assumed to need. The medical model of disability assumes that information for disabled people relates primarily to health or social service matters, while the social model recognises that disabled people need all the same kinds of information as everyone else. In addition, a consequence of adopting the social model of disability may be the recognition that information on its own may not be enough to help disabled people gain access to the goods and services to which they are entitled. Advice will be required to make sense of the information and advocacy may also be required to provide the support and representation which the disabled person may need.

### 2.2 The prevalence of disability.

An Office of Population, Censuses and Surveys (OPCS) survey of disabled people in 1985 estimated that there were 611,000 disabled adults and 33,000 disabled children in the Scotland.(5) Extrapolating forwards from these figures suggests that by 1993 the numbers would have increased to an estimated 688,000 adults and 32,000 children. The incidence of some degree of disability is probably even greater than these estimates suggest. The Informability Guide produced by the Central Office of Information states that:

- 7.5 million people in Britain do not have full hearing;
- up to 1 million people are sufficiently visually impaired to register as blind or partially blind, while a further 700,000 find it hard to read newspaper;
- over 1 million have some degree of learning disability;

- 4.5 million have a range of physical disabilities which make it difficult for them to travel or get into or around buildings;
- around 250,000 have some degree of both hearing and visual impairment;
- 6 million people are diagnosed as mentally ill every year of whom 197,000 are admitted to hospital;
- 6 million are over 70 years of age and constitute 10% of the population.

A recent study on the future of the family and state care for older people in the European Union has shown that the rates of disability amongst older people in the EU are 18-19% in the population over the age of 60, 25-33% in the over 70s, and 47% in the over 80s. (6) As the percentage of older people in the population increases, the percentage of the population experiencing disability will increase.

### **2.3 Economic characteristics of disabled people**

The economic circumstances of disabled people are considerably worse than the population as a whole: less than a third of disabled people of working age are in employment, and disabled people are three times more likely to be unemployed than able bodied people. Where disabled people are employed, their wages are below the average of non-disabled people. Sixty per cent of disabled people are claiming safety net benefits such as Income Support, and 47 per cent say they do not have sufficient income to meet their needs. A third of families with disabled children receive income maintenance benefits such as Family Credit, and 2.6 million disabled people and their families live on low incomes. (7)

### **2.4 Difficulties in accessing information**

Particular problems experienced by disabled people in obtaining information and advice include:

- attitudinal barriers;
- physical barriers;
- social isolation;
- problems in understanding information as a result of sensory impairment or learning disability; and
- lack of motivation resulting from a feeling of helplessness.

Various surveys and research projects have demonstrated that information does not always get through to the people who need it.

The OPCS survey of disabled people showed that ten per cent of disabled people did not know how to find out about services, and only four per cent mentioned disability organisations as a source of information. Forty per cent of

disabled people thought information about social security benefits was fairly or very difficult to get (8).

A study by the RNIB in 1991 showed that awareness of specific services for visually impaired people was extremely low. Two thirds of those not registered as visually impaired were not aware of such basic services as white sticks or canes.

A survey by the Automobile Association in 1992 showed that more than half of those who had difficulty in getting in and out of a car were unaware of aids that could help them.

Research by the Margaret Blackwood Housing Association into housing information and advice for physically disabled people indicates that there is very little written information available about the rights of disabled people in respect of housing.

## **2.5 Categories of disabled people needing particular consideration.**

**2.5.1 Children** are not quickly recognised as being disabled as their disabilities may only become apparent as they grow older, and health professionals may be reluctant to "label" a child as being disabled too early. There may also be strong social and cultural pressures which deter parents from labelling their own children as disabled, especially in some of the ethnic minority groups.(9) The community care legislation deals only with services for adults, although a similar requirement for the assessment of children with disabilities will be introduced in the Children (Scotland) Bill. The Working Group was told of a lack of awareness among professionals and people who work with children of what services and benefits exist for families of children with disabilities.

**2.5.2 Parents** of children with special needs and **carers** of people with disabilities may face similar barriers to disabled people themselves, often being housebound, having very limited amounts of free time, possibly not defining themselves as carers, or as people who might need "disability information" or the services which may be available to them. Professionals can often make false assumptions about the ability of middle class articulate parents to find out about the services to which they may be entitled. Equally, if parents are already living on social security benefits, they may be falsely assumed to be "in the system", and well able to find out what additional benefit they may be entitled to. It has been estimated that two thirds of carers receive no professional help at all, and that 40% of the 6.8 million carers in the UK are over retirement age and may themselves be frail and disabled.(10)

A Department of Social Security study in 1990 found that carers in families with disabled children had net weekly incomes between £58 and £92 lower than those of comparable households in the general population.

2.5.3 Finally some disabled people and carers face additional linguistic and cultural barriers because they are members of **ethnic minority groups**. Information may not be targeted at such groups in the most suitable format. The Coopers and Lybrand Report in 1988 found that the development of significant centres of mixed race population had little or no impact on the provision of information or services. Little information was available in translation and few professionals were able to interpret information. (11) The Working Group was given evidence that ethnic minority disabled people still suffer from a very considerable lack of information either because information is not available in the different community languages, or because translation is done in a formal style of language which is not clear and direct. There is a clear need for trained interpreters and advocates and a higher degree of awareness amongst service providers of ethnic minority cultures, and the main languages which are spoken and read (12). People from ethnic minority groups often experience a form of double discrimination.

## 2.6 Conclusion

The extent of disability is considerable, and there is a wide range of types of impairment and particular problems arising from those impairments. In particular, the impact of hearing and vision loss on accessing information can be considerable. In addition, carers may themselves be disabled. Disabled people and their carers share various characteristics in terms of their economic and social position, but some groups, such as disabled children, their carers and disabled people from ethnic minority groups face additional problems which must be addressed in different ways. To improve the provision of information and advice to disabled people it is necessary to address the various barriers which exist to disabled people gaining access to the information and advice which they need.

### 3 POLITICAL CONTEXT

3.1 The last 15 years have seen a growth in the political awareness of disabled people, and increasing demands that disabled people are given equal rights with the rest of the population. This parallels the emergence of the social model of disability. The demand for civil rights has been accompanied by the establishment of organisations of disabled people which are increasingly seen as more relevant than the charitable bodies which traditionally lobbied for people with disabilities. The creation in 1981 of the British Council of Organisations of Disabled People (BCODP) as an umbrella group was an important milestone in this process. There is at present no single Scottish organisation of disabled people, but there is an increasing number of local organisations both at Regional level, eg the Lothian Coalition of Disabled People and the Strathclyde Forum on Disability, as well as at more local level.

3.2 Britain has recognised the particular needs of disabled people in legislation, but has avoided any comprehensive civil rights legislation. The approach has been to try to effect improvements in the lives of disabled people without giving them the kind of rights not to be discriminated against which have been given in respect of discrimination on grounds of race or sex.

3.3 In this country the principal legislation dealing with disability has focused on services for disabled people. The National Assistance Act 1948 introduced the provision of local authority welfare services for disabled people. The Chronically Sick and Disabled Persons Act 1970 (as applied in Scotland by the Chronically Sick and Disabled Persons (Scotland) Act 1972) amongst other things requires local authorities to identify disabled people in their areas and find out what their needs are and to inform them of the range of services provided. The Disabled Persons (Services, Consultation and Representation) Act 1986 reinforces the duty on local authorities to assess people's need for services and requires them to provide them with as much additional information as possible about their own and other people's services. Care in the community, introduced by the National Health Service and Community Care Act 1990, is also of considerable significance for people with disabilities, and imposes a statutory obligation on social work departments to work with the health authorities and the independent sector to offer choice as to whether care is provided in the community or in residential accommodation.

3.4 There was, until the 1980s, no real attempt to challenge discrimination on the grounds of disability, as there had been on the grounds of race or sex. In 1979 the Silver Jubilee Access Committee report Can Disabled People Go Where You Go? and the report of the Committee on Restrictions against Disabled People (CORAD) drew attention to discrimination against disabled people, and viewed discrimination in a structural context. Pressure for anti-discrimination legislation built up during the 1980s with several private members' Bills being introduced in parliament, which ultimately led to cross-party support for the Civil Rights (Disabled Persons) Bill introduced by Dr Roger Berry in 1994, which did not proceed after the tabling of 82 minor amendments by Conservative back benchers. A similar Bill was introduced in the current

parliamentary session by Harry Barnes. As an indication of the level of support for anti-discrimination legislation, and of the way this has changed over the years, it is interesting to look at voting figures in the House of Commons. In February 1983 when Donald Stewart introduced a Private Members Bill, the Disablement (Prohibition of Discrimination) Bill, it failed to secure the 100 votes needed for the Bill to proceed (77 voted in favour). By contrast, Dr Roger Berry's Bill commanded cross party support. Early Day Motion 466 expresses support for Harry Barnes' Bill which secured a second reading in the House of Commons, and in particular for full citizenship rights for disabled people, backed up by a Disability Rights Commission. This Early Day Motion has received the support of 245 MPs to date, across all political parties.

After the defeat of Dr Berry's Bill, a study was published by Liberty (formerly the Council for Civil Liberties) in 1994 claiming that people with disabilities in Britain are living under a system of social apartheid, citing the fact that only 12% of polling stations were fully accessible during the 1992 general election, and claiming that disabled people are denied freedom of movement. This report was submitted to the United Nations' Human Rights Committee (13).

The issue of anti-discrimination legislation remains firmly on the political agenda with the introduction of the Disability Discrimination Bill in the present parliamentary session, and with the Barnes Bill also having received a second reading.

3.5 This political background is important in the consideration of the importance of information services to people with disabilities and their carers because:

- it helps to explain the growth in information services being provided by organisations of disabled people;
- it demonstrates why it is important that disabled people themselves are centrally involved in the development and control of information services, and has led to arguments that disabled people are themselves the best people to provide information and advice to other disabled people;
- it underlines the need for everyone involved in providing information and advice to disabled people to receive disability equality awareness training; and
- as stated in section 1.1 above, information itself plays a key role in the political process, and enables the citizen to participate in the democratic process.

3.6 Local government reorganisation in Scotland on 1 April 1996 will mean that the existing pattern of district and regional councils will be replaced by 32 unitary authorities. This will mean that all local authority services will be delivered by the same authority, and there will be potential for better liaison between departments and scope for streamlining and refocussing information about council services. One consequence of reorganisation will undoubtedly be some disruption of services, or at the very least, a period of stocktaking without any significant development of services. A further consequence of reorganisation will be the effect on the funding of voluntary

organisations in the independent sector by local authorities. The voluntary sector is of considerable economic and social significance: 30,000 people work in the voluntary sector in Scotland, and 50,000 serve on management committees. In 1992-93 local authorities funded the voluntary sector to the tune of £90 million.

Citizens Advice Scotland attempted to amend the Local Government etc (Scotland) Bill to require each local authority to draw up an information and advice strategy. This amendment was not accepted by the government. The Working Group does, however, consider that the scope for development of coherent information strategies at local authority level will be greater under the new authorities than it is at the moment.

## 4 BACKGROUND TO THE SETTING UP OF THE WORKING GROUP

### 4.1 Coopers and Lybrand report.

As a result of the increasing awareness of the needs of disabled people for information and advice about services, the then Department of Health and Social Security commissioned Coopers and Lybrand:

- to investigate the basic information needs of disabled people, their carers and service providers;
- to examine existing systems for meeting those needs and assess their effectiveness; and
- to identify possible options for improving existing arrangements.

Their report in 1988 recommended that the DHSS should take urgent action to initiate and facilitate developments by:

- establishing a national framework for the provision of information services. This would give greater coherence to the system and encourage common standards, consistency and good practice;
- enabling the creation of a federation of information providers at local level. Cooperation at local level would help reduce duplication of local collection and encourage local services to meet local needs; and
- supporting specific initiatives to develop improved common information services in line with the above. This could involve increasing access to particular databases.

The report was accepted by the DHSS, but money was not allocated until detailed work had been done on the cost of the project. Meanwhile local projects began to adopt the principles spelt out in the Coopers and Lybrand report, eg the Oxford Disability Information Project, the Disability Information Service Surrey, and the Devon Disability Information and Advice Federation.

### 4.2 PE International report

In 1989 the Department of Health commissioned PE International to look at the practicalities of taking forward the proposals made by Coopers and Lybrand, and to calculate the cost of the work. In its report in 1990, PE International recommended using Oxford Disability Information Project as a model for the federations which had been proposed by Coopers and Lybrand, and which were little understood at that time. They recommended the setting up of 4-8 local federations to be funded for three years. They stated that a project team would be needed to manage the project at local level,

and a steering group would be responsible for overall direction. PE International investigated the possibility of national information providers becoming Common Service Providers whose databases could be accessed by local information services. This showed that there were considerable problems in relation to compatibility and standardisation, and this was not taken any further in the ensuing National Disability Information Project.

### **4.3 The National Disability Information Project**

In 1991 the National Disability Information Project (NDIP) was set up as a three year project with funding of £3 million from the Department of Health. The aims of NDIP were:

- to promote closer working between national information providers;
- to encourage the development of local federations of information providers;
- to improve the quality of information; and
- to improve the information flow between national and local and between local providers.

The perceived problems which NDIP sought to address were:

- gaps and duplication at local and national level;
- problems in delivery of information from national to local providers; and
- how to get information out to those who need it.

A steering group of people with an interest in information and disability issues was chosen by the Department of Health. Following a competitive tendering exercise a Project Team was appointed to support the 12 pilot federations which were selected in September 1991, to run training courses, and to advise on good practice. The successful bid was from the Information Policy Group at the Policy Studies Institute (PSI). The Project Team produced a quarterly newsletter throughout the 3 years of the project with information about what was happening within NDIP, and a monthly Current Awareness Bulletin which was sent to all pilot federations as well as to other interested organisations. Annual conferences were held which were particularly valued by information providers themselves. Computer support was provided by the Computer Development Unit of the London Advice Services Alliance.

#### **4.3.1 Work with national information providers.**

A report was published by PSI in 1992 which discussed the policy issues involved in the provision of nationally-relevant disability information. The second part of the report provided details of information services and products currently available from a number

of national disability information providers. The issues identified in the first part formed the basis of the consultations which the NDIP project team have had with national providers and users. The interim report produced by RICA in 1993 suggested that the initial hopes of national providers had not been realised because of conflicting expectations and the problems of establishing a satisfactory forum, although the report stressed that in 1993 it was too early to reach definitive conclusions. In 1993 it was decided to establish working groups to address the following areas:

- pricing policies and funding
- quality
- gaps, duplication and cooperation.

A report of these working groups was published in November 1994 which made the case for continued government funding of national information providers, and recommended a strategy for improving the quality of national information services. (14)

#### **4.3.2 Work with local information providers.**

Of the three recommendations originally proposed by Coopers and Lybrand, the second, enabling the creation of a federation of information providers at local level, has been a dominant strand in the project. Much of NDIP's work has been with the development and support of 12 pilot projects employing a federated approach to disability information provision. Coopers and Lybrand suggested that all information providers in a locality should come together to "provide a coordinated approach to information provision and to improve the accessibility and quality of services... and should include statutory and voluntary agencies as well as groups of people with disabilities".

The experience of the pilot federations has been mixed, but many lessons have undoubtedly been learned about the important elements in a successful federation. The final report on NDIP by PSI does suggest that federations do not in themselves lead to an improvement in local services in the absence of strong local services. It says that experience gained during NDIP has made it clear that there is a significant need for effective information and advice services to help disabled people to cope better with the problems with which society confronts them.

"Such services should be vigorous and partisan in favour of the users. They should be controlled by disabled people; they should be located in the voluntary sector and they should be funded adequately by local authorities, possibly with support from health authorities. These local services should be supported by efficient and high quality national information providers that are themselves responsive to the needs of users." (15)

In the Working Group's opinion, NDIP's greatest achievement has probably been in the boost it has given to the development of services at local level, and to the formation of

links between the disability sector and the general advice sector, as well as placing disability information and advice on national and local agendas.

#### 4.4 Scottish Office Survey.

The Scottish Office decided not to take part in NDIP, preferring to conduct a small survey in June 1992 to try to establish whether the provision of information in Scotland was adequate, whether there was duplication, whether the quality was reasonable and what improvements were necessary. Questionnaires were sent to 512 information providers and 2863 users. A report, Survey of Information Services for People with Disabilities, was published in 1993.

The survey suggested that overall most people who sought information had received it. Amongst the users surveyed, some of the points to emerge were that:

- those with a mental illness experienced greater difficulty in obtaining information;
- there was a lack of provision for those with sensory impairments;
- the largest single type of information lacking was about aids and adaptations, followed by benefits;
- there was a regional variation in the ease of obtaining information;
- professionals found it easier to obtain information than other groups; and
- there was a demand for a one door system of provision.

The most commonly used sources of information were social work and social security offices, and also health professionals, although it was felt that doctors were not providing enough information.

Among information providers, 61% of respondents believed there were gaps in provision either in relation to access eg minority languages, braille, video or tape, or in relation to subject areas eg transport, accommodation and employment. The problem of keeping local information up to date was mentioned and 70% of respondents were aware of some duplication. 80% of providers saw a need for a network of both national and local providers and felt that the primary role of a local network should be as a disseminator of information. They also commented on the need to educate GPs in information provision and on the need for one door provision.

The survey was designed to give a "snapshot" of provision in Scotland rather than a comprehensive picture of a scene which is in a state of fairly rapid development. However, the report itself acknowledged the patchy response level, and conceded that the "low number of responses from several of the regions has limited the extent to which regional comparisons can be made".

4.5 On 3 February 1994 the Social Work Services Group (SWSG) convened a meeting to discuss how to take forward the results of the survey. Those attending the meeting included members of various branches of the Scottish Office, representatives from the Benefits Agency and the Association of Directors of Social Work, as well as from the voluntary sector, and from organisations of disabled people. It was agreed that a short life working group should be set up and that SWSG would convene the first meeting, although its role was to be a facilitator rather than having any control over the group. It was agreed at this meeting that the needs of children, those with a sensory impairment, ethnic minorities, and people living in rural areas should be covered. The meeting agreed on the bodies which would be invited to send representatives to the group.

## 5 INFORMATION TECHNOLOGY

As part of the background to the report, it is important to be aware of the role of information technology in this area. The relevance of IT in the field of disability information can be in three areas:

- in the processing and storing of information
- as a means of overcoming impairment
- as a dissemination tool.

### 5.1 Background

One of the things which the Coopers and Lybrand report considered would significantly improve the provision of information to disabled people, their carers and professionals was the possibility of linking locally based federations with so called Common Service Providers (CSPs) at national level, possibly making greater use of the developing information technology. In 1988 the role of computers was limited, often being driven by individuals who were enthusiasts, using donated equipment and systems which were poorly supported and conforming to few quality or technical standards. But there was enthusiasm about the potential of IT in providing easily accessible databases, partly as a result of the work of the Technical Liaison group in the Department of Trade and Industry. Coopers and Lybrand argued that standards for data definition and communications between computers should be developed as part of a national framework. (para 4.15). The CSPs could focus on a specific type of disability or a particular issue and wider access to these databases would be encouraged.

The report by PE International in 1990 looked at existing providers and demonstrated that there were considerable problems in relation to compatibility and standardisation. The computer facilities of most national information providers were not appropriate for access from remote terminals, many databases were incomplete, and there was inadequate control of the data held. Considerable investment and development would be needed to produce cost effective and easy to use information systems. The leading databases were only able to be used by experienced professionals. There was also a marked lack of coordination at national level. The report explored the possibility of linking the CSPs with local providers and identified four options, concluding that the most workable option would be for each data provider at national level to choose the medium most suitable for transferring data to local services. PE International proposed that technical support should be provided to potential CSPs to speed their development, as one of the factors which was inhibiting developments in this area was lack of resources.

### 5.2 NDIP

The project which finally took shape as NDIP had computer support provided by the Computer Development Unit of the London Advice Services Alliance. In addition the 12 pilot projects were given capital grants which allowed them to purchase computer equipment. The initial hopes that new technology could be used to create a "seamless

database of disability information" at national level which could be accessed on demand, were not realised. The significant disparities in the level of technology used by national information providers, the lack of resources and skills on the part of local services to access such a system, and the task of creating and maintaining such an information system, all made this an impossible goal.

The following issues were addressed in the course of NDIP, and are ongoing issues in this field.

### **5.3 Classification and organisation of information**

There was a demand within NDIP for the development of a classification system with which to organise paper information resources. Such a system could be used by local groups and if it was possible to agree on a system which could be used as standard, it could also be used by national information providers to pre-classify their information. The scheme developed by the Disability Information Service Surrey (DISS) appeared to be the front runner in this field, and the University of Central England was commissioned to evaluate the scheme and its potential. The report concluded that the DISS scheme had the potential to be developed into such a standard. Several organisations in Scotland are using the DISS classification scheme.

A classification scheme is also needed for organising information in a computer database. This can be a classification system like DISS, or can be based on a thesaurus, a controlled list of terms which are used as keywords. An example of this is the thesaurus created by Gloucestershire GUIDe, the Gloucester Updated Information Service for Disabled or Elderly Persons, one of the NDIP projects.

DIAL UK is currently developing a classification system which it plans to use for paper information and in conjunction with the shell database being developed by the London Advice Services Alliance (see section 5.4.2 below).

### **5.4 Databases**

The advantages of computerised databases is their capacity to store large amounts of data, and for users to access it quickly. This data will include information to be used in answering enquiries, but also information useful in running the service, and statistics. However, the experience of the NDIP pilot projects reflected the experience of other groups in this area, that creating a local database took longer, was more complicated and more expensive than expected. The average cost of creating a database with around 1000 records was around £40-50,000 and took the equivalent time of one person working full time for one year.

Various types of database can now be bought off the shelf:

- complete systems which come with software and information
- shell systems to which data can be added

- database development software.

5.4.1 **Complete systems** have been developed by DISS, GUIDE Gloucestershire, and Information in Cheshire (INCHES). The information already on the system is national, and local groups can add their own local information. The purchase price varies between £1500 and £3000, in addition to an annual subscription.

5.4.2 **Shell systems** are considerably cheaper, and, as part of NDIP, the Computer Development Unit of the London Advice Services Alliance has been developing a shell system to meet the needs of disability information services. This is currently being piloted by the Norfolk Disability Information Federation. DIAL UK is considering using this system, currently called Information Management and Retrieval Systems (IRMS), for disseminating national information to local DIAL groups, which could also use it to store local information. IRMS is designed to help agencies manage information about local organisations and contacts; to produce labels, lists and standard letters; and to provide a retrieval system to support advice and information giving.

One of the publications which has come out of the NDIP project is devoted specifically to the management of disability information and contains guidance on the use of databases. (16)

## 5.5 Networks

Developments in telecommunications mean that information can increasingly be made available through linked computer systems.

In Scotland, the Grampian Caredata project has shown how health and community information can be made widely available. Outlets throughout Grampian Region can be directly accessed by members of the public in libraries, health centres etc., while professionals can access the database in social work departments or within the health service. The database has also been made freely available to advice agencies in the voluntary sector.

One of the NDIP projects, the Devon Disability Information and Advice Federation, provided its database to the local authority mainframe computer system, which meant that it could be accessed in all local authority offices as well as in libraries. The authority has subscribed to the Disabled Living Foundation database of aids and equipment, so access to this is provided for all federation members.

However it is in Manchester that the use of information networks has been exploited most fully. Manchester has developed a sophisticated public access electronic information network called the Manchester Host. Subscribers to the Host can retrieve information from databases attached to it, as well as using it as a means of communication, for E mail and bulletin boards. It is also possible to gain access to the Internet through the Host. The Manchester Disability

Information Service (MDIS), one of the NDIP pilot projects, had hoped to use the Manchester Host, but for various reasons did not fully exploit the potential of this system, although a number of people did use it intensively to share information and communicate. The original aims of MDIS appear to have been too ambitious, and the project experienced difficulty in recruiting and retaining staff. The project failed to engage with the well developed advice sector in the city. A proposal emerged from outwith MDIS to develop a service for disabled people, Disnet, on the Manchester Host, which MDIS hoped to make use of, but this service has still not become fully operational.

Over the last few years the Internet, the so-called superhighway of information accessed through computers and phone lines, has become established and it is likely that this will be increasingly used by disabled people. The great advantage for many disabled people of information being made available through a computer screen is that it can be down-loaded by the user in the format most appropriate to their needs, whether in braille, large print or synthesised speech. The Internet is being used by Action for Blind People for making their journal Chariot which focuses on all national disability issues available to a wide international audience.

## **5.6 Use of IT in dissemination of information**

### **5.6.1 Public touch screens**

These systems allow access to information through a user-friendly interface, directly on screen rather than through a keyboard. There can also be an element of information exchange through these access points, for instance people could use them to apply for benefits or driving licences. There is considerable interest in this, and in Scotland the following projects are being developed.

A public access health information system, Healthpoint has been developed for use in Greater Glasgow.

In Edinburgh, the Community Development department of Edinburgh Libraries Service, has developed a touchscreen system for accessing a wide range of information about district council services, at Capital Information Points in all the public libraries in Edinburgh. It provides a free telephone linking the user to all council departments, a fax machine, and a post box for sending mail direct to the council. Information from the Health Education Board for Scotland, the tourist board and local groups will also be included.

The most technologically advanced project in Scotland is the LAMBDA project in Highland Region. This is part of a European wide initiative and aims to provide high quality multi-media access to services in remote parts of the Highlands. It will use touchscreens and allow interaction between the user and offices within Highland Region, and has information from other agencies such as the Benefits Agency.

### 5.6.2 CD-I

A CD-I disc is similar to a music CD, but with the added possibility of storing pictures and video. A CD-I is played through a television and the user interacts with the screen by clicking on-screen "hot spots". CD-I technology allows users to access the information they want in a range of languages including British Sign Language, and so is particularly useful for deaf people and ethnic minority groups. Gateshead Disability Information Project has developed the use of CD-I for disabled people.

### 5.6.3 Television

In France the use of television based information services through Minitel is considerably more advanced, and more widely used than the equivalent service in the UK, the Prestel service run by BT. To use Prestel you require a PC, a modem and communications software, or a Viewdata terminal, and a telephone socket. In addition to the basic services provided, additional services can be obtained at extra cost such as the French Minitel service, BR Inter City timetables, AA Roadwatch, and information about the weather, sport, and holidays.

BBC Ceefax has been used by RADAR to broadcast up to eight pages of disability information, four days a week. This information is updated weekly. In addition BBC Select is a night time service which provides programmes designed for reading at later date. Disability Agenda was launched in March 1994, and is funded by National Savings and the Benefits Agency.

The Gateshead Disability Information Project has experimented with the use of Cable TV in taking information directly into people's homes, and there is now a teletext channel available to carry disability information to providers. Initial indications are that people are subscribing to this service.

## 5.7 Scotland

The extent to which organisations are able to take advantage of the rapidly developing technology depends partly on their funding. A body like the Health Education Board for Scotland, which is funded by central government, has been able to take advantage of technical advances, and is producing information on CD ROM. In contrast Disability Scotland appears to have been hampered in being tied to cumbersome database software and to have lacked the funding to radically improve their systems. Disability Scotland has been tied to the software used in the Disabled Living Foundation database which forms a major part of Disability Scotland's database (DS Data).

At local level, Grampian Caredata stands out as the project in which the use of a computer database has created positive benefits for agencies in both statutory and voluntary sectors.

There are various specialist databases which have been created in Scotland and provide specialist information in particular areas.

The Scottish Sensory Centre produces the **Visual Impairment Service (VIS)** database which provides a UK wide information service, is updated daily, and is funded by Guide Dogs for the Blind and the Scottish Office Education Dept. VIS works with Action for Blind People, RNIB and Sense Scotland. Subscriptions to the database cost around £10 and the database is updated quarterly. VIS is accessible to blind and partially sighted users through synthesised speech output and double height characters and contrasted columns.

The Scottish Sensory Centre also produces the **Deaf Education Database**, a pilot scheme which provides an information service for hearing impaired children and young adults, their families and professionals which is computer based, and available at six centres.

The **Special Educational Needs Database (SEND)** provides information for parents, teachers, and therapists using computer technology on equipment, software, publications and contacts.

**Community Care Works** is a database of good practice in Community Care which has recently been established at the Nuffield Centre for Community Care Studies at the University of Glasgow.

There is an increasing development of public information systems by local authorities in Scotland, for instance the LAMBDA project in Highland Region, the Strathclyde Community Information Points (SCIP), and the Capital Information Project in Edinburgh. All these information systems would be capable of delivering additional disability information.

## 5.8 The appropriate role of technology

While some technological developments have clear benefits, an over emphasis on technology must not obscure the irreplaceable value of skilled information providers. The importance of the person providing information and advice should not be overlooked, and the following points must be borne in mind:

- people need to be listened to and given practical support -information, advice and support are inextricably linked;
- elderly and housebound people may be uncomfortable with high tech solutions;
- people with learning difficulties may want day to day practical help, eg with reading the mail, as well as information and advice;
- the "door handle syndrome" whereby painful issues are only raised once the client has decided he or she can trust the adviser; and

- only through interaction between the information seeker and provider can policy issues emerge.

## 5.9 Conclusion

While the Working Group does not feel able to make specific recommendations about technology, there is clearly the possibility of learning from developments throughout the UK, and it will be important to try to encourage cooperation between providers in relation to the classification of information and technical matters which could improve the transferability of information. Developments in this area will undoubtedly have considerable significance especially in the area of sending information directly into the home, whether through cable television or the Internet, and an increasing level of communication between disabled people and organisations through bulletin boards.

## 6 WORKING GROUP METHODS

6.1 The Working Group prepared a statement about its remit asking for examples of good practice and problem areas, and suggestions about where improvements could be made. This was circulated to over 900 interested organisations in both the statutory and voluntary sectors, and to the press. The statement was sent to all the social work departments, health boards and NHS trusts in Scotland, to all the CABx as well as to all Disability Scotland's subscribers and disability related organisations. A large number of responses to the statement were received (see Appendices 1 and 2 for details).

6.2 The Working Group held 9 meetings and at several meetings there were invited speakers with particular knowledge or experience relevant to the group. Members of the Working Group also gave presentations about the work of their own organisations. A list of these can be found in Appendix 3.

6.3 Three sub groups were set up in September 1994 to look at:

- the quality of information services;
- national information providers; and
- local information services.

These groups consisted of members of the Working Group and co-opted members (Appendix 4). The groups each held several meetings between October 1994 and January 1995 and produced reports which were considered by the Working Group as a whole in February 1995. The remits of the three sub groups are attached in Appendix 5.

## PART 2 EXISTING PROVISION IN SCOTLAND

### 1 INFORMATION PROVISION IN SCOTLAND

#### 1.1 Sources of information for disabled people

This section of the report and the following three sections of the report summarises the main sources of information currently available in Scotland. It is not based on a comprehensive survey but gives an indication of the scope, pattern, and types of provision.

It is important to distinguish between national and local information, between the role of national and local organisations, and between organisations in the statutory and independent sectors.

The range of organisations involved in providing information and/or advice to people with disabilities includes:-

- a service providers in both statutory and independent sectors;
- b information services which operate within a service providing department or are funded by such a department, or jointly with another agency such as a health board. Examples include
  - welfare benefits advisers
  - Disabled Living Centres which provide information and advice relating to technical aids and equipment which can assist disabled people, elderly people and carers to effectively and safely manage activities of daily life, and other similar centres such as the 12 Disability Resource Centres in Strathclyde, and the resource centres in Grampian;
  - information initiatives such as Grampian Caredata, jointly funded by the social work department and health board, which produces and maintains a database of local information on community and health matters in Grampian Region.
- c libraries. Although the library service is provided by local authorities, and so strictly speaking falls under the first category above, it is considered to differ from other service providers in that the provision of information is one of its primary goals;
- d the local offices of national service providers such as the Benefits Agency and the Employment Service;
- e health professionals, including GPs, health visitors and community nurses;

- f generalist information and advice agencies eg CABx;
- g general disability information services in the independent sector, such as Disablement Information and Advice Lines (DIALs), and local services such as Grapevine in Edinburgh, as well as national bodies such as Enable and Disability Scotland;
- h specialist disability organisations such as the Scottish Council for Spastics and the Multiple Sclerosis Society;
- i commercial bodies and service providers in the private sector; and
- j the increasing numbers of organisations of disabled people which are used as sources of information and advice to other disabled people.

## 1.2 Disability Scotland survey

Disability Scotland has been conducting a survey of disability related information over the last year with a view to creating a database of these services. A database has been created which can run searches to show the regional breakdown, the type of funding, the type of service provided, staffing, access, opening hours etc. The database is already being used within Disability Scotland but no date has been set for making this available as part of DS Data.

Sub group 3 of the Working Group considered the possibility of using the data from the survey to conduct a mapping exercise. This proved not to be feasible as there is such a wide range of types of organisation and it would be extremely difficult to indicate the level and type of service offered. The group considered that there is not necessarily any correlation between the number of apparent sources of information and whether those outlets are in fact meeting the information needs of people in that area. It was however considered that the survey might produce some useful information at a later stage.

## 2 NATIONAL INFORMATION

Local information providers have indicated in responses to the working group that they are often uncertain as to whether a particular measure applies in Scotland and that it is a time consuming process to find out. Scotland's separate legal system, education system, and administrative structure require that when we talk about national information we are talking about Scottish information.

### 2.1 The Scottish Dimension

In the disability information field there are several organisations operating at the UK level which are based in England and whose information products do not always make it clear whether the situation in Scotland is the same as that in England and Wales. This is the case for example with information coming from Royal Association for Disability and Rehabilitation (RADAR) and DIAL UK. Some national agencies do have separate Scottish organisations which operate independently from the UK organisation, for example Age Concern Scotland, or separate Scottish offices, such as the Carers National Association, and these should ensure that information produced for use in Scotland is accurate. Similarly there are Scottish organisations which are closely linked with organisations based in London, but which do not necessarily even share the same name, for instance Enable, formerly the Scottish Society for the Mentally Handicapped, and Mencap. Scottish organisations often experience difficulty when considerable press coverage is given to an English publication which fails to make clear that the situation is different in Scotland.

There are several national providers based in England which produce information which is useful in Scotland and does not require a separate Scottish organisation. For example, the Holiday Care Service provides information to enable people to choose a holiday suited to their needs. MAVIS, the Mobility Advice and Vehicle Information Service provides information and advice on all aspects of driving and disability. The Centre for Accessible Environments provides information and advice on the practicalities of providing an accessible environment.

#### 2.1.1 Screening for Scottish relevance

Citizens Advice Scotland (the Scottish Association of Citizens Advice Bureaux) can be used as an example of how national information can be screened for Scottish relevance. All information produced by the National Association of Citizens Advice Bureaux is sent to Citizens Advice Scotland (CAS) for checking for Scottish relevance. If it applies in Scotland it is sent out to Scottish bureaux, clearly marked that it applies in England, Scotland, Wales and Northern Ireland. If it does not, CAS produces an equivalent item that will only apply to Scotland and is clearly marked "Scottish extent". The closest parallel to CAS in the disability field is DIAL Scotland which, on a smaller scale, attempts to screen information produced by DIAL UK and adds any other information which applies in Scotland. Nonetheless, because the information sent out by DIAL Scotland has been produced by DIAL UK, it is not always clear to local groups whether the situation in Scotland is identical to that in the rest of the UK. DIAL Scotland

does not have the resources to provide the quality or range of information provided by CAS.

### 2.1.2 Level of service provided in Scotland

A different problem is sometimes experienced where a UK organisation is producing information which is equally applicable in Scotland but the organisation is not providing the same level of support in Scotland. For instance the Disability Alliance, which produces information which is applicable throughout the UK, is not able to provide training courses in Scotland. This gap is to some extent filled by other organisations, such as the Disablement Income Group (DIG) Scotland which provides a speaker who travels around Scotland, in tours organised and advertised by Disability Scotland, speaking about the operation of particular benefits and providing expert advice on benefit matters.

## 2.2 National information providers in Scotland

At national level there are several types of organisation providing information for disabled people. The National Disability Information Project (NDIP) identified 3 types of national disability information provider:

- **Common disability information providers** providing information aimed at all or a large proportion of disabled people, covering broad general subjects like aids or benefits. Examples would include Disability Scotland, DIAL, and the Disability Alliance.
- **Specialist disability information providers** such as the Special Educational Needs Database (SEND) or the Scottish Council for Spastics, which provide information aimed at a specific audience, relating to a specific disability or area.
- **Generalist providers** such as Citizens Advice Scotland (CAS), which provide information to local bureaux, much of which is as relevant to disabled people as to anyone else.

In addition, in the statutory sector, there is another category:

- **National service providers**, which may provide information and advice primarily through local offices, for example the Employment Service which provides information and advice for people on obtaining or keeping a job through Disability Employment Advisers working within a Placing, Assessment and Counselling Team (PACT). Alternatively such organisations may provide information and advice through local offices as well as providing a centralised national service, for example the Benefits Enquiry Line which is run by the Benefits Agency to provide information and advice to disabled people about benefits.

## 2.3 How do national information providers operate?

At national level organisations collect or create information which they either provide directly to enquirers, whether members of the public, professionals or carers, or to local branches of their own organisation or to other locally based information and advice services. There are three main types of organisation:

- Organisations which supply data for dissemination by local groups, and do not provide a service directly to members of the public, for instance:

#### **Citizens Advice Scotland**

**DIAL Scotland**, which sends a monthly mailing to its 18 member groups in Scotland.

- Organisations which produce information for use by local groups but also directly to enquirers. Many national bodies operate in this way, for example:

**Disability Scotland**, which produces 26 print directories on a range of topics, a quarterly newsletter, and a computerised information service (DS Data) which includes 7 databases, by far the largest of which is on Aids and Equipment and which is produced by the Disabled Living Foundation and licensed to Disability Scotland for use in Scotland. DS Data also has a bulletin board facility, a For Sale and Wanted list, and E Mail. This service, the potential of which has not been fully realised, is available at 25 sites in Scotland, predominantly within social work departments because of the cost of subscribing to it (around £1500 a year). At present 14 of these sites are in Strathclyde Region in resource centres and in one organisation in the independent sector. There are five sites in Highland Region, four of them part of the social work department and the fifth at the Children in the Highlands Information Project (CHIP). Three Disabled Living Centres have DS Data, in Grampian, Lothian and Fife, and the remaining two sites are the social work department in Orkney and a resource centre in Moray. Disability Scotland also provides an enquiry service which received 8207 calls in 1993-94, and used to provide a mobile advice service which has now been discontinued.

The **Health Education Board for Scotland** (HEBS) provides a national information service covering various aspects of health, and including a database of self help and voluntary groups, **HealthSearch Scotland**. HEBS initially provided information through a telephone enquiry service but is increasingly moving towards providing data for other services to disseminate. Information is supplied on CD ROM, up-dated on a quarterly basis, and will be provided free of charge to agencies working in the health care field and at cost to other agencies.

**Enable**, which provides services for its 74 local groups as well as directly to members of the public. Enable produces a quarterly magazine, Newslink, which contains benefit updates as well as information about events, branch activities, details of campaigns and projects. A current awareness bulletin Infoline is

produced 10 times a year, and Lawline, a quarterly legal bulletin, outlines any legal changes affecting people with learning disabilities. In addition factsheets, leaflets and posters are produced. The Information Service can be contacted by phone, letter or in person.

- Organisations which focus their information provision to the general public through a telephone helpline run on a national basis, for example the National Aids helpline, Saneline for people with a mental health problem, and the Arthritis Care helpline.

## **2.4 What is the focus of the information service?**

The pattern of information provision at national level is complex. The overlap between different types of organisation in terms of the kind of information supplied can be demonstrated by the range of organisations involved, each of which caters for a different group of people:

- Organisations which focus on a particular type of impairment, eg the RNIB, Enable, Scottish Association for Mental Health, Spinal Injuries Scotland, RNID and the Scottish Association for the Deaf. Much of the information produced will be the same, for example about benefits, while some will be of specific interest to the client group, or produced in a format to meet the needs of that group.
- Organisations which attempt to meet the needs of a particular group, for instance elderly people or carers, which may include a wide variation in the level or nature of impairment. For example visual impairment and hearing loss are widely considered by elderly people to be an aspect of aging, rather than a disability.
- Organisations which concentrate on particular types of information, eg Benefits Enquiry Line and the Disability Alliance focus on information about benefits, while the Employment Service provides information about employment. Even the service provided by the common disability information providers such as Disability Scotland and DIAL Scotland differs in the focus on the type of information provided. Disability Scotland's DS Data appears to be particularly valued by occupational therapists dealing with physical impairment, and local information providers find the DIAL Scotland particularly useful, with its emphasis on current awareness and social aspects such as benefits entitlement. DIAL Scotland also circulates some information from Disability Scotland to the 18 affiliated DIAL groups in Scotland.

## **2.5 Definition of national information**

National information providers are primarily involved in collecting and processing national information which is relevant to people wherever they live. The type of information which can most cost effectively be collected at national level and supplied to local agencies falls into several categories:

- information about other agencies operating at national or international level
- information about services which are the same throughout Scotland eg information about entitlement to benefits, rights in the employment or housing field, information about aids and equipment
- information about local services or facilities which it may be useful to have collected together at national level eg about holidays, transport or local stockists of aids and equipment
- current awareness information about new or forthcoming legislation and government policy
- current awareness information about research projects, articles etc.

## 2.6 Characteristics of national provision

The pattern of information provision at a national level in Scotland appears to be fragmented, with no regular forum for groups to share their experiences or discuss common problems. Such an informal forum has existed in the past and some organisations, for example Enable, have expressed a desire for a more formal re-establishment of such a forum.

At national level there is a lack of coordination, networking, or structured dialogue. Some information, eg equipment databases, are expensive and not user friendly. A concern was expressed that national organisations funded at least in part to provide a service to local organisations and service providers sometimes did not meet the standards which those local organisations themselves tried to meet. For example, the opening hours of national bodies may be more limited than those of the local service. The concern was expressed that national bodies sometimes did not do enough to publicise the existence of local groups. For instance it was felt that the Disabled Living Centres Council could do more to raise public awareness of the role and existence of disabled living centres in Scotland, and was constrained in promoting DLCs in Scotland as its present publicity budget comes from the Department of Health and so is limited to England. The range of disabilities has led to fragmented provision, and there is insufficient user involvement or control.

There are some problems experienced at local level which might be solved by changes in the way national organisations operate. These problems include:

- local agencies wasting time collecting national data;
- difficulties in accessing information about another part of the country;
- charging for information by national agencies;
- the lack of consistency at regional level;

- the fact that too much effort is spent in producing material, and not in distributing, updating, and sharing it; and
- competition between agencies for funding and possessiveness about information.

Both local and national agencies complain of under funding and short term funding.

## **2.7 Suggestions for improvement**

Some suggestions which have been made in responses to the Working Group's statement include:

- the creation of new structures at national level to distribute material, issue regular bulletins or packs of material possibly on computer disc or CD ROM, or act as a centralised information brokerage system;
- the integration of local and national services;
- the improvement of dissemination by using a nationally recognised logo, or by the support at national level of local federations of information and advice givers;
- making greater use of technology; and
- the organising of national seminars or conferences.

### 3 LOCAL PROVISION

The Working Group felt disadvantaged by the fact that it was unable to start with a clear picture of the pattern of provision of local information services at local level. The Scottish Office survey was limited and partial, while responses to the working group's statement similarly could not provide a comprehensive picture.

#### 3.1 Local authorities

As mentioned above (Part 1, section 3.3) local authorities have a statutory duty under the Chronically Sick and Disabled Persons Act 1970 and the Disabled Persons (Services, Consultation and Representation) Act 1986 to identify disabled people in their areas, to find out what their needs are and inform them of the range of services available, both about their own services and about any services provided by other agencies which they have knowledge of and which would be relevant. The National Health Service and Community Care Act 1990, imposes a statutory obligation on social work departments to work with the health authorities and the "independent sector" to offer choice as to whether care is provided in the community or in residential accommodation. If community care is perceived as involving a shift from professional dominance of resources and prescriptions to a situation where users and carers can more fully take control over their care needs, then information is of critical importance to the effective exercise of choice.

Research in 1980 into the information needs of physically disabled people showed that the 1970 Act, which required authorities to create a register of the chronically sick and disabled in their community had received limited enforcement and that one third of the names and addresses given were inaccurate. (17)

Research in England and Wales (18,19) has shown that local authorities need to give a greater priority to information provision as a service in its own right, that there is a need for information strategies to be developed, and that local authorities should involve users and carers at every stage.

There are indications that information services provided to users and carers are inadequate for instance in many comments made during the conference held by Glasgow Council for the Voluntary Sector in June 1994. One of the messages from the conference was that current information services available to users and carers are inadequate and in need of urgent overhaul.

"There is an urgent need, not being satisfactorily met by statutory agencies, to communicate clearly in plain language, to inform user and carers about the services available, about how to access them, about rights and responsibilities, about how to get independent advice and advocacy services."

Pleas were made for the better use of existing networks and information projects within communities and localities, and for resources to be deployed to address the specific

communication needs of people from ethnic minorities, and for those with hearing and visual impairments. (20)

The Scottish Office survey attempted to compare the ease with which respondents had obtained the information they sought. The responses suggested that it was easier to access information in some Regions than in others, with greater difficulty being experienced in Tayside, Lothian and Strathclyde, but the survey does not specify whether those experiencing difficulties were approaching the statutory or voluntary sector for information.

In 1993 KPMG Management Consultants conducted a piece of research for the Scottish Office on residents' choice in residential care (unpublished), which explored how far four local authorities were providing elderly people with clear information about their choices after assessment. The report was critical of some regions, but Fife was commended for producing clear objective information for service users.

There is no consistency in the way in which service providers in regional and district councils have attempted to meet their statutory duty. The diversity of approach can be seen in the community care plans which local authorities and health boards are required to produce. A variety of approaches has been adopted:

- No special effort is made to provide information: information is simply provided as an adjunct to service provision.

Some community care plans make no reference to information provision, eg Orkney and Shetland, while some give only a general commitment to its importance, eg Borders.

- Publication and display of written material such as leaflets.

The social work department of Tayside Regional Council produces a comprehensive range of leaflets which have been awarded the Plain English Campaign's Crystal Mark. Users and carers are involved in the planning of new publications. Tayside maintains information display racks in all social work establishments, as well as in some superstores, and staff ensure that the leaflets are kept stocked and up to date. Their information is also sent to agencies in the voluntary sector such as the Tayside Disabled and Carers Information Centre.

- Funding of information initiatives.

These may deal specifically with disability, eg Disabled Living Centres or similar organisations such as the Ability Centre in Dundee; with community care issues, such as Grampian Caredata; or with council services in general, such as the establishment of an advice forum in Cumnock and Doon Valley which has developed a database of both

regional and district council services and is opening one stop offices in the district.

- Funding of projects in the voluntary sector.

This may be the result of an explicit decision to meet the authority's statutory obligation through an organisation in the voluntary sector, eg Lothian Regional Council and Health Board's funding of Grapevine, the Lothian Disability Information Project. In Fife the provision of services to visually impaired people is met through the Fife Society for the Blind, which receives funding from social work, health, and education sources. Equally a project which has started off as an urban aided project in the voluntary sector and proves its effectiveness may then be funded by the statutory authority. This has happened with the Infobus in Renfrew and the Fernan Street Information Project in the East End of Glasgow.

- Incorporating a remit to provide information in resource centres.

The Disability Resource Centres in Strathclyde each have an information officer. The recently opened Moray Resource Centre in Grampian is another example.

- The development of a regional information strategy, with general services backed up by a specialised disability information service.

In Central Region the Council Help and Information Services are backed up by the Disability Information Service. In Grampian Region the health board and regional council have a joint information strategy and strategy group.

Many local authorities in Scotland are actively addressing the importance of providing information and advice, particularly since the introduction of the community care legislation. However there are problems which have been identified in responses to the Working Group's statement, and in the experience of members of sub group 3.

- The lack of consistency between councils makes it difficult to refer clients to appropriate sources of advice in another geographical area.
- The low priority given by service providing departments to the provision of information as an aspect of that service. The Working Group believes that it is desirable that information provision is recognised as a service in its own right and that the establishment of an information strategy within local authorities could strengthen the position of information provision in the local authority context.

This low priority is demonstrated by

- the lack of an information strategy within many social work departments;
- the lack of any systematic checking and updating of information;
- no one being responsible for information provision; and
- the tendency to prefer to spend scarce resources on services rather than information about services.

### 3.2 Health professionals

The Health Service has recognised that it has a role to play in information provision, for instance through the establishment of healthlines and the work of the Health Education Board for Scotland.

#### 3.2.1 GPs

One of the findings of the Scottish Office survey was that GPs were potentially well placed to provide information to people with disabilities either at the point of diagnosis of disabling conditions, or simply because disabled people and their carers may be frequent visitors to the GP practice. The Scottish Office survey also suggested that GPs were failing to make much use of this opportunity to pass on useful information to disabled people or their carers.

In Scotland the average GP practice has 1500 patients, the average patient sees his or her GP 4 times a year, and 90% of people see their GP once every three years. Research has shown that older people have more contact with their GP than they do with social workers (21) The main sources of information for elderly people are family, friends and neighbours, but health professionals, especially GPs fulfil an important role although they themselves are not always well informed (22) Doctors are well placed to provide information in that they are held in high regard and have a fairly high level of contact with disabled people and their carers. However GPs are under considerable pressures and do not have time to spend exploring a patient's information needs. GPs typically receive huge amounts of information but do not have anyone within the practice responsible for organising it. In addition, the range of information required may be very wide, and the patient may be under considerable stress and not able to assimilate information.

One significant development in this area has been in the use of a health centre or GP practice as a venue for other agencies offering information and advice. Following on from a project in Birmingham (23), Edinburgh Central CAB has begun to provide advice in two GP surgeries in Edinburgh. This is a two year pilot project receiving funding from CAS development funds, and is proving to be extremely successful. Patients can make an appointment to see the case worker who is a paid worker. The doctors involved are finding this a useful service, and CAS hopes that after the initial two years it will be able to continue with funding from the practice. This is also being tried in Grampian.

Research commissioned by the Berkshire Disability Information Federation found that GPs did not see it as their responsibility to provide non medical information and tended to delegate this responsibility to district nurses, health visitors and social workers. In

general the GPs were quite open to the idea that they could take a more active role in information provision and welcomed the possibility of some training being given as part of their post graduate training. GPs were however primarily signposters, and would welcome ways to refer clients more effectively, for instance by having a card from the Berkshire Federation to give out. (24)

The GP's role in information provision should be as a signposter, and this role is most likely to be accepted if GPs can be given information about one stop sources of advice and information, whether this is an in-house adviser or a local agency.

### **3.2.2 Hospitals**

Hospitals have an important role to play in providing information, particularly to the newly disabled person leaving hospital. A report by the Audit Commission in England and Wales found that hospital patients were not receiving the information they need because nurses and medical staff are confused about who is responsible for giving it. In hospitals where nurses have been given the responsibility of providing information, things have improved dramatically (25). The National Information Forum has shown that when a newly disabled person leaves hospital, he or she is more likely to take up information services if they are provided or supported by the health authority (26).

The availability of information in hospitals may be of crucial importance to the parents of children with special needs. This is very often the first place they will expect to be given information, and the Working Group would like to emphasise the importance of getting information as early as possible. Although the group espouses the social model of disability, disability is very often the result of a medical condition, and this makes a hospital or health centre an important place in which to receive information and advice.

Responses to the Working Group's statement suggest a low level of development of information services in hospitals in Scotland but there were some examples of good practice with hospitals recognising the desirability of developing their information services to patients in general, including disabled people.

The Southern General Hospital in Glasgow hopes to develop a central information gathering point within the hospital and stated in their response to the Working Group that they feel national organisations could do more to liaise with hospitals and health boards.

Tayside Health Board has produced a Discharge Information Booklet which gives practical advice about day to day living for someone who has spent a long time in hospital.

The Special Needs Information Point based in the Royal Hospital for Sick Children in Edinburgh provides information on services for parents and carers of children with special needs, and for professionals in this field. This voluntary sector service was developed to address the particular problems experienced by this group and has been extremely successful since it started in 1991.

Citizens Advice Scotland is funding an advice clinic in Glasgow Royal Infirmary specifically for gay men.

The Disablement Income Group (Scotland) operates an advice service in the Western General Hospital in Edinburgh two days a week, and gets referrals from hospital staff and social workers.

### **3.3 Libraries**

The strengths of the library network are that it has:

- a strong local presence;
- a wide geographical spread; and
- it employs information professionals.

Libraries increasingly want to be seen as sources of information, and librarians are attempting to meet local needs proactively through outreach. However there is still a perception amongst the general public that libraries are places to get books rather than information, and libraries could do more to promote the message that they are places to go for information. This contrasts strongly with the position in North America and Australia where libraries are seen primarily as sources of information. It must be emphasised that libraries cannot offer advice.

The situation in Scotland varies considerably between rural and urban areas, with libraries in rural areas having a particularly important part to play. Libraries do not always have the resources to provide information in a variety of formats, and it would help if they had access to reliable and efficient sources of braille etc.

The potential role of libraries may be strengthened by the reorganisation of local government, when all local authority services incorporating a responsibility for information provision will be the responsibility of the same authority.

### **3.4 Generalist advice agencies**

The CAB service in Scotland is well established with a wide geographical spread. Over three quarters of CABx in Scotland now have access for people with mobility difficulties, a quarter have accessible toilets, but only 10% provide facilities for those with a sensory impairment. Citizens Advice Scotland is also addressing the difficulties sometimes experienced in accessing a CAB by phone, by providing a telephone support service which will handle enquiries which cannot be dealt with by the local bureau.

Citizens Advice Scotland has been developing several initiatives in recent years which are relevant to the provision of information at local level.

In partnership with the Princess Royal Trust for Carers, CAS are addressing the advice and information needs of

carers. Funded by CAS development funds the first CAB advice unit for carers has been established at the Princess Royal Carer's Unit at Perth.

As discussed above in section 3.2 above, pilot projects are being held in GP practices in Edinburgh and also in Grampian.

Specialist services are provided either in house, eg specialist money advice workers supporting generalist advice workers, or out of house eg the Scottish Homelessness Advisory Service, which is a partnership between CAS and Shelter whereby Shelter fieldworkers provide support to a cluster of CABx. This is being funded by HomePoint, Scottish Homes.

The growth in specialised disability services and services for carers has been in part due to the perception that CABx, and indeed other service providers and sources of information, were often inaccessible and not appropriate sources of advice for disabled people. While CABx are generally perceived to be excellent sources of advice about money problems and benefit entitlement in the population at large, it was suggested by members of the sub group looking at local provision that they have not developed a similarly high profile among disabled people, who appear not to go first to a CAB for this advice. This has created a vicious circle in which CABx have not always had the opportunity to develop an expertise in issues such as disability benefits or information about aids and equipment. A disabled person or a carer may also prefer advice to come from someone who shares their experience of disability, and may not expect to find such a person in a generalist agency.

It is also worth noting that as part of NDIP, Berkshire Disability Information Project used an established network of CABx as the basis for developing disability information services.

The Federation of Independent Advice Centres (FIAC) is another network of generalist advice agencies which was established in 1977 to represent the interests of local neighbourhood advice services. It has over 50 members in Scotland. Only one of these groups specialises in disability information. A major incentive to become a FIAC member is the provision of low cost indemnity insurance. FIAC, which is a UK organisation, but is in the process of trying to establish a Scottish office, represents the interests of its members at national level, for instance in the development of SVQs in Advice, Guidance, Counselling and Psychotherapy. It sends out fortnightly mailings which include social security briefings and information about advice provision in general. FIAC and DIAL UK are currently cooperating on a management development project, funded by the Department of Health, supporting DIAL members and FIAC groups specialising in disability information.

### **3.5 Disabled Living Centres**

At local level Disabled Living Centres can be effective sources of information and advice. There are 6 Disabled Living Centres in Scotland, in Aberdeen, Edinburgh, Inverness, St Andrews, Grangemouth and Paisley. They are all funded by statutory agencies, either social work departments or health boards, whereas in England more than half are voluntary bodies. DLCs focus on providing information, advice, and assessment in relation to aids and equipment. One of their main tools is the Disabled Living Foundation database, which in Scotland is licensed to Disability Scotland. Users are mainly disabled people themselves although professionals also make use of their services. DLCs actively encourage enquiries from disabled people themselves.

Some regional councils in Scotland provide a similar service to that provided by DLCs through disability resource centres, for instance in Strathclyde and Grampian.

Compared with other countries in Europe the provision of aids and equipment in the UK is extremely complex. Information about aids and equipment can come from a huge range of sources and aids can be supplied by a wide range of agencies: the Employment Service, social work, health, housing or education authorities.

"The systems for provision of technical aids in the UK are very, very complicated. If you live in the right place with access to the right information and you have enough patience to pursue what should be available to a disabled person then you will ultimately get the service required".(27)

A report, as yet unpublished, by the Scottish Health Management Efficiency Group (SCOTMEG) on Patient Equipment in the Community, found considerable variation in practice across Scotland with the service having developed on an ad hoc basis to meet demand rather than to meet assessed needs. The report also suggested that there was very little evidence of collaborative working between agencies, and that there was no evidence that the issue of home equipment had been included in any strategic plans for community services. Particular problems were identified in the supply of communication aids to assist with speech and language difficulties. The report recommends that Health Boards and Trusts should be encouraged to set up a joint equipment service with local authorities, and that social work departments should be given the lead responsibility in this area. The report identified a clear need for national guidance to provide a framework of guidelines and principles.

In the Scandinavian countries where legislation gives disabled people a right to the aids and equipment necessary for them to live an active and independent life, all social welfare is provided by local authorities and financed via the tax system. Every local council has a technical aid centre as well as a hearing centre and a low vision centre. This clear focus for the provision of aids and equipment facilitates the flow of information both between professionals and to individual disabled people.

The Working Group believes that it is important that sources of information about aids and equipment should be available throughout Scotland. It does not consider it necessary to recommend that there should be one DLC in every new local authority area. For instance it may well be appropriate that there should be a DLC in Aberdeen

serving the whole of the existing Grampian Region. At present different organisations hold a limited range of equipment for particular purposes (eg a social work department has equipment for home use, while the Employment Service's PACT team has equipment for work). It would be better if each region had a central resource centre where the full range of aids and equipment was available. The coverage of DLCs should be increased and the level of public awareness of DLCs and other similar resource centres should be raised.

There is also a danger that peripheral areas of Scotland may be poorly served in relation to information about aids and equipment. Disability Scotland's Mobile Aids Centre used to tour remote areas of the country but is no longer doing so. In Strathclyde a mobile vision centre is attempting to meet the needs of visually impaired people throughout the region. The group is concerned that the needs of the peripheral areas should be reassessed and appropriate action taken by local authorities to meet that need.

### **3.6 Local disability information services in the independent sector**

Information may be provided by local branches of national organisations, eg local groups of Enable, Age Concern Scotland, or Chest, Heart, Stroke Scotland, by local DIAL groups, or by relatively well established and supported services such as Grapevine in Edinburgh, which aims to be an information resource for all disabled people in Lothian. While information may also come from organisations in the private sector, the Working Group has not looked at this area in any detail, although in respect of the standards described in Part 3, section 3 and Appendix 9 of this report, the Working Group believes that these standards are equally applicable to the private sector. There is evidence in the private sector, for instance banks and the privatised utilities, that services for disabled people and information about those services, are being taken seriously.

Specialist disability information services have developed alongside generalist services for various reasons.

- Mainstream services may not be accessible.
- Particular types of information are not readily available elsewhere (for example in relation to aids and adaptations, or about disability benefits).
- The growth in numbers of organisations of disabled people and their carers, which often aim to provide an information service for their members.
- There may be considerable advantage in disabled people and their carers talking to someone who shares his or her experience.

"Information by itself often does not go far enough. When it is backed up with the personal experience of disabled people it then becomes a powerful tool to challenge barriers, especially when disabled people work in partnership with

service providers." (Terry Daley, Strathclyde Equality Awareness Training in Disability (SEATID))

## 4 RELATIONSHIPS BETWEEN PROVIDERS

### 4.1 Relationships between the statutory and independent sectors

An important aspect of community care is the encouragement of greater integration of services provided by the independent and statutory sectors. We can see evidence of this in the practice of some regional councils. The increasing emphasis on the division of responsibility between the purchaser and the provider of services, and the move from a grant-based culture to one based on contract and service level agreements will to some extent facilitate the fuller integration of the voluntary sector in statutory provision. However the importance of independent sources of information and advice being available must not be overlooked.

Characteristics of the present relationship between agencies in the statutory and voluntary sectors can be described in terms of:

- Funding

The Working Group considers that local authority funding is extremely important and that many of the problems existing at present could be improved by a more effective use of existing funding. Funding may be given on an ongoing basis, or for particular short term projects such as the Carers Information Pack in Fife. The development of community care forums in Scotland demonstrates how the injection of funding can create "added value" in the voluntary sector.

- Information sharing

The extent to which information is shared between the voluntary and statutory sectors is significant in terms of the information available to the end user.

The Devon Disability Information and Advice Federation, as part of NDIP, has consciously improved the sharing of information between the two sectors, to the benefit of both: voluntary sector bodies have access to the DLF database, while local authority staff have access to the information produced by local disability groups, and to the Community Care database produced by the federation.

Grampian Caredata has chosen to operate in a similar way. Their database is made freely available to agencies in the voluntary sector, thus saving groups the time needed to collect basic information.

Similarly groups in the voluntary sector can be useful sources of information to people in the statutory sector, either about specialised conditions, or particular client groups. Leaflets produced by Age Concern are preferred by one local authority's staff to the leaflets produced by their own authority. Professionals are frequent users of information from organisations such as Disability Scotland, Enable and the Scottish Association for Mental Health.

- Referrals between the voluntary and statutory sectors

A successful voluntary sector organisation can attract considerable numbers of referrals, and the experience of SNIP in Edinburgh is that as health professionals and social workers have become more aware of the service offered, SNIP has received increasing numbers of enquiries from professionals.

The development of a network of agencies involved in providing information and advice to disabled people in Lothian has been prompted partly by a recognition of the importance of raising the level of awareness of what agencies in both the voluntary and the statutory sector have to offer locally.

- The relationship between specialist and generalist services

This is a sensitive area. There can be a problem if a social work department

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may "offload" clients to that specialist service rather than provide the service themselves.

The use of the "dustbin" may result in

an extremely low level of awareness amongst local authority staff about disability issues

. While it may frequently be desirable that people

are referred to specialist sources of information and advice, this should not detract from the goal that general service providers should be able to meet

the needs of all their clients, and that they should receive sufficient training to do this, and in particular, disability equality awareness training.

PSI has suggested in its final report on NDIP that one of the weaknesses of the Coopers and Lybrand report which shaped NDIP, was the failure to recognise that multi-agency working would lead to "tension, delay, and a lack of progress". PSI argue that the different organisational cultures of the statutory and voluntary sectors make it difficult to establish effective joint working arrangements, and this is compounded by the funding relationship between the sectors. As discussed in Part 1, section 3.6 above, this situation is unlikely to improve in the immediate future, with reorganisation of local government, but there is perhaps a greater degree of optimism in Scotland that it is possible to develop fruitful relationships between the statutory and independent sectors, as evidenced by some of the examples given in section 3.1 above.

#### **4.2 Relationship between national and local providers**

The relationship between national and local providers has changed in line with the developments within the disability movement as a whole, as described in Part 1, section 3. The traditional charitable bodies representing the interests of disabled people tend to be autonomous national bodies, relatively well funded by central government, and often with considerable capital reserves. In Scotland there are also several long-established locally based societies, for example societies for the blind and the deaf. Alongside these organisations, the emergence of local services, often provided by, or supported by local organisations of disabled people, has represented a challenge to these groups. Developments in this area have been piecemeal, and the lack of an overall structure has meant that the various players are not always clear about their role.

Work done by NDIP on the relationship between national and local providers showed that there was a lack of understanding between them, with local services often being unaware of what was available from national groups, and national groups often being unaware of what local services wanted from national groups (28). Overall provision of information for disabled people would be improved if activities at national level were more closely integrated with those at local level. This could possibly mean a greater degree of specialisation in what different bodies do.

The NDIP project team has suggested that a primary responsibility of national organisations should be in the collection and processing of information, with the main responsibility of dissemination resting with local groups. This division of responsibility is broadly accepted by the Working Group. It is, however, inevitable that there will be a degree of overlap. Disability Scotland, for example, receives around 8000 enquiries each year, and even if there is an effective network of providers operating in one area, Disability Scotland will continue to receive enquiries. The question is the extent to which a national organisation has confidence in local providers and is willing to refer enquiries on to local agencies.

Local information services use the services of national organisations in the following ways.

- As a source of information both computerised and paper based.

Local organisations are typically members of national organisations, for example DIAL or RADAR, in order to have access to sources of information. Two members of one of the sub groups of the Working Group, both working in the occupational therapy area, were heavily dependent on the Disability Scotland database on aids and adaptations;

- To refer to for further information.

While some local information services will approach a national body if it cannot answer a question, many local groups may turn first to other local groups especially if a network of providers is functioning eg in Lothian;

- To obtain information about services or facilities in other parts of the country.
- To obtain specialist or expert advice, for instance legal or medical advice, or for information about a specific condition or type of impairment.

In relation to existing use, the following problems were identified, both in responses to the group's statement, and in the experience of the members of sub group 3 who were primarily local information providers themselves.

- Difficulties in accessing national bodies.
  - opening hours may be shorter than those of local agencies
  - cost of phone calls
- Problems with information products.

Local providers were generally satisfied with the quality of information provided by national bodies, but particular problems were identified with the use of Disability Scotland's database:

- the cost of subscribing to DS Data, and of on line phone bills;
- it is hard to use (one subscriber described being always on the phone to Disability Scotland to ask how to use it);
- little support in using DS Data is provided although initial training is provided within the cost;
- the service provided would be improved by the employment of an occupational therapist at Disability Scotland;
- the large sums of money invested in a system used at only 25 sites in Scotland; and a general concern that for the amount of money spent on it this database was just not good enough.

The Working Group is aware that Disability Scotland is looking at ways of addressing these problems, and has been piloting a disc based version of the database.

- Not enough training is provided to local services.
- National bodies are not good at speaking to local services about their needs. There has been a proliferation of local services in recent years, often community-based and urban aided, but with funding from a range of sources including section 10 funding. There has also been a growth in organisations of disabled people offering information services, and there is evidence that some national organisations do not always feel confident that these local services can provide a high quality information service. This has led to a concern about quality standards in general, and the desire for a framework within which both local and national services can "place" themselves and develop effective working relationships in an atmosphere of mutual trust and respect.

#### **4.3 Relationships between all agencies operating at local level**

The focus of NDIP's work has been with the development and support of 12 pilot projects employing a federated approach to disability information provision. Coopers and Lybrand suggested that all information providers in a locality should, come together to "provide a coordinated approach to information provision and to improve the accessibility and quality of services... and should include statutory and voluntary agencies as well as groups of people with disabilities".

The experience of NDIP seems to suggest that this may to some extent have been putting the cart before the horse, and that if you do not have good quality direct service provision you will not necessarily achieve it by setting up a federation. This was the experience with the North East Yorkshire Information Service and with the Walsall Information Federation. In the draft final report on NDIP, the Project Team considers for each pilot project whether the value added by the federation is greater than the value which would have been added had the resources used by the federation been divided up between federation members. In some of the projects the Project Team suggest that the resources devoted to the federation could be justified because sufficient resources were already allocated to direct service provision (eg in Oldham). In six of the projects the outcomes of funding the federation have been better than increasing the funding of service providers. Four of the projects have not significantly added value, and in the remaining two it is unclear whether this is the case or not.

#### **Extent of networking in Scotland**

In Scotland there are no formal networks of disability information providers, but there are various examples of information providers getting together in informal networks to improve the sharing of information and referral of clients.

In Lothian, the Lothian Coalition of Disabled People has received funding from the Horizon project to employ someone to develop networking in Lothian. Two conferences have been held and many responses mention this as a positive development, although time-consuming for those involved.

In Grampian, a body called Grampian Information functions as an umbrella group for library and information services in Grampian. It organises training and provides networking possibilities. Its membership includes public librarians, CAB staff, social workers and, amongst other people, the manager of Grampian Caredata.

In Strathclyde, a report of the regional council's Poverty Officers Group in 1990 recommended that a strategy for information and advice provision should be developed and that it should be based on the establishment of local advice forums which would review existing provision, identify local priorities and develop networks of advice/information providers. Three pilots were set up to review existing advice services, in Cumnock and Doon Valley, Easterhouse, and in the East End of Glasgow.

The East End Information Services Planning Group was formed in March 1991 to research existing information provision as the basis for the future development of services in the area. In February 1992 they formed the East End Information and Advice Forum with representatives from various agencies and community groups such as CAB, libraries, Benefits Agency, Pensioners Action Group East, John Wheatley College, Poverty Advice Group, Community Education Service, Social Work Department and East End Community Information Project. The forum produces strategy for the development and coordination of information and advice services in the East End of Glasgow, and has also produced a variety of reports including a referral manual, and a report on developing quality of service in information and advice agencies.

Community care forums may provide the basis for some degree of networking, and councils for voluntary service in some areas are already well established and may be an alternative to specially created community care forums.

### **Advantages of networks**

The structure of networks or federations can vary widely, as demonstrated by NDIP's pilot federations as well by the many federations not involved in NDIP. A network can be directly involved in information provision, or it may concentrate on developing resources such as databases for use by member agencies, or it may primarily be involved in support or development work. Some of the advantages of the existence of networks are that they may:

- encourage cooperation and information sharing between agencies;
  - encourage effective referral to other members of the network;
  - raise awareness of all members of the services provided by others;
  - create the possibility of one stop;
  - enable duplication and gaps to be recognised and addressed;
  - raise awareness of disability issues in generalist services;
  - give disability information a higher profile and increased influence and credibility;
- and

- facilitate joint initiatives.

The view was expressed in responses to the Working Group's statement that networks of informed people working in the field may be better sources of information than 'information professionals', and that a network may provide for "one stop" advice more effectively than a single source of information.

### **Disadvantages**

Setting up and running a network may, however, be time consuming, and requires genuine willingness to work together. Existing groups may be possessive about their own information resources and feel that their funding may be threatened by a developing network. It is difficult to ensure that all the partners in a network make an equal contribution to that network. As already mentioned the strength of a network may depend on the strength of its members as well as on its funding and structure.

## **Experience of federations outside the NDIP project**

There are many federations which are not part of NDIP, some of which appear to have been quite successful initiatives in improving the provision of information to people with disabilities, for example, the Oxford Disability Information Project (ODIP), which operated across 4 counties and 8 health authorities, and was coordinated by project manager, with each county having its own federation, one of which (Berkshire) had NDIP funding. The federation was funded by a hospital trust, the Department of Health and Oxford Regional Health Authority. In a recent report on its work the project manager describes how by the end of the project's 5 year existence, all four counties had multi-agency groups and on-going funding; all had county wide databases, a greater number of physical outlets and mechanisms for monitoring their performance. (29) The successes of the project, as described by the Project Leader, are put down to strong committed chairpersons, a paid worker in each county, high level representation from the organisations involved and clearly established and recorded arrangements between the agencies.

## 5 CHARACTERISTICS AND PROBLEMS

5.1 The experience of the Working Group and its sub groups suggests that there is, in the area of disability information, an impressive amount of enthusiasm and commitment on the part of many individuals. Many of them are working in the voluntary sector and involved in a constant struggle for funding and recognition. Some organisations in the voluntary sector depend on this commitment to raise the profile of the service offered and to create links with the statutory sector. There are many examples of organisations in the voluntary sector proactively addressing the information needs of disabled people.

This contrasts with the more reactive stance sometimes adopted in the statutory sector, although as described in Part 2, section 3.1 above there are many examples of local authorities taking information seriously.

Criticisms of a more reactive approach sometimes taken by statutory agencies emerged in responses to the Working Group's statement, for example a submission which contrasted the service and support received from the Lothian Coalition of Disabled People and its Grapevine project, with the difficulty experienced in getting information and help from the Employment Service's Placing Advisory and Counselling Team (PACT). Disabled people felt that they had to take the initiative to discover the latest aids and equipment, and then persuade the Disability Employment Adviser that this was what they needed.

Meanwhile there are encouraging developments in the private sector, particularly in relation to the privatised utilities and banks, that more information is being made available in suitable formats.

It is important to sustain and encourage the enthusiasm and commitment which exists in the voluntary sector, in such a way as to recognise the position and value of the voluntary sector in the overall structure.

5.2 Without repeating the various characteristics already identified above, the Working Group considers that:

- there is a lack of consistency of provision across Scotland;
- statutory agencies do not give information a high priority;
- there are problems in the relationship of the statutory and the voluntary sectors; and
- there is rivalry for funding both between groups in the voluntary sector and between groups in the voluntary and statutory sectors.

5.3 In addition it does appear that the position in Scotland is not dissimilar to that found by Coopers and Lybrand in 1988. Provision is fragmented and compartmentalised and characterised by the following:

- There is no systematic assessment of users' needs.
- Provision is not consumer driven.
- There is a lack of evaluation and feedback: too few organisations ensure that the information provided can be acted upon.
- There is a proliferation of a large number of specialist providers with few links between them.
- An absence of quality standards and performance indicators.

## PART 3 PROPOSALS FOR IMPROVEMENT

### 1 FUNDAMENTAL PRINCIPLES

The Working Group believes that it is important to start from ways in which the delivery and dissemination of information to disabled people can be improved at local level. Most of the information that most people want is local, and it has been shown that people want to get information and advice locally and also want information to be "wrapped in a person". The recent concern with information services for disabled people has arisen out of a concern with developments at local level, notably the extent to which local authorities are meeting their statutory duty, and the rapid but piecemeal development of services in the voluntary sector. The Citizen's Charter initiative underlines the importance of information about services, consultation with users, and quality standards. The introduction of community care has had the effect of focusing attention on the desirability of multi-agency working and collaboration between the independent and statutory sectors.

The Working Group considers that there is a great deal of agreement about the ingredients of a good information service, and many examples of good practice which can be drawn on. The principles described in this section should be the basis on which all information services are based, and in particular, the basis for the local information strategies which the Working Group considers would significantly improve the pattern and quality of information services at local level. The content of some of the standards described in section 3, below, are based on these principles.

#### 1.1 The social model of disability

The social model of disability should be the basic philosophy underlying all information and advice services aimed at disabled people. The effect of adopting the social model of disability will be to focus attention on:

- how to remove barriers which limit access to information;
- how to provide a service which will enable people to access the goods and services to which they are entitled;
- how the service can help to overcome the barriers to those services, for instance by providing an advocacy service; and
- the importance of disability equality awareness training and race equality awareness training in reducing attitudinal barriers.

#### 1.2 Services should be user-led and accountable to users

It is a fundamental principle that any service provided, whether by the voluntary or statutory sector, and whether at national or local level, should be planned and shaped so as to meet the needs of users of that service. The Citizen's Charter states that there should be regular consultation with those who use services. Users' views about

services and their priorities for improving them should be taken into account. To achieve this goal it will be necessary to:

- find out what people need both by consulting users about the service they want, and by other means;
- ensure that mechanisms exist to continually feedback the views of users about the service provided; and
- involve disabled people and their carers in the management and delivery of the service.

The involvement of users is therefore vital at two stages - at the planning stage, and in the ongoing monitoring and evaluation of the service. In addition disabled people and their carers may seek some degree of control over the service, and the experience of NDIP is that the active involvement of disabled people has been critical in the success of information services and federations. The extent of the involvement of disabled people in managing services and as employees providing information and advice has grown considerably during the course of the project, and can be seen as a positive outcome of the project.

1.2.1 Users of disability information include not only disabled people themselves but also carers and service providers of various kinds. These groups will almost certainly have different needs and will certainly need to have information presented to them in different ways. In addition, local information services are themselves users of the services provided by national agencies, and national bodies will need to develop methods of consulting with local groups about their needs.

1.2.2 The involvement of disabled people, for instance in consultations about their service needs, may require the development of sensitive and effective ways of communicating, for instance with people with learning disabilities or children with special needs, and people from ethnic minority groups. Local access panels and organisations of disabled people may be useful sources of users for feedback on services.

1.2.3 An NDIP publication includes a set of guidelines to help people undertake research into the information needs of disabled people, drawing on the experience of pilot projects in Birmingham, Manchester, Oldham and Walsall. (30)

1.2.4 The Living Options initiative in England whereby multi-agency development projects are only funded if disabled people are involved as equal partners throughout the whole process is an example of how this involvement can be built in to the structure.

### **1.3 The use of standards**

Any service which provides information and advice to disabled people should commit themselves to working towards the quality standards described in greater detail in Section 3 and Appendix 8 below. The Citizen's Charter states that public services

should set, monitor and publish explicit standards for the services that individual users can reasonably expect.

#### **1.4 Training**

In some areas training is as important, if not more important than basic information resources. For instance, when disabled people need advice about benefits, housing or employment, an adviser needs access to nationally produced information like the Disability Rights Handbook or material produced by the Benefits Agency, but more importantly needs experience in the way the system operates, and training in how to help clients get what they are entitled to.

Training may be required in 4 areas:

- a training about particular subject areas, eg benefits;
- b information and advice training, which should also form part of the skills training of all service providers, eg social workers, health professionals and staff in the fields of education, housing and recreation;
- c training to enable staff and/or volunteers to understand and work towards the quality standards referred to in section 1.3 above; and
- d disability equality awareness training. Any service or information providing agency should run courses for its staff.

The high cost of training must be recognised by funding bodies, and the role of national bodies in the provision of appropriate training should be recognised.

#### **1.5 Dissemination and Publicity**

At local level, as great an emphasis should be given to the dissemination of information as to its collection and processing. Evidence suggests that a great deal of information already exists, that a great deal of effort is going into the collection and organising of information, but that not enough information is getting across to the people who need it, and that a great many people still do not know where to go to get it.

Publicity may itself be as important as the quality of written information or information services available. Again, there are several pieces of research which describe experiments with different approaches (31,32).

There are many examples of good practice to draw on. For instance, as part of NDIP, the Birmingham Information Federation developed a signposting service called Disability Link Line which directs enquirers to the most appropriate source of assistance. The experience of this suggests that such a service needs a high level of publicity which could be used as effectively to promote the services actually providing advice. The Berkshire Disability Information Federation produced a card which was

widely circulated and which GPs gave out to provide a point of contact for people in need of information and advice.

The Working Group considers that this is an important issue to be addressed, primarily at local level. Local strategy groups might consider the desirability of a single telephone point of contact within each local authority area for signposting to disability information.

## **1.6 Independence**

It is important to ensure sufficient sources of independent advice. While it may appear that a duplication of sources of information is wasteful of resources, this is not necessarily the case, particularly if the effort of collecting information is clearly focused on particular national bodies or on a network at the local level.

It is important that a disabled person has a choice about where to go for advice and information, and that services are available which can act on behalf of an individual who may be in dispute with the health service, the state benefit system or the housing authority.

## **1.7 The one stop concept and networks**

The desire for a one stop source of information, to prevent people being passed from one agency to another, was one of the themes emerging from the Scottish Office survey. A one stop or single door source of information does not necessarily mean a single physical point of access to information. Such a literal understanding of the concept would be extremely limiting, and might effectively make access more difficult for disabled people, particularly in rural areas. The concept of one stop is essentially to prevent the disabled person being referred from one agency to another, or between different people within an agency, without any of those people taking any responsibility for the outcome of his or her case. It is also about ensuring that all the aspects of a person's need for information and advice can be identified as well as appropriate ways of meeting those needs. Various approaches to creating one stop sources of information are being tried.

Within the Benefits Agency a staff member takes responsibility for a client, and sees the case through to an end.

In social work departments clients are allocated to a keyworker who is responsible for all aspects of a client's care.

In Lothian Region an Advice Shop has been set up in a city centre location staffed by the Consumer and Trading Standards and Social Work departments.

In Cumnock and Doon Valley, a joint initiative between the region and the district is providing a network of information points for members of the public providing information about all regional and district council services, as well as information about health services, employment, benefits and community information. People

are able to make appointments to see particular experts. As well as staffed offices, freephone services will be available at 11 outlets.

The Bridges Basement in Edinburgh, funded mainly by the Scottish Office, offers one door access to services and information for young homeless people in the east end of Edinburgh. The social work department, careers service, local CAB, Benefits Agency and Edinburgh district housing department are all involved. A full time social worker has been seconded for three years, and negotiations are underway with Lothian Healthcare and the Royal Edinburgh Hospital to provide on-site assessment and surgeries. Access to pre-vocational training is being offered. Despite being an interesting example of multi-agency working, this project is sadly not accessible to anyone with limited mobility.

Pave the Way is a publication for children and young people with special needs in Glasgow and their parents and carers, and covers all the services available to them, including benefits, health, transport, education and housing. This is the result of a joint exercise involving staff from social work, education, health and housing, as well as groups from the independent sector.

An important element in the one door concept can be seen to be multi-agency working. This can involve bringing different agencies to one place, as in the Basement or the Cumnock and Doon Valley project, or by drawing together a range of expertise into one source of information, as in Pave the Way. An equally valid approach to the one stop concept is through a network or federation of information providers, perhaps marketed jointly and with the resources to refer effectively to the most appropriate source of advice. Within the network the appropriate role of generalist and specialist services should be spelt out.

The Working Group believes that this type of collaborative working is increasingly necessary to break down the barriers which have tended to compartmentalise and segregate services. The Working Group recommends that local information and advice forums should consider ways in which collaborative working and effective referral procedures can effectively answer the need for "one stop" information and advice.

## **2 LOCAL STRATEGY**

The Working Group believes that a significant improvement in information services would be achieved if, after the reorganisation of local government, every new authority was required to develop an information and advice strategy which would take account of all the existing providers and develop and enhance provision. Local authorities should consider information provision as a service in its own right. (33)

### **2.1 Responsibility for strategy**

Under existing legislation local authorities have a statutory duty to provide information about council services and other relevant services to disabled people. The reorganisation of local government will have the effect of bringing all council services under one roof. This fact, combined with the increasing recognition that the key to the success of community care lies in the greatest possible cooperation between service providers, makes it appropriate that the responsibility for ensuring that information and advice strategy is given a high priority should lie with the chief executives of the new authorities.

Although the responsibility for coordinating a strategic framework should lie with the chief executive, or equivalent, it is desirable that agencies in both statutory and independent sectors participate as equal partners, and that disabled people are fully involved.

### **2.2 Strategy Group**

A strategy group should be created with coopted members from the independent sector as well as from the health field. The functions of the strategy group would include:

- the drawing up of an information and advice strategy for the local authority area;
- the identification of local areas within which local information and advice forums could be established;
- the establishment of local information and advice forums;
- the development of a common database, or other methods of sharing information resources, accessible to both statutory and voluntary sectors;

The problems and cost of doing this should be assessed realistically before a decision is made. Examples of good practice are Grampian Caredata and the community care database created by the Devon Disability Information and Advice Forum.

- the provision of advice and support for local forums;

- the organisation of training courses for local staff and volunteers;
- maintaining links with the proposed advisory body.

Strategy groups should be responsible for ensuring that the following are available within the authority's boundaries:

- sources of information and advice for disabled people;  
 Although the goal should be to make all sources of information and advice accessible to disabled people, there may still be a need for sources of specialist disability information. This is one of the findings of NDIP (see Part 1, section 4.3.2 above);
- a disabled living centre or similar central resource centre, which is well publicised to all service providers and information and advice agencies;
- facilities for producing information in the range of formats which are necessary, especially for braille, taping, videotaping and sign language interpreting; and
- facilities for translation and interpreting in relevant ethnic minority languages.

### **2.3 Local information and advice forums**

Local information and advice forums would be responsible for conducting audits of existing services, and identifying gaps and duplication. Each forum would draw up a local development plan.

The Working Group commends the document produced by the Strathclyde Poverty Officers Group of Strathclyde Regional Council in February 1990 "Towards the Development of a Strategy for Information and Advice Provision in Strathclyde". This report proposes that local advice forums should be established to review existing provision, identify local priorities and develop networks of information/advice providers. The group also commends the practice of the Glasgow East End Information and Advice Forum which has put much of this into effect.

The experience both of NDIP and of other information federations is that some pump priming finance of such developments is necessary as a short term catalyst to provide the incentive and focus for development (34). Local authorities should consider funding a development worker to initiate and establish local information and advice forums or networks, having regard to the existing situation at local level.

Local forums could provide practical support and advice about such things as drafting constitutions, establishing management committees, identifying and organising information sources, preparing grant applications, and establishing office procedures and accounting systems.

2.4 In a parallel development, HomePoint commissioned a guidance manual for developing local strategies in the housing information and advice field. This manual is being piloted in 4 areas.

### **3 STANDARDS AND ACCREDITATION: the components of a good service**

It is clear both from the Scottish Office survey, and from responses to the Working Group's statement, that there is a perceived need for widely accepted national standards as a benchmark both for information providers to assess their own service and to plan for improvement and training, and for use by funders, both local and central government.

#### **3.1 Can all agencies be expected to meet the same standards?**

The agencies involved differ widely in their staffing and funding arrangements, in who their clients are, and in their philosophy, but more significantly in whether or not they are primarily information and advice providers. In the case of social workers, health professionals or housing officials, and also in the case of commercial companies, the provision of information may well be seen as secondary to service provision, despite the statutory duty imposed on local authorities.

In relation to this latter category the Working Group would like to make particular recommendations about the way in which information provision is regarded, and the extent to which information training can be included in professional training. Nonetheless even where information is given as an adjunct to service provision, consumers have a right to expect the information to be accurate, current and appropriate to their needs.

Despite the variety of agencies involved, standards should be drawn up in such a way as to be relevant to all information providers. In the field of housing information and advice, draft national standards have recently been drawn up and broadly welcomed by the statutory and voluntary sectors. (35)

Similarly despite the wide range of disabilities, the Working Group believes that the standards should be expressed in such a way that it is unnecessary to have different or extra standards for particular disabilities. The particular needs of people with learning disabilities or with mental health problems should be incorporated in common standards. If a standard can be stated, for example that an information or advice giver should ensure that the client has understood the advice or information given, this will require the advice giver to take the steps necessary to ensure that the client has indeed understood the information and advice given, and that the client is then in a position to act on that advice. If the client is clearly unable to act on advice without help or advocacy, then it will be important that the referral procedures of that agency ensure that the client is passed on to someone better able to take his or her case forward. Very similar considerations apply to people from ethnic minority groups.

The Working Group recognises that not all agencies provide the same type of service, and that there is clearly a need for a variety of levels of information and advice. Libraries have an important role to play in improving information services, but cannot offer advice. Grampian Caredata which provides a computerised database of health

and community care information for the whole of Grampian, describes itself as a signposting service. In terms of quality standards, what is important is that the level of service provided by any particular agency is defined and made clear to users of that service.

The Working Group believes that it is desirable that any national standards apply to national bodies, as much as to local groups, and that it is essential that national bodies define quite explicitly what information service they aim to provide and who they are providing it to. This point was made by PSI in its report on the work done with national providers.<sup>(36)</sup> National providers have a wide range of users, including disabled people, professionals and local information services, and to ensure that a national provider is meeting the needs of its users it is necessary to define the service which it aims to provide to these various client groups and to have methods for finding out whether it is meeting the needs of those groups.

### **3.2 Content of Standards**

3.2.1 Agencies in the voluntary sector are increasingly recognising the need to work to standards: in some cases this may be a condition of receiving funding, or of being contracted to provide a service in a particular field. Quality systems such as BS 5750, the Scottish Quality Management System and Investors in People are increasingly being used in the voluntary sector.

BS 5750 has been called into question on the grounds (a) of its cumbersome technique and (b) that it is less relevant to services which have no tangible measurable output. The NDIP project team did not consider it worthwhile to use BS 5750 as the basis for a national quality framework, but worked towards ensuring that local projects set realistic objectives for themselves and monitored whether they were achieving those objectives.

In its work with national providers, NDIP produced practical suggestions on ways of improving and monitoring the quality of their services. The conclusion was that while it was difficult to define and measure quality, it was possible to evolve a three stage strategy requiring providers to:

- establish the needs of their users;
- identify the components of a good quality service; and
- take steps to implement improvements.

3.2.2 Because of the wide range of type of organisation providing information to people with disabilities, the resources available to meet standards may vary considerably. Nonetheless the Working Group believes that the same standards must apply to all agencies. Disabled people and their carers are entitled to good quality, up to date information and advice, appropriate to their needs and in a form which they can understand, whatever the type of organisation providing the information. National standards will provide a tool for the assessment of services, and provide goals towards which services can work. The failure to meet standards could result in the removal of funding whether from local or central government. The Working Group feels that it is

important that the standards are framed in such a way as to be relevant to, and achievable by all types of agency.

3.2.3 Following on from this, and looking at the various parts of the disability information continuum, it is equally important that all the players in the game, whether they be libraries, CABx or social work departments, should be fully aware of the services provided by other players, and have systems of referring people to the most appropriate source of advice or information for their particular needs. Effective referral should not be dependent on the particular knowledge of the first point of contact but should be the subject of clear guidelines. Referral should not be confused with signposting: referral implies that the person referring knows the best source of advice in a particular area and has a procedure for following through that referral, whereas signposting indicates a possible source of advice.

3.2.4 The Working Group is aware that quality standards have already been developed for use in the information and advice field, and that many agencies already work towards standards. The CAB service in Scotland has its own standards, while the library service works towards library standards drawn up by COSLA. In the housing information and advice field national standards have recently been drawn up by research consultants for HomePoint. The Federation of Independent Advice Centres requires a degree of community involvement and a commitment to equal opportunities, while DIAL UK requires that a majority of board members are disabled people. In addition service providers such as the Benefits Agency have quality frameworks leading to quality awards, often using self assessment procedures.

While recognising that some agencies are already working towards standards, the Working Group has tried to agree on standards which would be useful for agencies which do not already use standards, and could be used to add to or clarify existing standards, for instance by adding further detail about how access can be improved by providing information in appropriate formats or languages.

3.2.5 The Working Group has not tried to devise standards from scratch, but bases its suggestions on the following:

- Improving the provision of national disability information, a report by Nick Moore, Jane Steele and Caroline Boswell of PSI on their work with national information providers as part of NDIP. Part 3 discusses quality and the components of a good quality service.
- The **national standards for housing information and advice** drawn up for HomePoint, the housing information and advice network established under the auspices of Scottish Homes.
- The ten suggested principles for the development of information initiatives produced by the **National Information Forum**.
- NCC,s Good Advice for All, guidelines on standards for local advice services.

To provide a high quality service an information provider must take account of

- the service offered;
- the management of the service;
- the information itself; and
- training support and staffing issues.

An outline of the proposals from the sub group which considered quality standards and which should be taken into consideration in the drafting of national standards are contained in Appendix 8.

### **3.3 Use and enforcement of standards and accreditation**

The Working Group is concerned that it should be clear what the standards would be used for, and in particular whether some form of accreditation would be used.

#### **3.3.1 Financial incentives**

It may be possible to create financial incentives to meet standards or at least to show evidence of a commitment to working towards standards. There are two possibilities:

- Funding by local or central government is made dependent on meeting standards.
- A commitment to working towards standards may be required in order to gain access to other services such as cheap indemnity insurance or access to relatively inexpensive but good quality information resources (eg DIAL UK).

#### **3.3.2 Accreditation**

The Working Group considered the work done by Scottish Homes in this area. Following Scottish Homes' evaluation of the quality and availability of housing information and advice, an advisory committee was set up to advise the Chief Executive of Scottish Homes on various matters including the development of standards for the provision of housing information and advice and the development of an accreditation system. A report on accreditation systems was commissioned from Peter Gibson Associates. This report described existing forms of accreditation and made recommendations about the type of scheme Scottish Homes should adopt.

Various points were made in the report which would be equally relevant in the field of disability information:

- Public recognition of accreditation takes a very long time to become established.
- In a "quasi market" it is the funder rather than the end user of a service who is interested in whether the service meets the standards.

- It may be beneficial to staff to be working towards the achievement of an award which recognises the value of the work they are doing.

At the conference held in November 1994 to discuss the draft national standards for housing information and advice, while the standards were almost universally welcomed by both voluntary and statutory sectors, any early move towards an accreditation system was resisted. The Working Group thinks that this is also likely to be the case in the field of disability information. It is important that standards are allowed to evolve and develop before any more formal accreditation is introduced. All groups should be encouraged to use the national standards as a set of goals which they should be moving towards, even if they might feel daunted at the prospect of having to meet them all, or do not have the resources to meet them.

### **3.3.3 Advisory body**

The Working Group believes that the development and encouragement of the adoption of national standards should be overseen by an advisory body including disabled people, carers, and their representatives, as well as other people with relevant expertise. This advisory body would be responsible for modifying the housing information and advice standards so as to make them more applicable to information and advice services for people with disabilities, taking account of the points made in this report. These standards should be used as the basis for funding decisions by central and local government, and once they have become established and accepted could form the basis of an accreditation system, although the Working Group does not advise this in the short term.

The monitoring of the use of standards could be undertaken either:

- on a periodic basis, by a contracted third party; or
- on an ongoing basis, at local level, by local authority inspection units contracted to do this work, or some other agent appointed by the local authority strategy group.

The Working Group does not rule out the possibility that some form of accreditation would be acceptable at a later date once the standards have had time to become established.

The Working Group also recognises that it is in the nature of the disability field that local self-help groups will spring up to meet particular needs and it may not be appropriate to expect such groups to seek accreditation.

### **3.4 Development of SVQS in advice and counselling**

While accreditation would relate to an agency as a whole, a parallel development is the work which is going on to devise appropriate Scottish Vocational Qualifications in two fields: Advice, Guidance and Counselling, and Library and Information Services. In

both cases a lead body has drawn up draft standards which are currently being piloted and will be finalised by summer or autumn 1995. It may be that the lead bodies will become Industry Training Organisations. SVQs are certificates awarded for competence in the workplace.

These will undoubtedly have a role to play:

- in helping to identify staff training needs;
- in recognising staff achievements;
- in selecting staff;
- in demonstrating a commitment to quality;
- as an indication to funders about the qualification of staff; and
- in applying both to paid and unpaid workers.

## 4 NATIONAL STRUCTURE

The Working Group agrees that in the interests of:

- improving the quality of local information services;
- improving the consistency of provision across Scotland;
- increasing the reliability of Scottish information;
- avoiding duplication of collection and processing of information;
- improving communications between national information providers, and between national and local groups; and
- maximising the use of existing resources, and ensuring value in the use of public money;

there is a need for the creation of new structures or processes at national level.

In terms of the functions which are needed, the Working Group has identified the following:

- responsibility for taking forward the improvement of information services at both national and local level;
- the development of appropriate national standards;
- a means of monitoring those standards; and
- responsibility for the development and functioning of a Scottish disability information service.

### 4.1 Advisory body

An advisory body should be set up and given the responsibility for framing policy, overseeing the development and monitoring of national standards, and for the development and functioning of a Scottish disability information service.

The advisory body should be made up of disabled people and their carers, particularly those who represent organisations of and for disabled people and their carers, as well as other people with appropriate expertise. Members should as far as possible represent the range of types of impairment, as well as rural and more isolated parts of Scotland, and ethnic minority groups. The group should be large enough to be a genuinely representative body, but also of a size to be able to conduct its business efficiently. The Working Group recommends around 15 members.

It will be important that such a body is seen as being authoritative, both in terms of having the support of existing organisations, and in terms of recognition by the Scottish Office. The Working Group considers that the chairman of the advisory body should be appointed by the Secretary of State.

The advisory body should have secure funding for at least three years, and should be sufficiently funded to allow it to commission research, for instance in relation to standards, or to audit the quality of provision.

The advisory body should report annually to the Secretary of State, and account for its use of public money.

4.1.1 The way in which this body is established will be determined by the nature of the functions which it is required to perform, and the number of staff it requires. At one end of the scale it could be a purely advisory body with no executive functions, while at the other it could be more actively involved in overseeing the development of information services.

The Working Group sees the main responsibility of the advisory body as being in the development and approval of national standards, the monitoring of the use of those standards, and in overseeing and being responsible for the functioning of the national disability information service.

In terms of these functions, it is envisaged that the advisory body might need to meet between five and eight times a year, have a secretariat to service these meetings, and staff to prepare papers and oversee the work to be done in the development of standards and in their monitoring. It is envisaged that the work on standards and in monitoring would be contracted out to an outside agency, under the supervision of a member of staff responsible to the advisory body.

The alternative ways of establishing the body would be:

- as a self-contained independent body, with its own premises and staff; or
- as an independent body with its own staff but functioning under the auspices of an existing organisation and so drawing on that organisation for its office facilities and secretarial back up.

Existing organisations might be considered as appropriate "homes" for such a body, provided that they had suitable facilities, in terms of fully accessible premises, a meeting room, and the office capacity to accommodate the necessary staff. The types of organisation which might be appropriate would include:

- disability organisations;

This type of organisation would have high levels of accessibility and awareness of the needs of disabled people. Some organisations in this area would not have large enough premises to accommodate such a body.

- general organisations with experience in and facilities for hosting such organisations.

Accessibility cannot be assumed, but other facilities are likely to exist.

#### 4.2 **Scottish disability information service**

The Working Group considers that, on the basis of responses to the Working Group's statement and the views of members of the sub groups, there is a demand for some form of clearing house for the supply of national information to local services. This service should be funded by the Scottish Office, but function under the auspices of the advisory body. The Working Group considers that as local authorities stand to benefit from such a service, there is the possibility of the information service generating revenue from local authorities, possibly through COSLA.

The functions of the service would be:

- to provide a central source for a wide range of disability information provided by national organisations;
- to act as a channel for the distribution of information to local service providers and information services;
- to provide a screening service to ensure that all national information is applicable in Scotland;
- to act as a channel for government information;
- to provide training and support for local information services in relevant areas; especially where this cannot be provided at local level;
- to provide a current awareness service about legislation, government policy and research and articles;
- to refer enquirers to sources of expert advice, or to local advice services;
- to provide and develop databases using user-friendly software;
- to provide information in a flexible form which allows for output in a range of formats and languages, including ethnic minority languages;
- to fill gaps in existing provision, for example by providing signposting guides or directories of local providers; and
- to provide feedback to central government and to local strategy groups, through the advisory body, about the effects of government policy.

The service should be a secondary information service, that is, it should supply information to information and advice agencies and to service providers, and should not be funded to provide information directly to members of the public.

The Working Group has considered alternative models for providing such a service: the National Information Federation in Wales, the Dutch Institute for the Provision of Information to the Disabled, and the developments in the realm of housing information and advice in Scotland. Details of these 3 models, including assessments of their relative cost are contained in Appendix 6.

#### 4.2.1 Making it happen

The Working Group recognises that the cost implications of creating a new body in Scotland may make it more likely that such a unit would be established within an existing organisation, in line with the Scottish Homes model, or that on the basis of a competitive tender, the work might be awarded to an existing organisation. It is not for the group to recommend the most appropriate organisation, but organisations with relevant skills and experience could be considered. These would probably be either organisations already operating at national level in the disability information area (such as DIAL Scotland, Disability Scotland, or Enable) or organisations operating in the general advice area (such as Citizens Advice Scotland).

There are advantages and disadvantages of using either of these types of organisation.

- Disability information organisations have an advantage in being familiar with the field and the main national information providers, and aware of the issues, problem areas and ethos of the national providers. However they may already be identified with a particular aspect of disability, or a particular style of operation and may be perceived by other national providers as rivals for funding. While it would be important to establish the independence of the new service, it would be difficult to avoid the new service being perceived as part of the parent body.
- A generalist provider, while aware in general terms of the issues and other organisations in the area, would have to establish its credibility in the eyes of the main players in the field. Advantages of this type of organisation becoming involved would be that:
  - the information needs of disabled people would be recognised as being very often the same as other people's;
  - disability information services would stand to benefit from the huge range of general information held by the parent body; and
  - generalist providers would be encouraged to increase their expertise in disability areas.

There are, of course, other types of organisations which might tender to do this work, including commercial organisations. The Working Group has not considered this possibility in any detail, and it would appear likely that a commercial organisation would be unable to match the experience and contacts of some of the existing players in the field. The Working Group is concerned that the advisory body should not be bound to accept the lowest tender, but should be able to take into consideration other factors relevant to the likely success of the organisation in providing the service.

A change in the way information is produced or co-ordinated at national level will only be successful if the organisation providing the Scottish disability information service is seen to be independent of existing information providers, and if it has the wide support of all the main players in the field. This means that if the service is provided by an organisation which already exists, it must be provided by a distinct independent unit within that organisation. Existing national information providers must support the unit and be willing to use the unit as a channel for the dissemination of material which they produce, and to cooperate in ways in which information can be improved. The main players should be brought together at an early stage to create a network of organisations which want to be actively involved in taking proposals further.

#### **4.3 Forum of national organisations**

Irrespective of the structural changes suggested above, there is a need for regular meetings between national information providers for informal discussions and sharing of experience. Such meetings could be convened by the advisory body or information service, or by a neutral body such as the Scottish Libraries Association.

NDIP in England has shown the value of a regular newsletter and conference, which would be equally valuable in Scotland. This could be the responsibility of the advisory body, or the Scottish disability information service.

## 5 FUNDING

The development of effective information and advice provision depends on adequate and reliable funding.

### 5.1 Funding of national organisations

National information providers at UK level, and in Scotland, rely on grants made by central government. The trend in this funding involves a move away from funding on the basis of the core costs of the organisation to one which focuses on particular projects. This trend will inject more uncertainty into the present situation.

The final report by the project team on the NDIP project makes the point that compared with other areas, eg information about housing rights, the funding of organisations providing disability information is relatively generous. There is also quite a high level of funding of generalist advice services which can already meet many of the information needs of disabled people. For example, the Citizens Advice Bureau information system costs £1.5 million to produce annually.

One of the features of the funding of national organisations in Scotland is a wide variation in the level of funding between different organisations. Appendix 9 contains a list of grants made by the Scottish Office in the year 1993-94. The Working Group has felt constrained in the extent to which it can comment on these figures. Most of the organisations listed will be involved in active fund raising to supplement their grants, and they vary considerably in the level of their capital reserves. Furthermore it is not possible to specify what proportion of an organisation's funding is devoted to information services. The level of funding also bears some relation to the range of services provided by the organisation.

It can be seen from Appendix 9 that the funding of organisations which provide an information service as part of their remit ranges from £319,028 to Disability Scotland to £10,000 to the Disablement Income Group Scotland and £12,489 to DIAL Scotland.

The Working Group considers that the wide variation in funding at national level may be partly the result of the historical development of these organisations and that longer established organisations are often in a better position to receive funding than newer organisations.

One of the factors which limits national organisations in generating income from other sources, such as from sales of publications or other information products is the lack of purchasing power in the system. Disabled people and their carers are on lower than average incomes, and local information services frequently mentioned funding as a problem in responses to the Working Group's statement.

The Working Group believes that the Scottish Office Home and Health Department will remain the most important source of funding for national organisations. In allocating

funding to national organisations the Scottish Office should ensure that these organisations are meeting national standards, and in particular that they are providing a service which meets the needs of their users.

## **5.2 Funding of local information and advice services**

The funding of local services is to a large extent dependent on grants from local authorities. In addition, the Urban Programme can provide funding for projects in Areas of Priority Treatment (APTs), and has supported several information projects in Scotland which have subsequently gained main line funding from local authorities. In general the level of funding of local services means that these services usually have no long term stability and have an over-reliance on volunteers.

As has been discussed above, the practice of local authorities in relation to information varies widely as does the extent to which they support and collaborate with services in the independent sector. The move towards establishing more formal contractual relationships between local authorities and the independent sector through service level agreements will give voluntary organisations a longer term security and define more clearly the relationship between the sectors. In order to ensure that voluntary organisations continue to be accountable to users as well as to their funders, it is important that local authorities ensure that these organisations meet quality standards, in particular that the service is accountable to users.

Health boards also have a significant role in relation to funding as can be seen in joint initiatives such as Grapevine in Edinburgh. There is also a potential for the funding of advice services in health centres and hospitals.

## **5.3 Possible new structures**

There will be funding implications as a result of some of the recommendations which the Working Group is making. Nonetheless, the Working Group believes that one of the results of a restructuring of the way in which information for disabled people is collected and disseminated will be greater value for money and a reduction in duplication of services.

The effect of adopting national standards will have funding implications for local authorities, other service providers and for information services, in relation to training and the cost of equipment or adaptations necessary to improve accessibility of information to disabled people and carers.

### **5.3.1 Advisory body**

As described above the cost of setting up the advisory body will depend on how it is done. Assuming that it is broadly acceptable for the advisory body to function under the auspices of an existing organisation, it seems likely that the cost of this will be significantly less than those involved in setting up an organisation from scratch. The

following figures refer to the costs of using an existing organisation to provide premises for meetings and office space for staff and secretariat.

Central support

Staffing

|                              |        |        |
|------------------------------|--------|--------|
| Project development officer  | 25,000 |        |
| Part time personal assistant | 7,000  |        |
| Courses/conferences          |        | 500    |
| Travel                       | 500    |        |
|                              |        | 33,000 |

Committee expenses 15,000

Office expenditure and equipment

|                         |       |        |
|-------------------------|-------|--------|
| Supplies and stationery | 1,000 |        |
| Postage                 | 1,000 |        |
| Computer equipment      | 2,000 |        |
| Telephones              | 500   |        |
| Proportion of overheads | 5,000 |        |
|                         |       | 10,500 |

TOTAL 58,500

Funding to allow for

|   |       |  |
|---|-------|--|
| Development of national standards               | 5,000 |  |
| Monitoring of standards                         | 5,000 |  |
| Forum of national providers<br>(3 times a year) | 1,500 |  |
| Annual conference                               | 5,000 |  |
| Newsletter<br>(4 times a year)                  | 6,000 |  |

TOTAL 17,500

OVERALL TOTAL 76,000

**5.3.2 Scottish Disability Information Service**

The costing is based on the use of an existing organisation.

Clearing house

|       |                     |        |
|-------|---------------------|--------|
| Staff | Policy Officer      | 20,000 |
|       | Information officer | 17,000 |
|       | Training officer    | 18,000 |

|                                  |        |                |
|----------------------------------|--------|----------------|
| Computer support worker          | 20,000 |                |
| Admin staff (two full time)      | 25,000 |                |
| Travel                           | 2,000  |                |
| Conferences/courses              |        | 1,500          |
| TOTAL                            |        | 103,500        |
|                                  |        |                |
| Office equipment and expenditure |        |                |
| Supplies and stationery          | 2,500  |                |
| Postage                          | 2,500  |                |
| Computer equipment               | 5,000  |                |
| Telephone                        | 2,000  |                |
| Proportion of office overheads   | 5,000  |                |
| TOTAL                            |        | 17,000         |
|                                  |        |                |
| Creation of information products |        |                |
| Publication costs                | 22,500 |                |
| Printing                         | 22,500 |                |
| Newsletter                       | 5,000  |                |
| TOTAL                            |        | 50,000         |
| OVERALL TOTAL                    |        | <u>170,500</u> |

## PART 4 RECOMMENDATIONS

### 1 Addressed to the Secretary of State

- 1 The Secretary of State should promote the establishment of an advisory body to drive forward:
  - the framing of national policy in this area;
  - the development and monitoring of national standards;
  - the functioning of the Scottish disability information service; and
  - the convening of regular forums for the sharing of knowledge and experience between national providers, and between national and local providers; and to
  - provide feedback to the Secretary of State about the provision of information to disabled people and their carers at national and local level.
- 2 This advisory body should be made up of disabled people and carers, particularly those who represent organisations of and for disabled people and their carers, as well as other people with appropriate expertise. Members should as far as possible represent the range of types of impairment, as well as rural and remote parts of Scotland, and ethnic minority groups. Members should be paid a daily allowance.
- 3 The Scottish Office should provide the necessary funding through the advisory body for a Scottish national disability information service whose functions would include the distribution of material created by other bodies, the creation of information products, advising on the applicability of UK information in Scotland, and providing advice and training to local information providers. The service should not be funded to provide information or advice directly to members of the public.
- 4 The Secretary of State, in the interests of ensuring that the policy of care in the community is implemented consistently and to high standards, should issue guidance to local authorities about:
  - a the desirability of implementing local information and advice strategies within the new unitary authorities; and
  - b effective information provision at local level, and give examples of good practice in this area.

- 5 The Secretary of State should issue a national community care charter to the new shadow authorities elected in April 1995 which will become the new authorities in April 1996, identifying the legislative framework, and establishing core standards which should apply in all local community care provision. These would include the crucial role of information in community care and the importance of making information available in forms and languages which are most appropriate for clients.
- 6 In the funding of national organisations, the Secretary of State should consider:
  - a how far those bodies are meeting the national standards; and
  - b the extent to which national bodies are meeting the needs of local information services.
- 7 The Secretary of State should ensure that accurate records are kept about the amount of money which organisations which receive funding from the Scottish Office devote to information services.
- 8 The Secretary of State should conduct a consultation exercise on the basis of this report, with particular reference to:
  - the creation of an advisory body, its functions, composition, and establishment; and
  - the establishment of a Scottish disability information service, its functions and composition, and alternative methods of setting it up.

## **2 Addressed to local authorities**

- 1 Local authorities should draw up and implement information and advice strategies as outlined in this report, with guidance from the Scottish Office.
- 2 Within these strategies the need for targeted services for disabled people should be recognised, including:
  - general information and advice;
  - advice about aids and equipment; and
  - information and advice about independent living.
- 3 The local strategy should be based on the principles described in Part 3, section 1 of this paper, and should involve representatives from both the statutory and voluntary sectors.

- 4 Within the strategy, the importance of creating and encouraging one stop information and advice should be highlighted, and consideration should be given to ways in which networking between the whole range of agencies can be encouraged.
- 5 Local authorities should address in their strategy the particular problems highlighted in this report, for instance the need to raise the profile of libraries as sources of information, as well as the particular needs of children, ethnic minority groups, carers, and those living in remote or rural areas.
- 6 Local authorities should draw up community care charters based on any national charter or other framework document drawn up by the Scottish Office, or ensure that it meets the requirements of any national community care charter.
- 7 Local strategies should give a high priority to means of raising the awareness of all the local community, and especially of disabled people and their carers, of appropriate sources of information and advice.

### **3 Addressed to professional bodies**

- 1 Service providers at national and local level, in the statutory and independent sector, for instance in the fields of social work, health and housing, should receive information training as part of their professional training.
- 2 The various parts of the health service should address the pressing need to improve their role in the provision of information and advice, whether by becoming involved in local strategy groups, working with local forums to improve referral to appropriate sources of information, or through direct funding of advice services in health centres or hospitals.
- 3 The possibility of providing financial incentives, through the GP contract, to GPs and health centres which provide information and advice services should be explored.

### **4 Addressed to service providers**

- 1 Service providers at both national and local level in the statutory and voluntary sectors should receive disability and race equality awareness training, and should liaise better with disability groups.
- 2 All service providers should take account of the national standards to be agreed for use in relation to information and advice services for disabled people, and seek to comply with those standards.

## PART 5 THE WAY FORWARD

The Working Group believes that this report should be used in two ways.

1 The report describes the principles on which local information services and possible local strategy groups should be based, and outlines the content of national standards which the Group believes can be used:

- as a basis for a local strategy;
- as tools by which national and local services can assess the service they are providing;
- by generalist advice services to assess the extent to which they are meeting the particular needs of disabled people; and
- by service providers to assess the extent to which the information they provide about their service meets the standards.

The principles and standards should be further developed:

- to provide a benchmark for existing and future services (this work would be commissioned by the advisory body); and
- to provide practical guidelines for use by local authority strategy groups and information and advice forums (this work could be commissioned by the Scottish Office).

2 The report recommends various changes at national level, and the Working Group suggests that the way forward in this area is a process of consultation on:

- the advisory body; and
- the Scottish disability information service.

The method of conducting this consultation could be:

- on the basis of this report, or on the basis of a consultation document based on this report;
- through consultative seminars or conferences, or by means of written responses.

The consultation would cover such things as

- how the advisory body should be appointed;
- what the functions of the information service should be; and

- how the information service should be established.

It is difficult to overemphasise the importance of consultation as a means of gaining the support of the main players in the disability information field. If any new structural arrangement does not have the support of these players it will be a waste of time. An imposed solution is unlikely to work. Equally importantly it must also have the support of disabled people.

Following on from this consultation, the advisory body should be convened as soon as possible so that the process of establishing a new framework for information services for people with disabilities and their carers can be put in place, and the specification of the information service can be drawn up, and tenders invited.

## BIBLIOGRAPHY

Audit Commission, What seems to be the Matter, Communications between Hospitals and Patients, 1993, HMSO

Barnes, Colin, Disabled People in Britain and Discrimination, 1991, Hurst and Company in association with the British Council of Disabled People.

Barnes, Colin, From national to local: an Evaluation of the effectiveness of National Disablement Information Providers' Services to local disablement information providers, 1994, British Council of Organisations of disabled people

Berthoud, Lakey and McKay, The Economic problems of disabled people, Policy Studies Institute, 1993

Boswell,C, Moore,N, and Steele,J, Improving the Provision of National Disability Information, NDIP, Nov 1994

Central Office of Information, The Informability Guide, HMSO, 1994

Citizen's Charter Unit, The Citizen's Charter and People with Disabilities, a checklist, 1994, HMSO

Clarke, Alison, Raising a Din, Anglia and Oxford Regional Health Authority, June 1994

Fitzpatrick J, The Needs of Physically Handicapped People for Information about facilities and benefits, Institute for Consumer Ergonomics, 1980

Gay, Pat, First Link in the Chain, GPs as disseminators of non-clinical information, Berkshire Disability Information Federation, 1994.

Glasgow Council for the Voluntary Sector, Community Care: Conference report, June 1994. Hearing the views of service users and carers

Hinkley, Philipa, and Steele, Jane, National Disability Information Provision : Sources and Issues, 1992, Policy Studies Institute

ICTA, Technical Aids and Information - perspectives from 11 countries, 1988

KPMG Peat Marwick, Implementing Community Care : Informing Users and Carers, 1993, Department of Health

Liberty and BCODP, Access Denied, 1994

Martin,J, Meltzer,H, and Elliot,D, The Prevalence of Disability among Adults, 1988, OPCS, London

Martin,J, White,A, and Meltzer,H, Disabled Adults: Services,Transport and Employment, 1989, OPCS, London

Martin,J, and White,A, The Financial Circumstances of Disabled Adults living in Private Households, 1988, OPCS, London

McGlone, F and Cronin,N, Crisis in Care, Family Policy Studies Centre, 1994

Moore, N, Access to Information, PSI, 1995

Nankivell, Clare, Can the DISS classification scheme be developed for national use?, University of Central England, 1994

National Consumer Council, The Fourth Right of Citizenship, 1977

National Disability Information Project, Information Enables, Improving Access to Information Services for disabled people, Papers presented at the NDIP's 1993 conference.

National Information Forum, Information for Disabled People: The Hospital's Role, 1991

National Information Forum, Getting the message across - designing guides to local services and making sure they get to the people who need them, 1991

Office of Population, Censuses and Surveys, Survey of disabled people, 1985

Paris, JAG, and Player,D, report on project in Birmingham involving CAB in GP practice, British Medical Journal, vol306 5/6/93

Research Institute for Consumer Affairs, Evaluation of the NDIP,interim report and summary of work in progress, August 1993

Richardson,A, Unell,J and Aston,B A New Deal for Carers, Kings Fund Informal Caring Support Group, 1989

Rooney, M, and Shiner, M, Managing Disability Information: Guidelines on Directories and Databases, PSI, 1995

Scottish Homes, Housing Information and Advice Services, National Standards Manual, prepared for Scottish Homes by Chariton (Research and Consultancy) 1994

Simpkins, Rebecca, Researching the Information Needs of Disabled People, NDIP, Nov 1994.

Social Work Services Group, Survey of Information Services for People with Disabilities, The Scottish Office, 1993

Steele, Jane, Health Information for Older People, 1994, PSI Research Report 785  
Strathclyde Regional Council, Special Needs: the multi-cultural challenge,  
seminar report, November 1991

Tinkler,A, The information needs of Elderly People, 1993, Age Concern Institute of  
Gerontology

Welsh Consumer Council, Published Information for Users and Carers and the General  
Public, 1994

## FOOTNOTES

- 1 NCC, 1977
- 2 Central Office of Information, 1994
- 3 NDIP, Information Enables, 1993
- 4 Barnes, 1991, p2
- 5 OPCS, 1985
- 6 McGlone, F and Cronin,N, 1994
- 7 ibid
- 8 Martin, White, and Meltzer,H, 1989
- 9 Strathclyde Regional Council, 1991
- 10 A Richardson, J Unell, and B Aston, 1989
- 11 Coopers and Lybrand, 1988, para 3.12
- 12 see 10 above
- 13 Liberty and BCODP, 1994
- 14 Boswell, Steele and Moore,1994
- 15 PSI, 1995
- 16 Rooney and Shiner, 1995
- 17 Fitzpatrick, 1980
- 18 KPMG, 1993
- 19 Welsh Consumer Council, 1994
- 20 Glasgow Council for the Voluntary Sector, 1994
- 21 Steele, 1993
- 22 Tinkler, 1993
- 23 Paris, 1993
- 24 Gay, 1994
- 25 Audit Commission, 1993
- 26 National Information Forum, 1991
- 27 ICTA, 1988
- 28 Barnes, 1994
- 29 Clarke, 1994
- 30 Simpkins 1994
- 31 National Information Forum, 1991
- 32 Clarke, 1994
- 33 see 18 above
- 34 see 32 above
- 35 Scottish Homes,1994
- 36 see 15 above