From National to Local:
An Evaluation of the Effectiveness of National
Disablement Information Providers' Services
to Local Disablement Information Providers.

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Summary

Initiated in April 1993 this research forms part of the National Disability Information Project (NDIP) funded by the Department of Health. It set out to achieve two main aims. These are:

* to determine how well national disablement information
  providers meet the needs of 'intermediate users'-
  locally based voluntary and statutory information
  and advice services;

* to produce recommendations to help national information
  providers be more effective.

Findings are based on;

a) a postal survey of a representative sample of 200 local organisations providing
   disablement information to local people and;
b) tape recorded interviews with information workers from 30 of these organisations.

The report is divided into 6 separate but inter-related parts. Part 1 forms an introduction to the research and includes sections on the project's background and on the research methods employed to complete it.

Part 2 provides a general overview of the local organisations who participated in the project. It shows that, on the whole, local disablement information services are characterised by uneven provision, lack of resources, and a paucity of services in key areas. In certain key areas the involvement of disabled people in the data collection and dissemination process is very limited. This is especially relevant to issues of control and the employment of paid staff.

Resources - financial, environmental and human - are a major problem for all local agencies and this has an inevitable impact on the services they are able to offer. A major concern is the lack of peer support services for disabled individuals and their families, and general information services for minority ethnic, racial and other marginalised groups within the disabled community.

Part 3 examines the use local organisations make of the services provided by national agencies involved in NDIP. It shows that there is a lack of awareness of national information providers and their services among many local disablement organisations.

A third of the agencies associated with NDIP were not known, and while others were known their services were not. This is attributed to several causes; notably, a lack of resources among some national agencies, a tendency for local organisations to specialise in particular types of disablement information, and the general growth of information providers at both the local and national levels.
This proliferation of information providers enables local organisation to access information in a variety of forms and from a diverse assortment of national and local sources.

Local organisations' views on the quality of the services provided by national information providers are outlined in Part 4. The data show that local agencies experience a number of problems with national information providers' services. The cost of services, access difficulties, particularly with regard to telephone and postal services, and data not produced in accessible formats all create unnecessary difficulties for local organisations.

Yet several of the larger well established national agencies are widely used by local organisations, but some of the smaller more specialist ones are used by only a minority. This is explained with reference to the proliferation of information providers, both nationally and locally, and the subsequent duplication of data.

Although this enhanced choice has in many ways empowered local organisations, it is widely perceived as an unnecessary and wasteful drain on valuable and limited resources. In general, local organisations are only reasonably satisfied with the services provided by national information providers.

Part 5 looks at the reasons why local agencies do not make more use of national information providers' services. It shows that meaningful dialogue between local and national information providers is limited. Less than half the organisation studied have appropriate feedback procedures. Where they are in use, these take the form of written reports, questionnaires, representation on regional and national councils, and outreach work by representatives of national organisations.

Most people feel that good local contacts are the best form of feedback mechanism. But a lack of resources - both money and time - is considered a major barrier to improvement.

Besides poor communications networks, there are several reasons why local organisations do not make more use of national agencies' services. These include general organisation, cost, and the unprecedented growth of national and locally based information providers - some of which are run by the national providers themselves.

In addition, information workers generally believe that local organisations provide a far more personalised service and are more in touch with local needs.

There is a widespread belief among people working in local organisations that local information needs are quite distinct from those addressed by the majority of national information providers, and that increasingly these organisations are unable to meet those needs.

Hence, there is a general feeling that resources should be diverted from national information providers to develop more effective locally based services.

Recommendations are included in Part 6. They can be summarised as follows:

* Disabled people accountable to disabled people's
  organisations must be effectively involved at every
  level in the planning, process, and delivery of
  information services, both local and national.

* There is an urgent need for more resources to be put
  into the development of locally based services. This
  is especially relevant to the north of England and
  rural areas where adequate provision is particularly
  thin on the ground.

* Local authorities, health authorities and other policy
  makers must ensure that local information services are
  situated in easily accessible premises and locations,
  and staffed by people with the appropriate qualities
  and skills to offer peer support and services.

* Resources must be set aside to research and address
  the national and local information needs of
  marginalised groups within the disabled community.

* Measures must be introduced to ensure the development
  of more local user led federations of information
  providers.

* If national organisations hope to retain their share
  of the market then some of them must improve their
  p services to local organisations in certain key areas;

notably, charges and charging procedures, postal
response rates, telephone services, data access, format
and content.

* Extensive research must be conducted for the
development of a standardised manual and computerised
index and filing system which is both compatible and
acceptable to the needs of all local organisations.

* National information providers must make more effort
to improve the dialogue between themselves and local
organisations.

* To ensure the further and effective development of
NDIP a permanent and autonomous user led co-ordinating
body must be established. This organisation must be
equipped with the necessary remit and power to direct
and allocate Government funding and resources where
they are most needed.

* To reduce the demand for and, therefore, the cost of
specialist 'disability' information there is an urgent
need to tackle its cause; ie. hostile environments and
disabling social attitudes. This means the
introduction of a comprehensive anti-discrimination
policy similar to that already In place in America,
Australia, Canada, New Zealand and other democratic
countries.

Acknowledgements

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PART 1: Introduction

Background

Access to information is fundamental to meaningful participation in contemporary society. The disabled writer and founder member of Britain's first Disablement Information and Advice Line (DIAL) - established in 1976 - Ken Davis, described it as the 'fourth right of citizenship' (1).

But because, historically, disabled people have been excluded from the mainstream of community life they need specialist information in addition to that needed by everyone. This specialist or 'disablement' information includes all data relevant to disabled people, their families, and service providers.

This includes 'impairment' specific information pertinent to particular groups within the disabled community such as blind people, for example, and general 'disability' information appropriate to the disabled community as a whole as well as to associate professionals. Examples include information on accessible housing, technical aids and equipment, benefits, employment opportunities, disability organisations, and disability arts and culture.

Further, in view of the severe economic, political and social disadvantages experienced by the overwhelming majority of disabled people information alone may not be used to its fullest effect without appropriate counselling and advice. There is, therefore, an urgent need for a national network of disability information and advice services.

To some extent this was formally recognised almost a quarter of a century ago by the 1970 Chronically Sick and Disabled Persons Act. This required all local authorities to provide appropriate information about their services to disabled people. This was followed by the establishment of the National Association of Disablement Information and Advice Services - now known as DIAL UK - in 1978.

The following decade saw a range of initiatives including the setting up the National Information Forum in 1986, and the introduction of the 1986 Disabled Persons (Services, Consultation and Representation) Act. The latter required local authorities to provide information about all impairment and disability services.

Additionally, government departments provided funding for a variety of agencies to produce disablement related information. Also, the European Community's Bureau in Favour of Action for Disabled People initiated the pan-European disablement

database, Handynet.

Yet despite all this apparent activity successive research from a variety of sources showed that disabled people were not getting the information they needed. For example, the Office of Populations, Censuses and Surveys' national disability survey conducted in the mid 1980s showed that over 40 per cent of disabled adults found information on benefits 'fairly' or 'very' difficult to access (2).

In 1989 Jenny Morris's analysis of the experience of disabled women concluded that the lack of disability information 'is as common in the 1980s as it was during the 1950s, 1960s and 1970s' (3).

Since the 1970s self help groups had tried to fill this gap both locally and nationally. The growing network of local DIAL's controlled and run by disabled people themselves is but one example. indeed, their emergence may be seen as a direct response to the shortcomings of established information providers (4).

The outcome of all this was that disability information services at the local level were characterised by uneven quality, duplication, and fragmentation. In response, the Department of Health (DoH) commissioned a management consultancy firm, Coopers and Lybrand. to conduct a national review of disability information services.

They published their report 'Information Needs of Disabled People, Their Carers and Service Providers' in March 1988. Besides reiterating much of what was already known the report concluded that information services provided data only upon request, rather than developing ways of delivering it, and that due to the profusion of information providers the cost of providing information was unnecessarily high.

The report made three important recommendations. First, in order to establish a degree of coherence a national framework for disablement information providers should be developed. This would measure standards, encourage consistency, and reduce wasteful duplication.

Second, a nationwide network of local federations should be created to encourage co-operation, reduce duplication, and to develop ways of ensuring that information services met users needs. These federations should include 'statutory and voluntary agencies as well as groups of people with disabilities' (5).

Third, common information services should be developed. This referred to specific activities such as providing better information about technical aids and equipment and database access.

Subsequently, a number of projects were set up. These included the Birmingham Information Federation, the Devon Disability Information Federation, Disability Information Services Surrey (DISS), and the Oxford Disability Information Project (ODIP). Initiated by 'traditional' disablement information providers, these federations brought together both statutory and voluntary organisations to share resources and co-ordinate and develop strategies for data dissemination.

DISS, for example, was set up by Surrey County Council, East Surrey Health Authority, the Spastics Society, and the Queen Elizabeth Foundation. It developed a database to support its telephone information service and formed links with other local groups who used the database for their own information needs.

Subsequently PE International - another firm of business consultants - was commissioned to take Coopers and Lybrand's proposals forward. The PE International Report was produced in 1990 and included practical details of how the pilot federations could be set up, managed and evaluated, and how they could be linked in with the national information providers.

It also included an evaluation of the costs of this work enabling the Department of Health to make a bid in 1990 for the following financial year. Funding for what later became known as the National Disability Information Project (NDIP) was confirmed in January 1991.

The National Disability Information (NDIP) Project

NDIP was a three year project which concluded in October 1994. It was co-ordinated by a project team based at the Policy Studies Institute (PSI), London. The project had two broad aims: first, to encourage the development of effective local disablement information services, and, second, to improve the effectiveness of national disablement information providers and to promote greater co-ordination between them.

In order to fulfil the first of these two aims NDIP
provided financial support for 12 local federations of disablement information providers. These were selected from over a 100 applications to advertisements placed in the relevant media.

The 12 federations were selected to represent a range of ideas and services. Besides Birmingham Information Federation and Devon Disability Information and Advice Federation, mentioned earlier, they include:

the Berkshire Disability Information Network, the Gateshead Disability Information Project, Gloucestershire GUIDE, Kent Information Federation, the Manchester Disability Information Service, the Norfolk Disability Information Federation, the North East Yorkshire Information Service, Oldham disability Alliance, Southwark Inform, and the Walsall Information Federation.

As well as geographical location these organisations differ from each other in a variety of ways including history, size, organisation, sources and levels of funding, as well as the services they provide. The NDIP also supports other locally based services by providing information and advice. For a more detailed discussion of local initiatives involved in the NDIP see 'Disability Information Federations: Features and Issues' (1993) by Rebecca Simkins and Pamela Nadash.

The second of the aims has been addressed in two ways. First, an ongoing dialogue with 26 key national information providers (NIPS) - organisations which provide a nationally-available information service - to identify problems collecting, collating and disseminating data has been initiated with a view to develop strategies for resolving them.

The second is to let users and potential users know what services are available and how to access them effectively. In July 1992 a report on the issues raised by this work incorporating details of the 26 organisations involved entitled 'National Disability Information Provision, Sources and Issues' by Phillepa Hinkeley and Jane Steele was published.

Moreover, during 1992 and early 1993 a series of meetings and seminars was held to identify common areas of concern. It soon became evident that relatively little was known about the extent to which nationally produced information meets the needs of local information providers, or, indeed, of how NIP's services to local organisations could be improved. This research sets out to address these issues.

Research Aims and Objectives

Started in April 1993 the research has two main aims. These are: first, to determine how well national disability information providers meet the needs of 'intermediate users'- locally based voluntary and statutory information and advice services, and; second, produce recommendations which will help national information providers be more effective?

To fulfil these aims the project set out to achieve the following objectives:

to explore the extent to which national providers of information for disabled people are meeting the needs of local information services;

to investigate the level of awareness of the national services among local information services for disabled people;

to examine how these services are used locally and the uncover the constraints on their use;

to investigate the data needs of local information services and to assess the contribution which national information providers can make towards meeting those needs;

to identify the most effective and acceptable ways of accessing nationally produced information;

to identify ways in which local information services could provide regular feedback to the national information providers.

Research Strategies

To meet these aims and objectives two research strategies were employed: first, a postal survey of the views of a representative sample of 200 local disablement information services, second, a series of tape recorded in depth interviews with information workers from 30 of these organisations.

The survey was conducted during July and August of 1993. The questionnaire was constructed with the help of the NDIP team at PSI, and the sample was taken from a variety of sources, These included the membership lists of the British Council of Organisations of Disabled People (BCODP), the Royal Association of Disablement and Rehabilitation (RADAR), the Disabled Living Council, the Social Services Yearbook 1993/4, and the NDIP database.

In order to get as broad a picture as possible the sample was made up of a fairly wide range of local agencies providing general rather than specific disablement data and services. These included several of the 43 local information federations known to NDIP, disabled living centres, grassroots disability organisations and groups, and health and disability information services run by statutory authorities.

Before being included in the sample each organisation was contacted by telephone to ensure that they could and wished to contribute to the research. Of the 200 organisations sampled 137, 69 per cent, completed and returned the questionnaire.

Thirty of these organisations were then selected for interview (see Appendix 1). The interviews were conducted with appropriate staff members in the agencies' premises between September and December 1993. The shortest interview lasted three quarters of an hour and the longest 2 hours and 5 minutes. The average for the 30 recorded discussions was 1 hour and 10 minutes.

The survey data was coded and entered on to a computer database as it came in. A summary of each of the interviews was produced and added later. Detailed data analysis was conducted and written up between January and April 1994. A penultimate draft of the report was then circulated to all the organisations who participated in the interviews along with a request for further comment and respondent validation. Received comments were duly recorded and the report was submitted for publication in July.

Outline of the Report

The subsequent report is divided into five separate but inter-related parts. Part 2 provides a general overview of the local information providers who participated in this project in terms of general organisation, resources - economic, environmental and human, and the services they offer.

Part 3 looks at the use they make of the services provided by national agencies involved with NDIP. This includes details of their awareness of national information providers, what services are used, from which sources, and how it is used, Attention also focuses on the differences between local organisations choice of information and its source, how far national agencies go toward meeting local needs, and how significant their services are to local providers.

Local agencies' views on the quality of the services provided by national information providers are the subject of Part 4. This will focus on what constitutes a good or a poor service in terms of content, access, and format. The discussion will centre on questions of cost, generality and specialisation, ease of retrieval, and national agencies' marketing of their products.

Part 5 will examine the reasons why local agencies do not make more use of national information providers' services. Local organisations' relationships with national

agencies and mechanisms for communication and feedback will also be discussed.

The report concludes with a number of recommendations for all those involved in the production and dissemination of disablement information at both the local and national levels.

References

1. 'The Fourth Right of Citizenship' is also the title of a booklet published by the National Consumer Council in 1977.
2. MARTIN, J. and WHITE, A. (1989) The Financial Circumstances of Disabled Adults living in Private Households London, Her Majesty's Stationary Office.
3. MORRIS, J. (ed.)(1989) Able Lives: Women's Experience of Paralysis London, Women's' Press, p. 33.
4. BARNES, C. (1991) Disabled People in Britain and Discrimination: A Case for Anti Discrimination Legislation London, Hurst and Co. in association with the British Council of Organisations of Disabled People.
5. SIMPKINS, J. and NADASH, P. (1992) National Disability Information Provision: Sources and Issues London, Policy studies Institute.

PART 2 The Organisation of Local Disablement Information Providers.

Introduction

This section provides a general picture of the local information providers who participated in this study, their general organisation, resources, and the services they offer.

General Organisation.

Origin

Most of the organisations sampled were established during the 1980s and early 1990s. Some could trace their roots back to the 1940s - examples include, West Sussex Association for the Disabled, set up in 1942, and the Manchester Disablement Services Centre, established in 1948. A minority had only been operating for a matter of months. Macclesfield's Disability Information Bureau, for example, formally opened in April 1993.

Size

Overall, they represent a variety of agencies of varying sizes in various locations, both urban and rural, from all over England. Some are large well established organisations located in easily accessible premises while others are small individual operations situated in the operator's spare room.

A well known example of the former is Greater London Association of Disabled People (GLAD). Centrally located in a fully accessible building housing other disability organisations including SKILL, the National Bureau for Handicapped Students, GLAD is a London wide organisation controlled and run by disabled people providing a range of services besides disability information.

A good example of the latter is the Disability Information Services, Carlisle (DISC), based in the utility room of the organisation's only worker, DISC has been in existence for three years and represents the third attempt to establish a local disability information service in Carlisle.

Control

Only 26 per cent of the organisations sampled were controlled and run by non-disabled people, 41 per cent were jointly controlled by both disabled and non-disabled people, and 33 per cent were controlled and run by disabled people themselves.

Several of the organisations controlled and run by non-disabled people were Disability Information and Services Centres such as the Donald Todd Rehabilitation Centre at Fazakerley Hospital, Liverpool. Originally an Artificial Limb and Advice Centre (ALAC) run by the Department of Health (DoH), it is now administered and funded by the local health authority.

Disability Services, Huddersfield, is fairly representative of an organisation controlled by both disabled and non-disabled people. Originally a disablement information and advice line (DIAL) it was set up in its present form 2 years ago by Kirklees' social services department. Housed in a fully accessible former day centre it boasts a 'one stop shop' for all matters relating to disablement.

The Disability Resource Centre at Yardley, Birmingham, is an example of an organisation controlled and run by disabled people. Although its management committee includes 3 councillors from the local authority and 4 representatives form Birmingham's social services department only disabled committee members are allowed to vote on policy decisions, and 4 out of the centre's 5 permanent staff are disabled people.

In line with the general view that disablement information services should be user led, the data suggest that more local information providers are seeking to involve more disabled people in the running of services. For example, the Disablement Advice and Information Services. St Helens, were in the process of introducing changes to the constitution to ensure their transition from a jointly managed organisation to one controlled by disabled people.

However, there remains a degree of resistance to this trend. One information worker stated that 'joint control would be the best option - but it doesn't work in practice'. Another said 'we've tried to get disabled people to sit on our management committee but we don't seem to have had much luck'.

This may be because some organisations do not have written constitutions or clear policy statements with regard to the membership of management committees, voting rights or, indeed, to the employment of disabled people.

Funding.

Funding is a major problem for most of the organisations interviewed. Only 17 per cent were receiving financial support from one source such as health authorities or local authority social services departments. The Disability Information Centre, Middlesbosrough, is one example.
Situated in Middlesborough General Hospital it is funded solely by the local health authority.

However, the majority, 77 per cent, are jointly financed from a variety of sources; in most cases this means health authorities, local authorities, grant making trusts, and self generated fundraising activities.

For instance, besides core funding from statutory and voluntary organisations the Shropshire Disability Consortiuum generates up to 25 per cent of its income from consultation, Disability Equality Training (DET) and selling advertising space in its newsletter.

Self generated fundraising activities are becoming increasingly important because in most cases core funding is only provided on a short term basis - usually between one to three years - and its future is often uncertain. This means that any long term planning, staff development, service expansion and continuity of provision are extremely precarious.

The problem is made significantly worse by the fact that due to recent cut backs in local authority spending many local disability information providers are having their budgets severely reduced. As a result, they have little option but to reduce services or, in some cases, cease operations altogether.

For example, since its inception in 1987 Lewisham Disablement Association has produced a quarterly newsletter and information sheet with a circulation of 1750 copies. Due to consumer demand the newsletter became bimonthly in 1993. But recent cuts in funding mean that it is now produced only three times a year.

This type of service reduction will have significant consequences for local users. Poverty, transport problems, and an inaccessible environment mean that many disabled people are reliant solely on locally produced newsletters for local disablement information.

Moreover, some voluntary organisations receive no core funding whatsoever and are entirely dependent on local charities and self generated fundraising for their existence. Examples include the Barrow and District Disability Association, started in 1981 which operates from 2 converted terrace houses, and the Sunderland Society for the Disabled, an umbrella organisation for eight other local groups.

The latter began operations in 1984, has no separate premises, and its only data base consists of a number of box files stored in its principal information worker's bedroom. Both organisations are run entirely by volunteers.

There is a general view among local information providers that more resources should be put into the development of locally based disablement information services. Many believe that without appropriate support services will suffer rather than improve. Indeed, during the course of this study funding problems resulted in the closure of one local disablement information service, DIAL Honiton in Devon.

Premises and Location.

Apart from Sunderland, all the organisations visited were housed in relatively accessible premises but several were situated in unsuitable locations. As with the Disability Information Centre, Middlesborogh, some were located in hospitals or 'rehabilitation' units, some were situated in the 'backstreets' and were difficult to find with limited or no parking spaces available, and others were centred on the outskirts of cities and were poorly served by local bus services.

Some organisations, although offering a 'drop in' service felt that the high incidence of telephone enquiries, as much as 85 per cent in one case, were due to their unsatisfactory locations. Furthermore, many people, both disabled and non-disabled, find medical institutions oppressive. Good car parking facilities are essential for people with mobility related impairments, and regular accessible bus services are necessary for those without a car.

These factors are important because many service providers are aware that a great many users, disabled people, informal helpers or 'carers', and sometimes professionals, want more than just a 'telephone answering service'.

This was borne out by one information worker who reported that following their organisation's recent move to offices in a central accessible location personal enquiries 'had risen from 40 to 300 a month'.

Staffing

Inevitably, the organisation, finances and the location of local disablement information services have some bearing on their staffing policies. Consequently, there is much variation in this area.

The majority, two thirds, of the organisations studied, employed staff whose duties included information and advice work. These include both full time (35 hours per

week) and part time (less than 35 hours) workers. The remainder were reliant solely on volunteers for these functions.

In general, organisations controlled by disabled people employ mostly disabled people, whilst organisations that are either jointly controlled or run solely by non-disabled people tend to employ non-disabled people. Only one of the latter retained disabled people as paid information workers.

Fifty eight per cent of the agencies controlled and run by disabled people sampled had paid workers in their organisation. Only 9 per cent of these were non-disabled people. Often these workers are responsible for other tasks such as administration and development work as well as information services.

The Council of Disabled People South Warwickshire, Leamington Spa, is a good example. They employ a manager and part time administrator who, in conjunction with volunteers, runs their information services. Indeed, many of the organisations employing paid staff, in each of the three categories mentioned above, were heavily reliant upon voluntary workers - many of whom were disabled people.

Fewer disabled people were employed by organisations jointly controlled by both disabled and non-disabled people. Eighty four per cent of these agencies had paid staff but only 26 per cent of these were disabled people. For example, Gloucestershire GUIDE employs 4 full time and 2 part time workers, one of the latter is a disabled person.

Of the organisations controlled by non-disabled people
56 per cent employed paid information staff. But only one of these agencies employed disabled people as information workers. However, one respondent from one of these organisations said that 'some of our staff would be classed as disabled but I don't know whether they would define themselves as such'.

Many small voluntary organisations do not have specific individuals concerned primarily with information provision. It is often the case that everyone is involved at some stage in the process and incoming data and enquiries will be dealt with by whoever is in the office. This was the case for 13 per cent of the sample.

Others, 20 per cent, do have designated voluntary staff, but finding suitable candidates is a major problem for many organisations. It is particularly problematic for agencies situated in rural areas. A number of respondents said that the shortage of skilled voluntary staff had a significant influence on the type of services they were able to offer. Important examples include outreach, peer support, and advocacy type

services.

Principal User Groups

Most of the services provided by local disablement information agencies are demand led - in other words they are a response to locally perceived needs. The majority provide information to a wide range of user groups.

But limited resources - financial, spatial, and human - mean that many organisations have to prioritise their services for particular groups and individuals. Organisations such as the Birmingham Resource Centre, Yardley, for example, aim their services at disabled individuals and their families, and organisations controlled by disabled people.

Some organisations such as the Oldham Disability Alliance specialise in services for people who work with disabled people - informal helpers and individual professionals - rather than disabled people themselves.

Many well established organisations monitor enquiries to see who uses their services, and some of the newer ones said that they would be doing so in the future. But some interviewees pointed out that there were difficulties monitoring enquiries - particularly via the telephone.

Some agencies had neither the time nor the staff to monitor enquiries accurately, and several people pointed out that it is sometimes difficult to access the right information because 'people don't want to be asked a lot of questions when they ring up or they won't ring back'.

Nonetheless, as Table 2.1 shows most of the agencies studied had a clear idea of who their services were aimed at. As might be expected most organisations aim their services at disabled people generally, professionals, and informal helpers.

But relatively few, 18 per cent, direct their services at particular groups within the disabled community such as disabled members of minority ethnic or racial groups, disabled women, or disabled lesbians and disabled gay men, for example. Two organisations which do are the Greater London Association of Disabled People (GLAD) and the Keighley Disabled People's Council.

GLAD supports and provides relevant information to minority ethnic and Black disabled people's groups, stages conferences for marginalised minorities, and

publishes a monthly newsletter specifically for disabled women entitled 'Boadacea'.

The Keighley Disabled People's Council has on site interpretation services and can translate relevant information into a variety of minority ethnic languages without difficulty. As a result a large proportion of their requests for data come from people from or associated with these sections of the community.

Many respondents attributed the lack of specialist services to the fact that they do not get many requests for information from people from minority ethnic or racial backgrounds or other marginalised groups. In response to the suggestion that this might be because these groups do not expect information providers to cater for their needs some people said that there were no minority ethnic or racial groups in their area. Others suggested that even if there was a call for specialist services limited resources would prevent them from providing them.

Only 12 per cent of the sample provide information services specifically for people with particular impairments. This is because of the nature of the sample; as noted earlier, organisations were selected which provide a range of general rather than specific disablement information. There is, however, a growing network of local information providers specialising in these services, for instance, Arthritis Care, the British Deaf Association, MIND and Mencap.

It may also be due to a growing awareness among disabled people, their families, and professionals, of the important distinction between 'impairment' and 'disability' information. If this is the case then organisations providing data on disability will not get requests for impairment related information, hence they are unlikely to provide it.

Examples of agencies providing data for people with specific impairments include Lambeth Accord, which is developing an outreach service for deaf people, and Manchester Disablement Services Centre, which provides information for people with mobility related impairments.

Table 2.1 Users of Local Information Providers' Services.

User groups	Organisations
	%
Disabled people generally	92
Individual professionals who work with disabled people (eg. doctors, social workers)	69
Informal 'carers', helpers, or personal assistants	67
Specific groups within the disabled community (disabled Black people or disabled women, for example).	13
People with specific impairments Blind people, for example.	12
Others.	23
Base	137

Additionally, a growing number of organisations, 23 per cent, provide data for other groups including 'elderly people', residential 'care' staff, town planners, architects, builders, students, and teachers.

Type of Services Offered

Although all the organisations surveyed provide a range of disablement information services, the majority cited referral, 'sign posting' or 'directing' people to other agencies as one of their main activities.

There are several reasons for this. First, some organisations specialise in particular

information and cannot respond to the diversity of requests they receive. For example, Disabled Living Centres like the Frank Sorrell Centre at Portsmouth specialise in data on technical aids and equipment, clothing, and relevant organisations. Others such as the Hampshire Centre for Independent Living (HCIL) focus on information on independent living and personal assistance services.

Second, many smaller agencies such as Disability Information Services Carlisle (DISC) do not have the resources to run a comprehensive database; hence, referral is their primary function. Even the larger well established organisations like the Dene Centre in Newcastle or GLAD in London do not have the facilities to keep all the relevant data on disablement.

Finally, others, striving to provide a 'one stop' service - help, advice as well as information - said that within the current climate of rapid change in the disablement field - particularly with reference to benefits and 'community care' - referral was sometimes unavoidable.

But for many information workers referral was not a preferred option. Many felt that it was not helpful for users - whether disabled people, their families or, indeed, professionals - who are sometimes anxious and distressed to be 'passed from pillar to post'.

Others pointed out that many people wanted a personal localised service. Most of the information providers interviewed said that they tend to refer, wherever possible, people to local rather than to national organisations.

These respondents said that this was because they had a 'good working relationship' with other local agencies and, therefore, knew that people were more likely to receive a 'more personal' and relevant service. As we shall see later a growing number of local organisations are now linked to other agencies.

According to some information workers it is also the case that many people do not want to be referred to national organisations. This is because some national agencies try to recruit referrals as members, seek to include them on their mailing lists, and/or ask them for donations. This is not what most service users want when they are looking for information.

Eighty one per cent of the organisations sampled said that most of their customers wanted general 'factual' information and advice - particularly about 'benefits and anything to do with money, and how to get it'.

Moreover, many respondents felt that it was impossible to separate help, information

and advice. They believed that, wherever possible, it is essential that local organisations try to provide a 'one stop' service. As one respondent put it: 'information is useless if you don't know how to use it'.

Table 2.2 Type of Services Offered by Local Information Providers

Service	Organisations providing this service
	%
referral - directing people to other agencies	85
general factual information (eg. about benefits or access)	81
advice - helping with problems	71
counselling by disabled people for disabled people?	39
advocacy - helping someone to argue their point of view	35
representation - acting for someone in a formal setting such as a tribunal	27
counselling for informal carers	16
counselling for disabled people by non disabled people?	12
counselling for specific groups within the disabled population (black disabled people and disabled women, for example, and if so please say which?)	8
other	31

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Base   137

Note: Figures exceed 100% because all the organisations sampled provide more than one service.

Another pointed out that: 'sometimes people come in and ask about one thing and when you get talking to them you find that there's a number of issues they need help with'.

But, as we have seen, many organisations do not have the resources to provide such a service. Indeed, less than 50 per cent of the agencies sampled were able to offer a peer counselling or support service for disabled people. This is significant because since the 1970s this type of service has been regarded as the best method of disseminating disablement information to disabled individuals and their families (6).

Some organisations cited 'counselling, advocacy and helping with problems' as their principal role, and as we have seen, agencies in rural areas sometimes provide an outreach service. The Hertfordshire Coalition of Disabled People, for example, see their main function as 'advocacy' and 'benefit appeals', especially for people with recently acquired impairments. This is because: 'it is difficult to refer people for advice because of the lack of services in the county'.

In addition to the above many agencies provide a range of other services. These include consultancy and training services in a number of key areas; ie. access, campaigning, disability arts and culture, independent living and personal assistance, equal opportunities policies and rights, and Disability Equality Training (DET) for professionals and other agencies in both the public and private sectors.

Several organisations offer an equipment hire service. Others cited the provision of health and health service data as a major function. This includes information on hospital waiting lists, National Health Service (NHS) rules and procedures, and the Health Service Charter.

One organisation offered a consultancy service for house adaptations while another 'conducted research and development into the information needs of people with learning difficulties'.

Over three quarters of the sample, 81 per cent, provide information to the public at large. The general view can be summed up by one respondent who said: 'we're here to provide information about disability... and as far as we're concerned that means to

anyone who needs it'.

This approach is also reflected in the fact that most of the organisation studied, 88 per cent, said that they provide disablement data to other agencies. These include local and national statutory and voluntary organisations including local authority social services departments, health authorities, NHS Trusts, family health service associations (FHSA), general practitioners, district and county councils, local education authorities, trade unions, and voluntary organisations both 'of' and 'for' disabled people.

Federations of Local Disability Information Providers

This dissemination of data to other agencies might not be surprising considering that more than a third of the sample, 36 per cent, said that they had formal links with other agencies through their membership of Federations of Local Disablement Information Providers or similar umbrella organisations. These are listed in Table 2,3. It is notable that not all the 43 local federations known to NDIP in 1992 are not listed. This may be because some of the organisations no longer exist or that they did not complete the questionnaire.

Of these, 41 per cent, were jointly controlled by both disabled and non-disabled people, 36 per cent were controlled solely by disabled people, and 13 per cent were controlled by non-disabled people.

Overall, respondents involved in organisations belonging to a federation seemed to view the emergence of federations as a positive development. They said that it had enabled them to share resources and expertise, and, therefore, provide a better service. Besides giving local groups access to more information and sometimes resources it also meant that they became more familiar with other information services in their area. As a result, they were able to deal with more enquiries and/or, where necessary, direct people to other local services with whom they had an established working relationship. In this way they felt they were able to provide a better service.

It is important to note that some respondents working in areas where there are no federations of information providers, such as the north east of England, for example, felt that membership of a federation type structure would be beneficial. Some organisations such as the Barrow and District Disability Association were hoping to set one up in the near future with the help of the Council for Voluntary Services (CVS).

A number of interviewees, however, did express concern that there must be safeguards built into these structures to ensure that they are run on a democratic basis and that disabled people are included at every level of the organisation's hierarchy. This is essential if small grass roots organisations are not to lose their sense of identity and autonomy, and disabled people's interests are not to be overshadowed by those of other larger more established organisations.

Table 2.3 Federations of Local Information Providers

Berkshire Disability Information Network
Birmingham Disability Information Federation
Buckinghamshire Disability Information Network
Brighton and District Information Federation
Calderdale Council for Voluntary Services (Disability
        Advice and Resource Team).
Cheshire Disabilities Federation
Derbyshire Coalition of Disabled People
Devon Disability information and Advice Federation
Disabled in York
Disability Information and Carers Team
Disability Information Services (Carlisle)
Disability Information Network (Warwickshire)
Disability Information Service (Hertfordshire)
Disability Information Service (Surrey)
Gateshead Forum of Local Advice Groups
Greater London Association of Disabled People
Greater Manchester Association of Disability Information
        and Advice Services
Gloucestershire GUIDE
Keighley and District People's Council
        Information Network
HASC (Health and Social Care) Information Services
Kent Information Federation
Lambeth Disability Information Forum
Leicestershire Information Federation
Manchester Disability Information Service
Merseyside Coalition of Disabled People
North East Yorkshire Information Service
Norfolk Disability Information Project
Oldham Disability Alliance
Oxfordshire Disability Information Network
Portsmouth Information Group
Shropshire Disability Information Forum

Sunderland Society for the Disabled
Southwark Inform
Sutton Information Federation Team
Suffolk Coastal Rethink Assist
Thamesdown Voluntary Services
Tottenham Umbrella Group
Waltham Forest Information Group
Wiltshire Information Group

Further, a number of respondents were very cynical about the emergence of federation. This is due mainly to the fact that at the outset of the NDIP project many federations were hastily cobbled together in order to gain access to NDIP funding. Also, some of these organisations were controlled and run by people with relatively little experience of disability information provision. Perhaps unsurprisingly, many of the organisations have since collapsed. Moreover, because part of the NDIP remit was to encourage innovation some these ill conceived structures were awarded funds while established organisations appeared to be ignored.

Marketing local information providers' services

The wide variety of enquiries and services offered by local organisations might also be explained by the fact that a growing number are beginning to market their services within the local community. This can take a variety of forms. Some small organisations with few resources such as the Sunderland Society for the Disabled simply advertise their services in the local library.

Others, such as the Disablement Advice and Information, St Helens, distribute leaflets in libraries, doctor's surgeries, day centres and so on. They have also advertised in the local free press. There is a general view that more resources are needed to let potential users know what services are available.

Conclusion

The data show that despite recent developments it is still the case that, on the whole, local disablement information services are characterised by uneven provision, lack of resources, and a paucity of services in key areas. Whilst some areas of the country are well served by locally based federations of disablement information providers others are not - only a third of the agencies studied were members of these organisations.

In certain key areas the involvement of disabled people in the data dissemination process is very limited. This is especially the case with reference to issues of control and the employment of paid staff. Resources - financial, environmental and human - are a major problem for all local agencies and this has an inevitable impact on the services they are able to offer.

A major concern is the lack of peer support services for disabled individuals and their families, and general information services for minority ethnic, racial and other marginalised groups within the disabled community.

References

6. See for example DAVIS, K. (1980) Development of the National Association of Disablement Information and Advice Services paper presented at the Fourteenth World Congress of Rehabilitation International, Winnipeg Canada; EVANS, J. (1993) 'The Role of Centres of independent/Integrated Living and Networks of Disabled People' in BARNES, C (ed.) Making Our Own Choices Helper The British Council of Organisations of Disabled People.

PART 3: Local Organisations Use of National Information Providers' Services.

Introduction

Here we will examine local organisations' use of services provided by national information providers. Included are details of their awareness of national information providers, what services are used, and how they are used, Attention also focuses on the differences between local organisations' choice of information, factors influencing its source, and how significant nationally generated services are to local provision.

Local Organisations' Awareness and Use of National Information Providers Services

Relatively little is known about local organisations' awareness of national information providers or the services they provide. To shed some light on this issue we asked respondents if they had used any of the services provided by a selection of national information providers taken from Philipa Hinkley and Jane Steele's 1992 NDIP report 'National Disability Information: Sources and Issues'.

Arthritis Care and the BCODP were also added to this list since both are involved with NDIP.   (For a brief description of these organisations and the services they provide see Appendix 2).

As Table 3.1 shows not one of the national providers was used by all the local agencies sampled. It should be noted that this Table shows how many organisations in our sample use or have used particular national information providers it does not reflect the level of usage.

A third of the organisations listed were not known to all to the people interviewed. Around half the respondents had not heard of Carematch or Caresearch or the services they offered - others had heard of them but thought that they catered for the elderly only.

As one respondent working in an agency run by a local authority put it: 'The name rings a bell but we don't use them - it's to do with the age group - we don't get many

calls from the elderly and if we do we refer them to other departments'.

Others based in the north of England believed that these organisations were geared to the needs of the South East only.

Similarly, Action for Blind People, Contact a Family, The Council for Disabled Children, Disability Information Trust, Planet, and the Holiday Care Service were not particularly well known - see Table 3.2. Also, several respondents had heard of some of the agencies listed but had no knowledge of the services they offered - examples include the BCODP, Planet, and SKILL.

Table 3.1 Local Organisations' Use of National Information Providers' Services Associated with the NDIP Project

National provider	Local agencies using their services
	%
RADAR	81
Disabled Living Foundation	80
RNIB	66
Arthritis Care	64
DIAL UK	64
Disability Alliance	64
Age Concern	63
Holiday Care Service	59
RNID	58
Spastics Society	56
MAVIS	56
Centre for Accessible Environments	53
BCODP	50
Carers National Association	47
SIA	47
MIND	45
SPOD	44
Contact a Family	42
MENCAP	40
SKILL	35
Action for Blind People	31
Help the Aged	34

PLANET	22
Disability Information Trust	18
Council for Disabled Children	11
Caresearch	11
Carematch	10
Base	137

A number of factors might explain the lack of awareness of national agencies' services among local organisations.   These include: the resources available to some national organisations, the services they offer, the structure of local organisations, the increasing availability of information at the local level, the type of services needed, and the sheer volume of date being produced.

Resources.

A growing number of national organisations do not have the resources to promote their services to local agencies. The British Council of Organisations of Disabled People (BCODP) is a notable example. Despite the fact that the BCODP is Britain's national umbrella for organisations controlled and run by disabled people representing over 100 organisations it has an annual budget of less than œ50.000 a year.

Services offered

Several local organisations sampled tend to specialise in particular types of disablement information and, therefore, would not be obvious targets for national providers' marketing campaigns. For example, 'rehabilitation' centres such as the Donald Todd Centre which focus mainly on services for people with physical impairments are unlikely to receive or seek publicity material from agencies concerned solely with sensory or intellectual impairments.

Table 3.2 National Information Providers Associated with the NDIP Project Not Known Among Local Organisations

National information provider	Level of awareness among local organisations
	%
BCODP	83
SPOD	83
Centre for Accessible Environments	80
Contact a Family	70
Action for Blind people	70

Council for Disabled Children	68
Disability information Trust	52
Caresearch	50
Carematch	49
Base	137

The structure of local organisations.

As we have seen in Part 2, a growing number of local information providers are affiliated to other local agencies specialising in different areas through federations and other locally based umbrella groups. Consequently, although they might not be aware of a particular national information providers' services associate organisations may be.

Increasing availability of information.

Many local organisations access information from other sources, both national and local, so they do not need to look to agencies associated with NDIP. Forty nine per cent of the organisations surveyed said that they receive helpful information and advice from national organisations other than those mentioned above. These are listed in Table 3.3. At the same time, several local agencies are turning to other locally produced material because of its relevance to local needs rather than to that produced at the national level.

Table 3.3 Other National Information Providers Used by Local Organisations

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Alzeimers Disease Society
Arthritis and Rheumatism Council
Asian People with Disabilities Alliance (APDA)
Association of Spina Bifida and Hydrocephalus
British Association for Betterment of Infertility
    and Education
British Amputee Sports Association
British Institute for Leasing Disabilities
Black People's Disabled Group (BPDG)
British Limbless Ex-servicemens Association (BLESMA)
British Amputee Sports Association
British Deaf Association
Centre for Accessible Environments
Child Poverty Action Group
Council for the Advancement of Communication
    with Deaf People.

Disability Resource Team
Disabled Drivers' Association
Disabled Living Centres Council
Disablement Income Group
Family fund
Federation of Independent Advice Centres
Greater Manchester Coalition of Disabled People
Headway (National Head Injuries Association)
Help for Health
Horticultural Therapy
In Touch Trust
Independent Living Fund
Kings fund
Limbless Association
ME (Myalgic Encephalomyelitis) Association
Mental Health Media Council
Motor Neurone Disease Society
Multiple Sclerosis Society
National Association for Limbless Deficiencies
National Council for Voluntary Organisations
National Deaf Children's Society
National Disability Arts forum,
National Disability Information Project
National Federation for the Blind
Pregnancy Advisory Service
Parkinsons Disease Society
Partially Sighted Society
Physically Handicapped and Able Bodied Clubs
Reach (The Association for Children with Hand or Arm
     Deficiency)
R.E.M.A.P (Technical Help for Disabled People)
SENSE (The National Deaf, Blind and Rubella Association)
Stroke Association
Values Into Action
Waiting List Helpline

Services needed.

Some respondents stated that information is often sought on an ad hoc basis from a
variety of sources in response to individual enquiries consequently it is impossible to

list them all. As one respondent put it: 'because our remit is so wide ranging we use any organisations that we can contact quickly to help with individual cases. It would be impossible to list even the most helpful as we tend to have only limited contact with most of them'.

Volume.

Some local agencies - particularly the smaller under resourced variety - receive so much data through the post that material about a particular national organisation and its services can easily be overlooked. As one respondent put it: 'we seem to get so much stuff through the post these days that we could have had something about the organisations I'm not familiar with..., and if it isn't immediately relevant to our needs then it could easily have got lost'.

Type of Services Used by Local Organisations

Besides a general postal and telephone enquiry service many national and local information providers disseminate disablement data in a variety of forms. These include regular newsletters, information sheets, leaflets, briefing papers, journals, research reports, computer databases and training courses.

For example, the Royal Association for Disablement and Rehabilitation (RADAR), the most widely used national information resource in our survey, has over 30 factsheets covering subjects such as health, holidays, employment, and education. They also produce booklets and leaflets, 'Community Care - Your Rights Now' (a guide to disabled people's rights to services) is one example, a monthly magazine 'Bulletin', and a quarterly journal 'Contact', as well as a large range of books and research reports on disability related issues.

Not surprisingly then local organisations receive information in a variety of forms. These are listed in Table 3.4.

Table 3.4 Type of Services Used by Local Organisations

Services	received %	used %
regular newsletters/ information sheets	89	89
leaflets for distribution	80	80
directories/reference books	74	74
specific issues briefing papers and packs	73	64
journals/magazines	72	53
research reports	66	64
training courses	65	55
postal information services	36	34
telephone/fax information services	31	31
computer databases	26	26
other	2	2
Base	137	137

Newsletters and Information Sheets

Clearly, newsletters and information sheets are the most popular information resource. Apart from those mentioned above, widely used examples include Arthritis Care's 'Arthritis News' and the Spastics Society's 'Disability Now'.

Additionally, many local organisations also subscribe to newsletters and information sheets produced by other local information providers. Besides accessing data from national agencies a growing number of local organisations also do their own research. Frequently quoted examples include Greater Manchester Coalition of Disabled

People's (GMCDP) monthly 'information Bulletin' and London's Disability Resource Team's 'Disability Issues' - both of which contain an accessible mix of national and local information; both are available at the national level.

The popularity of newsletters and information sheets is due to the fact that the majority of people working in local agencies do not have the resources or the time to research all the latest developments in the disablement field themselves. In general, newsletters and information sheets provide this type of data in a clear and concise form. Information workers can then follow up relevant articles and data as and when appropriate.

Several respondents pointed to the fact that newsletters produced by other local organisations provide a valuable insight into what is going on in other parts of the country in terms of policy and user led initiatives. Such information is invaluable to local agencies striving to provide a user friendly service.

As one interviewee put it: 'locally produced newsletters are important because we need to know what's going on locally as well as nationally ... what has and hasn't worked in other areas.. so we can learn from other local groups' experiences'.

This type of information is also useful because it can be made available to users directly through agency run libraries or group meetings and discussions. A couple of interviewees said that access to newsletters and information sheets are important because they keep local people abreast of national and local developments and campaigns.

Leaflets

Leaflets for distribution are considered especially important for a number of reasons. Besides many of the information providers listed these can come from a whole host of sources such as the Benefits Agency and British Rail as well as from other local organisations.

As with newsletters, organisations can circulate them to members as and when appropriate along with other relevant material - this is particularly important in rural areas where disabled individuals and their families are frequently geographically and socially isolated. Many local organisations distribute leaflets along with locally produced newsletters and information sheets.

Leaflets are also useful because they can be used to support personal and or telephone enquiries: 'People need something they can study at home - even when they come in and you go through it (a leaflet or briefing paper) with them, they're much happier if they can take it away'.

'Leaflets are especially useful because often people will ring up and ask for information on a particular issue and want you to send them something...'.

Directories and Reference Books

In general, most people considered directories and reference books essential for internal use. Workers in small agencies pointed out that directories such as the Darnborough and Kinkaid 'Directory for Disabled People' are especially useful for finding out where to access information they do not have, and where to refer people if they are unable to help them. Another important example is the 'Disability Rights Handbook' produced by the Disability Alliance.

As with newsletters and information sheets, directories and reference books can also e made available to users through internal libraries. However, many smaller organisations expressed a desire to buy more directories and books but were unable to do so because of their lack of resources.

Specific Issue Briefing Papers and Packs

Respondents' views regarding specific issue briefing
papers and packs varied. Some people felt that they were invaluable because, on the whole, they provide 'in depth' information on particular issues and are useful for stocking internal libraries.

Others complained that sometimes they were too detailed and needed 'deciphering' before they could be effective - consequently, their use value is limited.

Magazines, Journals and Research Reports

A similar situation exists with reference to magazines/ journals and research reports. Examples include the weekly magazine for social workers and professionals working in local services 'Community Care', 'BCODP's quarterly journal 'Rights Not Charity', and a whole range of research reports on issues relating to 'mental health' produced by MIND.

Those organisations who do their own research and whose user group includes professionals such as Derbyshire Centre for Integrated living (DCIL) or Manchester Disablement Services Centre, for example, find journals and research reports especially useful.

Others, such as the Shropshire Disability Consortium consider them helpful for providing 'firm facts' on which to base Disability Equality Training (DET) courses, and/or local campaigns.

Some organisations like the Donald Todd Rehabilitation Centre take 'lightweight' journals such as the Cheshire Foundation's 'Chariot' and the British Limbless Ex Service Men's 'BLESMA Magazine' for stocking a users' library

However, some respondents pointed out that much of the data in many journals and research reports, particularly those produced by professional organisations such as the Centre for Accessible Environments (CAE), for example, is far too 'technical' for their needs and as a result are not used.

Training Courses

Although many people recognise the need for appropriate training courses it is often the larger better resourced organisations which use them. This is because they frequently prove too expensive for many of the smaller poorly resourced organisations.

Indeed, there is a general feeling that many of the courses sponsored by national agencies are too expensive (see below). Particular examples include courses by the Centre for Accessible Environments (CAE), and the Disability Resource Team.

As a result, people are increasingly opting for training courses run by local agencies both statutory and voluntary. These include courses sponsored by local authority social services departments, benefit agencies, and organisations of and for disabled people.

Postal and Telephone Services

Surprisingly, accessing disablement information through the post or via the telephone was used by less than a third of the organisations studied - and many of those which do use these services do so as a last resort. In the case of the former, this is due to the time involved; users want information quickly, they do not want to have to wait for it while it comes through the post.

Also, interviewees identified a number of problems arising from the use of telephones (see below).

Computer Databases

All the interviewees expressed an interest in computers but not necessarily with reference to computer databases. Many organisations, but not all, have access to a computer and the majority use them for administrative purposes or as word processors rather than as computer based filing systems.

Only 26 per cent said that they used computer databases. Some of the older more established organisations used the Disabled Living Fund's (DLF) system. Derbyshire Centre for Integrated Living (DCIL), for example, use it to complement their wide range of other disability information services.

However, a number of organisations said that they were in the process of buying a computer database. Several people mentioned the DISS system developed by the Disability Information Service Surrey in this regard. The DISS system is a national data base which can include an additional add on package for local information. Others opted for locally produced systems. Macclesfield disability information Bureau and East Sussex Association for Disabled People are two examples.

Macclesfield disability information Bureau uses a system developed by the Cheshire Disabilities Federation known as 'Inches'. A two tier system, it contains a section on national information which is updated as and when appropriate by a particular operator, and district sections containing local information which member organisations can update themselves.

East Sussex Association for Disabled People use 'CATALYST' - a database produced by a local voluntary sector consortium. Unlike nationally produced databases such as that produced by the Disabled Living Foundation users have to load all the information on to it themselves. While this can be time consuming it has the advantage that users can construct the data base in accordance with local needs.

Other Information Services

Several organisations mentioned services that they received and used other than those listed. These include: videos and audiotapes for use on training courses, information on disability art and culture - fiction, poetry, posters and display materials, and conferences, seminars and exhibitions.

Video and audiotapes are particularly useful for disability equality training (DET) and are being produced by a variety of organisations. Examples include the British Deaf Association (BDA) and the Kings Fund.

Disability arts and culture has become increasingly important over the past few years and several journals and information sheets are regularly produced. One of the best known examples is Disability Arts in London's 'DAIL' magazine.

A growing number of organisations now disseminate disablement information via conferences, seminars and exhibitions. Probably the best known example is the annual NAIDEX exhibition which focuses on developments in technical aids and equipment.

How Local Organisations Use National Information Providers' Services

As can be seen from Table 3.5 local organisations use national information providers services in a variety of ways. However, what local organisations do with disablement information once they receive it will be determined by a number of factors, notably, resources and principal user groups. For example, many organisations do not have the space to maintain a library for public use, and agencies who do not provide information services for organisations of professionals are unlikely to maintain an appropriate database.

Consequently, there is considerable variation in how national information providers' services are used.   Gateshead Council on Disability, for example, a well established NDIP pilot federation, whose main user groups include disabled people generally, informal helpers and personal assistants, and professionals maintain each of the facilities listed on Table 3.5.

Sunderland Society for the Disabled, on the other hand,
have very limited resources and aim their services at disabled people generally, are only able to maintain an in house filing system for answering enquiries and produce an information sheet for local consumption.

Table 3.5   How Local Organisations Use National Information Providers' Services

Service	Organisations %
To maintain a resource for answering enquiries	72
To update an in house manual filing system for use by organisation	69
To circulate to staff for informal updating	61
To maintain a library for public use	45
To produce a regular newsletter/ information sheet for local consumption	44
For training courses for information workers/professionals	39
To update an in house computer data base for use by organisation	34
other	19
to update an in house computer database for use by other	

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organisations                    15
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Base                             137
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Nineteen per cent of the sample used national information providers' services for other purposes as well as those listed. Local self help groups and organisations of disabled people involved in campaigning for disabled people's rights, such as the Derbyshire Coalition of Disabled People (DCODP), for example, circulate nationally produced data among members to empower them and to inform local campaigners.

Nationally produced data is also used to provide a sound basis for the effective monitoring of local authority services and health policies.

Moreover, some organisations might not produce newsletters and information sheets themselves but pass relevant data on to affiliated organisations which do. For example, a member of Gloucestershire GUIDE staff is on the editorial board of the local 'carer's' newspaper. So GUIDE provide appropriate information as and when they receive it.

Conclusion

This section has focused on local organisations' use of disablement data provided by national information providers. It has shown that there is a considerable lack of awareness of national information providers and their services among many local disablement organisations. Indeed, a third of the agencies involved with NDIP were not known, and while others were well known their services were not.

This was attributed to a variety of causes. These included: a lack of resources among some national agencies, a tendency for local organisations to specialise in particular types of disablement information, and the growth of disablement information providers at both the local and national levels.

As a result local organisation are able to access information in a variety of forms and from a diverse assortment of sources both national and local. It is significant that despite the proliferation of information providers at the national level, increasingly local agencies are turning to locally produced material to resolve their information needs.

Some of the reasons for this development will be discussed in Part 4 of this report.

PART 4: Local Organisations' Perceptions of the Services Provided by National Information Providers

Introduction

This part of the report will explore local organisations' views on the quality of the services provided by national information providers. It will focus on what constitutes a good or a poor service in terms of access, format and content. The discussion will centre on questions of cost, generality and specialisation, ease of retrieval, and national agencies' marketing of their products.

It will begin with a discussion of some of the problems local organisations encounter when accessing national information providers' services.

Accessing National Information Providers Services

Costs

Much of the information needed by disabled people is only necessary because society does not accommodate their needs. Many people involved in services at the local level are aware of this and they are also aware that they are asked to pay for data which is often free to the non-disabled population.

Moreover, given the shortage of funding among local information providers, it is not surprising that the overwhelming majority of people providing data at the grass roots level, 93 per cent of our sample, consider the cost of accessing national agencies' services to be far too expensive.

This is relevant to both direct and indirect expenditure. Direct costs relate to subscription charges and fees for particular items such as computer databases, resource packs and so on. Indirect expenditure refers to expenses incurred accessing information from national providers for which they do not charge a fee. An example

of which would be telephone charges paid to British Telecom for using a national agencies' telephone information service.

Concern over direct expenditure can best be illustrated with reference to data produced by the Disabled Living Foundation (DLF). Although the DLF is widely regarded as providing a 'good' service (see below) they are generally considered to be much too expensive.

The annual subscription charge for their loose leaf 'Information Service Handbook' is £95 + VAT, and their computer database with 'on line access' (via MODEM) is £1050 per annum. Also, additional advice notes and resource papers cost between £1.25 and £3.50 each (5, see page 6). As one respondent put it: 'the DLF is very good, especially on equipment; we have access to their database via MODEM, it's excellent, but very expensive'.

It is notable that a number of organisations in the sample said that they had used the DLF's services in the past but could no longer afford to do so: 'We used to subscribe to the DLF, but we don't anymore because they're too dear, as far as we're concerned they've priced themselves out of the market'.

Because of the cost of their services some local organisations advise people to contact the DLF themselves - the DLF's telephone answering service is free to disabled individuals and their families. For example: 'we used to keep their data sheets, but they got so expensive we just couldn't afford to keep them anymore. Their information might be very good but it's far too expensive. So, instead of dealing with enquiries ourselves we refer people directly to them...'.

But this is unsatisfactory because it means that the indirect costs of accessing the information passes on to the consumer.

Information workers can also be dissuaded from using incidental services if the initial outlay cannot guarantee a successful result. For instance; 'Carematch? (provides a computer based database of nationwide residential facilities for people with physical impairments),,,, we wouldn't use them..... the social services used them once and they didn't come back with anything - and it costs something like £20 a search'. (Local authorities can pay a subscription fee of £200 which allows them an unlimited number of searches).

As mentioned earlier, the cost of training courses run by national agencies is a significant barrier to greater participation by local information providers both in terms

of direct (course fees) and indirect (travelling and accommodation costs) expenditure. This is because many of the courses sponsored by national agencies take place in London or in other major cities such as Birmingham. This poses major funding problems for agencies situated in the north of England or in isolated rural areas.

A similar situation exists with regard to telephone services (discussed in more detail below) because many of the national information providers' helplines and telephone services are based in London or in the south east of England. Each of the three most widely used services in this survey, RADAR, The DLF and the Royal National Institute for the Blind (RNIB), for example, are situated in central London.

Local information providers also expressed concern about the way national agencies charge for their services. As we have already seen, some agencies do not charge disabled individuals or their families but do ask organisations for money.

This poses something of a problem for information workers when users ask them to ring national agencies on their behalf: 'I rang them (the Holiday Care Service) once or twice on behalf of a client......, and when they found out I was from an organisation they wanted me to send money so they could send me some leaflets'.

Another problem concerning the method of charging by some national agencies was raised in an interview with a woman working in an organisation sponsored by a local authority: 'Some organisations send leaflets and then ask for a donation. Well we're funded by a local authority and we're on a very tight budget and we can't make donations. We tend not to use organisations which do that sort of thing'.

It is evident that the cost of accessing data from national agencies contributes to the creation of a two tier service at the local level; ie. well resourced organisations which can afford nationally generated services, and poorly resourced organisations which cannot. Since the overwhelming majority of the latter are small user led initiatives this must be seen as a threat to this much welcomed trend.

Also, it is almost certain that the cost of nationally produced data is one reason why local organisations are looking elsewhere for relevant information.

Telephone services

As would be expected given that they are used by less than a third of our sample (see Table 3.1) telephone answering services seem to be a major bone of contention for local information providers. Although the cost of using the telephone poses the main problem for most organisations, this is exacerbated by the fact that it is difficult 'getting through'.

Many people commented that some national information providers' telephone lines are only operational at certain times - usually office hours when charges are at their highest. A much quoted example was the Disability Alliance whose telephone lines are only open between 11 am and 3 pm, Monday to Friday. A number of respondents also pointed out that many organisation's services are not available after 4 pm.

Forty three per cent of those who had used telephone information services said that lines were either 'always engaged' and/or when you do get through 'you're shunted from department to department'. A number of examples were cited including the DLF: 'When I've had to 'phone the DLF, I find it's very hard to get through... they always seem to be engaged'.

Being referred from department to department seems to be a problem associated with larger organisations such as RADAR or the RNID: 'RADAR - their information department is badly organised you get referred from one department to another and it can take ages to get what you want'.

Although a problem, being referred from department to department might be expected in large organisations which deal with a whole range of disablement issues but it also occurs in well established impairment specific organisations such as the RNID: 'The RNID seem very disorganised, often you can't get through to the right department and when you do they don't always have the information you want'.

It was also suggested that national information providers often respond to telephone enquiries with a request to ring back because there is no-one there who can deal with enquiries. Examples include SKILL - the National Bureau for Students with Disabilities and the BCODP.

Several people mentioned the fact that a number of national information providers' telephone services are not accessible to the deaf community. Important examples include the DLF, DIAL UK and the Disability Alliance.

The overriding view expressed by most information workers is that many of the problems associated with telephone services can be overcome through good interpersonal relations: 'if you know what you want and who to ask for...'. Indeed, many people suggested that there is a need for more training for those responding to telephone enquiries.

Postal Services

Accessing nationally produced information by post is a problem for many local information providers. The response time between ordering and actually receiving information, and the amount of data received are the main areas for concern.

It is clear that many national information providers are 'forgetters'; ie. do not respond to an initial enquiry without being prompted - sometimes several times. This is particularly disturbing if the requested data is to be passed on to an individual user or user group.

Although this criticism can be applied to several national agencies, two notable examples concern MENCAP, the Royal Society for Mentally Handicapped Children and Adults, and the Disability Alliance. The former because one respondent had paid for services which they had not received and the latter because it was easier to get the required item, the Disability Alliance's 'Disability Rights Handbook' from another national organisation:

'We sent MENCAP a cheque several months ago for one of their publication.... but we haven't heard anything since'.

'The Disability Alliance (DA) stuff is good but we've had enormous problems getting hold of their directory. Last year, 1992/3, they were very late in coming out so we weren't actually able to advice people in the way that we wanted.... we ordered it in February and got it in August. We decided to go to the Child Poverty Action Group (CPAG), they had a copy. We've found that it's quicker to get it from them'.

The general feeling among local organisations is that national agencies should be able to respond to reasonable requests for postal information within a working week, and that if they are unable to do so then they should let the local organisation know immediately.

Similarly, some people pointed out that requests for inclusion on mailing lists are often forgotten. For instance, one respondent reported that his organisation had contacted MAVIS, Mobility, Advice and Information Service, when they first started in 1992, and they had received a very impressive information pack 'but nothing since'.

The amount of data received also causes problems: 'Often if you ring up and ask for a supply of leaflets you only get a few - one organisations sent us three. So you have to photocopy them which costs money, and of course it doesn't look as attractive'.

This raises the issue of copyright. Several people were unsure of the legality of

photocopying printed material produced by national information providers. National agencies could help by clarifying their attitude to this issue.

Plain language

Almost 50 per cent of the sample expressed concern about the inaccessible language used by some of the national disablement information providers. One representative of a NDIP federation suggested that with notable exceptions - Arthritis Care, BCODP, DIAL UK and RADAR - much of the written data produced by national organisations appears to be written for 'professionals' and, as a result, has to be reinterpreted for non-professionals.

With reference to the material produced by the Centre for Accessible Environments (CAE), for example, she commented: 'They have some very strange publications - very heavy. People need information that is easy to use. Their publications may be useful to architects but they're not much good to us'. Similar criticisms were made of the DLF and the Disability Information Trust.

Clearly, some national organisations appear to be unaware that most of the people working in local disability organisations are volunteers - often without training or 'professional' experience. Equally important, is the fact that 'translating' information into every day language takes time; a commodity which many local information providers simply do not have.

In short, good graphics, straightforward well organised text in jargon free plain language written in easily readable print were considered essential by all those interviewed.

Information in accessible forms

Another problem frequently commented upon by people working in the disablement information field, is that often written data is not produced in accessible forms for people with learning difficulties, people with visual impairments, blind people, and/or people whose first language is not English.

With regard to people with learning difficulties it is important to remember that plain language is not always enough; many people are unable to read the printed word. Moreover, little use is made by national information providers of graphics when publishing material aimed at the disabled population as a whole.

Significantly, organisations specialising in this area often overlook this issue too. One respondent with experience of work with this section of the community suggested that

much of the data produced by MENCAP, for example, is aimed at 'carers' and 'is inaccessible to many individuals with learning difficulties'.

A similar situation exists with reference to the use of large print for people with visual impairments. Apart from specialist organisations like Action for Blind People or the RNIB, few national information providers produce material in accessible forms for visually impaired or blind people. DIAL UK, for instance, do not provide information in Large Print, on tape, or in Braille.

Moreover, some agencies have started to produce information sheets on coloured paper. While this may help with manual filing systems it should be remembered that this practice can be disempowering for people with visual impairments who often have difficulty reading it.

Similarly, it is often the case that poorly photocopied information sheets for local distribution are also inaccessible to people with visual impairments.

As we have seen services for minority ethnic groups are not viewed as a high priority by local information providers. Consequently, few respondent had a good working knowledge of what was available for this section of the community.

Those who had were in little doubt that accessing this type of material is extremely difficult. The problem is made worse because even when national agencies do produce data in accessible forms they do not advertise the fact. One interviewee commented that the Stroke Association, for example, had just stopped producing information in minority ethnic languages due to lack of demand. She went on to say that: 'they hadn't told anybody it was available'

Another respondent pointed out that national providers failure to address this issue might be due to the diverse nature of minority ethnic groups in different parts of the country, and that it was the role of local organisations to cater for the information needs of the local community.

This point was emphasised by someone working in an area with a large minority ethnic population. Although she felt that national providers could do far more to help local agencies on this issue by producing information in minority languages on request, the problem could only be solved by local people because many individuals from minority ethnic backgrounds are unable to read their own language.

Hence: 'besides information in minority languages there needs to be more emphasis on

verbal communication, people going out into the community - more outreach work'.

The format of nationally produced information

Once accessed, the format of disablement information is important if local information providers are to collate and disseminate it efficiently and effectively. Our sample were asked to comment on three recurrent problems associated with the format of nationally produced data: poorly organised information, data only available for computers, and access to video material for deaf people.

Organisation

Almost half of our sample, 42 per cent, considered poorly organised information to be a significant problem with regard to printed material. But this can take a variety of forms.

A primary concern relates to the way in which some national agencies juxtapose data about vastly different subjects in the same newsletter or information sheet. The most commonly quoted example referred to material produced by DIAL UK: 'it used to come all jumbled up.. with one paragraph on holidays and another about a new book.. I think it's improved..... but we don't use them anymore'2.

Others said that several organisations send out long documents with no summary and few subtitles. This means that valuable time has to be spent 'wading through it', before the reader gets 'to the main points'. Information workers then have to summarise the main points into another format before it can be used.

Additionally, badly organised data makes filing more difficult. Respondents were concerned that different organisations use different categories for the same subjects and, so far, attempts to resolve this problem have been unsuccessful.

Several organisations had adopted the DIAL UK A-Z system developed in the 1980s but had found it unworkable because information could be filed under various headings. For example: 'information about buses could be filed under Mobility or Transport - it was a waste of time'.

Many people felt that there was a need for the development of a universally accepted indexing and classification system. But others expressed concern that the emergence of such a system could lead to all disablement information reflecting one particular perspective; in particular, the 'traditional individual medical approach to disability'.

While it may be argued that a classification system from a particular perspective need not effect information content, there are at least two important reasons for this concern. The conventional medical approach to disability is founded on notions of individual pathology rather than upon social issues and environments; its language is regarded by the international disabled peoples' movement as oppressive to disabled individuals and their families. Additionally, as noted at the outset of this report, such an approach may be accurate for impairment related data but it inaccurate with regard to the more general disability related information. .

Computer based Information

Relatively few of those who took part in the survey, 18 per cent, had found that information was only provided for computer. Notably, none of those interviewed were able to cite specific examples of this problem. However, many people felt that it was very likely that this would happen in the future and this was viewed with some trepidation.

First. in the foreseeable future at least, computer based filing systems are only able to hold certain kinds of information, therefore, they can only complement manual filing systems rather than replace them. Many advocates of this type of technology seem to forget this when discussing the role of computers in information provision.

Furthermore, it is frequently overlooked that while empowering some people computers disempower others. For a variety of reasons, both medical and social, many information workers currently providing invaluable help, advice and support to disabled people and their families are unable to use computers. The growing emphasis on information technology can be seen as a direct threat to their involvement and effectiveness.

Videos and deaf people

Thirty seven per cent of those with experience of data in this format felt that until recently almost all of it was inaccessible to deaf people. They also said that the situation was improving.

Some people pointed out that some videos were subtitled and that this only resolved part of the problem. The makers of videotapes need to remember that to be fully accessible to the deaf community subtitles need to be accompanied by sign language interpreters. The new Benefit Agency videos were cited as an example of good practice.

It is important to remember, however, that many of the organisations sampled had little or no experience of data in this format. This was attributed to the fact that several local agencies had little cause to use information in this format and access information specifically for deaf people. This is because in many areas there are local organisations specialising in services for this particular section of the disabled community.

The Content of Data Produced by National Information Providers

The next section will look at common problems associated with the content of nationally produced information. These are the lack of information about national providers' services, the relevance of nationally produced data to local needs, and the problem of duplication.

Limited Data about National Providers' Services

As was evident in Part 3 many local organisation are unaware of what services are available at the national level.   Over a third of our sample, 39 per cent, explained this with reference to the fact that a number of national information providers do not provide sufficient data about what they have to offer.

However, there are two dimensions to this issue; ie. national agencies' failure to: first, publicise their organisation and its services and, second, keep people up to date with developments in their particular field.

With regard to the first point, whilst some organisations will undoubtedly have difficulty resolving this problem because of limited resources (see Part 3) the data suggest that if they do not then their services will go unused.

With reference to the BCODP, for example, one representative from a local organisation controlled jointly by both disabled and non-disabled people said: 'We've heard of them, but they haven't contacted us. Other organisation send out leaflets and so on, but they don't seem to do that. So we don't really know what they've got to offer'.

Another respondent when talking about services for young disabled people made a similar statement about SKILL: 'I've heard of them but I've no information about what they do so I've never contacted them'.

In terms of national information providers keeping local agencies up to date, the problem is not limited to recently established under resourced national organisations such as those mentioned immediately above. Large long standing organisations are prone to this particular problem too: 'The RNIB only let you know about changes every now and then'. Similar criticisms were made of DIAL UK and the Royal National Institute for the Deaf (RNID).

It is clear that local agencies expect a comprehensive 'professional' service from national agencies.

If the data they want is not forthcoming then they can and will get it from other sources; ie. either, from other national organisations with better marketing skills, or from another local agency.

Relevance to Local Needs.

Overall 61 per cent of our sample believe that much of the data produced by national agencies is not relevant to local needs. However, this view does not apply to all types of information.

Everyone acknowledged that it was important that local people be kept abreast of national developments in key areas which have a direct bearing on their lives. Examples include data on benefits, legislation, civil rights and new developments in technical aids and equipment. Moreover, they all expect national providers to keep them up to date on these issues so that they can pass on relevant information to users as and when appropriate.

But it is also the case that the majority of enquiries to local agencies are about local issues such as locally based support services - respite services, 'community care' assessment procedures and 'independent living' - local disability organisations and support groups, and transport etc.; issues which cannot be dealt with easily at the national level.

Moreover, interview data suggest that most of the enquiries to local agencies about benefits are concerned with how and where to claim. Similarly, a large proportion of requests for information about technical aids and equipment concern access and local availability.

'Other' information needs include data on counselling services for disabled people by disabled people, and locally based support groups concerned with sexuality. Data pertaining to local access was also mentioned by a number of organisations - see

Table 4.1.

It is almost inevitable, therefore, that much of the data produced by national information providers is far too general and not relevant to local needs. Particular examples cited by respondents included material put out by Age Concern, the Carer's National Association, Help the Aged, and SKILL.

Indeed, one respondent said that the data produced by the Holiday Care Service was too general and often out of date. Moreover, one representative of a NDIP federation suggested that several national agencies give the impression that local needs and issues are not their concern.
While it may be argued that national organisations should not be expected to provide local information, it is important to remember that many of them claim to provide a comprehensive service which implies that they can do precisely that. Relevant areas covered by many of the organisations involved with NDIP include employment, accommodation, transport, respite services, and residential care (see for example 'National Disability Information Provision: Sources and Issues' (1992) by Philipa Hinkley and Jane Steele). Moreover, as we have seen earlier several of these organisations actively encourage direct enquiries from local people.

Table 4.1 Local Organisations' Main Information Needs

Type of information	Percentage of local organisations requiring this type of information %
Support services	67
Benefits	66
Disability organisations	66
Transport	65
Technical aids and equipment	65
Leisure/holidays	65
Disability politics and rights	62
Education and training	57

Organisations/groups for people
with specific impairments - eg.
blind people   56

Employment   55

Housing   53

Specific impairments, health and
rehabilitation   46

Equal opportunities issues - race,
gender and sexuality   46

other   22

Base   137

Further, several respondents, particularly those working in user led organisations and organisations controlled jointly by disabled and non-disabled people, said that the data produced by some national agencies was irrelevant to local needs because they had apparently ignored shifts in attitude at the grass roots level. This was apparent in the patronising tone of their publications and some of the issues covered.

Particular organisations associated with NDIP which were mentioned include Help the Aged, MENCAP, and the Spastics Society. One London based information worker commenting on this issue put it this way: 'Too many of these organisations seem to cling to the medical/charity approach and a lot of the material they put out is a reflection of that..... It's about social issues (leisure) and fundraising; that's not what people want, it's useless'.

Similar concerns were expressed by some of the people working in rehabilitation units and health centres.
One woman working in a disabled living centre commenting on information produced by Age Concern stated: 'They produced a range of leaflets on incontinence which we felt were quite disgraceful..... so patronising'.

Duplication

The problem of duplication is well known. Seventy one per cent of the organisations

surveyed said that in most cases the same information was available from a variety of sources at both the national and at the local levels.

As we have seen, besides the 27 national information providers associated with NDIP there are at least 47 other national organisations disseminating information to local agencies in our sample. Moreover, many of these organisations also run a nationwide network of local groups themselves. Examples include Age Concern, Arthritis Care, DIAL UK, MENCAP, MIND (the National Association for Mental Health), and the Spastics Society.

Many of these local groups are also members of the local disablement information federations to which more than a third of the agencies in our sample belong. Furthermore, most of those organisations not affiliated to local federations are aware of other statutory and voluntary agencies in their area which can provide them with appropriate data as and when they need it.

The positive side to all this is that local agencies have more choice as to where and how to access the services they need. For example, although the Disability Alliance is widely used, because of the way it is organised (see Part 5) and the difficulties experienced accessing its services some local agencies opt for the Disablement Income Group (DIG) or even the Benefit Agency - both offer the same kind of information.

Some local organisations can also access data from other local groups before it is made available from national sources. For example, one worker in an organisation which once subscribed to DIAL UK stated: 'Quite often information was available locally before we got it from DIAL UK. The local DIAL usually had it before we got it from them - so we get what we want from them now'.

The negative side is that a number of respondents found the duplication of material to be both frustrating and wasteful. It is frustrating because different organisations use different classification systems which makes filing data needlessly difficult.

But most importantly, it is wasteful because many local information providers view the duplication of material at the national level as an unnecessary waste of much needed resources - resources which many feel would be far better spent on local rather than national services.

Local Organisations' Perceptions of National Information Providers' Services

In view of the above it is not surprising that local organisations' perceptions of

national information providers' services are not particularly good. Fourteen of the 27 national organisations associated with NDIP were perceived as providing a 'poor' service by more than 10 per cent of the respondents in our sample.

Table 4.2 Local Organisations' Perceptions of National Information Providers' Services.

National Disability Information Provider	Level of Usage by Local Agencies	Users' Perceptions of Their Services		
	%	Good %	Adequate %	Poor %
RADAR	81	68	28	4
Disabled Living Foundation	80	73	24	3
RNIB	66	59	30	11
Disability Alliance	64	69	23	8
Arthritis Care	64	61	33	6
DIAL UK	64	49	38	13
Age Concern	63	56	36	8
Holiday Care Service	59	63	28	9
RNID	58	61	30	9
Spastics Society	56	60	35	5
MAVIS	56	53	42	5
CAE	53	63	30	7
BCODP	50	57	36	7
Carers' National Association	47	52	36	12
SIA	47	63	31	6
MIND	45	49	41	10
SPOD	44	38	45	17
Contact a Family	42	68	27	5
MENCAP	40	49	38	13
SKILL	35	58	29	13

Help the Aged	34	52	37	11
Action for Blind People	31	48	33	19
PLANET	22	50	30	20
Disability Information Trust	18	54	33	13
Council for Disabled Children	11	47	33	20
Caresearch	11	27	53	20
Carematch	10	29	52	19

Average	47	55	35	11

Their views regarding particular organisations are listed in Table 4.2. They are ranked according to the level of usage by local agencies not according to the perceived quality of their services.

As might be expected there is some correlation between the level of use and the perceived quality of services provided by national agencies. For example, most people using RADAR or the DLF, the two most widely used organisations in our study, consider their services to be either 'good' or 'adequate'.

The notable exceptions are the RNIB and DIAL UK, both of which were considered to provide a 'poor' service by more than 10 per cent of the sample. It is probable, therefore, that their continued use by local organisations is attributable to necessity and tradition.

Necessity, in the case of the former, because so little material is produced specifically for people with visual impairments local agencies have little choice but to use the RNIB, and tradition in the case of DIAL UK. Set up over a decade ago DIAL UK is widely known while other national agencies are not - there is a nationwide network of local DIAL's who may or may not be affiliated to DIAL UK

However, it is important to remember that in most cases good communications and feedback mechanisms between local and national providers play a crucial role in shaping users' perceptions of national agencies' services. These are discussed below.

Conclusion

It is clear that local information providers experience a number of problems with national information providers' services. The cost of services, access difficulties - particularly with regard to telephone and postal services, and data not produced in accessible formats all create unnecessary difficulties for local agencies.

In terms of content, local agencies' lack of knowledge about what is available might suggest that some national organisation need to market their services better. The data show that several of the larger well established national information providers are widely used by local organisations while some of the smaller more specialist agencies are used hardly at all. This is partly due to the proliferation of information providers, both nationally and locally, and the subsequent duplication of data.

Although this enhanced choice has in many ways empowered local organisations it is widely perceived as an unnecessary and wasteful drain on valuable resources. It is not surprising then that many users are only reasonably satisfied with the services provided by organisations at the national level.

Part 5: Feedback Mechanisms and Why Local Organisations do not Make More Use of National Information Providers' Services.

Introduction

Here we will examine local organisations' relationships with national information providers and explore further the reasons why the former do not make more use of the latter's services. This part of the report is divided into three sections: the first, looks at local agencies' links with national organisations; the second, focuses on feedback mechanisms and; the third, discusses factors influencing the level of usage.

Local Organisations' links with national information providers

Local organisations can be linked to national organisations in a variety of ways. Many simple pay a subscription charge in order to receive their publications on a regular basis. Gloucestershire GUIDE, for example, subscribe to RADAR. the Disability Alliance and many other 'condition specific organisations'.

Some local groups are linked to national organisations through funding arrangements. For instance, The Council of Disabled People, South Warwickshire - Leamington Spa were given three years core funding from RADAR. Both RADAR and the Spastics Society act as agents for the Department of Health's (DoH) 'Opportunities for Volunteering' scheme for people with physical impairments. Local organisations can apply to either for grants of up to three years duration.

As mentioned earlier, many local groups form part of a nationwide network of local organisations affiliated to national information providers. Arthritis Care, for example, has 550 local branches of various sizes all over the country.

Although none of the local organisations in our survey could be termed 'local

branches' of a national information provider, 80 per cent said that they were linked in one way or another to one or more national information provider.

Of these, 31 per cent were associated to one national organisation, 18 per cent had links with two, 10 per cent were affiliated to three, 7 per cent had formal links with four, and the remainder, 44 per cent, were connected to five or more. Indeed, one respondent working in a well established local agency estimated that her organisation subscribed regularly to over 40 national information providers.

However, it is difficult to estimate the level of linkage between local and particular national information providers because several of those who said that they had links with national agencies did not tell us the names of all of the organisations they were associated with.

Some, like Gloucestershire GUIDE, named one or two organisations associated with NDIP and added that they were linked to several others but did not name them. Others, simply said that they had formal links with national agencies but named none of them. A common response was: 'too many to name them all'.

Notably, 51 per cent of the agencies who mentioned particular organisations said they were members of or subscribers to the BCODP. Whilst this will almost certainly be because the BCODP has, since its inception, been at the forefront of the struggle for disabled people's rights it will also be due to the fact that the BCODP membership list was one of the databases used to produce the sample, and because BCODP researchers conducted the research.

Yet despite this, the data does suggest that there is a relationship between use and linkage. Of those who named particular organisations, 74 per cent said that they were linked to RADAR - the most widely used national information provider in our survey, and 32 per cent cited the DLF - the second most widely used information provider.

In addition to the organisations mentioned above, 31 per cent said that they were affiliated to DIAL UK, the fifth most widely used national agency, and 25 per cent to the Disability Alliance, the sixth most widely used national provider.

Only the Centre for Accessible Environments, the Disabled Living Centres Council, and the Spastics Society were found to have formal links with more than 10 per cent of our sample; 18 per cent, 16 per cent, and 11 per cent respectively. Many organisations subscribe to the Spastics Society for their monthly 'Disability Now'

newspaper. This provides news and information on a whole range of disability issues relevant to the disabled population as a whole rather than just for people with cerebral palsy.

Indeed, each of the above provide 'disability' rather than 'impairment' related information services. None of the organisations providing data about or for people with specific impairments were mentioned by more than 10 per cent of the agencies sampled. This is likely to be due to several factors including the nature of the sample and the unprecedented growth of local self help groups and local organisations for people with specific impairments.

Feedback mechanisms

A major concern of the NDIP project and this research in particular is to examine the means of communications and feedback mechanisms between local and national information providers. Hence, we asked local organisations if they had an effective means of conveying their information needs; ie. monitoring procedures, evaluation forms, representation on regional or national councils, for example, to national agencies.

In response, only 39 per cent of the organisations sampled said that they had some form of feedback mechanism, 52 per cent said that they did not, and 9 per cent said that they did not know whether they had one or not.

Where applicable, the feedback mechanisms that are in use take a variety of forms. These include statistical reports and questionnaires, regular contact with local and regional representatives, and representation on regional and national councils or meetings of national information providers or a combination of all three.

Several information workers working in well established local agencies said that they keep records of enquiries and of their information needs, compile statistics, and subsequently feed them into national organisations via evaluation forms and questionnaires as and when required. DIAL UK, for example, collect this information on a monthly basis.

In terms of regional and national representation, several of the organisations belonging to local federations identified federation meetings as a method of feeding information in to national agencies.

This is because often federations include local branches of national agencies, and or are attended by representatives of national agencies. Additionally, some federations

have a direct link to national agencies because of their involvement with NDIP.

For instance, an information worker for an NDIP pilot federation felt that: 'by being part of NDIP we have had something of a dialogue with national organisations... and we have been able to convey some of our concerns via the NDIP seminars..... '.

In addition, some organisations are able to communicate directly with national organisations through local representatives and development workers. Several of the national information providers involved with NDIP such as DIAL UK, RADAR and the Spastics Society have regional representatives and development workers in various parts of the country.

Nonetheless, many people, particularly those working in user led or jointly controlled organisations felt that, on the whole, national agencies do not take local information providers' needs very seriously and that in many cases feedback mechanisms appear to be tokenistic rather than effective.

It is notable, that the majority of people working in traditional organisations involved in rehabilitation or the NHS were reasonably satisfied with their lines of communication to national agencies. One respondent commented: 'we're part of the NHS, we have good relations with all the local rep's... things can always be improved, but it's difficult to see how; our contacts are quite good...'.

It is important to note that all the agencies used by this respondent were associated with particular impairments. These included the British Amputee Sports Association (BASA), the National Association for Limbless Deficiencies (NALD) and REACH: The Association for Children with Hand or Arm Deficiency.

Moreover, in response to the question 'can feedback mechanism be improved'? another respondent working in a similar establishment simply replied: 'no'.

However, as mentioned above, the majority of people with experience of feedback mechanisms to national providers suggested that there was room for improvement. With regard to monitoring forms and questionnaires, a number of people working in small autonomous organisations said that they had neither the resources nor the time to complete them with any degree of accuracy.

Others felt that there was too much bureaucracy involved already with little or no apparent outcome: 'We seem to fill in lots of questionnaires ... especially since NDIP..., there seems to be a lot of information being collected but little coming back..'.

Another individual commenting on the same issue said: 'they (national information providers) could provide us with more information about how they use these statistics'.

With regard to regional meetings, many people said that there should be more regional conferences, seminars and meetings. For example, an information worker working in the north west of England summarised the general view when she said: 'there needs to be lots more contact at the local level - more regional groupings. More involvement by national providers with local groups'.

Several people pointed out that national conferences were not really the answer because many local organisations did not have the resources or the time to attend them.

Another problem with national conferences and seminars is that invariably they are dominated by professionals and information providers who are not really representative of the majority of people working in local organisations and groups. One respondent put it this way: 'ordinary people are intimidated by national conferences and can't get their point across'.

While interpersonal contacts at the local level are widely considered to be the most effective method of communication between local and national agencies several respondents felt that their effectiveness at the national level was limited: 'We can recommend things to local rep's, but if the local rep's aren't respected by the parent body then our message doesn't get through... '.

Moreover, several people from a variety of backgrounds
felt that ineffective feedback mechanisms were only a symptom of the problems faced by local organisations not the cause. This view suggests that, hitherto, the main reason why an effective dialogue had not been achieved was because of the way national information providers are organised. Thus: 'we need procedures which will encourage new people on to national committees.   There's a wealth of experience at the local level which seems to be ignored'.

Another respondent was more specific: 'They (national organisations) need to be run by people with experience of disability.. they should be run by people who know how important the right kind of information is ... not by people who see it as some kind of charity.. as an extra'.

It is significant that the organisations surveyed without experience of any form of dialogue between them and national agencies welcomed the development of an appropriate and effective feedback mechanism. Monitoring forms, regional and

national meetings, and improved personal contacts at the local level were advocated by these organisations.

But several respondents were concerned that the increased workload involved might be an additional drain on already stretched resources - both fiscal and human - and that this needs to considered in the development of feedback mechanisms.

Why Local Organisations do not make more use of National Information Providers' Services

Throughout this report it has been shown that there is a considerable variation in disablement information services at the local level. It is inevitable, therefore, that explanations as to why local agencies do not make more use of national information providers' services will be subject to similar variations and determined by a variety of influences.

Nonetheless, the data suggest that there are a number of key factors which influence local organisations' use of national information providers' services.

Organisation

In terms of organisation, who controls and runs local organisations will play an important role in determining their choice of national information provider and, to some extent, the level of usage. Local agencies sponsored by health authorities, for example, which are run by professionals and adhere to the more traditional medical view of disablement tend to look to national information providers which adopt a similar approach to both staffing and policy.

Alternatively, local organisations with a high level of user involvement are increasingly looking toward national and local agencies with a similar organisational structure and outlook. Several of the organisations surveyed which fell into this category made a concerted effort to use user-led information providers rather than those known not to be user controlled.

Examples of these organisations include the British Deaf Association (BDA) instead of the Royal National Institute for the Deaf (RNID), the Disablement Incomes Group (DIG) rather than the Disability Alliance (DA), and People First - the national user led organisation for people with learning difficulties instead of MENCAP.

Resources

A general lack of resources among local organisations is one of the main reasons why

they do not make more use of national information providers' services. In financial terms, this is particularly evident with reference to direct and indirect expenditure. Subscription charges, the cost of briefing papers, research reports, books, resource packs and telephone charges are notable examples.

Equally importantly, besides prohibiting what services can be provided locally, limited storage space, and a lack of suitably trained staff can severely restrict what information can be accessed, stored and processed.

Inadequate resources are particularly relevant to the issue of computer based filing systems. Some local groups and organisations - particularly the smaller user led variety -

do not have the necessary equipment to hold a large computer database, cannot afford the hard and software support services necessary to maintain such a system, and/or do not have the funding to send hard pressed voluntary staff on expensive training courses to learn how to operate one.

The outcome of all this is that the quality of service available to disabled individuals, their families, professionals, and other users is greatly diminished.

Inadequate communications

Inadequate communication between local and national information providers are another reason why local agencies do not make more use of national information providers' services. This can relate to several factors including: inadequate marketing on the part of national organisations, their failure to respond quickly enough to local agencies' initial requests for information, poor response rates, and ineffective communications networks and feedback mechanisms.

Local organisations cannot make more use of national agencies' services if they do not know what is on offer.
Moreover, some national organisations' failure to respond positively to initial requests for information, their inability to provide an adequate, appropriate and speedy service, and/or establish and maintain an effective feedback mechanism do little to encourage local information providers to access their services.

It is notable that with few exceptions communications networks between national and local information providers appear to be less effective in the north of England than they are in the south.

Local information needs

The data show that in terms of access, format and content several national agencies are not meeting the information needs of local organisations. This undoubtedly has a significant impact on local organisations' use of national information providers' services.

Information produced in inaccessible language and not in accessible forms for people with particular impairments and/or people from minority ethnic backgrounds will almost certainly discourage some local organisations from not using national providers' services. Similarly, badly organised information which is only available in formats that cannot easily be incorporated into existing filing systems are important factors.

Moreover, there is little doubt that local organisations do not make greater use of nationally produced information because much of it is irrelevant to local needs. With few exceptions, local people want readily understandable information about services and issues available within the context of their own community.

It is the kind of information which can only be produced and provided by local organisations staffed by people who live and work in the local community. Moreover, the knowledge and, to some extent, the interpersonal skills needed to provide this type of service can never be provided effectively by a national organisation situated in a central location.

Furthermore, it is the inability of national information providers to respond adequately to local needs that initiated the development of a nationwide network of local agencies producing information themselves.

Increased competition

It has been evident throughout this report that besides national information providers involved with the NDIP project, local organisations are able to access information from an assortment of other sources at both the local and at the national levels.

In terms of local services, as we have seen these include the growing number of self help organisations producing material for local and national consumption, local branches of national information providers, statutory authorities - local authority social service departments, health authorities, NHS trusts, and federations of local information providers.

Nationally, there is a multitude of voluntary agencies concerned with specific

impairments, disability, and organisations both of and for disabled people - many of which have been mentioned above. Additionally, there are other national bodies who, although not primarily involved in disablement, do provide information relevant to disabled people and their families. Examples include the Benefits Agency (BA), the Child Poverty Action Group (CPAG), the Citizen's Advice Bureau (CAB), and the Trades Union Congress (TUC).

This increased competition means that local organisations are unlikely to make more use of national information providers simply because they do not have to. Moreover, given that the majority of information workers at the local level believe that other local agencies provide a better service, both in terms of data relevance and interpersonal relations, it is doubtful whether it will increase in the future. With this in mind, it is frequently argued that significantly more resources should be put into the development of local rather than national information services.

Conclusion

Clearly, meaningful dialogue between local and national information providers is limited. In terms of feedback mechanisms, the data show that less than half the organisation studied have appropriate feedback procedures. Where applicable, these take the form of written reports, questionnaires, representation on regional and national councils, and outreach work by representatives of national organisations. But most people feel that good local contacts are the best form of feedback mechanism. However, a lack of resources - both money and time - is considered a major barrier to improvement.

Besides poor communications networks, there are several reasons why local organisations do not make more use of national agencies' services. These include general organisation, cost, and the unprecedented growth of national and locally based information providers - some of which are run by the national providers themselves.

As a consequence, local agencies are no longer dependent upon data produced by particular national organisations. In addition, information workers generally believe that local organisations provide a far more personalised service and are more in touch with local needs.

Moreover, there is a widespread belief among people working in local organisations that local information needs are quite distinct from those addressed by the majority of national information providers, and that increasingly these organisations are unable to meet those needs. Hence, resources should be diverted from national information providers to develop more effective local based services.

PART 6: Recommendations

Introduction

At present, there are 6.5 million disabled people in the UK. There are also 4-6 million informal carers - the majority of whom are women; one in four households are effected in one way or another by disability. Moreover, because of medical advances and Britain's rapidly ageing population these figures will increase substantially over the next few years.

It is clear that the provision of appropriate and accessible information on all aspects of disablement must be given a much higher priority by policy makers and politicians at both the local and the national levels. Hence, policies and practices must be introduced that ensure that the mistakes of the past are not replicated.

Recommendations

Organisation and control

To ensure that existing and proposed information services at all levels are fully responsive to users' needs it is essential that they be user led. This means that disabled people accountable to disabled people's organisations must be effectively involved at every level in the planning, process, and delivery of information services.

Moreover, it is essential that heightened user participation is not merely tokenistic. This means the development and introduction of legally binding constitutions and recruitment policies which ensure the meaningful involvement if disabled people in the

organisations and running of services.

Resources

There is an urgent need for more resources to be put into the development of locally based services. This is especially relevant to the north of England and rural areas where adequate provision is particularly thin on the ground. Funding should also be provided on a more long term basis to allow local organisations to research, plan, and develop services in response to locally perceived needs.

Location and staffing

Local authorities, health authorities and other policy makers must strive to ensure that local information services are situated in easily accessible premises and locations staffed by people with the appropriate qualities and skills to offer peer support and services.

Information needs of marginalised groups

Resources must be set aside to research and address the information needs of marginalised groups within the disabled community. It is evident that the majority of local organisations have little real insight into the information needs of minority ethnic, racial, and other marginalised groups within the disabled community.

Local federations

Measures must be introduced to ensure the development of more local federations of information providers. The emergence of these and other umbrella groups has, on the whole, been a welcome development. The pooling of information and resources by small local groups with few resources has, in most cases, enabled them to provide a far more comprehensive service.

Given that policies are introduced which will ensure that these existing and future structures are user led then every effort must be made to encourage their development and proliferation.

National providers' services

If national organisations hope to retain their share of the market then some of them must improve their services to local organisations in certain key areas. These include: charges and charging procedures, postal response rates, telephone services, data access, format and content. Of particular note is the lack of accessible information for people with sensory and intellectual impairments and marginalised minorities within the disabled community.

Standardisation

Research must be conducted for the development of a standardised index and filing system. There is clearly a growing demand for such a system - for both manual and computer based databases - to facilitate the effective and trouble free flow of information between local and national organisations.

But because there are so many different systems already in operation, the introduction of any new scheme would pose major problems for the majority of information providers. Therefore, work is needed to maximise compatibility and ensure its acceptance.

Communications mechanisms

National information providers must make more effort to improve the dialogue between themselves and local organisations. This, again, is particularly relevant to rural areas and the north of England where contact is often non-existent. Since research suggests that good interpersonal relations are the best form of feedback mechanism, this might be achieved by the employment of more local representatives and regional development workers, and the introduction of clearly defined policies and procedures for accommodating local people's views.

Co-ordinating body

To ensure the further and effective development of the National Disability Information Project (NDIP) a permanent and autonomous user led co-ordinating body must be established. This organisation must be equipped with the necessary remit and power to direct and allocate Government funding and resources where they are most needed. It must also be staffed by representatives of and accountable to the nationwide network of local disablement information providers.

Anti-discrimination legislation

Finally, the demand for and, therefore, the cost of specialist 'disability' information

will only be reduced by the introduction of policies which tackle its cause; ie. the hostile environments and disabling social attitudes which disabled people and their families encounter daily. This means the introduction of a comprehensive anti-discrimination policy similar to that already In place in America, Australia, Canada, New Zealand and other democratic countries.

1 HINKLEY, P. and STEELE, J. (1992) National Disability Information Provision London, Policy Studies Institute.
2 Since 1993 DIAL UK have been using a classification system developed by Disability Information Services Surrey (DISS). This is the improvement mentioned by this respondent.

Appendix 1: List of Organisations who Participated in the Interview Process

Barrow and District Disability Association
75/78 School Street
Barrow in Furness
Cumbria
LA14 1EJ

Council of Disabled People: South Warwickshire
Bath Place Community Venture
Bath Place Leamington Spa
Warwickshire
CV31 3AG

Dene Centre 1AS
Castles Fark Road
Newcastle Upon Tyne
Tyneside
NE3 1PH

DIAL Basildon
The Basildon Centre
Pagel Road
Basildon
Essex SS14 1DL

Disability Advice and Information: St Helens

Central Library
Victoria Square
Merseyside
WA10 1DY

Disability Information Centre
Middlesborough General Hospital
Ayersome Green Lane
Middlesborough
TS5 5AZ

Disablement Information Services Carlisle (DISC)
48 Grinsdale Avenue
Belle Vue
Carlisle
CA2 7LX

Disability Information Service Surrey (DISS)
Harrowlands
Harrowlands Park, South Terrace
Dorking
Surrey RH4 2RA

Disability Information Centre
The Health Centre
Victoria Lane
Coundon
Bishop Auckland
County Durham
DL14 8NL

Disability Resource Centre: Yardley Birmingham
Bierton Road Site
Bierton Road
Yardley
Birmingham
B25 8PQ

Disability Services: Huddersfield
Zetland Street
Huddersfield
West Yorkshire
HD1 2RA

Donald Todd Rehabilitation centre
Fazakerley Hospital
Longmoor Road Liverpool
Liverpool
L9 7AL

East Sussex Association for Disabled People
47 Western Road
Lewes
East Sussex
BN7 1RL

East Yorkshire Council of Disabled People
26 Marton Road
Bridlington
East Yorkshire
YO16 5AL

Gateshead Council on Disability
John Haswell House
8/9 Gladstone Terrace
Gateshead
NE8 4DY

Gloucestershire GUIDE
Gloucestershire Royal Hospital
Great Western Road
Gloucester
GL1 3NN

Greater London Association of Disabled People (GLAD)
336 Brixton Road
London SW9 7AA

Hertfordshire Coalition of Disabled People
Roundmead Hall
The Poplars
Stevenage
Hertfordshire
SG2 9PQ

Independent Living Alternatives: Middlesex
Fulton House
Fulton Road Wembley Park
Middlesex

Keighley Disabled People's Council
Temple Row Centre
Temple Row
Keighley
BD21 2AH

Lambeth ACCORD - Information Service
336 Brixton Road
London
SW9 7AA

Lewisham Disablement Association
67 Engleheart Road
Catford
London SE6 2HN

Macclesfield Disability Information Bureau
Pierce Street
Macclesfield
Cheshire
SK11 6ER

Manchester Disablement Services Centre
Withington Hospital
Cavendish Road
Manchester

M20 8LB

Oldham Disability Alliance
4 Eldon Precinct
Oldham
Lancashire
OL8 1JP

Oxfordshire Council of Disabled People
Rivermead Centre
Abingdon Road
Oxford
OX1 4XD

Shropshire Disability Consortium
Disability Resource Centre
Lancaster Road
Harlescott
Shrewsbury
SY1 3NJ

Southwark Inform
The Bearmund Centre
London
SE1 2AN

Sunderland Society for the Disabled
76 Stabekey Road
Seaburn Lane
Sunderland
SR6 8LD

West Sussex Association for the Disabled
10 South Pallant
Chichester
West Sussex
PO19 1SU

Appendix 2: National Organisations Associated with NDIP

Action for Blind People

Action for Blind People's information and advice centre was established in 1991. It provides data to blind people and people with visual impairments, their families and others on a wide range of subjects.

Age Concern England

This organisation provides a comprehensive range of information for older people, their families, professionals and policy makers; much of which is relevant to people with impairments. The range includes data on health, social services, income, housing, transport, heating and consumer affairs.

Arthritis Care

Arthritis Care provides information relevant to people with arthritis and related conditions, their families, professionals and others. They provide a range of information services including a national freephone helpline.

British Council of Organisations of Disabled People (BCODP)

The British Council of Organisations of Disabled People (BCODP) was established in 1981. It is Britain's national umbrella for organisations controlled and run by disabled people. In conjunction with its member organisations it provides information on a

range of issues pertinent to disabled people including: the campaign for equal rights and opportunities, independent living, housing, and disability arts and culture.

Carematch: RESIDENTIAL Care Consortium Computer Care Service

Carematch provides a computer based service for people with physical impairments looking for suitable residential care. It has a database of over four hundred residential homes throughout England, Scotland and Wales. The services is also available to disabled people's families, professionals and other organisations.

Carers National Association

This organisation provides an information and support service for informal 'carers' or helpers of disabled people, and for people who work with this increasingly large section of the community. Enquiries can be made either by letter or by telephone.

Where appropriate enquiries are referred to a regional or local branch - many of whom operate as local information providers themselves.

Caresearch

Caresearch provides information on residential accommodation for people with learning difficulties. This information is provided to all those who are looking for this type of provision, including parents, guardians, relatives and professionals, and professional organisations.

Centre for Accessible Environments (CAE)

The Centre provides information and advice on the practicalities of providing an accessible environment. It is an information and training resource for all those involved in access issues, including, disabled people, their organisations, architects, surveyors, access officers and other professionals. Their services are free although charges are made for information sheets, design packs and other publications.

Contact a Family

This organisation provides information and advice to parents and professionals on all aspects of caring for disabled children. Contact a Family recognises that parents are a valuable information and support source for other parents and relatives. They offer a nationwide support service and network to families with disabled children.

Council for Disabled Children

The Council for Disabled Children's library and information service are based at the National Children's Bureau. They provide information and advice on all subjects associated with children and young people with impairments. They provide data to parents, professionals and anyone interested in disability and childhood or adolescence.

DIAL UK

DIAL UK is the national co-ordinating body for information and advice centres for disabled people. Their service provides data on all aspects of disability to local DIAL agencies, and to other organisations. DIAL UK provide a sign posting service to local DIAL groups and other organisations where appropriate.

Disability Alliance (DA)

This is a national federation of over 200 organisations of and for disabled people. The DA campaigns on issues relevant to the income needs of disabled people. As associate organisation, the Disability Alliance Education and Research Association (DAERA) provides information and rights advice and produces the Disability Rights Handbook.

Disability Information Trust

The Disability Information Trust independently assesses and tests, with the help of disabled people, most of the disability equipment that comes on to the British market. The results are disseminated through the periodically updated Equipment for Disabled People. The information is aimed at anyone with a need for data on technical aids and equipment for disabled people.

Disabled Living Foundation (DLF)

The DLF provides detailed comprehensive information and advice on all aspects of living with impairment and disability. The information service can be contacted by letter or by telephone. The DLF specialises in data on aids and adaptations, continence, clothing and footwear. Information is free to disabled individuals and their families, and is available to other people and organisations through subscription.

Help the Aged

This organisation founded and runs SeniorLine, a free national information service for 'senior citizens', their families and friends. The service covers welfare and benefits, housing, support for informal helpers, mobility, community alarms, heating and insulation, and local support services and facilities.

Holiday Care Service

This organisation provides data to enable people to choose a holiday suited to their needs. The service is free to people over retirement age, disabled people, single parents, informal helpers of people with impairments, and people with severe financial problems. The Holiday Care Service runs a postal and telephone enquiry services but does not make reservations or bookings.

Mobility Advice and Information Service (MAVIS)

MAVIS provides data and advice on all aspects of driving for disabled people, driving instructors, driving examiners, and other professionals. Anyone can use the service either by letter or by telephone.

MENCAP (Royal Society for Mentally Handicapped Children and Adults)

MENCAP's information department provides data and advice for people with learning difficulties, both adults and children, their families and friends, professionals, policy makers, and the general public. Enquiries can be made by letter, telephone or in person; they have 7 divisional offices, 550 local MENCAP groups, and 32 field officers.

MIND (National Association for Mental Health)

MIND provides data to the public and professionals on all aspects of 'mental' health and emotional distress from its public information services, which is run by the central information unit and its regional offices. The unit also provides resources to MIND's regional offices which supports local groups. Enquiries to the central information unit can be made by letter or by telephone.

PLANET (Play Leisure Advice Network)

This organisation provides information and advice on play, leisure and recreation for disabled people, their families, and staff from health, social services and leisure fields.

Enquiries are made by letter or by telephone.

RADAR (Royal Association for Disability and Rehabilitation)

The information service at RADAR provides information and advice on all aspects of disability. It is aimed at disabled people, their families and friends, informal helpers, professionals and policy makers. The service can be accessed by letter or by telephone. Where necessary RADAR will refer enquirers to other relevant organisations.

RNIB (Royal National Institute for the Blind)

The RNIB is Britain's largest organisation for blind people and people with visual impairments. It provides a range of information services for this section of the disabled community, their families, professionals, professional organisations, commercial enterprises and members of the general public.
They also provide data in large print, Braille, Moon, and on audiotapes. Enquiries can be made by letter (in all formats), by telephone, fax, or in person.

RNID (Royal National Institute for Deaf People)

This organisation provides a wide range of information services relative to the deaf community and people with hearing impairments. The service is primarily for deaf people or those with hearing impairments, their families and friends, professionals, employers and lay people with an interest in deafness. Enquiries can be made by letter or by telephone.

SKILL (National Bureau for Students with Disabilities)

SKILL provides an information service on all subjects pertaining to post compulsory education and training for disabled students. This includes a wide range of issues such as access, admission policies, and financial support. The service is primarily for students with impairments, whether physical, sensory and/or intellectually based, their families, teachers, and professionals working in this particular field. Enquiries may be made by letter or by telephone.

Spastics Society

The Spastics Society provides information and advice on anything to do with cerebral palsey and related conditions. Free information and advice can be obtained from the Spastics Society's library and information service at their head office in London.
They also operate a freephone Cerebral Palsey helpline. The former will provide data

on request by letter, telephone and/or in person, and the latter by letter and telephone only.

SIA (Spinal Injuries Association)

The Spinal Injuries Association (SIA) is a self help organisation run and controlled by disabled people. It has a well established information and advice service providing services primarily for people with spinal cord injuries, their families and friends, and associate professionals. However, many of the factsheets and publications produced by the SIA are useful for people with other impairments. Much of the data held by the SIA is based on the individual and collective experience of its members.

SPOD (Association to Aid the Sexual and Personal Relationships of People with a Disability)

SPOD provides information and advice on sexuality and personal relationships for disabled people, their partners, and informal helpers. They also provide relevant information to professionals working with disabled people and their families. Enquiries can be made by letter or by telephone.