

Disabled people have rights

Final Report on a two year project funded by The Nuffield Provincial Hospitals Trust



Equal Voices – Equal Choices

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Published by The Royal Association for Disability and Rehabilitation 12 City Forum, 250 City Road, London EC1V 8AF

Telephone 0171 250 3222

Registered Charity No. 273150 October 1994

Price £5.00 (incl. p+p)

ACKNOWLEDGEMENTS

The Royal Association for Disability and Rehabilitation would like to thank all those individuals and organisations who have contributed to the Disabled People Have Rights Project. Special thanks are due to the Nuffield Provincial Hospitals Trust, which generously funded the project. Without the Trust's continuing support, the direct assistance the Project Officers were able to give to disabled people would not have been possible. The Project Officers would also like to express their appreciation to Lesley Browne, who devised the Project.

Furthermore, we would like to express our appreciation to all the disabled people who have shared their concerns with us and to the employees, elected members and the many Directors of Social Services who have met with the Project Officers to discuss these concerns and their authorities' services.

Finally, thanks also go to Claire Skinner, Linda Ramsay, Yemi Oni and Susan Ganz, who have shared the repeated typing of this report.

(NOTE: The examples used in this report to illustrate the problems people experienced in obtaining social services are real; however, names have been changed to protect the identities of the people concerned.)

INTRODUCTION

Just before the General Election of 1970 two important Acts were passed which changed the way welfare services were to be managed:

The Local Government Social Services Act 1970 - which set up Social Services Departments - and the Chronically Sick and Disabled Persons Act 1970 - Section 2 listing services local authorities had a duty to provide if an assessment identified a need for one or more of the services.

Just over ten years later - in 1981 - it was apparent that local authorities were evading their duties under the Chronically Sick and Disabled Persons Act, one of the reasons being that the provision of services was dependent upon an assessment of need but there was no explicit duty upon local authorities to undertake the assessment. This failing was rectified by the implementation of Section 4 of the Disabled Persons (Services, Consultation and Representation) Act 1986 which requires local authorities to assess need on request.

The National Health Service and Community Care Act 1990,

"aims to enable people to live an independent and dignified life at home, or elsewhere within the community, for as long as they are able and wish to do so."

If this aim is to be achieved it is essential that Social Services Departments fulfil their statutory duties.

The provision of services listed in Section 2 of the Chronically Sick and Disabled Persons (CSDP) Act 1970 is a cornerstone to care in the community and vital for the independence of disabled people.

Where is dignity when using a commode in the sitting room used by other members of the family? How can people maintain their dignity if they feel dirty and are told bathing is low priority? Why are disabled people expected to accept that as they are disabled they no longer have the right to a clean home?

During 1991 and early 1992 many disabled people contacted RADAR as they were having difficulty in obtaining social services from local authorities. The increase in the number of complaints greatly concerned RADAR which considered concentrated work was required to address the reasons for the difficulties. RADAR established a two year project, financed by the Nuffield Provincial Hospitals Trust, the immediate aim being to ensure that all disabled people receive the services to which they have a statutory right. In the longer term the objective is to clarify once and for all the mandatory nature of Section 2 of the 1970 Act, and to ensure that SSDs are aware of and fulfil their duties under the legislation.

During the two years RADAR received seven hundred complaints from people living in England and Wales. Over four hundred of the complaints required in-depth investigation and advocacy work. The project officers visited over one hundred and fifty disabled people in their own home travelling the length and breadth of England and Wales. From discussions with disabled people and local group meetings it is clear that the seven hundred complaints are but the very tip of a huge iceberg.

The White Paper Caring for People highlighted the importance of special equipment, home adaptations, personal and domestic tasks such as cleaning, washing and preparing meals "which will be essential to enable people to live in the community" (2). Throughout the two years, 91% of the complaints received by the Project Officers concerned these services.

Coping with everyday life can be arduous for most people, yet disabled people are expected to accept that decisions on meeting their needs cannot be taken quickly.

57% of the complaints RADAR received were from people caught up in the bureaucratic process of the Disabled Facilities Grant. The laborious process, the numerous assessments, and the number of local government officers involved has been the cause of unnecessary additional stress for many people.

A clean home is apparently of little importance to elected members and officers. Many local authorities have adopted policies which exclude cleaning from the services they provide. Such policies are against central and local governments' commitment to community care. These policies must continue to be challenged.

When information regarding criteria for eligibility for services is available it is often unclear. When a senior member of a social services department (SSD) was asked the definition of "essential needs", a part of the authority's criteria, he was unable to

answer. Yet the individual was supervising assessors. If he did not know the definition, how could he ensure that the team could undertake meaningful assessments? There must be a clear understanding of criteria within departments and by the public.

Complaints procedures have been established in social services departments. The operation of these, however, differs widely from authority to authority. The Department of Health policy guidance directives must be collated, made clearer, and reissued to local authorities. The complaints procedure is an important process which disabled people must be encouraged to use to ensure they receive adequate support from local authorities.

The Project Officers continued to find that people were wary about complaining, and there are some indications that they were right to have reasons to be cautious. It was difficult to prove conclusively, but nevertheless there was strong evidence to suggest that some people who have complained have been victimised.

Early in the project it became apparent that successful community care relies on "consultation, collaboration, co-operation and communication" between service users and service providers (1). The services that disabled people are entitled to under Section 2 of the Chronically Sick and Disabled Persons Act 1970 (3) are the foundation for independent living in the community. Yet, as the project has found, many disabled people are not getting the services they need or they are experiencing lengthy delays and, in some cases, their needs for services have increased because of the delays. At the end of the day, what the project hoped to achieve was:

- 1. A clear understanding by both local authorities and disabled people of what services should be provided under Section 2;
- 2. A system that ensures that local authorities listen to disabled people and respond to them;
- 3. Clear written statements for disabled people on what services are going to be provided; what services are not going to be provided with regard to assessed need; and the reasons why the services will not be provided;
- 4. Simple and clear complaints procedures that are made available to disabled people as well as to local authority staff so that should they need to be used everyone involved understands them.

5. Ongoing training for local authority staff and for disabled people on what Section 2 services can mean to both and how best local authorities can deliver the services and how best disabled people can use them.

The Project Officers have been in touch with the forty six County Councils, thirty three of the thirty six Metropolitan Boroughs and thirty one of the thirty two London Boroughs. Negotiations have also involved many District Councils.

There has been evidence of bad as well as good practice. However, it would have been simplistic to simply publish a league table of "good" and "bad" local authorities. Instead, the Project Officers have adopted a constructive approach with the aim of achieving effective partnerships between disabled people and local authorities.

(NB: the local authorities involved with the project are listed in Appendix E).

METHOD

It was important that the project should not be perceived merely as a statistical exercise. RADAR has therefore concentrated on taking action on each complaint received. In order to do so, each person who approached RADAR was sent a questionnaire (referral form) and an explanation of his/her rights under existing legislation. The questionnaire served two purposes: first, to provide information to be used when negotiating with the local authority; and second, to provide statistical data.

The most usual method of dealing with a complaint was to send a letter to the Director of Social Services requesting an investigation and/or clarification of the situation. Although it was common practice for the complaint to be passed to other members of staff, it was imperative that directors were made aware of the problems within their department.

Occasionally it was considered to be more appropriate to contact the complainant's key worker, or, when a complaint was not related to the provision of Section 2 services, it was referred to a relevant agency or individual.

In some instances, it was necessary to visit the disabled person, to attend case conferences and less formal on-site meetings, to discuss the situation with the complainant and social services staff. However, when this failed to result in the complaint being resolved, negotiations continued and, in some cases, a request was made through the complaints procedure for a review panel to be convened.

1. PROVISION OF SERVICES

"Social care and practical assistance with daily living are key components of good quality community care. The services and facilities, at present largely the responsibility of social services authorities, which will be essential to enable people to live in the community, include help with personal and domestic tasks such as cleaning, washing and preparing meals, with disablement equipment and home adaptations, transport, budgeting and other aspects of daily living."(2)

These services are listed in Section 2 of the Chronically Sick and Disabled Persons Act 1970 and are the cornerstone for living at home but lack of these services has been the cause of great distress for many disabled people.

(a) PRACTICAL ASSISTANCE IN THE HOME

Social services departments (SSDs) have a duty to make arrangements for the provision of practical assistance in the home, where the need for it has been identified. 34% of the complaints RADAR received related to practical assistance in the home.

The main concerns were:-

- * Reduction or withdrawal of service without a reassessment;
- * Domestic assistance no longer provided;
- * No service or reduced service when home help/home care assistant is unavailable;
- **★** Imposition of or increase in charges;

Reduction or Withdrawal of Service Without a Reassessment

In these circumstances, local authorities were reminded that once an assessment had identified a need for the service it was unlawful to reduce or withdraw it unless a reassessment had determined that the need for the service had diminished. This reminder invariably resulted in the service being reinstated.

In some cases the "reduction or withdrawal" of service was often a difference in understanding what originally had been agreed. When a formal complaint was made, it usually became clear that there was a difference in understanding between the disabled person and the authority about the assessed needs and about the number of hours to be allocated. Information was given verbally but no written confirmation was normally omitted. For example:

"The (Review) Panel acknowledge that Mrs Yates did firmly believe that three hours originally and fours hours in December 1992 were agreed and would be provided. However, there is no clear evidence that the Department did, in fact, agree to provide a fixed number of hours."

No note had been put in social services records on how many hours had been allocated. When asked if it was usual practice not to note the number of hours allocated, the Director replied:

"As was made clear in our report (to the review panel) the Home Care Service does not define an individual's needs in terms of hours per week to be allocated but rather in terms of tasks with which that individual needs help."

The Director did agree that a clear written agreement between the Department and the service user would help to avoid misunderstanding in the future and "...this is being considered within the context of the pilot scheme for customer service contracts within the Authority".

In an authority where a similar issue had been heard by a review panel the Director's response was more direct:

"It is agreed it is beneficial if the home care service were to provide clients with a statement which outlines the services to be provided and I have set a target of three months for the implementation of a system."

Section 3 of the Disabled Persons (Services, Consultation and Representation) Act 1986 (4) if it were implemented places a duty on local authorities, if requested, to

supply a written statement of a person's assessed needs and the services to be provided. Moreover, the authority is required to explain its decision if it is not going to provide services. However, the Government has not yet taken the decision to implement this Section of the Act.

Domestic Assistance No Longer Provided

In recent years, practical assistance has undergone a shift of emphasis from domestic assistance (home help) to personal care (home care). Domestic assistance includes housework, shopping, preparation of light meals and other light domestic tasks.

In a press release, issued on 23 July 1991, the Rt Hon Alf Morris MP stated:

".... any council which makes a policy decision not to provide cleaning services to disabled people in any circumstances is fettering its discretion and acting unlawfully." (5)

Many SSDs have made a policy decision not to provide housework:

Mr and Mrs White's home help/care service was withdrawn when Mr White went into residential care. The local authority had provided personal care and domestic assistance mainly for Mr White. However, as Mrs White was able to attend to her own personal care, prepare meals and go shopping with assistance from her daughter, the whole service was withdrawn.

Mrs White asked for assistance with housework to continue, as she experienced difficulty carrying out these tasks because of her own disability. She was told that "...it is not the normal policy of this department to provide (a cleaning service) solely, given the demands on the home care service"

RADAR challenged Mrs White's local authority and succeeded in getting assistance with housework restored.

There have been a number of studies concerning the provision of domestic assistance. There is general consensus that a dirty home is detrimental to the well-being of disabled and elderly people.

"Failure to provide an appropriate and adequate level of domestic help to all older people who need it not only undermines their dignity, but affects their general health and quality of life, and may lead to increased dependency in the future." (6)

"There appears to be a genuine lack of understanding in social services departments about how important a clean home is to people who, in many cases, have to spend the majority of their lives inside their homes. Apart from their distress in living in what they see as unhygienic surroundings, they also feel painfully humiliated at having to sit and look at what they see as degradation and by being told that housework is not important." (7)

The complaints received during the Project reinforced these findings. A clean home is a significant factor to the well being of disabled people and is an essential ingredient of community care.

No Service or Reduced Service When Home Help/Home Care Assistance is Unavailable

Sometimes, home help/home care has been reduced or withdrawn because the member of the staff responsible for organising or providing the service was absent from work. This may be due to annual or sick leave or training as in the following case:

Ms Black explained that she never knew "...what help (she was) getting in any given week, or whether (she would) be getting any help at all." Moreover, "...when help has been provided it has been by a lot of different agency workers, at odd times and for much less time than I have been assessed as needing." She went on to say that "...when they have provided any it has been because I have absolutely insisted (not something I find easy - each communication with the Council fills me with dread and I invariably end up in tears)."

This can cause considerable distress to disabled people, for whom a regular and reliable home care service is an essential part of independent living.

In some cases, when someone did turn up they had no idea of what was required. Although disabled people appreciated a new person would not know where items were in the house, they did expect home helps to have knowledge of what they were expected to do.

Miss Green was assured she would receive cover when her home carer was unable to visit due to illness or holiday. This did not happen. Twice within six weeks the home carer was ill. Miss Green was not told, neither was a substitute provided.

When Miss Green first contacted the home care manager, she agreed to send someone else. But no one turned up. When she contacted the SSD again, no one was able to help. The SSD told RADAR:

"It is acknowledged that over the past eighteen months the home care service has not achieved the level that is required. During that time the service has been reorganised, management has been halved and there has been a long period of industrial action. Inevitably this has meant that there have been periods of disruption, despite the effort which is made to maintain a regular service. To our regret this has extended to service users such as Miss Green, who are recognised as having a priority need for the support of the home care service."

Imposition or Increase of Charges

Section 17 of the Health and Social Services and Social Security Adjudications (HASSASSA) Act 1983 gave SSDs the right to charge for any of the services listed in Section 2 of the CSDP Act (8).

The Project Officers found that the imposition or increase of charges led to some people giving up their services.

Mrs Perkins had been assessed as needing home help and a telephone. These needs were met by $1\frac{1}{2}$ hours home help per week and the payment of the telephone rental.

In November 1993, following a financial assessment, Mrs Perkins was informed that the charge for her home help was to be increased by £8 per week. As she could not afford the new charge, she cancelled the service. Since then she has had to purchase home help from a private agency at a cost of £4.50 per week. She said "...when and if I can afford it." In January 1994 she was told that the payment of £20.80 for her telephone rental was to be withdrawn.

RECOMMENDATIONS

Local Government

- 1. Give written confirmation of agreed areas of assistance needed and details of the service to be provided to meet agreed needs (a suggested statement is shown in appendix A).
- 2. Give advance notification of a change in service and to make alternate arrangements when the regular home care assistant is on annual leave and where possible when on sick leave.
- 3. Rescind policies which state a cleaning-only service is not provided.
- 4. Take into account the full costs of disability when financially assessing disabled people's ability to pay for services.
- 5. Recognise that an individual's circumstances should be the principal concern regarding the timing of an assessment of their needs and the provision of services to meet their identified needs. Lengthy delays can increase service needs and should be avoided.

Central Government

- 1. Inform local authorities that an Attendance Allowance or Disabled Living Allowance (DLA) care component of a disabled person's income should not be taken into account when setting charges.
- 2. Inform local authorities that it is unlawful to refuse to assess for any of the services listed in Section 2 and that when a need has been identified, it is unlawful to refuse to make arrangements for the provision of assistance (including cleaning) to meet that need.
- 3. Bring into force Section 3 of the Disabled Persons (Services, Consultation and Representation) Act 1986.

(b) ADAPTATIONS AND ADDITIONAL FACILITIES

57% of the complaints received related to requests for adaptations and/or additional facilities (eg. special equipment) under Section 2(e) of the CSDP Act 1970.

In many instances, a SSD's responsibilities under Section 2(e) are carried out on its behalf by the local housing authority through Disabled Facilities Grant (DFG). However, the Local Government and Housing Act 1989 (9), which introduced Disabled Facilities Grants, did not supersede Section 2(e) of the CSDP Act. It merely provides local authority social services departments with an additional means of meeting a disabled person's need for adaptations and additional facilities.

The policy guidance which accompanies the DFG legislation states:

"The continuing responsibilities of welfare authorities (ie SSDs) under Section 2 of the CSDP Act are unchanged."

Moreover, "The responsibilities of the welfare authorities under Section 2 of the CSDP Act 1970 to provide help with equipment are not affected by the introduction of the 1989 Act." (10)

This cannot be stressed enough. When making enquiries concerning a person's request for adaptations to their home, the Project Officers were frequently told that social services had made a recommendation to the local housing authority, which was then incorrectly regarded by social services staff as responsible for providing the adaptations.

A Director of Social Services wrote:

"I will consequently be making a recommendation to the Borough Council that your bath be replaced with a smaller one. I must stress, however, that the decision as to whether to provide the bath is one for the Borough Council." (Note: this case has not been resolved).

Several local housing authorities have written to Disabled Facilities Grant applicants informing them that the recommended adaptations could not be carried out in the current financial year because of a lack of resources.

One District Council Housing Officer wrote:

"I am writing to confirm that we have received a referral from the Occupational Therapist requesting adaptations to be carried out at your property.

Unfortunately, the number of households in need of such work far exceeds the budget set aside for adaptation work in the current financial year, which runs from April 1994 to 31 March 1995. It is, therefore, unlikely that this office will be able to fund the adaptations you need this year." (Note: the District Council is only obliged to administer DFGs and consider whether a recommended adaptation is reasonable and practical, considering the age and condition of the property. The SSD has the ultimate legal obligation to make arrangements for the provision of the adaptation).

As the lead authorities for community care, it is essential that SSDs continue to monitor the processing of a DFG application. This would avoid unnecessary anxiety to disabled people who may be unaware of the progress of their grant application and the various stages reached.

An SSD must inform the grant applicant of its continuing responsibility, should a DFG be unavailable. This would reduce the chance of people from withdrawing their grant application, believing there is no alternative but to arrange the work themselves, or to continue to struggle without these essential adaptations or - as a last resort - to seek residential care.

Disabled people's concerns over Disabled Facilities Grants:

- * Delay in the Provision of Adaptations and Additional Facilities;
- **★** Delay in the Provision of an Occupational Therapy Assessment;
- * Inability to Meet Financial Contribution.

Delay in the Provision of Adaptations and Additional Facilities

Over half of the seven hundred complaints were due to delays in the provision of adaptations and additional facilities.

In shire areas social services are the responsibility of the County Council and housing is the responsibility of the District Council. In Metropolitan and London Borough areas, social services and housing are the responsibility of the same local authority.

Whether social services and housing responsibilities rest in the same authority or in different autonomous authorities, numerous Officers are involved, with no single person taking overall responsibility for coordinating the many different roles. This issue must be addressed within existing authorities and when setting up the new unitary authorities.

Mr and Mrs Cooper waited over three years for their home to be made accessible for Mr Cooper. The delay was because of the local authority's procedures for processing applications for adaptations and additional facilities. This was compounded by faulty building work, which had not been properly supervised. Overall, twenty-two local government officers were involved. It was left to Mr Cooper to discover what action was being taken and by whom.

The flow chart (Appendix B) illustrates the general steps a disabled person must take before adaptations and additional facilities are provided.

Mrs Parsons applied for adaptations to her home. An Occupational Therapy assessment was undertaken and the need for adaptations was identified. One month later, Mr and Mrs Parsons approached the occupational therapy team and were told that this assessment had not been "good enough" and the OT who had carried out the assessment had left the department. Mrs Parsons would therefore be allocated to a different OT, but a date for a reassessment could not be given.

On behalf of the Parsons, RADAR made an official complaint, which went to a review panel. The panel recommended that Mrs Parsons' needs be assessed within two weeks of the panel hearing. This recommendation was accepted by the Director of Social Services and a further assessment was carried out by an independent OT.

Four months later, adaptations had not been confirmed and the social services department was insisting on another OT assessment, by a member of its own staff, even though Mrs Parson had been informed that the SSD was supporting the initial recommendations of the independent OT.

Such a cumbersome bureaucratic system is of benefit to no one. It merely results in a waste of local authority resources and can be detrimental to the mental and physical well-being of disabled people and carers.

Delay in the Provision of an Occupational Therapy Assessment

Almost one fifth of the complaints related to delays in assessing the need for adaptations and additional facilities.

When Mr Green was discharged from hospital in January 1992, he was told that arrangements had been made for an Occupational Therapist assessment of his need for adaptations to his home. Two weeks later he contacted the social services department and was told that, as there was only one OT carrying out assessments, he had been placed on the waiting list.

Cont...

...cont'd

Mr Green approached RADAR in February 1993, as he was still waiting for an OT assessment. He explained that he was climbing the stairs on his hands and knees. When contacted, the social services department could not locate the original assessment referral. However, the Officer did confirm that there had been a waiting list for OT assessments and explained that extra staff had been recruited to reduce the list.

Another disabled person, Mrs Scott, asked for social services support in May 1991 but was not assessed until August 1993 - over two years later.

Inability to meet Financial Contribution

Almost one fifth of those people who had experienced difficulties in obtaining adaptations had been unable to afford their financial contribution towards the cost of the necessary works, as assessed under the DFG means test.

There is general agreement among local authorities, disability organisations and people who apply for DFGs that the means test is inequitable. The Government places great importance on the community supporting disabled people, acknowledging that most care is provided informally by family, friends and neighbours.

"Helping carers to maintain their valuable contributions to the spectrum of care is both right and a sound investment." (2)

The Government has an express commitment to community care:

"The Government is firmly committed to a policy of community care which enables such people to achieve their full potential."(2)

However, it is quite clear that the two principal government departments involved with Disabled Facilities Grants (the Department of Environment and the Department of Health) are at variance over this commitment. Under the Local Government and Housing Act 1989 the regulations which govern the means test provide for the

income and capital of the disabled person and any other household member with a legal interest in the property to be taken into account. Moreover, the regulations do not allow household costs, such as mortgage repayments or the extra costs incurred by individuals as a consequence of disability to be taken into account.

This contradiction in government policy, which imposes unnecessary additional anxiety on disabled people and carers, is morally unjust and must be rectified.

Mrs Jay was finding it increasingly difficult to climb the stairs. She requested an OT assessment and the need for downstairs bath and toilet was identified.

Mr and Mrs Jay's financial contribution towards any works was assessed at £13,000. However, because it was estimated that the work could be carried out for less than their financial contribution, ie. for £10,000, they were not eligible for grant assistance.

Mr and Mrs Jay had been informed that they could approach the social services department for assistance with their contribution under Section 2(e) of the CSDP Act. Initially, the department offered a deferred interest loan to be re-paid on the sale of the property. But once it was established that their property had fallen in value since they purchased it, the SSD withdrew the offer, as there was insufficient value in the property to repay the proposed loan.

Following considerable debate about the test of resources, the Government is contemplating whether in "specific circumstances" the income of the owner of the property, when s/he is not the disabled person, could be disregarded (11). This would improve the test. However, a more equitable means test would allow household expenditure and the extra costs of disability to be taken into account.

Furthermore, only the income and capital of the disabled person requiring the DFG (or the parents/guardian of the disabled person if under 16) should be assessed.

Before considering assisting people with their assessed financial contribution, some SSDs are insisting the applicant tries to secure a loan from a bank or building society. No account is taken of the extra cost the disabled person will incur as a requirement of taking out a commercial loan:

Mrs Young had been assessed as needing a stairlift and applied for a DFG. Following the means test, Mr and Mrs Young were informed that their financial contribution would be £1,200, which they did not have. Social services refused to help unless they were unable to secure a bank loan. Mr and Mrs Young did get a bank loan, but in addition to the repayment of capital and interest were required to take out insurance costing £30 per month.

In RADAR's experience, many disabled people are unaware of SSDs' continuing responsibilities under Section 2 and may withdraw their DFG grant applications. If the assessed needs of disabled people are to be met with minimum delay, RADAR considers it essential that adaptations and additional facilities be provided solely by social services departments. During the Project, discussions with Directors of Social Services indicate there was general support for a shift of administrative responsibility and finance from housing to social services.

If SSDs were to become the sole providers of adaptations and additional facilities under Section 2(e) of the CSDP Act, charges for the service could be made in the same way as for the other services listed in Section 2, in line with Section 17 of the Health and Social Services and Social Security Adjudications (HASSASSA) Act 1983. However, it must be noted that RADAR opposes on principle charges for services which local authorities have a statutory duty to provide.

Disabled People's Perspective of the Disabled Facilities Grant System

RADAR sought information on the level of grant assistance provided to the people who participated in the Project. Three hundred and fifty questionnaires were distributed at random (Appendix C). One hundred and five questionnaires were returned. These showed that 70 people had never applied for a Disabled Facilities Grant. Nevertheless, there were some interesting comments.

* A number of people stated that they had not known DFGs existed. - One person was unclear about eligibility, asking "do DFGs apply to mental disability (such as Alzheimer's) or only to physical disability".

- * Mr Abbot referred to the use of emotional blackmail by local authority staff. "If I had a stairlift costing thousands of pounds this would deny other disabled people things they need". Since then, he had fallen downstairs on at least three occasions.
- * Another person had experienced difficulties in obtaining a DFG application form through the social services department.
- * Mrs Bennett expressed discontent over the financial assessment. She "...
 refused to fill in the means test (because it was) too demanding...I asked
 for a grant towards altering my kitchen, but the forms sent were too much
 for me."
- * Mrs Crabtree stated that "...the reason for not applying was that my husband felt that the questions were far too probing with no regard for the expense already laid out or the expenses that are relevant to disability needs. The OT gave us no help with our questions, he said the only option was to fill the form in or pay ourselves...why will no one in authority discuss the implications with you before the form is submitted and give straight answers to simple questions? The time wasted over planning and the need for the commodities meant that we did not need more prolonged fruitless negotiations ... I do feel better, letting someone know how cross I felt about all the bureaucracy I met when I endeavoured to acquire the necessary facilities for my needs."
- * Mr and Mrs Fry were "... point blank refused ..." a DFG because of their savings. "We take it for granted to do without what we cannot buy. For twenty-three years we have coped. The biggest unfairness is that those who scrimp and save are penalised and expected to pay all".
- * Having been refused grant assistance, Mr Peters was forced to use "my life savings" to purchase a second-hand stair lift.
- * Miss Mann explained that she had "certain adaptations and I received a few items of equipment from social services after a long wait". However, she stressed that she was "... not being ungrateful ... (and did not) want to moan too much."

The New Disabled Facilities Grant Limit

There was no maximum limit on DFGs until 5 April 1993, when a limit of £50,000 was imposed (12). On 14 January 1994 this was reduced to £20,000 (13). RADAR will monitor the effects of this reduction. According to figures from the Department of Environment the average mandatory Disabled Facilities Grant is £4,200 (14). However, many of the people who contacted the Project Officers required works over £4,200 and some of the grant applications were in excess of the £20,000 limit.

The grant limit has restricted the work that can be considered for DFG approval and therefore discriminates against people with more severe disabilities who require more extensive and therefore more costly adaptations. If the average DFG is only £4,200 it is difficult to understand why a limit had to be introduced.

RECOMMENDATIONS

Local Government

- 1. Ensure that SSDs make suitable arrangements for the collection of information regarding the need for adaptations. Where there is a shortfall of resources to meet identified needs this information must be presented to the Department of Health and the Department of Environment so that they are aware of the shortfall local authorities face in meeting assessed needs and future funding must be adjusted accordingly.
- 2. Implement the legal duties of SSDs under Section 2 of the Chronically Sick and Disabled Persons Act and ensure staff are aware of and understand these duties. Provide staff training as necessary.
- 3. Review the procedure for considering DFG assistance, ie OT Services, financial assessment, technical services, formal application consideration, with the aim of eliminating delays and ensuring applicants are treated with dignity and respect.
- 4. Ensure that there is good communication and cooperation between all local government officers concerned with the provision of Disabled Facilities Grants.

5. Ensure that all staff involved are given training in disability awareness and disability legislation as it relates to the provision of adaptations and additional facilities. This training should be ongoing.

Central Government

- 1. The Department of Health and the Department of Environment should review the allocation of finance to local authorities; allocations should be based on the need for adaptations and special equipment.
- 2. That social services departments are given the sole legal responsibility for administering the provision of grant assistance for adaptations and additional facilities needed to secure a person's greater safety, comfort and convenience within the home.
- 3. If SSDs are given the sole responsibility for the provision of adaptations and additional facilities under Section 2 of the CSDP Act, any charges to be made should be in line with Section 17 of the Health and Social Services and Social Security Adjudications Act 1983.
- 4. If the DFG system remains with the Department of Environment, the regulations governing the means test should be amended to take into account household costs and the extra costs of disability. Furthermore, only the income and capital of the disabled person requiring the DFG (or parent/guardian of the disabled person if under 16) should be assessed.

2. SOCIAL SERVICES DEPARTMENTS IN OPERATION

Reorganisation

Most SSDs have reorganised during the last three years. Many variations around the purchaser/provider split have appeared. It is clear that workers in the departments are still coming to terms with the changes which have a direct effect on services.

"As there have been a number of reorganisations in the department over the last few months, it has proved almost impossible to identify the manager responsible for withdrawing the Family Aid Service" (Senior Manager, London Borough).

This illustrates the disruption caused by reorganisation and the lack of communication within the organisation.

Criteria

A questionnaire was sent to all Directors of Social Services (Appendix D) which asked if the authority had published criteria for service provision. Of the 53 who replied, 35 had published criteria, 5 had not, 5 replied that criteria were being considered and 8 did not answer the question (Table 4).

One authority replied:

"Not quite clear about the stage this department has reached about publication. It was decided to publish and plans have been made. Some already published and incorporated into the Joint Community Care Plan."

Budgets

Devolving budgets down to the level where decisions are taken concerning service provision may be commendable, but only if it does not hinder the decision-making process or compromise the decision-maker. A negative approach will perpetuate the

stance of "what services do we have that we can provide for this person?" instead of the positive approach of "what services does this person need?"

Splitting of budgets between services - children, mental health, disabled people and elderly people - can result in several meetings and case conferences being needed to agree where the finance will come from to meet the family's needs. When a disabled person has multiple disabilities and other members of the family also have needs, the situation can be complex and the process before decisions are made can be unnecessarily prolonged.

Following a formal complaint concerning a family with a disabled child the independent investigator recorded:

"They (the parents) struggled with the complexity of compartmentalisation of service provision within as well as outside the social services department. Understandably they could see no logic as to why particular departments provide particular services."

Mr Woods had a spinal injury following a road traffic accident. His wife had cancer, was receiving chemotherapy and had periodic spells in hospital. The couple had two children; the younger aged 13 was hyperactive and had learning difficulties. There were also marital difficulties. Individual needs were identified, but it was more difficult to get acceptance that the family as a unit also had needs. The allocation of resources became a major obstacle.

Attitudes

The attitude towards disabled people of local authority staff in all departments (social services, housing and environmental health) who are involved with services is one of the main problems disabled people face. The first contact with social services sets the tone of the future relationship between the disabled person and the SSD.

The individual a disabled person speaks to in social services represents and in effect is social services. People with disabilities feel that local authority staff treat them as a race apart, who, because of their disability, should not expect to live a normal, independent life. If they display anger they are told they have difficulty in accepting

their disability. It is essential for all local authority staff who have contact with disabled people to be aware of disability issues and to have ongoing disability awareness training. People must not be pigeon-holed. Each person is an individual with individual needs.

Mr Turner approached the local authority for assistance with the provision of accessible bathing facilities. Mr Turner informed RADAR that in a subsequent conversation the Housing Manager said "...his brother-in-law was really ill, not like me and that he had to pay for everything for him, not expecting it for free like I was." Mr Turner was very upset by the manager's attitude.

Much energy is expended giving reasons for services not being provided or explaining lengthy delays. A more positive approach must be made to the provision of services.

Some social services departments have published leaflets with slogans such as "We Want To Hear From You" and "Here to Help". Staff can implement these slogans by adopting a positive attitude to disabled peoples' needs - "What Do You Need?" "How Can We Help?"

Following a complaints review panel, a Director of Social Services wrote to Mr Day accepting the panel's recommendations "...as positive contributions to social services in helping us to improve the quality of our services to people with a disability. The difficulty for us will be ensuring that the culture of the organisation changes to bring about those improvements in attitudes that are so necessary".

Liaison between all the services that can work with disabled people is essential. The buck must not be passed to from one authority to another or from committee to committee.

Social services departments exist to provide support to the community. Treating people with dignity and respect is important. To be effective there must be a partnership between the disabled person and social services.

The response a disabled person receives on first contact with social services is

fundamental to the way his/her perceives the department. If the response is uncooperative or patronising, it will provoke resentment which will be difficult to overcome. As far as the disabled person is concerned, that contact is social services.

Designations

The titles "Social Worker" and "Occupational Therapist" are beginning to disappear and being replaced by the title of "Care Manager" or "Assessor". But what does an Assessor do? The following definitions of an assessor, if put into practice, would be encouraging to disabled people:

- "One who shares another's dignity" The Chamber 20th Century dictionary
- "A person who sits beside another" Oxford English Dictionary
- "A person who shares another's position" Oxford English Dictionary

In practice, the designation of "Assessor" gives no clue to the duties required of this role. Similarly, the term "Manager" means a person who is responsible for an organisation or a group of people. Local authorities should use designations which clearly convey the roles of their staff to the public.

Trust

There will be occasions when there is no rapport between a Social Worker, Occupational Therapist, the Care Manager and the disabled person. When this happens, the manager must be prepared to change the workers. Mutual trust between the assessor and the person being assessed is pivotal to an accurate assessment.

Age Range

In many authorities "younger disabled people" are in the age range of 18 years to 60 years. In other authorities, the upper limit is 65. No consideration is given to a person's functional age and when the upper age limit is reached, the person is moved

into the "elderly category" irrespective of their disability.

When one disabled woman reached the age of 60, she was transferred to a different part of the service and was reassessed. The main reason for the reassessment was that the cost of her service would in future come from a different budget.

RADAR heard from a social worker that a disabled woman who had attended a day centre for many years had been told she could no longer go there as she had reached 60 years of age.

Flexibility

The Government's White Paper, Caring for People, recognises the need for:

"Services that respond flexibly and sensitively to the needs of individuals and their carers."

Following considerable correspondence with social services and two meetings with Ms Taylor and social services staff, it was confirmed that she had a need for meals. Her special dietary requirements were acknowledged by social services. A few weeks after the second meeting a letter was received from the Domiciliary Care Manager stating:

"You requested a gluten-sugar-yeast-free diet which the mealon-wheels service has been unable to provide. Subsequent to this you requested assistance to help pay for your diet at (name of centre) and enclosed figures with costs. I have looked into this possibility and it is not possible to provide you with this subsidy".

But the centre could have provided the meals as Ms Taylor's diet required.

Not only was the authority inflexible, it was not fulfilling its legal obligation to ensure an assessed need was met.

3. ASSESSMENTS

A disabled person can request that a local authority assess his/her needs for any or all of the services listed in Section 2 of the 1970 Act. The local authority then has a duty to assess the need. Once an assessment has identified the need for one or more of the services listed in Section 2, the local authority has a duty to ensure the need is met.

Section 4 of the Disabled Persons (Services, Consultation and Representation) Act 1986 reinforced the duty upon SSDs to assess on request the needs of disabled people for any of the services listed in Section 2 of the CSDP Act 1970. The National Health Service and Community Care Act 1990 does not supersede Section 4 of the 1986 Act; in fact, Section 47 of the 1990 act makes specific reference to it and, by implication, to Section 2 of the 1970 Act.

During the initial contact with the local authority, it is not always clear what services a disabled person needs. This is because the disabled person does not know what services are available.

Mr Richards requested a list of services which he might be entitled to. The social worker said no such list was available, but offered to do a full assessment of his needs. Although the social worker's response was reasonable, Mr Richards felt he should have been given information on the services the SSD has a duty to provide.

It is not unusual for disabled people to understate what they can and cannot do. Perception and good communication skills on the part of social services staff are essential if an accurate assessment is to be carried out.

The disabled person should feel he/she has a right to contact social services and a right to the services needed. The Project Officers found that many of the disabled people and carers who have contacted them had had an unsatisfactory experience beginning with their first contact with social services.

Most local authorities have struggled to get to grips with drawing up a comprehensive assessment form. The Project Officers found these varied from one of over 50 pages to one of 6 pages.

Assessment forms usually start with a section on functional assessment, for example, dressing without help. Only at the end of the form is the all important question asked, "What do you need to live at home conveniently, comfortably and safely?" and of the carer, "What assistance do you need to continue to provide care"?

An assessment should not be a snapshot of needs at "a moment in time". Not only do people's lives and needs change over time, but with some disabilities related needs may change throughout the day, and the assessment process must recognise this.

There must be trust between the assessor and the person having the assessment. The disabled person and his/her carer should be fully involved throughout the assessment. So often unnecessary problems arise because the disabled person is asked to prove he/she is unable to undertake tasks.

Mrs Jones applied for adaptations to her kitchen. She was unable to bend down without losing her balance and had burnt herself on several occasions when getting things out of the oven. In addition, she was unable to extend her left arm, which made it difficult for her to reach things from the cupboards. She requested a split level oven and alterations to the existing kitchen units.

Mrs Jones was asked to "perform" on a number of occasions, before the social services department eventually agreed that the requested adaptations were necessary. This was extremely distressing for her and she would have given in, had she not received support from RADAR and local campaigners.

The Project Officers found that when people are not fully involved in their assessment, they invariably disagreed with the assessor's interpretation of their identified needs. In such circumstances some SSDs agreed to a reassessment. However, repeated assessments can be distressing.

Following an assessment, a care plan should be written and agreed with the disabled person. The care plan should include the services that will be provided by the local authority, the name of the individual who will take action to make the provision, and who to contact if there are any difficulties.

However, at the assessment the implications of the care plan may not be fully understood. It is therefore important that there follows a "cooling off" period, for example two weeks, during which the disabled person can ask for clarification or withdraw from the care plan, a similar arrangement to that which exists when taking up a hire purchase agreement. Should the disabled person question his/her care plan a further visit should be made to answer the concerns expressed.

A care plan is not cast in stone but should be mutually acceptable, flexible and above all should meet the disabled person's needs. If there are disagreements, however slight, it is essential the assessor alerts the responsible manager to the disabled person's concerns. If this stage is reached the manager should actively consider whether the concerns can be resolved or whether a complaint should be logged.

Of the 700 complaints received by the Project Officers, 15% related to difficulties in obtaining an assessment. As promised in RADAR's interim report, further information was collected on this issue through the questionnaire which was sent to all Directors of Social Services in England and Wales (Appendix D).

From the information received it was impossible to draw any meaningful conclusions. In one local authority there were 251 Social Worker posts, 157 of which were allocated to work with disabled people. In another, there were 417 social worker posts, with only four working with disabled people.

Over two thirds (38) of the 53 responding local authorities had few vacancies for Occupational Therapists. It would appear that either Directors of Social Services have insufficient resources - established Social Worker and Occupational Therapist posts - or the existing resources are not allocated to supporting disabled people.

Section 6(6) of the Local Government Social Services Act 1970 (16) states:

"A local authority which has appointed, or concurred in the appointment of, a director of social services, shall secure the provision of adequate staff for assisting him in the exercise of his functions."

Directors should report to the Social Services Committee, on a regular basis, the length of their waiting list for assessments and the period of time people are expected to wait for an assessment.

RECOMMENDATIONS

Local Government

- 1. A copy of the assessment must be given to the disabled person.
- 2. A copy of the care plan agreed with the disabled person must be given to him/her.
- 3. A "cooling off" period must be part of the care plan.
- 4. Assessment forms should be concise and simple to understand.
- 5. The line manager (supervisor) should sign the completed assessment form.
- 6. Directors of Social Services should report on a regular basis to the Social Services Committee details of the waiting list and waiting times for assessments of need.

4. LEGAL AND FINANCIAL RESPONSIBILITIES

Section 1 of the Chronically Sick and Disabled Persons Act requires each local authority to maintain a register of disabled people in its area. However, it is not a requirement that disabled people be registered to be eligible for social services.

Little, if any, attempt has been made by SSDs to collect information about the services required to meet disabled people's assessed needs. Collection of information has been done mainly to satisfy central government's demand for statistical information.

Consequently budgets have been based on an estimate of services SSDs may be required to provide during the fiscal year and not on factual information. Subsequent budgets have been influenced by the take-up of the previous year's budget which may have been affected by staff vacancies and a consequently reduced number of assessments carried out with fewer needs identified and services provided as a result.

The collection of information about disabled people must serve a useful purpose: identifying the services people need and the shortfall. The information should be presented to elected members annually to coincide with draft budgets. It is evident that this is not being done.

Of the 53 local authorities who responded to the questionnaire which was sent to Directors of Social Services (Appendix D) 65% recorded unmet need, but of these, only 19% presented the information to the Social Services Committee at the 1994/1995 budget round.

Historically, budgets for domiciliary services have been the first to be cut when there has been a need to reduce an authority's overall spending. In order that due care and consideration is given to the authority's legal responsibilities Social Services Committee should have information on unmet needs when considering budget proposals.

There is no single comprehensive Act which sets out the powers and duties of local authorities and social services departments. The principal Acts relating to SSDs legal responsibilities are:-

Duty to Assess:

Chronically Sick and Disabled Persons Act 1970
Disabled Persons (Services, Consultation and Representation) Act 1986
National Health Service and Community Care Act 1990

Duty to Provide Services:

National Assistance Act 1948 (17) Chronically Sick and Disabled Persons Act 1970 National Health Service Act 1977 (18) - Schedule 8

In addition to the principal Acts, the duties and responsibilities of the local authorities are set out in Department of Health circulars, directions and guidance notes. The Local Government and Housing Act 1989 and accompanying policy guidance relate to Disabled Facilities Grants.

The Project continued to find that there was a lack of knowledge on the part of social services staff of disability legislation and the local authority's statutory duties. A student social worker on placement in a London Borough asked the Project "what is Section 2?" Such lack of knowledge was not confined to students. Senior officers often confused internal policies with the local authority's legal responsibilities.

When Mr Long clearly asked under which legislation services to his daughter were being provided, he did not get a clear answer.

An often quoted statement when a service was not provided or an assessment not made is "IT IS NOT COUNCIL POLICY" and "HE DID NOT MEET THE CRITERIA". Yet when requests were made for a copy of the Council's policy and criteria, it was often not possible for documentary evidence to be produced. It was apparent that such policies and criteria were often based on "handed-down information".

The following information was provided during the course of an investigation into a formal complaint:

The Social Worker gave information orally. He had acquired considerable expertise and knowledge over the time he had been in post but there was no formal means whereby clients, the public, new staff and elected members could be properly informed.

Similarly there was ample evidence that elected members were unaware of the local authority's and therefore their legal responsibilities.

RECOMMENDATIONS

Local Government

- 1. Ensure existing staff and elected members are fully aware of all the relevant legislation and the local authority's legal responsibilities.
- 2. Provide ongoing training for newly recruited staff and newly elected members to brief them on the local authority's legal responsibilities.
- 3. Directors of Social Services should ensure that within their region college curricula for training of social workers includes sufficient time to ensure that future care managers/assessors have a good understanding of disability issues and legislation.

Central Government

1. Consolidate the legislation relating to services for disabled people for clarity and ease of reference.

5. SOCIAL SERVICES COMPLAINTS PROCEDURE

Since 1 April 1991, social services departments have been required, under Section 50 of the NHS and Community Care Act 1990, to have a formal complaints procedure in place. This "...should be uncomplicated, accessible to those who might wish to use (it) and understood by all members of staff" (19).

There are three stages to this procedure:

- * service users should be encouraged to discuss any problems or misunderstandings with the member of staff providing the service, or if this is inappropriate, with the relevant Senior Officer;
- * if the matter is not resolved, the complaints procedure must be explained to the service user. At the next stage the complaint must be made in writing; the SSD must consider and respond to the complaint, in writing, within 28 days of its receipt, or no later than three months. If the complaint is not resolved at the second stage, the complainant must be informed of his/her right to a review;
- * the complainant must request a review panel in writing within 28 days of receipt of the SSD's reply and the department has 28 days to convene the panel. Following the review, the panel has 24 hours to record its recommendations. Copies must be sent to the Director of Social Services, the complainant and other interested parties. The director then has 28 days to decide what action to take and to convey this in writing to the complainant and any other relevant person.

If the complaint is perceived as local authority maladministration then the complainant can contact the Ombudsman to request an investigation. This action will not affect the complainant's right to use the social services official complaints procedure. If the complaint is not resolved through the complaints procedure, the complainant can refer the local authority to the Secretary of State for Health with a request that s/he makes enquiries of the authority.

Mr Pearce's complaint which was heard by a review panel contained an item that the complaints procedure had not been discussed with him. The panel recorded:

"The Panel is aware that information (The Complaints Procedure) is available for people who may wish to complain. However, this information is not always easily accessible."

One authority's leaflet on making a complaint proclaims:

"We have a clear procedure, so that your complaints can be dealt with thoroughly, fairly, quickly and in strict confidence."

The authority hoped complaints could be resolved at stage one; however it explained:

"For the problems that cannot be sorted out to your satisfaction, the complaint must be put in writing and passed to the Complaints Officer who will arrange for it to be looked into. It may be that the complaint becomes formally registered, when a full investigation will take place and the matter considered with 28 days"

When RADAR wrote making a complaint on behalf of Mr Johns, the authority, in consultation with its designated Complaints Officer, took the view that RADAR's letter constituted a "Notifiable Complaint" - a stage not mentioned in the complaints leaflet. All SSDs with which RADAR had contact had a complaints procedure, indicating that social services wished to resolve complaints informally at the first stage. Directors were asked if complaints were recorded at this stage; 20% said they were not and 80% said they were.

Comments from authorities that did record complaints at the first stage included:

- "They are recorded when received by Complaints Officer and Area Officers".
- "Some are, many are not".
- "Most are but not all e.g., if resolved with local manager".

"Only at manager level".

"First stage complaints are basically initial enquiries, usually a note is made in case an enquirer wishes to make a formal complaint at a later stage".

RADAR considers all complaints should be adequately recorded, giving a clear indication when the complaint was resolved to the complainant's satisfaction.

Whilst most complaints made with assistance from RADAR were settled before they reached the third stage of the formal complaints procedure, 20 were pursued through to the review panel stage, each with a different authority.

Investigations were undertaken at the second stage of the procedure with varying degrees of success. An investigation should be an impartial look at the complaint involving all the social services officers concerned, including an examination of the correspondence and other written records together with an interview with the complainant and carer.

Some investigators saw their role as making a reassessment and informing the disabled person of their decision. The investigator's report should make recommendations but not decisions. A copy should be sent to the complainant, the carer and/or the advocate.

The investigator's report should then be sent to a senior officer of the department who has the authority to make a decision on the action social services will take. Some investigations did not involve interviewing the complainant. In one case the investigator was only asked to look into part of the complaint.

All complaints procedures seen by RADAR indicated that complaints could be made by someone on the complainant's behalf. However, how such complaints were received varied considerably from authority to authority. There is a reluctance to complain. It can be unhelpful, sometimes intimidating, for social services to seek confirmation from the disabled person that they do wish to complain before embarking on an investigation of the complaint.

A letter to RADAR from a Complaints Officer stated:

"The complaints procedure does allow for complaints to be received on behalf of a disabled person. However it is equally important to consult the person concerned directly."

The letter sent to the complainant said:

"This is to confirm that full details of the (complaint) and your preferred outcome have been received from (RADAR). The matter will be registered when you have met the investigating officer to confirm all of the above".

The review panels attended by the Project Officers were conducted impartially and sensitively and in all but two cases the complainant was happy with the recommendations of the panel.

All panels had an independent person as the appointed Chairperson. However, two of the hearings were "chaired" by another member of the panel. Although this was not detrimental to the disabled person, it illustrated the importance of training for all members of a review panel. RADAR considers it is essential that the Chairperson of a review panel is independent, not an employee or an elected member of the Council, and that s/he has knowledge of the local authority's legal responsibilities.

In some authorities, there was uncertainty over the review panel's role. Two authorities understood the role was to review the way the complaint had been investigated.

An Assistant Director in one authority wrote:

"The panel's purpose is to review the way in which the department investigated your complaint and attempt to solve any outstanding problems."

The Social Services Inspectorate in their report of inspection of complaints procedures stated:

"They (review panels) should be concerned primarily with considering whether the action or decision being complained about was appropriate and whether it still is appropriate. Considering only whether the procedures have been followed correctly seems not to accord with the intention of the Department of Health guidance." (20)

Compensation

At no time during the complaint process was the question of compensation raised by any local authority. Neither the complainants nor the advocates where asked for details of expenditure they had incurred attending the review panel. At one review RADAR asked for compensation for the disabled person. In their report, the panel responded:

"In response to the request made for compensation the panel recognise the stress that may have been caused by this whole process but feel they must leave it to the Director of Social Services to consider whether compensation, and of what type, would be appropriate."

The Director decided:

"Whilst acknowledging as does the panel the stress that may have been caused to you in pursuing your complaint, it is not felt that this provides sufficient grounds for considering monetary compensation".

Although complainants are not legally entitled to compensation, if central and local government are serious in their wish to provide customer satisfaction and welcome complaints from people who are dissatisfied with the statutory services they are receiving, they must treat complaints seriously and consider to providing compensation.

All complainants incurred expenses, travelling, telephone and postage. A considerable amount of time was spent by the disabled people and RADAR in pursuing complaints to the review panel stage. The Project Officers visited the disabled person at home to clarify information and gain a visual picture of the difficulties before attending a review panel. In addition to the written complaint, the Project Officers made a verbal presentation at each review panel.

Director's Decision

RADAR considers that the authority's decision on the review panel's recommendations should be signed and therefore owned by the Director of Social Services.

In one authority the Complaints Officer:

Convened the review panel.

Transported the complainant and advocate from the complainant's home to the meeting.

Attended and minuted the meeting and advised the panel.

Conveyed the panel's recommendations to the Director of Social Services and the complainant.

Wrote and signed the authority's decision on the panel's recommendations.

Justice was not seen to be done!

Another option may be to seek legal advice regarding the possibility of applying for a Judicial Review, in the High Court, of the local authority's decision.

The Project Officers sought a Barrister's opinion on one complaint:

Mr Howe was provided with a careline facility, which would enable him to contact someone by pressing a button. This would only be used in an emergency and was directed through a central control, which operated on a 24 hour basis, for which there was a weekly monitoring fee.

The local authority accepted that Mr Howe needed the careline, but would not accept responsibility for the monitoring fee. The Project Officers challenged the SSD's decision and made a formal complaint in

Cont..

October 1993. The local authority sought the opinion of Counsel, who advised that the authority had fulfilled its legal responsibilities by the provision of the alarm. Counsel also advised the authority that there was no legal reason why they should not meet the monitoring fee.

In the expectation that their legal advice would not be overturned, the local authority refused a request for the complaint to be heard by a review panel.

Through the Public Law Project, RADAR sought legal advice on this case on two counts! Firstly, that the authority had refused a request for the complaints to be heard by a review panel; and secondly, that the authority refused to pay the monitoring charge. The legal opinion given to RADAR was that the authority was acting unlawfully on both counts.

The Public Law Project prepared papers to seek leave for a Judicial Review. The day before the papers were to be lodged, the authority agreed that the complaint could be heard by a review panel. (Note: the case is ongoing).

To reach the stage of seeking leave for a Judicial Review takes a considerable amount of time and, perhaps more important, energy. Many disabled people find coping with everyday life physically and mentally draining. For these people, the additional effort required to make a complaint and see it through the various stages is just too much. This illustrates the need for advocacy services on a national basis.

Advocacy

Definitions of an advocate:

Intermediary, speaker, motivator, adviser, counsellor, negotiator (Roget's Thesaurus).

One who pleads the cause of any other (Oxford English Dictionary).

The Director of one of the authorities with which RADAR pursued a complaint to the review panel stage stated in a letter to the Project Officer:

"In this particular case I was not clear whether you were acting as an advocate or as a friend and adviser."

To avoid any confusion, it is crucial for key words to be used when making a complaint, such as "advocate" and "official complaint".

As stated, the majority of complaints received by the Project Officers were resolved at the first or second stage of the complaints procedure. The advantage of having access to an advocate was noted and welcomed by the complainant and local authority staff, most of whom were very supportive of RADAR's involvement.

In their role as advocate, the Project Officers had to be conscious of the potential "to take over". An advocate must support, advise and motivate the complainant, not make the complaint his own. Moreover, it is important to remember that everyone is unique, with different needs and different capabilities. Some people required more support than others. Some **thought** they needed a high level of support, based on their previous experience with the local authority. However, with advice, information and support, many were able to pursue their complaints themselves, using the Project Officers as sounding-boards.

RECOMMENDATIONS

Local Government

All complaints should be recorded at the first stage of the complaints procedure.

Resources should be made available to support local voluntary organisations to enable them to develop an independent advocacy service.

Central Government

Sections 1, 2, and 3 of the Disabled Persons (Services, Consultation and Representation) Act 1986 should be brought into force in full and without delay.

THE WAY AHEAD

Building on the experience of the Section 2 project, RADAR plans to establish a Community Care Unit to carry forward this essential work.

The majority of disabled people wish to live in their own homes and wish to participate in their communities. This is what community care means. It is a cost-effective way for statutory authorities to meet disabled people's needs.

However, during the project it became clear that statutory authorities are not clear about their legal responsibilities towards disabled people. Equally, many staff in local authorities have little understanding of disability and what it means to individuals.

The purpose of the Unit at RADAR will be to enable disabled people to live independently in the community by assisting them in obtaining the services and housing to which they are legally entitled.

The Unit will: (1) produce packs and provide training for service providers, disability organisations and disabled people; (2) coordinate the establishment/development of advice, support and advocacy services; investigate the effects of the limit on Disabled Facilities Grants; and monitor community care policies and practices and promote good policy and practice.

RADAR and the Association of Directors of Social Services Disability Committee are working together to produce a good practice guide for Social Services.

SUMMARY OF RECOMMENDATIONS

LOCAL GOVERNMENT

Section 1 (a): Provision of Sources: Practical Assistance in the Home

- * Provide written confirmation of agreed areas of need and details of the services to be provided to meet these needs.
- * Provide advance notice of any change in services and make alternate arrangements when a regular home care assistant is on annual leave/sick leave.
- * Rescind policies which state a cleaning-only service is not provided.
- * Take into account the full costs of disability when assessing disabled people's ability to pay for services.
- * Recognise that individual circumstances should be the principal concern when timing an assessment of needs and providing services to meet identified needs. Lengthy delays can increase service needs and should be avoided.

Section 1 (b): Provision of Services: Adaptations and Additional Facilities

- * Social services departments should make arrangements for collecting information on the need for adaptations. If there is a shortfall of resources to meet identified needs, this information should be given to the Department of Health and the Department of Environment so that they are aware of the shortfall and so that future funding can be adjusted accordingly.
- * All social services staff must be aware of their duties under Section 2 of the Chronically Sick and Disabled Persons Act 1970. Training to ensure this should be provided.

- * Procedures for considering Disabled Facilities Grants (DFG) (ie OT services, financial assessments, technical services, formal applications) should be reviewed with the aim of eliminating delays and ensuring applicants are treated with dignity and respect.
- * There must be good communication and cooperation between all Local government officers concerned with the provision of DFGs.
- * Social services staff involved in the provision of adaptations and related facilities should be given disability awareness training. This training should be on-going.

Section 3: Assessments

- * Assessment forms should be concise and simple to understand.
- * The line manager (supervisor) should sign the completed assessment form and a copy must be given to the disabled person.
- * A cooling off period must be part of the care plan to ensure that the disabled person can fully consider all aspects of the care plan.
- * Directors of Social Services should report on a regular basis to the Social Services Committee details of the waiting list and waiting times for assessments of need.

Section 4: Legal and Financial Responsibilities

- * All social services staff and elected members should be fully aware of all relevant legislation and the local authority's legal responsibilities under it.
- * There should be ongoing training for staff and elected members on the local authority's legal responsibilities.
- * Directors of Social Services should ensure that college curricula within their regions for training of Social Workers achieve a good understanding of disability issues and the relevant legislation.

Section 5: Social Services Complaint Procedure

- * Ensure complaints are formally recorded at the first stage of the complaints procedure.
- * Resources should be made available to enable local voluntary organisations to develop an independent advocacy service.

CENTRAL GOVERNMENT

Section 1 (a): Provision of Services: Practical Assistance in the Home

- * Inform local authorities that Attendance Allowance or Disability Living Allowance (care component) should not be taken into account when setting charges.
- * Inform local authorities that it is unlawful to refuse to assess for any of the services listed under Section 2 of the CSDP Act 1970 and once a need has been identified that it is unlawful to refuse to make arrangements for the provision for assistance (including cleaning) to meet that need.
- * Bring into force Section 3 of the Disabled Persons (Services, Consultation and Presentation) Act 1986.

Section 1 (b): Provision of Services: Adaptations and Additional Facilities

- * The Department of Health and the Department of Environment should undertake a review of the allocation of finance to local authorities to ensure that adequate resources are available to meet needs for adaptations and special equipment.
- * Social services departments should be given the sole legal responsibility for administering the provision of grant assistance for adaptations and additional facilities needed to secure a disabled person's greater safety, comfort and convenience within the home.

- * If social services departments are given the sole responsibility for the provision of adaptations and additional facilities under Section 2 of the CSDP Act, any charges to be made should be in line with Section 17 of the Health and Social Services and Social Security Adjudication Act 1983.
- * If the DFG system remains with the Department of the Environment the regulations governing the means test should be amended to take into account household costs and the extra costs of disability. Only the income and capital of the disabled person requiring the DFG (or parents/guardian if the disabled persons is under 16) should be assessed.

Section 4: Legal and Financial Responsibilities

* Legislation relating to services for disabled people should be consolidated for clarity and ease of reference.

Section 5: Social Services Complaints Procedure

* Sections 1, 2 and 3 of the Disabled Persons (Services Consultation and Representations) Act 1986 should be brought into force in full and with out delay.

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- 14. Housing and Construction Statistics for Great Britain. March quarter 1994, Part II. HMSO.
- 15. National Health Service and Community Care Act 1990.
- 16. Local Authority Social Services Act 1970.
- 17. National Assistance Act 1948.
- 18. National Health Service Act 1977.
- 19. Department of Health. Community Care in the Next Decade and Beyond. Policy Guidance 1990. HMSO.
- 20. Progress on the Right to Complain. Monitoring Social Services Complaints Procedures 1992/1993. Social Services Inspectorate 1993.

TABLE A

SUMMARY OF COMPLAINTS RECEIVED

Number of people who contacted RADAR and as a result of which action was taken involving liaison with local authority	385	55%
Number of people who contacted RADAR, completed questionnaire, but only required advice and guidance	112	16%
Number of people who contacted RADAR but did not followup complaint and did not complete questionnaire	168	24%
Number of people who contacted RADAR requiring advice and guidance who did not complete questionnaire	35	5%
	700	100%

TABLE B

NATURE OF COMPLAINT

	%
Difficulty obtaining assessment	15
Disagreed with assessment	7
Service not provided (lack of staff, no budget provisions, budget already spent)	3
Service withdrawn/reduced by local authority	12
Service inadequate or unsuitable	25
Delay in provision of service	20
Housing unsuitable	5
Required to pay for service	7
Other	6
	100

This table is based on an analysis of 497 completed questionnaires.

TABLE C

OUTCOME OF COMPLAINT

182
23
46
12
54
68
385

This table is based on an analysis of 385 completed questionnaires involving liaison with local authorities.

TABLE D

NATURE OF DISABILITY

Alzheimer's Disease	6
Amputees	17
Arthritis	59
Back Problems	2
Brittle Bones	_
Cerebral Palsy	24
Cystic Fibrosis	
Diabetes	2
Emphysema	3
Epilepsy	6
Head Injuries	4
Hearing Impairment	•
Heart Disease	12
HIV/AIDS	
Learning Difficulties	19
Mental Health	4
Motor Neurone Disease	5
Multiple Disability	116
Muscular Dystrophy	17
Multiple Sclerosis	47
Parkinson's Disease	1
Polio	24
Spina Bifida and Hydrocephalus	7
Spinal Injuries	24
Stroke	16
Tetraplegic/Paraplegic	14
Visual Impairment	15
Other	53
Total	497

This table is based on an analysis of 497 completed questionnaires.

TABLE E

AGE RANGE OF PEOPLE SUBJECT TO COMPLAINT

Age range	<u>%</u>
0 - 9	2
10 - 19	6
20 - 29	5
30 - 39	10
40 - 49	16
50 - 59	16
60 - 69	11
70 - 79	10
80 - 89	6
90 - 99	2
Not known	16

TABLE F

WHERE PEOPLE LIVED

%
3
19
2.
31
38
1
6
100%

These tables are based on an analysis of 497 completed questionnaires.

APPENDIX A

Suggested Contract Between Social Services and Disabled Person

An assessment has identified that you have a need for the services listed below which the authority has a statutory duty to provide.

Under Section 17 of the Health and Social Services and Social Security Adjudications Act 1983, the local authority has the power to make a charge for these services. The charges should be reasonable and the user should have the ability to pay.

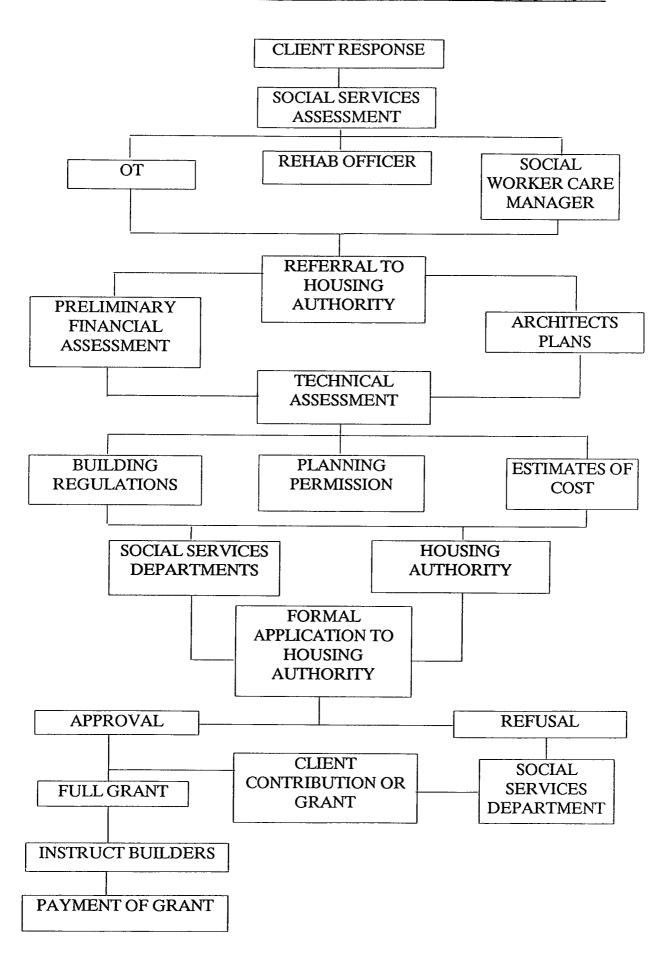
In order that we can assess what is reasonable for you to pay, we need details of your income and expenditure. Under expenditure allowances will be made of the additional costs you incur as a result of your disability eg window cleaning, grass cutting.

If you do not wish to provide financial information or do not pay the amount you have been assessed to pay, the authority may take legal action to recover this as a debt. Such action would be through the civil courts and would not mean you would have a criminal record. Even if you do not pay what you have been asked to the authority will continue to provide the service. It would be unlawful for us to do otherwise.

The services the assessment has identified you need which will be provided by the local authority are:

signed	•
Position	
Contact Telephone No	•
Date	•

DISABLED FACILITIES GRANT - APPLICATION PROCEDURE



n c	
Ret	no
1/01	1111.

DISABLED PEOPLE HAVE RIGHTS

<u>RADAR</u>

<u>Disabled Facilities Grants</u>
1. Have you ever applied for a Disabled Facilities Grant (DFG)? (Tick as appropriate).
YES (go to question 2)
NO (Please return questionnnaire)
2. If yes, state the estimated/actual cost of the work required as necessary and appropriate for meeting your needs.
•••••••••••••••••••••••••••••••••••••••
3. Following the means test, how much of this cost are/were you responsible for financing?
4. You may be aware that the DFG means test fails to take account of household costs. If you have approached the social services department for top-up assistance/a hardship grant to assist you with your financial contribution, how much has been approved/provided?
5. What was the length of time between:
a) the date you first requested assistance with the provision of adaptations and/or special equipment and the date of the assessment of your need for this assistance?
b) the date of the assessment of your need for his assistance and the completion of the work?
РТО

	nts (ie. to make the property fit for human habitation)
. If renovation he Disabled Fac	n work is/was required before the local authority would give approval for cilities Grant work:
) What is /was	s the estimated/actual cost of this work?
Are/were yo	ou required to make a financial contribution? If so, how much was your
***************************************	***************************************

APPENDIX D

In October 1993 all Directors of Social Services in England and Wales were sent a copy of the project's interim report together with a questionnaire (Appendix D). The project officers are grateful to the 53 Directors who arranged for the questionnaire to be completed.

County Councils

Avon

Berkshire Bury

Bedfordshire
Buckinghamshire
Cleveland
Clwyd
Cumbria
Dudley
Kirklees
Knowsley
Leeds
Liverpool

Dyfed Newcastle

Essex Newcastle
Gloucestershire North Tyneside

Gwent Oldham
Hereford & Worcester Rotherham
Hertfordshire St Helens

Isle of Wight Sheffield

Kent South Tyneside
Lancashire Stockport
Mid Glamorgan Wirral

Norfolk Wolverhampton

North Yorkshire

Powys London Authorities

Somerset

Suffolk
Surrey
Croydon
Warwickshire
Ealing

West Sussex
Wiltshire
Hackney

Willishire Hammersmith

Harrow

Metropolitan Authorities Lewisham

Newham

Bolton Redbridge

APPENDIX D

Chronically Sick and Disabled Persons Act 1970 - Section 2 -

Provision of Welfare Services

Loca	al Authority	•••••
Dire	ctor of Social Services	
Con	tact in Department	
1.	HAS YOUR DEPARTMENT BEEN RESTRUCTURED SINCE THE 1 JANUARY 1991?	YES/NO
2.	IS THE DEPARTMENT SPLIT INTO PROVIDER/PURCHASER STREAMS?	YES/NO

SOCIAL WORKER POSTS

- 3. NUMBER OF FULL-TIME EQUIVALENT FULL TIME SOCIAL WORKER POSTS IN THE DEPARTMENT?
- 4. NUMBER OF FULL-TIME EQUIVALENT SOCIAL WORKER POSTS WITH ADULT DISABLED PEOPLE?
- 5. NUMBER OF FULL-TIME EQUIVALENT SOCIAL WORKERS IN POST WORKING WITH ADULT DISABLED PEOPLE?

OCCUPATIONAL THERAPY POSTS

- 6. NUMBER OF FULL TIME EQUIVALENT QUALIFIED OCCUPATIONAL THERAPY POSTS ESTABLISHED?
- 7. NUMBER OF FULL TIME EQUIVALENT POSTS CURRENTLY VACANT?
- 8. NUMBER OF FULL TIME STATE REGISTERED OCCUPATIONAL THERAPISTS CURRENTLY EMPLOYED?
- 9. NUMBER OF STATE REGISTERED OCCUPATIONAL THERAPISTS OCCUPYING MANAGERIAL POSTS WHICH ARE NOT DIRECTLY OCCUPATIONAL THERAPY SERVICE?

- 10. NUMBER OF FULL TIME EQUIVALENT OCCUPATIONAL THERAPY ASSISTANT POSTS ESTABLISHED?
- 11. NUMBER OF FULL TIME OCCUPATIONAL THERAPY ASSISTANT POSTS CURRENTLY VACANT?
- 12. NUMBER OF OCCUPATIONAL THERAPY TRAINEE POSTS ESTABLISHED?

ASSESSMENTS

- 13. WHICH STAFF UNDERTAKE ASSESSMENTS?
- 14. IF OCCUPATIONAL THERAPISTS ARE NOT DIRECTLY EMPLOYED BY THE LOCAL AUTHORITY, WHO UNDERTAKES THE ASSESSMENTS FOR SPECIAL EQUIPMENT/ADAPTATIONS?
- 15. DO YOU HAVE DIFFERENT TYPES OF ASSESSMENTS?

YES/NO

16. IF YES, PLEASE ATTACH A DESCRIPTION OF THE TYPES OF ASSESSMENT.

REFERRALS

- 17. DO YOU HAVE A PUBLISHED CRITERIA FOR ACTIONING REFERRALS? YES/NO
- 18. IF YES, PLEASE ATTACH A COPY.
- 19. DO YOU KEEP A WAITING LIST FOR ACTIONING REFERRALS? YES/NO
- 20. IS THE WAITING LIST REVIEWED?

WEEKLY	YES/NO
MONTHLY	YES/NO
NOT REVIEWED	YES/NO

SERVICE PROVISION

- 21. DO YOU HAVE A PUBLISHED CRITERIA FOR THE SERVICES YOU PROVIDE?
- 22. IF YES, PLEASE ATTACH A COPY.

23. DO YOU HAVE A WAITING LIST FOR SERVICES?

COMPLAINTS

24. DO YOU HAVE A COMPLAINTS PROCEDURE?

YES/NO

- 25. IF YES, PLEASE ATTACH A COPY.
- 26. ARE FIRST STAGE COMPLAINTS RECORDED?
- 27. HOW MANY COMPLAINTS HAVE BEEN HEARD BY THE REVIEW PANEL?
- 28. HAS A REPORT BEEN PRESENTED TO SOCIAL SERVICES COMMITTEE?
- 29. IF YES, PLASE ATTACH A COPY.
- 30. IF NO, HOW MANY COMPLAINTS HAVE BEEN RECEIVED AND ACTIONED AT FIRST STAGE
 SECOND STAGE
- 31. IS UNMET NEED RECORDED.

YES/NO

- 32. IF YES, WAS THE INFORMATION PRESENTED TO COMMITTEE IN THIS YEARS BUDGET ROUND.
- 33. <u>CHARGES</u>

PLEASE ATTACH A COPY OF YOUR AUTHORITY'S CHARGING POLICY.

NOTE

STATE REGISTERED OCCUPATIONAL THERAPIST WHO ARE EMPLOYED TO DISCHARGE THE LOCAL AUTHORITY'S DUTIES UNDER CSDP ACT.

Questionnaire (Appendix D) sent to all Directors of Social Services and the Number of Returns

TABLE 1

	Questionnaires Sent	Questionnaires Returned		
County Councils	47	26		
County Councils London Authorities	32	9		
Metropolitan Authorities	36	18		

Does the Authority record unmet needs and if so was the information presented to Social Services Committee during the 1994/5 budget round?

TABLE 2

	Needs Recorded			Social Services Committee Informed			
	Yes	No	Not Known	Yes	Yes No		
County Councils	17	7	2	4	16	6	
London Authorities	5	2	2	1	7	1	
Metropolitan Authorities	9	7	2	1	15	2	

Does the Authority have Published Criteria for Actioning of Referrals?

TABLE 3

	Yes	No	Not Known
County Council	22	3	1
London Authorities	7	2	Nil
Metropolitan Authorities	9	2	7

Does the Authority have Published Criteria for Service Provision?

TABLE 4

	Yes	No	Not Known	Being Considered
	20			
County Council	20	3	-	3
London Authorities	7	1	1	-
Metropolitan	8	1	7	2

Complaints

Directors were asked if their authority had a complaints procedure, if complaints were recorded at the first stage and if a report on complaints had been made to the Social Services Committee.

TABLE 5

	Complaint procedure held		Complaints recorded at first stage			Report presented to Social Services Committee		
	Yes	No	Yes	No	Not Known	Yes	No	Not Known
County Council	26	ı	24	2	1	25	1	-
London Borough	9	1	4	5	-	6	3	-
Metropolitan	18	1	13	4	1	15	1	2

APPENDIX E

List of Local Authorities which the Project Officers contacted Regarding Individual Complaints

County Councils (All 47)

AVON HUMBERSIDE BEDFORDSHIRE ISLE OF WIGHT

BERKSHIRE KENT

BUCKINGHAMSHIRE

CAMBRIDGESHIRE

CHESHIRE

CLEVELAND

LANCASHIRE

LEICESTERSHIRE

LINCOLNSHIRE

MID GLAMORGAN

CLWYD NORFOLK

CORNWALL NORTHAMPTONSHIRE
CUMBRIA NORTH YORKSHIRE
DERBYSHIRE NORTHUMBERLAND
DEVON NOTTINGHAMSHIRE

DORSET OXFORDSHIRE

DURHAM POWYS

DYFED SHROPSHIRE EAST SUSSEX SOMERSET

ESSEX SOUTH GLAMORGAN

GLOUCESTERSHIRE STAFFORDSHIRE

GWENT SUFFOLK GWYNEDD SURREY

HAMPSHIRE WARWICKSHIRE

HEREFORD & WORCESTERSHIRE WEST GLAMORGAN

HERTFORDSHIRE WEST SUSSEX

WILTSHIRE

A number of district councils were also involved in negotiations.

APPENDIX E

Metropolitan Districts (33 out of 36)

GREATER MANCHESTER

BOLTON BURY

MANCHESTER

OLDHAM

ROCHDALE

STOCKPORT

TAMESIDE

WIGAN

MERSEYSIDE

LIVERPOOL

ST HELENS

SEFTON

WIRRAL

SOUTH YORKSHIRE

BARNSLEY

DONCASTER

ROTHERHAM

SHEFFIELD

TYNE & WEAR

GATESHEAD

NEWCASTLE

NORTH TYNESIDE

SOUTH TYNESIDE

SUNDERLAND

WEST MIDLANDS

BIRMINGHAM

COVENTRY

DUDLEY

SANDWELL

SOLIHULL

WALSALL

WOLVERHAMPTON

WEST YORKSHIRE

BRADFORD

CALDERDALE

KIRKLEES

LEEDS

WAKEFIELD

APPENDIX E

London Boroughs (31 out of 32) Other

BARKING & DAGENHAM

BARNET

BEXLEY

BRENT

BROMLEY

CAMDEN

CROYDON

EALING

ENFIELD

GREENWICH

HACKNEY

HAMMERSMITH & FULHAM

HARINGEY

HARROW

HAVERING

HILLINGDON

HOUNSLOW

ISLINGTON

KENSINGTON & CHELSEA

KINGSTON

LAMBETH

LEWISHAM

MERTON

NEWHAM

REDBRIDGE

RICHMOND UPON THAMES

SOUTHWARK

TOWER HAMLETS

WALTHAM FORREST

WANDSWORTH

WESTMINSTER

GLASGOW

TAYSIDE

LANARKSHIRE

BELFAST

COUNTY DOWN