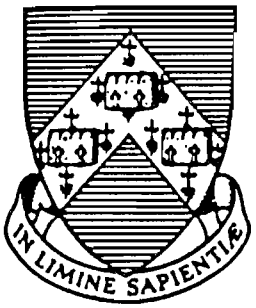


UNIVERSITY
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INSTITUTE FOR RESEARCH IN THE SOCIAL SCIENCES

CENTRE FOR HEALTH ECONOMICS

# An Evaluation of the Work of the Walbrook Disabled Persons Housing Service 1985 - 88

by

Glennis Whyte

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Glennis Whyte
February 1991

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Glennis Whyte

# PREFACE

## INTRODUCTION

A number of recent reports (for example, OPCS 1988, Griffiths 1988 and Beardshaw 1988) have served to highlight yet again the urgency of addressing the rights and needs of physically disabled people in respect of independence and full participation in society. The recent survey on the prevalence of disability among adults in Great Britain estimated that over 6 million people over the age of 16 years had some disability and of these about one third were in the five most severely disabled categories (OPCS, 1989, p. 16).

The prevalence of disability increases proportionately by age; for every thousand people aged between 60 and 69 years 57 were in the five most severely disabled categories whereas for people aged between 70 and 79 this proportion increased to 125 per thousand and to 354 per thousand for people aged 80 years or more. This increasing frailty in old age coupled with the growing numbers of elderly people in the population will increase the demand for purpose-built or adapted housing accommodation.

Whilst we have seemingly turned the corner and moved away from social policies, practices and philosophies which segregated people in institutions, we have yet to find ways of providing widespread and adequate community services which can enable disabled people and their families to improve their quality of life.

Numerous studies, and disabled people themselves, have reported consistently that people continue to face barriers, hurdles and bureaucracy in their attempts to exercise choice and control over their preferred way of life and standard of living. As Fiedler put it in her recent report on housing and support services (1988) people with physical disabilities are subject still to a "lottery" system: "the amount and kind of help a disabled person receives is determined less by need than by chance".

Throughout the United Kingdom there have been varied attempts by local councils, health services, local authority social services and voluntary organisations to develop new and innovative services. In particular, there has, over recent years, been a growing recognition of the importance of housing to the achievement of independence and the ways and means by which homes can be adapted or constructed to eliminate environments which disable rather than enable.

One such attempt to enable disabled people to remove the barriers to independent living is that of the Walbrook Housing Association based in Derbyshire who, in 1986, launched a three-year pilot project to provide a Disabled Persons' Housing Service (DPHS). This study is a report on that service and the opinions and experiences of those people who have used it.

## STRUCTURE OF THE REPORT

### The Research Project

The main aim of the research project was to assess how well the DPHS was able to achieve its objective of responding individually, flexibly and imaginatively to the most complex and multi-faceted housing and related needs of severely disabled people who wished to live in the community. In particular the research addressed the following issues:

- the key components of the service;
- the degree and nature of the liaison with and interaction between statutory and voluntary organisations and DPHS staff;
- the development and effectiveness of a multi-disciplinary approach in responding to the housing (and related needs) of disabled people;
- the role of the service in assisting disabled people living in institutions to be rehabilitated in the community;
- the costs of providing the service and outcomes achieved for users;
- the organisation, staffing, training and other requirements needed to develop similar services in other areas.

These issues were pursued by several methods. Firstly, by interviews and discussions with the staff of the DPHS, staff in relevant statutory agencies and members of voluntary organisations in the locality. In addition, discussions were also held with organisations in the statutory and voluntary

field who were providing a similar service to obtain a variety of perspectives and alternative methods of providing a disabled persons' housing service. Secondly, the first 450 referrals to the Walbrook DPHS were recorded to give broad details of personal characteristics, household circumstances, housing and related needs and eventual outcome in terms of the assistance gained from the DPHS. Thirdly a stratified sample of 45 people was drawn from these 450 referrals in order to gain some insight into the users' perception of the service received and their satisfaction with both the progress of their requests and the eventual solution offered.

The historical development of legislation and policy in respect of housing, health and social services for disabled people is well documented and this report therefore focuses on a particular service and its evolution within a local community. However, the service is an independent part of a wider network of services which have been developed in the county of Derbyshire to promote the achievement of independent or integrated living opportunities and therefore Chapter One discusses briefly what an integrated living philosophy entails.

Chapter Two places the Disabled Persons' Housing Service in its local context by looking at some of the initiatives taken in Derbyshire by the county Social Services Department and the Derbyshire Centre for Integrated Living and also outlines the way in which the DPHS came into being.

In order to examine the aims and achievements of the DPHS from the point of view of those who have chosen to use it, a study was undertaken to determine who was using the service and in what ways. This information is presented in Chapter Three and is illuminated further by interviews with a

number of service users whose opinions and experiences are documented in Chapter Four.

The costs of the service are discussed in Chapter Five and a summary of the findings of this study, together with recommendations for further research, is given in Chapter Six.

# CHAPTER ONE

# INTEGRATED LIVING

## INTEGRATED LIVING AND DISABLED PEOPLE

Historically, disabled people have been categorised by assessments of what tasks they can and cannot perform; labelled as members of a homogeneous group, for example, 'the disabled', 'the blind' and so on; and marginalised from participation on equal terms with others in society by their segregation into accessible parts of the community:

> "Up and down this country there are hundreds of people living unreal lives either segregated in institutions or in their own homes. These people know that they are still human beings with the rights of all members of a democratic society to freedom of choice, freedom of expression and freedom of movement. But society does not tell them how to obtain those freedoms. Often, society believes it is not possible for those freedoms to be enjoyed by disabled people".
>
> (Hurst, 1986)

Against this situation have been the voices of disabled people through organisations such as the Disabled People's International, the British Council of Organisations of Disabled People and numerous local groups and individuals committed to the goal of independent or integrated living. Such organisations have sought to challenge existing definitions of disablement (Davis, 1986) and assert the centrality of human rights within the debates on social policy and practice which have flourished since the 1981 International Year of Disabled People and which have been brought to the fore within

discussion on how best to provide community care. But, as Hurst (1986) also notes:

> "... issues such as 'rights' and 'freedoms' pale into insignificance beside how to pay the milk bill or how to get to work .... After all, it is the practicalities that have put disabled people into institutions".

The way our society is organised to take account of these practicalities of daily life has, however, failed consistently to enable everyone to pursue their own choices of how and where to live and work, and with whom.

Physical disability has long been theorised as a personal tragedy which one must 'overcome' by characteristics such as heroism or determination. Whilst not minimising the physical and psychological impact of disability on the individual and his/her family, such a tragedy theory locates the origin of the problem and the sources of solutions with the individuals concerned. Within this tragedy theory, disabled individuals are rarely seen to act as normal human beings whose daily lives are comprised of major and minor successes and failure. Too often disabled people's ability to live, love and work 'normally' is patronised by what Shearer describes as the "aren't they wonderful" attitude. Failure to live independently is either anticipated ("we told you so") or ascribed to the individual ("he lacked the motivation", "she couldn't come to terms with her disability"). Disabled people therefore constantly face a paradoxical situation within which it is hard to win: on the one hand their behaviour, attitudes and the problems they encounter are perceived as being influenced solely by the nature of their individual physical condition, and on the other hand support services are organised on the basis of a mythical homogeneous 'disabled' category within which

individual needs are subsumed. For too long physical impairment itself has been seen as 'the problem' rather than our inadequate response to it.

## THE ROLE OF HOUSING

One of the most crucial responses to disability is the provision of adequate housing to provide the focal point for exercising control over one's quality of life and retaining, or regaining, one's autonomy. However, within the dimensions of traditional housing design, physical impairment or lack of strength and dexterity is seemingly punished by one's world contracting ever smaller to those accessible parts of the home as one is disabled increasingly by an environment inflexible to changing circumstances. The failure to maximise disabled people's abilities through employment and the resulting dependence of many disabled people on state benefits or low incomes further reduces disabled people's choices of how and where to live, consigning many to poorer quality housing with few amenities and scope for improvement.

However, whilst accessible housing is pivotal in preventing segregation inside institutions, bricks and mortar alone cannot guarantee independence. The availability of purpose-built or suitably adapted housing may still leave one isolated if access to neighbourhood or town, to public amenities and channels of social participation are restricted through poor environmental design, inaccessible public buildings and transport. The demand for communities to be planned in accordance with everyone's basic needs must also be coupled with the demand for sufficient and appropriate personal help in and outside the home through the provision of domiciliary support to the individual and assistance for those who help, whether friends or family.

## A HOLISTIC APPROACH

Thus, a holistic approach to disability is required. This approach encompasses a range of life needs and has as its goal the full integration of disabled people according to their preferred levels of formal and informal support. Such an approach does not focus on what is impossible or static based on narrow criteria of physical impairment and functional limitation, but identifies what is possible and changeable. A holistic view of disability which promotes 'integrated living' also highlights and draws strength from the interdependent nature of communities and the way we shape, and are in turn shaped, by our environments.

An integrated living model acknowledges that no-one in present day society is truly independent. It is almost inconceivable that one could survive from day to day without the efforts of others, no matter how insignificant or remote those efforts appear. Thus, interdependence and integration are the bases of our overall material, physical and psychological well-being. The concept of integrated living for disabled people does not, therefore, seek to reject the fact that we all depend on others, at different times and for different reasons in an integrated society, but this concept does reject the imposition of dependence where others articulate one's needs or where personal relationships are distorted adversely by caring. Above all, integrated living means effective choice and control about how to live one's life.

Recent debates on the nature of care in the community and the funding mechanisms required to provide a comprehensive network of support have facilitated discussion between disabled people and the providers of housing

and support services as to how choice and control can be maximised. This debate has been challenging insofar as it raises fundamental questions concerning the rights and opinions of disabled people and the respective roles of provider agencies such as local authority social services departments, housing departments, health services and those private and voluntary organisations offering accommodation or personal care.

Within this debate there is the growing consensus amongst providers and policy-makers that a medical model of care which focuses on the individual's physical condition and which views disabled people as patients or passive recipients of help, is inappropriate. This philosophy which underpinned so much of our response to disability is now being replaced with a social model of care which takes a wider view of people's lives and which acknowledges the disabling effect of communities designed by and for so-called 'able-bodied' people. A social model of disability necessitates discussion and planning on how services can be reoriented in their design and delivery to allow for increased consultation and participation of disabled people.

By emphasising the importance of the disabled person's identification of his/her own needs and their taking an active rather than passive role in the determination of services, a social model of disability poses considerable challenges to the professional provider agencies. The prevailing structure of provision often sets disabled people and providers in a confrontational relationship rather than a collaborative one. Within a system of rationed state provision, some confrontation is arguably inevitable as professionals act as gate-keepers for a variety of claimants competing for scarce resources. However, by redefining disablement to articulate the individual's relationships with the immediate (home) and wider (community)

environment, the social model of disability proposes a new agenda for change and a different role for the professional.

**THE IMPACT OF BUREAUCRACY**

Imaginative projects have been developed in some parts of the country in respect of housing, health and social services which seek to extend the partnership model and allow staff the flexibility necessary to work with the individual to achieve agreed goals (Fiedler, 1988). However, the current deadweight of complexity of service provision ensures that disabled people are still subject to differing policies and practices, restrictions and barriers in respect of their living choices. Nearly twenty years after the Chronically Sick and Disabled Persons' Act of 1970 provided a clearer statutory framework for local authorities to plan services, it remains the case that the extent to which people are able to "... make the most of being alive" (Goldsmith, 1976) will depend on one's chances on the wheel-of-fortune which characterises housing, health and social service provision. On paper one's recourse to certain forms of statutory support is clear - in reality where one lives and who else is in competition locally for scarce resources may determine how far one is successful in achieving even basic assistance. It is not known how far the development of agency-style services will break through what Heginbotham described (1984) as the "webs and mazes" of bureaucracy and fragmentation of provision between the various health welfare services, the public and private sectors.

At present, each agency, committee, or local team may have its own defined "client group" - its own targets and goals, its own budgets and its own assessment, eligibility and rationing criteria. The result for the

individual can be confusion, anxiety and yawning gaps in support. In the 1970s Blaxter found that in one city, fifty-nine separate agencies, both statutory and voluntary, had responsibility for various aspects of adult sickness and disability. This complex overlapping structure of provision would still be familiar in many areas today and as Blaxter noted, service provision was continually complicated by the differing rationing-eligibility procedures:

> "Who are the clients? Are the provisions statutory, discretionary or voluntary? Is any given service available to everyone who may be in need of it (health services, employment services); only to groups of people specially and legally defined (national insurance system, services for the blind ...); statutorily, but only to people unable to provide for themselves (means tested benefits); to groups of people defined by the agency providing the service (many local authorities); or to groups of people selected by complex social processes which are not made explicit (the services of voluntary agencies)".
>
> (Blaxter, 1976)

Add to this the present reality of financial constraint, staff shortages (in particular, the national shortage of occupational therapists) and other demands on professionals' time and energy (for example, the rise in child abuse being dealt with by social workers) and one is left often with a system characterised by immense good will but ultimately immense frustration for all concerned. An example of this frustration is the experiences of some people involved in Project 81 in Hampshire who decided to live independently based on their own care proposals. When they first embarked on their proposals some found that their assessment of their own needs was doubted:

> "We were told that the medical profession knew best as they had the experience of caring for severely disabled people"

or, their plans were initially fraught with delays and bureaucratic barriers:

> "I was growing increasingly concerned. There appeared to be some discussion going on, yet nothing was communicated to me. I had little or no idea what was happening .... During these months I became aware that my case was the subject of discussion for two entirely different District Health Authorities, and two very separate departments of the Social Services - the local office and the head office. It was like wrestling with an octopus - no single person or office appeared to be responsible for promoting my cause. Nobody seemed to know what the other limbs of the service were doing; nobody ever advised me or kept me informed of what was happening. I began to feel that mine was an "interesting academic case" to be savoured, and that there was not actually someone's life involved".
>
> (HCIL, 1986)

The above example illustrates how individuals can become entangled in a bureaucratised system of professional boundaries and responsibilities within which one can feel powerless to influence decisions.

**LACK OF CO-ORDINATION**

Different aspects of life which have implications for total well-being and independence, for example health, employment, income, housing, education, and practical and emotional personal support are frequently addressed by as many different agencies or individuals with the potentiality for gaps in services and help. A health survey of disabled young adults found that over half the sample:

> "... had health problems that were severe enough to warrant intervention [yet] less than a third were receiving any form of regular hospital care; regular contact with physiotherapists, speech therapists and dentists was also poor".
>
> (Bax et al, 1988)

This report gives one example of a person with severe health problems who, despite receiving daily help from community nurses, regular attendance at a day centre and social worker support, experienced persistent health and social problems which were not addressed. Moreover, the report discovered that whilst approximately half of the sample required support at night, help with bathing, dressing and feeding, less than a quarter of the families received practical help in the home, and this was provided overwhelmingly by friends and relatives.

The Bax study showed that there may be gaps in services and a lack of overall co-ordination, and that the situation will be compounded where an individual lacks information on what is available, who is responsible and what is being done in his or her name. Too often there is no straightforward channel for the articulation of disabled people's needs, views and preferences (and those of their families) which can break through the bureaucratic barriers between respective services and increase the individual's exercise of control. Freedom of choice in respect of help and services requires, above all, accurate information and answers to questions such as: what are the possibilities for change? What service options are available? How is access to services achieved? How can services be assessed in the light of personal and unique needs? What are one's rights? Without information on the full range of possibilities for change and the structure of local and national provision across the public-private-voluntary divide, informed decisions cannot be made and disabled people are not empowered to make effective choices. The fear is that advice and information may be consciously or unconsciously limited by the providers' role as rationers of their own resources and the desire, however well-intentioned, not to raise

expectations that cannot be fulfilled. Objective information, particularly that based on the direct experience of other disabled people who have faced similar circumstances and problems, coupled with advocacy services for those who require them, can help to redress the balance of power between providers and 'consumer'.

The Griffiths Report (1988) and the Government White Paper on Community Care, Caring for People (1989), have addressed some of the above issues and in particular, the existing fragmented structure of 'community care' by proposing a new, co-ordinating and budget-holding role for local authorities.

In theory, some of the confusion and lack of information which have hitherto hampered disabled people's ability to gain access to appropriate support will be overcome by the requirement of local authorities to plan, publicise and submit for inspection, their precise strategies for community care services. The questions surrounding the issues of choice and the need to respond flexibly to individuals' unique needs and preferences are answered in the White Paper by an emphasis on the procurement of 'packages' of services from a variety of sources including the private or independent sectors.

Whilst noting that not everyone will require such 'packages' of care, the government proposes a new system of 'assessment' for those people "whose needs extend beyond health care". Given that assessment has formed an integral part of service provision and has traditionally focused on community occupational therapists' gate-keeping role in respect of access to aids, equipment, adaptations and alternative housing, a new system which can consider a wider range of daily living needs and which can ensure

collaboration between providers, appears welcome. The White Paper also notes that assessments should "take account of the wishes of the individual and his or her carer ...".

However, the mechanism for ensuring 'consumer' participation in decision-making is not made explicit, nor are the rights of individuals and their families within the assessment and provision process. This is particularly worrying given the other function of assessment which determines eligibility and priority within a rationing system, for as the White Paper states "decisions on service provision will have to take account of what is available and what is affordable".

The crucial question of funding not only to facilitate structural change but also to recruit and train necessary staff is side-stepped by the White Paper which concentrates attention on new mechanisms for funding and gives no assurances on designated long-term funding safeguards.

The report also fails to place housing in its central role in respect of disability and in particular, the way in which appropriately designed and located housing can prevent disablement. Whilst the need to assist people to remain in their own homes and the requirement for authorities to "work closely" with housing agencies is recognised the question of how housing providers are to fit in with community care plans and assessment procedures is only vaguely answered by the statement that "where necessary" housing needs should form part of needs assessment in conjunction with occupational therapist advice.

In 1985 when the Walbrook Housing Association began its Disabled Persons' Housing Service it saw the need not only for a specialist advice and information service but also the necessity of working within an accessible and non-bureaucratic structure to ensure that a partnership model of provision was achieved with the disabled person concerned. The DPHS has therefore contributed to existing patterns of community care by mitigating the effects of a fragmentary statutory response and the service is now well placed to contribute further to comprehensive care strategies as proposed in the White Paper.

**THE HOUSING AND LOCAL GOVERNMENT ACT 1989**

The new Housing and Local Government Act serves two main purposes so far as housing for disabled people is concerned. Firstly, it provides a formal framework for the co-operation of housing and welfare agencies in the provision of houses suited to disabled people. Secondly, it provides a system of grants (Disabled Facilities Grant) for improving and adapting houses for disabled people.

The co-operation between welfare and housing agencies in the provision of houses for disabled people is based on an appropriate division of professional skills. The main area in which the housing authority will be offering a professional judgement in assessing a grant application is in determining whether it is "reasonable and practicable" to carry out the relevant works", having regard to the age and condition of the dwelling or building" (Department of the Environment, Circular 10/90, paragraph 24). Welfare authorities will have to be consulted to advise "whether or not the

works for which a disabled facilities grant is sought are necessary and appropriate to meet the needs of the disabled occupant" (Ibid, paragraph 23).

The Disabled Facilities Grant (DFG) is means tested and comprises a mandatory and a discretionary element. The mandatory element is for works to make a property fit for a disabled person to gain access to and live in it. It is clearly recognised that "fitness" of property for this grant is more than the standards set for other renovation grants.

The requirement behind the mandatory element is accessibility into the building and the provision of essential amenities and facilities. The discretionary element covers works which would make a property suitable for the accommodation, welfare or employment of the disabled person.

Although the new Act will encourage co-operation between housing and welfare authorities, it is clearly recognised that agencies such as DPHS will have an important role to play in advising disabled people about the availability of grants and the sources of financial help. In addition it will continue to work on training disabled people in the use of new adaptations and equipment, and providing an "open-door" by which they can gain access to and information about a range of other services which can improve the quality of their lives and the lives of their main carers. The development of the Walbrook agency is described in the next section.

## CHAPTER TWO

## THE ORIGINS OF THE DISABLED PERSONS' HOUSING SERVICE

### INTRODUCTION

The Walbrook Housing Association, based in Derby and founded in 1966, found that in common with many other housing associations it was receiving an increasing number of enquiries from disabled people for appropriately designed or adapted homes which would enable them to increase their mobility and independence. The Association had considerable experience in housing their elderly tenants and in designing home environments for those with restricted mobility, and lessons learned from these initiatives formed the basis of their service to disabled tenants.

However, it soon became clear to Walbrook that the demand for a more specialised service came not only from those who wished to become Walbrook tenants, but also from owner-occupiers, council house tenants, people living in short-term and long-term hospital or institutional care and people wishing for general advice and information on a range of housing and care options.

Whilst Walbrook continued to increase the number of dwellings in their housing schemes designated for disabled people, they perceived a gap in existing housing advisory services which called for a more holistic and comprehensive approach to disablement. In pursuing their aim to provide housing which alleviated disability and maximised independence they quickly realised that the provision of mobility or wheelchair-standard accommodation was, in many instances, not enough. In order to minimise people's

dependence, isolation and segregation a thorough overview was required of the person concerned - their needs and preferences, their lifestyles, the availability of family and person support networks, the design requirements of housing, fixtures and fittings to increase mobility, the range of financial options required to achieve goals and so forth. To ensure that these interrelated needs were addressed, it was necessary for Walbrook to liaise closely with other agencies, for example local authority housing departments, social services, the health services, and voluntary sources of help to pull together the separate pieces of a community living jigsaw. Prior to establishing a separate service, the Association therefore held discussions with disabled people and professional staff in Derbyshire to consider the feasibility for such a scheme and in what ways it could assist both the disabled community and those bodies with statutory responsibility in the sphere of housing and personal support.

The proposal to launch a Disabled Persons' Housing Service (DPHS) was put forward in a county where there was already a growing commitment to the participation of disabled people in service planning and delivery. The Derbyshire Centre for Integrated Living (DCIL) run by and for disabled people, had received County Council support and members of the Derbyshire Coalition of Disabled People were also prominent in the movement towards improved services and access to decision-making. The DPHS was therefore launched at a time when a number of initiatives were being tried throughout the county in a climate of opposition to traditional medical models of care and as part of a national trend away from institutionalisation.

## THE PROVISION OF SERVICES IN DERBYSHIRE

The context of provision to which the DPHS sought to contribute had developed since 1981 when members of the Derbyshire Coalition of Disabled People (DCDP) instigated discussions with the County Council, and in particular with the County Social Services Department, concerning the aims of the International Year of Disabled People. After negotiation, the Council and DCDP agreed on a "statement of intent" in respect of the rights of disabled people and this formed a pledge to the achievement of seven objectives within the County:

1. the involvement of disabled people in decision making
2. the promotion of an accessible, barrier-free built environment
3. the promotion of integrated, independent living opportunities
4. the development of accessible public transport
5. integrated education
6. integrated employment opportunities, and
7. the dissemination of information/advice, advocacy and support.

Following this pledge to promote more fully both the needs and the views of disabled people, the structure of service provision in the County had to be reviewed and where necessary, amended, to facilitate this philosophy and in 1983 the County Social Services Department issued their Strategic Framework in respect of people with sensory or physical impairments which had as its focus the need to:

"... secure independent, integrated living opportunities for disabled people in order to promote their full participation in the mainstream economic, social and political life in Derbyshire".

A Disability Project was established in 1984 to examine the design and delivery of services in residential, day care and field work settings and a number of posts involving Community Living and Disability Project workers were created.

In the North of the county in 1984 the Joint Planning Group (Services for People with Physical Handicaps) which included North Derbyshire Health Authority, Derbyshire County Council, the Derbyshire Centre for Integrated Living and district councils, commissioned a survey of local need to inform discussions on a joint strategy for the development of services for younger physically disabled people (aged between 19 and 64 years). The resulting county strategy document identified a list of seven categories of interrelated needs which represented an integrated context in which to respond to disablement, the aim being to reorient services away from the perpetuation of dependency towards an enabling role. Summarised, these needs are:

1. Information
2. Counselling
3. Housing
4. Aids
5. Personal help
6. Transport
7. Access

Most of the above categories were felt to fall within the remit of health and social services funding requirements, but the document stressed the need for a "joint method of service development and provision amongst all participating agencies". The strategy proposed for future services was based on several basic principles and "value statements" which included:

(a) that long-term institutions were not an appropriate service response;

(b) that preventive services were better than emergency services i.e. that the means should be found to overcome practical problems to ensure independence in the community;

(c) that local services should be planned in consultation with people with disability, their carers, families and voluntary organisations based on local information;

(d) that additional training should be provided to general NHS and social services staff;

(e) that rehabilitation services needed to be developed hand-in-hand with counselling, opportunities for shared experiences, resources for aids, adaptations, personal assistance and transport facilities;

(f) and, that in certain instances, the needs of clients would be better met if health and social services were to fund provision of those services by other agencies with consumer involvement and control.

Thus the strategy document stressed the importance of participation by disabled people in the planning and design of services and committed statutory bodies to consider ways in which a flexible, co-ordinated response to disability could be secured. In particular, the Joint Planning Group noted that it was "committed to the notion of interactions in relation to the seven needs identified ... and urges readers to stop thinking in terms of service packages and boundaries".

The findings from the survey of need, carried out by the University of Nottingham led to a review of existing service provision and some of the recommendations are outlined below. They illustrate the extent to which the county had embarked on a major overhaul of its services to disabled people at the time the Walbrook Disabled Persons' Housing Service was proposed.

(i) Access

Access to health and social services buildings and public amenities was to be examined and, where necessary, improved.

(ii) Aids for Daily Living

The strategy document recommended that aids for daily living should be provided through a joint/integrated aids service in the North of the county complemented by a demonstration and exhibition service based within the Derbyshire Centre for Integrated Living at Ripley. A "try-before-you-buy-or-receive" service in conjunction with aids manufacturers was also recommended. The document also suggested the need for a reappraisal of the role of community occupational therapists in assessing for and supplying practical aids and noted that "occupational therapists are a scarce resource, who have a vast range of counselling and therapeutic skills which are rarely used".

At the time of this study, aids for daily living were provided mainly by county social services through the various area offices using occupational therapy assessment. Health authorities also have responsibilities in respect of the provision of nursing aids and there had been criticism in the past

that aids provision was badly co-ordinated, leading to both gaps and duplication of provision. Health service personnel interviewed for this study were concerned about overlap between themselves and social service workers when addressing the requirements of those being discharged from hospital. They felt that there was often insufficient time between a clinician's decision to discharge and the individual returning home to plan adequately for rehabilitation or mobility-related aids.

Social services personnel also expressed concern about aids provision and echoed the Joint Planning Group's concern that occupational therapists were spending an inordinate amount of time providing aids which could, they felt, be administered by suitably trained social work or occupational therapy assistants, leaving qualified staff to be more free to develop independent living alternatives or major adaptation work.

In an attempt to explore the question of aids services within the county, Derbyshire Social Services in conjunction with the two District Health Authorities and the Derbyshire Centre for Integrated Living, formed a working party to survey provision in other parts of the country and discuss the feasibility of a joint system of provision "incorporating maximum flexibility and consumer involvement". A questionnaire survey was carried out receiving 183 responses. This survey found a number of common problems across the country, for example, high waiting times, inappropriate or unacceptable aids, confusion, disputes concerning areas of responsibility, budget constraints, and ineffective recall and recycling procedures. It was anticipated that the findings of this survey would assist the county to develop a much improved and co-ordinated service.

(iii) Personal Assistance

The strategy document noted that personal assistance was crucial to the "knife-edge existence of disabled people living in the community". The report concluded that a hospital unit for younger disabled people was not recommended in the North of the county (the South of Derbyshire has 25 residential places, ten of which are for long-term care but it too aims to avoid unnecessary admittance of disabled people to hospital). Hospital rehabilitation services were cited as in need of improvement and development in order to facilitate moves into the community, and community-based Link Workers (via the DCIL) were encouraged.

Meals on wheels services in the county are operated by social services and distributed via the Women's Royal Voluntary Service. In 1986 this service provided approximately 650,000 two-course meals per year.

County social services had been developing its domiciliary support services, including those to disabled people, for a number of years and between 1979 and 1985 the number of home help recipients had increased by 48%. The county had developed a three-tier approach to such services: home helps provided mainly shopping and housework assistance, Monday to Fridays, with the number of hours allocated through area organisers. Home Care Aides provided more personal support, for example, dressing and washing in addition to domestic tasks. A third tier of "flexicare" assistance was also provided for those people requiring more intensive and flexible home support. This scheme utilises Home Care Aides who are contracted to work for a specific individual in accordance with an individually-designed package of support agreed with the recipient. Attendance allowance may be used to contribute

towards this care, for example, for weekend support. The flexicare system is funded from a central budget and is not confined to providing extra hours' assistance to disabled people who accounted for approximately a quarter of flexicare expenditure at the time of this study. Area offices bid for the allocation of hours and when interviewed, some area social services personnel were considering whether local budgets for flexicare would be more efficient.

There are four day centres in Derbyshire offering services to approximately 600 people based in Alfreton, Chesterfield, Derby and Long Eaton.

(iv) Advice and Information

The strategy document recommended that priority consideration be given to funding a comprehensive information centre based at the Derbyshire Centre for Integrated Living in addition to an extension of information services in district council areas, via social services and other outlets. The County Council and area social services offices provide a variety of leaflets and information booklets aimed at providing disabled people with details concerning local services, welfare benefits and national and local helping organisations. A County Welfare Rights Service was introduced in 1982 following evidence of unclaimed benefits and in 1988 the advice provided by welfare rights staff resulted in an estimated £2 million in additional benefits being claimed.

(v) Transport

Derbyshire County Council provide reduced-rate travel permits to those registered as disabled people and there are also a number of concessionary fare and travel aid schemes to provide lower priced road and rail travel within the county. A Dial-a-Taxi service operates from 8.00 am until 11.00 pm, seven days a week in Derby and offers a door to door service and Dial-a-Ride using mini-bus type vehicles will collect people from their own homes for two-hour trips to the city centre and is aimed at people who find public transport inaccessible. Helpers can be provided or friends and relatives can travel with the individual concerned. A number of voluntary groups also provide transport and there is a transport scheme which particularly helps with travel to and from day-centres.

The Joint Planning Group hoped that ambulance services for disabled people would be improved and that voluntary and community transport schemes could be evaluated through consultation with a Transport Research and Development Officer based within the DCIL.

(vi) Counselling

The joint strategy document gave high priority to general counselling but felt there was less need for specialised counselling and there was support for the quality of existing health and social services counselling services. However, the availability of peer counsellors via the DCIL was noted and it was recommended that support be given to the extension of this form of advice.

(vii) The Derbyshire Centre for Integrated Living

Mention has been made throughout this outline of service structure of the DCIL based in Ripley and its establishment in the county has raised considerably the profile of disabled people in Derbyshire and typifies the endeavours to work towards a partnership model of provision by professionals and disabled people throughout the county.

The "seven needs" structure adopted by statutory services also forms the basis of services offered by the DCIL which operates as a charitable company and is funded from a variety of sources. It is financed partly by Derbyshire County Council, district health authorities (through joint and mainstream funding) and from the EEC Social Fund. The DCIL's administrative structure reflects its commitment to a partnership approach to full social integration of disabled people. Its governing bodies have 50% disabled people as participants and the Derbyshire Coalition of Disabled people are also represented alongside members of the county council, district councils and health authorities. In practice, the DCIL is an organisation of disabled people putting their various skills and experience at the service of other disabled people as well as professionals and volunteers in the statutory and non-statutory sectors.

The DCIL offers advice and practical help in respect of the above seven needs or aspects of life and also provide more specialised services, for example a Disabled Peoples' Employment Agency, a planning and design consultancy, outreach work through link-workers in the community, a welfare benefits information service, regional advice services, training, and

personal assistance. With regard to technical aids, the DCIL have a computer link with the Disabled Living Foundation to hold a database of information. Many new services are planned as the DCIL has expanded gradually and these have been outlined in the DCIL Strategic Plan for 1986-1991.

The DCIL employed a Housing Research and Development Officer to pursue housing options with disabled people and promote the development of a coherent housing policy within the county. Proposals have been put forward to develop closer links between the DCIL and housing agencies particularly in the housing sector. Links between the DCIL and the Disabled Persons' Housing Service have been strong and a working relationship has been achieved which should be strengthened by plans to create jointly a housing options guide for disabled people.

(viii) Housing

The health authorities' commitment to decreasing hospitalisation coupled with developments in community care services, raised again the need to ensure an adequate supply of housing available to disabled people, both to prevent institutional or hospital living and to enable those leaving long-term care to be integrated fully with maximum independence.

There are nine district councils who have responsibility for housing provision in the county. In Derby city, where the majority of people using the Disabled Persons' Housing Service are located, public housing is administered through the Housing and Environmental Services Department of Derby City Council who manage approximately 21,000 dwellings of which some 1,600 are for elderly or disabled people and are

mainly within sheltered housing schemes. Derby operate a mobile warden service to back-up staff in sheltered housing and there is a central control station staffed 24 hours per day offering personal alarm systems. At the time of this study Derby Council had 17 properties which were purpose-built for wheelchair bound tenants in addition to those properties which had been adapted.

Housing for disabled people is categorised in Derby as "special needs" housing and is managed by designated officers of the department who also co-ordinate a Special Housing Panel in conjunction with social services and health authority personnel to discuss, for example, medical priority for rehousing.

At the time of this study Derby had experienced a number of problems common to many authorities in trying to target housing for disabled people. The housing department had yet to develop adequate methods of recording precisely who on their housing waiting list was disabled and therefore they were less able to prepare in advance for the potential demand for adapted dwellings. Neither did they have sufficient information regarding their existing housing stock, for example, what adaptations had already been carried out and to which properties. The department also found themselves with less and less room for manoeuvre in placing people in appropriate housing - there had been no newly-built property for three years (whereas ten years previously they were constructing 1,000 properties per annum) and over 20% of existing housing stock had been sold. Whilst new building was curtailed severely, the number of house adaptations had risen dramatically in recent years and their 1987 budget was £220,000.

The rise in house adaptations and the requirements placed on authorities by legislation such as the Chronically Sick and Disabled Person's Act, have led many authorities to review existing procedures in respect of assessment and provision. A number of local councils have attempted to streamline their housing and adaptations work by developing a centralised unit or department which can bring together housing, environmental health, and the skills of social workers and occupational therapists under one roof and within one organisational framework, thus eliminating some of the bureaucratic confusion and amount of time hitherto needed to access the system.

In Wakefield, for example, the number of requests for adaptations was growing rapidly, resulting in increased pressure on staff and the need for more co-ordination of services. However, five separate departments were involved in the provision of mobility aids and adaptations: the Chief Executive's department, social services, environmental health, the building department, and housing. With five different 'systems' operating in each single case there was inevitable delay in processing each request for help. It was therefore decided to create a specialist Aids and Adaptations Unit within the housing department which would react to requests for assistance through a team work or multidisciplinary approach, for example, building services. This centralisation has been successful in processing aids and adaptation requests more quickly and effectively from both the Council's and the disabled person's point of view.

In some authorities, housing departments have begun to perform an agency role in respect of owner-occupiers wishing to adapt under the grant system and offer advice on plans, contractors and legal requirements.

In Derbyshire accommodation for disabled young people was also available through various charitable organisations such as the Spastics Society and the Cheshire Foundation providing long-term residential homes. There were, in addition, a number of other housing agencies besides Walbrook and in Derby there were 13 housing associations and trusts who had constructed various housing schemes which often included some provision for disabled people.

At the outset an agency working to provide a housing service for disabled people faces general questions:

- how would the opinions and preferences of disabled people themselves and their families be represented in the design and delivery of the service?
- what skill-mix of staff would be required to address an integrated approach to housing problems?
- what level of funding was sufficient to meet demand and how would that funding be obtained?
- how would the service be publicised and should it be targeted at certain groups of people?
- what would be the relationship and parameters of responsibility between DPHS and those statutorily responsible for housing and support services, aids and adaptations?
- how could the service be monitored and evaluated?

Within Walbrook Housing Association there was considerable existing expertise on which to base advice to the local community, for example, housing management skills, design and architectural services, surveying,

costing and financial management experience, links with the housing association movement, the Housing Corporation and other housing agencies nationally and locally, and the advice and opinions of their disabled tenants on what was required.

Following the consultation period with statutory bodies and disabled people in Derbyshire, a proposal was put forward in 1985 for a three year pilot DPHS at an estimated cost of £60,000 per annum. Limited funding for the project was secured from housing trusts, the EEC Social Fund and public fund-raising, and an Advisory Committee was established to monitor progress, advise on policy and where necessary, on specific people's problems, comprised of representatives from building societies, the Derbyshire Centre for Integrated Living, Walbrook Housing Association, Chartered Surveyors and estate agents, and co-opted advisors.

**THE THREE YEAR PILOT PROJECT OF THE DPHS**

The climate of service provision for disabled people in Derbyshire in the mid 1980s was therefore one of change and experimentation with the County social services department and the DCIL at the forefront of new initiatives in service strategy and philosophy. Whilst this local context is important in illustrating the support given to the launch of the DPHS it is, however, necessary to stress that Walbrook's proposals were put forward in the light of their own independent experience of people's housing problems.

Whilst the overwhelming majority of services continue to be provided by statutory bodies, it was felt that Walbrook had developed a degree of expertise and specialisation in one aspect of life - housing - which could contribute

to the overall county-wide commitment to the improvement of quality of life for disabled people and they (Walbrook) were asked to share that knowledge.

The Disabled Persons' Housing Service, launched by Walbrook, did not aim to substitute itself for the services of the various local authority housing departments within Derbyshire, but aimed to help Council tenants amongst other clients. However, for the DPHS, some of the questions raised within the public sector still pertained, namely:

- how should the allocation of available property be carried out so as to be fair to both disabled people and others on Walbrook's housing waiting list?
- what system of priority, if any, should there be in certain circumstances, for example, ill-health or overcrowding?
- would re-housing mainly through one agency (i.e. Walbrook) lead to 'ghettoisation' of disabled people in certain parts of the city or county?

A DPHS Housing Advisor was appointed who was an experienced community occupational therapist and who would be responsible, in the first instance, for contact with users of the service, a home assessment of needs and circumstances, and the organisation and co-ordination of service delivery. However, Walbrook staff, and especially the Director, Deputy Director and Housing Manager and the Principal Architect and his staff, continued to participate closely in the work of the DPHS, often having direct responsibility for liaison with users of the service and their families. An external Advisor to the housing association on housing for physically disabled people was also a member of the DPHS team, advising particularly on the development of non-standard technical aids and equipment and building design. As the service expanded, receiving approximately 200 new enquiries per year over the duration of the pilot project, an additional

Housing Advisor was employed, plus a clerical/secretarial assistant. The service was based in the Derby city headquarters of the Walbrook Housing Association and could therefore minimise financial overheads and take advantage of close contact with Walbrook staff. This building was close to the city centre but unfortunately had poor wheelchair access until more recently when full ramping was installed to the reception area of the building. However, from the outset it was decided to base the service on people's own homes, whatever the extent of their mobility, in order to discuss and assess problems in situ.

The launch of the DPHS was given maximum publicity through local media and leaflets explaining the service and inviting enquiries were distributed through a number of outlets, for example doctors' surgeries, social services offices, and so on.

In practice, people contact the service by telephone, mail or a personal visit to the Walbrook offices and preliminary details are taken by the Housing Advisors of the individual's particular problems. Each person (and where appropriate his or her family) is allocated a number for record-keeping purposes and arrangements are made for a visit to the person's home, or wherever that person is currently based, for example, in hospital or residential accommodation. A home visit is usually available within a matter a days.

At the home visit the Housing Advisor (or that person within the DPHS felt to be most appropriately skilled to assist the enquirer) will discuss housing, mobility and personal support problems with the individual and his/her family and people are encouraged to express their own preferences for

the nature and extent of assistance they require: what are the changes desired? how might they be achieved and at what cost? what might the impact of change be on the individual and his/her family? The Housing Advisor will therefore consider what avenues might be pursued to achieve the individual's aims and which other statutory and non-statutory support will need to be co-ordinated or consulted. Whilst liaison with other Walbrook staff and other helping agencies is required, the organisation of help continues to be focused on a personal relationship between the individual and the designated members of the DPHS staff who act as the focal point of assistance negating the need for the individual to access personally a number of different systems of provision.

Whilst trying to ensure that bureaucracy was kept to a minimum and a personal service was maintained, Walbrook recognised that such a service required a clear framework of aims and ideals, checks and balances if its operation was to be evaluated and best practice identified.

The DPHS identified its own seven aims as a framework for the service:

1. to fill a gap in the housing advisory services which is available to all;

2. to offer the opportunity for disabled people and their relatives to discuss their housing difficulties;

3. to create in commerce, industry and the other professions, an awareness of the work of the DPHS;

4. to encourage closer co-operation amongst all those involved in the provision of housing for disabled people;

5. to encourage a change in attitude which will ensure that within the community, independent housing for disabled people is a realistic choice;

6. to encourage the creation of a disabled persons' housing service in other areas of the country;

7. for the service to be self-supporting.

With regard to the last aim in respect of funding, it is important to stress that the service is offered free of charge to enquirers irrespective of income, although standard eligibility criteria apply for housing solutions requiring the local authority or social services grant system. The DPHS has been particularly reliant on the goodwill of the local community in raising money through charitable activities. Whilst this public fund raising was necessary to maintain and expand the service it was arguably time-consuming but it had the indirect advantage of raising awareness within the county of the work of the DPHS.

In order to monitor the extent of demand within the county and to evaluate the DPHS' effectiveness in responding to a wide range of housing and associated problems, it was decided not to target specific groups of disabled people, for example those leaving institutional care, but to operate an 'open door' policy in respect of all disabled people irrespective of their location within the county, their degree of mobility, housing circumstances or financial status. The service further decided to adopt a wide definition of disablement to encompass all those who, for whatever reason, were disabled or handicapped to any extent by their housing conditions or need for technical and personal support. There was therefore no requirement for users of the service to fulfil certain medical or social criteria concerning mobility, age, income or family and housing circumstances.

In the local context of Derbyshire, the DPHS has evolved a philosophy which accords broadly with the partnership model of provision being developed by county statutory services and which is based on its personal relationship with service users. However it remains a separate and financially independent service which has not adopted formally the integrated living strategy based on the 'seven needs' framework previously outlined. Nor has it adopted the level of disabled peoples' representation on its management bodies which, for example, the DCIL have done. The role of the DPHS is clearly based within housing, although it recognises that the maximisation of independence requires a response to other aspects of life, for example, access, transport and information.

The extent to which it can successfully assist users of the service to achieve enhanced autonomy and independence therefore depends considerably on the strength of its relationship with other sources of help, for example county social services, the health authorities, local authority housing departments, the DCIL, specialised transport schemes, volunteers and so on. This fact is recognised within the service's seven aims by its commitment.to continued liaison and co-operation with all available service providers.

The service's need to recognise its place within a network of statutory and non-statutory provision is particularly relevant in the case of personal support within the home, as apart from the services of Walbrook warden staff and volunteer helpers, the DPHS does not offer domiciliary support as part of the service. The DPHS' ability to provide assistance for people seeking to increase independence is therefore governed, to some extent, by both local and national developments in community care and the organisation of spheres

of statutory responsibility. However, its undoubted expertise in the field of housing design makes it well-placed to contribute to whatever pattern of service provision is adopted ultimately.

Since its inception Walbrook have been keen to ensure that the lessons and experience learned through the three year pilot project of the DPHS are not lost within the local and national debate on services for disabled people and to this end they have welcomed the support of the Joseph Rowntree Memorial Trust in commissioning a study of the service. The following chapters give the findings of that study.

Walbrook Housing Association is not alone in seeking to provide housing for disabled people either in Derbyshire or nationally, and organisations such as Habinteg, the John Grooms Association, the Cheshire Foundation and numerous others offer accommodation and 'care packages' of varying kinds and based on varying philosophies of provision. However, the Walbrook Disabled Person' Housing Service is unique in its agency-style approach offering free housing advice and practical assistance backed up by its recourse to a housing stock and has therefore been an innovative experiment worthy of further research within a context of the developments in independent living and community care opportunities available to disabled people.

## CHAPTER THREE

## THE USERS OF THE WALBROOK DISABLED PERSONS' HOUSING SERVICE

### INTRODUCTION

The previous chapter outlined the seven aims of the Disabled Person's Housing Service (DPHS) which included the need to:

(a) fill a gap in the housing advisory services and provide a service available to all,

and

(b) to offer the opportunity for disabled people and their relatives to discuss their housing difficulties.

The service has also perceived its role as a "catalyst" in identifying sources of help and working closely with other agencies to achieve a comprehensive response to people's problems. In this respect, the DPHS were piloting a single agency-style approach to the procurement of services.

In attempting to assess how far the DPHS is achieving these particular goals, this study posed three main questions:

1. **Who uses the service?**

- to what extent had the 'open door' policy attracted a wide range of people in respect of age, sex, mobility, housing tenure and how did people find out about the service?

2. **Why did people seek help?**

- what problems were people experiencing which led them to seek assistance and which aspects of the DPHS (and other agencies) were utilised to address these problems?

3. **What was the outcome of using the service?**

- how many people experienced a change in their circumstances as a result of using the service and what did they receive in respect of aids for daily living, personal support, adaptations to the home or new housing?

To consider these questions which are answered in the following sections, information was recorded on all 450 people who made enquiries about the service from 1985 until March 1988.

The DPHS recorded information about the users of the service from its inception in order to monitor its progress and practices. At the time of the initial approach to the service, basic information is recorded including name, address, age, source of enquiry and an outline of the problem to assist the Housing Advisor and other DPHS staff when making the home visit. Following this visit, information is expanded to record more precisely the person's home and support circumstances, for example, mobility details, physical impairment, housing tenure, income, family circumstances and services already received. The DPHS proposed course of action is also recorded with review dates to monitor progress.

However, this information could not reveal the answer to a fourth major question - to what extent had the outcome or use of the service enhanced people's quality of life and how satisfied were they with the help they had

received? In order to answer this, 45 people who had used the service were interviewed in their homes to ascertain their opinions of the DPHS and whilst these experiences are discussed in more detail in the next chapter, some of the information provided by this sample is used here for illustration.

**WHO USES THE SERVICE?**

Between 1985 and March 1988, 426 households approached the DPHS for assistance. Another twenty-four enquiries were received which were termed as 'non-users' being variously enquiries directly concerning the methods of the DPHS, for example from researchers and other housing or care organisations; from individuals or bodies seeking DPHS expertise, for example, an hotel seeking information about access and design requirements for disabled guests. It is worth noting however that these 24 enquiries do not represent adequately the amount of interest aroused by the development of the DPHS which has received enquiries and visits from a range of interested parties during the study period. The enquiry from the hotelier cited above is interesting in that it highlights the way in which the DPHS expertise is now recognised locally and their role as design consultants is one which could be perused to generate income for the service. The DPHS has been keen to share its experience and the lessons it has learned during its pilot phase with other housing associations, disabled people's organisations and professionals. For example, the DPHS, together with people who have used the service, have been advising a group of disabled people in Coventry whose group home is due for closure and who wish to explore the options concerning independent living: visits to an appropriate Walbrook housing scheme have been organised and discussions held between the Coventry group and Walbrook tenants who have left institutional life in order that their experiences and opinions can be shared.

Generally, the DPHS received enquiries from a wide range of people and a profile of service users is given below in respect of:

age

gender

household composition and marital status

nature of physical impairment

mobility

employment

ethnic origin

housing tenure

location

how contact was made with the DPHS

(a) **Age**

Details of age were obtained from 418 of the 426 people who approached the DPHS. The details are set out in Table 1. On the whole there was a fairly even balance between the proportion of people from the 'younger' age groups (under 60 years) approaching the service (54%) and 'older' (over 60 years) age groups (46%).

**Table 1: Age Distribution (n=426)**

| Age group | No. of people | Per cent of total |
|---|---|---|
| 0 - 15 yrs | 16 | 3.8 |
| 16 - 19 yrs | 4 | 0.9 |
| 20 - 29 yrs | 43 | 10.1 |
| 30 - 39 yrs | 47 | 11.0 |
| 40 - 49 yrs | 41 | 9.6 |
| 50 - 59 yrs | 70 | 16.4 |
| 60 - 69 yrs | 80 | 18.8 |
| 70 - 79 yrs | 86 | 20.2 |
| 80 yrs and over | 31 | 7.3 |
| Age not known | 8 | 1.9 |
| TOTAL | 426 | |

The National Disability Survey (OPCS, 1989) shows that the prevalence of disability increases with age (58 per 1,000 aged 16-19 years and 355 per 1,000 aged 60 years and over) and therefore one might have expected a higher percentage of users to be over 60. However, it is important to stress that the 426 people studied are not a representative sample of the national or Derbyshire population as a whole, but a cohort of people actively seeking alternative or supplementary housing and/or support solutions to those provided by the statutory sector. We do not have, unfortunately, similar data from the respective social services, health or local authorities to compare the age distribution of those receiving disability-related services across the spectrum of statutory care. It could be argued that motivation amongst the younger age groups to use a service such as the DPHS might be higher, also that a proportion of elderly disabled people in Derbyshire have already received housing/care solutions through statutory or private sheltered and

residential accommodation.

The OPCS also found that "there are considerably more disabled women than men at all except the lowest severity levels ... however, women outnumber men substantially only at higher ages". The information on 426 main DPHS users supports this finding.

(b) **Gender**

The 426 people studied showed a similar trend to that of the OPCS data when age and sex were examined.

Table 2: **Gender and Age**

| | % male | % female |
|---|---|---|
| 0 - 15 yrs | 62.5 | 37.5 |
| 16 - 59 yrs | 50.7 | 49.3 |
| 60 - 74 yrs | 46.1 | 53.9 |
| Over 75 yrs | 36.6 | 63.4 |
| ALL USERS | 47.7 | 52.3 |

(c) **Household composition and marital status**

(i) Household composition

The 426 files were analysed on the basis that the primary user was the person considered by the DPHS to be most disabled by their housing or care circumstances. Of these 426 households, 338 (79%) refer to households where

only one person was disabled; 81 (19%) refer to two disabled people; five households (1%) had three disabled people; and two households had four or more disabled people. The total number of disabled people having contact with the service was therefore 525.

Some people lived in residential or group homes at the time they contacted the DPHS, however, we have not included details of fellow residents in these circumstances unless they too were seeking help from the DPHS.

Given that disablement has implications for all members of a family it should be noted that these 426 households represent a total of 957 people known to the DPHS as being, or living with, a disabled person - all of whom will be affected to a greater or lesser extent by the outcome of the service.

To estimate the availability of potential informal care, information was collected on the size of each household using the service.

**Table 3: Household Size**

| No. of people in household | % of households (n=426) |
|---|---|
| 1 | 33 |
| 2 | 36 |
| 3 | 16 |
| 4 | 8 |
| 5 | 4 |
| 6 and over | 3 |

A third of people using the DPHS therefore lived on their own and whilst the precise support needs of each individual is not known, nor their access to such help from outside the household, for example through friends or relatives, given the present-day move towards care in the community, and the important role of informal carers, this figure is worth noting. It was found that women, in particular, had less recourse to potential informal care within the home: over 40% lived alone; and women lived in smaller-sized households.

**Table 4: Household Size by Sex**

| No. of people in household | % of all males | % of all females |
|---|---|---|
| 1 | 26 | 40 |
| 2 | 41 | 31 |
| 3 | 16 | 15 |
| 4 | 9 | 7 |
| 5 | 4 | 4 |
| 6 and over | 4 | 2 |

All of the under-16 age group and 81% of those in the 16-59 year age group lived in households with only one disabled person. Of those in the elderly age group, 76% lived in households with one disabled person.

(ii) Marital status

The marital status of users was as follows:

**Table 5: Marital Status**

| | Number of people | Per cent of total |
|---|---|---|
| Married/partner | 187 | 44 |
| Single | 107 | 25 |
| Widow(er) | 88 | 21 |
| Divorced/separated | 38 | 9 |
| Status unknown | 6 | 1 |
| TOTAL | 426 | 100.0 |

When the above data are analysed by age they show, predictably, that a much higher percentage of elderly people are widows/widowers and far fewer in this group are divorced or separated. Over a third of the younger disabled people who approached the service were single.

Major differences were found in the marital status of the sexes: fewer women were married (37%) then men (52%) and fewer women were single (19%) compared to men (32%). There was no significant difference in the divorce pattern, but women far outnumbered men with regard to bereavement: 34% of women were widows, and only 6% of men were widowers.

**Table 6: Marital Status by Age**

| | Percentage of people aged: | | |
|---|---|---|---|
| | 0-15 years | 16-59 years | Over 60 years |
| Married/partner | - | 44 | 49 |
| Single | 100 | 35 | 8 |
| Widow(er) | - | 5 | 39 |
| Divorced/separated | - | 16 | 2 |
| Status unknown | - | - | 3 |

(d) **Physical impairment**

The physical impairments people experienced were categorised as follows:

| Category | Description |
|---|---|
| 1. | Congenital/genetic conditions |
| 2. | Heart/respiratory/blood/endocrine conditions |
| 3. | Bone tissue conditions (e.g. arthritis) |
| 4. | Nervous system/brain/spinal cord/meninges |
| 5. | Muscular conditions |
| 6. | Mental handicap and mental illness |
| 7. | Conditions associated with being 'frail elderly' |
| 8. | Sensory impairments |
| 9. | Injuries/amputations |
| 10. | Cancers |
| 11. | Bladder/bowel conditions |
| 12. | Dermatological conditions |
| 13. | Other |

In the main, the DPHS only records conditions which were relevant to the person's housing and personal support needs and where those conditions (generally chronic but sometimes acute) had implications for mobility or dexterity and housing design and accessibility. Unlike local authority housing departments who, when allocating property, usually require evidence concerning an individual's medical condition for prioritisation purposes, the DPHS relies instead on people's own definitions of their problems. A person's complete medical history is not necessarily known and therefore the following information may understate the extent of health problems actually experienced.

Findings for the primary user only (not other members of the same household who may be disabled) showed that half of the people experienced one impairment; a further 28% experienced two impairments, and 22% of people experienced three or more impairments. The percentage of people experiencing impairments in each category is as follows.

**Table 7: Frequency of Impairments, Primary User Only**

| Category | Percentage of users | No. of people |
|---|---|---|
| Congenital etc | 3 | 11 |
| Heart etc | 29 | 126 |
| Bone etc | 42 | 177 |
| Nervous system etc | 47 | 201 |
| Muscular etc | 3 | 13 |
| Mental handicap/illness | 8 | 34 |
| Frail elderly | 2 | 9 |
| Sensory | 15 | 62 |
| Injury etc | 11 | 47 |
| Cancers | 1 | 5 |
| Bladder/bowel | 6 | 27 |
| Dermatological | 2 | 8 |
| Other | 4 | 17 |

Thus the most frequently cited impairment referred to problems of the central nervous system, brain, spinal cord or meninges. This includes people who are most likely to experience paralysis as a result of their impairment (including ex-stroke patients).

The second highest category refers mainly to the condition of arthritis and to a lesser extent rheumatism and spinal injuries, and ranged from those with severe arthritic disablement to those with relatively minor impairment.

The figure of 6 per cent almost certainly understates the number of people with bladder or bowel dysfunctions in that these conditions are often inherent in some forms of paralysis and with ageing, and may not have been recorded separately by the DPHS.

When examining impairment data by age, the frequency of experience in each age group is given in Table 8.

Information on the prevalence of each medical condition within the categories shows that strokes, heart disease and arthritis are frequently experienced as in the population nationally but there were significant differences between the sexes. A total of 36% of all males experienced problems in the heart/respiratory category compared to 22% of women. Over half of all women (52%) experienced impairments relating to arthritis and similar conditions compared to 31% of men.

Children (under 15) using the service were more likely to be severely disabled from birth and to experience some form of mental handicap. Parents

contacting the DPHS were often acutely conscious of the need to not only maximise their child's current independence, but to prepare for their future autonomy.

**Table 8: Impairment by Age**

| Category | % of children | % 'younger' age group | % elderly people |
|---|---|---|---|
| Congenital etc | 25 | 3 | - |
| Heart etc | 25 | 18 | 41 |
| Bone etc | 19 | 31 | 55 |
| Nervous system etc | 62 | 61 | 31 |
| Muscular etc | 12 | 4 | 1 |
| Mental handicap/illness | 31 | 11 | 3 |
| Frail elderly | - | - | 5 |
| Sensory | 12 | 14 | 15 |
| Injury etc | - | 13 | 10 |
| Cancers | - | 1 | 2 |
| Bladder/bowel | 6 | 8 | 4 |
| Dermatological | - | 1 | 3 |
| Other | - | 2 | 7 |

The above figures do not, of course, indicate the degree of severity and cannot inform us of the quality of life of each individual and the extent to which he or she is 'disabled'. In this respect the DPHS staff, in their assessment process, take account of the individual's physical condition in the overall context of their environment in addition to factors such as mobility, family and household circumstances, and personal preferences. Clearly, however, it is often necessary for the service to establish a prognosis for each person in that whether a condition is degenerative, stable or likely to improve will influence the housing and personal support solution pursued, and assessment of mobility (to what extent an individual can walk, lift, bend, stretch, climb, etc) is important to determine how best to design an environment in which disability can be mitigated.

(e) **Mobility**

The DPHS classified the mobility of people seeking assistance in the following way:

Group 1 - people who are bed-bound
Group 2 - people who are wheelchair-bound
Group 3 - people who are wheelchair-bound but are able to stand and transfer
Group 4 - people able to walk indoors but who use a wheelchair outdoors
Group 5 - people able to walk with walking aids (Zimmer frame, sticks)
Group 6 - people able to walk without help

It should be stressed, however, that this assessment of mobility does not necessarily relate to the degree of illness, pain or discomfort experienced by people using this service. For example, some people in the sixth group who are able to walk may, in fact, experience pain when walking but they do not use walking aids. Similarly, others who are able to walk may be extremely ill, for example, with cancer.

The DPHS system for categorising mobility helps the staff to address the possible practical requirements a person might have, for example, the need for wheelchair access, hoists, stairlifts or rails. It is nevertheless only one factor in the total assessment process which takes into account above, all, the person's preferences and his or her own definition of the problem. The pattern of mobility of the primary users is set out below.

**Table 9: Mobility Group, Primary User by Sex**

| Group | % of total users (n-426) | % male | % female | % of total males (n=203) | % of total females (n=223) |
|---|---|---|---|---|---|
| Bed-bound | 2 | 29 | 71 | 1 | 2 |
| Wheelchair-bound | 14 | 61 | 39 | 18 | 10 |
| W/chair bound but able to transfer | 14 | 51 | 49 | 15 | 13 |
| Walk indoors, w/chair outdoors | 18 | 41 | 59 | 15 | 20 |
| Walk with aids | 24 | 47 | 53 | 24 | 24 |
| Walk without aids | 29 | 45 | 55 | 27 | 30 |
| Not known | 1 | 50 | 50 | 1 | <1 |

Where other members of the household were disabled the overwhelming majority were able to walk without help or aids.

As noted in the information regarding physical impairment, the majority of people in the so-called 'severely disabled' group (either bed or wheelchair-bound) were in the younger-disabled age group and 56% of children using the service were either bed-bound or wheelchair-bound. Only two of the children (13%) did not use a wheelchair compared with 49% of those aged between 16 and 59 years and 58% of those in the elderly age group.

Just over half of all people using the service (52%) were ambulant with or without aids confirming that disability is not synonymous with wheelchair use.

The figures showed that men aged between 16 and 59 were much more likely than women of the same age to be using a wheelchair or relying on walking aids to walk about whilst many more women than men could walk about unaided indoors but had to use a wheelchair outdoors. There were also more women who were ambulant than men.

Conversely, in the over 60 age groups, elderly women were much more likely than men of the same age to be restricted to their beds or to a wheelchair - no men were in the 'severe disablement' groups and taking the 75+ age group separately, women significantly outnumbered men in all mobility groups except group 4.

(f) **Employment**

Whilst information on age, sex, physical impairment and mobility revealed that DPHS users were extremely diverse in their characteristics and reflected a wide cross-section of people, in other respects people shared the same experiences.

Altogether 223 of the users were assessed as being within the working age groups 16-60 years for women, or 16-65 years for men, yet 85% of these people were unemployed. Only 29 people out of 223 had either full-time or part-time work, the majority of workers being men. Five other people were in education.

The DPHS try to ensure that they have an accurate picture of people's levels and sources of income (for example which welfare benefits are received) where this will have a bearing on the person's request for assistance. This

information was therefore only available for a limited number of households and has not been analysed for the 426 people studied. However the 45 people subsequently interviewed were asked about their own (and household) income and its sources at the time they contacted the DPHS and the findings from this sample revealed low income levels, particularly amongst those living alone.

### (g) Ethnic origin

The ethnic origin of people seeking help from the DPHS also shows uniformity. In Derbyshire the 1981 Census recorded 2.5% of the population as "being born" in the new Commonwealth or Pakistan (22,064) and 4.3% of children living in NC/Pakistan households. A total of 0.3% of the Derbyshire population were recorded as being born in the Caribbean countries. The overwhelming majority of ethnic minority families in Derbyshire live in Derby city - 81% of those from Pakistan and the New Commonwealth and 78% of those from the Caribbean. The Pakistani community is found to be the less mobile and 93% of people live in Derby city with 81% of the county's Pakistani population living in just two city wards. The Census data found a significant correlation between those communities with both overcrowded housing and a lack of plumbing amenities.

Given the above figures for the ethnic minority population in Derby city it was therefore interesting to find that over 95% of the 426 DPHS users were classified by the DPHS as "white British" when the DPHS is committed to providing a service to all sections of the community. The DPHS experience is at variance to that of Walbrook Housing Association who have a substantial proportion of ethnic minority tenants and who own housing stock within traditional ethnic minority areas of Derby. By contrast, discussions with

staff at the SW Derby area office of the Social Services Department, revealed a high number of referrals from the ethnic minority population for mobility aids, adaptations and services in respect of physical disability. There did not appear to be any evidence that this section of the population had fewer needs in respect of disability-related services.

The housing association movement nationally has paid considerable attention to the accommodation needs of ethnic minorities over the past few years and there are now a number of specialised associations catering for - and administered by - members of these communities. Discussions with the Derby Council for Racial Equality (Health and Social SErvices Panel) revealed a divergence of opinion as to why ethnic minorities in Derby might not use the DPHS. It was felt by some that the DPHS had not been targeted sufficiently to this community and that non-English language publicity material needed to be extended. The Derbyshire Centre for Integrated Living has a designated linkworker for the ethnic minority community and all their literature is available in translated versions. Others on the Panel felt, however, that the ethnic minority population would be made aware of the DPHS through the aegis of community workers allied to social service departments.

It was also speculated whether Walbrook itself was culturally relevant, particularly to the Asian community. Specialised housing associations in other parts of the country (such as ASRA) have found the need to develop, for example, sheltered housing which accords with the cultural needs of elderly Asian people. They found that Asian people requiring warden controlled accommodation were deterred from taking up tenancies in majority-white complexes (or areas) where language problems and cultural misunderstandings might occur and where wardens and other staff were unable to relate to the

specific needs and customs of all their tenants. Studies (Blakemore, 1982) in other areas have shown that the extended family system within the Asian community is undergoing a process of change and there are a growing number of particularly elderly people living alone. It remains to be seen what pattern of informal care exists within the Asian communities of Derby. A report by the Greater London Association of Disabled People in 1987 highlighted some of the cultural differences which might affect uptake of services for physically disabled people (GLAD, 1987) and members of the Derby Council for Racial Equality felt that more research was required in the Derbyshire area regarding the specific needs of physically disabled people from all cultures.

### (h) Housing tenure

People's housing tenure at the time they contacted the DPHS is given in Table 10.

The number of people specified as homeless should be considered in conjunction with the number of people living temporarily with friends or relatives who may be dependent on the goodwill of others to prevent homelessness. These figures refer to the main tenure category of the user only and in fact, 33 people mentioned "homelessness" as one of the reasons for contacting the DPHS (see Table 14) in that they were living in other people's property on a short-term or longer-term basis. A third of the people in this category in Table 10 were in the over-60 age group.

**Table 10 Tenure**

| Tenure category | No. of users | % of total |
|---|---|---|
| Owner occupier | 148 | 35 |
| Council tenant | 103 | 24 |
| Walbrook tenant | 81 | 19 |
| Private tenant | 25 | 6 |
| Other housing association tenant | 23 | 5 |
| Living with friends or relatives temporarily | 18 | 4 |
| Private or voluntary organisation residential care | 8 | 2 |
| Local authority/social services residential care | 7 | 2 |
| Hospital/NHS accommodation | 2 | 1 |
| Homeless | 2 | 1 |
| Not known | 9 | 2 |
| | 426 | |

The two people specified as being in NHS care understates the number of people who were in hospital when the DPHS was contacted. It was frequently the case that such in-patients were in rehabilitation wards (for example, following strokes) until suitably accessible housing could be found. However, some of these patients did have housing elsewhere, albeit perhaps unsuitable for their mobility needs, and it is possible that they would have been eventually discharged to that housing had not the DPHS or other agencies intervened.

In 14% of the records it was not known how long the individual had occupied their particular housing, but the remainder showed that just over a third of people had lived in their home for between one and five years; 15% had lived in their home for over twenty years, whilst 11% had been in their housing for just a few months prior to contact with the DPHS.

A quarter of people lived in semi-detached properties and one in five were in terraced housing (the largest proportion, 44%, being owner-occupiers and 27% being Walbrook tenants). Bungalows are often seen as being particularly practical dwellings for people with disabilities, especially wheelchair-users. Nevertheless, 12% of people approaching the DPHS for assistance already lived in bungalows (over a third of which were owned by local authorities) and were experiencing difficulties.

Prior to these findings it had been anticipated that a high proportion of those seeking housing advice might be owner-occupiers whose requirements for alternative housing or adaptations would not be identified by statutory housing authorities. Whilst owner occupiers did represent over a third of all DPHS users, it was interesting to note that nearly a quarter of users were in council housing and 11% of users were in privately rented accommodation (either with private landlords or housing associations other than Walbrook), that is, in situations where mobility problems and housing difficulties should have been known to housing agencies. Indeed, a majority of council house tenants in the sample were wheelchair-users.

The overall pattern showed that the DPHS was attracting interest from people who experienced a wide range of housing circumstances.

With regard to personal mobility a small majority of people who were owner-occupiers, private tenants and tenants of other housing associations (52% in each tenure group) did not use a wheelchair. In the case of Walbrook tenants, however, 72% did not use wheelchairs. Council tenants were more likely to use wheelchairs (62%).

The type of housing occupied by people who used a wheelchair was as follows:

**Table 11 Wheelchair Use by Type of Housing**

| Housing type | Number of people (n=426): | |
|---|---|---|
| | Using wheelchairs | Not using wheelchairs |
| Detached | 7 | 11 |
| Semi-detached | 54 | 51 |
| Bungalow | 37 | 14 |
| Terraced | 30 | 55 |
| Ground floor flat | 35 | 38 |
| Above ground floor flat | 8 | 23 |
| Hospital/residential home | 13 | 5 |
| Other (eg, caravan, bed-sit etc) | 4 | 7 |
| Housing type unknown | 14 | 20 |
| TOTAL | 202 | 224 |

Therefore just under half of those using wheelchairs lived in accommodation with more than one storey. Whilst it was not recorded how many of these people had facilities on the ground-floor, for example downstairs bathrooms and toilets, or had access to their upper storey through stairlifts or lifts, it is likely that most of these people experienced great difficulty getting around their homes.

One person interviewed lived in an inner-city (two-up, two-down) terraced property where wheelchair access was extremely limited. This person was unable to reach the first floor and therefore a bed had been brought downstairs resulting in cramped conditions and a loss of privacy; an experience all too common. Toilet and bathing facilities were also upstairs so a commode was used and a bowl for all-over washing. Getting around downstairs was also limited by narrow doorways and there were problems using kitchen facilities. The DPHS recommended that a lift between storeys could be installed, that the bathroom could be adapted and the kitchen floor raised to enable wheelchair access. Subsequently, social services (using grant aid) provided ramps to the garden and inside the house and a lift in one corner of the living room to reach upstairs. This person was awaiting the provision of a raised bathroom floor, a new bath, a sit-in shower and a raised w.c. and a relative had carried out the work to raise the kitchen floor.

It was also the case that relatively minor changes inside the home, for example to the height of working surfaces, were all that was required to increase a person's autonomy and improve quality of life.

As stated previously, the categorisation of people as 'severely' or 'partially' disabled according to their functional limitations can only be one limited indicator of an individual's quality of life. People were interviewed who were wheelchair-bound and who, within any classification method, would be termed as severely disabled, but they were leading what they described as independent and fulfilled lives. Conversely, some people who could walk and some who used wheelchairs less often felt themselves to be extremely restricted in their independence and frustrated in their daily lives prior to receiving help from the DPHS.

### (i) Location of users

From the outset the DPHS aimed, in principle, to provide a county-wide service open to all - there being no eligibility criteria for using the service. In theory the service has stipulated that users should be resident in, or have links with, the county, but in practice this restriction has been exercised sympathetically to assist those, who, for example, wish to move to Derbyshire for employment, or to be closer to relatives. Where possible, the service will offer advice to those people living outside the county and will refer people to their own local provider agencies. There is no restriction on the part of the Housing Advisors or other staff in pursuing enquiries in outlying areas - enquirers in all parts of the county are visited and dealt with on an equal basis and people living away from Derby have not had to wait longer for a home visit. Nevertheless, the DPHS has developed most extensively in the Derby city area, where it is based, and has yet to receive enquiries to any great extent from other parts of the county as the following table shows:

**Table 12 Original Location of User**

| Area[1] | Number of users | % of total users | |
|---|---|---|---|
| North West Derby (city) | 105 | 25 | ) |
| South West Derby (city) | 88 | 21 | ) 76% |
| South East Derby (city) | 85 | 20 | ) of |
| North East Derby (city) | 45 | 10 | ) total |
| Outside Derbyshire | 25 | 6 | |
| Amber Valley | 23 | 5 | |
| South Derbyshire | 21 | 5 | |
| Erewash | 13 | 3 | |
| Bolsover | 8 | 2 | |
| High Peak | 5 | 1 | |
| Derbyshire Dales | 4 | 1 | |
| Chesterfield | 3 | 1 | |
| North East Derbyshire | 1 | <1 | |
| TOTAL | 426 | | |

NOTE: (1) County Social Services geographical boundaries

The 426 households analysed do not represent only those where people pursued the recommendations of the DPHS - they also include people who later withdrew from using service, or who were unable to be helped for some reason by the DPHS. The figures in Table 12 therefore reflect the number of enquiries received from the various areas of the county.

**(j) How contact was made with the DPHS**

Information was collected on how each person found out about the service, or which referral route had been used. With regard to the statutory services, a differentiation was made between those who contacted the DPHS via its own publicity made available in statutory service offices, and those people who were referred directly by professional workers.

The figures show that despite publicity attempts, there have been few people outside Derby city who have responded to media publicity or advertising leaflets about the service. The DPHS, via its umbilical link with Walbrook, has the advantage of inclusion in Walbrook's general housing association publications, but funds for DPHS-specific publicity have been limited. Any similar service established independently which seeks to pursue an open door policy will need to assess its advertising needs and budget accordingly.

Word-of-mouth is obviously one of the most important ways of disseminating information amongst a community and clearly, where there are few people in an area with experience of the DPHS, common knowledge about the service will be limited. Elderly people were found to be particularly likely to have heard of the service through friends or relatives.

i) Contact through the Derbyshire Centre for Integrated Living

Contact via the DCIL and also the Derbyshire Coalition of Disabled People (DCDP) was found to be limited, but evenly spread throughout the county despite the DCIL location several miles from Derby. Nine out of ten DCIL contacts were in the younger-disabled age group.

ii) Contact through Walbrook Housing Association

An important route of contact was through Walbrook itself as one might expect (29% of users). The concentration of Walbrook property in and around Derby and the use of the DPHS to provide a service to its tenants will result inevitably in this being a major factor and will account, in part, for the

greater proportion of service users coming from Derby city.

However, whilst 19% of all people were existing Walbrook tenants (81 households) none of whom lived outside Derby city, it was interesting to note that a high proportion of these (over 40%) did not contact the DPHS via the housing association.

As with any other group of individuals, Walbrook tenants will differ in their perception of their own needs, how they should be met, and by whom. They may not consider themselves as 'disabled' and therefore awareness of the DPHS in itself may not prompt them to seek assistance from the service. They may be unaware of the division of responsibility between Walbrook (their landlords) and social services for example, regarding the provision of mobility aids and housing adaptations and may seek statutory support first. This is also likely where people are already in receipt of services or help regarding mobility problems or where they have regular social worker contact and access to a system of provision.

Altogether 22% of Walbrook tenants were referred to the DPHS by area social services teams as in the example of a woman with a number of medical conditions who experienced difficulty getting in and out of her bath. She approached her general practitioner in the first instance and the GP then referred her to social services. Social services in turn contacted Walbrook regarding adaptations to her home. This tenant felt that her mobility problems were primarily the concern of her doctor, even though she had direct local access to her landlord through an on-site Walbrook warden.

Interviews with Walbrook tenants included two other people who had been referred to the DPHS after contacting social services first. In these instances people had sought social worker support on other matters and it was in the process of social services assessment that their mobility needs had come to light.

Another woman interviewed who subsequently received adaptations to provide a shower, raised w.c. plus additional poles and rails in her home had fortuitously met and discussed her problems with the DPHS Housing Advisor. She had not contacted Walbrook before because she did not want to "trouble" them for anything. She felt very grateful for all they had done for her as landlords and did not "like to put them to any bother". In fact, she offered to pay for the rails herself but was reassured that this was not necessary. She was not deterred from seeking support elsewhere, indeed she had been engaged in prolonged discussions with social services over their proposal to reduce her home help entitlement.

It may be anticipated that Walbrook tenants will continue to represent a high proportion of those using the service, particularly as an increasing number of disabled people become tenants and their needs and preferences for mobility aids, personal support and adaptations change over time.

iii) Contact through social services

In social services area offices there was no formal referral procedure to the DPHS. Referrals came from social service Occupational Therapists and staff such as social workers by mail or telephone, asking for the DPHS to

visit someone and assist in whatever way possible. A majority of all social service referrals, which accounted for 15% of enquiries to the services, were from the "younger-disabled" age group.

iv) Contact through other housing associations

A small number of people (16) were referred to the DPHS by other housing associations who asked the DPHS to visit their tenants so that recommendations could be made regarding adaptations or daily living aids. In these situations the other housing association is the 'client' of the DPHS and the householders involved usually do not see themselves as being direct 'users' of the DPHS. For example, a person living in a housing association flat was a recent stroke patient whose mobility was gradually improving and her eventual requirement for mobility aids was unknown. Her landlords contacted the DPHS to advise on her immediate need for bathroom adaptations and the DPHS visited and recommended referral to social services for bathing aids. On being interviewed, this person had no comments to make about the DPHS service per se. She did not realise fully that another agency had been involved in the assessment and provision process - her relationship was with her own housing association.

In another instance the tenants contacted their GP initially over problems with bathing. The GP then contacted their housing association as landlords, who in turn referred to social services. However, being told by social services that an assessment visit could not be made for three months, the housing association sought help from he DPHS who were able to visit the tenants within a few days. The DPHS recommended adaptations which the housing association then carried out.

Overall from the information gathered, it was clear that users had learned of the DPHS through a variety of sources ranging from statutory agencies to voluntary groups and outlets for public information, but by far the largest source of referrals came from within Walbrook Housing Association itself through its housing management system or through the association's initiatives in publicising the service locally.

**WHY DID PEOPLE SEEK HELP?**

Although problems with accommodation are the main cause for people seeking help from the DPHS, the very nature of the problems faced by disabled people as explained in Chapter One means that several concomitant problems will need to be tackled if the person seeking help is to lead a satisfactory, independent life. The details of the reasons for people seeking help from the DPHS show the predictable pattern of housing difficulties interspersed with other problems of low incomes, diverse needs for help with self-care, unsatisfactory neighbourhoods and access to the various agencies who provide community care. In response to this variety of needs, the DPHS has to act in a number of ways: as a provider, as a referral agency, as an advisor, an advocate, and as a co-ordinator of a multiplicity of services.

**Housing and associated problems**

The 426 people who approached the service experienced a variety of problems in the home either through lack of appropriate amenities, design and access considerations or lack of domiciliary support. People sometimes seek help with relatively minor problems - for example, the 'fine tuning' of aids for daily living or equipment for ease of use - or with a number of

interrelated problems requiring the coordination of internal (DPHS/Walbrook) and external (social service/health services/local authority) resources.

It is unusual for people to experience problems with just one aspect of their home. For example, where stairs are difficult to manage they may well also find that they cannot reach the bathroom or toilets easily. Other people have difficulty actually using these facilities rather than just reaching them. Table 13 shows the range and extent of difficulties people were experiencing in getting around their home. A much higher level of difficulty was revealed in the sample of 45 people interviewed in greater depth as discussed in the next chapter which looks at some of these problems in more detail.

i) Access

Whilst a majority of people in each mobility group had no problems getting in and out of the home, it was interesting to find that nearly a third of those who experienced problems with this access (32%) did not use a wheelchair. People who were able to get around on one floor often found steps and stairs difficult or impossible to climb. As previous findings showed, only a proportion of people using the Disabled Persons' Housing Service were wheelchair users and people with, for example, heart and respiratory conditions were often equally disabled by their environments. A quarter of people having problems with stairs were able to walk unaided. Door handles, locks, and window=catches that require a firm grip may be unusable for those people with arthritis as well as those with paralysis, decreasing people's ability to use their living space to the full and putting a question mark against the issue of personal safety and ability to live with the minimum of

Table 13 Main Housing Problems by Mobility

% of Each Mobility Group[i] (No of People):

| | Bed-bound | | Wheelchair bound | | Wheelchair bound - able to transfer | | Able to walk indoors W/chair outdoors | | Able to walk with aids | | Able to walk | | Not known | | Total | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| Problem area | % | No | % | No | % | No | % | No | % | No | % | No | % | No | % | No |
| Access | 43 | (3) | 39 | (23) | 29 | (17) | 35 | (27) | 17 | (17) | 13 | (16) | 50 | (1) | 24 | (104) |
| Circulation | 71 | (5) | 46 | (27) | 39 | (23) | 20 | (15) | 12 | (12) | 4 | (5) | - | | 20 | (81) |
| Stairs | 86 | (6) | 37 | (22) | 30 | (18) | 55 | (42) | 46 | (46) | 36 | (44) | 50 | (1) | 42 | (179) |
| Bathroom | 71 | (5) | 54 | (32) | 49 | (29) | 50 | (38) | 49 | (50) | 33 | (40) | - | | 46 | (194) |
| Toilet | 57 | (4) | 44 | (26) | 34 | (20) | 30 | (23) | 15 | (15) | 7 | (9) | - | | 23 | (97) |
| Kitchen | 43 | (3) | 36 | (21) | 34 | (20) | 21 | (16) | 12 | (12) | 6 | (7) | - | | 19 | (79) |
| Bedroom | 57 | (4) | 39 | (23) | 24 | (14) | 18 | (14) | 9 | (9) | 7 | (8) | - | | 17 | (72) |
| Lounge | 43 | (3) | 22 | (13) | 15 | (9) | 8 | (6) | 1 | (1) | 2 | (2) | - | | 8 | (34) |

(i) Percentage total more than 100% because some people experience more than one problem.

personal support.

Altogether approximately one in five of those people experiencing problems moving in and out of rooms (circulation) also did not use a wheelchair. An example of this situation being a person who had had his leg amputated. His motive for contacting the DPHS (via Walbrook, his landlords) was that the step into his kitchen was too high and he could not negotiate it easily even when using a stick and Walbrook subsequently fitted hand-grips to the kitchen doorposts to assist him.

Again, apart from those who were bedbound, a large majority of people in all mobility groups had no problems getting in and out of rooms although a number of service users already had ramps, rails or other ways of achieving easier circulation around the home.

ii) Bathrooms

Nearly half (46%) of all the people requesting help had problems with bathrooms and, as may be expected, this was particularly noticeable amongst people who were bedfast (71%) or wheelchair-bound (54%).

Amongst all the people not using wheelchairs, 40% had bathroom problems and the sub-sample of 45 people discussed in the next chapter revealed a number of ambulant people with arthritic and other conditions whose ability to bathe was limited owing to the height of the bath, lack of grips, poles or other aids.

By contrast, with the exception of those people who were bedbound a majority of people in each mobility grouping experienced no problem using the toilet although this included a number of people already possessing toileting aids or specialised fittings or who had already had their homes adapted to provide greater space. As might be expected, the highest frequency of difficulty was found amongst people using wheelchairs.

iii) Kitchens

Excluding those people who were bed-bound who were unable to use a kitchen, the majority of people in each mobility group had no problems using this part of their home, but again those most likely to be experiencing problems were wheelchair users who often found kitchens particularly ill-designed in terms of working heights, space for wheelchairs under sinks and surfaces, and location of cupboards.

iv) Bedrooms

Apart from the problem of reaching upstairs bedrooms for those who did not have help with stairs, transferring between wheelchair to bed was often difficult and was exacerbated for those with small rooms with insufficient turning space for chairs.

v) Lounges

Living rooms often had features which caused difficulty for people necessitating the support of others, for example, inaccessible power-points or light switches, fires which were difficult to make or use.

**Other problems**

It is one of the central strengths of the DPHS that people are offered help more than on the basis of 'straight-forward' housing problems. For example, problems of loneliness and the neighbourhood may, in fact, be the sole reasons for an approach to the DPHS and these worries are given equal consideration by the DPHS when pursuing options with the individual even to the extent of re-housing. Data on these 'indirect' problems were categorised and these are shown in Table 14.

The DPHS found that two-thirds of the people who approached them for help were experiencing one or more of the problems summarised in Table 14. For example, a person living as a tenant of another housing association experienced problems with noisy neighbours living in the flat above. Another couple had been rehoused by the council into ground-floor accommodation, but their main concern was their local environment. They experienced burglaries and vandalism and were afraid of local youths and children, feeling vulnerable to harassment. In the latter example, the location of housing, rather than the quality of housing itself, was the major cause for their concern. Some people were concerned about being able to keep pets if they had to move house or were finding difficulties coping with caring. A women who had felt unable to look after her family pet and provide support for her husband was extremely distressed at having to give up her pet and the importance of pets to their owners, especially where owners live alone, should not be understated. Some people approached the DPHS because Walbrook allow their tenants to keep their animals.

Table 14. Other Problems Experienced

| Problem category | Example | Number of people |
|---|---|---|
| Homelessness | Living with friends temporarily. | 33 |
| Wanting independent living | Wanting to move from parental home or from residential care. | 30 |
| Wanting to move location | To be nearer carers, to care for others, to find work. | 28 |
| Repairs/upkeep of home | House damp. House and garden too big to maintain. | 25 |
| Financial problems | House being repossessed by building society. | 25 |
| 'Fine tuning' | Cannot reach window handle. | 24 |
| Relationships | Wanting to marry. Marriage breaking up. | 22 |
| Accessibility | No room for wheelchair. Lack of space. | 20 |
| Heating | Too expensive. Inefficient. | 19 |
| At risk | Prone to falling. Frail. | 19 |
| Psycho-social problems | Stress. Loneliness. Depression. | 18 |
| Need for ground-floor accommodation | Lift to flat unreliable. | 17 |
| Lack of amenities | Too far from shops. No garden for child. | 16 |
| Overcrowding | Sharing house. Extended family. | 13 |
| Assessment/expertise | Other housing association seeking DPHS opinion. | 12 |
| Safety design | Need for toughened glass. | 11 |
| Neighbour problems | Noise in flat above. | 10 |
| Fear of crime | Vandalism. Hostile neighbourhood. | 9 |
| Bereavement | Unused to living and coping alone. | 5 |
| Local environment | Area too noisy. Too hilly. | 5 |
| Carer's health | Respite care needed. | 1 |

The range of problems listed here illustrates the advantage of having a service which can respond to a variety of circumstances. It is unlikely that a statutory authority would have the obligation or discretion to act on many of those issues which the DPHS was able to tackle. This complementarity of the DPHS with other statutory services was appreciated by the users and the agencies concerned.

Whilst many people interviewed felt that alternative housing was what they most wanted because their neighbourhoods or their homes were inaccessible, it was also the case that for a number of people the decision to move had not been an easy one to make. The need for accessible housing had to be weighed against several factors such as the potential loss of friends or neighbours in areas that were familiar to them, perhaps the loss of a garden which had been cultivated over a number of years or their location near to accessible shops or other amenities. Moving to new homes might also necessitate expenditure on curtains, carpets or other furniture.

**HOW DID THE DPHS RESPOND?**

The DPHS offers a range of services and these are described under eight headings (see Table 15). The majority of people required more than one form of advice or assistance. Often people will participate with the DPHS in a process of elimination - they may initially seek help with a housing adaptation only to find, after assessment or discussions with an architect, that re-housing is the only feasible option. Similarly, some people may initially request help with re-housing, but subsequently accept interim adaptations because of long waiting lists or the unavailability of suitable property.

**Table 15 DPHS Services Required**

| Service | Number of people | % of total[1] |
|---|---|---|
| Advice on: | | |
| Re-housing | 270 | 63 |
| Adaptation | 157 | 38 |
| Aids for daily living | 86 | 20 |
| Housing costs | 51 | 12 |
| Support services | 36 | 9 |
| Counselling for independent living | 31 | 7 |
| Training for independent living | 22 | 5 |
| Welfare benefits | 8 | 2 |
| Other (various) | 38 | 9 |

(1) Percentages total more than 100 as often more than one service is required.

There have been instances where people have had considerable help from the DPHS and Walbrook in terms of the provision of individually-adapted properties, counselling, and the coordination of services and have then changed their minds or been subject to changed circumstances which deter them from pursuing the recommendations. In this respect the DPHS have learned the value of adequate counselling and discussion to ensure, for example, that those people making more dramatic changes in their pattern of daily living are fully supported.

The above table shows the services required from and provided by the DPHS irrespective of whether that option was the one finally chosen by the service user. Each of the main services required is discussed in the

following sections.

**Re-housing**

Advice on finding alternative accommodation was asked for by 77% of people in the 16-59 year age group, 63% of households with children, and 50% of people over 60 years old and was clearly one of the major reasons why people approached the DPHS.

Unlike local authorities, the DPHS do not operate any grading or 'points' system for pursuing a request for housing, although in certain circumstances people's applications for housing may be placed 'on hold' until such time as their physical condition stabilises in order for the appropriate, long-term recommendations to be made.

However, where people go on to be placed on external waiting lists (for example, with local authority housing departments, other housing associations and social services) for re-housing, domiciliary support or aids and adaptations, they may then become subject to categorisation by other agencies regarding the urgency of their needs. In acting on behalf of an individual, the DPHS cannot, of course, intervene in the provision mechanisms or eligibility criteria of other agencies. Whilst the DPHS may act in an advocacy role to articulate someone's needs or by providing other agencies with an assessment or design profile, their direct role in assisting a family may end with the individual joining a queue for housing or other services, although the 'file' will not be closed finally until the DPHS is satisfied that their ability to help is at an end and people are free to re-contact the service at any time.

The service therefore sometimes appears to act as a direct substitute for the statutory occupational therapy services when the DPHS staff perform an assessment role only and refer someone for statutory assistance. The incentive for people to use the DPHS in this way is because, at present, the service is able to offer an almost immediate home visit and discussion of people's requirements and problems.

An example of this role was a person experiencing difficultly using the stairs in his home who learned of the DPHS through his local Stroke Club. The DPHS visited within a few days of this enquiry and advised on the suitability of a stairlift to allow access to upstairs rooms. As an owner-occupier he was referred by the DPHS to local social services staff, but it was twelve months before a stairlift could be installed. This person's 'file' remained open with the DPHS until they had ensured that the lift had been provided. This example shows, therefore, how the DPHS can act promptly in assessing requirements and making recommendations, but the problem was only solved after considerable delay in the provision system of another agency outside DPHS control.

In the case of people joining the Walbrook housing waiting list, the DPHS (through its close working relationship with the housing association staff) will be able to provide full information to assist Walbrook's Housing Management. Walbrook provides housing to a wide range of people who have particular accommodation or personal support needs, and within their overall housing allocation system, the needs of disabled people on the waiting list must be weighed against the needs of others. However, as with the DPHS the housing association does not operate a points system for the allocation of

properties. In practice, it was found that disabled people rise to the top of the waiting list comparatively quickly. Walbrook recognise that disabled people are handicapped in pursing housing solutions because they are less mobile than others on the housing waiting list and their opportunity to travel the area themselves to seek and view properties is constrained. It is also felt by Walbrook that since suitably designed housing for disabled people is at a premium, where such housing becomes vacant one's position on the waiting list will not be a barrier to provision - housing is fitted to the person, not the person to the housing.

**Adaptation**

Adaptation may refer to the modification of existing or alternative housing and may be small-scale, for example, a stair-rail, or large-scale, for example the necessity for a full ("Maxi") Design brief to ensure that the home environment is as accessible as possible. In the youngest age group 44% of the 16 families involved asked for advice whereas for people aged between 16-59, 30% sought advice and 44% of elderly people required advice on adaptations. Where Walbrook are the landlords, then they will undertake the adaptations (the costs being borne usually by the Housing Corporation) and the local authority grant system is used for owner-occupiers wishing to adapt their own property.

The DPHS will, where requested, prepare a Design Brief for the use of other agencies.

The data show that 11 people (3%) had a Maxi or "Mini" (smaller) Brief prepared for either newly constructed housing and that 60 people (14%) had Briefs prepared for adaptations or daily living aids. Again, the

recommendations of these Briefs may not, eventually, be pursued. The Brief has to be prepared on the basis of a very detailed assessment of the individual (and his/her family). The underlying principle adopted by the DPHS with regard to these detailed assessments is that architects cannot write them: it is the disabled person's role, in conjunction with the DPHS staff, to translate needs and preferences into written plans. The DPHS have found that whilst this Brief is often of major importance in ensuring that all the dimensions of the environment are suited to the person's requirements, it still needs to be complemented by a visual representation of that environment. The DPHS staff have now developed considerable skills in the preparation of sketches and plans (as opposed to architects' drawings) which can communicate to the designers, architects and builders the significance of often very precise details or features required by the individual. These plans will show how the person will use the total space within the home and their accuracy and suitability for short and long-term requirements therefore requires considerable collaboration between the individual concerned, the DPHS staff (using occupational therapy skills) and other relevant personnel. Where users of the service require a Design Brief they are encouraged to produce a list of activities which they need and want to do in the home, or a list of mobility and personal authonomy goals they wish to achieve. Equally, there may be tasks or activities which the individual does <u>not</u> wish to do for themselves or which members of the family prefer to carry out and these personal preferences also have to be catered for in preparing a comprehensive plan for the design and/or construction of the dwelling. The Brief will not only concentrate on basic daily living activities such as cooking or washing but will also take account of hobbies, the need to work from home and the requirements of other family members, friends or partners.

It is recognised that needs can change over time and the Design Brief needs to be continually updated in the light of increased or decreased mobility, or improved or deteriorating health, a change of circumstances, or altered preferences. This is particularly important in the case of people moving to a new home or where major adaptations take some months to complete. Because of the obvious time lag between the preparation of original plans and new homes being built, the DPHS try to ensure that people are able to visit the construction site to see progress and, as early as possible, get the 'feel' of their new home.

**Aids for daily living**

This aspect of the service refers not only to the provision of standard aids for daily living, usually provided through social services, but also to customised gadgets and equipment for use around the home. Only one of the 16 families with young people requested this advice, but 20% of the elderly people and 17% of people aged 16-59 years sought advice on daily living aids. Where necessary the DPHS staff will help the user shop for specific items and, whilst not strictly speaking 'aids', household items such as kettles, cookers and so on will be tested to see which design most suits the individual. The DPHS have found, for example, that microwave cookers are particularly useful instead of standard ovens since they can be located at a convenient height and can often be used by people in wheelchairs.

Non-standard aids which have been developed by the DPHS team help meet particular needs not catered for by standard items of equipment and they have been especially useful in helping some people achieve more independence. These aids might take the form of devices to help someone use a cup without help, for example where the person has no use of his/her arms; 'sticks' designed to reach, grab or use particular fixtures around the home such as window-catches and handles.

Here mention must be made of the work of one of the DPHS team who spent long hours in his own home workshop developing prototypes and final versions of original aids. He and more latterly other members of DPHS staff, have found that even where people do not require specialised items of equipment to be manufactured, the suitability of standard aids and items of equipment is often questionable and time has to be spent modifying and adapting standard items to suit the highly individual and unique needs of each person.

**Housing costs**

Advice on housing costs was sought by 51 people (12%). Only three (19%) of the families with children and 8% of elderly people sought this advice, but 15% of people in the age group 16-59 years requested it.

The DPHS have developed, in particular, strong links with the local building society movement to promote the opportunities for disabled people to secure mortgages and loans for housing needs and over the years Walbrook Housing Association have developed expertise in harnessing financial resources and advising on grant systems. An example of this advice occurred with one

person who lived in a family home. It was sufficiently large to accommodate the conversion of a downstairs room into an en-suite bedsit, but there were still access problems and the family wanted to ensure that accessible housing was acquired for the future. They contacted the DPHS who offered their advice on all aspects of this decision, including the suitability of prospective housing, adaptation requirements, aids for daily living, claiming benefits and arranging finance for purchase. The DPHS liaised with a building society and a bank and the young person concerned subsequently secured an interest-only mortgage for part of the purchase price of a bungalow, the remainder being handled by the parents via a trust fund in the young person's name.

Given that disabled people often have very limited income or few assets, especially where they have lived for many years in institutional environments, advice on meeting the costs of housing is likely to remain an important aspect of the DPHS.

**Support services**

Relatively few people required advice on support in the home including home helps, home care aides and the 'flexicare' assistance outlined in Chapter Two. The precise extent of statutory home support for each of the 426 users of the DPHS is not recorded, but records show that there was almost no change in the number of people receiving such support before and after they used the DPHS; 60% of service users were in receipt of statutory home support before contacting the DPHS and 59% received support afterwards. The 45 people interviewed similarly experienced few changes in informal and formal care provision as a result of their contact with the DPHS. However, it has to be remembered that the sample was drawn to be representative of personal and housing characteristics rather than of support services received.

The question of informal support in the home is discussed in Chapter Four.

**Counselling and training for independent living**

Whilst the numbers of people requiring this aspect of the DPHS' advice is small, the service has been successful in helping people to leave institutional care or achieve independent living away from their parental homes and examples of people helped in this way are given in the following chapter.

Counselling in respect of the issues raised by independent living was required by 19% of the under-16 age group, 12% of the 16-59 year age group and just 2% of people over 60. This specialised advice has largely been offered by the DPHS staff but it is recognised that people might prefer to talk over fears and doubts with someone in a similar situation. The Derbyshire Centre for Integrated Living offer peer counselling to people in Derbyshire and the DPHS is able to refer people to the DCIL.

Those people requiring training are offered the facility of the Walbrook Training Flat situated in one of the Housing Association's sheltered housing schemes. This flat, funded largely by past donations is small: one room divided into a living/kitchen area and a sleeping area, with an adjacent large bathroom and toilet. The limitations of its size are recognised by the DPHS but it had been used for short-term, weekend and occasional one-off occupation by DPHS users (and Walbrook tenants) who are offered the opportunity to: (i) practice and perhaps learn domestic skills such as cooking, cleaning and living independently; (ii) determine with the DPHS staff the specifications required for future fixtures and fittings in their

new home, for example heights of cupboards and working surfaces; (iii) see what aids may be required; and (iv) practice with equipment such as hoists and specialised toilet facilities.

The flat is also of benefit to the DPHS (and Walbrook if they are the prospective landlords or builders) in that design implications can be determined in advance of building work and therefore obviate the need for perhaps expensive modifications after the person has moved in. It also has the advantage of being located relatively near to Derby town centre which allows those people leaving institutional life to practise shopping or indeed to 'test' the town environment for accessibility.

The size of the flat, however, does not allow fully for existing or potential helpers to 'learn' alongside the disabled people.

### Welfare benefits

Only 8 people were recorded as requiring advice on welfare benefits. This information is at variance with the experience of those 45 people interviewed who had a number of queries concerning benefit entitlement. Clearly DPHS users do not see the service as being the most obvious body to deal with this aspect of their lives and they therefore may not raise these worries with the DPHS staff.

## WHAT WAS THE OUTCOME OF USING THE SERVICE?

Altogether 92 files (22%) were still open with no final outcome yet achieved. The remainder (334) were categorised as 'closed' for research

purposes although people might still require follow-up assistance from the DPHS. The outcome of using the service (bearing in mind the complex advice process which might have been preceded it) is given in Table 16.

**Table 16 Outcome of Using the Service (n=334)**

| Outcome | Per cent of closed cases | |
|---|---|---|
| HOUSING: | | |
| Entered residential care/NHS | 1 | |
| Rented from Walbrook | 13 | ) 27% of people rented housing |
| Rented from other sources | 14 | ) |
| Bought from Walbrook | 2 | ) 5% of people purchased housing |
| Bought from other sources | 3 | ) |
| Awaiting Walbrook housing | 27 | ) 37% of people were awaiting housing |
| Awaiting housing from other sources | 10 | ) |
| ADAPTATION: | | |
| Existing home adapted by Walbrook | 14 | ) 23% of people adapted existing homes |
| Existing home adapted by other bodies | | ) |
| Alternative home adapted by Walbrook | 2 | ) 4% of people adapted alternative homes |
| Alternative home adapted by other bodies | 2 | ) |
| AIDS: | | |
| Received 'standard' aids for daily living | 11 | |
| Received 'original' aids for daily living | 3 | |
| RECEIVED SUPPORT SERVICES | 3 | |
| RECEIVED ADVICE ONLY | 13 | |

In examining the use made of the DPHS we were not only concerned to describe those people who pursued the recommendations of the DPHS. We have

therefore included people who were described by the DPHS as having withdrawn from the service either because they did not wish to pursue the recommendations made or they chose housing or personal support offered by other agencies.

The figures show the prime role of the DPHS as being able to provide a housing solution for its users irrespective of whether people also required daily living aids, home support or adaptations. A total of 42% of people whose files were considered closed had chosen to be rehoused by Walbrook, either in rented property or through the shared-ownership/leasehold scheme.

In order to see what was achieved by Walbrook tenants, council tenants and owner-occupiers, the data on outcomes were examined in relation to these three major tenure groups.

The majority of existing Walbrook tenants (56%) had their homes adapted by their landlords as a result of using the DPHS and 28% received daily living aids. Whilst 44% of council tenants decided to move into Walbrook property, 37% chose to move to either other housing association property or to alternative local authority accommodation. Amongst owner-occupiers, 28% had either moved to or were awaiting Walbrook property compared to 17% of owner-occupiers who chose to seek alternative housing from other sources.

With regard to adaptations only very few council tenants or owner-occupiers had their homes adapted by Walbrook (2% and 1% respectively) however, given the expertise that has been developed by the DPHS team, it is to be hoped that those people wishing to remain in their own homes are enabled to take advantage of the DPHS design service through increased collaboration

between the DPHS and other housing and design agencies, for example county architects and local authority housing departments. Other housing associations (notably Habinteg) and the Department of the Environment in particular have published extensive guides to designing accommodation suitable for disabled people and the DPHS could be encouraged to share their own expertise more widely within the housing association movement and especially to organisations of disabled people.

The average length of time to help people approaching the service was one year and seven months, whereas if people required follow-up services their files would remain open for, on average, two months longer.

Chapter One outlined the necessity of information and objective advice for physically disabled people to ensure maximum choice and control in their daily lives. The DPHS' roles as advisors is therefore extremely important and the information presented on the outcome of using the service does not represent adequately this aspect of their work. The statistics show, nevertheless, that one of the central strengths of the DPHS lies in its ability to access 'bricks and mortar' via the Walbrook Housing Association. Should numbers using the service increase, the demand for such housing may have implications not only for the DPHS (in being able to provide a 'fast' service for its users) but for the housing association also.

Whilst one might attempt, statistically, to identify a 'typical' DPHS user, this would be misleading insofar as such data cannot provide a picture of the highly individual experiences of the range of users. Neither can statistics reveal the quality of the service delivered and the extent to which it can contribute to those aspects of one's life which are difficult, if not

impossible, to measure - for example, a sense of well-being and feeling more in control.

It was noted above that a number of people withdrew from the service (37% of total users) and whilst this is a high proportion it must be seen in the context that the majority of people did receive help from the DPHS, namely a discussion of their problems and advice on possible solutions and it might be argued that the DPHS were therefore influential in assisting them to make an informed decision on the choices and opportunities open to them.

Of those people that withdrew, 30% went on to find housing from other sources - 21% being rehoused by a local authority, 5% by another housing association and 4% of people found housing through their own means.

A total of 15% did not respond to the DPHS - they may have been referred by another agency without their knowledge and did not themselves wish to involve the DPHS; they moved after contacting the service and left no forwarding address; or they did not respond to letters or visits.

Some people (12% of those who withdrew) were categorised by the DPHS as "reluctant" in that they decided, for various reasons, against the advice of the DPHS but did not pursue other options. A further 10% of withdrawals took advice but nevertheless decided on a different course of action other than rehousing and unfortunately, 9% of people approaching the service died before their problems could be resolved.

Only a small number of people (5%) could not be helped at all by the DPHS: for example, where people requested rehousing in an area of Derbyshire

where no Walbrook properties were available, or where they lived outside the county and their requests were more appropriately catered for by their respective local agencies. The remainder of those withdrawing did so for diverse reasons, for example:

- remission: the person was able to walk again

- a solicitor acting for a disabled person did not follow up the initial enquiry

- the person broke off an engagement

- marital problems were resolved

- the person would not view the offered flat

- after a week's trial in new housing the person found it too exhausting.

In only 7% of situations was the closure of the file deemed "unsatisfactory" from the DPHS' point of view. In some instances the DPHS felt that the person still required assistance and in others, they felt with hindsight that more could have been achieved. An examination of some of the DPHS files revealed that in the early stages of the service's pilot phase a number of people withdrew because the DPHS had yet to develop the skills or services necessary to solve the problems presented. The information on withdrawals must also therefore be seen in the context of an evolving service which has developed over time.

Overall, statistics on total users of the service showed that the DPHS was attracting enquiries from a diverse range of people who were being disabled in a number of ways by the design of their homes. People received a fast and free advice service which was followed up in the majority of instances by recommendations regarding rehousing, aids and adaptations and personal support. The main delay in achieving help was caused by the waiting time for rehousing although this was not inevitable - a number of people received a very rapid offer of accommodation through Walbrook, and the quality of housing offered was welcomed.

Existing Walbrook tenants, in particular, received an excellent service from their landlords through the experiences learned prior to and during the pilot phase of the DPHS and people becoming Walbrook tenants can be assured that their future needs will be considered.

The service is well-known in Derby but has yet to receive many enquiries from throughout the county. Given the number of people choosing to be rehoused by Walbrook, the concentration of their property in and around Derby city may limit the options open to those living further afield.

Although the number of 'formal' referrals from statutory agencies is relatively small, the relationship between the DPHS and, for example, health and social services, is strengthening and has worked well in those instances where a number of agencies including the DPHS need to be involved in achieving a successful outcome with the service user. This is particularly the case for those people leaving institutional care where the DPHS has worked with the person concerned and all other relevant bodies to coordinate plans, housing and support services. The two DPHS Housing Advisors were previously employed

as occupational therapists and they have the advantage of a wide network of contacts within the statutory services and an obvious knowledge of the 'system' which is vital if they are to secure help for those they assist. Statutory occupational therapists, disability project coordinators and social workers interviewed during this study expressed respect for the work of the Housing Advisors insofar as they are recognised as fellow professionals who understand the problems faced by statutory workers. Collaboration between the DPHS and other agencies is necessary, especially in the area of personal support in the home and whilst only a minority of people using the DPHS asked for advice on support, a change in circumstances, for example rehousing, will still require some reorganisation for statutory bodies already in contact with the individual.

The relationship between the DPHS and other agencies in Derbyshire is further discussed in the next chapter which also looks at some of the issues raised in the above sections from the viewpoint of those who have used the DPHS.

## CHAPTER FOUR

## A DETAILED SURVEY OF 45 USERS OF THE SERVICE

### 1 INTRODUCTION

One of the central findings from interviews with 45 people using the Disabled Persons HOusing Service is how diverse and unique each person's problems and circumstances are and that the factors to be taken into account when considering these problems are equally diverse and complex. When examining the information provided by people through the interview process, it became apparent that statistical analysis alone could not portray their circumstances adequately. The necessity for service providers to develop flexible responses to the demands of this heterogeneous group (whose requirements will vary considerably and will concern a number of agencies) was confirmed.

It was felt important to use these interviews to try and articulate the user's view of the service. The data of 450 users set out in Chapter 3 was provided from the viewpoint of the service, that is from the information contained in the DPHS files and the staff's own knowledge of the individual.

In evaluating the service and its response to each person, (and users overall) it should be noted that the 45 people interviewed were at various stages in the process of seeking and receiving help and therefore it was possible to elicit a range of views and experiences - from those who spoke of minor problems and limited contact with the service - to those experiencing major problems and extensive use of the DPHS. People were asked to describe

their circumstances and difficulties both at the time they contacted the DPHS and following their experience of the service. With regard to the latter, people may have been faced subsequently with new problems, that is ones which could not have been dealt with by the DPHS because they had not been present. Other problems were clearly not within the remit of the service per se to solve, for example, some Walbrook tenants mentioned difficulties more properly the concern of the Association as landlords, irrespective of whether the tenant was physically disabled. Similarly, some interviewees spoke of problems concerning the role of the state or other agencies, for example, difficulties with benefits entitlement, the nature of domiciliary support and other services provided by statutory authorities.

No attempt was made to asses the individual's mobility or diagnose his or her physical condition and the information presented in this respect is the individual's own perspective and description of his or her situation. Similarly, no prognosis is made of the person's future prospects for achieving enhanced mobility.

Nineteen people were seen after they had been rehoused, of which:

15 had been rehoused by Walbrook (including 1 Walbrook tenant who had been relocated)

2 had been rehoused by a local authority

1 had been rehoused into owner occupied property with parents

1 had been rehoused into owner occupied property but without parents.

Therefore, 26 people were seen in their 'original' homes and they had received mobility aids, adaptations or were awaiting rehousing. Two people's circumstances remained unchanged following their approach to the service.

Three people were interviewed twice to supplement the initial questionnaire - once whilst awaiting a resolution to their problems and once following. Of these, one person remained in the original home having received a mobility aid, and two people were eventually rehoused into Walbrook property.

The interviews were undertaken using a prepared schedule which had been piloted on four users of the service. The majority of people interviewed were extremely welcoming, more than willing to participate in the study, and talked frankly about their circumstances and their opinions of the service. A few, however, were less able to go into great detail because their time was limited or they were not in the best of health at the time they were seen.

**SAMPLE SELECTION**

A total of 45 people were interviewed and this sample also forms the basis for Chapter 5 which discussed the costs of the service. All users were categorised for the purposes of selecting a sample, on the basis of housing tenure and age at the time they first contacted the DPHS. They were classified within four tenure categories:

* Walbrook tenants
* Owner occupiers
* Council tenants
* Others (to include tenants of other housing associations, those in NHS or residential care).

Three age categories were used:

* Under 25 years old
* 26-59 years old
* 60 years and over.

All these groups were represented in the sample of 45 with two exceptions - council tenants under 25 years old and those of 'other' tenure from the same age group.

The sample was selected on the basis of the experience of the 'primary' user of the service only which is the person deemed by the DPHS as being the main disabled person in the household. However, eleven of the cases (24%) refer to households where more than one person had health problems. Of these eleven cases, two households contained more than one disabled person.

Because of the need to study the outcome of the service and its impact on the circumstances of the people interviewed, it was necessary to restrict the sample to those cases considered 'closed' by the DPHS (n=334). Notwithstanding that these 45 are not a strictly representative sample of the total number of users studied, they do represent closely a cross-section of all users in respect of factors such as age, sex, marital status, tenure and mobility and the outcome achieved. However, as stated, their individual circumstances and resources, their need for advice or support, and their own preferences for the type of service required, varied widely.

## SUMMARY OF FINDINGS

This section presents a broad summary of the findings. The main details on the characteristics of users, their housing circumstances, their attitude to the DPHS are presented in more detail later.

### Age and Sex

* The majority of people seen were women (56%) again reflecting national trends and the age range of interviewees was as follows:

**Table 17 Age and sex distribution of interviewees (n=45)**

| Age group | % male | % female | % of total |
|---|---|---|---|
| 0 - 15 years | 100 | - | 2 |
| 16 - 59 years | 45 | 55 | 44 |
| 60 - 74 years | 44 | 56 | 40 |
| Over 75 years | 33 | 67 | 13 |

### Household Situation

* People lived in a variety of households or family situations. Altogether 12 of the interviewees lived alone prior to contacting the DPHS and a further 4 people lived in residential care. The majority (29 people) therefore had recourse to differing levels of informal care in the home (53% of the sample were married) and only 6 out of the 45 people interviewed (13%) stated that they had no requirement for either formal or informal support. The overall sample showed a picture of low statutory service provision and

high levels of informal care in terms of personal support in the home.

* The most striking change in household composition following use of the DPHS was in the number of people living alone.

**Table 18 Household size before and after seeking help**

| HOUSEHOLD SIZE | NO. BEFORE DPHS | NO. AFTER DPHS |
|---|---|---|
| 1 person | 12 | 20 |
| 2 people | 18 | 19 |
| 3 people | 6 | 2 |
| 4 people | 2 | 1 |
| 5 people | 3 | 2 |
| Residential | 4 | 1 |
| | 45 | 45 |

* Changes in household size took place for a number of reasons, some unconnected with the individual's use of the service, for example bereavement. Three people left residential homes to live on their own; three cases refer to people choosing to be rehoused from homes they had been sharing with sons or daughters; and two people left their parental home to live independently although one of these had the support of her family each weekend when she returned from college.

**Employment**

* Whilst 60% of those interviewed were of working age, none were employed and only eight people (18%) lived in households where other members were in employment. The level of income for the majority of people was low and

dependent on state benefits.

**Tenure**

* Housing tenure and type of housing were mixed, the majority of those seen (53%) being tenants of either local authorities, Walbrook, or other housing associations. Owner-occupiers represented 36% of the people interviewed either owning homes themselves or living in parentally-owned homes.

* Bearing in mind that this study was carried out before some people were rehoused and that therefore it is a 'snap-shot' of people at a particular stage in seeking help, a change of tenure was experienced by 14 out of 19 people who had received alternative housing:

6 owner-occupiers became Walbrook tenants
4 council tenants became Walbrook tenants
3 in residential/institutional care became Walbrook tenants
1 other housing association tenant became a Walbrook tenant

* Only one person who had previously been an owner-occupier and had become a tenant stated that he would have preferred to remain a house-owner. The others who were asked stated that their change of tenure had not mattered to them so much as gaining suitable housing.

* Of the remaining five people who had been rehoused, none had changed tenure: two council tenants, two owner-occupiers and one Walbrook tenant who had been relocated from terraced into fully adapted ground floor sheltered

housing.

* The quality of people's housing differed greatly. For example, one person in semi-detached council housing lived in a home which was in very poor repair internally and externally and he was surrounded by housing at varying stages of renovation. Other council tenants lived in pleasant areas and had no complaints concerning the internal or external quality of their homes. Similarly, owner-occupiers lived in a variety of homes from small terraced inner-city property to modern suburban housing.

**Impairments**

* People experienced a number of medical conditions or physical impairments representing a range of mobility problems. The majority (26 people - 58%) were ambulant either with or without walking aids, but nevertheless required help in using their home or the neighbourhood. It was noticeable that the overwhelming majority of people had more than one condition or a combination of long-standing and recently experienced conditions which resulted in often fluctuating need for support in the home as problems occurred, stabilised or worsened. Some 10 people had experienced strokes and 11 had heart problems.

**Help from other agencies**

* Some people had a history of contact and involvement with other agencies, for example, the health authority and local authorities' social service departments, in relation to their mobility needs or personal circumstances and had some awareness of the existing system of local and state

provision. Others, however, had little contact with potential helping agencies, either through choice or because they were unaware of what might be available in terms of services and support. The motivation to use the DPHS and expectations of the service therefore also differed, possibly influencing levels of satisfaction with the outcome achieved.

**Problems experienced**

* Interviewees had presented to the DPHS with a range of problems from those who required mobility aids (for example, for bathing), minor adaptations (for example, rails) to those who required the full spectrum of DPHS services complemented by statutory input. With regard to housing, a high proportion of people interviewed had difficulty with using bedrooms, kitchens and access in and out of their homes or within the home. The highest proportion of people (32 out of 41 living in private dwellings) experienced difficulty with either bathing, toileting or both. A number of people had also approached the DPHS because of 'other' concerns for example, dissatisfaction with local neighbourhoods and loneliness. Others were seeking to live independently either away from parents or from residential care.

* The clear finding from these interviews was that whilst people may present with one primary problem or preference for example, wanting to move to more accessible housing or needing bathing aids, closer examination of their situation revealed a combination of problems concerning mobility, accessibility or personal support which require thorough advice, a comprehensive assessment of their initial situation and a monitoring period to identify any subsequent difficulties. Thus an initial request for a ground-floor flat because of problems with stairs may require not only the

provision of property but also mobility aids, adaptations, domiciliary support, financial advice, counselling, warden support, and voluntary help.

* This finding is by no means new - the remit of occupational therapists within social services for example, is to assess all such aspects of one's situation (and those of a 'carer') to promote maximum independence and mobility. However, underlying all the primary reasons for approaching the service (see below) was the expressed demand for what people perceived as objective advice on what could be improved and achieved. For some people this meant seeking a 'second opinion': alternative or supplementary advice to that already received from statutory agencies. For others this advice was sought because they were unaware of potential help from local authority social services, departments or other agencies.

**Table 19 Primary Reason for Seeking Help**

| Reason | No. of users | % |
|---|---|---|
| Rehousing into accessible accommodation | 17 | 38 |
| Adaptations to existing home | 17 | 38 |
| Rehousing into 'independent living' or housing with warden-control | 7 | 16 |
| Mobility aids | 4 | 9 |
| | 45 | |

**Outcome of the Service**

* The outcome of people's approach to the DPHS also varied. Some people's lives were completely changed from living in an institutional environment to having their own home and relative independence in the community. Others moved to alternative accommodation which was more accessible and adapted for

their circumstances or remained in the same home with adaptations or mobility aids (often through a DPHS referral to social services). Some required financial advice and the co-ordination of funding. However, whilst the eventual outcome of using the service and the amount of time spent on solving problems differed, everyone received an assessment visit from a DPHS Housing Advisor, a discussion of their requirements and advice on the options available. The main outcome of the service (see below) might be achieved in just a few weeks or over many months and in collaboration with statutory agencies.

**Table 20 Outcome of Using the DPHS**

| Outcome | No. of users | % |
|---|---|---|
| Moved to independent living from residential care | 3 | 7 |
| Moved to independent living from original family home | 2 | 4 |
| Moved to more accessible housing | 14 | 31 |
| (Awaiting rehousing) | 6 | 13 |
| Original home adapted | 12 | 27 |
| (Awaiting adaptation) | 1 | 2 |
| Mobility aids only | 5 | 11 |
| No change | 2 | 4 |
| TOTAL | 45 | |

The following sections examine some of these findings in more detail.

**SEEKING ADVICE AND SUPPORT**

People heard about the service from a number of sources. For example, eight out of the ten people who were existing tenants of Walbrook Housing Association were referred to the DPHS directly through its relationship to the Association. A total of five people approached the service following contact with social services, through direct referral from social workers or via publicity in social service offices. Others learned of the service through friends or relatives, via charitable organisations (for example a Stroke Club), local authority housing departments or their GP.

However in 35 out of 45 households, the DPHS was not the first agency to be contacted. People frequently used the service in addition to help received (or following unsuccessful or unsatisfactory requests for help) from other statutory or non-statutory sources. The exception to this being existing Walbrook tenants and other housing association tenants who tended to contact their landlords first. The four people who were referred for DPHS 'assessment' by their own housing association and who therefore had limited contact with the DPHs had few opinions to give on the service.

**Table 21 Contact with Other Agencies**[1]

| Agency | No. of approaches |
|---|---|
| Local Authority | 19 |
| Social Services | 16 |
| Other housing association | 12 |
| Charity/housing trust | 6 |

Note (1) Some respondents contacted more than one agency.

People pursued a variety of solutions to their housing and mobility problems, reflecting the respective roles of the statutory services regarding housing, mobility aids and adaptations. In this respect the group interviewed were clearly motivated to seek solutions to their problems and explored a range of options until their desired outcome was achieved. Where people sought re-housing they often approached a number of agencies and depending on the response received, either sought help elsewhere or remained on a number of waiting lists. The six owner-occupiers who originally sought accessible housing all contacted their local authority housing department for assistance suggesting that the potential loss of an asset was less important than the procurement of a suitable home.

Those requiring mobility aids, adaptations or both via social services departments all received help, although some people still preferred to seek alternative accommodation and it was in finding suitable housing that people encountered the most problems and in particular with the waiting times or eligibility criteria for accessible local authority property. For example, those interviewees who felt dissatisfied with waiting times had been quoted a wait of 3 years, 4 years and 5 years respectively for ground-floor or bungalow housing. Two families had been informed they were "too young" for specialised accommodation - one disabled person being under 16, the other being 62. Another person in residential accommodation was told she was too old at 82.

Other housing associations or housing trusts contacted had either been unable to offer suitable properties, had placed restrictions on the tenancy ("no pets") or had offered accommodation which had been considered unsuitable (eg, "at the top of a hill").

**Accessing 'the system'**

Underlying people's comments on their experience of statutory provision was that they saw it as a complex system which was inaccessible unless one adopted a personal strategy for receiving attention. Whilst some had very good relationships with their social service contacts and could not praise them more highly, others commented on the fact that they had some difficulties in making contact, for example:

> "It's difficult to get in touch with them. There are so many part-time staff. Messages don't get through"
>
> "My social worker keeps changing. I don't know who to contact."

People had firm but conflicting opinions on how best they could access statutory services. Some expressed the view that the only way to have one's demands met was to "pester" continuously otherwise one would be overlooked. Others, however, stated that they had received assistance because they had not "made a fuss". Of course, Social Services Departments are very busy places. They receive many enquiries and referrals and have to cope with the national shortage of qualified occupational therapists. These factors and the need for staff concerned to carry out their duties outside the office, may explain some of the difficulties that people experienced in making the required contacts.

Eleven people stated that they wanted more information on what was available from statutory helping agencies. A number of people mentioned specific social services or other statutory help that they required but did not know how to access, or had difficulty in obtaining:

* Benefits advice
* Help for carers
* Concessionary fares

* Help with TV licence
* Help with laundry costs or extra sheets
* Information on mobility aids
* Help with holidays
* Information and help with telephones
* Emergency or crisis support
* More social worker assistance

**Using the DPHS**

Asked their opinion about the DPHS, people welcomed the fact that with the DPHS they had easier access to information and assistance, for example:

"[We] dealt with one person throughout"

and this opinion was mirrored by the views of some local authority social service staff who noted that they could contact the DPHS Housing Advisors or the Director of Walbrook for immediate decisions concerning referrals.

A common opinion was that, compared to statutory agencies, the DPHS could act more quickly:

"[The DPHS] acted with speed and courtesy"
"Quick - on the ball"
"Quick - they got on with it."

Current caseloads of DPHS staff and their specialisation in helping physically disabled people allows them to respond to telephone, mail or

personal enquiries in a matter of days, arranging for a home visit or a discussion with someone in hospital or residential care. For their occupational therapist counterparts working in the statutory sector there are, of course, much heavier caseloads and other demands on their time and skills than those presented by disabled people. At the time of this survey a number of posts had been established within the county social services department to develop community living projects and an improvement in the co-ordination of services. However, in common with other authorities nationwide, there was an overall shortage of trained staff.

The DPHS recognises that in some instances they act as a substitute for statutory service workers who are unable, at present, to offer such an immediate assessment service. One might argue that this is a duplication of effort or an incursion into the spheres of statutory responsibility. However social service staff appeared to welcome this complementary input. Given that demand on social services and other statutory agencies is likely to increase and that they will remain in the forefront of provision, alternative sources of advice and skills such as those provided in Derbyshire by the DPHS and the Derbyshire Centre for Integrated Living should be welcome adjuncts to those provided by county authorities or local councils.

People interviewed frequently mentioned the attitude of the DPHS staff as being a positive experience for them, and especially that of the Housing Advisors:

"The OT is lovely"

"The DPHS had a good attitude. They were genuine and concerned with all aspects of life including work."

"... very obliging. They listened."

The impression given to the interviewer time and again was that people felt they had developed a personal relationship (and often a friendship) with the Housing Advisors and other Walbrook staff, and whatever the outcome of the service this was almost always the first thing they mentioned when asked to describe their experience.

Only one person expressed some reservations about the service's ability to maintain this personal contact in that he felt they were now becoming "too much like a business" and were a little "less caring" than when he had fist made contact. In any service, the quality of staff and their commitment to a set of values and aims will often determine the extent to which that service achieves a satisfactory outcome with its users. Derbyshire Social Services had developed a statement of values which underpins the structural framework of provision and which can help to ensure continuity in the way the service is provided when personnel change. This type of continuity was clearly important for DPHS users, many of whom were in touch with the service for a considerable period of time.

The availability of objective and informed advice is necessary if disabled people are to exercise full choice and control on how and where to live, and with whom. The ability of the DPHS to provide advice on housing and mobility-related issues is one of its most valuable contributions to the spectrum of statutory and non-statutory services available in Derbyshire. It

should be noted that this advice service is available free of charge and disabled people are less likely to have incomes sufficient to pay for services.

Social service workers who were interviewed noted that there was a tendency, conscious or otherwise, for advice from the statutory sector to be influenced by what they knew could be provided. On two occasions, mention was made of the "fear" of raising expectations which could not be fulfilled. Clearly, however, disabled people need to be aware of all that they are entitled to and all that could be available to them as of right. In this respect the Derbyshire Coalition of Disabled People and the Derbyshire Centre for Integrated Living have also made an enormous contribution to progress.

The DPHS, whilst being able to provide advice on a range of housing and housing-related options is nevertheless constrained by finite resources, in particular the availability of housing stock via Walbrook Housing Association and given the proportion of service users who opt for this form of housing, there will inevitably be waiting lists for suitable property. Whilst people are always informed of the estimated time it may take to achieve rehousing, some might experience many months' wait. Two people who were awaiting rehousing felt they had been given insufficient progress reports, for example:

"We don't know what's happening on our behalf."

One of these stated that had they not contacted the DPHS themselves they "would have gone seven months without contact" which they found unacceptable.

## PROBLEMS PRESENTED AND SOLUTIONS ACHIEVED

People were asked to describe the problems they experienced, either because of their housing, their mobility needs or requirements for personal support both before and after their use of the service.

### Impairment and mobility

Altogether, 41 out of the 45 people interviewed had experienced more than one medical condition which had affected their mobility to greater or lesser degrees. The sample represented a range of circumstances - from those who had been born with physical impairments and were not, currently, subject to any medical treatment to those who had recently experienced, for example, strokes or heart attacks and whose condition might be subject to change and more frequent contact with health services.

The extent to which people experienced impaired mobility was explored by asking about their difficulties visiting others, using public and voluntary transport and the accessibility of their local neighbourhood, in addition to the disabling effects of their housing circumstances. People were also asked to place themselves in one of six mobility categories. The results are set out in the table below:

**Table 22 Impairments Experienced by Primary Interviewee[1]**

| Category | No. of people | % of all users |
|---|---|---|
| Congenital/genetic problems | 6 | 13 |
| Heart/respiratory/blood/endocrine problems | 23 | 51 |
| Bone tissue problems eg, arthritis | 16 | 36 |
| Nervous system/brain/spinal cord/meninges | 26 | 58 |
| Muscular problems | 2 | 4 |
| Mental handicap and mental illness | 3 | 7 |
| Problems associated with being 'frail elderly' | 2 | 4 |
| Sensory impairments | 6 | 13 |
| Injuries/amputations | 4 | 9 |
| Bladder/bowel problems | 4 | 9 |
| Other medical conditions | 8 | 18 |

Note (1) The majority of respondents experienced more than one impairment

**Table 23 Mobility Category of Primary Interviewee**

| Category | | No. of people |
|---|---|---|
| 1 | Bed-bound | 2 |
| 2 | Wheelchair-bound | 5 |
| 3 | Wheelchair-bound but able to stand and transfer | 7 |
| 4 | Ambulant indoors but needing to use a wheelchair outdoors | 6 |
| 5 | Ambulant with walking aids eg, Zimmer frame or sticks etc. | 11 |
| 6 | Ambulant | 14 |
| TOTAL | | 45 |

As was noted in the previous chapter, being able to walk without aids or a wheel chair did not necessarily mean that mobility was easy. For example one person had no such walking aids and classified himself as "ambulant" but because of a heart condition he found walking difficult and had to keep pausing to regain his breath. He became tired very quickly. His mobility was therefore impaired because of the unavailability of transport which he needed for all but the shortest of journeys, and in fact he rarely went out. Conversely a wheelchair-user who classified himself as category 3 (wheelchair-bound, but able to stand and transfer) felt that the only problems he had with mobility were those posed by the inaccessibility of most buildings and the lack of ramping on kerbs and he was able to leave the home whenever he wished

Given that the majority of people interviewed had been in contact with a range of statutory and non-statutory services prior to their approach to the DPHS, it was not surprising to find that the majority had also received previous help with their mobility and housing problems.

**Residential Care**

The four people living in residential homes or institutional settings (two men and two women) had varied experiences. One man was living in social services residential care where he was receiving training and counselling towards independent living. Prior to this he had lived for 22 years in an institutional setting and his opinion was that it had been extremely difficult to leave such an environment even though he had wished to do so for a number of years. He felt he had not been allowed to do anything for himself; not to come and go as he had liked: "there were no privileges" and

a lack of visitors had caused him anxiety. Through the support of social services staff he was learning all those skills required to live autonomously, for example cooking, shopping and budgeting and his eventual wish was to live in his own home. His desire to move was given impetus by his relationship with someone whom he wished to marry.

The second man living in an institutional setting had done so for 26 years and as his original home had been outside the county, he had therefore been subject to another authority's statutory responsibility. However, he stated that between 1960 when he entered residential care and 1986 when his desire to live independently was pursued by the staff at the charity's residential home, he had received no visits from a social worker or other local authority worker. Despite his mobility problems (he was wheelchair-bound) he was able to use his powered wheelchair to get out and about, but the local environment was extremely hilly and this, combined with a lack of accessible amenities, restricted his social life. As with most examples of institutional life, his capability to perform tasks for himself was not explored to his satisfaction and was curtailed by the limited facilities for individual mobility and experimentation. There was little opportunity for him to develop any domestic or personal grooming skills - these being performed in the main by resident staff.

These two men were both in their forties, having lived half their lives in residential care. The two women, however, were elderly (aged 78 and 82 respectively) and had been living in residential homes for only a short time before contact was made with the DPHS. The younger woman had been in hospital following a serious operation where it was felt her home situation (she lived alone) demanded a decision to seek alternative housing. She

therefore accepted a temporary placement in a residential home until suitable ground-floor accommodation was found. The older woman had been a council house tenant for sixty years until the mobility problems caused by a stroke and her general frailty required increasing input from social services in terms of home helps, home care aides, mobility aids and so on. She lived with her daughter and both wanted to remain together in more suitable property but neither the local authority nor another housing association contacted could assist. The elderly woman therefore entered a private residential home where the fees were paid by the Department of Social Security.

**Previous assistance**

Out of the remaining 41 people living in private accommodation, 26 had received some form of assistance prior to their contact with the DPHS, either through the provision of mobility aids, through adaptations to their homes, or both. Three people whose homes had been previously adapted had used the local authority grant system to fund alterations in addition to receiving help from the social services department.

**Table 24 Aids and Adaptations Prior to Using DPHS: Private Householders**

| Provision | No. of people |
|---|---|
| Major adaptations eg, room extensions, hoists, shower/bath rooms etc | 7 |
| Medium adaptations eg, stairlift, ramping, specialised toilets etc | 7 |
| Minor adaptations eg, rails, poles, alarms etc | 18 |
| Mobility aids and equipment eg, commodes, bath seats etc | 20 |

**Problem areas of the home**

Despite this level of previous assistance, people interviewed still experienced a number of problems in using their homes without assistance and in a number of cases problems remained after their use of the DPHS. From the interviews held, it appeared that some people had not raised these matters with the Housing Advisor, perhaps because they were not aware that something could be done, or because they had contacted the service with a specific problem which they wanted resolved. In a number of cases it was apparent that areas of difficulty around the home were often masked by the availability of partners and family to help, or the traditional division of labour within the home.

i) Bedrooms and sleeping arrangements

Altogether 21 people in private households had problems with their bedrooms or with sleeping arrangements in general. A total of 17 had problems with stairs in that they had great difficulty in using stairs or were unable to use them at all. Eight people had had to move their bed to a downstairs room with a resulting loss of privacy. Two people interviewed mentioned the fact that being prevented from sharing a room with their partner had adversely affected their relationship. Having an accessible bedroom did not necessarily solve people's problems, for example, one person had no room for transferring from wheelchair to bed and required help from friends; another could not operate the heater in her bedroom and another could not use the cupboards there because they had been placed too far out of her reach. One of those interviewed who was bedbound had obvious difficulties exacerbated by having to be carried from the bedroom to the

bathroom. This person required hoist-track to be fitted but the structure of her housing association flat would not lend itself to this adaptation.

Not surprisingly those who experienced problems with stairs and sleeping arrangements experienced a much improved quality of life following rehousing into ground-floor property. Of those who expressed problems with this area of their lives, only three still had problems following their use of the service: one person had had a stair-rail fitted by Walbrook but still found the stairs too difficult; and two people were in negotiation with their housing association landlords over sleeping problems which had not been the subject of the DPHS intervention. Only one person experienced problems with sleeping arrangements as a result of using the service: this person had been rehoused into a ground-floor flat but found the bedroom too cramped and felt there was no room for her wheelchair.

ii Kitchens

People were asked about the accessibility of the kitchen in terms of being able to use it without assistance. For example, cooker, working surfaces, wall and floor cupboards, sink, taps and the ease with which they could make meals, hot drinks, and wash-up. Excluding those in residential care who did not have the opportunity to test out a kitchen environment, over half of the remaining people had problems in using a kitchen prior to contacting the DPHS.

**Table 25 Problems with Kitchens: Private Householders (n=41)**

| Item | No of people: | | | |
|---|---|---|---|---|
| | Use easily | Some difficulty | Very difficult | Unable |
| Cooker | 16 | 4 | 11 | 10 |
| Work surfaces | 19 | 6 | 10 | 6 |
| Wall cupboards | 17 | 5 | 10 | 9 |
| Floor cupboards | 19 | 5 | 11 | 6 |
| Sink | 20 | 6 | 8 | 7 |
| Taps | 20 | 6 | 8 | 7 |
| Washing up | 20 | 6 | 8 | 7 |
| Making hot drink | 21 | 5 | 8 | 7 |
| Making hot snack | 19 | 5 | 9 | 8 |

Where people expanded on this information, they frequently cited problems with pain on standing, being unable to bend and their cooker and other kitchen amenities were badly sited or at the wrong height. This was particularly the case for wheelchair users who required space beneath sinks and working surfaces.

A total of 11 people who had problems with their kitchen had no improvement following their use of the DPHS. This was for a number of reasons. Some were awaiting rehousing or adaptations. One such person was still awaiting the resolution of her problems in using kitchen cupboards and a cooker but the DPHS had acted, in liaison with a housing association and social services, to assess her situation and recommend the redesigning of her kitchen. Others had not raised this aspect of their lives (perhaps because their spouses traditionally did the cooking or this form of housework) or the

DPHS had been called in by a housing association to assess another particular problem. Those people who were bed-bound were unable to be helped in this respect.

Including those people who left residential care and were able, following practice, to use their new kitchens without assistance, 13 people experienced improvement in their use of kitchens to greater or lesser degrees.

iii) Living rooms

People were asked about their use of general living space and whether or not they experienced difficultly with: opening/closing windows, access in and out of the home; using light switches and power points, and using the fires or heating - without assistance. These questions were asked not only to elicit how convenient or comfortable the home was for each individual but also to gain some insight into how far they were at risk, say in an emergency, if they were on their own. Over half of those in private households had difficulty getting in and out of the home unaided.

**Table 26 General Use of the Home: Private Householders (n=41)**

| Difficulty | No of people[1] |
|---|---|
| Access | 23 |
| Windows | 19 |
| Fires | 11 |
| Switches | 10 |
| Power points | 10 |

Note 1: The majority of respondents experienced more than one problem.

Again, those who had been rehoused into adapted ground-floor accommodation experienced the most benefit in this respect. Others awaiting rehousing or who had not raised these problems themselves experienced little change. Where people had been rehoused from residential care or into independent living away from parents there were no problems with use of general living space. For example, one user who had been unable to open and close windows, gain easy access in and out of the home without assistance, and who had difficulty with light switches and doors in his previous parental home found that none of these problems remained following rehousing, lessening the need for personal assistance.

iv) Bathroom and toilet

Of those people living in private households, 32 out of 41 had difficulty with either bathing, toiletting or both despite the fact that a number of these already had already received aids or adaptations to help. For example, one person had a pole and a handrail in the bathroom provided by Walbrook as the landlords, but these could not be used because of the tenant's arthritis. Another had received a bath mat and two types of bath seat but because of difficulty with stairs, she could not reach the bathroom. One couple lived in a bungalow which had already been adapted for wheelchair use but they required an additional toilet, and sought advice about adaptation.

Some people had difficulty using facilities which were upstairs, or if they used wheelchairs, with the amount of space inside the bathroom or the design of fittings.

The main problem experienced was getting in and out of the bath unaided which had obvious implications for one's privacy and dignity.

**Table 27 Difficulty With Bathroom and WC: Private Households**

| Problem | No. before DPHS | No. after DPHS |
|---|---|---|
| Very difficult or unable to use bath | 31 | 24 |
| Difficulty using WC | 20 | 11 |

Those people waiting to be rehoused or waiting for the completion of adaptations, obviously experienced less change in their circumstances but 9 people continued to experience some difficulty with bathing or toiletting after rehousing and 6 people had similar problems following adaptations to their home.

**Other problems**

People talked of a number of other problems with their housing situation or personal circumstances. However, these had not always been raised with the DPHS. Three people mentioned high heating bills and the need for extra heating owing to their being inactive; three people also expressed a need for an alarm or "a way of getting help in an emergency" but as far as could be ascertained only one of these people had approached the service for this facility. Other people spoke of the need for household repairs, help with gardening and for particular items of furniture to help with their comfort, for example a higher chair. One user had contacted the service for help in raising her legs as she had severe swelling of her legs. The service lent her a Mangar booster to act as a leg-raiser prior to the provision of

this item from social services. Another person, however, had the same problem but it appeared she had not raised this matter during the Housing Advisor's visit.

Where people sought rehousing it was occasionally due to neighbourhood problems as well as the desire for accessible housing, and in five instances people specifically spoke of their feelings of vulnerability in respect of burglary or vandalism. Two elderly couples felt considerable reassurance at being rehoused into sheltered accommodation (one with a warden on site and one with a warden neighbour).

Feelings of loneliness and/or depression were expressed by seven people and five of these were seeking rehousing. One person who wished to move particularly sought help for himself as the sole carer in the household.

Two people wanted the back-up of a warden-alarm system and one moved into sheltered accommodation and the other was placed on the Walbrook radio alarm scheme. A man who had difficulty using the stairs and who felt vulnerable living alone asked for an entry-phone system to be installed, whilst another called upon Walbrook (his landlords) to provide a flashing-light system because he was deaf.

**Access and transport**

A number of people interviewed who used wheelchairs experienced problems. The chairs were uncomfortable for those using them for long periods or they required alternations to make them suitable for the individual's requirements. One person stated "You have to fight for

modifications." Another person needed a hood or apron on his chair to shield his eyes from light, yet all those provided did not fit his chair. Having access to a wheelchair does not, however, increase independence if one is unable to propel the chair without assistance or if the chair is so designed that its use results in fatigue. A few people mentioned their need for someone to push them outside the home and the restrictions this placed on their ability to socialise or act for themselves fully.

A total of 31 people could either not visit others at all or only with assistance and there were few differences in their situation before and after using the service.

Similarly there was no difference in the accessibility of public transport. Only six people interviewed had used voluntary transport such as the Dial-a-Ride service. Seven people had wanted to use this service (or Dial-a-Taxi) but had various complaints, for example:

"The times clash with [those of] the home help service."

"Dial-a-Ride is always full up. It carries able-bodied carers and disabled people can't get on."

"Dial-a-Taxi is too expensive."

Even where people had moved house their access to local neighbourhoods remained largely the same and the majority of people had problems using streets, shops and leisure facilities.

## INCOME

People were asked about the amount and sources of their income to try and establish the extent of economic choice available. However, eleven people preferred not to reveal this and only three people were willing to reveal the amount of savings they held. Given this groups' dependence on state benefits with all the accompanying regulations it is perhaps understandable that they were wary about revealing this information.

The average net income for people living alone was £50 per week. The highest income for this group was £80 (received by two people) and the lowest income was £35 per week.

Those living as couples received an average joint weekly income of £93, the highest income for two people being £250 and the lowest just £38 per week, where marital difficulties had prompted a reduction in benefits.

The financial circumstances of people living in family situations were more complex in that they often appeared reluctant to reveal the contribution made by sons or daughters. It was therefore difficult to obtain accurate data on income available to the disabled person in these situations.

Over half of those interviewed had some savings which was a higher figure than had been anticipated and included some of those with the lowest recorded weekly incomes. Whilst the amount of savings was not known in the majority of cases, the researcher's estimate is that few people had savings to a level which would affect state benefit entitlement.

People were asked about their income after contact with the service to detect any change in circumstances. However, the interviews coincided with a period of change in the state benefit system and a number of people were unable to predict how these changes would affect their income as they were awaiting the outcome of an assessment or new claims. Three people, in particular, expressed considerable anxiety over the benefit changes: one was anxious that he might not be able to afford the rent on his new (Walbrook) property; another had been asked to attend a local benefit office by a certain date but he had no transport and was concerned that he could not attend. One person did receive £2.00 extra income as a result of benefit changes, but found this his water rates were increased by the same amount and he was not better off. One interviewee who lived alone had his weekly income reduced from £52 to £41 as a result of benefit changes. He had no cooker at the time of the interview and had been offered a 'loan' under the Social Fund scheme to purchase one. However, he felt unable to repay such a loan from his weekly income and remained without any means of making hot meals. His financial position was exacerbated by the inaccessibility of public transport and when he needed to visit the city centre he used expensive taxis.

Where people left the parental home to move into independent living their personal income normally increased due to their eligibility for various benefits. However, one of the men who left residential care to live alone lost his attendance allowance, the assessment being that his increased independence meant he was no longer eligible.

**FORMAL AND INFORMAL PERSONAL SUPPORT**

The sample of 45 people were asked what kind of every day things they needed help with and who, if anyone, gave that help - both before and after they had used the DPHS. The position for those people interviewed prior to the completion of a housing/care solution had not changed with the exception of one person whose spouse had died and who subsequently had less informal support than when she first approached the service.

Identifying the precise extent of informal care is problematic insofar as people in families or shared households will, as a matter of course, help each other in the home, for example bathing, toileting and grooming is more easily identifiable, household tasks such as shopping, laundry and cooking, may be the subject of a preferred division of labour within the home and the carer may have performed those tasks even if their partner or relative was not immobilised in some way. It was therefore necessary during the interviews to distinguish as far as possible between the help which was given because the person was unable to perform the task him/herself, and that help given as a result of custom and practice. For example, where men stated that they had help with cooking and housework, we attempted to discover whether this was because of the traditional division of labour within the household and whether, in fact, the individual could perform that task without assistance. The results therefore reflect those task which the individual cannot perform for themselves in their former or present environment and may therefore understate the actual amount of work performed by the carer for the disabled person with whom they lived.

For example, one person whose mobility had improved following a stroke could in fact do light housework and some shopping (albeit with some difficulty) but his wife usually performed these tasks. She worked part-time and was apparently fit but was an ex-stroke patient herself and was due to undergo cardiac surgery. This couple received no statutory domiciliary support - they "had never asked for any" and were anxious about who would care for the husband during and after his wife's hospitalisation.

The four people in residential care received help with a variety of activities depending on the particular regime of the establishment. One of the women in residential care required extensive nursing and practical help.

Of the 41 people in private accommodation, only six said they had no requirement for either formal or informal support. Two of those who had left the parental home to secure independent living still received help from their parents in their new home. Eight people requiring help lived alone, but two of these received help from a relative living elsewhere and one had help from friends. One person lived with a spouse but had no informal support because he was less mobile than her, and in this case the primary user of the service was also the principal helper.

One helper (an ex-nurse) who assisted her husband also provided substantial medical care with the agreement of his clinician and gave injections, put on dressings and other tasks.

Nine people requiring help had no informal support within the home.

Of those people not living alone, and including those who received informal care from people living elsewhere, fifteen had male helpers and thirteen had female helpers.

The average statutory home help input was one hour per week, representing a particularly low level of formal care. Although at one time it was the policy of the Social Services Department to take account of the presence of informal care in the assessment of the need for home help, that policy was revised to ensure that the needs of and pressure on carers were reflected in the assessment of domicilary requirements.

One person interviewed had had her home help hours reduced from 3 hours a week to 1 hour but had appealed against this decision and now received 2.5 hours. Another user of the service who had previously lived with her son on a temporary basis moved to live alone in ground-floor Walbrook property where she received home help support. However, when her son stayed with her for a short-time, this home help support was removed and at the time of the interview she was trying to have this help restored. The helper of four disabled family members received daily home help assistance but it was during the daytime when the three youngest members of the family were out of the house - he felt frustrated and not a little bemused that the help was not available at the times it was most needed, that is when all the members of the family were at home and there were demands on his time.

Three people who paid for domestic help including housework and shopping, did so in preference to obtaining social service home help and one other person paid for someone to put her to bed outside normal home-help working hours.

**Table 28 Number Receiving Informal Support in the Home**

| Help received | Before DPHS | After DPHS |
|---|---|---|
| Housework | 22 | 17 |
| Heavy tasks | 24 | 21 |
| Visiting | 22 | 19 |
| Shopping | 25 | 22 |
| Laundry | 21 | 19 |
| Cooking | 19 | 16 |
| Grooming | 2 | 2 |
| Feeding | 2 | 2 |
| Bathing | 15 | 9 |
| Washing (face/hands) | 6 | 4 |
| Toileting | 7 | 6 |
| Medical | 3 | 2 |
| Dressing/undressing | 17 | 14 |
| Transferring | 11 | 8 |
| Getting in/out of bed | 10 | 8 |
| Correspondence | 6 | 5 |

**Table 29 Number Receiving Paid or Statutory Support in the Home**

| | Before DPHS | After DPHS |
|---|---|---|
| Home Help | 16 | 17 |
| Home Care Aids ('flexicare') | 1 | 1 |
| Bath attendant | 9 | 8 |
| Paid domestic help | 4 | 4 |

Six helpers living with disabled peopled also experienced health problems which may or may not have consequences for their ability to support other household members. For example, one person who was bedbound and required 24 hour total care was looked after by a husband who had multiple hernias. Another household contained four members who were disabled by the

same condition and the principal carer had problems with his spine.

Of equal concern was the number of helpers who were above the age of sixty and who could not therefore be expected to continue their contribution to support indefinitely or without risk to their own health. Eleven helpers were aged over 60, the average age being 67.5 years within a range of 60 years to the eldest who was 80 years old. Three of these older helpers were female and eight male. Given that 46% of the 426 people studies in the previous chapter were aged over 60 and that a similar pattern of informal care might prevail, there is a clear need to emphasise the importance of considering the needs of helpers and disabled people both in the short and long-term.

It had been hoped to interview some of the helpers alone regarding their own circumstances and to allow them to talk freely, if they wished, about their supporting role. Early on in the survey, however, it became apparent that the majority of helpers wished to be present at the interview and wished to participate by also relating 'their' perception of the household circumstances. Disabled people often appeared 'apologetic' for the amount of support they required from relatives, friends or family members, and one person stated explicitly that he felt a burden to his wife and he had sought psychiatric help for depression.

The interviews revealed no clear relationship between mobility and the amount of informal help used. Some people who had restricted mobility and were virtually wheelchair-bound were able to perform most household tasks for themselves by the use of appropriate aids and technology, whilst others who might be classified as 'less disabled' used more informal support. This

raised the question as to how far aids and adaptations are pursued when helpers are available (and willing) to help? Here, individual preferences must be paramount: some helpers might feel that they want to contribute to the well-being of their loved ones, but need support in this role. Aids and adaptations will play a part in this role but it is possible that carers and clients would prefer to live in a "conventionally organised" household rather than go through the upheaval of moving home or having the accommodation improved or adapted.

Some people were still settling down in new housing and their needs for support had yet to be firmly established, but with the exception of those who entered independent living from institutional life, these findings suggest that there was little change in the amount of informal or formal support following use of the DPHS. This was especially true, for example, where a spouse had traditionally performed certain tasks within the home (shopping, housework etc) and continued to perform the same role in new accommodation.

## SATISFACTION WITH THE SERVICE

### Assessment and advice

People were generally pleased with the assessment and advice service they had received. They felt that the discussion of their problems and preferences had been thorough:

> "The DPHS gave a full assessment. They talked and took trouble. The best you could ever find."

"They didn't miss a thing. I now feel safe. I only have to pull the alarm cord to get help. The family no longer has to worry - I have got my independence back. [They were] very kind. they've said if there is any problem, just ring - don't sit and worry ..."

"Brilliant. Very helpful. Can't speak too highly of them."

**Rehousing**

Those rehoused by Walbrook were unanimous in their satisfaction with the new accommodation, for example:

"Very pleased with the flat".

"DPHS very helpful. Lovely. Can't think of anything we want now. Walbrook very security-conscious [re sheltered complex]. We like the peaceful surroundings."

"Very caring. They listened. Nothing too much trouble..."

Relocation into flexible housing - that which can be readily adapted for maximum accessibility should informal care cease - is obviously an important consideration. Here, however, there must be a note of caution. Two people interviewed who had been rehoused into Walbrook flats (one in a sheltered complex) reflected on the fact that this accommodation was populated largely by people much older than themselves. One person noted that she had been the youngest person in the locality (she was in her

forties) whilst the other person housed into a sheltered complex recognised that her future needs were being addressed but had been faced with the prospect that at a comparatively early age she was at the 'end of the line' - this might be where she was going to stay. The concentration of elderly people in sheltered or wheelchair and mobility standard housing may pose problems for younger disabled people or those disabled people with children who naturally wish to be in a younger or mixed age community not only for social reasons but to have a source of potential helpers.

Only two people expressed negative opinions about becoming Walbrook tenants - one had been rehoused into another landlord's property and one felt that his complaints had not been addressed and preferred to adapt his own property. However, even these two people felt that the DPHS and in particular, the Housing Advisor, were very helpful.

Where people were not rehoused they also had very positive opinions of the service.

**Follow-up services**

Eight people, however, did raise the issue of progress reports and follow-up services. Two of these were awaiting rehousing and wanted more information on what stage their application had reached. One person who did not achieve a solution through the DPHS over the laying of slabs to provide car-access to his home, stated he was also unaware of what was being done on his behalf. The remaining five people felt they needed more monitoring of their progress following their move to Walbrook property, for example:

"We feel as if we have been left."

"I want someone to call and see how I'm getting on."

"The DPHS have not been in contact again."

**The attitude of DPHS staff**

There appeared to be confusion in some people's minds as to how their future requirements would be identified and met once they became tenants of Walbrook Housing Association. Their contact had been with the DPHS and once they were tenants that sphere of responsibility lay primarily with their landlords. It is understood during the period of this study that the housing association have discussed the feasibility of providing more advice to tenants as to which body is appropriate for which service, for example, repairs, income/benefit advice, or personal/domestic support.

Overall the consensus of opinion was that the Housing Advisors were extremely helpful and were particularly caring and conscientious in their attitudes to people. The standard of housing provided was pleasing, and most people felt much happier since moving. Everyone felt that the service had been extremely helpful (to the point where some were almost lyrical in their praise).

Some of the more limited services offered by the DPHS and other statutory and non-statutory agencies can make a significant difference to the degree of autonomy and mobility experienced. These services can appear small for example, the provision of a mobility aid, or an extra hour's personal assistance - but they may make all the difference between dependence and independence. All too often debates concerning community care strategies

for disabled people concentrate on those most severely disabled, ignoring the reality of daily lives for those who perhaps do not use wheelchairs or who are in ill-health and are disabled through their environments nevertheless. A number of people interviewed would not, under some criteria, be classified as 'disabled', for example those with heart conditions, yet their need for accessible housing and a comfortable, easily managed environment was just as critical.

However, it is perhaps in the cases of those people living in institutions who leave to live independently that the range of DPHS services can be witnessed most clearly.

**Moving to independent living**

The original situations of the four people living in residential care have previously been outlined, and the full case history of one such person is given in Appendix A in addition to a flow-chart of services and input from the DPHS included at the end of this chapter. This chart depicts the full range of DPHS-Walbrook services and roles: advice, information, counselling, liaison and coordination, design and adaptation and the provision of housing. This chart also shows the degree of collaboration often required to achieve an effective and satisfactory solution in partnership with the individual concerned and external agencies. The DPHS cannot, as previously stated, provide the personal assistance required for their users, but their role as designers of an environment can be crucial in determining the extent of domiciliary support required.

The other man living in long-term residential care similarly required considerable coordination of services and planning by the DPHS and by staff working at his social services' accommodation and in the community. A full Design Brief was required for his housing and a number of case conferences were held (with the participation of the DPHS) to plan for all aspects of his housing and support needs. A Walbrook ground-floor flat was fully adapted for his use and when interviewed, he was extremely pleased with his new environment which he was still testing out for minor modifications. Domiciliary support was provided by a home help once a week and more intensive support as required. He had received advice and help with benefit entitlement and was budgeting for himself for the first time in many years. There was no aspect of his new home which he could not use and he was happy with the standard of work that had been provided. He was also pleased with the local neighbourhood and he felt able to visit others without assistance (although pavements caused some problems) and he had used community transport services. He stressed he was now "able to do everything for myself."

He had previously been concerned at his isolation in residential care and felt that now it was easier for people to visit him. He was engaged to be married.

The DPHS are therefore part of a network of service provision and resources within the county and in cases such as those described above, they join with others to provide an integrated response to the individual's needs.

## THE VIEWS OF SOCIAL SERVICES STAFF

Informal interviews were held with a number of social services staff whose role it was to coordinate a range of housing and support services to improve mobility and independence in Derby and other parts of the county. They gave their opinion of services for disabled people and the DPHS and a summary of the points raised is as follows.

* Overall social services staff related to the DPHS/Walbrook housing association as a source of good quality, well-designed housing alongside other sources such as other housing associations and local authority housing departments.

* The extent to which local housing authorities (the District Councils) had been able to provide suitable housing or adapt council properties to the requirements of their tenants varied across the county. In Derby the availability of housing stock had once been the major problem, but latterly it was less so. However, local authorities tended to prefer moving tenants rather than adapting their homes to their needs. One Derby social service worker commented that in recent years "care" had been available and not the housing, whereas more recently this trend was reversing. Although these were the perceptions of the staff, the statistics of increased provision of domicilary care provided by the Social Services Department would suggest that it is not a correct interpretation of recent policy.

* In other parts of the county social service workers felt that local housing authorities were less convinced of the needs of disabled people and there had been some problems achieving cooperation. For example, the

attitude was sometimes "prove you can live alone and then we'll help" which placed the disabled individual in a Catch 22 situation, for without the housing they could "prove" nothing.

* Social services staff in the northern half of the county were less able to comment on the role of the DPHS since their experience of working with the service and their understanding of its operations was limited. Only one such worker expressed a wish for the service to be extended to that area of the county and outside Derby social services staff were working with other agencies and local housing authorities as their first port of call for housing.

* Those who did have experience of the DPHS were supportive because of its proven quality and their good relationship with the two DPHS Housing Advisors (and members of Walbrook staff). One interviewee felt that the DPHS had pushed forward the boundaries of independent living in the county and that their expertise and commitment to caring was excellent.

* It was felt that the service had performed well hitherto because it did not appear to be subject to financial constraint - staff could advise on a whole range of options whereas in cases where there is a cash limit there could be a tendency to recommend the cheapest option.

* One person queried whether the DPHS might unwittingly contribute to the 'ghettoisation' of physically disabled people because of their frequent

relocation of people into Walbrook housing which was concentrated in particular areas of Derby, and that therefore some social service areas might come under increased pressure because of demands on a finite budget. However, discussions with one such area office revealed no such worries.

* Staff felt they were working in a period of considerable change and development, opening up possibilities to work more closely with disabled people. They welcomed this challenge and in particular the role played by the Derbyshire Coalition of Disabled People and the Derbyshire Centre for Integrated Living.

* Developments in integrated living were taking place, however, in a climate of restraint and scarce resources and collaboration between agencies such as social services and the DPHS also needed to take account of the efficient use of such resources. Joint planning initiatives (for example with health authorities) had improved but one senior officer noted that schemes had often suffered due to lack of joint management, and that professional barriers and divided spheres of responsibility still prevailed.

* Two senior officers felt that given the DPHS' dependence on county social services for domiciliary support, collaboration over the planning and allocation of care services could be improved and that the DPHS might more properly be housed within the Derbyshire Centre for Integrated Living (or collaborate more closely with this centre) to avoid duplication of effort.

**PROBLEMS IN THE COMMUNITY**

The problems that people experienced with the wider environment (using shops or finding accessible transport, for example) and with obtaining sufficient income to manage - problems which largely remained even following rehousing, were not ones which the DPHS could control, but they have implications for the degree of independence and autonomy which can be exercised by disabled people. The experience of one person who was rehoused from residential care is worth noting in this respect.

He was refused attendance allowance following rehousing because of the extent to which his new home had been designed to allow him to perform certain tasks. Following his departure from the residential home he had been left without income for three months whilst his claims for benefit entitlement were assessed and he was critical of the system which, he felt, could not cater for his circumstances. The forms sent to him could not adequately reflect his situation and he questioned why he could not have been assessed in his own home. Access to the surrounding neighbourhood and the city in general was restrictive. He could reach local shops in his powered wheelchair but having arrived, their doors were not wide enough for a wheelchair, or there were steps. Pavements were an additional problem and public toilet facilities for disabled people only catered for small-size wheelchairs. He relied on others to help him with his financial transactions - "there is not one bank I can get into in Derby" and the community transport schemes (Dial-a-Ride etc) only had two vans capable of carrying his wheelchair. The transport service was under such demand that it was not always available at the times he needed it and he had finally resorted to asking the organisers what dates they could give <u>him</u>, rather than booking the

dates he required.

## CONCLUSION

To conclude, no two people's circumstances are precisely alike and it is not possible to compare the support needs of the disabled people interviewed with any accuracy. Neither is it possible to state what each person's circumstances would have been had they not used the DPHS - some may have remained in the same housing situation, others may have eventually pursued other options. We cannot state what would happen to these people were they to lose their present informal support. It might be argued that in one or two cases the only alternative would be a residential placement, but this would only be speculation and would not take account of the possible statutory, private and voluntary care options now being developed within the county. For example, the Derbyshire Centre for Integrated Living has plans to train helpers to work with disabled people; there are two private care agencies in Derbyshire which are available for those with sufficient income; and Derbyshire County Social Services are continuing to develop and improve home support services. Walbrook Housing Association have developed volunteer schemes which might be more fully extended (perhaps in collaboration with the training programme at the Centre for Integrated Living) to ensure that community living is maintained.

The majority of people interviewed had not, in contrast to certain users of the DPHS, received substantial services in terms of adaptations or statutory support. Notwithstanding the input (and cost) of housing, the cost to the service was arguably due in most cases to the hours of advice, counselling, preparation and coordination to achieve the respective goals of

people seeking assistance. The opinion of all those spoken to, irrespective of whether they had achieved increased mobility (and even some of those whose problems had yet to be solved) was that their quality of life had improved immeasurably as a result of receiving practical help via the service, advice, or merely by knowing that someone understood their problems, had treated their preferences with respect, and had placed no barriers in the way of an eventual solution.

The effectiveness of the DPHS has been assessed in the main by its contribution to the improvement in the quality of life of users and their principal helpers and their satisfaction with the help and advice received. Measures of performance used in other evaluations of home improvement agencies (Leather and Mackintosh, 1990; Department of the Environment, 1990) based on the value of work completed and its effect on the value of property have not been used since these were considered insufficiently representative of the DPHS functions. Such measures undervalue the merit of the advisory aspects of agencies and of minor works which, as shown here, have a major effect on users' satisfaction with the service and with their housing accommodation. In addition, the essential repair of property and the enhancement of its value are components of the functions of the DPHS, but are almost incidental in the provision of accommodation which is purpose-designed to give a disabled person suitable access to all the living space it contains.

# CHAPTER 5

# THE COSTS OF THE WALBROOK DISABLED PERSONS' HOUSING SERVICE

## METHODOLOGY

This chapter is concerned with the costs of the Walbrook DPHS during the financial year 1986-87. The essential preliminary step in any economic costing exercise is to identify the decision context of the service which is to be established or extended. The reason for this is the identification of the changes in resource use which this development will produce. Generally a new or expanding service will call forth increases in some resources while decreasing the use of others. Specifically the development of a disabled persons' housing service is likely to affect resource use as follows:

(a) Increases in resource use

(i) Establishment and running of the service

(ii) Increased take-up of housing aids and adaptations

(iii) Increased use of housing accommodation

(iv) Increased use of some domiciliary care services

(v) Increased take-up of social security benefits

(b) Decreases in resource use

(i) Reduced demand on long-stay accommodation (e.g. hospital, residential or nursing home care)

(ii) Reduced demand for some domiciliary care services

Only the costs of establishing and running a service can be assessed at this stage without recourse to a fully controlled experiment. All the other changes in resource use need to be established through a study of

resource usage with and without a disabled persons' housing service. This research project did not use a controlled experimental design, and therefore, it is possible only to speculate on the other resource effects of the development of the Walbrook DPHS.

## COSTS OF THE WALBROOK DPHS

The following costs were kindly provided by members of Walbrook DPHS:

| Item | Annual Cost £ |
|---|---|
| Management | 12510 |
| Advice | 2030 |
| Assessment of buildings and adaptations | 1000 |
| Occupational therapists | 22275 |
| Clerical | 3485 |
| Architectural Fees | 4950 |
| Office accommodation | 2300 |
| Postage and telephone | 1045 |
| Printing and stationery | 930 |
| Travelling expenses | 2250 |
| Training | 540 |
| Publicity | 1250 |
| Provision of personalised aids | 960 |
| Total | 55525* |

* Current costs (1990) are running at around £72,000 per year

These costs were estimated to cover 200 referrals per year from a population of around 500,000.

## COSTS OF AIDS AND ADAPTATIONS

The costs of housing accommodation, aids and adaptations have to be added to these general service costs. In effect, different agencies bear different sets of costs and this varied picture is set out in the table below for 41 of the people included in the Survey reported in the previous chapters.

| Case No | Hours of Advice Received Hrs | Cost of Adaptation £ | Borne by | Cost of Aids £ | Borne by | Rehousing |
|---|---|---|---|---|---|---|
| 1 | 20 | 1001-2000 | Hsg Corp | - | - | Walbrook HA |
| 2 | 4 | - | - | - | - | None |
| 3 | 5 | - | - | - | - | Walbrook HA |
| 4 | 8 | 5000-10,000 | SSD+ LA Grant | 501-1000 | Client | None |
| 5 | 4 | 5000-10,000 | SSD | - | - | None |
| 6 | 4 | 1000-2000 | SSD | - | - | None |
| 7 | 4 | - | - | - | - | Walbrook HA |
| 9 | 8 | 101-500 | Client | 101-500 | SSD | Owner/occupier |
| 10 | 8 | - | - | 501-1000 | SSD | None |
| 11 | 4 | - | - | - | - | Walbrook HA |
| 12 | 8 | 51-100 | Client | - | - | None |
| 13 | 8 | 1001-2000 | SSD + LA Grant | - | - | None |
| 14 | 4 | - | - | - | - | Waiting |
| 15 | 63 | 501-1000 | Hsg Corp | 101-500 | H/A | Walbrook HA |
| 16 | 8 | 1001-2000 | Hsg Corp | - | - | None |

| Case No | Hours of Advice Received Hrs | Cost of Adaptation £ | Borne by | Cost of Aids £ | Borne by | Rehousing |
|---|---|---|---|---|---|---|
| 17 | 8 | 51-100 | Hsg Assoc | 501-1000 | SSD | None |
| 18 | 5 | 0-50 | Hsg Assoc | 0-50 | SSD | None |
| 20 | 4 | 101-500 | Hsg Assoc | - | - | None |
| 21 | 16 | - | Hsg Assoc | - | - | Owner/occupier |
| 22 | 8 | 10,000+ | SSD+ LA Grant | - | - | Owner/occupier |
| 23 | 62 | 5001-10,000 | Hsg Corp | - | - | Walbrook HA |
| 24 | 9 | - | - | - | - | Walbrook HA |
| 25 | 8 | 101-500 | Hsg Corp | - | - | None |
| 26 | 5 | 0-50 | Hsg Corp | 0-50 | SSD | None |
| 27 | 8 | 101-500 | Hsg Corp | - | - | None |
| 28 | 8 | 101-500 | Hsg Corp | - | - | None |
| 29 | 4 | - | - | - | - | Local Authority |
| 30 | 4 | - | - | - | - | Walbrook HA |
| 31 | 15 | 101-500 | Hsg Corp | - | - | Walbrook HA |
| 32 | 15 | - | - | - | - | Residential Care |
| 33 | 5 | 101-500 | Hsg Corp | - | - | None |
| 34 | 5 | 51-100 | Hsg Corp | - | - | None |
| 35 | 5 | 51-100 | Hsg Corp | - | - | None |
| 36 | 16 | 501-1000 | Hsg Corp | - | - | None |
| 37 | 15 | 101-500 | Hsg Corp | - | - | Walbrook HA |
| 38 | 15 | - | - | 0-50 | SSD | Local Authority |
| 39 | 8 | - | - | - | - | Walbrook HA |
| 40 | 35 | 1001-2000 | Hsg Corp | - | - | Walbrook HA |
| 42 | 63 | 1001-2000 | Hsg Corp | 101-500 | H/C | Walbrook HA |
| 45 | 4 | - | - | - | - | Local Authority |

This table illustrates how the costs of housing, aids and adaptations fell on local authority departments, Walbrook Housing Association, the Housing Corporation and families or individuals. The hours of advice shown all came from the Walbrook DPHS.

Some of the examples which used a considerable amount of advisory help involved people who needed a very thorough investigation of their circumstances before being rehoused in adapted accommodation. This thorough investigation was greatly appreciated by the people concerned who expressed great satisfaction with the advice given.

Only one of the families which received a considerable amount of advice was also amongst the four examples in the sample where the expenditure or adaptations was greater than £5,000. This person was moved from his family to independent living in accommodation rented from Walbrook Housing Association. The other three families concerned owned their own house. Several members of one family were disabled and the adaptations therefore covered all of them. In another family, the house was adapted for a teenage daughter and in the fourth example the house was adapted for an elderly couple.

**COSTS OF A COMPREHENSIVE SERVICE**

The costs set out in the previous section have been disaggregated to show the way that costs fall on different agencies or individuals. The estimates for a comprehensive service at constant year 1 prices were estimated as follows:

| | Average number of households | Cost £ |
|---|---|---|
| Year 1 | 100 | 136,000 |
| Year 2 | 150 | 168,000 |
| Year 3 | 200 | 224,000 |

These costs includedthe costs of aids and adaptations as well as the general administrative and service costs. However, they did not include the costs of housing accommodation.

These costs were in effect the gross costs of a disabled persons' housing service. There will be offsetting costs if the service reduced demands for long-stay accommodation or for domiciliary care services. In order to quantify and evaluate resource savings in other sectors it is necessary to know

(i) that the change would not have occurred without the intervention of a DPHS.

(ii) the scale of the changes and their effects on the costs of running the services affected.

It is not possible without a controlled evaluation to say whether resource changes are brought about solely by the intervention of the DPHS. Similarly, to estimate the effects of resource changes it is necessary to know how usage affects a particular service. At one extreme, a DPHS may facilitate a person's discharge from or prevent admission to a long-stay hospital. However, it would not be correct to use the average cost of an inpatient stay

at that hospital to evaluate the cost savings. Hospital costs are not very sensitive to certain small scale changes in resource use. One or two patients more or less in a ward has very little impact on total hospital costs. Unless a disabled persons' housing service can be shown to save several beds in one hospital, its development will have little or no effect on hospital costs. It is even possible that moving one or two people from a long-stay hospital would increase overall resource usage. For example, take a single person moving from the hospital to his or her own house. The reduction in hospital costs would be virtually zero. The costs of living at home in the community were estimated at:

(i) Increased personal living expenses - In hospital a person was allowed £8.25 per week "pocket money" under social security allowances. In the community these personal expenditures depend on the entitlement to Income Support, disability and attendance allowances which would have been around £80 per week.

(ii) Increased use of housing accommodation - a person moving to independent living would occupy a house or flat with a possible value of say £60,000. The usual approach to convert this capital sum to a weekly equivalent was to discount the capital at 5% over the 60 years of estimated life of the dwelling. Such an exercise would put a value of £61 per week on the £60,000 dwelling.

(iii) Increased use of domiciliary care services - a person moving from hospital to independent living may need some help with household duties, laundry, shopping and items of personal care. The cost of an hour of home help time was around £4. Thus if someone

needed say, 4 hours of help per week the costs of domiciliary care would have been £16.

The total cost of moving from hospital to the community would have been:

| | £ per week |
|---|---|
| Personal expenses | 80 |
| Housing accommodation | 61 |
| Domiciliary services | 16 |

The offsetting cost of hospital care was £8 per week so the net cost of the move to the community was £149 per week.

Moving people from or preventing admission to residential home or nursing home care may show cost savings because the demand for residential and nursing home care, especially in the private sector is generally on the increase. For the person in the community the £157 per week remained the same as in the previous example. However, the costs of private residential home care including the "pocket money" allowance were £198 per week and the costs of private nursing home care were £238. Thus, the cost savings for private residential care would have been £41 per week (£2,100 a year) and for private nursing home care they would have been £81 per week (£4,200 per year).

These examples show that the costs of alternative modes of care need careful calculation. Information is needed on the exact details of personal expenditure, the value of housing accommodation occupied and the use of

health and personal social services in different forms of care. Care is also needed in establishing the effects of changes in occupancy on hospital costs since the use of average costs of inpatient stays to estimate the value of small changes will be misleading.

So far as Walbrook DPHS is concerned the first 426 cases showed very little effect on the use of long-stay hospital beds. Only two people referred were discharged. This would suggest cost savings of around £15,000 - £29,000 per year. Some people may have been kept at home through the intervention of Walbrook DPHS. None of this change or lack of change can be proved at this stage to be the result of the work of Walbrook DPHS.

Some people were discharged from shorter stay hospital facilities and it is possible that the DPHS would help to reduce length of hospital stay. In these cases a contribution is made to increase the availability of hospital beds and to reduce waiting lists for those facilities.

Similarly, because there was no attempt to use a controlled experimental research design, it is not possible to estimate the net resource effects of the use of domiciliary services arising from the interventions of the Walbrook DPHS. The usual example of possible resource savings occurs where the installation of bathing aids substitutes for the visits of a bath nurse. No exact estimates of these savings were available.

**COST-EFFECTIVENESS CONSIDERATIONS**

It can be very misleading to concentrate on just the costs of the service without also looking at its effectiveness. The previous two chapters have shown how the Walbrook DPHS has improved users' quality of life and

produced high levels of consumer satisfaction. The main extra cost of the service was £56,000 per year spent on the establishment and running of the service for 200 users. So, for around £300 per user the Walbrook DPHS produced considerable benefits for its users, especially in ensuring that people received the help to which they are entitled and were placed in the most appropriate housing accommodation. The other net costs were difficult to quantify because of the problems of identifying the take-up for aids and adaptations, health and personal social services, social security benefits and places in long-stay accommodation with or without the intervention of the DPHS.

No attempt has been made to discuss the cost-effectiveness of the DPHS since the rather restrictive framework of cost-effectiveness is not robust enough to encompass the appraisal of services which improve quality of life but at some increase in costs.* These circumstances require subjective judgements as to whether the increase in quality of life is worth the extra costs involved having regard to other priorities for resource use.

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Footnote

* Cost-effectiveness analysis is used when one alternative is clearly more effective but not more costly than another or is less costly but not less effective than another. Where one alternative is more costly and more effective than others, cost-utility analysis is used to assess the cost per unit of quality added. However, this methodology is still in its experimental stage and would not at this stage be applicable to this study.

# CHAPTER 6

## SUMMARY AND RECOMMENDATIONS

### Summary of the research findings

This study of the Walbrook Disabled Persons' Housing service was undertaken at a time of considerable debate concerning the provision of institutional and community-based services for physically disabled people. Within this debate, the nature of statutory and non-statutory provision and consumer participation have been discussed in the context of the goal of independent living (Royal College of Physicians, 1986(a); Keeble, 1983). Disabled people have added their voice to this debate to achieve increased choice and control in the nature of provision and quality of life achieved (Oliver, 1981; HCIL 1986). A number of studies have highlighted the central role of housing and housing design with regard to community care and the potential for increased independence that appropriate forms of housing can offer (Royal College of Physicians, 1986(b); National Federation of Housing Associations/MIND, 1987; Fiedler, 1988; Wheeler 1985) and the question of housing provision has been addressed by government legislation, local authority housing departments and the housing association movement.

The Walbrook Housing Association, based in Derby, responded to a growing demand for accessible housing for physically disabled people from all sections of the local community and in doing so, identified the need for such housing to be considered in relation to other aspects of life which may influence independence, for example, personal support, aids and equipment, the appropriate design of housing, fixtures and fittings. They found too that

there was a demand for objective advice on the range of statutory and non-statutory services and following consultation with various local bodies, established the Disabled Persons' Housing Service as an agency of the housing association.

This service which is free of charge now offers practical help and advice regarding all aspects of housing, housing-design, finance, aids and equipment to people from all walks of life, irrespective of age, degree of disability, existing housing circumstances, income etc. Operating mainly in the Derby city area it has become recognised by disabled people and statutory bodies as a source of information on housing and housing-related services. It has developed its policy of collaboration with local authorities, health authorities, social services and the Derbyshire Centre for Integrated Living to form part of the network of cross-referral in response to the multiplicity of needs expressed by those who approach the service.

Data were collected on a total of 450 'cases' of the Disabled Persons' Housing Service (ie, all those cases between 1985 and March 1988) of which, 426 were identified as relating to disabled users of the service. Forty-five of these users, selected to represent a range of age and housing circumstances were interviewed in greater detail in respect of their requirements before and after their use of the service, and their opinions of the service.

It was found that the service was used by a wide cross-section of the local community: by existing tenants of the Walbrook Housing Association; by council tenants; owner-occupiers; private tenants etc., and by those in hospital or institutional environments. Those who made use of this service included:

- those living in institutional environments who were seeking a move into the community to independent living

- people in hospital either on a short or long-stay basis who required suitable housing prior to discharge

- younger people who were seeking independent living away from the parental home

- parents of disabled children who wished for advice or practical help in respect of future housing needs

- wheelchair-users and those with impaired mobility whose home, or parts of that home, were inaccessible

- those who required aids or customised equipment

- people in need of personal support and assistance

- people who felt 'at risk' and in need of sheltered accommodation or alarm systems

- people whose neighbourhood caused them anxiety or mobility problems who were seeking accessible housing elsewhere

- relatives of disabled people who themselves required support in looking after their loved one

- people requiring advice on all aspects of housing finance and meeting their housing costs.

The service has also been approached by other housing associations to advise on the needs of their tenants and to make recommendations in respect of adaptations, aids and equipment. In addition, the DPHS has been consulted by researchers in the housing field, disabled people in other parts of the country, and local bodies seeking advice on accommodation design for physically disabled people.

It was common for users of the service to experience a number of interrelated problems concerning their housing circumstances, their need for aids and adaptations, and personal assistance. The nature and complexity of these circumstances which were unique to each user and his/her family demanded an individually-tailored response based on an assessment by the DPHS Housing Advisors in partnership with the individual concerned. The assessment process is not used for the purposes of rationing provision or for the determination of eligibility for this or that service. Rather, it is an in-depth discussion with individuals to identify all aspects of their circumstances which might have a bearing on the problem presented and the eventual solution. The solution pursued might involve a number of statutory and non-statutory agencies whose participation can be sought and coordinated by the DPHS but whose own criteria for providing services are maintained.

A majority of cases closed following an approach to the DPHS resulted in a rehousing option being pursued, either through the Walbrook Housing Association, the purchase of property, or the renting of property from local

authorities or other housing agencies. The relationship between the DPHS and Walbrook Housing Association has resulted in the Housing Association staff developing considerable expertise in the design of homes appropriate for those with restricted mobility and the allocation of properties to physically disabled people is based on the principle that existing and new housing stock will be adapted to suit the individual, rather than expecting the individual to adapt to available housing.

In respect of rehousing and adaptations to existing or alternative homes use is made of personalised Design Briefs (completed in partnership with the disabled person) to describe accurately the environment required for each person and family members were appropriate. This Design Brief, augmented by drawings to provide a visual representation of space and other requirements, can then assist the service user, the DPHS, architects and builders, to plan for both immediate and future needs.

Forty-five people were interviewed at length concerning their experience of the Disabled Persons' Housing Service. These interviewees represented a range of housing and mobility problems and disabilities and a similar range of outcomes in respect of their use of the service. All of those interviewed expressed considerable satisfaction with most aspects of the service especially in terms of the following:

1 The service is free. The experience of those users interviewed was that they relied heavily on state benefits (pensions, mobility benefits, income support, housing benefit etc) and that income levels were generally low.

2 There was no eligibility criteria for using the service. Therefore those who may be considered too old, too young, or less severely disabled in terms of provision by other agencies were able to receive assistance from the DPHS.

3 The DPHS offered an immediate response: there was no waiting time for an assessment or discussion of people's requirements, although the eventual outcome of the service (for example, rehousing) might involve a period of waiting time dependent on the complexity of the service response and the extent to which other agencies were able to undertake provision.

4 People were particularly impressed with the thoroughness of the assessment process and felt that they had developed a personal relationship with the DPHS staff. Comparing their experience of the DPHS with that of statutory services users welcomed the informal structure of the service and the fact that they could gain immediate access to (and decisions from) the DPHS staff.

5 Users felt that they were able to contribute to the delivery of the service in that their opinions and preferences were considered. They were able to exercise control and choice over the eventual outcome.

6 The availability of advice and information on all aspects of housing and mobility-related services was particularly welcomed in allowing the user to exercise choice within the spectrum of statutory and non-statutory support.

7 The DPHS could act as a coordinator or facilitator to access other services and liaise across professional and bureaucratic boundaries.

8 The quality of housing provided by Walbrook Housing Association and the design of the home environment was excellent.

9 Individually-designed or adapted aids and equipment could be provided.

10 As an agency of the Walbrook Housing Association the DPHS could gain access to other amenities such as Radio Warden schemes, furniture, Care and Repair advice and volunteer helpers.

11 Through the facility of the Walbrook 'Training Flat' disabled people were able to learn new skills, test out their own preferences for independent living and gain self-confidence.

The DPHS has been able to develop a relationship with local building societies, banks, estate agents and solicitors to increase awareness of the need for private housing options and financial resources for disabled people.

As a housing-oriented service it does not have the resources or the relevant expertise to address all those facets of daily living which contribute to the quality of life of disabled people, for example, the need for appropriate transport facilities, the need for accessible public amenities and local environment, the need for trained peer counsellors and advocates, the need for appropriate personal support in and outside the home. Disabled people are therefore reliant on the availability of such resources from other agencies and bodies within the county. As a service outside the statutory

sector the DPHS cannot control, and has restricted influence on, a range of certain housing and care-related resources which it may advise upon.

Less use of the service has been made by ethnic minorities within Derby and the orientation of the service to these communities is still being developed.

The DPHS welcomes enquiries from all parts of the county, but three-quarters of all users come from Derby city where Walbrook Housing Association has been established for over twenty years and is known to have properties available for rent. There have been far fewer enquiries and referrals from statutory agencies from those areas with little or no Walbrook housing stock and given that a majority of service-users opted for a rehousing option and, in particular, one which resulted in their becoming tenants of the Walbrook housing association, it is apparent that the service has developed a reliance on the availability of this housing stock.

This service is concerned with a group of people whose health and mobility needs are often subject to change, and whose requirements for personal and practical support require a similarly flexible response. Where disabled people are rehoused (for example by Walbrook) these new home environments may begin to cause problems or restrict independence at a later stage and whilst the service encourages past users to re-contact at any time if they experience problems, evidence in this report suggested that they do not always do so. This group will therefore require more effective follow-up or visiting to prevent future problems.

The cost of providing the DPHS was around £57,000 per year in 1988. The costs of providing housing accommodation, adaptations and aids to mobility and daily living fell on a variety of agencies. Without the DPHS many of these would still have arisen. The DPHS acted as a housing agency service in ensuring that people gained access to the most appropriate source of help and it can be argued that many of those people would have gained access to some source of help if the DPHS had not been in existence. Similarly, some of the people who moved from residential homes or hospital care to adapted housing in the community may have stayed in that mode of care longer or permanently without the advice and help of the DPHS. At the present state of knowledge it is not possible to say what the costs of accommodation, adaptations, aids and personal care services would be for a given set of users with and without the DPHS. However, it is possible to say that for around £300 per person, the users of the DPHS are gaining access to services which greatly enhance their quality of life.

There are key elements to the Disabled Persons' Housing Service which combine to offer a comprehensive housing-oriented service. These can be classified under the following headings:

- information
- advice
- coordination/referral
- design/adaptations
- housing provision

These key elements are all underpinned by the philosophy that disability can be created by unsuitable or inaccessible environments which in turn can be changed to enhance independence and reduce the need for personal support. The partnership approach to provision, where the individual disabled person uses the service as a resource to pursue his or her own preferences is also integral to the success of the service.

**Information and Advice**

Discussions with those who used the DPHS identified Information and Advice as the two most important elements of the service. This confirms the view stated by Oliver (1981) in describing "information disability" where physically impaired people are disabled by the lack of access to specialist information and are therefore unable to make effective choices and participate in the process of change over their daily lives. Information and advice on resources for housing, aids, adaptations, personal support etc, is available through the offices of statutory personnel (for example social workers, occupational therapists, community living projects). Information is also available in some parts of the country from disabled people's organisations (for example the Disablement Information and Advice Services and centres for Independent or Integrated Living).

The DPHS method has been one which falls half-way between these two approaches. The service is able to offer what people perceived as objective advice which is not subject to criteria for rationing provision or professional boundaries. It cannot, however, offer experiential advice in that the staff of the DPHS are not themselves, disabled people. The staff of

the service feel that their specialisation - coupled with their commitment to a partnership model of assessment with the individual concerned - has allowed them to learn from and with the service users to act as enablers or agents of change rather than as assessors of 'need'. Such a model of Information and Advice can be provided whether or not the housing association has housing stock available.

**Co-ordination and Referral**

The research demonstrated the necessity for the service to collaborate closely with both statutory and non-statutory bodies in that the provision of and responsibility for many services (eg, domiciliary support, local authority housing, aids etc) cannot be provided by the DPHS.

In this respect it is important to place the service in the context of overall demand: to date the service has dealt with just over 600 enquiries (in three years). County social services deal with, on average, 1,004 enquiries per month from people requiring aids and adaptations and over 400 major adaptations each year.

No formal system of referral has been adopted by the service and these agencies, but a good working relationship has been developed based on the acknowledged expertise of the DPHS staff to the extent that cross-referral is now common practice and a joint DPHS/statutory/non-statutory response can often be offered to the individual. In this respect the DPHS is able to act in a coordinating role on behalf of the user which again was welcomed by those who were interviewed. However, it must be noted that the DPHS has hitherto operated in an area committed to consumer-led model of provision where the

participation of disabled people (through the Derbyshire Centre for Integrated Living) is supported and where the DPHS was established after consultations and discussions with the statutory authorities. The ability of a similar service elsewhere to act as coordinators and referrers will depend on the particular system of provision pertaining to that area and the degree of cooperation and collaboration which can be developed over time.

**Design/Adaptation**

With regard to Design and Adaptations the DPHS was found to be most successful where it was able to link these services to Walbrook housing stock. For existing Walbrook tenants or those awaiting Walbrook housing these services could be pursued effectively at all stages of the work - from the preparation of the Design Brief through to adaptation work or new-build construction. Whilst non-Walbrook tenants could make use of the DPHS expertise to develop their own ideas about living environments, where other agencies were then responsible for the funding and implementation of such adaptations then the DPHS might have less influence on the outcome. The construction and adaptation of non-Walbrook properties is subject to the differing practices, policies and financial constraints of other agencies.

The research showed that users were impressed with the quality, attention to detail, and the respect for their own wishes afforded by the DPHS design and adaptation service. Whilst the DPHS experience has been that this service is mot effective when the process can be influenced at all stages via the provision of housing, it might be possible to provide a similar service on a consumer-advice or consultancy basis only or by pursuing collaborative policies with providers of housing in the public and private sector.

**Housing provision**

The DPHS has no housing stock of its own - but as an agency of Walbrook Housing Association it can provide access to that housing. Walbrook is only one of a number of housing associations across the country who are able to offer homes designed to wheelchair or mobility standard and adapted for the individual tenant. Nevertheless two such housing associations in Derbyshire felt that they were lacking the necessary depth of knowledge developed by the DPHS to provide a similarly thorough service and were happy to seek the recommendations of the DPHS in respect of particular tenants. Housing association property is becoming an increasingly attractive option for those seeking rented accommodation and whilst debate on issues raised by government housing legislation and community care policies have yet to be resolved it is clear that the movement plays an important role in the provision of housing for disabled people and will do so in the future. The availability of good quality housing from an association linked to specialised expertise in design and mobility-related services was clearly welcomed by service users, who were prepared to join a waiting list for suitable Walbrook property.

A number of those interviewed had applied elsewhere for suitable housing but had been deterred by waiting-times or eligibility criteria in respect of, for example, sheltered and ground-floor property. The allocation system adopted by Walbrook which ensured provision of suitable housing which fitted the requirements of the individual regardless of length of time on the waiting list reassured those waiting for alternative housing that their interests were being pursued and enabled some users to enter new housing in a matter of weeks or months.

## RECOMMENDATIONS

This research has confirmed that disabled people have wide-ranging and interrelated needs which require a varied and flexible response. However other studies (eg, Borsay 1986; Beardshaw, 1988) have shown that this response often results in a confused, fragmented and bureaucratic system within which disabled people have little influence over the nature of provision. In contrast bodies such as the Derbyshire Centre for Integrated Living have been seeking to encourage the promotion of an integrated response to the needs of disabled people based on their own daily living experiences and encompassing all aspects of life which influence full participation in the community.

The Disabled Persons' Housing Service as established in Derbyshire is independent of statutory services and disabled persons' organisations, yet is part of the overall integrated network of resources being developed in the county through the strategies of health and social services, local authorities and the DCIL.

The perception of other agencies in Derbyshire, is that within that framework, the DPHS is primarily a housing resource for disabled people in the county, given that most of the other services offered, for example, advice and adaptations, are offered by both statutory and non-statutory bodies. County authorities believe that the existence of the DPHS has provided a safety valve for severely pressurised services. However, it is also recognised that the integrated nature of disabled people's needs demand each and every service to consider a 'holistic' approach to its consumers, so that an agency which provided the bricks and mortar of housing without consideration of mobility

aids, personal support or an accessible local environment, would be perpetuating a system of service provision where 'gaps' could occur and disabled people would be disadvantaged. It is therefore felt that the success that the Disabled Persons' Housing Service has achieved in improving the quality of life for its users is, in part, because it can offer a partnership model of provision where elements other than bricks and mortar are fully considered and where collaboration and cooperation with other agencies, statutory and non-statutory is encouraged.

The inevitable question with a service like the DPHS is whether it is an alternative or a complement to the hard-pressed service provided by the statutory agencies. The scope of the work of the DPHS set out in Chapter 3 suggested that its role was mainly complementary. However, this in turn raises the question whether the statutory agencies, with equivalent resources, could expand to provide an equally effective service. The answers to these questions will vary by locality and the existing services provided there. Thus a main recommendation of this study is that further action-research is required into the feasibility of such a service in other areas of the country where differing networks of provision and consumer participation pertain, and in particular where the respective roles of county, district and metropolitan district authorities may differ in respect of housing and social services provision from that of the Derbyshire model. Consideration also needs to be given to the range of organisational models which could suit differing local circumstances and needs, and the extent and nature of a housing association role in that context. Consumer opinion would need to be canvassed with regard to local requirements - and avenues for - the participation and involvement of disabled people.

This study of the Walbrook DPHS was undertaken prior to the full implementation of major changes in housing, disability and social security legislation, all of which may influence the nature of housing and personal support services for disabled people in the near future. Implementation of the White Paper on Community Care (Department of Health, 1989) will have a further bearing on any service concerned with the needs of disabled people. Further feasibility or pilot studies elsewhere in the country, would be able to additionally study the role of such a service in relation to these altered circumstances and inform debate on varying models of provision.

Following examination of various localised networks of provision, pilot services could be established in different parts of the country, in cooperation with different bodies (for example housing associations, disabled people's organisations, local authority agencies) to evaluate different service models. It is unlikely that a universal model of provision will apply in such a complex and varied area of consumer needs.

The way in which Care and Repair and Staying Put agency services for elderly people have been developed and piloted across the country provides a useful model for the monitored development of housing agency services for disabled people. The current expansion of schemes through a non-profit making development agency (Care and Repair Limited) has also enabled a systematic research exercise to be mounted funded by the Department of the Environment and carried out by the School for Advanced Urban Studies (Leather and Mackintosh, 1990). The significant overlap of disability and old age, reflected in the user profile of both Care and Repair schemes and the Walbrook agency, would indicate scope for considering the potential role of Care and Repair Limited as a development agency for schemes arising directly

from the Walbrook experience as well as those provided for older people.

There are some more general recommendations arising from this study, all of which are clarified by the research summarised in the previous paragraphs.

1 Consumer participation: disabled people's participation in the determination and delivery of services is growing and must be encouraged by increased representation at all levels of provision. Consultation and collaboration with consumer organisations run by and for disabled people should be extended.

2 Collaboration: a more concerted effort is required on the part of professional and other bodies to make collaboration more effective across the housing/care barrier.

3 Advice and information: statutory authorities need to assess and improve their performance in providing an integrated and comprehensive advice and information service for disabled people.

4 Training: a reorientation of training policy is required to equip professional staff (for example, occupational therapists and social workers) with the skills necessary to develop integrated living opportunities in partnership with disabled people.

5 Further action research: a further major experiment based on action research is required to (a) assess how far and in what ways different local housing responses to disabled people's integrated living needs

mirror the Walbrook agency experience and success in Derby; (b) to examine further and more systematically the requirements and views of disabled people from all cultures who are in receipt of such a service, living in both urban and rural areas; (c) to explore the respective training needs and roles of professionals, disabled people, and volunteers in providing such a service; (d) to investigate the differing cost of provision.

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CASE STUDY No. 7 DATE OF APPLICATION August 1986

| REFERRED BY | PRESENT HOUSING TENURE | LOCATION | No. IN PRESENT HOUSEHOLD | No. IN FUTURE HOUSEHOLD |
|---|---|---|---|---|
| a) Nottinghamshire Social Services<br>b) Self due to DPHS publicity | Residential Home | High Peak | One of 10 residents | 1 |

DISABLED APPLICANT

| Name | Age | Disability | Mobility |
|---|---|---|---|
| Mr. R | 44 | Cerebral Palsy | Wheelchairbound (able to transfer from wheelchair with equipment) |

OTHER MEMBERS OF HOUSEHOLD

| Name | Age | Relationship to Disabled Person |
|---|---|---|

DISABLED PERSON'S INITIAL ENQUIRY

Assistance with achieving independent living in the community