Front Cover

Provision of aids and adaptions for hospital patients discharged into their own home

by

Ursula Keeble

October 1984

Price £2

Contents

THE PROVISION OF AIDS AND ADAPTATIONS FOR HOSPITAL PATIENTS DISCHARGED INTO THEIR OWN HOMES

A follow-up study of patients seen by occupational therapists in three London hospitals between 1 May, 1981 and 30 June, 1982.

SECTION A — Introduction

A.1__The Background of the Study

Some patients with physical disabilities need special aids, often quite simple ones, to help them overcome handicap; and perhaps adaptations to their homes to help them live as independently as possible. Assessment for aids and adaptations is done by hospital occupational therapists while the patients are in hospital. Patients may also be taken home on short visits to see how they can cope in their normal environment. A good deal of professional time and skill goes into determining what disabled patients need and which aids would be the most appropriate. Formal requests are then made by the hospital occupational therapists to the agencies empowered to provide them. These are the health authorities, the Red Cross and, most frequently, the social services departments. Unfortunately, hospital occupational therapists can do no more than make requests and cannot ensure that urgent recommendations are carried out promptly. Indeed, some requests may not be acted on at all. Yet the provision of an aid or adaptation can help to improve the quality of the life of a handicapped person and make all the difference between their having to rely on another person for help with the normal activities of daily living and achieving some measure of independence.

A.2 Aims of the Study

The main aims of the study were to find out to what extent social services departments in the catchment area of three district general hospitals in London were failing to fulfil their responsibilities under the Chronically Sick and Disabled Persons Act, 1970 to help with the provision of aids to daily living for disabled persons discharged from hospital, and with adaptations to their homes; also to investigate delays in providing these, why such delays occur and how they might be avoided. The provision of services which also make it possible for disabled patients to return to their own homes after discharge, for example home helps and meals-on-wheels, also needed to be examined.

A.3 The hospitals

Three district general hospitals were chosen for the study: the Whittington Hospital, Highgate, with 951 beds (excluding children and psychiatric patients), the London Hospital (Mile End) with 410 beds, and the London Hospital (Whitechapel) with 717 beds.

A.4 The catchment areas of the hospitals

Patients in the sample came from 13 Greater London boroughs, more than one-third of the Greater London area. All three hospitals took in patients from Hackney and Islington and, in addition, the Whittington Hospital drew patients from Barnet, Brent, Camden, Ealing (one only), Haringey and Waltham Forest. Other patients in the Mile End and Whitechapel samples came from Barking, Enfield, Newham, Redbridge, Tower Hamlets and Waltham Forest, the catchment area being much the same for both hospitals which are within a mile or so of each other. Both branches of the London Hospital also drew several patients from the neighbouring county of Essex, while the Whittington sample showed only one patient from Essex but, exceptionally, one from Bedfordshire and one from Shropshire.

Most patients came from close at hand; from within a three-mile radius of the Whittington Hospital and from the local borough of Tower Hamlets to the Mile End and Whitechapel hospitals. Of the 98 patients in the Whittington sample, 31 went home to the Hornsey area of Haringey and 26 to the Holloway area of Islington. From the Mile End and Whitechapel areas 47 out of the 99 patients returned to Tower Hamlets with the greatest number living in Stepney, Bow and Bethnal Green.

A.5 Variations in the policy of social services departments

Because the patients in the sample came from a number of different local authority areas the study uncovered considerable variations in the policies of social services departments towards the disabled as a whole and in the priority given to the provision of aids and adaptations. The amount of money allocated for aids in the financial year 0-81 varied from as little as £6,000 in one inner London borough to £46,000 in an outer London borough. The willingness or otherwise of local authorities to spend money on the disabled was also reflected in the number of staff specially trained to care for people with disabilities that they were prepared to employ and in what they were prepared to pay them.

Some employed one occupational therapist for each social services area, whereas others were hard put to keep just one to cover a whole borough or county. All too often the place where the discharged patients lived determined the speed with which their needs were met after they left hospital and, sometimes, whether their needs were met at all.

A.6 The occupational therapist: nomenclature and job description

Not all social services departments call the occupational therapists they employ by that name. However, for the purposes of this study the term domiciliary occupational therapist is used to describe professionally trained occupational therapists who have chosen to work in social services departments rather than in hospitals. Hospital occupational therapists is used to describe professionally trained occupational therapists who work exclusively in hospital occupational therapy departments. At the time of the study no occupational therapists were jointly employed by a social services department or by any of the three hospitals.

The main work of domiciliary occupational therapists takes place in the homes of clients. Although at times they are called on to assess clients for Part III accommodation (residential care in local authority homes), their main efforts are directed towards keeping disabled people in their own homes. To make this possible aids and adaptations are often necessary. Assessing clients for aids, choosing the most appropriate and ordering, storing and distributing them, takes up a good deal of their time - some would say a disproportionate amount. In addition, recommendations for adaptations also have to be made.

Some local authorities call their domiciliary occupational therapists disabled living advisers, which is a clearer description of their job. Others use the term rehabilitation officer, which can be misleading because heavy case loads seldom leave time for genuine rehabilitative work, either with the physically handicapped or the mentally handicapped, who also come under their care.

Time spent with clients by professionally trained staff is in itself a valuable therapy and it is important that the provision of aids and adaptations should be seen as part of the whole process of caring and not as an end in itself. Unfortunately, long waiting lists for home visits by occupational therapists mean that aids are frequently delivered by untrained staff and many discharged patients do not get the professional support they need on their return from hospital.

Domiciliary occupational therapists are supervised by head occupational therapists, sometimes called senior disabled living advisers or senior rehabilitation officers, who keep their staff fully briefed about the most appropriate aids available in a constantly changing commercial market. They are also responsible for administering the money allocated for aids and adaptations. In this study they are referred to as head occupational therapists.

A.7 The timing of the sample and its effects on the results of this study

The study concentrated on the in-patients seen by hospital occupational therapists in the three hospitals. With the exception of children under sixteen and psychiatric patients, all the in-patients seen over a period of thirteen weeks were included, provided they had been discharged into their own homes. Patients who had been discharged into convalescent homes or Part III accommodation were not included.

The thirteen week period at the Whittington Hospital ran from the week beginning 4 May, 1981 to the week beginning 27 July and follow-up about aids and adaptations continued until the middle of October, a time when social services budgets were still not exhausted. Material from the London Hospital (Mile End) was collected between 6 November, 1981 and 29 January, 1982, the follow-up continuing in February and March, the bleakest months of the financial year. Collecting material from the London Hospital (Whitechapel) had been planned for the same time as at Mile End but it was interrupted by a strike of hospital porters and the period had to be extended by seven weeks until the week ending 19 March, 1982 when admissions returned to normal. This meant that some of the follow-up on patients discharged from Whitechapel took place in the new financial year beginning 1 April, 1982, when money could be expected to flow more freely.

The rhythm of the financial year undoubtedly influenced the provision of aids and adaptations and this is reflected in the results of the study. Patients discharged from hospital during the last quarter were less likely to get aids quickly, no matter how urgent their needs might have been. For example, some boroughs stopped issuing bath aids during February and March and there were instances of more expensive items, such as geriatric chairs or a shower, being either disallowed or held over for some months. This periodic drying-up of supplies was the direct result of cuts in local authority expenditure during the previous years. Because they are separate items in social services budgets, allocations for aids and adaptations proved easy to cut and although the allocations for the financial year 1980-81 showed a slight increase on the previous year in most boroughs, and had been adjusted for inflation, they had not kept pace with anticipated demand. By the time the study began, under-provision of aids and adaptations had become a habit in some social services departments throughout the financial year.

A.8 The numbers in the sample

Ninety-eight in-patients at the Whittington Hospital were seen by hospital occupational therapists over a 13-week period; 69 in-patients were seen over 13 weeks at the London Hospital (Mile End); and 30 at the London Hospital (Whitechapel) over an extended period of 20 weeks. A total of 197 patients were seen by hospital occupational therapists during the 33 weeks, all of whom were discharged to their homes.

A.9 The letters, questionnaire and form asking for a visit

One month after the date of their discharge from hospital all the patients in the sample were sent a letter asking if they had received the aids and adaptations which hospital occupational therapists had asked for on their behalf. These aids and adaptations were named. If aids and adaptations had not been requested by hospital staff the patients were asked whether there was anything they felt they needed. The period of one month was chosen so that staff in social services departments had time to order and deliver aids which were not in their stores. A questionnaire sent with the letters was designed to discover how discharged patients managed to carry out daily activities with or without the use of aids, whether they had all the aids and adaptations they needed and felt safe using them; or whether they no longer used them at all. Questions were also asked about the kind of property patients lived in because where they lived, either in the public or private sector, determined the contribution made by local authority housing departments towards adaptations. This is discussed in more detail on page 10. Questions were also asked about domiciliary services. Conventional questions were asked about age, marital status and composition of the household in order to build up a general picture of the kind of patients seen by occupational therapists when in hospital. Space was left for patients to make independent comments on how they had managed since returning home, whether they were satisfied with the services they had received and whether they had any problems that had not been overcome.

In addition to a letter and questionnaire, each patient was also sent a form asking if he or she would like a visit from the researcher and, if so, on what day of the week and between what times a visit would be preferred.

It was hoped to visit all the people in the samples who were found to be still waiting for an aid or adaptation one month after discharge.

In all, 42 respondents (37.5 per cent of those who sent in completed questionnaires) were waiting, of whom 33 were visited. Long telephone conversations were held with the other nine.

A.10 Response to the questionnaire

Of the 98 patients in the Whittington sample, it was learned from relatives that two had died within a month after returning home and two had been re-admitted to hospital. This reduced the working sample to 94, of whom six returned blank questionnaires. These, although willing for the researcher to visit them, are classified as non-respondents. Fifty-nine sent in completed questionnaires, a response rate of 63 per cent.

Forty-one of the 69 patients in the sample from the London Hospital (Mile End) returned completed questionnaires, a response rate of 59.4 per cent. One of these patients had died after being home for four weeks but as a completed questionnaire was sent in by a relative this patient was classified as a respondent.

Of the thirty patients in the sample from the London Hospital (Whitechapel) one was known to have been re-admitted and none had died. This made 29, of which 12 returned completed questionnaires, a response rate of 41 per cent.

The figures from Whitechapel are small not because of the strike but because the majority of patients seen by occupational therapists are out-patients attending consultants’ clinics. At Mile End, the sister hospital, the majority of patients seen by occupational therapists are in-patients and very few attend out-patient clinics. The work done by the two hospitals is closely linked administratively and the contributions by occupational therapists can be considered to be complementary.

The responses from Mile End, Whitechapel and the Whittington totalled 112. The analysis that follows is based on these 112 completed questionnaires.

There may have been other deaths and re-admissions. The researcher had to rely on relatives for this information.

SECTION B — ANALYSIS OF RESPONSES TO THE QUESTIONNAIRETHE GENERAL PICTURE

B.1Sex and age of respondents

The average age of the men in the sample was 72 years 5 months at the Whittington, 63 years 11 months at Mile End and 63 years at Whitechapel. The average of the women was 71 years 5 months at the Whittington, 70 years 3 months at Mile End — one woman however withheld her age - and 63 years at Whitechapel.

The average age of men in all three hospitals was 66 years 6 months; the average age of women was 68 years 4 months.

Of all the 112 respondents, 33 were in the 65-74 age group (29 per cent); 31 in the 45-64 age group (28 per cent); and 29 in the 75-84 age group (26 per cent). Therefore, the majority of patients who filled in the questionnaire were between the ages of 45 and 84, 83 per cent of the total sample, with 55 per cent being 65 and over.

Age did not apparently deter people from returning completed questionnaires. Two respondents over 80 asked their home helps to fill them in, one asked a general practitioner and two asked district nurses. It is assumed that the helpers recorded the views of the people they helped and not their own. The distribution of the ages of patients is shown in Table 1.

TABLE 1 - DISTRIBUTION OF AGES IN THE THREE HOSPITALS

Men								

Hospital	16-24	25-44	45-64	65-74	75-84	Over 85	Total	Average yrs. mths.
Whittington	0	0	6	6	7	3	22	72 5
Mile End	0	0	5	3	1	0	9	63 11
Whitechapel	0	1	0	1	0	0	2	63 0
Women								
Whittington	0	3	7	11	12	4	37	71 5
Mile End	0	1	8	10	8	4	31*	70 3
Whitechapel	0	1	5	2	1	1	10	63 0

Twenty-three women were 65 or over, but only 11 men; 21 women were 78 or over, but only 9 men. * One woman withheld her age.

B.2 Status of respondent

Of the 22 men in the Whittington sample, 12 were married, six were widowers and four were single. Of the 37 women, eleven were married, 20 were widows, five were single and one had been divorced. Of the nine men in the Mile End sample, six were married, one was a widower and two were single. Thirteen of the 31 women were married, 16 were widows and two were single. Two of the twelve respondents in the Whitechapel sample were men, both married. Six of the women were married, one was divorced and three were widows. These figures are in Table 2.

TABLE 2 — STATUS OF RESPONDENTS

Hospital	Married Men	Married Women	Widowers	Widows	Single Men	Single Women	Divorced Women	Divorced Men
Whittington	12	11	6	20	4	5	1	0
Mile End	6	13	1	16	2	2	-	0
Whitechapel	2	6	-	3	-	-	1	0
Total	20	30	7	39	6	7	2	0

By far the largest number of patients seen by hospital occupational therapists were widows (39); married women (30) made up the next largest group.

B.3 Composition of household

The composition of the household is very important in any study of disabled people. For example, a widow living alone may be better able to cope with living independently than an elderly widower. An elderly single man may have been dependent on his mother for many years, while an elderly single woman might be more accustomed to fending for herself. Inferences such as these can only be drawn from interviews and not from statistics, but it is reasonable to assume that the majority of handicapped people living alone, both men and women, will need more help from the social services and, possibly, the health services than people living with relatives. However, domiciliary support for relatives can be a crucial factor in keeping disabled people at home.

B.4 Respondents living alone

Of the 112 respondents, 43 were living alone. In the Whittington sample of 59 respondents, 24, four men and 20 women, lived alone. One man was single and the other three were widowers. Of the 20 women, 15 were widows, one was divorced and four were single.

Of the 41 respondents in the Mile End sample, 15 lived alone and two, aged 79 and 80, were in warden-supervised accommodation. Thirteen of the 15 living alone were over 80 and two of them over 85. Only one man was living independently but he was in a room let off in a council house and not isolated.

Of the 12 respondents in the Whitechapel sample, four women were living alone, three of whom were widowed and one divorced. One of the widows was 89 years old and suffered from arthritis. The wife of one of the two married men, himself suffering from advanced multiple sclerosis, was severely spastic and her brother had moved in to look after them. The composition of the households in the sample is in Table 3 below.

TABLE 3 — COMPOSITION OF HOUSEHOLDS

Hospital	With spouse	With relative	With Friends	With warden	In lodgings	Alone	Total
Whittington	21	9	2	2	1	24	59
Mile End	19	4*	-	2	1	15	41
Whitechapel	7***	1**	-	-	-	4	12
Total	47	14	2	4	2	43	112

*Two were temporarily with relatives before re-housing.

** A wife had left her husband because of handicap.

*** A man with severe multiple sclerosis lived with a severely spastic wife. The wife's brother had recently moved in to help them. The wife was not part of the sample.

B.5 _ Nationality of respondents

No questions were asked about nationality. The researcher was asked to visit one West Indian respondent and three Asians. Two of the Asians, both severely disabled women, had sent home, one to India and one to Ceylon, for a female relative to come to England to help them with their children and hoped the researcher could persuade the Home Secretary to extend the visas of their relatives. The third Asian, who had Parkinson’s Disease, lived with a daughter who was out at work all day. The West Indian was slightly incapacitated after a mild stroke but neither he nor his wife had been able to come to terms with his illness and both were very depressed. They had no family over here and took no part in community affairs. Visits were also made to an Italian, a Cypriot and an Iranian, and to two Irish families.

The way in which different ethnic groups react to traumatic experiences and sudden changes of circumstances merit research.

B.6 The type of property lived in

Because the catchment areas of the hospitals are wide, the samples, taken together, represent a wide variety of housing conditions reflecting local policies. On the whole, the outer London boroughs have fewer council flats and council houses and more owner occupied and privately rented property; the inner London boroughs have more council flats. There was rather more privately owned property in the Whittington sample than in the others.

Of the 59 respondents in the Whittington sample, 30 lived in council property and 29 in privately owned or rented property, but of the 41 respondents in the Mile End sample, 28, more than two-thirds, lived in council property and only 13 in the private sector. Seven out of the 12 respondents from Whitechapel lived in council property (slightly more than half), four in private property and one in a Church Army development.

Adaptations for disabled people living in property owned by the council are the responsibility of local authority housing departments. In the private sector they are the responsibility of local authority social services departments. People who own their homes and live in a borough or county that uses means-testing may have to pay the whole or part of the cost of a minor adaptation, although most local authorities write off all adaptations costing less than £100. Should a major adaptation be needed an owner-occupier can apply for an improvement grant from the housing department to help with part of the cost, but this application must have the backing of the social services department. In some cases the social services department may also agree to pay that part of the total cost which is not covered by improvement grants. The percentage covered by improvement grants varies according to the kind of housing area in which applicants live and there are also higher grants for cases of financial hardship.

Adaptations to privately rented property cannot be made without the landlord’s permission, and if the landlord is likely to be held responsible for the cost permission may be delayed and given reluctantly. It may be necessary for the disabled tenant to take his case to the county court before permission for an adaptation is obtained. The distribution of respondents between the public and private sectors of housing is in Table 4. It also shows the kind of property lived in, as this can be an important factor in determining the scale of adaptations needed. Some properties are impossible to adapt and the disabled people living in them may need to be re-housed.

TABLE 4 — TYPE OF PROPERTY RESPONDENTS LIVED IN

Hospital	**Flat**	**House**	**Maisonette**	**Bungalow**	**Bedsitter with warden**	**Bedsitter (Alone)**	**Lodgings**	**Total**
Public Sector								
Whittington	14	4	5	2	3	-	2	30
Mile End	20	3	5	-	-	-	-	28
Whitechapel	2	-	4	-	-	-	1	7
Total	36	7	14	2	3	-	3	65
Private Sector (owner occupied)								
Whittington	2	17	-	-	-	-	-	19
Mile End	-	8	-	1	-	-	-	9
Whitechapel	-	3	-	-	-	-	-	3
Total	2	28	-	1	-	-	-	31
Private Sector (Rented)								
Whittington	4	3	2	-	1	-	-	10
Mile End	1	2	-	-	-	-	1	4
Whitechapel	-	1	-	-	-	-	1	2
Total	5	6	2	-	1	-	2	16

Slightly fewer people lived in houses than in flats (43). Sixteen lived in maisonettes, but only three in bungalows. Four were in sheltered accommodation and five in lodgings, whether defined as a room let off in a council house or in a private house.

B.7 Accessibility of property

Seventeen of the 112 respondents could not get in or out of their homes without help from another person. An amputee and three old persons with bad legs could not negotiate steep steps to their front doors and were waiting for hand-rails. Two could not get down steps into their gardens or into the street. Four were completely isolated by flights of outside stairs in blocks of flats without lifts. Two elderly women living in flats with lifts could only get to the lifts when ambulance men called to take them to a day centre. One elderly lady could get out with difficulty using her walking frame but was self-conscious about using it in the street. The remaining four house-bound respondents were either so frail or so disabled that accessibility was no longer relevant.

Outside and inside their homes. Twenty-three respondents were cut off from some parts of their homes, including bedrooms, toilets, bathrooms and kitchens. Three were confined to one floor of the house because they could not manage stairs and two of these stayed in one room, had to use a commode and could not wash themselves. Two managed to negotiate stairs, once in the morning and once at night. Seventeen needed hand-rails to help them negotiate passages, two could not manage internal steps down to the kitchen and two could not manage internal steps down to the toilet.

Three people in wheelchairs were waiting for steps to be ramped both outside and inside their homes. There were two unrealistic complaints by disabled people about not being able to reach a water tank in a loft and a meter in a cellar. There were five complaints from women about cupboards being out of reach, a point designers of purpose-built property need to bear in mind, and two complaints about out of reach windows.

B.8 Condition of property

Nothing was asked about the condition of the property that respondents lived in but three drew attention to damp and dilapidation and a fourth tried to persuade the researcher to make complaints on her behalf. This respondent, who lived in privately rented property, had to share an outside lavatory with five other people.

B.9 Re-housing of respondents

No specific questions were asked about re-housing. One respondent had been re-housed in sheltered accommodation within a month after returning from hospital and two were waiting to move into new accommodation that had been allocated within a month after discharge. Interviews were to show that some respondents resisted any move to be re-housed.

B.10 Transfers to Part III accommodation

One respondent was eagerly awaiting a transfer from a purpose-built bungalow to Part III accommodation. The transfer was being handled sensitively and she had already spent a weekend in the home. Another respondent was apprehensive about an impending move to residential care. The relatives of three respondents who had filled in the questionnaires on their behalf tried to enlist the researcher’s aid in getting them transferred to Part III accommodation.

B.11 People in wheelchairs

Eleven respondents in the Whittington sample had wheelchairs, ten of whom reported that they used the wheelchairs ‘sometimes’ and only one ‘every day and constantly’. Seven respondents in the Mile End sample used wheelchairs but again only one used a wheelchair all the time. Four out of the twelve respondents in the Whitechapel sample had wheelchairs which were used all the time; a fifth had a ramshackle wheelchair that needed to be pushed.

B.12 Diagnoses as reported by respondents

Respondents were asked about the diagnoses. Almost all of them answered the question and the diagnoses in Table 5 are in their own words. Some patients suffered from more than one disabling disease; others left the space blank. Altogether 102 clinical conditions were reported. See Table 5.

TABLE 5 —- DIAGNOSES AS REPORTED BY RESPONDENTS

Diagnosis	Whittington	Mile End	Whitechapel
Amputation	1	1	
Arthritis (Rheumatoid and Osteoarthritis)	11	13	4
Back Injury	1	1	-
Balance (loss of)	1	-	-
Blind & Partially Sighted	1	1	-
Brain Damage	1	-	-
Brain Tumour	1	-	-
Brittle Bones	1	-	-
Bronchitis	1	-	-
Cellulitis	1	-	-
Chest Complaints	1	-	-
Diabetes	1	-	-
Diabetic Neuropathy	-	-	1
Deafness	1	1	-
Dizziness	2	2	-
Effects of operation	1	-	-
Fractures	5	2	-
Gangrene	2	-	-

Diagnosis	**Whittington**	**Mile End**	**Whitechapel**
Girdlestones	2	-	-
Hip Replacement	4	5	-
Joint Replacement (elbow & knee)	2	-	-
Head Injury	1	-	-
Heart Trouble	-	1	-
Hypertension	1	-	-
Knee Injury	1	-	-
Multiple Sclerosis	-	-	1
Nerves	1	-	-
Old Age	-	1	1
Parkinson's Disease	1	1	2
Stomach Trouble	1	-	-
Slight Stroke	-	-	1
Stroke	12	3	-
Unsteady Legs	1	-	-
TOTAL	60	32	10

B.12 Diagnoses as reported by respondents (continued)

The most frequently reported disease (28 mentions) was arthritis of various kinds. Strokes (16 mentions) came next. No fractures, hip or joint replacements were reported by respondents from Whitechapel but there were seven fractures and thirteen hip and

other joint replacements reported from the Whittington Hospital and Mile End. Four respondents were severely disabled by Parkinson's Disease, one by multiple sclerosis and a sixth by a disease referred to as ‘brittle bones’. The incidence of the disease treated may reflect in part the specialisations of consultants at the three hospitals.

No cases of people severely disabled by accidents were reported.

B.13 The incidence of difficulties with daily activities

Questions were asked about how respondents managed to carry out daily activities, whether independently, with or without an aid and with or without help from another person. Sixteen respondents reported that they had no difficulties at all with performing daily activities, twelve of the Whittington sample and four from Mile End,

although one had cancer of the stomach and a hernia, one a chronic chest complaint, one had had a slight stroke, one a hip replacement, one a knee injury, and two were amputees. Two severely disabled respondents from the Whitechapel sample, one with multiple

sclerosis and one with Parkinson's Disease, reported that 'on good days' they could do everything except bath themselves. It is important to remember the part played by character and determination in overcoming and disregarding handicap as well as the practical help given by aids and adaptations. The support given by families and friends is also important, especially if the handicapped person lives alone.

Specific questions were asked about bathing, dressing, getting on and off the bed, making the bed, getting in and out of a chair, getting on and off the toilet and making a cup of tea. The frequency of the difficulties reported is discussed below.

(1) Bathing

By far the greatest number of difficulties reported concerned bathing (88 cases out of a possible 112). Forty-two of the 59 people in the Whittington sample reported some difficulty. Five could bath with the help of aids but nineteen only with help from another person. One of these was bathed weekly by a district nurse. Six had decided not to try to bath at all. Thirty-three in Table 6 of the 41 people in the Mile End sample reported difficulty. Three could just manage without aids and five with the help of aids; twenty could only bath with help from another person and six had given up, two of these being too nervous to use the aids they had been given. All twelve of the people in the Whitechapel sample reported difficulty with bathing. One was bathed by a nurse and one heavy person had to have two nurses to bath her. Seven had help from a relative or friend and one managed with aids. Not surprisingly, bathing aids were what hospital occupational therapists most frequently asked social services to supply. Delivery tended to be slow, however, and in some boroughs none was being provided until the following financial year.

Showers, which can be the answer for some disabled people are expensive to install. One respondent had had a shower installed privately, another was waiting for a privately installed shower and two were waiting for showers to be provided by their local authorities. One person living in a council house could not use her shower because the water was scalding hot and could not be regulated. Some bathrooms were so cold that elderly people preferred to strip-wash, especially in winter, in front of the fire.

(2) Dressing

Dressing themselves was next in order of difficulty - 63 out of a possible 112 (56 per cent) - although aids such as stocking gutters, zip-aids and dressing sticks were occasionally mentioned as useful. Twenty-three of the 59 Whittington respondents reported difficulty, only one of whom mentioned using an aid, and eight relied entirely on help from another person. Of the 41 respondents in the Mile End sample, 32 reported difficulties with dressing, five of whom used aids. Two of these aids had been bought for them by relatives.

Two respondents were waiting for dressing aids to be delivered. Eight of the 12 respondents from Whitechapel had difficulty with dressing and three of these needed help from another person.

(3) Getting on and off the toilet

Another difficulty frequently reported was getting on and off the toilet. Exactly half of the respondents (56) said they had trouble, some of them even with a raised toilet seat. Twenty-one of the Whittington sample could not use the toilet comfortably (and another two could not get on or off a commode). Ten had raised toilet seats. No mention was made of grab-rails. Difficulty was reported by 27 of the 41 Mile End respondents.

Thirteen had raised toilet seats or screw-down toilet frames. One needed help from another person. Three were waiting for grab-rails and one said the grab-rail was on the wrong side. Two people had given up trying, one of whom was using a commode. The other had fallen off a commode and had reverted to using a bed-pan. Eight of the 12 in the Whitechapel sample had difficulty in getting on and off the toilet, even though three had special seats.

(4) Getting on and off the bed

Fifty of the 112 respondents (44.6 per cent) reported difficulty in getting on and off the bed. Several used walking sticks to help them and one a carefully placed walking frame. Three of the Whittington sample could not get in or out of bed without help from another person, as did seven of the Mile End sample and three of the Whitechapel. No special beds had been asked for by hospital occupational therapists and bed blocks had been requested for only two respondents. None of the respondents reported receiving help from a district nurse or a 'twilight' service for getting to bed at night.

(5) Bedmaking

Fifty of the 112 respondents could not make their beds and this is important because of the effect an unmade bed can have on morale. Twenty-three of the Whittington sample reported difficulty, of which 21 had never made their beds. It proved a difficult or impossible task for 19 of the Mile End respondents, as it did for eight of the 12 in the Whitechapel sample, even with help from another person. Many of the people lived alone and were without a home help every day; consequently their beds were sometimes unmade for days. Some married men were clearly surprised at being asked a question about bed making and replied with a firm 'never' They also replied that they never made a cup of tea!

(6) Getting in and out of a chair

Fifty-one out of a possible 112 respondents had difficulty getting in and out of a chair. Twenty-one people from the Whittington sample reported problems. Two out of 22 people reporting difficulties from the Mile End sample could only manage with help from another person, but both, fortunately, were married. Of the eight reporting difficulties in the Whitechapel sample, four could only manage with help from another person.

(7) Making a cup of tea

Being able to make a cup of tea is an important boost to a disabled person's morale. it is also a reliable measure of independence in the kitchen. In all 46 out of the 112 respondents could not make themselves tea - 19 from the Whittington sample, 19 from Mile End and 8 from Whitechapel. Three of these respondents reported that they used an aid - a walking stick - and one had bought herself a special light-weight kettle. One tea pot tipper had been asked for by a hospital occupational therapist but there had been no requests for special kettles or wall-mounted water heaters.

TABLE 6 — INCIDENCE OF DIFFICULTIES WITH DAILY ACTIVITIES

Hospital	Bathing	Dressing	Getting on & off the toilet	Getting on & off the bed	Bed making	Getting in & out of chair	Making a cup of tea
Whittington	42	23	21	21	23	21	19
Mile End	34	32	27	22	19	22	29
Whitechapel	12	8	8	7	8	8	8
Total	88	63	56	50	50	51	46

The use made of aids and adaptations to help overcome handicap and achieve as much independence as possible is discussed in the next section.

SECTION C - The Need for Aids and Adaptations

C.1 The picture as shown by the study:

There were two sources of information about the aids and adaptations thought to be needed by discharged patients - the hospital occupational therapists and the questionnaire. From the therapists the researcher got details of all the aids they issued to patients leaving hospital and the aids they asked for from health authorities, the Red Cross and, most frequently, local authority social services departments. From the 112 responses to the questionnaire the researcher was able to find out what aids and adaptations were already in use before the respondents had gone into hospital and whether or not they were still waiting for newly requested aids and adaptations one month after their return home.

The aids already in use at the time the questionnaire was sent out, the aids issued by hospital occupational therapists and the aids they had asked for, are summarised in Table 7.

C.2The quantity of aids issued and requested

It was not possible to quantify exactly aids for bathing, dressing and eating, or kitchen aids, since these were frequently referred to by hospital occupational therapists as a category rather than as specific items such as bath stool, stocking gutter or special knife.

Most respondents were issued with at least two bathing aids and often two or more dressing, eating and kitchen aids, so that a closer approximation to the numbers of aids issued and asked for would be 100 plus for bathing aids, 26 plus for dressing aids, 12 plus for eating aids and 24 plus for kitchen aids, making the total number around 350.

Not all the respondents discharged from the three hospitals were thought to need aids, although some already had them. None was thought necessary for 32 of the 59 at Whittington, 15 of the 41 at Mile End and three of the 12 at Whitechapel. Since 50 of the 112 respondents did not need aids, the number of discharged patients to whom aids were issued, or on whose behalf aids were requested, was 62. Table 7 shows that over three periods of 13 weeks, plus the seven week extension for Whitechapel, only 116 aids were issued by hospital occupational therapists (plus duplication of bathing, dressing, eating and kitchen aids). Even fewer aids were requested; only 92 for 62 patients (plus the duplicates). A few commodes came from health authorities and the Red Cross but the rest had to be supplied by social services departments. This is not a high level of demand, particularly when spread over the 13 Greater London boroughs in the catchment areas and the county of Essex. The patients from Bedfordshire and Shropshire did not need aids. It can be assumed that the level of demand from the 85 patients who did not respond to the questionnaire was of the same order. Because demand was modest and the aids were needed urgently, their prompt supply might have been expected. This did not always happen for the reasons discussed in Section F.

TABLE 7 - SUMMARY OF AIDS USED OR NEEDED BY 112 DISCHARGED PATIENTS (INCLUDING AIDS TO MOBILITY)

Table 7 was quite a complicated table to recreate so the information has been summarized below.

- **Bath Aids**: 54 people needed bath aids
- **Beds and Bed-related Aids**: 4 people needed beds, 7 needed bed blocks, and 1 needed a bed table.
- **Commodes**: 35 people required commodes.
- **Dressing Aids**: 13 people needed dressing aids.
- **Eating Aids**: 6 people required eating aids.
- **Ejector Chairs**: 6 people needed ejector chairs.
- **Geriatric Chairs**: 5 people required geriatric chairs.
- **Helping Hands**: 14 people needed helping hands.
- **Kitchen Aids**: 12 people required kitchen aids.
- **Toilet-related Aids**: 28 people needed raised toilet seats, 6 needed screw-down toilet frames, and 2 needed toilet paper holders.
- **Walking Aids**: 22 people needed walking frames.

C.3 _Under-provision of aids by hospital occupational therapists

It would be unrealistic to attempt to match the number of aids requested with the number of difficulties experienced by patients in daily living. For some discharged patients it is medically necessary to keep on struggling in order to prevent muscles seizing up. For others, not giving in to handicap is an important way of holding on to independence. Nevertheless, the study suggests that there is considerable under-provision of aids for those who need them and would use them,

The importance of aids in the improvement of the quality of life for disabled persons needs to be stressed. With the possible exception of one book-rest, none of the aids, either in use of recommended, had anything to do with improving the quality of the respondents' lives, only with helping them to get on with the mechanics of living. The lack of aids that might be considered ‘luxuries’ (wrongly in my opinion) reflects the awareness of severe cuts in social services budgets rather than the legitimate needs of some of their patients.

There were occasional examples of domiciliary occupational therapists offering more adequate aids than those proposed by hospital occupational therapists; for example, geriatric chair instead of chair blocks, a chemical toilet instead of a commode; and they sometimes issued aids (a trolley for example) that had not been asked for but which simplified the life of the disabled person.

C.4 Types and cost of aids required

What is outstanding is the number of bath aids that discharged patients were thought to need - estimated at around one hundred. Next in order of importance are walking sticks (55), commodes (35), raised toilet seats (28) and dressing and eating aids (about 25 of each). It is noticeable how run-of-the-mill the aids are, simple and inexpensive things which make daily activities easier, like the 14 'Helping Hands', a kind of pick-up stick for arthritic patients, the special knives and plates and the two toilet paper holders. Few expensive aids were ordered; the four special beds already in use at the time of the survey had been paid for by the respondents themselves. The family of another respondent was buying an orthopaedic bed for their elderly mother who had had an unsuccessful operation on her hip.

The only aids ordered that cost more than £100 were three hoists, five geriatric chairs, an ejector chair and one chemical toilet. However, a set of bath aids can quickly add up to over £30 and the numbers required will cost several hundreds of pounds in the course of a financial year. In the middle price range of around £30 there was only one trolley requested and one stool. Yet a trolley used as a walking frame allows a disabled person to carry things around, and a stool helps an amputee to sit more easily at a work top.

The braille cooker for a partially sighted old man replaced an unsuitable design with controls at the back, which was common to all the units in the purpose-built sheltered accommodation in which he lived. As a result, the social services department was having to pay for new cookers for other elderly people living in the same block. ‘This costly mistake by the housing department was being rectified by using money from the social services department's allocation for aids.

C.5 The sources of aids

Sources fell into six categories:

1. Already issued before the patients were admitted to hospital.
2. Issued by hospital occupational therapists.
3. Requested from social services departments but not necessarily issued within one month after discharge.
4. Issued by community health authorities.
5. Issued by the Red Cross, possibly acting as agents for social services departments and health authorities.
6. Aids to mobility issued by hospital physiotherapists.

Aids already in use were not studied in detail. Aids issued by hospital therapists: it was difficult to detect any clear policy, partly because sending a patient home with an aid depended on where the person lived. One borough in the Whittington catchment area had agreed with the district occupational therapist to allow hospital occupational therapists to issue aids against retrospective payment from the borough's social services budget. This borough also paid for raised toilet seats and stored them at the hospital. A few boroughs were prepared to authorise retrospective payment for aids on an ‘ad hoc' basis only. This means that some aids listed in Table 7 under 'Aids issued by hospital occupational therapists' were a disguised social services responsibility.

Other boroughs had refused retrospective payment and their patients could only take aids home if they had paid for them.

Occupational therapists in all three hospitals kept a small stock of aids most likely to be needed urgently. These were for eating, toileting and dressing, and generally useful aids like pick-up sticks. Given the choice of buying an aid outright or waiting an indefinite period for one on loan from a social services department patients were likely to buy. Two respondents said they had been glad to buy their aids; a third had insisted on doing so 'for political reasons’. Two others of a different political persuasion reported that they had been pressurised in front of relatives into buying aids they could not afford and were upset because their relatives had felt obliged to pay for them. There was one case of a discharged patient being lent an aid by a hospital occupational therapist because the patient could not afford to buy it.

Any money from the sale of aids went to replenish stocks and the extra work this caused was gladly undertaken by the therapists. The service they offered to patients was clearly useful but it should not obscure the fact that the system of issuing aids was arbitrary and inequitable. The only criterion should have been the degree and urgency of the patients’ needs, and none should have had to buy their aids.

As a result of the cuts in social services budgets, some local authorities have reverted to the practice - common before the Chronically Sick and Disabled Persons Act, 1970 - of hiring aids for a charge or even selling them. None of the boroughs covered by this study did so at the time, but should matters change the agreements under which social services departments assume retrospective responsibility for the cost of aids supplied by hospital staff might become impracticable.

Lists of aids kept in stock at hospitals were not available to the researcher; nor was she able to find out how many aids had been sold during the period of the study.

Aids requested from social services departments: this is discussed in detail in Section G.

Community health authorities: issued a few of the aids shown in Table 7. The social service departments of Islington and Camden had agreed that the area health authority should be responsible for wheelchairs for temporary use, special hospital type beds, electronic beds, and commodes, whether for short or long-term use. These were issued free of charge. In the catchment area of the two London Hospitals, commodes were the acknowledged responsibility of social services departments and were free of charge.

However, in the three outer boroughs in the catchment area of the Whittington the Red Cross was responsible for commodes. They cost 25p or 5Op a week, an example of inequity determined by geography rather than by need.

Aids to mobility: are a substantial category in Table 7 – 55 walking sticks and 22 walking frames. They were issued by physiotherapists, but are included because of their importance. Strictly speaking, walking sticks and walking frames for disabled people who are ‘substantially and permanently handicapped' are the responsibility of social services departments, while those required for a limited time, by patients recovering from fractures or joint replacements for example, are a charge on hospital budgets.

By-passing the social services departments and sending patients home with the aids to mobility they needed made certain that the aids had been correctly measured by trained staff and the patients taught to use them properly. There was no time limit on how long patients could keep them.

This is a great improvement on what can happen in health districts where discharged patients cease to be a 'health' responsibility and become the responsibility of the social services department the moment six weeks is up. Walking frames can then be taken back and disabled people left stranded until replacements, sometimes inappropriate, are issued by social services departments. The same can happen with commodes.

The practice of issuing all mobility aids out of the hospital budget at the three hospitals surveyed cuts out laborious cross-accounting and makes sound administrative sense. It is also more than justified in human terms.

C.6 Waiting for aids

Toileting aids are most often needed urgently by patients returning home. Nearly all domiciliary occupational therapists had at least one horror story of people unable to get to the lavatory because bed-pans, urinals or commodes had not arrived. However, only three respondents had been kept waiting for commodes, all because hospital occupational therapists had failed to order them. Two of the therapists had not realised that patients who could get to the toilet in hospital tended to wait too long at home: the third had overlooked the fact that an amputee wore her false leg by day only and found it difficult to get to the bathroom at night.

Eventually commodes were supplied to all three by occupational therapists from the social services. One chemical toilet was also supplied by a domiciliary occupational therapist.

Twenty-seven respondents at the Whittington had aids ordered for them by the occupational therapists and only five were without them one month after discharge. Three were bath aids, one a wall-mounted can opener and one a stocking-gutter. Of the 26 needing aids in the Mile End sample, nine were still waiting a month later for some and three for all. An expensive ejector chair and three geriatric chairs had not been delivered; the others were inexpensive aids such as a stocking-gutter and a jar opener. Nine out of 12 respondents in the Whitechapel sample needed aids and seven had received all of them within a month of discharge. The other two were waiting for bath aids because the borough in which they lived was not issuing them until the next financial year.

Small, inexpensive aids like stocking-gutters and jar openers are usually ordered in bulk and disabled people have had to wait some weeks for them when stocks run out. How much more sensible if the patients in the sample could have taken their stocking-gutters and jar openers home with them from hospital!

In three cases, hospital occupational therapists did not request specific aids but asked domiciliary occupational therapists to check aids already in use to see if the patients could continue to use them sensibly and safely. Although the general condition of these patients was clearly a cause for concern, no one from social services departments had visited them within a month of discharge.

C.7 Wheelchairs and appliances

Respondents did not distinguish between aids and appliances. There were patients waiting for a surgical corset, a pair of surgical shoes and a raised shoe-heel. A shoe-raise had been issued to one patient as an aid to daily living.

Respondents looked upon wheelchairs as aids to daily living. Three hospital occupational therapists had ordered standard wheelchairs from DHSS appliance centres but no electric wheelchairs were considered necessary. One domiciliary occupational therapist disagreed and an electric wheelchair was ordered by a general practitioner. Another general practitioner ordered a standard wheelchair for a patient although the hospital occupational therapist thought it unnecessary.

C.8 Adaptations already made at the time the questionnaire went out

No distinctions were made in the questionnaire between adaptations made in their homes before patients went into hospital and those completed within a month of discharge. Two people in the Whittington sample had been given bannister rails by the time the questionnaire went out and one bannister rail had been repaired. Another had not only bannister rails but rails in the passage and on the outside steps to the garden; these had definitely been installed before the respondent went into hospital

Of the 41 respondents from Mile End, twelve had a grab-rail by the bath and eight a grab-rail in the toilet. At Whitechapel, two had had rails fitted by the bath and two in the toilet. Hand rails of all kinds are a very important way of helping disabled people to get about the home. One respondent from Mile End had had a concrete ramp fixed for his wheelchair before going into hospital.

In all, 32 adaptations were asked for by hospital occupational therapists and they are set out in Table 8. Many were in fact aids that had to be installed, for instance a grab-rail that had to be screwed on to a toilet wall, but local authorities nowadays classify anything that affects the fabric of a building as an adaptation.

A portable hoist, of which there were three in the sample, is considered to be an aid, but a hoist attached to a wall or ceiling is classified as an adaptation. Even a simple installation like a screw-down toilet frame is counted as a minor adaptation.

TABLE 8 - MINOR ADAPTATIONS ASKED FOR BY HOSPITAL OCCUPATIONAL THERAPISTS

Feature	Whittington	Mile End	Whitechapel	Total
Alarm system	-	-	1	1
Bannister rails	5	3	1	9
Electric plugs raised	2	2	-	4
Flashing lights	-	1	-	1
Grab-rails in passages	-	1	1	2
Grab-rails in bath	2	4	-	6
Grab-rails in toilet	1	-	1	2
Rails on outside steps	1	-	1	2
Shower hose fitted	1	-	-	1
Shower fitted	-	1	-	1
Taps converted	1	-	-	1
Ramp to front door	1	-	-	1
Total	15	12	5	32

C.9 Major adaptations

These are distinguished administratively from minor adaptations by their cost. In most local authorities anything costing more than £500 is a major adaptation.

Only one request - from a hospital occupational therapist at the Whittington - was made for a major adaptation. This was for a downstairs shower and toilet extension for a patient who had had a stroke. There was an upstairs toilet but the patient found it difficult to negotiate a bend in the stairs and frequently reached the toilet too late. The patient lived in private property and the hospital occupational therapist hoped the domiciliary would support an application for an improvement grant on the grounds of disablement and inaccessible amenities. Part of the total cost would have to be paid for by the social services department as the client was unable to afford the whole of his share, which could have been as much as 35 per cent. At first the area domiciliary occupational therapist said that the extension was unnecessary but she was finally over-ruled by the head occupational therapist from the social services department. In all two months were lost over building work which would, in any case, take six to nine months from start to finish. Meanwhile a very old, smelly wooden commode in the sitting room was replaced by a more modern one that was easy to keep clean.

C.10 Waiting for minor adaptations

Many discharged patients in the sample had to wait more than a month for even the simplest minor adaptations. The length of time often depended on whether they lived in council or private property. All minor adaptations in council property have been the financial and practical responsibility of local authority housing departments since 1 April, 1979 and those that use direct labour, of which there is usually a shortage, can be very slow. Private property is the responsibility of social services departments who usually place contracts with private builders. Processing the adaptations takes time but, on the whole, work in the private sector is completed more quickly. The quickest system is when social services departments employ their own technical assistants with their own transport and answerable to the head occupational therapist. They can install urgently needed grab-rails, for example, within 24 hours.

Very occasionally hospital technicians are allowed to put in rails. This was done twice for patients from the Whittington sample after the researcher had reported unacceptably long waiting periods. However, local authority technicians are generally unwilling to allow hospital technicians to do this kind of work and attempts in the past to establish joint appointments - for example, by the Borough of Tower Hamlets and the Tower Hamlets Health District - have foundered on union opposition.

Nine patients from the Whittington and nine from Mile End needed one or more minor adaptations and all were waiting for work to begin one month after their discharge. Six in the Whitechapel sample needed adaptations and three were still waiting at the time the questionnaire went out.

The minor adaptations needed fell into four categories: (i) handrails of all kinds; (ii) ramps; (iii) electrical work, and (iv) plumbing. What the survey disclosed is described in detail.

(i) Handrails

The largest number of requests for adaptations, as shown in Table 8, were for handrails, with some 21 discharged patients needing them in one or more places. One month after discharge two respondents were still waiting for a grab-rail in the toilet, an unpardonable delay, and two for grab-rails by the bath. They all lived in council property.

A respondent living in privately owned property waited six weeks before a set of rails for the bathroom was delivered by a technician from the social services department. They could not be installed because the old fashioned bath was set at an odd angle to the wall. The technician said he would 'have to go back to square one'. There had been no preliminary visit by an occupational therapist.

Three respondents were waiting for bannister rails on the stairs. Two had had strokes and one a hip replacement. All lived in council property, one in a house and two in maisonettes. Until the bannister rails were installed two of them could not get upstairs to the bedroom, bathroom and toilet and were marooned with a commode in the sitting room. This was having a bad effect on their morale. The third, who was very unsteady on his feet, wanted to be able to get down a steep flight of steps into his cellar where the electricity meter was kept. This was less urgent but the meter had to be fed by coins and neighbours were not always available. (The domiciliary occupational therapist had thought of having the meter moved upstairs).

The wife of one of the respondents who could not get to a toilet had become so fed up after waiting a month for a bannister rail that she had one installed privately, borrowing £85 from a relative in the hope that the local authority would refund the money. By the time the researcher called the case had gone to their MP but the domiciliary occupational therapist held out little hope of retrospective payment. This couple was not the only one to complain that the system prevented initiative. ‘Because we can't afford to pay', said one respondent, 'we have just to wait helplessly’.

The respondent who could not get to his meter was also waiting for a handrail on the steps up to his front door. He was at risk every time he went out, 'But', said the domiciliary occupational therapist, 'he would have to wait at least six months’. The reason was ‘a shortage of blacksmiths'. Only one blacksmith was employed by the borough housing department and he worked for a different housing district.

A respondent living in a different borough, and not in council property, suffered similar delays. A middle-aged amputee, she lived in property rented from British Rail and needed a handrail on the flight of steep steps to her front door. British Rail took five weeks to give permission for the handrail to be installed, but refused to pay for it. In this borough the social services department used the housing department as their agent for work in private property and, again, there was no one on the strength who could work in metal.

Two sets of passage-rails ordered by a hospital occupational therapist had been installed within a month of discharge but a third set, ordered by a domiciliary occupational therapist for a patient who had not been visited at home by a hospital occupational therapist, was still not installed six weeks after the order went to the local authority housing department.

(ii) Ramps

Two permanent outdoor ramps had been asked for by hospital occupational therapists. One for a patient who lived in council property had been disallowed because it might have proved a hazard to passers-by and the council would have been liable for damages. The council was not prepared to insure against risk to the able-bodied.

The second ramp was for a respondent living in a privately owned house who needed a long concrete ramp from a side door in a passageway which was the only possible exit. He was a director of a building firm and could easily have arranged for the work to be done privately but was determined to ''get his rights' and have it done free. He was very angry when the researcher called because 'builders were going bankrupt due to the recession but the council would only use direct labour’. In the meantime a temporary ramp consisting of a plank over two steps had been rigged up at rather too steep an angle for safety.

A third respondent at first included in the sample, could not go home until a ramp had been provided. He was discharged at Christmas to a hospital nearer his home. A fourth ramp had been suggested to a respondent by the caretaker of a block of flats. The caretaker had gone to the trouble of telephoning the social services department, but no one from the department had called to see the respondent a month later.

(iii) Electrical Work

There was a shortage of electricians on the direct labour force of all the local authorities in the sample. A simple task like raising electric points was likely to take at least two months and the other electrical work asked for by hospital occupational therapists - installing an alarm system and a flashing light - was delayed indefinitely because of lack of staff.

(iv) Work involving plumbing

One respondent was waiting for a telephone type shower that had still not arrived from the manufacturer six weeks after her return home. The installation of a shower cabinet for another respondent was being held over until the next financial year. Modifications to taps for two respondents had not been carried out because of shortage of labour.

C.11 Minor adaptations – the need for more involvement by domiciliary occupational therapists

Considering how vital minor adaptations are to preserving the independence of disabled people the attitude of domiciliary occupational therapists who are prepared to tolerate delays of six weeks or more is as unacceptable as the delays themselves.

It is well known that cuts in social services budgets have reduced the satisfaction that many domiciliary occupational therapists get from their jobs. They have become resigned to a falling-off in services and, consequently are unwilling to do battle on behalf of their clients. Yet more rather than less involvement is necessary if delays in providing minor adaptations are to be avoided.

None of the therapists with whom the researcher discussed these delays kept a watch on work in progress. Not because they feared bad relations with housing staff but because they considered their job to be done once they had asked the housing department to carry out the works. This attitude would not have been tolerated before financial responsibility for adaptations in council property was transferred to housing authorities. The therapists were not prepared to keep tabs on work done in private property either. They said they were much too busy with current work to involve themselves with follow-up, and clerical and administrative back-up was often inadequate.

A few head occupational therapists, however, held fortnightly or monthly meetings with housing authority staff in the hope of educating them in the needs of the disabled. At these meetings enquiries were made about work in progress and priorities suggested.

Two head occupational therapists depended on clients to let them know if work on minor adaptations had begun. One sent out a standard letter asking clients who needed to have electric points raised to write in if the work had not been done within two months - she felt a delay of two months to be ‘reasonable’. A second sent out a similar letter when a minor adaptation had been ordered asking clients to let her know if work had not begun one month later. Encouraging clients to participate is an obvious advantage; nevertheless, sending these letters assumes, and even condones, delays.

C.13 Contracting out

The overall shortage of direct labour revealed by the study suggests that, under certain circumstances, local authority housing departments should be compelled to contract out work that they are unable to do or that they cannot complete within a reasonable time. Defining ‘a reasonable time’ should not prove difficult because delays are bound to cause hardship. It is clearly unacceptable that disabled people should be left at risk, kept as prisoners inside their own homes, or forced to submit to deteriorating standards of personal hygiene because local authority housing departments do not employ enough staff, or the right kind of staff. Directives from central government, backed by generous grants, make it quite clear that local authorities are expected to provide minor adaptations for disabled council tenants, but so far central government has done nothing to force laggardly authorities to meet their obligations quickly and efficiently.

C.14 The safety of aids and adaptations

Questions were asked about whether respondents felt safe using their aids and adaptations. All felt safe using their adaptations, except for one who said her hands were too weak to get a safe purchase on the grab-rail in her toilet. Several respondents, however, felt unsafe using aids. This underlined the importance of assessing clients in their homes. Six felt unsafe in the Whittington sample, one of them because her bath seat was unsuitable for an acrylic bath, a danger that had fortunately been spotted by a domiciliary occupational therapist. Another respondent, an amputee, said her bath seat was too high and her one leg did not reach the bottom of the bath. As a result of these cases hospital occupational therapists at the Whittington are no longer allowed to issue bath aids without first having tried them out in the patients’ homes.

Eight respondents from the Mile End sample felt unsafe using their aids. One had fallen off a commode and another reported that the seat of her commode was unsafe. One with Parkinson’s Disease felt unsafe using a walking frame; two felt their hands were too weak to control their frames and one said crutches were too heavy. Another respondent felt very unsafe in an old, rickety wheelchair with failing brakes.

Four of the ten people using aids in the Whitechapel sample felt unsafe with their aids. Two complained about wobbly commodes, one said her walking stick was notched too high and one was unhappy using her walking frame.

C.15 Wastage of aids

Despite some occupational therapists in social services departments believing that hospital occupational therapists over-prescribe, very little wastage of aids showed up in the three samples. Three respondents admitted to not using their bath aids and one said she would not be using them when they were delivered because her bathroom was too cold. One respondent complained about a cumbersome book rest. A patient with multiple sclerosis did not like the design of a urinal and had bought another from Boots. Respondents whose condition had improved no longer needed a ‘Helping Hand’, a stocking-gutter, a raised toilet seat, crutches and walking frames. Three other respondents had discarded their walking frames for other reasons, two because they felt unsafe using them, the other because she refused to make space for it by removing an armchair from her cherished three-piece suite. She managed well enough in the sitting room but was at risk elsewhere in her flat.

Collecting unused aids to daily living is the responsibility of social services departments and collecting aids to mobility is the responsibility of hospitals. Attempts to reclaim aids were haphazard, however. Patients attending out-patient clinics usually took back aids to mobility they no longer needed and occasionally relatives delivered aids to hospitals or social services departments, but there were no organised attempts at collection by either hospitals or social services departments. Because of the high cost of petrol and a shortage of drivers, sending vans or ambulances to collect all but the most expensive aids was not cost-effective. Respondents, however, who wanted to get their discarded aids out of their way saw the failure to collect them as inefficient and wasteful.

C.16 Quality of aids

Apart from the obsolete design of a urinal (discussed under ‘Wastage of aids’) there were no complaints about the quality of aids. There were two complaints about push-type wheelchairs but none about wheelchairs for permanent use issued by the DHSS.

The researcher was pleased to see that the one trolley issued was a modern design in chrome and formica and not a cumbersome wooden model from a local authority workshop that is unpopular with clients. However, no attempt was being made to issue special chairs in colours that matched sitting rooms because black chairs are cheaper.

C.17 Aids suggested by other people

Fourteen respondents reported that aids had been suggested by other people; by three district nurses, three home helps, a health visitor, two general practitioners, a Naja and a caretaker. The general practitioners had not in fact suggested aids; one had rung up the social services department about a wheelchair and the other had told the respondent he thought there were special paper sheets for the incontinent. This respondent had to ask the researcher how to set about getting them.

Three respondents had heard about aids issued to other people when visiting out-patient clinics, those valuable meeting places for the dissemination of welfare rights: One wanted a footstool, one a geriatric chair and one a bed-table. The respondent who wanted a foot stool asked for one from the social services department and was indignant at having been refused.

SECTION D - Services used by Respondents

D1 Services

The main services needed by respondents after discharge from hospital were those of a district nurse, a bathing attendant, a home help and meals—on-wheels. The questionnaire also asked about visits from social services staff and visits from health and geriatric visitors. Some respondents also wanted chiropodists to visit them and to have holidays.

(a) District nurses

District nurses had visited 18 of the discharged patients in the Whittington sample, seven in the Mile End sample and only one in the Whitechapel sample. Daily visits were restricted to one Whitechapel " patient and one from the Whittington. The Whittington patient was elderly and lived alone, but the frequency of visits depended on the clinical needs of the patient rather than social distress. Visits tailed off and ceased altogether as a patient's condition improved or relatives learned how to take over.

Only one respondent complained that the district nurse did not call often enough. Three others would have welcomed more frequent visits but realised the nurses were over-stretched.

(b) Bathing attendant

Only one respondent was bathed by an attendant but four said they il a were on a waiting list and one asked the researcher to 'get her on the waiting list', although there were no bathing attendants ' employed by the borough in which she lived. Two complained that

il If they had not had a bath in the month since their return from hospital, and one said her home help bathed her 'although she was not supposed to.!

There is an overall shortage of bathing attendants (social services) and auxiliary nurses (health services) to bath disabled people.

(c) Home helps

Referrals for home helps came from many sources and response was flexible and quick. Twenty-five of the Whittington respondents had a home help for one or more hours a week, as did 15 in Mile End and five in Whitechapel.

The provision of free home help by the social services departments depended on local authorities. Three respondents refused the service when they found they would have to pay a flat rate of £2.00 a week for only one hour of help. Another refused because, following a means test, she would have been charged more than the going rate for a private home help. Two respondents who were living on supplementary benefit found it difficult to pay a flat rate of £1.00 a week, but could not manage without the service.

Only one respondent complained about ‘slipshod’ work, although three felt it could have been done better; one of these had spent years 'in Service’ herself. Two respondents wanted picture rails to be dusted, and four wanted their windows cleaned, both tasks home helps are not allowed to do. For the most part respondents pale realised there was an overall shortage of home helps and gratefully accepted the limited service offered.

Two of the respondents who lived alone said they would have welcomed one hour of home help daily rather than longer visits twice weekly. Others who lived alone had help for only one hour one a week but said it was enough to keep them going. None without any home help felt that it ought to have been provided.

(d) Meals-on-wheels

Only nine of the Whittington sample were receiving meals-on-wheels. Three had meals-on-wheels at weekends as well as week days, but two of these were due to be transferred to Part III accommodation. Two working husbands would have liked meals-on-wheels for their wives to ensure that they were visited during the day, but their wives had refused them. An alcoholic needing meals-on-wheels because of malnutrition was always at the pub when they were delivered and the service was stopped because he had not paid for it.

Only six respondents in the Mile End sample had meals-on-wheels. All said they had them at weekends as well as on weekdays, which was surprising because none seemed to be living alone.

Three respondents from the Whitechapel sample had meals-on-wheels on weekdays only; another had them at weekends as well.

The service was valued because, as one respondent said, it ‘brought someone into the house'. There were no complaints about the food, but only one respondent volunteered that it was good to eat. One said the food was ‘all right' but complained at the way it was served with 'all the vegetables piled on top of the meat so that you could not get at the meat until the last’. Apparently segmented dishes had ceased to be used by her local authority because they were too expensive.

(e) Visits from social services staff

Answers to questions in this section were unclear because few respondents were familiar with the term ‘occupational therapist’, although they knew what a social worker did. One referred to ‘the young lady who brought the toilet seat' under ‘other visits and two referred to a ‘Disabled Living Adviser', a term often used by local authorities instead of ‘occupational therapist’.

Home Help Organisers were thought of as social workers by two of the respondents interviewed. Nevertheless it became clear from the replies that social workers and domiciliary therapists had not been quick to respond to requests from hospitals. Four respondents in the Whittington sample had not received a visit from the social services department one month after discharge.

Two had had to wait three weeks. Sixteen had been visited at some time in their lives and therefore could be presumed to be ‘known to the social services', but they had not been visited since leaving hospital. Eighteen respondents in the Mile End sample had been visited but it was not clear when. One had been visited a week after her return home and given all the aids she needed, but another complained that an occupational therapist had failed to keep an appointment (there was heavy snow at the time). Four said the aids they needed were being ordered for them following a visit from an occupational therapist; three said 'the person from the social services department' was going to give them 'more aids than the hospital had asked for'.

Six respondents in the Whitechapel sample had been visited at some time and one said a disabled living adviser had called about a ramp a week after his discharge but nothing had happened so far.

(f) Visits from health and geriatric visitors

One respondent reported a visit from a health visitor and another had regular visits from a geriatric visitor.

(g) Visits from chiropodists

Only two respondents wanted chiropody. One had been told the waiting time was nine weeks; the other that the waiting list had been closed.

(h) Holidays

Most local authority social services departments still offer subsidised holidays for disabled people although the service has been very much curtailed for financial reasons. Waiting lists are long and summer holidays are rationed to one every two or even three years. During the winter, however, there are often vacancies in the hotels used by the authority and two elderly women in the sample were going to have a winter holiday two months after their return home. Two married couples were expecting to go as soon as vacancies occurred. These holidays are not a form of convalescence but meant to give disabled people and their families relief from the monotony of their dives: Looking forward to a holiday sometimes makes it possible for relatives to continue to look after a disabled person. Providing holidays is one of the most valuable domiciliary services and all too often under-rated. An emergency holiday was arranged for one respondent whose wife was on the verge of a breakdown after only six weeks of constantly caring for him.

D.2 _The role of the general practitioner

Respondents were asked had they been visited by their GPs after returning home. Only three patients said that their general practitioners had been helpful - ‘he is always ready to help me with my sister when I need him’ and ‘I have a marvellous GP’; and one old man told the researcher ‘my lady doctor is marvellous even though I’m just an old drunk’. The rest had not been visited by their GPs within a month of discharge. In five cases the doctors had not been told by the hospitals that the patients had been sent home. No effort had been made by respondents to get in touch with their doctors, either because they were afraid of being thought a nuisance, or they were housebound and had no telephone.

On the whole, general practitioners took little or no interest in aids and adaptations. One respondent with very severe rheumatoid arthritis reported that her doctor ‘carried on and railed about all the aids’ she had been given. ‘He had never seen a pick-up stick before and played about with it’. When he discovered that a wall-mounted can opener had been provided out of the rate-payers’ money ‘he said it was a scandal’.

Leaflets about simple, inexpensive aids in common use would help to educate GPs. Unlike drug manufacturers, however, manufacturers of aids have limited resources and often rely solely on annual exhibitions - which few doctors attend - to demonstrate their products.

Many over-worked GPs tend to ignore disabled patients because they are often incurable. This is a subject that merits detailed research, but in the meantime it would be helpful if hospitals told GPs quickly when their patients are discharged. Doctors should also be told what their patients can do by themselves and what they can do with the help of aids or another person.

The head occupational therapist of an outer London borough was so concerned about the lack of information for GPs that she began notifying them about all the disabled people seen by her staff. She hoped that this would encourage them to take an interest in their disabled patients and be more aware of their needs.

Only one example was uncovered by the study. This happened in an interview with an elderly lady who had had an unsuccessful ‘Girdlestones’ operation and was unable to leave her bedroom or get out of bed unaided. A devoted son and daughter cared for her day and night and had not realised that professional help and advice was available and necessary; nor had they been told how to obtain help. No request for aids had been made by the hospital occupational therapist; the social services therapist had not been asked to help; the patient had not been visited by a district nurse or geriatric visitor; and contact had not been made with her GP. Following a deterioration in the old lady’s condition, the researcher was able to help her son contact the doctor. The researcher also arranged a visit by a domiciliary occupational therapist in order to rectify some practical problems, such as the height of the patient’s bed. As a result, bed blocks were supplied and the family spared the cost of an orthopaedic mattress which was unnecessary

SECTION E — The Problems of Disabled Patients Discharged from Hospital

The questionnaire left a space for respondents to comment on any problems they had had after returning home. The problems were common to all three samples and were reinforced by the 42 interviews, all with respondents in their own homes. Some of their main worries follow.

(a) Fears for personal safety

Fear about mugging, violence and vandalism was very evident. Everyone, even those who lived high up in tower blocks, had more than Jae one lock on the door. By chance the researcher hit on the code knock for one old lady, otherwise she would not have been admitted. Such fears, although they sometimes verged on the paranoid, were widespread and genuine and cases of violence that had been reported by the media were quoted at interviews. One man who had had a stroke and was isolated in his flat by two flights of outside steps, longed to go to a Stroke Club and a Day Centre but the ambulance men refused to carry him downstairs. Nonetheless, he had turned down the offer of a ground floor flat because, as he said, 'how could I protect my wife?'. This reveals the helplessness of the disabled person, unable to defend himself and also prevented from fulfilling what he saw as his normal role before his illness.

An elderly woman with limited mobility and a husband with heart trouble was also cut off by two flights of steep stairs. She too had refused an offer of re-housing because she was afraid to live on laid the ground floor. She preferred to stay safely inside and higher up, watching people out of the window.

Three elderly people living alone on the ground floor were frightened to open their front doors and so was one living on the second floor of a two-floor block of housing for the elderly. Two old people were afraid to go out, one because of children playing football, the other because of unemployed teenagers ‘lurking round the estate’. (They were!)

One man regretted the absence of 'the old type of caretaker who knew a where everyone was and what was happening'. This is a valid point and suggests a practical solution that housing authorities today seem determined to ignore.

(b) Isolation

A number of respondents said their main problem was 'not being able to get out of the house! or ‘being unable to get out and about'. Some who could get out, at least in good weather, were nevertheless too frail or disabled to manage the walk across the large courtyards of estates built between the wars; two living in streets could not get as far as the corner shop. Two others were unable to go to a luncheon club (in their borough transport was not provided to local authority luncheon clubs), to 'Bingo' and to the pub. One who missed the pub was in a wheelchair and could not get up the pub steps. The landlord told the researcher that he did not want cripples in anyway - it spoiled other people's enjoyment.

Some respondents living with a spouse or with their families missed old cronies and felt isolated as a result. Sadly the illness of a spouse frequently meant both partners becoming isolated because the able-bodied one had to give up outside activities as well. There was a general feeling that ‘once you get disabled, people don't want to know you anymore'. A wife said 'at first his mates brought in some beer on Friday nights but seeing him like this depressed them and they soon stopped coming'.

One couple for whom isolation was a serious problem lived in a council block well away from a bus route and thirty minutes walk from a doctor. The husband had Parkinson's Disease and inoperable prostrate, and at the time the researcher called the catheter had slipped out and his legs were alarmingly swollen. They had no telephone, the nearest call box had been vandalised and the wife felt her husband was too ill to be left. The researcher got the doctor, who responded immediately, but had she not happened to call no one, the wife said, would have been there to help because all the neighbours went out to work. They did not fulfil their local authority criteria for help with a telephone because the wife was able-bodied.

A few respondents were isolated by bad weather only. Some who used walking sticks were afraid of slipping on wet pavements or wet leaves; one, with chest trouble, seldom went out in winter.

(c) Lack of neighbourliness

Some neighbours were said to be out at work all day but others simply ‘didn't want to know'. Only one respondent said a neighbour popped in regularly to make a mid-morning cup of tea - 'it breaks the monotony’, and only one had a neighbour who did all the shopping. Another neighbour ‘sometimes offered to fetch the bread if it was raining and she thought of it'. Some neighbours said they would have liked to do more ‘but my husband won't let me get involved'. The fear of over dependence may have been a reason why some neighbours were reluctant to help when respondents came home from hospital.

Where people lived affected neighbourliness. Those respondents who lived in small, privately-rented houses in streets where the same families had lived for years said they had wonderful neighbours, but no one living in council blocks had anything good to say about theirs.

Some respondents could only get help if they paid for it. One old lady gave an old man a packet of cigarettes for doing her shopping, although he could afford to run his own car; another paid an eleven year old girl 50p to do her errands.

There was some racial prejudice. A white couple said their black neighbours were ‘useless! and a West Indian couple said their white neighbours were 'bad people’. Both couples lived in very run-down neighbourhoods. A severely disabled old man who lived next door to a young Asian married woman, who could not speak English and never left the house, felt that he had no one to call on in an emergency.

Personalities must also have had some influence on neighbours attitudes. The researcher noted that the people who said they had ‘wonderful neighbours! also had very supportive families and friends. They prided themselves on not ‘moaning! and one said she was very careful to keep her demands to the minimum.

An elderly and confused old lady had been victimised by an apparently friendly neighbour who had persuaded her to sign away some property. This was discussed with a social worker and referred to the local authority legal department.

(d) Loneliness

Not everyone who was isolated or living alone felt lonely, but two were especially lonely after returning home from hospital. They missed the noise and bustle of the ward and a middle-aged spinster who had ‘always managed before' found it difficult 'being back at

home and having to look after myself’.

Living in sheltered accommodation has disadvantages and it is a fallacy to believe that it overcomes loneliness. An elderly man whose main problem was ‘loneliness after being eight months in hospital’ wanted to visit a day centre but could not be considered for the waiting list because he lacked a social worker to recommend him. He was in this quandry because he lived in sheltered accommodation, was no longer thought to be at risk and,

consequently, was not visited by a social worker. When the researcher suggested to a senior social worker that this was a Catch 22 situation she was asked, 'do you want to precipitate industrial action?'. The social worker added, 'His file says he is a rather nasty old man and he probably wouldn't be welcome at the day centre anyway’.

This man was visited by his warden for only a few minutes each day. Without relatives or friends calling on him he had no one to take him out in his wheelchair and it seemed likely that he would be lonely and housebound for the rest of his days.

One of the most poignantly expressed complaints about loneliness came from a West Indian who had had a mild stroke: ‘please help me to fill my empty days'. He went twice a week to a stroke club and wanted to go to a day centre. His wife worked at a school canteen and got home by three in the afternoon; but the mornings dragged, he was afraid of falling and unwilling to get out of bed. The trauma of his illness affected them both and they spent most of their time together in useless tears. They took no part in the life of the neighbouring West Indian community, had no children and no extended family in England. They did not get on with their doctor who was ‘rich and white' and had called the respondent 'a hysterical hypochondriac'. The researcher was relieved to discover that the staff at the stroke club were working hard to help the wife to come to terms with the situation and they intended to ask her doctor for help with her depression. There were, however, no vacancies for the day centre.

Sometimes the respondents had brought loneliness upon themselves. Two old ladies had quarrelled with their families but one had a daughter-in-law who visited her secretly - 'my son would half kill her if he found out' - to clean the house. The other saw a grandchild once a week, but not his parents. A third old lady had solved the problem of loneliness by hallucinating. Her seven children by two marriages had given up coming to see her, but she was convinced that her first husband, who had died in the 1914/18 war, was alive, visited her frequently and was after her pension. She was completely housebound and saw no one except her home- help once a week. Enquiry revealed a supportive social worker in the background.

(e)Pain

Pain was referred to as a major problem by four respondents, all of whom explained that it was hardest to bear when it prevented mobility. One respondent regretted being unable to use her right hand to write letters.

(f) Inability to do household chores

A number of respondents chose to stress the difficulties they had with bathing, with using the washing machine and with hanging out washing, points which had already been covered by the questionnaire.

(g) Marital problems

The sudden and totally unexpected illness and disablement of a husband or wife puts even the happiest of marriages under a severe strain. Marriages that were unhappy before disability struck are likely to remain unhappy. The researcher was distressed by the widespread consequences of marital problems, of which depression, usually untreated by doctors, was the most common.

All wives with disabled husbands felt it their duty to look after them but many complained, in front of their husbands, of the effect the extra work was having on their health. They seized on the researcher to talk about their bad backs, their bad legs and, most frequently, the state of their nerves, and it was clear that they needed a good deal more encouragement, approval and emotional support from family, friends and GPs. Some wives, however, went to the opposite extreme and over-compensated by devoting themselves completely to their husbands, ‘doing everything for them', and undermining their independence. This was likelier if the wives had no children.

There were only two husbands doing everything for their wives. Both were pensioners and appeared to relish the role-reversal, one boasting about how well he cleaned the deep freeze and the other about his cooking. However, both wives, although physically helpless, remained very much in command of the way their homes were run. One husband said that, despite retirement, he had no time to be bored. The other had turned down the offer of a home-help because he did not want 'a stranger in the house who might come between my wife and myself’. This suggested a welcome degree of closeness between them.

The most commonly voiced marital problem was boredom. Before disability their interests had centred on activities outside the home - for example, going to football matches or a drink with friends.

Now there was nothing to do except watch television. (A man whose vision had been impaired by a stroke left the sound on for company). None of the disabled people visited had developed hobbies, such as woodwork or collecting things; nor did they read for pleasure.

Their able-bodied partners were usually just as bored. As one wife said, 'all we do is row all day', adding ‘but that's how we always used to be, rowing to pass the time'. Sudden rages clearly helped to relieve boredom.

A man who had been very hot-tempered before he had a stroke was becoming increasingly aggressive, frequently lashing out at his wife with his walking stick. She was in a very nervous state when the researcher called. A domiciliary occupational therapist had recommended a home-help, mainly to give the wife some emotional support, but the husband had gone into a violent rage when he heard he was expected to pay and matters deteriorated.

A number of wives continued to go out to work and said they would not have been able to 'stick' looking after their husbands if they did not have a job. Once they got home, however, they seldom left their husbands for longer than a quick dash to the shops and none of them followed any interests of their own. One had stopped going out with a girl-friend for the evenings once a week - 'it wouldn't look right with him disabled'. Another complained about being solicited sexually by one of her husband's former friends - 'you have to expect that if they know he can't give it to you'. Several said that friends did not come round any more and that they missed the company of other couples.

A wife who had never worked found looking after her husband all day intolerable. She had, she said, never liked him much anyway and now threatened to 'leave him to rot' unless the social services department took him for a holiday immediately. She had successfully blackmailed the holiday officer into fixing something, but the long-term problem remained. No social worker was involved.

(h) Incompatibility between respondents and professionals

The researcher discovered that two respondents were feeling unhappy because their district nurses bullied them. The researcher met both nurses. One lady had had a colostomy and was in trouble for using too many disposable bags. The nurse could not accept that this old lady - the daughter of a regimental sergeant major and widow of a police sergeant, and who had always lived by the most rigid rules of conduct - was finding it difficult to cope with excreta. Routine and cleanliness had long been the order of the day and ‘it was only because of the tradition of the services', she said, that had stopped her throwing herself out of the window, The nurse agreed to send round a nurse who specialised in patients with stomas, but said to the researcher, in the hearing of the patient, ‘she's got you fooled, she's just plain cantankerous’.

Dislike for a patient was also expressed, again in the patient's hearing, by another nurse. The nurse also indicated by gesture that the patient had a screw loose. The old lady was refusing to pay 5Op hire fee for a Red Cross commode on the grounds that her husband had fought in two wars. The social services department had agreed to provide a commode free of charge as a way out of the impasse, but the nurse was bitterly opposed to this - 'the son she lives with can afford to pay, why should the community?' - and was threatening to take the commode away.

These cases show that difficulties stemming from personalities on both sides will inevitably arise from time to time. Unfortunately patients and clients are usually afraid to complain if they are dependent on a service and if they are brave enough to want to protest do not know how to set about it. One old lady, however, boasted that she had 'sent a very young social worker packing’ and a second had ‘got rid of' a young occupational therapist because her daughter thought it 'shameful' to be visited by someone from the social services. Both had kept their aids and were no longer reliant on the good will of the workers they had sent off.

Occupational therapists and district nurses should be encouraged to discuss their feelings about 'difficult' clients and patients with senior staff.

(i) Financial problems

Financial problems were not mentioned in the questionnaire but they were referred to four times in the problems section. Each concerned allowances and the researcher provided the appropriate leaflets.

Other problems cropped up at the interviews, especially problems about heating during the heavy snow of January, 1982. One couple had had their telephone cut off because they could not pay the bill, a very heavy one due to the respondent telephoning a lot since becoming housebound. Two couples had got into debt over having their sitting room decorated - 'if he's going to be stuck in here all day it might as well look nice'. One respondent had got into debt through paying for bannisters (See Section C).

(j) Partial solutions to problems

Many of the problems reported by respondents, or which showed up in interviews cannot be remedied immediately. On the practical side craft instructors of the kind which used to be employed by the old welfare departments might do something to encourage some housebound people to take up hobbies. More places at day centres, particularly day centres with organised activities, would also help to alleviate boredom for limited periods. There was a clear need for more emotional support from social workers and domiciliary occupational therapists for the able-bodied partner as much as for the disabled, and for a more caring attitude by general practitioners, particularly in cases of depression. There was also a need for more involvement by members of the local community. Not one of the respondents visited had been helped in any way by local organisations or by concerned volunteers.

SECTION F - The Role of the Hospital after Patients have been Discharged

F.1 Follow-up by hospital occupational therapists

For disabled people at the Whittington Hospital and the London Hospital (Whitechapel) their date of discharge was the cut-off point. The responsibility of the hospital occupational therapists who had been looking after them ceased the moment the patients returned home, leaving them without anyone to check whether they had received any of the aids requested. At the London Hospital (Mile End), however, the hospital therapists followed up their cases by sending a standard letter a month after patients had been discharged asking how they were managing at home. If necessary a second letter went out three months after the first - a useful way of picking up delays over starting and completing adaptations. A copy of the letter is reproduced below.

‘Dear

I am writing to find out how you are managing at home and if:

1. the social services have contacted you?

2. they have provided the aids/services requested? .....

3. you are using the aids/services supplied? ....

4. you have any problems? ....

When are you next seeing the Doctor? ....

Please write and let me know if I can help any further.

Yours sincerely,

\Occupational Therapist.

The same standard letters also went out for a time from the London Hospital (Whitechapel) but the practice had been discontinued by the time this research project began.

Initially these letters were used in 1979/80 by the head occupational therapists of both hospitals as a way of collecting facts to use against social services departments who were failing to meet the essential needs of discharged hospital patients. Their joint attempt at influencing policy was, however, unsuccessful and the letters from Mile End, which are still being sent in 1984, are still uncovering discharged patients who have not received aids and services.

F.2 Response to the follow-up letters

Respondents from the Mile End sample told the researcher that it was easier to complain to hospital occupational therapists than to social services departments. First, because they had enjoyed friendly relationships with their occupational therapists while still in hospital and the therapists knew about the things they found difficult. Second, because the letters invited them to write and, by sending an addressed envelope, made it easy to reply. In contrast a number of respondents did not know how to get in touch with social services staff and two said they would have been afraid to complain to the social services for fear of being branded as trouble-makers and barred from future services.

By the time the researcher called, three patients from the Mile End sample were able to say that hospital occupational therapists had been in touch with the local social services departments about aids that had not been delivered. Patients from the other two hospitals who were still waiting for aids had no one to speak on their behalf except the researcher whose brief, fortunately, included following up cases with social services staff

F.3 Rehabilitation by hospital occupational therapists

Two respondents went to the new geriatric day centre at the Whittington Hospital for intensive rehabilitation and one to the London Day Hospital. Two went twice a week to a stroke club run jointly by a social services department and a health authority. Although the aim of this stroke club was to help patients - and their relatives - to come to terms with the fact that nothing more could be done to improve their condition, neither of the respondents

Both complained because they were not getting intensive therapy, especially electrical treatment, and one said he was ‘going backwards fast'. Four other respondents were upset because electrical treatment had been discontinued after they left hospital. Electrical treatment is given by physiotherapists not occupational therapists, but the indignation expressed by one respondent - ‘everything just stopped at once! — suggests that some patients need more help in adjusting to being alone once they leave hospital. Unfortunately very little rehabilitation work is done by domiciliary occupational therapists in the community and more respondents might have benefitted from seeing hospital occupational therapists as outpatients during the first few weeks after discharge.

F.4 Grievances

A few respondents complained about things that went wrong after their return home because of failures on the part of hospital staff. These included:

(a) Lack of contact with General Practitioners

Consultants did not write to GPs and GPs were not automatically notified that their patients had returned home.

(b) Uncertainties about the hospital appointments system

Some respondents had noticed that other patients had left the hospital with appointment cards for an out-patient clinic and were worried because they had not been given one. They watched the post anxiously until a card arrived and felt insecure until they knew for certain when they would be seeing the consultant.

One respondent who could not keep an appointment was worried because a new appointment had not been made a month later. She had returned her original appointment card as instructed but had since heard nothing. The researcher discovered that her file had been lost. Eventually a new appointment was made after consultation with the medical secretary.

(c) Uncertainties about transport to the out-patient clinic

Respondents who had gone home in an ambulance expected to return to a the hospital in an ambulance even if, some weeks later, they might be expected to get there by themselves. This should have been explained to them before they left hospital. Only consultants can authorize collection by ambulance and responsibility for ordering one rests with their medical secretaries. Ordering is done by ticking the appropriate box on the form that goes to the appointments clerk.

One clerk complained bitterly to the researcher about being ‘blamed all the time because the medical secretaries forgot to tick'. Appointment cards sent to patients should state clearly in words whether transport is being provided or not so that anxious people do not sit around, dressed in their outdoor clothes from early morning, for ambulances that will not come. Disabled people who live alone and are not on the telephone cannot check with the hospital about what is happening; nor is it easy for them to make a new appointment when one is missed because of a misunderstanding over transport.

(d) Ambulancemen refusing to take wheelchairs

The number of wheelchairs an ambulance carries has to be restricted and ambulancemen will only take chairs that have been authorised. A severely disabled respondent suffered considerably because his wheelchair could not go with him on the ambulance and there were difficulties about propping him up at the hospital until a push-chair could be found. Once again, someone had forgotten to tick the appropriate box, in this case a physiotherapist. Until the mistake was discovered and new instructions issued, ambulancemen continued to refuse to take the wheelchair in spite of the patient's obvious disabilities.

(e) Failure to record names and addresses accurately

Two respondents said that hospital staff had spelt their addresses wrongly and one complained that 'my name was spelt wrongly all the time I was in hospital'. Inaccuracies of this kind could contribute to the loss of files, with serious consequences if a patient needs to return as an out-patient or to be re-admitted. The researcher found other examples of inaccuracy. In particular, failures to record complete addresses, for example, the name of the road as well as the block of flats, and correct postal districts.

None of these complaints will be new to hospital administrators. All the more reason, therefore, for designing forms that reduce the possibilities of human error to a minimum, and for reviewing administrative processes regularly.

F.5 Goodwill towards the hospital

The experience of being in hospital was still vivid in the minds of some respondents and a few of them went to great trouble to express their thanks to doctors, nurses and occupational therapists in the blank portion of the questionnaire. Those from the Whittington sample also remarked on the good quality of the food.

SECTION G - Liaison between Hospital Occupational Therapists and Social Services Departments

G.1 The statutory duties of social services departments

Social services departments have certain statutory duties towards chronically sick and disabled people under the Chronically Sick and Disabled Persons Act, 1970. These duties include helping to provide aids to daily living for 'the substantially and permanently handicapped' and helping with adaptations to their homes. The majority of patients seen by hospital occupational therapists have some sort of permanent disability and, although the health services may provide a certain amount of after-care, their welfare becomes the responsibility of the social services departments as soon as they leave hospital. Other duties include providing meals-on-wheels and home helps.

G.2 Putting in requests

(a) Requests by telephone

Requests for aids, adaptations and services are made by hospital occupational therapists to their opposite numbers in the social services departments, usually to a domiciliary occupational therapist in the social work area in which the patient lives.

If there is no area domiciliary occupational therapist the case goes to the social worker on intake duty.

Most requests are made, initially, by telephone and there are obvious advantages in hospital and domiciliary occupational therapists discussing cases in detail, particularly where the need is urgent. Unfortunately, getting hold of domiciliary occupational therapists is difficult as they do most of their work outside the office. In one social services department where all the domiciliary occupational therapists are based centrally, the therapists are in the office at certain times on certain days. There were still difficulties in reaching them, however, because all calls had to go through the main switchboard which, like all switchboards in social services departments, was frequently jammed. Hospital occupational therapists do most of their work on the wards and have only limited time to make telephone calls.

When following up cases the researcher often spent whole days trying to contact domiciliary occupational therapists: ringing the switch board at twenty minute intervals, getting through eventually to discover that the therapist had gone out; ringing back at the time suggested to find she had still not returned; leaving a message, often with the telephonist, asking for the therapist to ring back; and waiting around in the hope that she would. Small wonder that clients frequently give up!

The question of the provision and manning of telephones needs serious consideration by social services administrators.

Communication was likely to be more successful when the domiciliary occupational therapists were organised into teams with their own administrator, clerk and, possibly, typist available throughout the day. Unfortunately, few therapists had this kind of back-up and telephones frequently rang in empty rooms. Getting through to hospital occupational therapists could also be difficult for the domiciliaries. Two departments had only part-time clerical help and there was often no one to take messages while the hospital occupational therapists were on the wards.

(b) Taking messages

Although pads of special message forms may be provided, messages in social services departments are all too frequently taken down on any scrap of paper that might be handy, and then dumped on the desks of the persons for whom they were intended. These bits of paper were easily lost or overlooked. Switchboard operators in social services departments often relied on catching the eye of a therapist but usually failed. Some offices had pigeon-holes for messages but overworked staff did not always look in them.

The importance of good message-taking needs to be stressed.

(c) Written requests

All requests to social services departments for aids and adaptations had to be submitted in writing on special forms, which were also used. to confirm telephone requests. Some social services departments had collaborated with hospital occupational therapists to produce forms designed to help with their own administration; otherwise standard hospital forms were used. Duplicate copies were filed with the patients' index cards. Unfortunately, there was no system by which hospital occupational therapists could check the progress of written requests once they got to the social services departments. They had no means of knowing if they reached a domiciliary occupational therapist or the appropriate social worker, or if they were shelved.

Discussing cases over the telephone is one of the best ways of ensuring the interest of domiciliary therapists and of emphasising urgency, but telephone calls should always be confirmed in writing. Formal requests to social services departments are made in duplicate on special forms. In some boroughs head occupational therapists had cooperated with the district occupational therapist in designing forms that would simplify the administration of retrospective payments by social services departments.

The researcher investigated six cases of departments claiming not to have received written requests and found five to be untrue. Hospital occupational therapists were able to produce duplicates, with dates. The six patients had been at home for more than a month before the researcher's investigation drew attention to them. A simple form of acknowledgement is needed, perhaps a tear-off slip for the department to return to the hospital, but this minor improvement would not ensure that hospital therapists would know if their requests had been dealt with or how much longer their patients would have to wait. Some delays could be avoided if forms were designed to give information to social services staff, in particular a patient's telephone number.

This would help to save fruitless journeys by occupational therapists. The name and telephone number of the patient's general practitioner should also be given. Of course, specially designed request forms will not be effective unless hospital occupational therapists fill them in properly.

G.3 Delays in providing aids and adaptations due to the shortage of qualified staff in social services departments

Written requests for aids and adaptations sometimes went astray because there was no obvious person to whom they could be allocated. Some social work areas did not have a domiciliary occupational therapist, and the scarcity of social workers qualified to work with the disabled meant that cases of physical handicap were frequently shelved. One case, reported by the researcher, was eventually referred to a domiciliary occupational therapist covering another area of a very extensive county, but there was no guarantee that she would be able to fit in a visit.

In one area without a domiciliary occupational therapist the respondent had been seen by an unqualified social work assistant who was not allowed to indent for the aids needed. Only domiciliary occupational therapists in this borough could authorise the issue of aids. At the suggestion of the researcher the social work assistant asked the hospital occupational therapist to send a duplicate of the original request to a person much higher in the hierarchy of the department.

G.4 Lack of priority for hospital patients

It would seem sensible that patients assessed in hospital as needing aids and adaptations should be given them at the earliest possible moment. Nevertheless, none of the staff of social services departments was prepared to give them automatic priority. Unlike the hospital occupational therapists, whose concern was concentrated on their patients for a short period, domiciliary occupational therapists had to cope with referrals from a number of different sources, and for a wide variety of needs. They also had to decide between varying degrees of urgency in the context of inadequate budgets.

On the whole, domiciliary occupational therapists were not prepared to accept on faith the recommendations of their hospital colleagues. Only two head occupational therapists always supplied aids that had been asked for as a matter of policy and provided they were in stock. No aids were ordered until the patient had been visited to see if they were essential. In other boroughs, domiciliary occupational therapists might take the portable aids that had been requested on their first home visit, but they would not necessarily issue them. Once again, each case had to be considered in relation to the limited amount of money available for aids at the time.

In general, domiciliary occupational therapists respected the judgments of their hospital colleagues, but it was obvious to the researcher that some felt that hospital therapists, divorced from the need to find the money for them, ordered aids that were not strictly necessary. The findings of the study showed the opposite - that hospital occupational therapists were so aware of the limited budgets of social services departments that they did not always order enough aids.

Most of the aids ordered by hospital occupational therapists were likely to be kept in stock by departments and, although stocks fluctuated and were often run down at the end of the financial year, delays in issuing them were often a way of deliberately rationing scarce resources.

G.5 Meetings between hospital and domiciliary occupational therapists

Liaison was better if they had already met. Many individuals arranged meetings with each other and the researcher was relieved to find no evidence of the bitterness which had at one time divided the two branches of the profession. Meetings between teams also took place. The researcher sat in on one where grievances about the provision of aids and adaptations were aired.

G.6 Joint assessment by hospital and domiciliary occupational therapist

A way of making sure of continuity of care for a severely disabled patient after discharge is for the hospital occupational therapist to set up a joint visit with the domiciliary occupational therapist. Much depends on whether the domiciliary believes in joint visits. Some consider them to be time-wasting and some dislike feeling obliged to make decisions in the presence of a hospital colleague. Only one example of a joint visit came to the researcher's attention. It was in connection with a major adaptation and caused the patient/client considerable distress because the two professionals disagreed about the necessity for the adaptation.

G.7 Complaints from domiciliary occupational therapists about lack of sufficient notice

Most domiciliary occupational therapists were slow to visit discharged patients and some laid the blame on their hospital colleagues who had not told them soon enough about patients' needs. This is unfortunately true and is due in part to the fact that consultants frequently discharge patients without notice, sometimes because the bed is needed. In spite of hospital policies to the contrary, patients are often discharged at weekends and the therapist can go to a ward on Monday only to find the patient gone.

Before ordering aids and adaptations, hospital occupational therapists may need to see how patients manage in their own homes. Ideally, the therapist should take the patient home for a short visit before discharge. This allows time for the social services to be notified of requirements. Shorter stays in hospital mean, however, that home visits before discharge are difficult to arrange and therapists have to accompany patients the day they are discharged, or visit them soon after. This makes it impossible to give advance notice of requirements.

Early notification is only possible for patients with severe physical handicap who have to stay in hospital for a long time. Only one case came to light of a severely disabled patient being kept in hospital longer than necessary because adaptations to his home had not been completed. He was transferred to another hospital and was therefore excluded from the sample. Two patients in a geriatric ward were kept for several days longer because bed-blocks had not been delivered to their homes. A strike of administrative staff had led to a strike of van drivers, and the domiciliary occupational therapist would not deliver the blocks for fear of being considered a black-leg.

It was publicity given to the strike in the local press that stopped the patients being discharged before their bed-blocks were delivered. This strike also caused a backlog in the delivery of aids but did not affect the results of the survey as delivery services were back to normal by the time the first discharged patients had been home a month.

G.8 Failure of domiciliary occupational therapists to visit discharged patients

All domiciliary occupational therapists agreed on the importance of visiting discharged patients as soon as possible after their return home in order to help them to adapt to home conditions and to strive for a measure of independence. Failure to make an early visit was likely to result in discouragement, apathy, regression and even re-admittance to hospital. Sadly, however, there were too few therapists to cope and long waiting lists often meant patients having to wait an unacceptable time for a visit. Some were never visited at all

Some boroughs eased the problem of long waiting lists by employing social work assistants to help domiciliary occupational therapists. Whenever possible, one of these 'aides', as they were often called tried to visit discharged patients within a week of their return home. Although not professionally qualified, these assistants were invariably experienced and blessed with commonsense and the fact that they called at all meant that the discharged patients did not feel completely abandoned. They were also used by the therapists to deliver portable aids and to teach clients how to use them properly and safely.

Technicians attached to teams of domiciliary therapists often delivered and installed aids without a preliminary visit from the therapist. This had the advantage of speeding up provision but once the aid was installed there was a danger that the therapist would no longer feel compelled to visit the patient to provide other forms of help and support.

G.9 _ Good practice

Cooperation between hospital and domiciliary occupational therapists varied with each local authority but the head therapist of one social services department had built up an excellent relationship with the district therapist and together they had introduced practices which greatly benefitted newly discharged patients, cutting red tape and reducing paper work to a minimum. Hospital occupational therapists were able to issue aids without first obtaining permission from a domiciliary therapist. The money was paid retrospectively from the social services budget. At the time of the study this was the only social services department in the catchment area of the three hospitals to give blanket permission of this kind.

Again, to make things easier for patients due for discharge, the head occupational therapist asked the hospital therapist to store a number of raised toilet seats that had already been paid for by the social services department. The department had also come to an agreement with the Area Health Authority, as it was then called, to provide special beds and commodes needed by disabled patients out of community health funds. Feelers had also gone out about establishing a centre for aids, jointly financed by the social services department and the health authority, with joint storage and joint distribution. This was held up because of the reorganisation of the Health Service, but in the long term more aids centres of this kind are likely to be established. One of the advantages aids centres offer is that hospital occupational therapists can by-pass the social services departments and order the aids needed by their patients on their own authority.

Since the study ended three more boroughs have decided to store essential aids, including commodes and raised toilet seats, at hospital occupational therapy departments. This has been done not only for the convenience of patients but because the boroughs have finally admitted that they do not have enough staff to provide a professional service or to ensure prompt delivery of the aids required. Storage space at the hospitals is limited, however.

G.10 Patterns of staffing in social services departments

During the course of the study the researcher came upon a great many different patterns of staffing. One of the most effective is the following example.

The diagram shows the example of a Head Occupational Therapist in charge of 4 Area Ots and a Roving OT. Each of these have a social work assistant reporting to them. An administrative Officer serves the four areas. Two technical assistants a Clerk and a typist report to the Administrative Officer.

There is one domiciliary occupational therapist for each area, with a social work assistant for three and a vacancy for the fourth. There is also a roving therapist with special responsibility for day centres, an unusual but valuable appointment because she also filled in when area therapists were sick or on leave. The administrator worked exclusively for the team and, like the clerk and typist, was able to take a keen interest in the day-to-day work of the therapists because they were all housed together. The technical assistants reported daily to the administrator.

There is, however, one category of employee missing which the researcher would have liked to have seen - a craft instructor. None of the local authorities covered by the study employed instructors although many of the respondents could have done with help filling the time that lay so heavily on their hands.

The key figure is the head occupational therapist whose responsibilities include controlling the budget for aids and adaptations, shaping policy and cultivating good relationships with the staff of housing departments and hospital occupational therapy departments. Other duties, of equal importance, are the supervision of newly qualified occupational therapists, apportioning work-loads and relieving the guilt felt by occupational therapists who could not keep up with the demands made on them. In boroughs where there was no head therapist, domiciliary therapists left on their own frequently felt guilty and anxious because there was no one in authority to help them decide on priorities and share the strain. Inadequately staffed departments in these boroughs had a very rapid turnover of staff. Once they got a bad reputation for their policy towards the disabled, it became difficult to attract new staff, vacancies remained unfilled, problems multiplied and waiting lists became even longer.

More money for services to the disabled is an obvious solution, put only a partial one because demand is growing faster than the number of people trained to cope with it and waiting lists in boroughs with a good reputation for helping disabled people could still be as many as 200 or more. Until more domiciliary occupational therapists are trained and more social workers take up the option on training courses of specialising in work with the disabled, vacancies will remain and waiting lists grow.

In such circumstances it is difficult to assert that disabled patients newly discharged from hospital should be given priority. Nevertheless for many of them the risk of regression is considerable if they do not receive the aids, adaptations and professional support they need soon after their return home. Creating a post with special responsibility for all the newly discharged patients in the borough who had been refer ed to the social services departments (an extension of the idea of the 'roving' therapist) might be the answer. This would take the strain off the area therapists. As it is estimated that the referrals from local hospitals account for between five and seven per cent of the total workload, the number of patients to be handled should not be too great for one therapist. These referrals would be taken off the main waiting list and transferred to a much shorter list with its own priorities. This system would also provide a continuous link between hospitals and social services and make communication easier. It would only work, however, if the two waiting lists did not have to compete with each other for scarce resources, a problem that could be overcome by allocating a proportionate sum of the budget for aids and adaptations for expenditure on discharged hospital patients.

In the long term there are four main solutions to the problems faced by patients newly discharged from hospital.

(1): more money for both social services departments and health authorities;

(2) better administration;

(3) more staff, including back up staff for occupational therapists - social work assistants,

administrative officers, clerks and typists;

(4) more involvement by the local communities.

Under the present government, (1) and (3) are unlikely, which makes (4) essential.

SECTION H — Summary

The aim of the study was to find out as much as possible about the provision of aids to daily living to disabled patients discharged from hospital: and about any adaptations needed to their homes to help them overcome handicap. Concern had been expressed by hospital occupational therapists over delays by local authority social services departments in providing aids and by local authority housing departments in providing adaptations. It was hoped that the study would lead to suggestions about how to

avoid delays.

The sample was drawn from three district hospitals in London over a period of 33 weeks and consisted of all the in-patients discharged into their own homes who had been seen by hospital occupational therapists, a total of 197 discharged patients. Questionnaires were sent out one month after the date of discharge and 112 responded (A.10). Of the 112 respondents, 62 needed one or more aids to daily living and/or adaptations to their homes. Of these 22 were still waiting for an aid a month after discharge and 21, not always the same people, were waiting for minor adaptations (C.6 and C.10). One respondent was hoping for an improvement grant for a major adaptation (C.9).

The aids are known as ‘aids to daily living’ to distinguish them from the 'aids to nursing patients at home’ which are supplied for a limited period and are the responsibility of health authorities. ‘Aids to daily living’ for disabled people who are ‘substantially and permanently handicapped’ are, with a few exceptions, the responsibility of local authority social services departments (G.1). The most important exception in the study were aids to mobility issued by hospital physiotherapists when patients went home. Although some would count as ‘aids to daily living' all were paid for by the hospitals. There were also some local arrangements about the supply of commodes; one with an area health authority to supply all the commodes needed in two inner London boroughs —- an arrangement that was seen as the first step towards a joint aids centre (G.9). Three outer London boroughs had arranged for the Red Cross to hire out commodes (C.5 (iv) and (v). A few patients bought their aids to daily living from hospital occupational therapists (C.5 (ii) but this, like the hiring charges for commodes, was inequitable because aids supplied by local authority social services departments were, at the time of the study, free of charge.

For hospital occupational therapists to be able to send patients home with their aids to daily living requires retrospective payment by social services departments. Getting ad hoc permission to supply aids could be very time consuming (G.2). Only one local authority had given blanket permission for hospital therapists to issue all the aids needed by patients living within its boundaries (G.9). It had also bought raised toilet seats and had them stored at the Whittington Hospital for patients to take home. Not all the local authorities within the catchment areas of the three hospitals were prepared to cooperate with hospital occupational therapists. Whether or not patients went home with aids too often depended on their ability to pay or where they lived, instead of the degree and urgency of their need

(C25). Some domiciliary occupational therapists felt that their colleagues in hospital issued too many aids because they were divorced from the need to find money for them. The study proved the opposite to be true - that hospital therapists were so conscious of the financial difficulties facing their colleagues outside that they issued too few rather than too many aids and only those that were essential for overcoming handicap (G.4). With the possible exception of one book rest, no aids to improve the quality of life were issued (C.1, Table 7).

Requests for adaptations to the homes of disabled patients went first to social services departments and then to the local housing authority if the patient lived in council property. This done, departments showed little continuing concern about progress (C.11). Housing authorities using direct labour were often short of key technicians and delays of more than two months before electric plugs were moved or taps modified were reported (C.10). Some respondents had to wait more than two months for bannister-rails to help them get to bedrooms, bathroom and toilets (C.10). Contracting out to private builders could have avoided some of these delays (C.13).

Disabled people who lived in private property remained the responsibility of social services departments who often preferred to use private contractors. Even so, there were administrative delays before work started on an adaptation. The luckier respondents lived in boroughs where the social services departments employed their own technical assistants who could, if necessary, install grab-rails within 24 hours. Disabled people in privately rented property had to suffer additional delays because work could not begin without the landlord's permission. Both owner occupiers and landlords might be required to pay part or the whole of the cost of an adaptation (B.6).

Policies towards the disabled varied between authorities and there were considerable differences in the amounts of money allocated for aids and adaptations. In the financial year 1980/81 these varied from £6,000 to £46,000. Most local authorities adjusted their allocations for inflation but none took sufficient notice of rising demands. In some boroughs money ran out before the end of the financial year and respondents had to wait for their aids until the next financial year began (A.7).

Local authorities with a bad reputation for services for the disabled found it difficult to attract and keep staff (G.10) and where respondents lived frequently determined the speed with which their needs were met and whether their needs were met at all (A.5). Even the better social services departments had long lists of disabled people waiting for a home visit from a domiciliary occupational therapist.

Although domiciliary therapists agreed that patients discharged from hospital usually need prompt professional support (G.8), none was prepared to give them priority over other disabled people (G.4). Some respondents reported that they had waited three weeks or more for a visit, while others had had no professional attention at all.

In an attempt to cut down numbers on waiting lists some social services departments used unqualified but experienced social work assistants to make the first home visit and to deliver aids to daily living. Technical assistants were also used to deliver aids. These early visits from the social services were not necessarily followed by visits from domiciliary therapists (G.8).

Hospital occupational therapists did not know if their written requests had reached the appropriate domiciliary occupational therapist (G.1) without contacting their former patients. This was done successfully by therapists at the Mile End hospital who sent out a standard letter to patients one month after their discharge and again three months later (F.1).

The study also looked at the provision of domiciliary services like home helps and meals-on-wheels, and at the after—care provided by health authorities in the form of district nurses, health and geriatric visitors and general practitioners (D.1). Of the 112 respondents, 43 lived alone and many of them would have been unable to remain in their own homes without the help from the domiciliary services (B.4). The relatives of severely disabled people also needed practical help and support.

The questionnaire invited respondents to note down any problems they had had after returning home. These ranged from practical difficulties, like not being able to hang out the washing, to feelings of isolation, boredom, rejection and loneliness. None of the local authorities in the catchment areas of the three hospitals employed craft instructors.

A space in the questionnaire for additional comments was used by some respondents to complain about the hospital appointments system, confusion over transport to out-patient departments and the failure of hospitals to tell general practitioners that their patients had returned home (F.4). Some respondents felt that doctors did not bother to visit them because they were incurable. There is a need for more research into the involvement of general practitioners with disabled patients (D.2). More involvement by the community is also needed.

More research into how patients from different ethnic minorities react to traumatic illness and adjust to changed circumstances would be valuable.

Some problems of communication were uncovered. Domiciliary occupational therapists complained that they were not given enough notice before patients were discharged (G.7). Written requests from hospital therapists did not always reach the right staff in social services departments; medical secretaries and hospital appointment clerks did not always see eye to eye; ambulance men were not given instructions about wheelchair patients; patients were not properly briefed about transport to outpatient clinics. Some of these problems arose because staff were not sufficiently concerned about keeping accurate records which led, on occasion, to hospital files going astray. Poor message taking could also cause delays and avoidable distress for newly discharged patients.

The researcher visited 33 out of the 42 respondents who were waiting for aids and adaptations and had long telephone conversations with the rest. Following up delays in providing aids and adaptations led the researcher to draw attention to cases that had been overlooked or shelved (G.3), or had gone astray completely. This was a fortuitous spin-off from the research project. The important result of the study, however, was that it revealed breakdowns in administration, unnecessary delays and an unacceptable lack of continuity in caring.

Examples of good practice, including a pattern of staffing that bore good results, are given in the final section of the report (G.9), and some solutions are suggested.