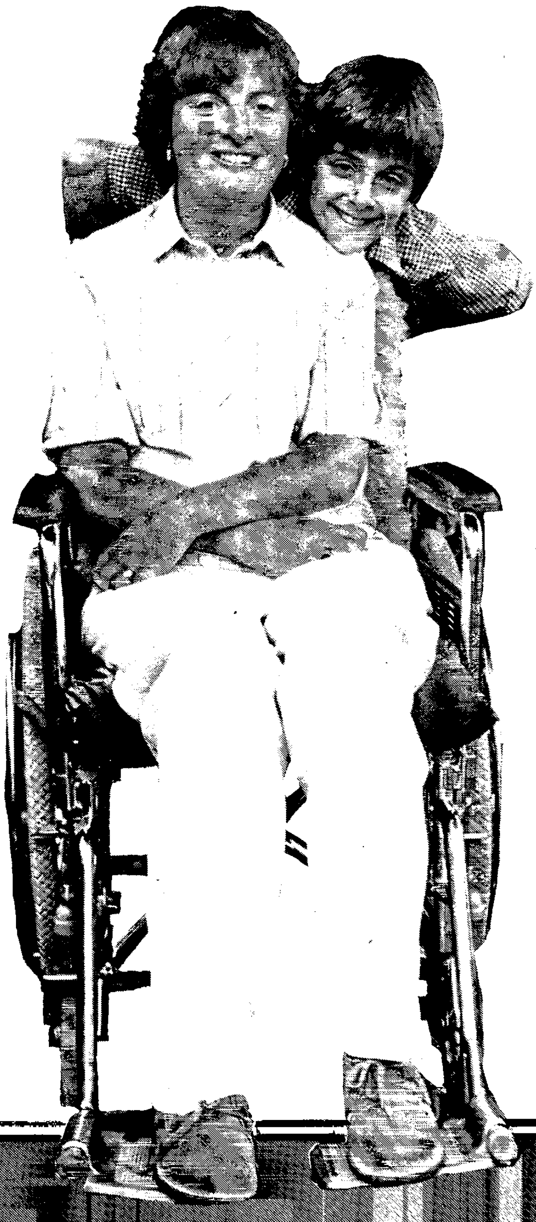
Living Independently

Ann Shearer



CEH and King's Fund

Living Independently

BERNARD BRETT 1935 – 1982

Bernard Brett, whose life is one of those recorded in this book, died in September 1982, before it was published. The generosity of interest and encouragement he brought to the project would be recognised as characteristic of the man by anyone who knew him. It is a great sadness that he did not see the project completed.

The text about Bernard remains unchanged. If it, and the rest of the book, stands as a small witness to the values he lived by, then that is a privilege, as it was to know him.

'As the years pass with growing speed, I feel increasingly strongly that we are all on a great journey of faith and time. How we use this life, which is the only one we can be certain about, is up to each one of us. I know very well that I have made many mistakes and actively damaged some people's lives in rather terrifying ways. The fact that I have helped or guided quite a few other people's lives in their time of need may not be so very important. The hurt and evil which we do can only be redeemed by the love and grace of Christ.

'Yet for all the mistakes I may have made and will continue to make, I know that each one of us has the opportunity and the divine gift of being able to grow into more full and loving human beings, if we allow the Spirit of God to work in the yeast of our inner beings . . . I am sure that we are asked by God to accept ourselves just as He accepts each one of us. I believe that each of us has a task given to us, whether it is great or humdrum. We have the opportunity to do the will of God and for myself I pray that I may be given the strength to serve my Maker as best I may.'

Bernard Brett, in a talk to the Corrymeela
Community, Easter 1980

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Ann Shearer

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Thanks are due to the Commission of the European Communities for the grant which made this study financially possible, and to all the organisations which cooperated in putting it together.

But most especially, thanks are due to the nine people whose lives are here recounted. The project would not have been possible at all if they had not given so freely and patiently of their time, hospitality and insights. They welcomed me to their homes for 24 hours; they put up with my questions; they went through the draft text to correct my misunderstandings and misrepresentations. They could not have done more to ensure that the finished product turned out as they hoped. If it hasn't, the responsibility, as well as for any errors in the material or the conclusions I have drawn from it, rests with me.

Ann Shearer
1982

Introduction

MOST PEOPLE whose physical disabilities are severe enough for them to need help with the details of daily living live with relatives who provide most, if not all, of that help. Others live in residential establishments where people are paid to do the same. This book is about people whose disabilities are just as severe, but who do neither. They live independently, either alone or with a partner who is equally disabled, in a way and in a place which they have chosen and for which they are responsible.

Twelve years ago, when Jack and Margaret Wymer set up house in Norwich, this third option seemed almost unthinkable for people whose physical limitations were as severe as theirs. In the rules and regulations which govern the provision of housing and community support services, it still is. The official options are still either a dependence on able relatives or a place in a residential home.

Yet for a growing number of people for whose benefit the rules and regulations are supposedly made, this is no longer enough. They are taking seriously the 1975 United Nations Declaration of Rights of Disabled Persons, which asserts their right to be as self-reliant as possible, to live as they choose and to participate in the social, creative and recreational activities of their community. They are claiming their right to no more than what the majority of the population take for granted as the basis of their own self-reliance, choice and participation—a home of their own and the variety of support they need to live in it.

What this book tries to do is to explore, through detailed descriptions of six households, just what a complexity of financial and practical support people may need to turn that right into a reality if their disabilities are very severe. It makes no claims that the nine people who live in those households are 'typical' of what planners and providers of services like to define as 'the disabled population', or to come up with a blueprint for future support. The majority of people with physical disabilities are elderly; these people are not. The majority of people with disabilities are poor; some of these, at least, have had private financial resources to draw on. Yet these two facts raise some fundamental questions about current patterns of community support that are still geared to the aspirations and needs of people who *are* elderly rather than those who want a more active life, and about the financial policies which still impose such constraints on their efforts to achieve it. And the rejection of the 'typical' sample in favour of individual realities perhaps poses its own challenge to the notion of a 'disabled population'. There is, in the end no such entity, but only a number of individuals, each with their own needs, wants and aspirations, who happen to have a variety of physical limitations. That is the real challenge to planners and providers of services, not the creation of catch-all solutions for a tidily homogeneous group.

The challenge has barely been tackled. The 1970s saw an unprecedented concern with the opportunities available—or more often not—to people whose disabilities are severe. But the concern was overwhelmingly with making the 'either-or' option work better than it had done in the past. By the end of the decade, the legislative and imaginative constraints in the way of developing the third option remained almost the same as they had been at its start.

There were, however, some developments within these constraints. Some housing, of both the 'wheelchair' and the 'mobility' sort, was developed specifically with the needs of people with disabilities in mind. There were attempts to weld housing with support services; the last section of the book looks in more detail at some of the ways this has been done in this country and elsewhere. But the barriers to providing support on a scale that some people may need still remain.

So Habinteg, the national housing association which started as an offshoot of the Spastics Society, and whose first scheme figures in these pages, has grown during the 1970s. It now provides over 600 dwellings in 11 schemes; in all of these, and in the seven further schemes (400 units) in development, a quarter of the tenancies are for people with disabilities. But Habinteg, like other housing associations, cannot attract either Housing Corporation or local authority finance for support services beyond what a 'community assistant' can provide. Those services remain the responsibility of local authority social services departments and others.

Social services' support for people with disabilities did increase during the 1970s. The decade also saw the launching and development of the Association of Crossroads Care Attendant

Schemes Ltd—an important initiative for bringing people the help they need in a way that suits them rather than the service providers, which the last section looks at in more detail. But official social services support and the 30 or so Crossroads schemes remain essentially an addition to, rather than a substitute for, what an 'able' family can itself provide. The Community Service Volunteers' One-to-One Scheme was, by the start of the 1980s, beginning to show one way of providing that substitute, and figures in these pages, too. But although the scheme aims to have 360 volunteers placed by 1985, it is still, with about 40 of them now at work, small beer.*

So Habinteg's tenants, like those of other housing associations, must generally be people who can cope with a minimum of regular help. So, generally, people who need more support in their daily lives than housing authorities can provide and who either cannot or do not wish to remain in their 'able' families must still very often forfeit their claim to housing altogether. They still end up in Part III social services accommodation or a hospital unit. They must still move to where 'care' is traditionally provided, rather than remaining in a house and having it brought to them there. People who have managed to take the third option—by doing just that—like those in this study—remain a minority. Yet how many others would choose that option if it were available to them?

The rest of this Introduction looks in more detail at the general context of resources within which people's choices must be made, before coming to the particular context of this study.

THE CONTEXT

The 1970s started with the shocked realisation not just that people with physical disabilities make up a very considerable minority of the population, but that on every count public policies had failed them. The Office of Population Censuses and Surveys studies estimated that there were three million people with some physical impairment in Britain, well over a million of them

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* The scheme is, however, growing. By August 1982, when it was renamed the Independent Living Scheme, it had 110 volunteers at work in about 70 projects.

appreciably or severely handicapped in their everyday life.* A third of all of them — and four-fifths of those whose disabilities were most severe — were dependent on State benefits which very often took no account at all of their financial needs, and an estimated quarter of a million were not even getting the money to which they were entitled; not for nothing had the survey been set up in response to continued pressure for a decent disability pension by the Disablement Income Group. Housing was no more adequate than financial support. More of the people who needed 'special care' than of any other group with disabilities were living in places which lacked the basic amenities or had stairs that made caring for them harder. In all, nearly a million people, in well over 800 000 households, needed rehousing.[4, 15]

The statistics became even more disturbing in the light of Peter Townsend's monumental *Poverty in the UK*, also based on a survey made at the end of the 1960s. On his wider criteria, which included people with mental handicaps and mental illnesses, the number of people with disabilities was more than doubled, to over 6.5m; over a million of them were severely incapacitated, twice that number appreciably, as they went about the activities of daily living.* The correlation between disability and poverty was firmly established. More than half those with severe or appreciable incapacity were in households in or on the margins of poverty, compared with only a fifth of the 'ordinary' population; the greater their incapacity, at any age, the poorer they became. Their poverty was reflected in their housing, which got worse, not better, as their degree of incapacity increased. While 18 per cent of those with no incapacity lacked sole use of indoor WC, sink with taps, bath and cooker, that proportion rose to 26 per cent among people whose incapacities were appreciable or severe.[26]

By the time Townsend's study was published, however, there had been a decade of reform on behalf of people with disabilities. 'Most disabled people', Alf Morris told the House of Commons in 1969, 'want more than anything to lessen their dependence on others, to get on with living their own lives as

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* These definitions of 'handicap' and 'incapacity' of course say more about the inadaptations of the environments people find themselves in than they do about any limitations that inevitably come with physical or mental impairment. We have become more sophisticated since these studies were made in the crucial business of separating disability from imposed handicap. We now know, for instance, that inability to reach an object on an overhead shelf says nothing definitive about how individuals can manage, but everything about the way the positioning of shelves can help or hinder them in doing so.

normally as they can in their own homes with their own families and whenever possible to have the opportunity of contributing to industry and society as fully as their abilities allow.'[20]

Morris's 1970 Chronically Sick and Disabled Persons Act promised a plethora of local authority services to people with disabilities living in their own homes, ranging from the provision of aids and telephones to support from the home help and meals services. It promised greater access to communities by laying down that public buildings should be made accessible 'in so far as it is in the circumstances both practicable and reasonable' and making provision for accessible public lavatories. It also tackled housing: local authorities were to make adaptations—a job which fell to the new social services departments—and housing departments were to 'have regard to the special needs of chronically sick or disabled persons' when considering the housing needs of their area.

The Act has certainly brought benefits to very many people—including those who feature in these pages. But, as certainly, it has failed to bring anything like a guarantee of equitable support to people with disabilities, according to their needs. From the very start, the Conservative Government undermined its intentions by assuring local authorities that the identification of all people with disabilities on their patch was not the aim; it warned them against seeking out needs which could not be met. There was no extra public money to implement the Act's promises. So while national and independent surveys suggest an incidence of disability of between 5 and 10 per cent, one local authority has a register of only 0.8 per cent and most registers hover between 1.5 and 2.5 per cent.

Variations in the identification of people who might need the help the Act promised have inevitably led to variations in the delivery of that help. By 1977-8, one local authority was delivering aids to 17.9 people in every thousand of its population, another to only one; one was providing adaptations to 8.3 private households in every thousand, another to none at all; in one area, help towards radio and television went to 63 people in every thousand, in another to no one.

By the end of the 1970s and beyond, public expenditure cuts were further weakening the Act's promises. Surveys were showing that it was precisely the services it offered which could most easily be lopped; home help services were being spread more thinly and rationed by new or increased charges in many authorities. Some were making clear that there would be no more housing adaptations for the foreseeable future. While pressure groups were trying to make the Act's provisions truly mandatory, the Association of County Councils was hardly bothering to press its own case for making them permissive, as they were clearly as good as that already.*

Meanwhile, the Act's aspirations for the provision of suitable new housing for people with disabilities had had its effect. 'Wheelchair housing' had been introduced in 1968, but it was only six years later, with the introduction of 'mobility housing'—which is simply ordinary housing made convenient for people with disabilities—that housing authorities started taking their needs seriously. Between 1970 and 1980, local authorities and new towns provided 16 000 units of mobility and 4000 of wheelchair housing, and housing associations nearly 3000 of the two together. But provision has fallen off sharply since then. In the first three-quarters of 1981, local authorities' starts of wheelchair and mobility housing together were down by 63 per cent on the same period in the previous year, and housing association starts were down by 87 per cent; only 1916 units were started altogether, and only 57 of these were contributed by housing associations.[10]

By the beginning of the 1980s, the Government was making it clear that its own priorities for housing lay with adaptations rather than building, and with the private rather than the public sector. Adaptations for people with disabilities have been fairly minor in nature while social services departments took the principal responsibility for them: though their numbers rose from 23 000 in 1973 to 60 000 by 1978, only 2600 of these were to the value of more than £150. After a circular from the Department of the Environment, the Department of Health and Social Security and the Welsh Office in 1978 (59/78) on the proper division of responsibility between social services and housing departments, business looked up. Between 1978 and 1980, the Department of the Environment reported 22 000 'major' structural alterations to the homes of council tenants who had disabilities. By the end of 1982, the results of a study on the division of responsibility between the different departments should offer more information. Meanwhile, there have been improvements in grants to owner-occupiers. The 1980 Housing Act abolished the ceiling on rateable values above which people with disabilities were debarred from qualifying for discretionary improvement grants. From the beginning of 1982, the home improvement grant scheme was made more generous for them—but in the context of a budget that was

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* For discussion of the Chronically Sick and Disabled Persons Act and its effectiveness read the chapter by Ann Shearer 'A Framework for Independent Living' in *Disability in Britain*[27] and also *A Charter for the Disabled.*[25]

hardly rising in real terms. The home insulation scheme also offered more generous terms to people with disabilities from this date—but in spite of a rising budget, this scheme was oversubscribed.

The financial situation of people with disabilities had also improved during the 1970s. The attendance allowance was introduced in 1971, to match the constant attendance allowances paid under the war and industrial disablement schemes. In 1976, the non-contributory invalidity pension gave people who had been unable to 'buy' invalidity pensions through national insurance schemes a pension as of right for the first time—though at only 60 per cent of the contributory rate. The mobility allowance, phased in for different groups between the ages of 5 and 65 from 1976 on, brought financial assistance to people who were unable or virtually unable to walk. In 1976, too, the invalid care allowance became payable to people who had to give up work to care for relatives with severe disabilities—unless the carers were married women. Finally, the non-contributory invalidity pension for married women with disabilities—for which the Disablement Income Group had been campaigning since the mid-1960s—was at last introduced in 1977, though only for women who were unable to perform normal household duties' as well as to work.

What does this mixture of developments in housing, services and financial benefits actually amount to for the people for whom they are intended? By the start of the 1980s, it was clear that none of these reforms was sufficient to guarantee a real choice in how they live to those who are severely disabled.

Such special housing as there is, is hardly efficiently used. Wheelchair housing is often underoccupied, partly because local authority housing and social services departments often lack a coherent policy on its use. And it has become clear, too, that the fact of 'special' housing being available is not in itself incentive enough to many people to move. They prefer, normally enough, to remain in the place they know, suitably adapted, than to move to new areas. And especially if they are young, the planners' assumption that they will fit neatly into a 'disabled ghetto' where most of their neighbours are elderly has had to give way to people's actual preferences.

Community support services remain grossly inadequate. The Association of Carers, set up in 1981, got an immediate and often despairing response from people who knew that the promises of 'community care' in reality meant that relatives still had to cope with very little help indeed. The fact that, of the first 1200 letters to the Association, only five came from men underlines the central assumption on which public provision still depends: married women will bear the brunt without any financial acknowledgment that they, too, may have given up work to do so.

Their position is just one of the inequities of the new system of benefits, which still leaves very many people without the resources with which to build the life they choose. Different benefits, at different levels, are still paid, not according to the severity of a person's disability, but according to how they came by it. Some benefits are taxed, others are not. The tests of disability on which some depend are often arbitrarily applied. The earnings rule attached to invalidity pension still acts as a positive disincentive to people who want to earn their own way as far as possible but know they cannot become fully self-supporting. And the value of benefits is, in many cases, falling, not rising. In 1980, there was a cut in the real value of the long-term invalidity pension which left a single pensioner £65 worse off a year. The abolition of the rule which kept benefits in line with the rise in prices or average earnings, whichever was higher, meant that many people with disabilities went into the International Year of Disabled People (IYDP) worse off than they would have been had the rule still been in force.*

Housing provision, support services and financial benefits, in short, remain inadequate in themselves. But as important, they do little, as presently conceived, to dent the 'either-or' pattern of housing and Part III accommodation. Housing grants still allow for only a minimum of care services. Additional services, as provided by social services departments, still rest on the assumption that the bulk of support will come from families. So people who either want to leave their own families—as is normal for young adults—or who cannot remain with them, still cannot turn to a coherent unified system of housing and support. Very often, they still lack anything like the financial means to buy themselves that support. Their only alternative remains a place in a residential unit.

For all the rhetoric about enabling people with disabilities to live in their own homes, the Chronically Sick and Disabled Persons Act had in fact made its own contribution to ensuring a huge investment in residential provision rather than the seeking of imaginative alternatives. Shocked by the realisation that thousands of younger people with disabilities were living either in geriatric or general hospitals or in local authority old people's homes, it laid down that they should have separate accommodation of their own. So residential services burgeoned alongside

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* For discussion on the detail of financial provision read the chapter by A Walker 'Disability and Income' in *Disability in Britain.*[27]

community support. The notion of 'younger chronic sick units' was first urged on hospital authorities in 1968, when a survey had found over 2000 younger people with severe disabilities in geriatric wards and another 1300 in general wards. The 1970 Act brought a special central Government grant of £5m for a crash building programme of special units, and their number has grown ever since. In 1978, there were 72 of these in England alone, catering for well over 1700 people.

By this time too, local authorities had sometimes taken seriously their own duties to provide special establishments. There were 53 of these, catering for nearly 1600 people. Local authorities also continued to rely heavily on voluntary provision. The Cheshire Foundation provided the same number of homes in England, for nearly 1400 people; the Spastics Society offered nearly 800 people a home in its 31 establishments; other voluntary organisations provided 28 homes between them for about 1350 people.[12] By 1982, the Cheshire Foundation's provision for adults with physical disabilities had risen to 58 homes in England, catering for about 1460 people, as part of its total UK provision of 66 homes for nearly 1700. In addition, some thousands of younger people with disabilities remained in local authority homes for elderly people.

But already at the start of the 1970s, people with disabilities were making it plain that the limitations of life in many residential institutions were intolerable. They were likening the 'young chronic sick units' to prisons, and pointing out that people whose disabilities were every bit as severe as those for whom the units were intended were living with support from families in their own housing, or in far less restrictive residential establishments. They were attacking the residential establishments as well. And researchers were documenting the deadening effects of the 'warehousing' which was what these places too often provided.[19]

The effect has been not that those responsible for residential services have looked to turn their energy to housing which offers the considerable support people may need but that, at best, they have concentrated on making traditional provision better than it was. The Cheshire Foundation in its 1981 handbook of residential care takes the UN Declaration of Rights of Disabled Persons as its starting point, and includes among its objectives the help, care and counselling which will enable people to move to more independent living if they wish. But its emphasis on the freedom of residents to go to bed, come and go, and receive visitors as they wish, on the paramount need for single rooms and privacy (and double rooms for married couples when possible) and on the advantages of small group living, perhaps shows as much where it is coming from as where it is now or where it hopes to go. Although it is also developing family support services, the Foundation is clear that the need for residential care will continue.[17]

Other agencies have also made often striking attempts to minimise the restrictions of institutional living. Boundary Road, the London Borough of Camden's home for younger disabled people, aims to provide a care service which amounts to no more —and no less—than the availability of arms, legs and bodies to do what residents would do for themselves if they were able. The Spastics Society's Neath Hill development at Milton Keynes, which provides 24 flats scattered through ordinary housing and an on-call care assistant service backed by full-time staff, is an attempt to make Part III accommodation as 'uninstitutional' in appearance and content as it can be. But as Dartington, Miller and Gwynne show in their assessment of the early days of the two schemes, Boundary Road's approach raises issues of where the power and authority really lie as between residents and care-staff which are not easily solved. The Neath Hill development they characterise as 'enlightened guardianship': the residents do not equip their own flats or pay their own bills; they remain dependent on the derisory 'pocket money' rates of State benefits; getting into the scheme involves a process of assessment far more demanding than anything that an ordinary tenant would be put through; getting out is not so much a question of quitting as applying for a transfer to another link in the caring chain. The 'essential infantilism' of Part III accommodation, in short, remains.[7]

And meanwhile, many other residential establishments are not making these attempts to combine the maximum of self-reliance for their residents with essential care services. They may refuse to allow people to live together under their roofs; they may impose a series of rules or more subtle sanctions which govern the hours of getting up, going to bed and coming out and in; they may not allow their residents to handle their own drugs; no smoking signs may be put up in the living room. The residents do not, very often, see them as home.[9]

The nine people around whose lives this study is built do not see residential establishments as home, either. If there is any unifying factor in their decision to establish and maintain their own place, it is their rejection of institutional living. For the six who have sampled this, often over a period of many years, its limitations are only too apparent. For them, and for the others as well, the possibility of ending up in a residential home is very often one of the spurs that keep them going during the difficult patches that independent living may bring.

THE STUDY

The individual shape of independent living is what this book describes and it seems important at the start to define what it means. Five out of the nine people whose lives are described cannot move without help; three of them cannot eat unaided. So to talk of 'independence' in the most usual sense of being able to cope without help with the normal activities of daily living would clearly make no sense to them at all.

But independence they nevertheless have, at a more subtle level – and one which, if we reflect on the dependence we all have on the water workers, the gas and electricity people, those who sell us food and a host of others as we go about our 'independent' lives, is a sight nearer the truth of the concept. As Margaret Wymer puts it, 'We're not independent, but we are responsible'.

This is a definition that people with disabilities are recognising and asserting in other countries as well. It is one on which the Center for Independent Living in Berkeley, California, bases its own approach – and on which the 60 or more centres across the United States which it has spawned are built. As one young man, blind and with cerebral palsy, who lives on his own in Berkeley says: 'Sitting at home as a younger kid, it was one of my fantasies that if I could learn to cook for myself or dress myself, then I'd really be on the road to independence. But for me, that's really not what independence is. For me, it's on a larger scale of knowing that I live in this apartment. It's my territory. I have a say. I don't have to ask anybody but me'.[18]

So the people whose patterns of living make up this book may depend on an often considerable input of help, from paid and unpaid others. But they have all broken through to the third option. The main source of that help is *not* that of 'able' relatives: we deliberately excluded from the study people who drew extensively on that help. There is one partial exception, in that Diana Staples now shares her house with her mother. But it seemed right to include her. One of the hard things for people whose disabilities are very severe may be an inability to take part in the 'normal' pattern of mutual help between parents and their children, whose balance naturally swings as parents get older. Diana Staples and her mother are able, through the help provided to the household, to participate in that 'normal' pattern.

To spell out individual patterns of independence, dependence and interdependence, and the often very considerable energy that people must expend to perform ordinary daily tasks brings its own dangers. There is the risk that the reader will simply gasp at the achievement and move on, briefly comforted with the thought that such wonderful and even heroic people exist. The risk is inherent in the approach, as Irving Zola points out in his Prologue to *Design for Independent Living* which takes the living arrangements of individuals, this time in Berkeley, as the starting point for a comprehensive discussion of what independence for people with severe disabilities may demand by way of housing, aids and support services. 'To read the stories with awe and admiration', he says, 'is a mistake. If the reader stands in awe, it should not be of their courage, but of a society that makes their daily lives so awesome.'[18]

Yet 'aren't they wonderful?' attitudes abound. They had a fair outing during the International Year of Disabled People, as we were bombarded with stories of people who have 'overcome' seemingly impossible odds to find that job, perform a service for their community, raise funds for charity. To question the attitude is not at all to belittle people's real achievements, any more than to question the attitude's own 'isn't it tragic?' flip-side is to deny the reality of an individual sense of tragedy. But it is to suggest that the attitude is an essentially defensive technique, designed to put as much space as possible between the 'able' majority and the 'unable' other.

At a personal level, as the late Paul Hunt pointed out, the assumption that people whose disabilities are severe 'must' be tragic is an important strand in the majority's defence of its values of physical perfection, competition and material success – for if the people who challenge those values are nevertheless unimpaired in their essential personhood, where does that leave the majority in its striving? If those people obstinately continue to appear contented as they live with their imperfections, the challenge is the greater. As Paul Hunt said: 'When confronted with someone who is evidently coping with tragic circumstances, able-bodied people tend to deny the reality of the adjustment. The disabled person is simply making the best of a bad job, putting a good face on it. There may be some truth in this. But when it becomes obvious that there is also a genuine happiness, another defensive attitude is taken up. The "unfortunate" person is assumed to have wonderful and exceptional courage... This devalues other disabled people by implication, and leaves the fit person still with his original view that disablement is really utterly tragic.'[16]

This book tries to get beyond the easy assumptions to individual realities. So if 'aren't they wonderful?' is the readers' only reaction, it will have failed in its first intent, which is simply to present a series of people in their daily lives, whose ups and downs may have their 'special' tinge but whose essence is surely that of us all. As the Halls say, 'We are people first, and disabled second'. The point seems so obvious that we should perhaps wonder why so many people with disabilities find it necessary to emphasise it again and again in their dealings with their society.

It is in those dealings that the assumptions of tragedy and exceptional courage in the face of disaster bring a danger at a political as well as a personal level. Both assumptions serve to let politicians, bureaucrats and planners and providers of public support cleanly off the hook of examining just how society handicaps people with disabilities. If they are essentially tragic, after all, then no intervention can change that melancholy fact; if they are wonderfully courageous, then no intervention is needed. Mike Oliver's challenge is a fundamental one: 'Why does this image of disability as a personal disaster persist if it does not reflect the personal reality of disabled people? One possible answer might well be that to acknowledge that the problems of disability are caused by the failure of our society to provide disabled people with the economic and material resources to live life to the full, is to acknowledge our failure as a caring society. By continuing to see disability as a personal disaster we can justify our own failure, for after all, a disaster is a disaster, and nothing can compensate for such a happening. Can it?'[21] The second purpose of this study is to tease out how the reality of individual lives can become more full through the provision of a coherent system of financial and other support. If it rejects a blueprint for a 'disabled population' that doesn't in fact exist, it nevertheless explores, in the last section, the range of support on which individuals might wish to draw to create their own patterns of living.

But another disclaimer is needed. The fact that the book explores the third option for those patterns, the one that depends neither on the 'able' family nor on a place in a residential establishment, shouldn't be taken as prescriptive. The fact that the people who feature in these pages have themselves rejected residential care shouldn't be taken as a suggestion that everyone who has a very severe disability should metaphorically pick up their bed and walk out of the establishment in which they have been living. If anyone, after reading about the shape of these nine lives, takes it as a rod with which to chastise people who choose to live in residential care as lazy, weak or lacking in adventure, then the book will have failed again. At a time when anti-institutional philosophies are dovetailing so neatly with cuts in public expenditure, when what seems 'better' so conveniently appears to be also what may be cheaper, this point needs all the emphasis that the Wymers give it.

For some people, the search for alternatives to residential care will be nothing but welcome. The Union of the Physically Impaired Against Segregation, for instance, has anathematised all residential establishments as 'prison-like scrapheaps of this society', in which the isolation and segregation which oppresses people with disabilities finds its bleakest expression. But others argue for 'specialised living environments' as one important element of the choice that should be available for people who have severe disabilities, and emphasise the need to work – as the Cheshire Foundation, Boundary Road and Neath Hill are doing – on the context and content of those environments.[7]

The point is surely that people whose disabilities are severe should have choice in their patterns of living, that the third option with which this book is concerned should be added to, and not substituted for, the choice. The question is how real that choice can be, given the present inadequacy of financial and support systems outside the institution on one hand and the 'able' family on the other. Just how those systems have worked and are working for nine individuals and how the choice can be made real for others in future is what this book is about.

The People

Margaret and Jack Wymer

MARGARET AND Jack Wymer live in Norwich. He was born in 1930, she in 1938, and they married in 1967. They have both been involved in running the local club for people with disabilities, and now manage the Toy Library and holiday play scheme for handicapped children which they set up. He writes regularly for the local newspaper on disability affairs, and their autobiographical book, *Another Door Opens*, was published in 1980 by Souvenir Press.[28]

When, in 1960, Jack moved to Bishop Herbert House, Norwich's home for people with disabilities, he thought his life had reached its zenith. For the first time since he became an adult, he had access to different rooms in which to sleep, wash, eat and live. For the first time, he could get about independently. Arriving there was very different from arriving, at the age of 20, at the first of the two geriatric hospitals at which he was to spend the next decade. 'Sitting in the big ward full of old men on the first day', he remembers, 'I could smell a mixture of disinfectant and stale urine. I kept asking myself, "Is this really me?". I kept repeating "I am Jack Wymer" over and over again in my mind, because I couldn't believe it was happening to me.'

But there was no alternative to life in the chronic ward. When Jack had left his special boarding school at the age of 19, it had been impossible for him to return home. His father had died in a prisoner of war camp, and his mother was left with five other children, one of them also severely handicapped. He had lived for a year with his grandparents, but they were getting older and couldn't cope with his needs indefinitely. And after all, to make long-term plans for Jack's future seemed hardly worthwhile. When he left school, the doctors told his parents that he had only six months to live.

Then, and right up to 1974, it was thought that Jack had Duchenne muscular dystrophy. It was only in 1974 that his

Jack operating the Possum machine through a suction tube

condition was diagnosed as spinal muscular atrophy – a slowly progressive disease which affects all the voluntary muscles. For Jack, it has meant that his legs have never worked for him, and that he is unable to move his body; he has only limited use of his hands, and can eat unaided only if someone positions his hands for him and if the distance between his food and his mouth is short.

Bishop Herbert House offered Jack his first chance to borrow and learn to use an electric wheelchair – which meant that he could go as he wanted through the house and into the garden. The home offered him the chance to go out with friends, who pushed him to football matches, pubs, theatres and cinemas. It gave him the opportunity to work on the costume jewellery which added a small supplement to the income he got from social security. And it gave him, quite simply, his first chance for ten years to feel part of his community, as he watched the neighbours go about their ordinary lives and got to know them. There were no rules and regulations in the home; residents and their visitors were able to come and go as they pleased. The possibility of getting up late and staying up late seemed like privilege after the hospital routines.

And the chance of seeing Margaret regularly made the place seem the most he could ever hope for.

They had met six years earlier, when he was 24 and she 17, at the club for people with disabilities of which he subsequently became secretary. Their friendship had grown and deepened over the years. But that they would one day be able to marry, let alone have a place of their own, seemed outside the bounds of possibility altogether.

When Margaret was small, her inability to walk was vaguely diagnosed as the after effect of polio; later, she too was said to have muscular dystrophy, and later again, the diagnosis was changed to spinal muscular atrophy. Its effects are less severe for her than for Jack; she has more use of her hands and arms, if they are properly supported. But she too cannot use her legs or the rest of her body.

Between the ages of five and ten, Margaret went to a special boarding school for girls, where she learned the love of books that has never left her. By the time she left, she was already learning the shorthand and typing that she assumed would form the basis of her career. Her father's army career took the family about the country, and her parents at each new stop would seek out what specialist opinion they could find on their daughter. So after she left school, she spent a year in hospital in Bath, with the hope that its physiotherapy regime would enable her to learn to walk. When it didn't, she moved to a children's convalescent home in Great Yarmouth: 'Here', she says, 'my only education was that unfairness and cruelty did indeed exist in the world'.

When she was 13, Margaret returned home. Her father's new shift work as a bus conductor meant that he could help her mother with her care. But, she remembers, 'it was a difficult time for all of us. My brothers Michael and David were seven and six years old respectively, and almost strangers to me. The small council house seemed packed with all of us, compared with the accustomed spaciousness of the hospitals. I became quite hysterical when left alone indoors, and preferred sitting in the garden, even for hours on end'. But she adjusted to her new life, and settled down to enjoy her teenage. Then, when she was 16, she nearly died of pneumonia, an experience which gave the simplest details of her life a new meaning. When her mother became gravely ill during her fourth pregnancy, Margaret found herself taking on more and more responsibility for the household. Her sewing machine, books, and darning found their way to the bed in which she spent most of her time — and so did the food to be prepared for the family's meals and, after his birth, her youngest brother Gerry.

The early friendship between Margaret and Jack at their club deepened through her short spell at the hospital he lived in. But her attempt to move into the hospital permanently met with total opposition from her parents. The fabric of Jack and Margaret's courtship was woven from the letters they constantly wrote to each other and such occasional meetings as they could manage. But their chances of being together were so slight that there came a point when the letters seemed almost pointless. 'We felt strangely disillusioned, concluding that we had absolutely no control over our own destiny. This limited friendship was all we could ever expect. Handicapped people were moved around like pawns, to comply with the wishes of everyone else. They had no say in what mattered to them. That was the way things were – and there was no prospect of any change. What was the use of pledging ourselves to one another, when it was obvious that we needed a *normal* partner?'

After six years of only occasional meetings, Bishop Herbert House seemed all they could hope for. Margaret's brothers got used to pushing her the three miles between their house and the home once a week. Their social life was expanding – not least through the harmonica group they formed with Jack's sister Sheila (who also had spinal muscular atrophy and lived in Bishop Herbert House and who died in 1964, when she was 27). Jack cashed in all his savings to buy a second-hand van for £45, and Margaret's father would drive the three of them to their gigs in pubs and clubs. There was, for Jack and Margaret, even the occasional chance to go together on a special holiday for people with disabilities. 'And the future? Oh, if only we had lots of money!'

It was after six years of sharing as much of their lives as they could through Bishop Herbert House and their friends that Margaret asked Jack why they didn't get married. 'There was silence for a moment. Jack never answers quickly at any time! He stroked my hand thoughtfully.' 'Yes, well, I suppose there's nothing to stop us doing that much.' Getting married would, they knew, do nothing to change their circumstances. But it would seal their relationship to each other and it would declare it to the world. And it would also, as Jack said, make it harder for people to separate them.

The Wymers married in July, 1967 – and the £50 grant from the local muscular dystrophy society that bought them two week's honeymoon at a WRVS home in Surrey seemed more good fortune than they could have dreamed of. When they returned, Margaret went back home; Jack went back to Bishop Herbert House. For a year they met once a week, as they had done before their marriage, and then twice. They dreamed of being able to live together, but they saw no way of that being practically possible. They knew of no

The tray on Margaret's knee holds the gadgets she may need

precedent of a couple as severely disabled as they setting up a home of their own; they knew of no residential home to which they could move as a couple. They had very little money: even after their marriage, their careful savings, from Jack's jewellery-making and Margaret's lavender bags and the other small home-works of the past years, amounted to no more than £150.

But when Jack's social worker asked him if they'd like a flat of their own, Jack replied: 'You give us the chance!' It began to seem as if dreams and reality might not always be so far apart. They had already met Elizabeth Barnes, then assistant director of welfare for Norwich, whom they remember today as the person who was 'willing to put her trust in our limited abilities and to take a risk', the person who made possible the life they now have. The reality of how much they could learn to cope for themselves was tested at Mary Marlborough Lodge, the assessment centre in Oxford*, and if at the start of their first visit there they were overwhelmed at the enormity of their aspirations, by the end of their second they were finding out that what seemed impossible doesn't always turn out that way. They both acquired electric wheelchairs of their own, and Jack, whose frustrations at being able to contribute so much less to their life together than Margaret had been growing greater and greater, discovered that with a rubber-tipped stick he could use an electric typewriter, which he bought at the special discount price of £25.

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*This is where Diana Staples works, see page 63.

It was 18 months after the subject of a flat was first seriously broached that Elizabeth Barnes – constantly prompted by a stream of letters from the Wymers – came up with what was to prove the place they needed. Getting that flat built, adapted and ready to move into took another year. 'When the weather was good', Margaret remembers, 'Jack and I sometimes left the hostel in our powered chairs, to view the site together. We would take a camera expectantly, perhaps to find that only five more layers of brick had been laid. One day a workman posed on his scaffolding for a photograph, when we thought that perhaps an action picture might be more acceptable.' But their home slowly came together. The furniture was boosted by a spin dryer, a fridge, carpets, an electric tin opener, a Baby Belling oven and hotplates and an electric hoist. The bill for that lot, together with the house adaptations, came to £800. The Round Table gave £600, the welfare department found the rest. In time for Christmas, 1969, the Wymers moved in.

The next couple of years, they say, were spent in simply surviving. 'We had', Jack says, 'to live for ourselves. It is not until you get your own house in order that you can begin to look outside.' They were fiercely independent, needing to prove that they could cope – as they had ever since they sensed at Mary Marlborough Lodge that the more they could do for themselves, the more likely they were to get a flat.

But once their house was in order and their life securely enough established, they learned to accept help when they needed it. Then they could begin to look outside, towards making their own contribution to their community. Their search for satisfying work was frustrating; when Jack was offered the chance of trading his secretaryship of the club for full-time, paid, clerical work, he reluctantly decided that a regular job couldn't offer him the flexibility he needed. But when they heard of the Toy Libraries Association, it seemed to them that Norwich's children could do with a library – not just handicapped children, for the Wymers had had enough of the effects of segregation in their own lives – but their brothers and sisters as well. Within six months, and with the help of friends, the Wymers had raised £300 and got a steering committee together. The social services department offered them the use of a room in its new centre for people with disabilities on one day a fortnight.

Now, the Toy Library has upwards of 200 registered users and about 40 children usually come to its weekly afternoon sessions; in the morning there is a playgroup for up to 16 handicapped children. Margaret and Jack find themselves not just coordinating the project, but advising parents, and putting them in touch with other sources of help. They also run a playscheme for severely mentally handicapped children on two days of each week of the Easter and summer holidays – a venture they took on at the suggestion of, and with the backing of, the social services department. They find themselves giving talks about the schemes to student nurses and others.

They take delight, too, in watching their friends' children growing up as well as feeling it a privilege to share with many parents the ups, downs and sometimes tragedies of their children's lives. They enjoy watching the birds on their birdtable, making their own wine and growing tomatoes; they enjoy going to the theatre, collecting stamps or simply listening to music, listening to the radio or watching television. 'In many ways, since coming to this new life', they say, 'we have been greedy for experience. Perhaps we were simply wanting to make up for lost time. Yet we know that without those lost years, today would not be so satisfying. Despite our voracious appetite for life, and all it brings, we still relish every morsel slowly and gratefully.'

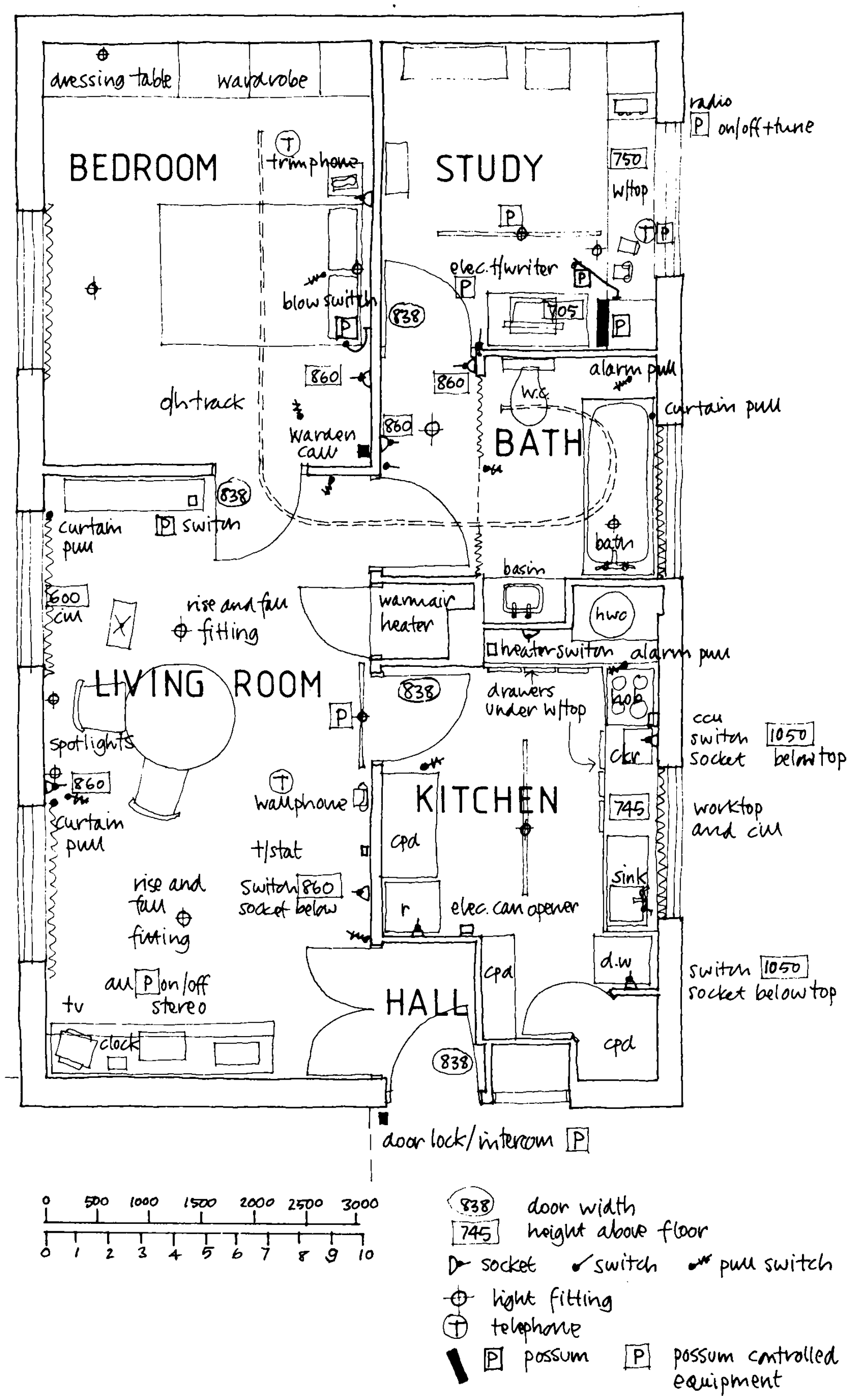
THE CONTEXT OF LIVING

Housing

The Wymers' two bedroomed flat was not designed specifically for people with disabilities, but is on the ground floor of a small council housing development on the edge of a sheltered housing scheme for elderly people. In one direction, it just misses looking out on the accident and emergency entrance of the Norfolk and Norwich hospital; in the other, it looks on to an attractive terrace of older housing.

The main alteration to the original plans is the positioning of their bedroom, which was intended to be opposite the bathroom; that arrangement wouldn't have allowed the space for a wheelchair to turn into it. The bedroom now opens directly off the living room, and the corridor to the bathroom and second bedroom – which has become Jack's study – has a door to close it off from the living room. There is a curtain across the bathroom itself. All the doorways were doubled in width, and the doors have kickplates on the bottom.

The least satisfactory aspect of the adaptation has been the relationship between the bedroom and the bathroom. The overhead track for the electric hoist runs through the living room between the two – which means first that there are gaps above both the bedroom and the bathroom corridor doors, and second that the Wymers have no privacy to go between bedroom and bathroom in their hoist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spotlights
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curtain pull
wallphone
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745
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switch 860
socket below
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switch 1050
socket below top
HALL
clock
cpd
838
door lock/intercom P
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0 1 2 3 4 5 6 7 8 9 10
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socket
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pull switch
light fitting
telephone
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P possum controlled equipment

if there is someone in the living room. They sometimes wish the arrangement could be changed.

The kitchen surfaces are all at a workable level for someone in a wheelchair, with drawers below them – as there are below every possible surface in the living room. The fridge is installed at a convenient height.

Finally, a detail that no one thought of until the Wymers pointed it out. The windows have been changed so that the bar which originally ran straight across them at their eye level no longer obstructs their views; and the kitchen window has been lowered so that Margaret can look out on the birdtable when she is working in the kitchen.

Aids

The aid that has made the most difference to the Wymer's life is the Possum machine, which Jack got in 1974. Before that, he was very dependent on Margaret; she was the one who had to open the door and answer the telephone, whether she was in the middle of cooking or not. But with the Possum, Jack can open the front door, and turn radio, television, lights, taperecorder and his typewriter on and off. Most important of all, he can answer the telephone and use it independently, instead of relying on Margaret to do the first and using it through the loudspeaker that the social services department had installed. He operates the Possum through a suction tube from his study or the bedroom; there is also a switch in the living room which Margaret can use.

Other aids are less spectacular, but for Margaret not much less useful. As well as the electric tin-opener, she has a stand which enables her to pour from the kettle without lifting it. She has two pairs of tongs which help her lift things – one for reaching the floor, the other for shorter distances. And the tray on her knee on which they sit throughout most days also holds a pair of scissors.

Finally, the flat is fitted with an alarm system that runs directly from the bedroom, kitchen and bathroom to the flat of the warden of the sheltered housing scheme next door.

Help with routine

Jack and Margaret wake early and hate to lie in bed in the mornings; their usual getting up time is around 8 am. It takes about an hour and a half for them to wash, go to the lavatory and get dressed and set for the day. They have their main meal at midday; Margaret may shop for this at the local shops, which are only five minutes away. Their toilet routine in the middle of the day takes half an hour. They go to bed at about 9.30 pm.

The Wymers both need help with every part of this routine. Once they they are in bed, they cannot move at all on their own. Once they are in their clothes and their chairs, they cannot get out of them without help. They need assistance to use the lavatory – although the handle on Jack's specially-made urinal enables them to meet most of his needs during the day. Margaret is a health-food enthusiast and enjoys cooking; the meals on wheels they used to get came to an end because they didn't reach their standards of what food should be. But it takes Margaret, as it always has done, five minutes to peel a single potato, and her hands go limp if she uses them too much.

With limitations like this, as Margaret points out, the Wymers are hardly 'independent'. But they are responsible for their lives. To keep these going, they need 22 hours of personal help a week – three each day, with the extra hour for a bath once a week – and an additional six hours domestic help. They generally have six helpers at any one time.

Right at the start of their life in their flat, Elizabeth Barnes suggested that their biggest problems might arise from depending on too few helpers. There was the sheerly practical question of having enough people to call on in emergency, or if a helper fell sick. But there were also psychological considerations: it was essential for no one helper to feel that she or he was carrying too great a responsibility for the Wymers' care, and essential, too, if relationships were to remain as tension-free as possible, that helpers should feel free to leave when they chose. So, over their dozen years in the flat, the Wymers reckon to have had about 20 different helpers.

Some have been long-serving – like Trevor, who first met Jack when he was a nurse in one of the hospitals Jack lived in, and has been coming once a week to put the Wymers to bed for the entire 12 years; he and his sister Thelma, who does the same twice a week, are among the Wymers' closest friends. Margaret's youngest brother Gerry, who works just round the corner in a hostel for homeless young men, comes in most middays and on two evenings each week. Pat has been getting them up on four mornings a week for seven years. Others stay for longer or shorter periods, recruited through a card in the post office window, or through the local press.

As well as their personal helpers, the Wymers used to have a home help for two hours on two mornings a week. But the arrangement was unreliable. The days on which Margaret had prepared the washing tended to be the days when, without warning, the home help didn't turn up at all. Their dissatisfaction came to a head in 1980, when they were informed they would have to pay for this service. They refused in principle to do this; 'we knew how the charges would affect elderly people'. They also felt that if they were going to pay for domestic help, they should at least have some control over what their helpers did and when. So they simply ignored the letter about the charges. The next they heard from the council was a letter saying that as they hadn't paid for two weeks, the service had been withdrawn. They wonder how many others, more vulnerable than they, got that letter, and how many others didn't receive a visit to check their circumstances before it arrived; they are, as they point out, fairly well known to the social services department.

Now the Wymers have a special domestic help allowance under the supplementary benefit scheme; this enables them to buy six hours' help a week. Pat helps with additional household chores. Helpers and friends cultivate their garden.

The exactness of Margaret's culinary arrangements is one illustration of how carefully life must be planned and of the help it demands. On Saturday evening, a friend or the evening helper will prepare a load of vegetables, which Margaret cooks in a large pan on Sunday, and which they eat with meat that day. There is enough left over for Monday's main meal. On Tuesday, Margaret makes a pulse soup, which they have with wholemeal bread. On Wednesday, it's either liver or omelettes, both of which are easy for Margaret to cook; Pat prepares vegetables to go with this. On Thursday, Margaret's mother visits with a by now traditional homemade meat pie and they have risotto – again, easy to cook – or omelettes. On Friday or Saturday there's another tradition: Gerry's curry. The meat pie takes care of the other main meal. Tea, throughout the week, is lighter: a sandwich, egg or salad. Apart from the food that Margaret herself buys at the local shops – which is expensive – most is bought by a friend at a supermarket; she collects next week's list when she delivers this week's order.

'You act confident', Jack says of the arrangements for helpers, 'but it's a dodgy business'. It used to seem like the end of the world when a helper left; it's hardly that now, but when it takes a new one at least three months to master essential details – like exactly how to position Jack in his hoist – change brings its stresses. It is tiring, as Margaret points out, to have to explain each detail, and to remain friendly and patient however often you do it. Lack of change can be tiring too. There have been a couple of helpers who stayed up to three years whom the Wymers just didn't like. But they needed them.

The routine brings its need to compromise with more than compatibility. At the moment, the Wymers get up at 9 am on four mornings a week, which is far later than they'd like. But Pat has to take her child to school before she comes in, and after seven years of help and friendship, as Jack says, 'you repay faithfulness with faithfulness'. In the same way, the 9 pm bedtime is geared to suit the helpers rather than the Wymers' own preference. 'It's all', says Margaret, 'part of living'.

The Wymers know they have many friends and ex-helpers on whom they can call if their arrangements go awry. They know too that the warden of the sheltered housing scheme is available. She has been in on one memorable Sunday, when Margaret tipped their entire roast lunch on the floor between the kitchen and the living room, and it just lay there congealing into an insuperable barrier between her and the rest of the house. She has brought hot soup during power cuts. She came in during the night when Margaret had a severe cold and needed someone to help her cough. (It was when she had the third bad cold in a year that someone for the first and only time came and slept in: Gerry spent one night at the end of the Wymers' bed.)

But they make as little use as they can of the backup service the warden can provide, and they don't take up other help the sheltered housing scheme could offer either. They preferred, for instance, to buy their own washing machine and drier than to use the drier over there. And they use the phone rather than the alarm if there is anything they need. They prefer the warden to know that if their alarm does ring in her flat, it signals an emergency which has quite literally to do with life and death.

Getting about

Their DHSS electric wheelchairs give Jack and Margaret freedom of movement within their house, and she can use hers to get about outside. The way to the local shops is completely accessible, if she goes the long way round, and the shopkeepers will bring goods to the door if she can't get in for them. The Wymers live only about 15 minutes from the city centre; with a friend to push Jack, they can go in their chairs to the main shops or the theatre. Each Saturday that Norwich City plays at home, Jack faithfully goes with friends to cheer them on, on the field and in the pub.

Since 1976, the Wymers have had a dormobile with an electric lift, which can take two wheelchairs. They hold this van from the Possum Users Association for people in Norwich who would benefit. The association is responsible for insurance and tax;

the Wymers maintain it and lend it for the cost of the petrol. They themselves have a rota of four or five drivers, and they use the van for getting to the Toy Library; it has also enabled Margaret to go to adult education art classes for a couple of terms, and makes possible more frequent visits to the theatre.

Because Margaret and Jack need so much help, and because their budget is tight, holidays have been infrequent. But they have been to stay with friends in their completely unadapted house in London.

Finances

When the Wymers' flat was first ready, they were in a fix. They couldn't move in until they had the money to keep them there, and they couldn't get the money to keep them there until they moved in. Fortunately, a three-week advance from a charity enabled them to break the bureaucratic deadlock.

In fact, the rulings that govern the financing of support systems were not so rigid then as they have since become. Though now it is possible for supplementary benefits to cover the 'reasonable cost' of visiting domestic help if this is not provided by the local authority and to provide up to £37.20 a week for live-in help, it was then possible for Elizabeth Barnes to negotiate for supplementary benefits to cover the Wymers' particular system of helpers.

Their weekly income amounts to £130.12* plus mobility allowance. Their non-contributory invalidity pensions yield £28.40. His attendance allowance at the higher rate, hers at the lower ('because I can pull a cover over him!') bring in £39.40. The rest of their income comes from supplementary benefits, which pays their rent, rates and heating allowances, and makes up the deficit on domestic and helpers' payments. This doesn't happen automatically, however; every time pensions and allowances go up, the Wymers' supplementary benefit is docked accordingly, until they apply to have the cut restored.

Not far short of half the Wymers' income – just over £56 a week – goes on employing their helpers; the basic rate is £1.60 an hour plus 50p fares for each visit, but there is also overtime for morning, evening and weekend visits. Other costs of disability are high, too. Heating is important; Jack cannot eat unaided if his hands are cold. Clothes get easily worn; £5 is set aside each week for mail order. The washing machine and fridge are essential pieces of equipment, which must be maintained and replaced if broken. The heating allowances do, the Wymers reckon, cover their heating

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* At 1981-2 rates.

costs; the social services department pays the telephone rental and the DHSS maintains the wheelchairs. But after essential bills have been met, there is £25 a week left, of which £17 goes on food. It is the £33 a week brought in from the Wymers' mobility allowances that enables them not just to run and maintain the van, but to go on outings, decorate and improve the flat, and have a certain flexibility for emergencies when they need extra help.

* * *

The Wymers feel strongly that nothing in their story should be taken to say that people with disabilities 'should' live the way they do – or to chastise them as 'lazy' if they opt for residential care instead. But they also feel that residential establishments should do a lot more to help people gain responsibility in their own lives – and that authorities should do more to make it possible for them to exercise it as they choose. That responsibility, they feel, is something that Margaret had in her own family life from the age of 17; it is something that Jack, after 20 years and more of institutional living, had to learn.

What the Wymers would like for themselves now is the full-time employment that would enable them to pay their own way. They are dreaming of finding a permanent home for the Toy Library, in its own building, which could become a centre for children and their families. They would like, too, to feel that there was a reliable back-up service to their own system of helpers – though they want to remain responsible for that system and not to turn it over to the local authority. They would like it to be possible for all their helpers to do six months with them and then leave, unless there was mutual agreement that they should stay on. On some days they would like simply to pay an agency to work the whole business out for them. But on others, they wouldn't want anything different from what they have now.

The Wymers wonder sometimes what would have happened if they had not married and found the confidence and encouragement that they have been able to give each other. They remember how neither of them took proper care of their needs before their marriage, and they wonder if they would even be alive today. They have, they often say, been lucky.

Bernard Brett

BERNARD BRETT was born in 1935 in Northern Ireland. He now lives in Colchester, in Essex, in a house he bought in 1964, from which for the past 16 years he has run the Christian Action (Colchester Quaker) Housing Association, and latterly a housing advice service. He has been secretary of the local branch of International Voluntary Service and of the local Council of Churches; he is currently a member of the local community health council. He has an MA in social policy and administration from Essex university and is active in both the Disablement Income Group and the Disability Alliance. He has been awarded the MBE for his services to disabled and disadvantaged people.

Bernard with typewriter and alphabet board—vehicles of communication with the outside world

Soon after Bernard was born, doctors told his parents that he was 'mentally subnormal' and should be quietly put away. 'Fortunately', he says, 'my parents thought they could see a sparkle in my eye which suggested that I was not as "subnormal" as the doctors in their wisdom thought.' He does, however, have severe cerebral palsy, which means that he has no movement in his left arm and only limited use of his right, and that his legs don't work for him. It has also meant a lifetime's difficulty with eating and drinking, and a hard, and eventually abandoned, struggle to achieve intelligible speech. He now communicates entirely through an alphabet board and typewriter, spelling out words with that workable right hand.

These disabilities were severe enough to ensure that Bernard never went to school. Instead, his parents tutored him at home, while he tried to develop the speech that only members of his family and close friends could ever understand. When he was 12, he learned to read and write – and so to communicate with a wider world. His learning was bolstered by tutoring from student volunteers.

By the age of 17, it seemed increasingly important to Bernard that he learned to do more for himself, rather than remaining, as he now says, 'impaled in immobility'. 'I had practically no friends, let alone anyone of my own age group, and my only real way of passing the long hours of each day was either through going for walks around my home or reading the many books which enriched my life and gave me the broader horizons which have proved to be very useful.'

At this time, he was still totally dependent on his mother for nourishment, which brought its own considerable and lasting problems. 'I really disliked food and drink, as they were such a struggle. There were days and even weeks during which I could not make my throat muscles work, because of fear and nervous tension. This meant that I was very distressed – but also that I knew real agonies of thirst and hunger, with the added pain of knowing that however thirsty I was, I could not, at that moment, relieve it. It also meant that my mother was sure that only she could keep me alive. It meant a dependence on her which I detested and feared – and unfortunately ruined my relationship with her all her days, because I so deeply resented the power she had over me during those formative years.'

His brother and sister were able, in some ways at least, to dispel the tensions of this period; Bernard remembers how relieved he was when, during his adolescence, they took his side and pointed out to their mother that he was not as selfish as she claimed he was.

But as he grew up, his expectations of what his life could hold were very low: the choice seemed either to remain at home with his parents, or to move to a residential home, and neither prospect was attractive. It never crossed his mind that he could, for instance, go to London regularly or have the sort of control over his life that he has now.

But after a visit from a doctor who specialised in cerebral palsy and was appalled at the narrowness of Bernard's opportunities, his life began to change. After six months in Dublin at the age of 21, intensive speech therapy relieved many of the worst of his eating and drinking problems. A good psychiatrist put in a lot of the 'debunking and rebunking' which Bernard reckons he needed – showing him that he was indeed pretty self-centred and over-protected, but building up his self-confidence, too, to the point where he believed that, with help, there *were* things he could do.

Then, through a friend of his sister's who was a physiotherapist, he heard of Prested Hall, the Spastics Society's first residential home, near Colchester, and he moved in with 30 other people who also had cerebral palsy. He remembers his seven years there as a 'rich and difficult time'. He shared a room with four others – two of whom found it even harder to communicate than he did. Few of the others shared his interests – but with the help of the warden, he was able to exchange his basket-making for the study of politics. And he met women who convinced him that he was not as unloveable as he had feared. He sums up this period: 'I lived and loved and passed my matriculation exams – and grew up'.

Grown up, he wanted to start playing a real part in the life of his local community and to meet more people; he also had the ideal of starting a Christian community. Prested Hall was hardly well placed for the first – stuck as it was two miles up its own drive, in the depths of the country. He needed a house in which to explore the second. So in 1964, with financial help from his family, he spent £2750 on a large, detached house within easy walking distance of the centre of Colchester. And with the invaluable help of a woman friend, he moved in. Most people, he says, thought he'd last two weeks. He's been there ever since.

The house may not have turned out to be quite the sort of Christian community that Bernard originally dreamed of. But it has become both a resource for people in housing difficulties and a refuge for those who are desperate for somewhere to lay their heads. It houses a dozen lodgers, who in its time have included political refugees, people who have left mental hospitals and distressed young people who have left their families. It has been home, for instance, for a nurse who was brought to despair by the discovery, at the age of 23, that she was going blind. It is currently home for a young couple aged 16 and their dog, alienated from their families by the fact of her pregnancy, and unwelcome elsewhere because of their situation and the animal they refused to part with. The house can cope with more immediate emergencies too: the sun-room is usually available for people who have simply nowhere else to go on a given night, until something better can be found.

The life of the house brings its inevitable and sometimes serious tensions. But from his room at the foot of the stairs, there's not many of its comings and goings that escape Bernard's attention and, if necessary, intervention. Meanwhile, there's also his work, and there's a fair flow of that, because it's known on the local grapevine that Bernard Brett is something of a fixer.

So on one recent day, there were the phone calls around a man who had recently left Rampton after 20 years, and was waiting for a probation order: where could he stay? There were the phone calls around the family who had recently returned to this country and had nowhere to live except a friend's house, creaking under the strain of fitting five adults and six children into three bedrooms. There was the visit from the young girl, driven by family tensions to seek refuge with her grandmother, needing someone to talk to about her boyfriend, her job, and her need for somewhere to live, and glad that someone else would take on the business of advertising for rooms and vetting the replies to weed out the more suspect ones. There was the visit from the woman who had finally, after nearly 30 years of physical and mental abuse, simply packed a suitcase and left her husband, and who was still stunned by the enormity of her action. Where could she live? She couldn't, she felt, go on imposing on her sister. How could she regain custody of her daughter? She couldn't contemplate leaving her with her father.

His lack of speech can seem almost an advantage to Bernard in his work. As he says, he has good control over his spelling – good enough to leave the untutored eye way behind his pointing finger. This control of the board, he feels, gives him control of the situation – and the advantages of escaping any class or regional pigeonhole that a voice might land him in. And certainly, when people come to him in distress and confusion, there's only the smallest flicker of initial embarassment as they discover that his gently probing questions and perceptive and humourous comments are going to be bounced through an interpreter; it's the message that's important, not the medium.

He's got no hesitation, either, in making the most of the shock that his appearance and speechlessness can bring to people expecting someone else. 'If I have to be disabled all my days and have to put up with my strange appearance, then, my God, I want to put these disadvantages to whatever use I can.' To judge by the confusion of a first-time caller from the DHSS, at first sniffy when Bernard didn't talk to her direct on the phone, then embarassed when she found out why, there are occasions when catching people off their official guard can have its uses.

THE CONTEXT OF LIVING

Housing

There is little to distinguish Bernard's house from others in the road. When he moved in, he had the plumbing redone and central heating installed. But the only 'special' adaptation he made was to have the downstairs bathroom enlarged for his own use. (The lodgers have their own, upstairs bathroom as well as a separate upstairs kitchen.) Bernard himself lives in one, ground-floor room, which acts as bedroom, living room, dining room and office.

There are only two pieces of 'special' equipment in the house. The first is the amplifier attached to the telephone, which enables him to listen to calls while his interpreter holds the receiver and speaks for him. The second is Bernard's chair – an armchair on castors, which his father made for him 30 years ago, and for whose endurance he fears, because he doesn't see that it could ever be replaced.

There are no pulleys, hoists or other aids to mobility. This was a deliberate decision on Bernard's part, but one which he himself sometimes questions. 'My body is a bit funny and as I can't tell people if they put slings on wrong, I would find that rather worrying. But it's a great failing on my part, as I could cut my staff quite a lot if I had mechanical aids. Or maybe not. I think most people would get very bored and lonely if they were the only helper. In a way, not being able to speak, I'm not very good company.'

Help with routine

Bernard stresses the importance of a stable daily routine. His day starts at 8 am, when he gets up, has a drink, goes to the lavatory and has either a bath or a wash: that takes an hour and a half. He then works until lunchtime on two days a week, with Anne, his housing association colleague, on other days on housing advice or, when the telephone and doorbell allow, on his own writing. Lunch is his only substantial meal of the day. In the afternoon, he tries to get out – either to shop (he does all his own shopping) or to visit people, or simply to get some air and escape the telephone. He has tea at around 5 pm.

One evening a week is given over to housing association work, again with his colleague. (What started as a single home for unmarried mothers has outgrown that purpose and scope to encompass 45 different housing units. The housing association caters specifically for people who would otherwise be homeless, providing, it hopes, a short-term bridge to more permanent accommodation. So apart from the sheer administration of the association, there is a need for constant liaison with local housing authorities.) The other evenings are free, and the day ends at about 10 pm.

None of this would be possible without constant help. It takes two people to lift Bernard, whether to bathroom, to chair or to bed. Easy communication with his visitors and any at all with his telephone callers depends on having an interpreter to hand. His food must be prepared, minced and fed to him, as must his drink. Every trip out of the house depends on either one man or two women to push his chair. So Bernard's helpers are an ever-present and intimate part of his life.

There have been permutations enough, over the years, to ensure that they are there when needed. The woman friend who made it possible for him to move out of residential care in the first place stayed with him for a year; the first of his series of housekeepers was a couple who had a child with Down's Syndrome. Since then, the housekeeper who stayed for ten years provided the greatest core of stability the house has known; most helpers stay for a year or so.

The ideal is that there should be two of them working full-time with one working part-time to cover weekends and evenings. It hasn't always happened that way, and there is a constant balance to be maintained in the selection of lodgers between those whose need for housing is desperate and those who can help out in an emergency. At the moment, as it happens, Bernard has more help than he has ever before had at one time. Sue and Debbie come in every weekday between 8 am and 6 pm; both live locally, which Bernard finds a far healthier arrangement than having someone live in the house. Fiona is a lodger who works for him at weekends. In addition – as an experiment and possible insurance policy against the day when local help dries up or he cannot afford to employ people — there is Tom, a CSV One-to-One Volunteer*, who lives in and works five days a week, mostly in the afternoons and at weekends.

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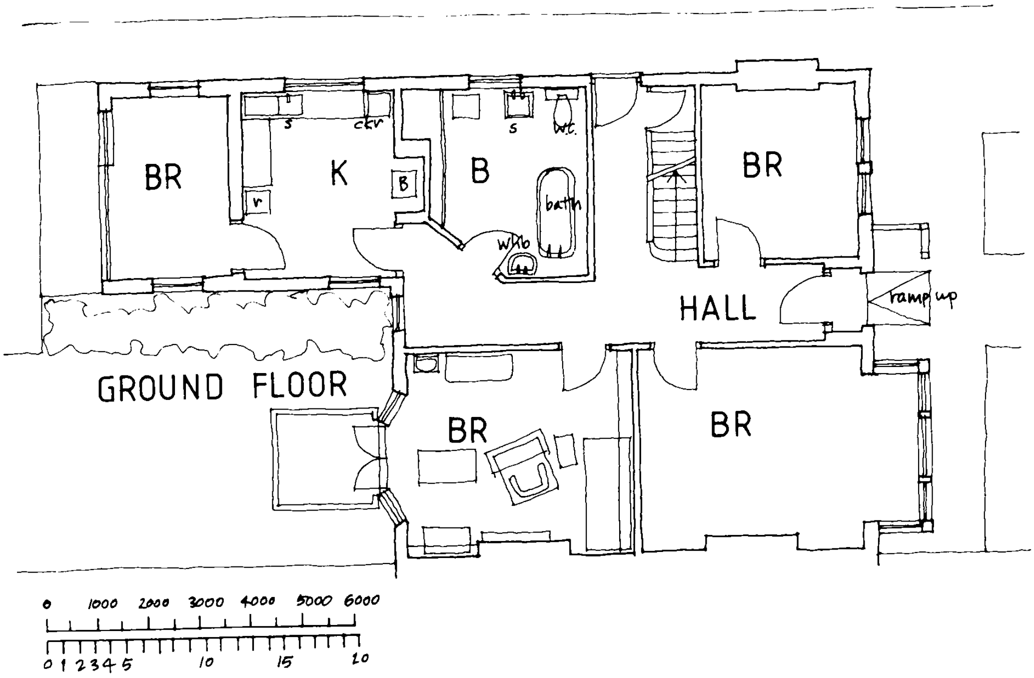
* See the final chapter for a description of this scheme.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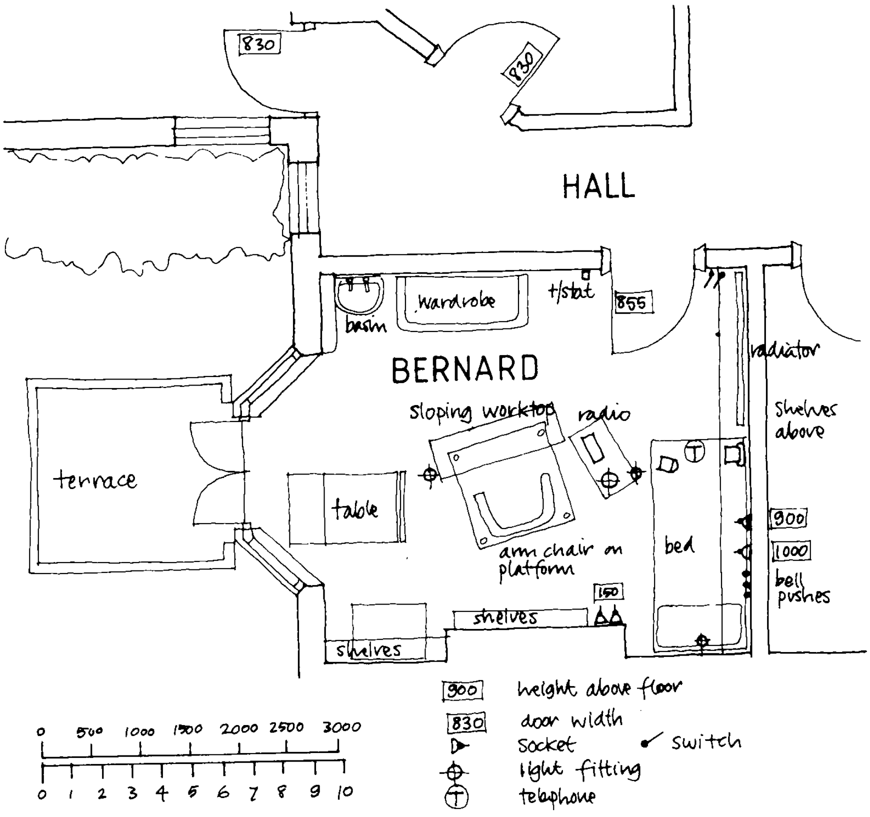
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Whether this pattern will last and what will succeed it is as uncertain as any arrangement has been since Bernard moved to his house. But one thing he has learned over the years, and that's just how important it is to have enough help at all times. 'Nothing is quite as corrupting for all concerned as being completely dependent on too few people. This also tends to exhaust the helpers, who feel under too much strain, and can lead to the risk of various kinds of abuse. I can promise you, there are few less pleasant things than to be cared for by somebody who is constantly tired and under too much strain. This makes life tense, unpleasant and unfulfilled.'

Getting about

Meetings locally and in London and, more occasionally, beyond, are part of Bernard's life. Outside the house, he uses a standard DHSS-issue wheelchair – a model which again brings worries about endurability, because it's no longer made. The substitute is designed, so its makers say, for house, patio, and garden; a liking for rough country walks is apparently not supposed to be part of the life of someone with Bernard's degree of disability.

For travel, he has a camper, which has been fitted with a hoist. To live in, it's hardly practical for him, but it serves as a van. He actually prefers to travel by train, because that way he meets more people; he has got to know a variety of guards' vans pretty well over the years, too. He's also got to know which London underground stations have few enough steps to be negotiable. And he's learned that with two strong helpers and a willingness to rope in passers-by, destinations which might seem quite inaccessible are more possible to reach than they might appear.

Finances

Each time he works out how much he has to live on, Bernard says, he gets a nasty shock.

His income amounts to some £8600 a year. Attendance allowance at the higher rate and mobility allowance between them yield just over £2000 of that.* After many years of working voluntarily for the housing association, he is now paid £2400 as a part-time employee; this salary replaces the allowance he used to receive from his family. In addition, he gets about £1200 income from investments and £3000 from rents.

Not far short of two-thirds of this entire income goes to

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* At 1981-2 rates.

paying for help— over £5900 at present levels.* The bill for helpers would be even higher if the weekend one didn't get a free room (worth £15 a week) in lieu of pay, and the CSV got a full wage rather than the agreed 'pocket money' of £24 a week and his board (plus, however, a £10 a week payment to CSV for this service). The two full-time helpers get £90 a week between them. With a household of 13, heating bills are a major additional expense— about £500 in a winter quarter. Rates, with rebate, amount to some £140 a year.

★ ★ ★

There have been periods in Bernard's life when the sheer living of it has almost ceased to be worthwhile at all, when work has seemed without value, friendships empty and his God beyond his understanding. Twice, he has seriously attempted suicide. 'Sometimes I see no prospect of getting a better and less lonely life-style. I have found that depression may be one of my greatest enemies, as when I have no energy or drive, things pile up and my arrangements get more muddled.' He still sometimes, he reckons, needs the good 'debunking and rebunking' he got from that Irish psychiatrist.

But bouts of depression are, he reckons too, normal enough. On the whole, he feels that things work out quite well. He doesn't minimise the difficulties. There are the constant adjustments that his life-style brings, the balancing of the advantages of a changing band of helpers against the fact that it takes a new one six months fully to master his routines. There are the inevitable incompatibilities. 'Even if I really dislike someone I am usually able to disguise it, but I do get very irritated by some people, which gets very hurtful to them, and I feel bad about it too. It gets very difficult if physically I am not keen on them, as they don't see why I don't want them to handle me, and I can't very well tell them.' There's the need to construct some privacy in a life which by its nature must have little of it. 'I tend to be rather secretive, which my helpers find very difficult, but I think it is a defence. I may be over-warm in some ways and over-distant in others, but it's hard to keep a balance.' There's the difficulty of starting and sustaining intimate relationships within this setting; his marriage was unhappy and short-lived.

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*At the beginning of 1982 Bernard managed to reduce his bill for helpers by £45 a week, by reducing the paid help to one full-time plus his CSV.

Bernard's room is bedroom, living room, dining room and office for his housing work

There's a considerable restriction on wider social opportunities, too, when finance is so very tight and the sheer cost of travel has to be set against the inevitable demands on the budget, when the assurance of additional capital to come has to be set against the knowledge that repairs costing £3000 need to be done on the house right now. The social restrictions aren't just the kind that more money would dissolve either. Bernard has visitors enough, but it was only after four years in his house that he was invited for the first time to someone else's. (One of the things which attracted him to the Society of Friends was their openness to friendship; he became a Quaker, characteristically, on condition that he remained a member of the Churches of Ireland and England.) Even now, he is reluctant to share meals with others, because he is unsure whether they can really be easy with his difficulties in eating, and this limitation he finds sad. But he sees it as his job, too, to keep oiling the wheels of friendship: 'when one is reasonably lively, one is attractive to people.'

So difficulties, restrictions and sheer hard work there inevitably are. But there would have to be a lot more of them before they began to outweigh the advantages. Community living can bring its gains as well as its stresses. For a start, 'if someone happens to become over-stressed and starts to ill-treat the disabled person, or the latter exploits overmuch the helper, there are enough people about to be aware of what is going on and to exert community pressure'. And what is the likely alternative to community life?

As part of his MA thesis, Bernard spent time in units and homes for 'the younger chronic sick' and he has no doubts at all that life in such places is out of the question for him. Yet he knows how easily he might have ended up in one. 'There is little doubt', he has written, 'that if I had accepted the advice of social workers and medical men, I would have allowed them to admit me to a ghastly hospital unit for the younger disabled, cut off from the community, unable to assist many hundreds of families in distress or hardship through homelessness, sickness, or other forms of social handicap. I would also have cost the taxpayer, or ratepayer, about £9000 a year to keep me in a hospital bed, which would have been a form of living death.'*

That he is now able to earn a living of sorts, pay taxes and lead a relatively full social life, he puts down mainly to the fundamental fact of having the security of his own house. Although he knows that his particular form of community living would not suit all the people all the time, he feels strongly that many more people with severe disabilities should have the chance to find the security of their own house in their own way.

Clearly, as he says, buying will be out of the question for many, as even if they find employment, they may have great difficulty in getting a mortgage. But, he suggests, there is a very strong case for local or central government, as well as voluntary bodies, making access to that fundamental security possible. It could be done through a special Housing Corporation fund which made loans to, or arranged mortgages for, people who have severe disabilities. Or, preferably, home ownership could be recognised as a right—a form of positive discrimination which could help many thousands of people with disabilities to find a real place within the community. This could be realistically done through the Housing Corporation, or perhaps through a specially-created fund, similar to the Family Fund which channels central government money to the families of children with disabilities, if local authorities were unwilling to provide the necessary accommodation, services or security. 'Such a programme would almost certainly be a better national investment than having thousands of people with

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* See Bernard Brett's chapter 'The Meaning of Disability' in *Disability in Britain*.[27]

disabilities living in unsuitable and restrictive residential centres, or in units for the younger disabled, at vast expense to the public.'

This sort of arrangement, Bernard argues, would offer the security that brings opportunity. It could also offer, as his house has for him, the security that makes it possible to look to new opportunities for the future. He is wondering now about the possibility of selling his house and moving either to London or to Northern Ireland, where, he feels, there would be more opportunities for imaginative hard work in housing and the creation of community. (A major disincentive, however, is the sheer cost of moving – which he reckons would be double what an able-bodied person could expect. A 'really sensible' grant to help people with disabilities move home, he reckons, would enable more to use the asset their house represents to the full.)

In the end, however, he remains optimistic. 'In my situation, there is always the prospect of possibility of change. I can look out for possible new friends or helpers. And I know deep down that the difficult patches do pass.'

In a talk to an Easter meeting of the Corrymeela community in Northern Ireland, Bernard once said this: 'Some persons, very close to me, often tell me that if they were in my boots, they would rather be dead than have to be so completely dependent on others for their every need. Maybe they do have a very valid point, and I am sure a great many people may think this privately, even if they can't say it in as many words to my face. Yet I cannot deny that most of the time, I am proud and happy to be just plain me. I know I am a stinker of a person in many ways, as well as being a real humbug in other ways. But I am sure that we are asked by God to accept ourselves just as He accepts each one of us. I believe that each of us has a task given to us, whether it is great or humdrum. We have the opportunity to do the will of God and for myself I pray that I may be given the strength to serve my Maker as best I may.'

Joan and Robin Dawe

JOAN AND Robin Dawe live in Chinnor, in Oxfordshire. She was born in 1935, he in 1934. He works part-time from home for two local garages. She has been a receptionist and switchboard operator and is a founder member of the Spinal Injuries Association. Both are very active in local affairs, and offer counselling and advice to people with spinal paralysis.

When Joan found herself, at the age of 25, sharing a room and a commode with eight elderly women, in a private residential home whose origins as a barn were only too evident, she thought that this couldn't be all life held for her. When, after three months, she moved to a private nursing home, where she and four other people ate, slept, were washed and toileted in just one room, she thought 'I won't be here for ever'. They had told her at Stoke Mandeville, after all, that she would be lucky to live for seven years. And that was easy for her to believe. She was severely paralysed and almost totally dependent on others; she couldn't even control her bowels or bladder. It was a psychological impossibility, she says, for her to work anything out. She simply lived from day to day.

Five years earlier, Joan had broken her spine in a diving accident in Kenya, where she had grown up. The high break (C6 complete) means that though the top of her arms, her shoulders and her neck work well enough, the rest of her body, from her upper chest downwards, is completely paralysed. Though she has some feeling in her first two fingers, she has no independent movement in any of them.

After three months in hospital in Kenya, Joan came to England. She did a spell in Hillingdon hospital—which was, she remembers, totally lacking in the expertise needed to cope with her serious injuries. Then, complete with heel sores and a bladder infection, she moved to the spinal unit at Stoke Mandeville, where she stayed for two years. It was decided before she left there that she would return to Kenya as soon as facilities there were prepared

to receive her. But between leaving Stoke Mandeville and leaving England, there were five months with her mother, who lives permanently in the North of England. She remembers the time in that upstairs flat, during which she never once got beyond its walls, as hell for them both. But the only alternative had been a home for people with cerebral palsy, and the prospect had horrified her.

She stayed in Kenya for a couple of years. It seemed impossible to return to her original job as a Post Office switchboard operator, or indeed to find any paid work; but she volunteered time in the office of the local Red Cross. Then her father had to cope with the after-effects of a heart attack and with the breakdown of his second marriage; it became clear that he couldn't cope with Joan as well. Which is how she found herself in those two English nursing homes.

Her time in a third residential home, the Cheshire Home in Dulwich, south London, lasted a lot longer; her assumption when she moved there was that she could look no further than the life it offered. After two of her eight years there, she married a fellow-inhabitant, who had had respiratory polio. It wasn't easy to live a married life in that setting. They were the first married couple the Home had had, and its routines weren't geared to the demands that makes. Though they had their own room, where they had their meals together, they felt a lack of privacy; there were tensions between them and the other inhabitants. But her husband was even more dependent on others than she was. There seemed no alternative.

Then a man who was also tetraplegic visited the Home, to play table-tennis. Joan was astounded to learn, when she asked him what his residential home was like, that he didn't live in one at all, but had his own place and ran his own life. 'If he can do it', she thought, 'why can't I?' She began to work towards independence from then on. She learned to cook in the Home's kitchen, whose surfaces and equipment were geared to people in wheelchairs. She learned, through the use of a suppository inserter, to take care of her bowels independently. She learned to drive a car. 'I could see a way of getting back to society, of being a normal, whole person again.'

And then she decided that it was time to leave the Home. But her husband didn't have her independence; it was impossible to think of moving out together. She began to realise that if she had foreseen the possibility of becoming able to fend for herself, she would not have married him. The tensions mounted. 'I found it hard to talk to anyone about this. I felt that the others were all against me, that they thought I was wicked to want to go.' She had what she now calls 'a bit of a nervous breakdown'. Finally, in 1969, she and her husband (who has since remarried and has two children) parted company. Two years after she first decided to leave the home, she moved into a St Giles Housing Society (now Raglan Housing Association) flat in Balham, especially designed for people with physical disabilities.

The next year or so was something of an endurance test. She had no help at all at home—which meant on one memorable day, for instance, when a power cut left her stranded in her hoist in mid-air, she had to throw herself onto the floor and drag herself to the phone to summon the police to pick her up. But she remembers the period as exciting: 'It was terrific—I could cope!' She was mobile, too, with the adapted Mini that the Ministry of Health had provided for herself and her husband, and which she eventually bought.

But finding work was harder. She was determined to be self-supporting, but soon discovered the penalty of being a pioneer: in those days, she says, it simply wasn't thinkable that tetraplegics should aspire to full-time jobs. She had started work as a volunteer with Rehab, an organisation for people with disabilities, six months before leaving the Cheshire Home, to get a foot in the door of employment. But neither Rehab nor the Disablement Resettlement Service could find her a job and 30/– (£1.50) a week for what amounted to full-time office work was hardly enough to live on. She had a horror of asking for social security; so, with some financial help from her husband, she just scraped by.

Then in 1970, through Rehab, she found a job working a clinic switchboard for the NHS's Inner London Executive Council (now Family Practitioner Committee). She stayed there for three years. But coping with a full-time job and living unaided was hard work. In 1972, she had to return to Stoke Mandeville for a kidney operation. Only five weeks after she got home she broke a leg. That was when she finally got a home help—but only on Saturday mornings. She decided to move to the John Groom sheltered housing scheme for people with disabilities in north London, where help was available if she should need it.

By now, she was involved in setting up the Spinal Injuries Association. This brought her into contact with the King's Fund Centre, where the SIA had its first home. When the Centre offered her a job as a receptionist, she took it - and for more than two years started her day before 6 am so that she could get to work on time.

By now, too, she had met Robin Dawe. Her broken leg had taken her back to Stoke Mandeville again, where he was doing a spell as an inpatient. They swapped notes on how they coped with life. They enjoy saying now that they came together through a suppository inserter.

The Dawes' kitchen and the dining room beyond

Robin had completed his National Service and was working as an agricultural representative when, at the age of 23, he had broken his spine in a car accident. His injury is the same as Joan's—except that in his case, the break is incomplete. This gives him some advantage over her: although he can't feel heat, cold or pain in the paralysed parts of his body, he does have enough feeling to know, for instance, where his feet are—which makes him less liable to fall out of his chair than she is. His arms, however, are less strong than hers, which means that his shoulders get more easily tired and very painful.

After two years in Stoke Mandeville, Robin had returned home to his parents' farm, where he started doing some typing and clerical work for a friend who has a garage; when his parents moved to Princes Risborough, he went with them. He was very dependent on their help, and on the district nurse who came each day to manage his bowels. When his mother died in 1968, he had to think seriously about his future. 'What would I do when dad couldn't cope any longer? The one thing I knew was that I didn't want to go into a residential home.' It was when he met Joan that he began to realise that he might not have to. Through sharing her experiences of coping independently, and visiting her flat to try to put them into practice for himself, he learned to manage his own daily routines.

Joan and Robin's decision to set up house together was one thing. Finding that house took two years. Robin wanted to stay in the Princes Risborough area, where his family had been and still were farmers. But the waiting list for a council bungalow was five years long. They tried charitable foundations without success. It seemed that they would have to buy their own place, raising the deposit for a mortgage from Robin's stocks and shares and Joan's savings.

When they saw the three bedroomed, £14 750 bungalow in Chinnor, they knew it was the one they wanted. The deposit they could cope with; the problem remained money for converting it to their needs. Joan had the idea of appealing through any newspaper that would listen and the Round Table for books of Green Shield stamps: the 2000 books that came in from all over the country raised the £600 that paid for the conversions to the kitchen. Oxfordshire County Council made an interest-free loan of £1958 for other internal conversions; the social services department made a grant of £200 towards equipment and loaned some until such time as the Dawes wouldn't need it. Other donations came in: Rotary, the Round Table, the local college and others chipped in to the tune of £400. The bed in the spare room is still the one offered by a widow in Surrey. A legacy from an aunt paid for the adaptations to the garden. Friends levelled the ground round the house as a wedding present. In May 1976, Joan and Robin moved into their own house and they were married from it.

Since then, life has hardly been idle. Robin now works from home on the paperwork for two local garages. He is treasurer of the local drama group and the village hall. Though Joan doesn't rule out a part-time job, now that she is over the ill-health that has dogged her for the last two years, she has been glad to give up full-time work; she remembers how when she got in from her job she was too exhausted to do anything with her evenings except flop. Now, she makes all her own clothes, sewing as well as knitting, and ensures that very nearly all the vegetables they eat in a year are home-produced. She has taken up painting again and is a member of the Thame Choral Society. Though she has now come off the national committee of the Spinal Injuries Association, she has started a local branch—which brings its quota not just of meetings, but of paperwork and envelope-addressing. She is a member of the planning committee of the new spinal unit at Stoke Mandeville, which is only 12 miles away. And both she and Robin offer counselling, advice and practical help to others who have spinal injuries, whether through discussion (Joan has done a counselling course) or teaching them to drive (both Robin and she have passed their advanced driving test) or having them to stay.

THE CONTEXT OF LIVING

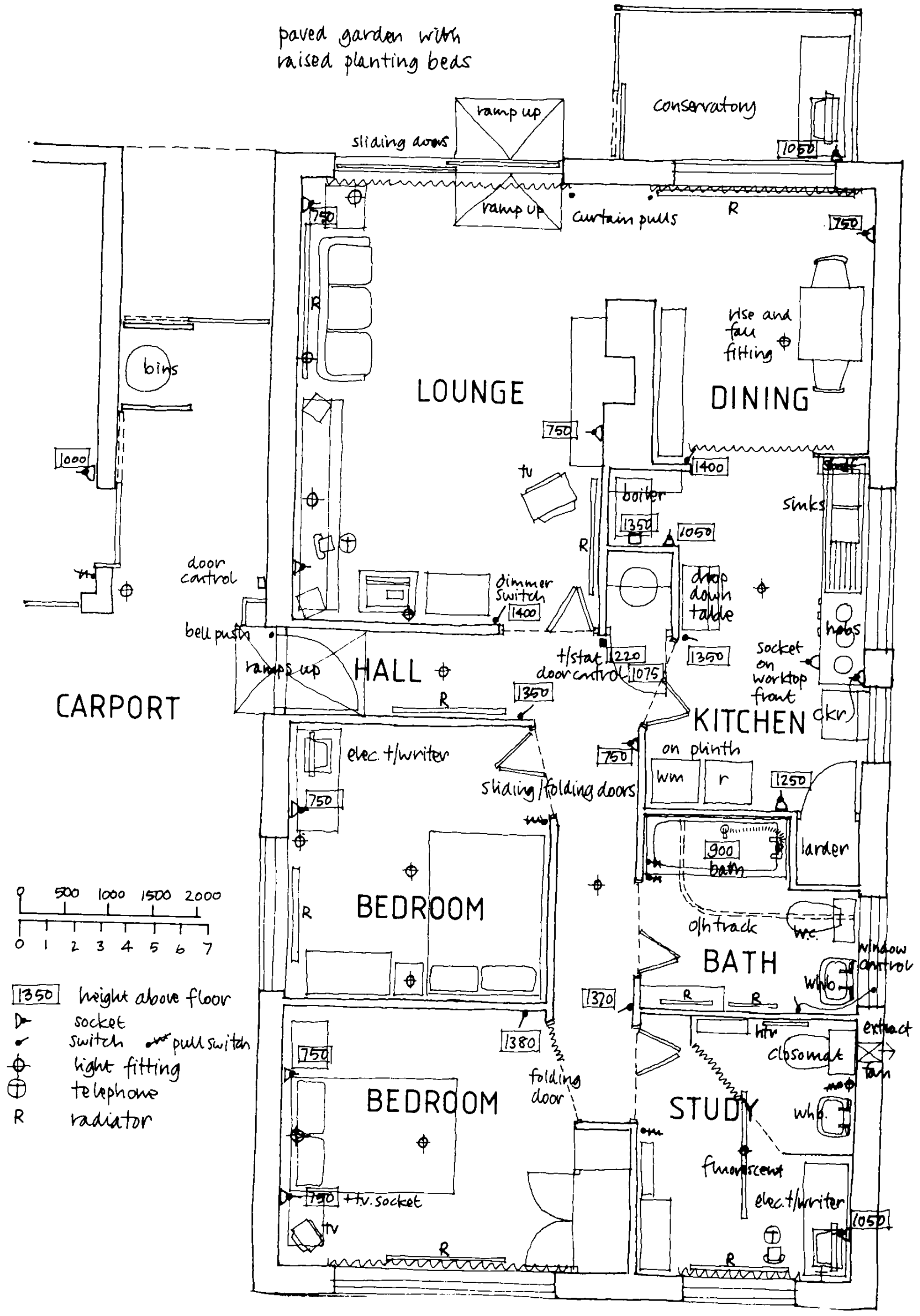
Housing

The two rooms which most usually give trouble to people with disabilities are the kitchen and the bathroom—both of which are often, in an ordinary house, too small to leave room for manoeuvre for one wheelchair, let alone two. But in the Dawes' bungalow, this wasn't so. The bathroom needed no structural alteration at all, and the kitchen was ready to be refitted once the wall and doorway between it and the dining area had been removed and the external door, which wasn't needed, had been blocked up. The partially open-plan living and dining area was an advantage, too. The wall dividing them stops about four feet from the external wall, so once the wall between the kitchen and the dining area had been removed, this gave a completely circular and very useful thoroughfare — from hall to kitchen to dining room to living room to hall again.

Before they moved in, the Dawes had all the internal doorways widened and sliding-folding doors put in; these take up less wall space than the ordinary sliding kind and they find them very easy to manage. The only place where this proved impossible was in their own bedroom, where the new doorway was set at an angle to give more space; this has a simple folding door.

Both Joan and Robin feel the cold very much and it was essential to make the bungalow as warm as possible. So they added more radiators to the existing oil central heating system, had cavity wall insulation injected and increased the fibreglass loft insulation to about four inches. They had all the (rotting) windows replaced with double-glazed, sealed unit aluminium ones; these open from the bottom and are easy for them to use. In the living area, they replaced the picture window and inconvenient door to the garden with a sliding patio door that gives them easy access to the outside.

Although they now think that an L-shaped kitchen would be more convenient to use than the long thin one they have, it works well enough. They had a new split-level cooker installed into the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telephone
R radiator

blocked-off external door area, with three electric hobs on the left of it and a double sink unit and drainer, with a pull-out working surface underneath it, next to these; all are at a comfortable height for their wheelchairs. Other fittings include a plinth with storage space under it, on which the fridge and washing machine stand at a comfortable working height and a drop-down table/working surface fixed to the internal kitchen wall.

The only other major alteration was to convert the third bedroom into a study/toilet area for Robin. When he needs to use the lavatory or basin, the folding door between the two areas can be pushed back, leaving him plenty of room for manoeuvre; when he doesn't, the door shuts to conceal the toilet area completely.

Other alterations were details—but important ones. All the power points in the house were raised so that they are easy to reach from a wheelchair. A window opener was installed for the fanlight window in the bathroom. Lever taps were fitted in the bathroom, as throughout the house. The bath was fitted with a mixer tap, with the shower head low down on the wall midway along it, which makes hairwashing easy.

The outside of the house also lent itself well to adaptation. The garage, which was too small to take both car and wheelchair, became home for the freezer and a general store and garden shed; a car port was installed to stretch out over the driveway. The driveway has been made level with the road and front door sill, and this level carries on through the covered passageway to the back of the house, where a nine foot wide patio now runs along the width of the house. Paved paths give complete access all round the house. The back garden has raised beds all round it, with a paved path between them and raised beds in the centre; it is ideal for wheelchair gardeners.

Aids

There is an electric hoist over the bath and lavatory in the bathroom, which enables Joan to manage unaided. In Robin's toilet area, off his study, there is a Clos-ó-mat lavatory. This was very expensive, but is also essential; without its automatic 'wash-and-dry' action, he would not be able to use the lavatory independently.

In both bedrooms, there is a pole and chain which enables the Dawes, as well as guests who have disabilities, to haul themselves into bed. At first, Joan despaired of ever sleeping in anything but a 'hospital bed'. But she found that a brass bed, cut down to a suitable height, works fine.

The other invaluable gadget is an electric door-opener. The

corridor from the hall to the front door is narrow, which would make it extremely difficult, to say the least, to push a wheelchair up to the front door, turn and hold the latch and push backwards to let someone in. Instead, the Dawes simply press a wall-switch in the hall to open the door and another outside the house to close it. There's a fail-safe mechanism: the door can also be opened and closed in the usual way, in case neither of the Dawes can get to the switch, or in case the power fails or the gadget breaks.

An electric hoist in the bathroom enables Joan and Robin to transfer from chair to bath or lavatory

Help with routine

Joan and Robin get up at about 7.30 am, when he makes them a cup of tea. The time it takes them to prepare for the day will vary according to whether or not they have a bowel movement; they organise this on alternate days, so that one of them is free to open the door or cope with anything unexpected that may turn up during the morning. Joan has a bath every day; on her 'loo day', her morning routine will take two to three hours. Robin is also quite independent; but the same routine will usually take him about an hour longer. During the day, Joan has good control over her bladder; it is easy enough for her to move from her chair to the lavatory. Robin has a catheter.

Running the household is a cooperative business, though most of the chores fall to Joan because Robin is working. She prepares and cooks for their main meal in the middle of the day and the lighter one in the evening. If they must, they use the local shops, which are only five minutes away. But that works out as expensive. So once a month Joan goes with a friend to stock up at a supermarket; every two months, she has a major expedition to a cash and carry emporium for household goods. Meat for the freezer is delivered three times a year, and the freezer stores their garden vegetables as well.

Joan and Robin go to bed at about 11 pm. Their night-time routine takes between half an hour and an hour.

Their only regular assistance comes from the home help who comes each weekday, for a total of eight hours a week—bumped up from four since Joan has been unwell—and a schoolboy who comes once a week to do the heavy work in the garden. Apart from helping with the housework, the home help will help Robin put his shoes on if necessary and, once a week, stand Joan in her standing frame. Once a month, the district nurse comes to change Robin's catheter.

At first, say the Dawes, the neighbours were wary. But now they provide a lot of regular support. This can be relatively simple: they will come in, for instance, to do up the top buttons of Robin's shirt if he is going somewhere that demands the formality of a tie. (Generally, he leaves the top buttons undone and simply pulls his shirts over his head.) But sometimes, the support is more urgent than that, from both neighbours and other friends.

When Robin was ill recently, for instance, and at the height of his fever simply couldn't get off his toilet, two neighbours came to lift him back to bed; friends came to sit with him while Joan went shopping. When Joan has been ill, either at home or in hospital, neighbours have come to do the cooking. They have come running one morning at 8 am, when the bed collapsed and Robin was on his way to falling onto the floor. That hasn't happened again. But when Joan fell out of her wheelchair in the garden, she simply yelled till the neighbours heard and came to haul her back in again. When she landed on her nose in a rose bush in the front garden, she just stayed there until a passer-by could be enlisted to help.

If she falls out of her chair in the house, though, there is a routine that doesn't involve outside help. She rolls herself onto her stomach, drags herself into the bathroom and straps herself into the hoist. Robin wheels her chair into the bathroom and positions it so that she can hoist herself back in.

The Dawes have little provision for emergencies, apart from a battery-operated lamp for power cuts. There's a phone in the living room and another in Robin's study which can be unplugged and replugged in their bedroom, within reach of the bed. But they don't bother to do this regularly; they would, they say, if either of them were ill. They see no need for any alarm system to back the phone.

Getting about

Both Robin and Joan have two DHSS-issue manual wheelchairs each. The first they use in the house and garden; the second is kept in the car, because neither of them can haul a chair in and out. They chose the thin carpets and other floor coverings in the house with care, so that they aren't just hard-wearing and easy to keep clean, but easy to push on as well. In addition, they have one electric wheelchair, which they bought, and which they use to go to the local shops and about the village.

For any journey longer than that, they use the car. When they first married, they had a car each, but they have since traded these for the most suitable estate car the market had to offer, and had it fitted with standard hand controls.

Holidays, they have found, are perfectly possible, if expensive. Once they are outside their own environment, both of them are very dependent on others, so they have to travel with one or usually more helpers, drawn mostly from among their family. To ask people to cope with the needs of both of them at once seems to be asking a very great deal, so they sometimes take holidays independently of each other. They have once been on holiday together—when they borrowed a house in Switzerland which was entirely adapted to the needs of people with disabilities; they got to know about that one through contacts in the world of disability affairs. But last year, for instance, Robin went to visit Joan's relatives in Kenya with friends, and she went, again with friends, to visit her sister in South Africa. When Robin is away, Joan manages on her own; when she is away, her mother comes to stay with him.

What both Joan and Robin want is to increase their independence outside their own home. They know of a van which has an electric lift at the back and which takes two electric wheelchairs, its driving controls adapted so that the driver doesn't have to transfer from the chair; they have seen such a van in an American catalogue. If such a one could be further adapted to include a bed and a lavatory, then they would not only be quite independent for day outings, but would be able to go and stay with friends as well. If they had a great deal more money, they say, that is what they would spend it on.

Finances

The Dawes' income amounts to some £7500 a year. Robin's invalidity benefit (invalidity pension of £28.35 a week, plus £6.20 invalidity allowance and £17.00 for Joan*) yields about £2600 of this. This is supplemented by Robin's earnings—which can't be more than £16.50 a week if he wants to keep his pension. If it weren't for attendance allowance at the high rate, and mobility allowance, which both he and Joan receive and which brings in

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* At 1981-2 rates.

about £4000 a year, it wouldn't be possible, Robin reckons, for them to manage. He feels strongly that the 'therapeutic earnings' rule is anything but helpful and that anyone who gets an invalidity pension ought to be able to earn whatever they can (as indeed is the case for industrial and war pensioners).

Outgoings include mortgage repayments and rates, which amount to £1500 a year. The main extra cost of disability is heating. Central heating costs £450 a year, and, in spite of the careful adaptations the Dawes have made to ensure that their bungalow stays as warm as possible, they have to use electric heaters to boost the temperature. The only concession they get on their finances is payment of their telephone rental by the social services department—which they only achieved, Robin says, because they went straight to the director rather than waiting for a social worker to organise it.

★ ★ ★

There are times when the sheer routine of daily living gets to be tiring for the Dawes. It's made easier by the fact that there are two of them to share the chores. So, for instance, when Robin goes to get meat out of the freezer, he can put out the milk bottles on the way. It's out of constant thought for such small things that their routine is constructed. But even with two of them, there are days when simply to do the washing up after preparing a meal can seem a huge task.

But both Joan and Robin are adamant that if they could do with anything, it's not more help but more money. Joan has always, since those days in the Cheshire Home, hated being helped; any more of it now would amount to an invasion of their privacy. 'It's not easy. But I like work and enjoy doing things in a difficult way. I've plenty of energy for it. Perhaps I'm a bit of a masochist. Or perhaps it's my pioneering blood. I've always liked to be the first one to do something.'

What both she and Robin feel strongly is that they shouldn't be the last. The counselling and advice they offer to other people who have broken their spines, and the talks they give, are all geared to show others that they too can regain their independence and live the way they choose to. Both of them know, after all, just how important it was in their own lives to meet someone who gave them that confidence and started them learning about possibilities, rather than simply settling for what they'd got.

Diana and respirator—a crucial aid to living

Diana Staples

DIANA STAPLES was born in 1937 and lives in Kidlington, on the outskirts of Oxford. She is senior clinical psychologist at Mary Marlborough Lodge, part of Oxford's Nuffield Orthopaedic Centre and one of Britain's National Demonstration Centres in Rehabilitation for people with severe physical disabilities. Through its functional assessment programmes, Mary Marlborough Lodge aims to help those who come to it and their families in the skills of daily living, and to encourage independence through the provision of special equipment, often made in its own workshop, which has connections with the Oxford Orthopaedic Engineering Centre. It works on techniques of rehabilitation, the development of equipment and the continuing care of people with disabilities, and runs courses to pass on its expertise to different professional groups.

After she left school, Diana was set to read medicine at Manchester University. But while she was working during the holidays as a laboratory assistant in Surrey, she contracted polio. She became completely paralysed and totally dependent on an iron lung.

After a year, she was able to breathe independently, by using part of her diaphragm and boosting it with the muscles of her neck and shoulders. She managed without a respirator for six years, but wonders now whether lack of oxygen during that time left her with some minimal brain damage, or whether what she detects as impaired spatial abilities are simply part of getting older. After a serious bout of illness, she began to use a respirator at night again, and has done ever since—one of the few people in Britain to depend on this aid to living. Without it, she says, she would first lose concentration, then develop headaches and breathlessness and eventually go into a coma.

The polio has left her with very restricted movement. She can use her left hand and arm enough to write, type, eat unaided, wash her face and put on her makeup; she has power in her elbow and some in her fingers. Otherwise, although the sensation throughout her body is unimpaired, she is completely paralysed.

When she was 20, and after 18 months in two different hospitals, Diana went home to Surrey to live with her parents and two younger brothers. The family built an extension to their house which gave her her own room, bath and lavatory. But apart from the services of a district nurse who came on three mornings a week to help her get up, there was no outside help. The arrangement lasted four years, but by then it was evident that the strain on her mother, who herself has serious asthma, was simply too much.

By then, too, Diana knew that she didn't want just to stay at home and pass the time. She wanted and needed to get into a position where she could earn her own living and be as independent as possible. She had already started studying for an external psychology degree from London University. A grant from Surrey County Council paid for postgraduate students to come and advise her. But it was hard to get hold of books, impossible to do experimental work, difficult to sustain the discipline needed to keep working and never easy to study in the atmosphere of home without the stimulation of other students.

So she moved to a Cheshire Home near East Grinstead. 'I really', she says now, 'hated that place. It was horribly paternalistic – personal freedom, the opportunity to make decisions on how to spend one's time, didn't exist. I made some good friends there. But it's simply not me to live in a big group, with all the pressures to be a jolly extrovert. I hated the infighting, and the attempts to draw me in to take sides when I was just not interested.'

After two years at the home, she became very unwell, with severe headaches and difficulty in breathing. The GP reckoned she was depressed after her father's death and gave her some pills. Luckily a nurse at the home thought that she was showing signs of a serious respiratory problem. She went to the Western Hospital in London, then a centre for the treatment of respiratory polio, and the nurse turned out to be right. The combination of age, smoking and weight gain had made her breathing harder, and she went back onto a respirator each night – as she has been ever since.

This restriction brought its own liberation. When the Cheshire Home heard of Diana's new needs, it said that it couldn't take her back. Her reaction to this was a simple 'hooray'. So she stayed on in the Western Hospital—to take a breathing space and work out what to do next.

In the event, she lived there for four more years, and she remembers them as good ones. She had her own room to study in, she met up with old school friends and made new ones, and lived a decent social life. She was accepted into the second year of Bedford College's psychology course and a social worker arranged transport for her on a special school bus—so off she went to work in the company of the maladjusted children. She took her degree and spent two years working three days a week as a research assistant at London University.

In 1968, the Western Hospital was due to be closed, and the plan was to disperse its inhabitants who had respiratory polio to local hospitals. But it was clear to the people most concerned that these hospitals simply wouldn't have the resources to cope. Staff and residents mounted a campaign to save the unit and newspaper publicity had its effect. The St Thomas' group took the patients as a job lot into its South Western Hospital, whose other inhabitants were old and chronically mentally ill. The Phipps ward it set up, under the medical direction of Geoffrey Spencer, became and remains the national respiratory centre and its 16 beds now support nearly 300 people across the country and some from EEC countries too, two-thirds of them paralysed by polio.

Diana's time at Phipps was spent working out ways to move out and live independently. Her first thought was to live in London, where there were theatres and friendships. She thought of moving in with some of those friends—'but I realised that I needed too much help, and that friends could become enemies'. She thought of finding a house with a friend from the hospital, and paying for the au pairs they would need from what she earned, but eventually decided against this. People said her plans were unrealistic, that the emotional and physical anxieties of coping with independent living and a full-time job would be too great. But she remembers no anxiety at all. 'Perhaps I am a bit psychopathic. It was simply a question of ways and means—of using people and situations to beat the system.'

Then, the situation and the person which were to enable the system to be beaten presented themselves. By chance, Richard Crossman, then Secretary of State for Social Services, came to the hospital to open a geriatric day centre. 'With great encouragement from Dr Spencer and Michael Mordaunt, an administrator, we decided to speak to him. So we did—while the Board of Governors, the senior Matron and all the top brass looked on. He was hurried off by embarrassed administrators—but not before we'd given him our paper outlining our ideas. He later came back for a whole morning and what was so good was that he actually listened to what we had to say.'

Crossman remembers that morning in his Diaries.[6] He'd already been made forcibly aware of the difficulties of people with respiratory polio when he'd visited a woman who 'can't breathe without a machine which goes punk, punk behind her chair, but . . . lives at home, with a woman to look after her night and day. It brought home the whole issue with a bump. I had to feed her dry Martini and listen to her case. She is right. It saves money to have her in her own house rather than in a hospital . . . She is spending her capital and she ought to be given a disability pension and more money. I knew very well that we couldn't possibly concede this principle, because it wouldn't only be her, but 50,000 other people demanding exactly the same thing.'

But a couple of months later, the Phipps inhabitants made a strong case that they weren't just to be written off as a few among 50 000. 'The discussion was all about their rights, and how they needed vehicles and accommodation and they all said they would like the hospital to recognise the need for domiciliary services. Even if they had all this equipment at home, it would save the hospital a bed and the vast cost of keeping them. They also said they would like to have an income tax concession like the £100 for business expenses that the blind get. It was an excellent meeting. They were staggering people. There are only twenty or thirty of them in the whole country and they asked me to treat them as a special class. It was stimulating to see them and I learned a great deal about the problems of the constant attendance allowance.'

Out of that meeting, the St Thomas' responaut attendant scheme was born—financed at first as a DHSS-sponsored research programme, then as a DHSS special service. Since 1980, when it cost £67 000, it has been the responsibility of the St Thomas' Health District. Currently, it employs 12 attendants to enable nine people to live in their own homes—and Diana is one of them.

Civil servants being what they often are, it took her until August 1970—nearly a year after Crossman's visit—to become one of the first to use the scheme. Her plan was to employ her mother, now living alone, as a part-time attendant – 'let's get the relatives some money' – and to advertise for a full-time helper as well. She took a terraced house in London, her mother moved in and they were joined by a woman with a small child. It turned out to be a false start. The child got a sore throat, Diana got pneumonia, and she was back in hospital only 10 days after leaving it for good. (Colds are still a hazard in her life, as she can't summon the force to cough to clear her lungs. This means that she needs the help of a physiotherapist or even a spell in hospital – but she hasn't needed the latter for three years.)

Four months later, her plans changed again. She had already visited Mary Marlborough Lodge two years earlier to be assessed for an electric wheelchair, and had met May Davidson, consultant clinical psychologist for Oxford, whilst there. They had discussed the possibility of her coming to work there, but there had been no vacancies. Now, however, they wrote and offered her a three-year clinical training. She moved to Oxford and her mother stayed on in the London house.

Diana found a ground floor flat in old Kidlington, not far from where she lives now, with a 'super' landlady who lived on the premises. She was joined by a succession of care attendants and drivers, some recruited locally, some through advertisement from further afield. Some were good, like the Spanish auxiliary nurse who had a man friend in Oxford and stayed for a year and a half, and Anne, a nurse turned painter who lives locally, who has been working with her since 1974, at first full-time, now part-time, and became a close friend as well. Others were less good—like the woman who turned out to be too alcoholic to be a reliable driver, or the one who got private messages through the television screen.

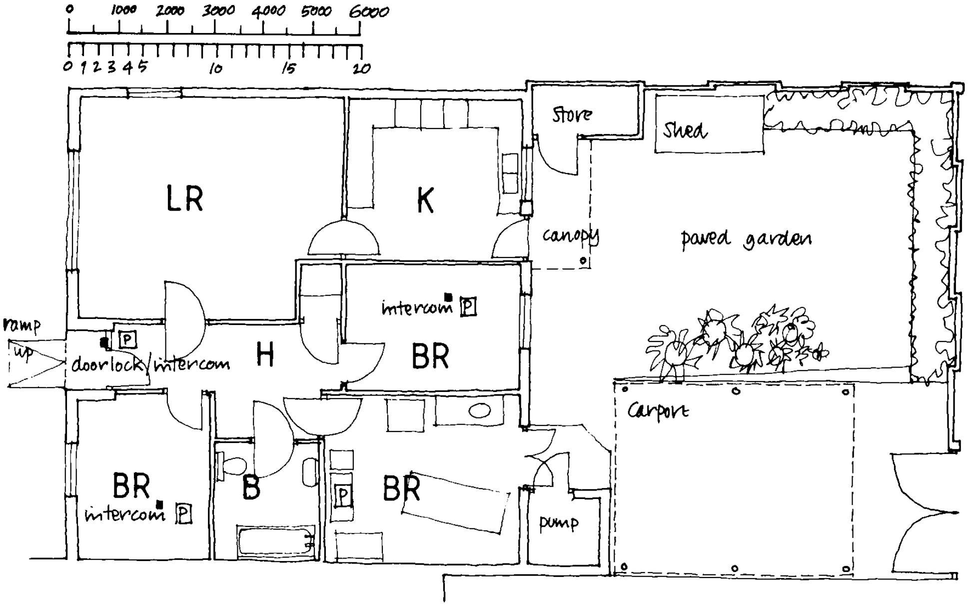
In 1976, her mother, whose own health was by now not good, came to live with her. As the years went on, the flat became more difficult to manage, because of its age and dampness. So when her mother heard, quite by chance, that the local council was planning a clutch of bungalows specifically for people with disabilities on a new housing estate, Diana investigated. They moved in October 1980.

THE CONTEXT OF LIVING

Housing

The three bedroomed bungalow was specifically designed for someone with a physical disability; Diana got Selwyn Goldsmith, author of *Designing for the Disabled*, to look over the plans and ensure that that meant it would meet her needs. This resulted in some amendments to the original plans: her bedroom is now where the bathroom was first designed to be, which gives her not just an external window but a door to the garden and gives her respirator easier access to its pump house as well.

Within the house, Diana can move from her bedroom to the bathroom to the living room/dining room and the kitchen. Light switches are at a level she can reach and the bathroom basin is at a convenient height for her. The kitchen fittings have not been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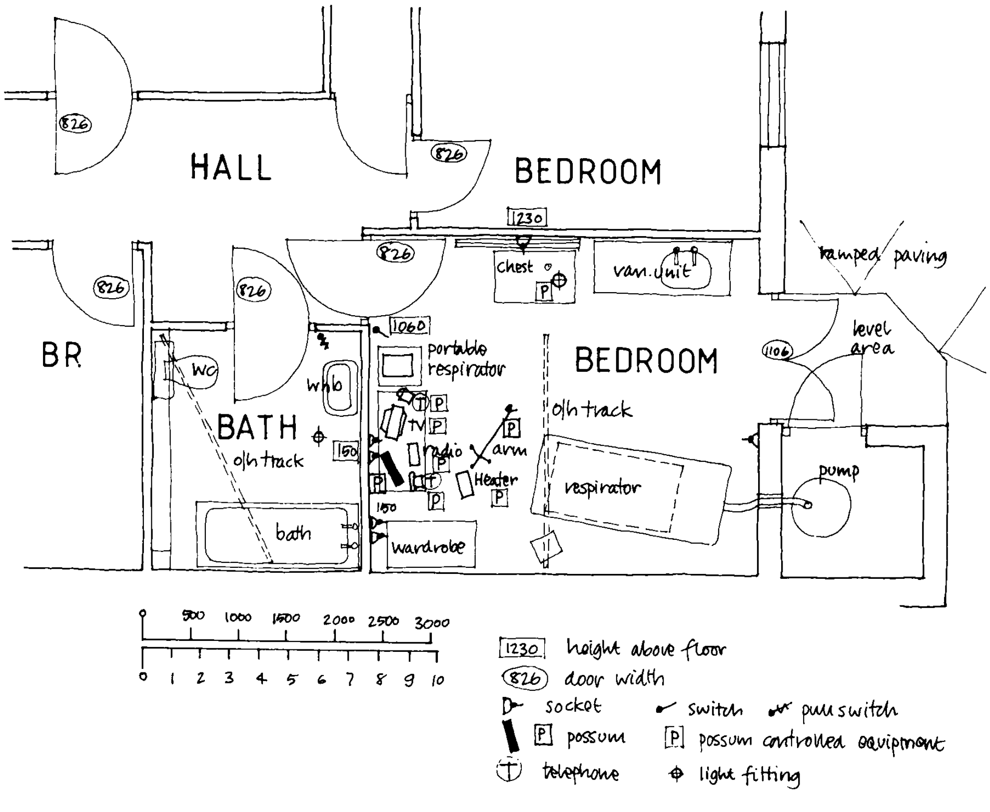
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adapted, as she couldn't work there. And with access for her chair through the front door as well as the outside bedroom door, it doesn't matter that the kitchen door is inaccessible to the garden.

Aids

Shortly after Diana moved in, a small neighbour came to look her over. 'Someone told me', he said, 'that you sleep in a coffin.' Together they examined the respirator and agreed that it was more like a bed with a lid. 'Gosh', he said, 'I wish I had one.' Diana reckons her stock among the local children to be pretty high.

The respirator takes up a good deal of the space in the bedroom. A power failure during the night brings discomfort but not disaster. Diana can breathe unaided as long as the machine is opened, and as she always wakes if its power goes off, she can make sure of that.

Two overhead tracks, one in the bedroom and one in the bathroom, and the electric hoists and slings that go with them, were installed by the social services department.

The Possum machine, which is installed in the bedroom, gives Diana a fair amount of control over her environment. By using her chin when she is in bed, and a switch on her chair the rest of the time, she can work a buzzer in her mother's room and, if there should be a fire, set off an external alarm which automatically opens the front door. The machine enables her to use the telephone (though its speaker system means that calls can't be private), to control lights, radio, television, heater and taperecorder and, with an intercom, to open the front door. Thunderstorms put the Possum out; if there is a power failure, its battery will last for two hours.

Help with routine

It takes Diana between an hour and a half and two hours to get up and ready for work each morning — from having a wash in the respirator to going to the lavatory to getting into her chair to complete her dressing. 'It's not difficult, but it's fiddly.' Her attendant drives her to work, and once there she rarely needs any personal assistance; if she does, there are nursing colleagues who would provide it. Her attendant collects her at 5.30 and she goes to the lavatory as soon as she gets home. She goes to bed at about 11 pm, and it takes her about an hour to get ready for the night. She reckons herself an insomniac, and one of the things the Possum can't provide is decent radio and television programmes during the night.

Diana has been assessed by St Thomas' as needing 60 hours attendance a week. Forty of those hours come from her full-time attendant, who apart from providing personal help, works for two hours each day in the house. Diana's mother coordinates the household and does most of the shopping and cooking. But though she can sometimes walk to the nearby local shops, she gets easily tired. So the attendant drives her and does the heavy housework as well.

This schedule leaves the full-time attendant free from noon until she picks Diana up from work. She also gets two evenings off one week and three the next, with every other weekend off, from Friday evening to Monday morning. This time off is covered by Diana's part-time helper Anne, who works for her for 20 hours a week.

Practically, these arrangements work well. There is provision within the scheme for agency nurses to cover the people who use it if one of the attendants falls ill; Diana knows plenty of ex-nurses around Oxford on whom she can call. The attendants themselves are employed by St Thomas' which takes care of the paperwork and also the business of recruitment, if this isn't done on personal grapevines by the scheme's users themselves. Whoever recruits, however, it is the individual users who decide whether or not to take on their own attendants. The EEC has brought its advantages to the scheme. For the past two years, Diana, like some other users, has had Danish attendants, who seize the chance to get the six months practical experience they need before they can start training as occupational or physiotherapists in their own country and get in a bit of foreign travel as well.

Getting about

Diana has had an electric wheelchair since her second year at university. The current model, now four years old, gives her independence of movement at home and at work – where, by the nature of the place, everywhere she needs to go is accessible to it. She buys her chairs herself, because the ones the DHSS will provide are for indoor use only. What even her chair can't get over is planners' thoughtlessness. If there is a flight of steps between her and somewhere she wants to go, she has to forget it, unless there are four strong men on hand to lift her.

She also bought her dormobile van and had it adapted to include an electric tail-lift for herself and her chair. The chair is then fixed into place where the passenger seat would usually be. As transport, it is convenient enough. But the inevitable dependence

on a driver can bring its tensions. When she goes out to dinner with friends, for instance, her attendant must either come along too – and pass the evening with people much older than herself, whom she doesn't know and whose company she has not chosen – or hang about until Diana is ready to go home. 'My one aim, ambition, wish and desire', she says, 'is for a car which I could drive from my wheelchair with my one weak hand. But that's cloud cuckoo land.'

Holidays away from home, and other trips as well, are quite possible with the aid of a portable cuirass to replace the respirator. It is less effective than the big machine, but adequate. It has seen her, for instance, through a holiday in Denmark with the family of one of her ex-attendants and on camping trips to France and Portugal.

Finances

There was a time, during her clinical training, when Diana's finances were very tight indeed. In 1971 she earned just £1100, and that was before mobility allowance was available to help her with the costs of running a car. Now her salary is at the top of the senior clinical psychologist scale — about £9300. Attendance allowance at the high rate and mobility allowance bring in about £2000 more a year.* She sees no career advancement, as she would have to move from Oxford to get it, and she simply isn't prepared to take on the hassle.

Outgoings include rent and rates which between them amount to about £110 a month. The extra costs of disability include £25 a year maintenance charge for the hoists in the house, enough central heating to keep it at a constant 70 degrees, and electricity for the machinery, including the washing machine and tumble drier which must cope with a set of sheets a day because the respirator makes her so sweaty. Other major costs are always on the horizon of possibility: these include repairs to the wheelchair and the cost of a new one, or a new van, whose hoist alone would cost £1000. Since August 1981, repairs to her van and chair have amounted to £1206 – and that's before running costs.

Some of the extra costs are met under the St Thomas' scheme. All its users get an annual contribution to their electricity bills, calculated to cover the cost of running their respirator; the sum is reassessed every quarter to keep up with rising prices. The hospital also maintains the respirators through regular visits from its specialised technical staff, and guarantees to have a technician visit within a day to repair the machines if they go wrong. This offers an absolute security to the users which Diana, for one, much appreciates.

St Thomas' also, and this is the core of its scheme, pays the 'responaut attendants'. They are on NHS domestic rates (Ancillary Grade 3), which yields them £61.80 for their 40-hour week (plus £15.87 if they work in London).* In addition, they are paid a flat £15 a week 'enhancement fee' to cover a limited amount of overtime, as they can hardly clock off if there is work still to be done at the end of their shift, at weekends or on bank holidays. Board and lodging is deducted from the attendants' salary and given directly to the person for whom they are working. This covers the expenses of a 'guest' in the house; the amount varies from £22.82 in inner London to £15.30 outside it.

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There are times, says Diana, when all she really wants, apart from that cloud cuckoo car, is a 'robot carer'. The relationship with a full-time attendant who lives with you, eats with you, travels with you, spends a great deal of time with you besides, and yet is not a 'friend', is perhaps bound to be complex. Diana knows that some

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*At 1981-2 rates.

others on the St Thomas' scheme are looking for friends and companions and hope that their attendants will stay with them for a long time. She is looking for something different. She enjoys her own company; the problem can be to get enough of it. She wants from her attendant simply the help she needs to get on with her life; if friendship develops between them, that is something extra.

She finds it essential to spell out her own expectations of the relationship from the start, and to get across that she isn't being rejecting when she encourages her attendants to go out as much as possible, make friends of their own and join in outside activities. The short-contract Danish attendants suit her better than many she has had in the past. For a start, she is convinced that looking after someone like her is not a 'life's work'; for attendants to see it as a short part of their own training, before taking up nursing or one of the remedial therapies is, she thinks, a far healthier approach – especially if their 'real' work in Oxford is learning English at one of the local language schools. She has seen in the past how the sheer lack of built-in stimulation in the job has led attendants to do less and less – until they're not even coping with the housework. She makes efforts enough to try to ensure that this doesn't happen – from introducing her new attendants to a circle of au pairs as a way into Oxford's social life, to informing them about the English classes and other courses in Oxford, to offering them a bicycle to use for as long as they're with her.

Usually, that mixture works. But it doesn't always guarantee Diana the space she seeks. If an attendant hangs about the house and remains dependent on her, instead of developing her own interests, that six-months' contract can seem particularly useful.

So there are times when Diana would prefer a rota of living-out attendants and drivers to the present arrangements. But she knows, under the present system, that wouldn't work, because each helper would be separately taxed and insured and if there were several the cost to St Thomas' would increase. She also knows that to keep a rota going reliably would bring huge headaches and that to find enough people who live within easy reach of her could turn out to be impossible.

Meanwhile, she has no doubt at all about what people with severe physical disabilities most need to enable them to live as fully as they can. It is not, as she knows after years of meeting very many of them through her job, a single way of living – for no one pattern can suit the variety of individual needs and preferences. It is, quite simply, cash. 'Give people enough money', she says, 'and then let them choose for themselves how they can achieve a certain kind of freedom and control over their lives.'

Barbara Pestell in her garden with her younger son Simon

Barbara Pestell

BARBARA PESTELL was born in 1944 and lives in Luton in Bedfordshire. By the time she was 21, she had her own business as a greengrocer and florist. She now looks after her two sons – Mark, aged 14, and Simon, who is 11. She is active in fundraising for the International Spinal Research Trust and has begun to take on some public speaking.

In November 1976, Barbara, her husband John and the two boys were set to emigrate to Canada. They had visited relatives during the summer, and liked what they saw of the country. John had gone ahead to find a house and prepare for the family's arrival. On 16 November he phoned to say that the house was found. Everything was set for the family's departure nine days later.

On 17 November, Barbara drove the boys to school as usual. Then, on the way to collect a friend's mother to take her to hospital, she drove down a steep hill which ended in a blind corner and collided with a fire-engine which was coming the other way. If that fire-engine hadn't been carrying oxygen, she reckons she wouldn't be here today.

She spent seven weeks in the intensive care unit of the local hospital, and then moved to the spinal unit at Stoke Mandeville. She was sure that it was only a matter of time before she learned to walk again; she'd gathered as much from the physiotherapist at the local hospital. When she was told the extent of her injuries, on her third day at Stoke, she simply didn't believe it. When the man came to talk to her about the sort of wheelchair she'd need, she remembers, she sent him away again, because she didn't believe she'd need any sort at all.

But, as she came to recognise, her body had been very badly damaged in that crash. She had a very high break in her spine (C3/4 incomplete), which means that apart from a tiny movement in her little finger, and the involuntary jerking of her paralysed arms, she is paralysed from her neck down. She has some sensation as far down as the bottom of her abdomen but this brings the disadvantages of pain, discomfort and aching. It also means that she can feel her body against the wheelchair, which makes her less likely to fall out of it.

Barbara spent five months in Stoke Mandeville learning to cope with this new body, while John went on looking after the children and working in her father's garden centre business, as he had done ever since the accident. She remembers life at Stoke as sometimes good, sometimes bad. Being in a mixed ward, she feels, helped; there was a lot of laughter as the patients learned not just how they would cope, but how the other sex would as well. The hardest work, she reckons, was teaching eight neck muscles to do the work of 40 before she could lift her head and hold it up. As time went on, she learned 'silly things' too – like wearing longer trousers than she used to if she didn't want them to hang at half mast, and avoiding full clothes if she didn't want to look fat as she sat in her wheelchair.

For four months after her accident, Barbara didn't see her children at all, not even at Christmas, reckoning it better that they saw her only when she was freed of machinery and looking 'normal' again. She remembers their first visit to Stoke. Each carried a pot of polyanthus, and went to give them to her, not realising that she couldn't take them. She remembers asking Simon, then six, to pick something off the floor, and how he refused, saying, 'You can't make me, you can't do anything any more, because you can't move' – and how the three of them just burst into tears. She can remember how she felt when Mark, then nine, brought in some school work to show her, and she read his exercise on the meaning of the word 'accept': 'I've got to accept that my mummy will never walk again'. She remembers watching the children walking along, holding their father's hands, and kicking a football with him, and the enormity of the realisation that she would never again be able to hold their hands, or go to them and hug them, or play with them.

Barbara came home in June 1977. That home was still where it had been still seems extraordinary; the only thing they hadn't sold when she had the accident was the house. The place looked quite familiar, too: many people, when they heard of the accident, had returned furniture they'd bought. But pretty well everything that went on in the house had to be different. Barbara now reckons that the worst part of her rehabilitation was this period of trying to reconstruct normality – a period for which Stoke hadn't prepared her, or any other of its patients, at all. 'They rehabilitate you as if you were all one, and it doesn't work. Everyone is different.'

John's job left him free to look after her at weekends and to put her to bed during the week as well; they installed a baby alarm between her new bed in the dining room and his bedroom. A district nurse came every morning to look after her toilet and get her up, with the help of the housekeeper who came for five full days each week. The housekeeper and John both learned to express her bladder, which had to be done every three hours. During the week, a woman came to help with the housework – employed privately, because Barbara didn't know that she was entitled to home help from the social services.

After Barbara had been at home for five months, and after something of a battle, Bedfordshire social services department installed a lift, which meant that she could once again sleep upstairs. She found that there were a lot of simple things to learn, as well as complex ones: that if a fly sat on her face in the garden, she couldn't brush it off; that if the birds started spitting cherry stones at her when she was lying under the tree, she couldn't move out of their range; that it was very difficult indeed to explain to Simon how to lace his boots without using her hands. It was during this period, she says, that she learned patience.

It was not an easy time, and culminated in a spell back in the intensive care unit because she was on the verge of a breakdown. Just two years after the accident, and some 17 months after Barbara came home, John decided to leave; he didn't, she says, see why two lives should be ruined instead of one. He said he would take the children with him. She refused. They were, she said, all she had left. So the search for new structures of living began again, both for her and for the boys, who had just got used to her and now had to get used to their father's absence.

It was then, she says, that she really learned how to ask for help. Two days after John left, she asked for and got a head-phone from Bedfordshire social services, so that she could use the telephone. She thanks God that she had so many friends who had known her before the accident, and who now rallied to help. Her parents – though they were both working – moved in temporarily. A home help came in for eight hours a day until she could find a permanent housekeeper. As well as the district nurse who came in the morning, a series of others came to put her to bed at night. She remembers the children's glee when on the first day of this new arrangement, the nurse arrived at 8 pm – which meant that their mother went to bed before they did. It didn't, though, take long to convince the nurses to leave her until the end of their rounds.

But the search for and coping with housekeepers became a nightmare. There were six of them in two years. There was an

Australian girl who stayed for three months. There was the one who helped herself to the linen. There was the one who lasted five weeks, gave a week's notice one Friday night and was never seen again, leaving Barbara on her own all night with the boys. There were the dramatic marital problems of another one. But there was also Yvonne, who stayed, with her son, for 11 months, became a close friend, still visits and has had Barbara to stay with her in Sweden, where she now lives.

Then in May 1981, Barbara saw a television programme about Community Service Volunteers' One-to-One scheme. She immediately contacted the organiser, and at the beginning of June her first two volunteers moved in. She has no doubt that she has found the system of support she wants. The sheer amount of work to be done – not simply looking after her, but running the house, cooking and looking after the boys – was impossibly heavy for one housekeeper; it meant very often that time off became a great problem. With two helpers, Barbara can finally be assured of the 24-hour support she needs; she can, for instance, be turned during the night if necessary, which didn't always happen in the past. She is spared the recurrent dread of advertising for and interviewing housekeepers, as this is done by CSV itself. And, she reckons, there is a big difference between volunteers who choose to come and housekeepers who come because they need the money and somewhere to live.

So Barbara now feels more free to enjoy her friends, two of whom still come round on Wednesdays and Fridays – a habit which started to give the housekeepers a break. She can give more attention to the International Spinal Research Trust, whose work she finds enormously important, following up those 200 letters she signed (by mouth) with a friend who is also paralysed, which raised nearly £3000. She has more energy to plan outings, and visits to friends for the weekend, and holidays.

THE CONTEXT OF LIVING

Housing

Barbara is fortunate in her house, whose wide doorways and open-plan living room needed no adaptation for her wheelchair at all. She is fortunate, too, that the house has five bedrooms, which leaves a spare one after her helpers have taken one between them. This amount of space also meant that the only major structural alteration, the installation of the lift which enables Barbara to get up and down stairs, was easily done. The shaft runs discreetly from a hidden corner of the living room straight into that fifth bedroom, and still leaves plenty of room for its bed and other furniture.

Otherwise, the only adjustment to the house has been the introduction of ramps at the front and back doors. Barbara had one put in, Bedfordshire social services provided the other.

The only possible lack is a downstairs bathroom. But as Barbara has to lie down for any attention she may need during the day, it is convenient enough for her to go upstairs and lie on her bed, and to use her own, private bathroom, which opens off her bedroom.

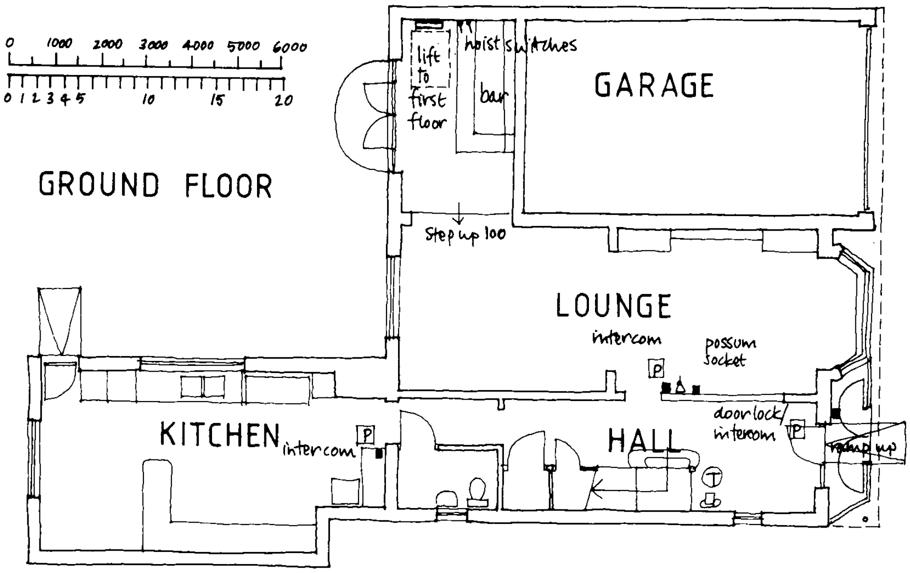
Aids

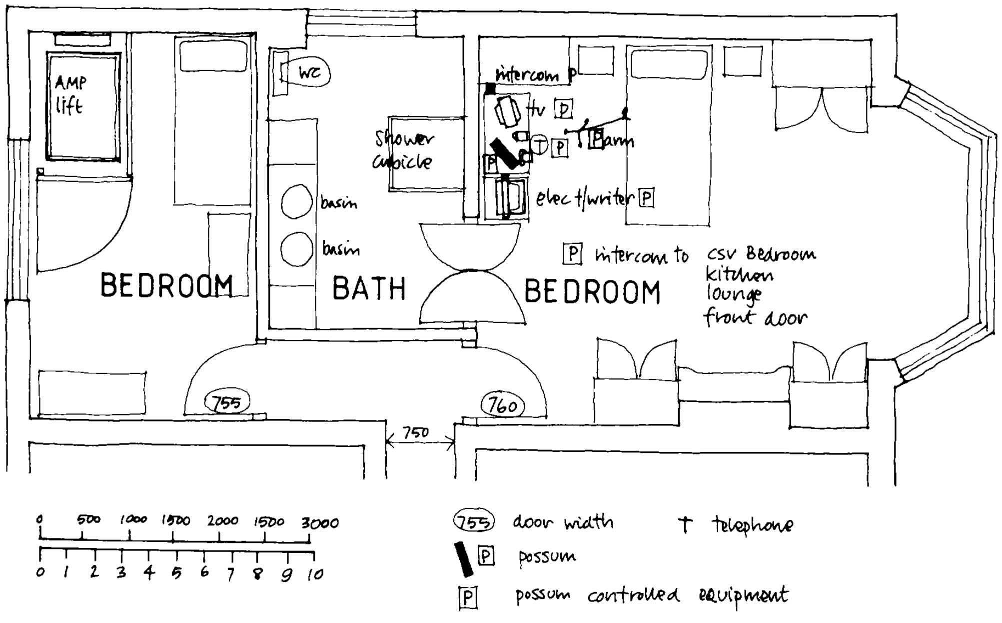
When Barbara was first offered a Possum machine, she decided against it. 'I felt it would be an attempt to make me independent beyond what I could be; I'd still have to be wheeled to it to use it.' So she settled for the baby alarm, which now ran from her bedroom to the housekeeper's. But she has since changed her mind, and finds the Possum 'marvellous'. It's installed by her bed, and enables her to use the telephone and turn the television, radio, lights and heaters on and off, as well as opening the front door; it provides communication with the door, the helpers' room and the kitchen.

The head-set is still attached to the phone downstairs. Barbara rejected the alternative of an amplified receiver, because that would take away her telephonic privacy. Bedfordshire social services have also provided the electric bed, which can be tilted to the angle that suits her, and her electric typewriter. REMAP provided a bookstand, and she can both type and turn the pages of books with the mouthstick that clips over her bottom teeth and was made for her in Stoke Mandeville.

Help with routine

Mark has a morning paper round; he and Simon get their own breakfast. Barbara gets up at about 8.30, after her bowels have been emptied, and she has had a bed-bath; she is usually up and dressed within half an hour. Each day, she should do 60 arm-movements, to reduce the spasticity and prevent her arms becoming too rigid for her to get her clothes on. On two mornings a week, she goes to the local hospital for physiotherapy. Otherwise, there is the household to organise and occasionally the local shops to visit. Once a week, she lays in major supplies at the town's central shopping centre.





Barbara's bedroom and bathroom are over the garage

Once on the platform, Barbara can operate the lift herself by blowing into the tubes, one for up, one for down and one to stop

Lunch is a light meal. The boys come home from school around 4 pm, and the main meal of the day is at about 6.30. Barbara lies on the sofa during the evening, and usually goes to bed between 9.30 and 11.30. It can take up to 40 minutes for her to get to bed and to find a position in it which will be comfortable until she is turned some four hours later.

Barbara needs help throughout her day. Before it begins, suppositories have to be inserted. Two people are needed to get her up. Someone must be on call to wheel her from room to room, and to answer the telephone, fit her head-set and take it off again. Someone has to feed her and to bring her the frequent drinks she needs between meals; although she now has a catheter, which makes life easier, the bag has to be frequently drained. Every time she moves from her chair, two people are needed to lift her; and two are needed, again, to help her to bed.

The district nurses who come morning and night make possible the start and finish of each day – though the timing of their arrival may vary by up to an hour in the morning and two at night. In the past, they have worked with the housekeeper, or, if she was off-duty, with one of Barbara's friends. Now, the nurses work with the CSV on duty. Barbara has had the same nurse in the morning since she came home, and much appreciates the sureness of the routine. She can still find it hard to cope with the variety of evening and weekend nurses.

During the day, Barbara's routine is made possible chiefly by the CSV on duty. The house is kept going by the home help, who now comes for two hours, five days a week. The ambulance services provide transport for the physiotherapy sessions. Barbara's GP calls regularly every fortnight — which is important, as she has had two bladder infections in the past 18 months, one of which has landed her briefly in hospital.

But apart from this basic and 'official' help, there is another, more informal network. The boys help with washing up and do some housework at weekends. Barbara's friend Elaine comes regularly on Monday to do the ironing and wash her hair. Her father comes once a week to do the garden. Once a week, a neighbour's son, Graham, takes her to the shopping centre. Another friend regularly shops for greengrocery. Others will help with a special bit of cooking, or simply drop in to see if there's anything to do. 'There is always', says Barbara, 'someone to call on. I have super friends.'

Getting about

Barbara's wheelchair is a standard DHSS manual issue, which makes her entirely dependent on others to get about. She is looking for an electric wheelchair which works well enough on carpet to give her the independent run of the house and, she hopes, the garden as well. So far, she has tried two which don't meet the bill. A third does, but it is not available on the NHS.

Since John left, the family has had no car. But the local shops are only about 10 minutes' walk away, which makes visits to them more than possible – if nervewracking if the pusher isn't used to wheelchairs, because the kerbs are high and the pavements shocking. It's easy enough for Barbara to get into a car, especially if there are two people about who aren't too cautious about the manoeuvre; her chair can be fitted in too. So friends with cars mean access to the town's shopping centre – which gets points from Barbara for accessibility and helpfulness from staff. They also mean access to London theatres, weekends at a friend's farm and, more generally, to the community. Barbara would, however, ideally like a mini-van with a ramp so that she can travel in her chair – though she knows, too, that a car could be more useful to the boys if she had CSVs who could drive.

More ambitious travelling presents no problems. Quite soon after John left, Barbara's parents took her to Portugal. Now, especially since her discovery of a canvas travelling seat with four handles by which she can be carried, she feels she would never worry about air travel on her own.

Finances

It has taken Barbara five years, she reckons, to work out the benefits and allowances she's due – and she's not sure she's got it right even yet. Despite a visit from a DHSS official after John left, specifically to explain her entitlements, it was another 18 months before she discovered she was entitled to the lone parent supplement to her child benefit. The rules, she was told, say that if people don't discover this within six months, they lose their arrears. She went to a tribunal for them – and got them.

She had to wait six months for her attendance allowance, too. She still remembers the doctor who came to assess her for it. 'What's wrong? Tetraplegic, eh? Can you walk, then?' he asked, as she lay there on her bed in disbelief.

Benefits* currently amount to just over £80 a week, made up of attendance allowance, child benefit and non-contributory invalidity pension, with additions for the children and housekeeper. Mobility allowance brings in another £66 a month.

There is absolutely no way, Barbara says, that she could manage on the money she gets from the State without the regular help her brother gives her – and always has – towards meeting the energy bills and the cost of her regular help. Food for the household alone costs £50 a week. There are all the costs that two growing children must bring – the clothes and shoes, the school trips. In addition, there are the extra costs of disability: because Barbara is very sensitive to cold, there can be no economy on fuel, and the central heating bills amount to over £400 a year; electricity bills mount with the washing machine in almost constant use. As well as money for the CSVs, there is £4 a week for Elaine, who comes in regularly once a week to help.

Rates are well over £600 a year. The house is still in the joint names of herself and her husband, and there is, she knows, a battle eventually to come over it.

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* At 1981-2 rates.

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There are many days when Barbara feels she simply can't go on. Even now, the smallest break in her routine can make her nervous to the point of sickness. Simply keeping the household going to her own high standards brings its strains. She can find herself worrying about the silliest things – like whether the cream has gone bad and should be thrown away – which in years past she'd not have fretted over for a moment.

She knows that she asks a great deal of her young helpers – not just the care she herself needs, but a responsibility for the house and a great deal of practical help for the boys. She knows that this is bound to bring its ups and downs in her relationships with them, as different personalities come and go and new adjustments have to be made every three or four months. She and the volunteers may have different notions of the standards to which the house should be run, or the cooking done; things that seem obvious to her might not to people who have never had responsibility for a house before; not all the volunteers will have the degree of spontaneity and initiative that she'd ideally ask for.

The adjustments aren't just hers, as she knows only too well: they're the boys' as well. On the whole, Mark and Simon enjoy living with the CSVs more than they enjoyed the company of most of the housekeepers – but that brings its own wrench when the volunteers leave. Bringing up the boys is not easy. Like many mothers, Barbara feels she can't just take a day in bed when there is their supper to organise, when she feels the need to check with the CSVs that they have thought to keep a meal hot if the boys come in late. Like most parents, she worries if they are late at night; unlike many, she can't jump in the car to collect them and, unlike most, she is sometimes not able to stay up until they come in. Like many mothers on their own, she worries about bringing up the boys without their father, who now has a new daughter and may not see his sons for six weeks or more at a stretch. The problems of discipline are the greater when all she can do is talk, when she can't go and sort out a fight between them. The limitations on the ways she can express her love for them are great.

It's not easy, either, for Barbara to get away from the tensions. The lack of privacy is one of the hardest things to cope with, she reckons. She can't just go and shut herself in her bedroom when she feels upset or frustrated – someone has to take her. She can't even have a good weep to herself – someone has to mop up her tears and help her blow her nose. One of the first things she learned, she says, was that it's no good crying in bed. The pillow gets soggy and your nose gets bunged and there is nothing you can do about it.

But whenever she feels she can't go on, Barbara remembers the 'disabled holiday' she once took for a break. She vowed that she would never subject herself to that again. She knows, when she thinks of the loss of independence and the treatment as one of a group rather than as an individual, that she could never live in a residential home. And she says to herself, 'Take a grip, Barbara!'

She feels strongly about the help that people with disabilities should get to lead fuller lives. During her visit to Sweden, she was very impressed by the Fokus flat she visited, and the constantly available rota of care-staff attached to the flats which makes this sort of independent living possible. She found the Swedish buses, with their side-doors and ramps for wheelchairs, the accessible Stockholm underground, and the subsidised 'dial-a-taxi' schemes a very long way ahead of what Britain offers.

She feels strongly, too, that help towards independence should mean more than that. After her own experience at Stoke Mandeville, she would like better opportunities for people on their way out of rehabilitation centres to meet with others who have been the same route and know what readjustment to ordinary living can mean. She feels that her own experience over the years has much that could be of value to others. And she feels, too, that she could gain a lot in sharing with others in her position mutual problems and different solutions to them. 'I'd like', she says, 'to feel part of something that I know something about.'

Meanwhile, there's a home to be provided for the children and their adolescence to come. 'They're my life', says Barbara. 'I love them so much. They're my salvation, my kids. Everyone has something that pulls them through, and for me, it's the boys – even though they do drive me to distraction.'

Yvonne and John Hall outside their front door with Yvonne's mother, CSV Debra Braithwaite and their dog Rufie

Yvonne and John Hall

YVONNE AND John Hall live in Haringey, North London. Both were born in 1946. Since their marriage, ten years ago, they have both taken honours degrees in politics and government. Both have been actively involved in setting up the Haringey Disablement Association; she is vice-chairwoman and he is secretary of its steering committee.

When Yvonne was 19, she moved to The Bedford, a Spastics Society home in Derbyshire. 'I've never seen my father so close to tears; he thought I was crazy to go. I was a bit worried myself. But I felt that in order to be independent, I'd got to get away from home.'

Yvonne was born with cerebral palsy; this means that she can't walk and that her hands are weak, which makes coordination difficult. By the time she was eight, she had spent a total of two and a half years in hospital. 'My memory of that time is mostly of pain – I felt like a guinea pig, cut off from my family.' The six operations on her legs didn't have the hoped-for effect, either; they have left her legs stiff, and she has one stiffened hip as well.

The spells in hospital meant that Yvonne had little education in her early years. She had been, in any case, classified as 'educationally subnormal', and there was no special school near her home in Crewe for her to attend as a day girl. Her parents refused to accept this educational classification; eventually, they won their point, and she had a home tutor for two years. But the authorities still insisted that she should go away to school. And so at the age of 11, she went to a boarding school for children with physical disabilities in Hampshire, and stayed there until the school closed and she was 15.

By the time she left school, Yvonne was on her way to taking some O levels, and she resented the break in her studies. A home tutor visited for the next couple of years, but they weren't easy ones: 'I had the typical teenager's problems with my parents – and I wasn't exactly mobile'. When she was offered a place at Crewe college of further education, and her mother set herself adamantly against her taking it up, she realised that if she was to achieve anything, she'd have to leave home. And so, through her own contacts with the Spastics Society, she moved to The Bedford.

She remembers it with no affection. 'It was a typical institution. We had to share rooms, and life was very regulated. There were rules about when we went out and came in; we weren't allowed any alcohol on the premises; relationships with the opposite sex were carefully watched. It was totally against my own approach – which is that people should be treated as individuals, not forced into uniformity. We had to bend to the institution, rather than the institution bending to our needs.' But it was also at The Bedford that she met John Hall.

John was also born with cerebral palsy – in his case, the athetoid type. Although his legs work for him better than Yvonne's, he also gets about in a wheelchair; his hands can't grip, which means that he has to be fed and that he must use a stick strapped to his forehead to type. He has involuntary movements of his arms and body; his speech is very hard to understand for anyone who doesn't know him well.

He counts it as good fortune that he was referred, when he was two and a half, to what became the cerebral palsy unit at Queen Mary's Hospital at Carshalton, where a specialist had brought back from America the then revolutionary notion that children with cerebral palsy were not necessarily mentally handicapped as well. 'She grabbed hold of my feet, hung me upside down with one hand and gave me a hearty slap across the bottom with the other – much to the horror of my parents. But according to her, my response was such that it signalled I was mentally bright.'

So John moved to the unit, where he stayed until he was 11. 'Without blowing my own trumpet, I was doing school work which was far advanced on that of the so-called "ordinary" child of my age.' He counts himself lucky, too, in his family: 'to them, my physical disabilities always remained secondary to my mental alertness'. Some of the children in the unit, he remembers, never saw their parents. His visited each Sunday, and latterly took him home each weekend.

When the time came for John to leave the unit, his parents were desperately pressing the housing authorities to find them a home he could come back to. To bring him into the three upstairs rooms in the house that they shared with his uncle, aunt and two cousins was clearly impossible. Eventually, they accepted a council house in one of the new towns. But the area was neither physically nor educationally suitable for John. 'I was becoming increasingly frustrated and fed-up because the lack of full-time education for disabled youngsters seemed to drag the days out endlessly.'

After a year, however, his parents got the hoped-for housing exchange, which enabled the family to move to a ground floor flat in North London, from which John was picked up each day to go to an ILEA special school. He stayed there until he was 19 – and remembers taking an IQ test which showed that he was indeed above average ability. But he wonders now whether his intellect has been slightly impaired by the series of neurological operations, spread out over two years, that he had during his early adolescence. These did, he feels, have the desired effect of controlling his involuntary movements; but the last one left him with a worse speech impediment, he reckons, than he'd had before.

John's time at The Bedford was not easy, either. His physical disabilities meant that he wasn't able to work in its sheltered workshop, even if he'd wanted to. He was the first resident who had wanted to pursue studies by correspondence; it was made clear to him that he could expect no special help with this. After a couple of years, he applied to go to Oakwood, the Spastics Society's further education college (now closed) and he moved there in October 1967.

By then, John and Yvonne knew that they wanted to be together. But she felt that she needed more qualifications if she was to get a place at Oakwood too. So she returned home and, with help from Cheshire education authority, studied partly at college and partly with home tutors to get two O levels. She joined John at Oakwood at the beginning of 1969 and they got engaged during that year.

They both have the highest of praise for Oakwood. After the restrictions of The Bedford, its physical, mental and emotional freedoms came like a release; its emphasis on helping its students become independent showed them that their dream of getting married could become a reality. 'In less than two and a half years', Yvonne recalls, 'I got six O levels, three A levels – and got married!'

But the path wasn't easy. The Halls were the first students to get engaged while at Oakwood, and some people made plain their scepticism that a relationship between two people with such severe disabilities could last. Yvonne's parents were quite set against the match, foreseeing that the academic career they now hoped for for their daughter would be ruined if she married a man as disabled as John. Even now, John and Yvonne feared that they might be separated, that someone would tell them that they just couldn't marry. Yvonne had already had a very hurtful experience

The Halls feel the lack of any private garden space

at The Bedford, when a member of staff to whom she had become attached was sent away from the place. It was hard for her to trust that separation wouldn't happen again.

But the Halls got married at Oakwood two years after they had become engaged. They chose as one of their wedding hymns, 'Fight the Good Fight'. That made everyone laugh. Sometimes, it's seemed to them, they've been fighting ever since.

They knew before they married that they wanted to move out of Oakwood and live independently. Though they had two rooms there – furnished by themselves on John's insistence, as a bulwark against being moved against their will – they found that even its liberal regime became confining. 'In a sense', Yvonne reckons now, 'we caused our own problems by wanting an individual life in an institutional setting.' Their status seemed ambivalent. She did a certain amount of cooking for them, but they continued to take most of their meals with the other students. There was a question over how much personal help they should get, over whether they should become more responsible for cleaning their own rooms or continue to get staff help to do this. There were some tensions with the staff. 'We felt the onus was on us to prove we could cope.'

For 18 months, the Halls continued to live at Oakwood. Then Habinteg, the housing association which started as an offshoot of the Spastics Society but is quite independent of it, opened its first estate in Haringey, North London. When John and Yvonne moved into their flat there, it was something of an act of faith. They didn't know the area, or the state of support services. They knew they would get some assistance from home helps, but they didn't know how much. They hadn't so much as met a Haringey social worker when they moved in. It was only three months later that they sorted out their rent and rates payments with the social security people; until then, they had just over £10 a week to live on.

Fortunately, their families rallied. John's mother found them a second-hand fridge and a table and chairs. She filled the cupboard with two week's worth of food for when they moved in; she was, Yvonne remembers, putting up the net curtains as they did it. Yvonne's parents, who were still living in Crewe, sent some furniture as well.

There wasn't too much time to spend on sorting out the house. The previous year, John and Yvonne had applied for a degree course at the City of London polytechnic; they had thought at the time that if they were accepted, they could use this as leverage to get housing within travelling distance. When the college had realised the extent of their disabilities, it had been reluctant to accept them. There had been mutterings about unadapted buildings and fire risks and the difficulty that John, with his typing stick, and Yvonne, with her very slow handwriting, would have with written work. The Open University seemed, to the college at least, a far more sensible proposition.

'That', Yvonne remembers, 'made us all the more determined that we wanted to study in an ordinary environment.' The college offered to send someone to interview them at Oakwood; they pointed out that it was how they would cope in the college, not how they lived in a home they hoped to leave, that mattered. Eventually, they spent three days at the college, staying with John's mother, and discovered that though the college was indeed ill-adapted for people in wheelchairs, they could manage it. So negotiations went on. In March 1973, they had neither the place at college nor somewhere to live.

But eventually they got both. Now all that remained was the vital question of transport to college. Haringey social services department felt that the commitment to ensuring this would be too great; the Spastics Society was unwilling to get involved in providing initial help that might turn out to be long-term. Two weeks before the course was due to start, the Halls still had no transport.

Then the college's students union took up their cause. An interview on Radio London drew a promise of a major award from Haringey education authority, plus an agreement to pay the cost of mini-cabs if a firm could be found to take on the commitment. The college, by now publicly committed to having the Halls as students, found the firm. So for four years – an extra one because of their disabilities – they went to college on either two or three days a week. The education grant was generous: 'it relieved us of our second disability – poverty' – and included money for tape-recorders so that they could tape lectures.

But coordinating studying with running the house was not easy. For their first year at college, the Halls had meals on wheels; but they dropped them because the quantities seemed geared for someone with a very much smaller appetite than John's, and they had to cook anyway. The home help who came for eight hours a week could do nothing about the constant anxiety of getting ready in time for the mini-cab – which meant starting the day before 6 am. She could do nothing, either, to ensure that the cab always did turn up as promised.

'During my second year at college', Yvonne says, 'it dawned on me that I wasn't coping as well as I should have been. I was constantly complaining about the transport. I went through periods of thinking "God, I can't carry on like this". I knew I had the capacity to get a degree. But I feared that because of exhaustion I might fail.'

At the end of that second year, the college phoned the Hall's social worker to ask whether anything was wrong at home. It was then that the social worker suggested to them that it might be helpful if someone came to get John up in the morning. So during their third year, that is what happened on college days – at least, in theory, because sometimes those days changed and there wasn't enough flexibility in the system for the help to change with them. The Halls took half their final exams that year; they got through, Yvonne reckons, because they went back to Oakwood to do them.

It seemed to her by now that they couldn't finish their final year unless they had someone to help John get up five days a week. But the social services department said that this wasn't possible. 'It was the first and only time I've ever panicked', Yvonne says now; 'I just said I couldn't do it.' Though her parents had by now moved to

Leytonstone, ten miles away, she felt she couldn't call on them. They didn't want to commit John's mother, or worry her by letting on how exhausted John was. In the end, the social services offered help on one more morning. For the last six weeks of the course, when the Halls were revising for the final batch of exams, the college organised and paid for a nurse to provide the intensive help they needed, through a split shift system that covered the hours at which they needed it. They got through the exams.

Since then, their domestic arrangements have changed and changed again. And that means that a very great deal of their energy goes in simply keeping their household going. Even if they could find work, they doubt whether they could cope with its practicalities without a quite different pattern of help. John can do the paperwork for the Haringey Disablement Association at home; but though Yvonne would like to be able to put in more than the one day a week that she does at its associated advice centre, that's simply not possible.

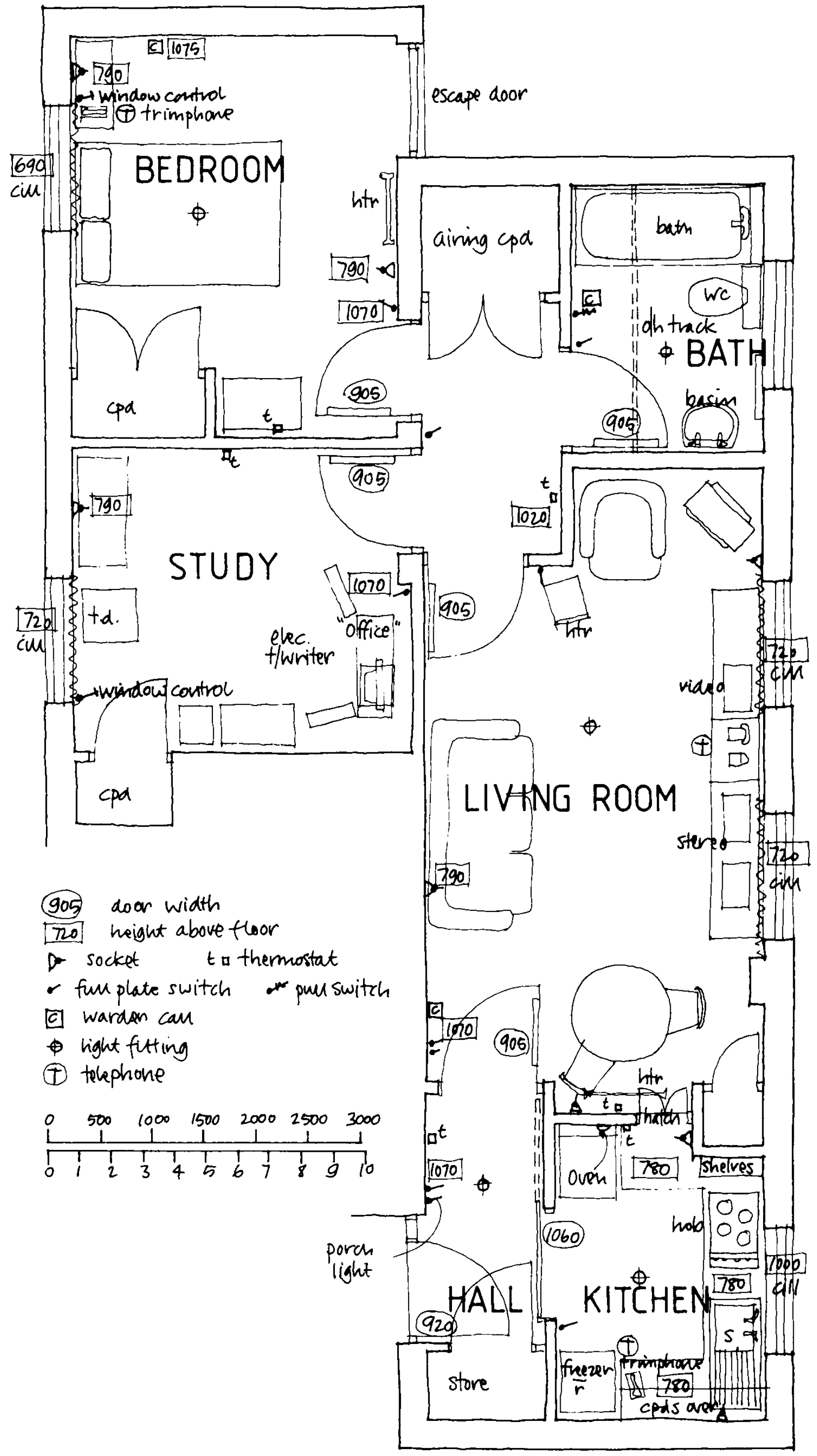
There are family worries, as well. Both John and Yvonne are only children, and their concerns are those which any others would recognise. Yvonne now thinks that her parents moved south because her father felt that her mother would need her support if he died. So it has turned out. After his death, two years ago, Haringey was quick to find his widow a flat within walking distance of the Halls. This means that they can ensure she eats enough by having her round every day for lunch; it means that Yvonne can help her with the complexities of paperwork that stand between people and their pensions and allowances. It meant that after she was mugged, walking between their flats, John could walk her home until she regained the confidence to go out alone. Meanwhile, John's mother, also a widow, is getting older too.

'It does', says Yvonne, 'seem to get harder. John thinks that's because I have such high standards. They are high, but to let things go would be the easy way out. People might feel we couldn't cope.' The possibility of ending up in Part III accommodation is both a threat and a spur to keep going.

THE CONTEXT OF LIVING

Housing

The estate on which the Halls live was the first designed by Habinteg to offer an opportunity for 'integrated' living to people who have disabilities and people who don't. So their two-bedroomed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flat was specially designed with the needs of a disabled tenant in mind.

But what might suit one person in a wheelchair is not necessarily what suits two. A squarer living room would have offered more space for two wheelchairs to manoeuvre and pass than does the long, fairly narrow one. The Halls have made their own improvements to the kitchen – like installing a much larger oven than the one fitted by Habinteg. But they have not been able to get round the fact that to get two wheelchairs into the kitchen is more than a squash. Yet Yvonne cannot reach the hatch to pass food to the dining table; John cannot take a tray on his knee; she finds carrying dishes very tiring. So in the kitchen is where they mostly eat. There is no room there for the washing machine; that is fixed into the airing cupboard at the other end of the flat, and the tumble drier is in the second bedroom, which doubles as John's study. The space-saving storage under the oven means that Yvonne, who already finds it hard to carry dishes out of it, has to sit sideways rather than directly facing the oven every time she uses it.

The bathroom presents its own problems of space and design. When both John and Yvonne are in there – which is necessary more than once each day – there is no room for the door to close; a sliding or folding one would give them privacy. There is no room for two wheelchairs alongside the basin, which leads to problems when Yvonne is helping John to wash in it. The lavatory is in the way of her chair when she is helping him to bath. It is not ideally placed, either. If it were next to the wall, and had a firm wall-rail, instead of standing away from it with a wobbly rail alongside, then both John and Yvonne would have the confidence to stand when they transferred from chair to lavatory by standing up; that would be a lot more convenient than their substitute sideways shuffle.

Other details make life difficult, too. Though there is an emergency alarm which connects the flat direct to the Habinteg 'community assistant', it is too high on the living room wall for either John or Yvonne to reach it from the floor – which is one place they'd likely be if they needed emergency help. There is no emergency alarm of this sort in the kitchen, which is another. Neither of the Halls can open the living room window, because it opens in the middle and that is too high for them to reach. The louvre windows in the bedrooms work better for them, but they can only open the top, which means they can get very hot in summer. They fear that in an emergency they would be unable to open the fire escape door in their own bedroom. They feel the lack of any private garden space.

Aids

It was 1979 before the Halls got, through the social services department, the electric hoist for the bath. They had been reluctant to get one at all, because Yvonne was not confident that she could use it either for herself or for John. But they got it at a period when it seemed that the problems of finding help were insurmountable. Yvonne can use it, but she still, because her legs are too stiff to give her much control over her direction, prefers to have someone with her when she baths – as she must do at least three times a week, because of a skin complaint. She is also not happy to use the hoist for John unless there is someone else in the house, as he is unable to pull the cords to direct it.

When the Halls moved in, there was no phone in the house; they were told that the alarm to the community assistant was enough. But they eventually got a phone, with extensions in the bedroom and the kitchen; the social services department pays the rental. It also installed the loudspeaker which enables John to participate in conversations, while Yvonne interprets for him.

Help with routine

It takes Yvonne about an hour to help John up in the mornings, or an hour and a half if she baths him. She learned to manage the lavatory independently while she was at Oakwood, but John needs help with this. Both of them can partially dress themselves and they can help each other with the rest.

Yvonne finds that it is usually 11am or even later, before she is dressed herself, as she has to be on hand to open the door to visitors or answer the phone because John needs her to interpret for him. The morning is taken up with chores. There is a lot of washing, because John spills food on his clothes. He can go to the nearby shops if there is anything they need; Yvonne prepares the main meal which they share at midday with her mother. This can be tiring. Yvonne hasn't the strength in her hands, for instance, to prepare vegetables or cut bread or meat, and it is not easy for her to lift pots and pans. She also has to feed John his meal. The evening meal is a lighter one, and the Halls go to bed fairly late. It takes Yvonne three-quarters of an hour to help John to bed, and about half an hour to get ready herself.

The help that the Halls have had with their daily routine has changed bewilderingly over the years. After they finished college, their home help hours were reduced from eight hours a week to six, while the man who had been coming to help John get up in the morning continued to come on three mornings a week. For about a year, the Halls supplemented this arrangement by breaking the rules and paying the home help to come for a few extra hours. By the time the social services department found out, she was retiring anyway, and at least the discovery got across the message that the Halls needed more help than they were getting. So the arrangement became that 'whenever possible' a home help would come for two hours each weekday morning and that 'for a little while' John's helper would also come each weekday.

But when John's helper fell ill and was off for four months, there was no replacement. There are the days when the home help doesn't come. One of them was the day that the Halls were throwing a party to celebrate their tenth wedding anniversary — and that without any warning.

Even on days when all goes as it should, Yvonne finds the system far from ideal. There is a great deal for the home help to do in just two daily hours — from preparing the bits of the meal that Yvonne can't cope with, to helping her complete her dressing, to doing the main shopping at shops which may be cheaper than the local ones, but are a bus-ride away. If the home helps vary, as they do, the work takes longer, because there is more explaining to be done. In general, Yvonne finds the service geared to elderly people rather than young ones whose need may be for flexible rather than strictly routine help. She finds the same of the meals on wheels service and district nursing, which she has used for baths in the past. Of the last, she says: 'It's alright if you have nothing to do all day but sit and wait in your dressing gown for them to come'.

The 'community assistant', on call to tenants, is one feature of Habinteg's schemes. In the past, the Halls have used this service more than they do now. There was a time when the assistant's wife used to come and help Yvonne bath, and another when Habinteg paid for the same service for John. Now, however, the Halls call the assistant in an emergency — when John occasionally falls in the bathroom, for instance, or when they need other specific help, as when one of their wheelchairs needs attention.

In a truly 'integrated' community, neighbours could perhaps be relied on for such aid. The Halls find both their immediate neighbours very helpful in emergencies, or when Yvonne feels she just can't manage. In general, though, they find that it's up to people with disabilities to work for integration. 'Children are the biggest force for it — and both our immediate neighbours have them.'

In the end, much of the extra help that the Halls need comes from their mothers. Yvonne's helps with setting the table and washing up after lunch; she also prepares their bed for the night, helps Yvonne with her bath and collects their money for them. At weekends, when they have no 'outside' help at all, John's mother often comes to stay. Yet they know that she is beginning to find the sheer physical work tiring, and are reluctant to call on her too much.

Getting about

Apart from the difficulties of the flat's layout, both John and Yvonne can get about in it easily enough. Inside, he uses a DHSS manual chair; the electric one he bought himself enables him to go independently to the shops, or to take their dog for a walk. Yvonne feels that a certain amount of exercise is necessary to keep her arms supple, so she doesn't have an electric chair; if she needs to go far outside the house, however, someone must push her. She bought her own manual chair, at the cost of £200, because the DHSS issue was too heavy and less easily manoeuvred in and out of cars.

Though both the Halls can get into cars without trouble, they don't have much opportunity to do so. Most of their shopping is done by others or, when it comes to clothes, by mail order. The social services department provides transport for meetings of the Haringey Disablement Association, and to take Yvonne to her one day a week at the advice centre — though sometimes at a time which suits its own timetable rather than the Halls'. Otherwise, they must rely on mini-cabs.

As a result, they don't get out as much as they would like to. 'It's manageable', Yvonne says, 'because so many people come to see us. But we would like to be able to say "damn the lot of it" and just get out.' What they'd like is a second-hand car of their own — and a helper on hand to drive it for them.

Because it's hard for the Halls to cope outside their own environment, they must take helpers with them if they want to go on holiday. They have managed to get away in the past, usually with John's mother. But this year, they felt it would be too much for her. And they have no wish to go on a 'disabled holiday'. John sampled one or two of those in the past, and vowed never to go on one again.

Finances

For the first three months after John and Yvonne moved to Haringey, before their social security and then their education grant were sorted out, they had just £10 a week to live on after they had paid their rent and rates.

Now, their income is £151.93 a week.* John's non-

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* At 1981-2 rates.

contributory invalidity pension (plus the addition for Yvonne) is £28.40. Attendance allowance — his at the higher rate, hers at the lower — adds £39.40. Two mobility allowances bring in £33. Supplementary benefits make up the balance.

Outgoings include £7 a week for rates and £15 for rent, including the garage. The extra costs of disability are high. Both the Halls feel the cold and the ceiling heating is both expensive and, in the winter at least, ineffective. They have to supplement it with a Calor gas heater in the living room, which in winter uses up a cylinder of gas — at a cost of £8 — in about 10 days. Heating bills usually amount to £10 a week; in winter, Yvonne reckons, the whole of her attendance allowance goes on energy costs. Maintenance of the different bits of essential equipment can be costly, too, especially as much of it is second-hand. The fridge-freezer had to be replaced; there can be no question of doing without the washing machine and tumble drier. New batteries for John's electric wheelchair cost £70 a time, and maintenance costs are high. In addition, Yvonne feels it important that the house is kept in a state which makes it easy for the home helps to work in; redoing the kitchen to both meet that end and make it convenient for the Halls cost £150. And finally, the cost of transport can be very high indeed. A single trip to the dentist by mini-cab recently left hardly any change from one of the week's mobility allowances.

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The Halls know what they would like to enable them to live more fully. They would like to live in a social and political environment in which attitudes among the majority were adjusted so that people with disabilities were seen as people first, and disabled second. They would like a good many more hours of help, and they would like it to come in a way and at a time that were flexible to meet the variety of activities a week can bring, and a weekend as well. The CSV One-to-One scheme, they feel, is exactly the sort of thing they need.

'For such a long time', says Yvonne, 'the onus has been on us to prove that we could cope. If we didn't, there would be pressure to return to Part III. But it's our right to live in the community. We have got to the stage now where we feel that we have proved our point, where we have shown that we can cope. Now, can we have more help?'

Postscript

In February 1982, the Halls got their first pair of CSVs. Haringey social services department has promised to find the volunteers somewhere to live; it has promised home help which reduces to six hours a week as the routine with the volunteers gets established. The Halls will pay Haringey £20 a week towards the cost of the volunteers; they reckon that their food bills will go up to £35-£40 a week. But, 'I can hardly believe it yet', says Yvonne. 'I keep thinking of things I should be doing and then remembering that there's someone there to help.' Already, the Halls have applied for another university course, this time an MA in public and social administration at Brunel. The university is clear on the other side of London from where they live. So they have just bought a car — on payments of £75 a month — in the hope that CSV will be able to find a volunteer who can drive them.

Implications

IMPLICATIONS FOR INDIVIDUALS

THE SIX households described here pose a fundamental challenge to the traditional assumption that people 'must' move into residential establishments if they need regular help with daily routines and cannot assure it through an 'able' family. The people who figure in these accounts have between them over 80 years of experience to show that there is no 'must' about it. They suggest that there are very few people for whom the option of independent living must be closed.

That has its implications for people who need a lot of help with daily routines and are planning how to live their lives. But it has implications, too, for the people whose job it is to advise them, and who may exercise a quite decisive control over the resources they may need to draw on. What preconceptions do those people bring to their work? What are their expectations of the 'possible' range of options among which people with severe disabilities may choose? 'There is little doubt', says Bernard Brett, 'that if I had accepted the advice of social workers and medical men, I would have allowed them to admit me to a ghastly hospital unit for the younger disabled, cut off from the community . . .'

But he also met, at the start of his adult life, a doctor who opened for him some possibilities of more independent living. And nearly all the others in this study, at a critical point in their lives, also met people who either had control over resources they needed or were in a position to influence the shape of their lives. Often these were professional workers; but among them were also a politician and other people who had severe disabilities. As a small child, John Hall met a specialist who challenged the then conventional wisdom about the 'inevitable' limitations of people with severe cerebral palsy. Yvonne Hall and her parents, by contrast, came up against an education authority which dubbed her 'educationally subnormal' until she was nine. Both of them subsequently met the staff of Oakwood further education centre, who believed in the abilities of their students, rather than getting stuck in their disabilities. The Wymers met Elizabeth Barnes, the social worker who, as George Meredith (Norfolk's director of social services) says in his introduction to their book, 'risked, in backing the venture initially, the harsh criticism that can be meted out to professionals if failure results in accident or injury.[28] Joan Dawe met a man who was himself tetraplegic and for the first time enabled her to feel that independent living could be possible for her. Robin Dawe met Joan, who by then knew that it was more than a possibility. And Diana Staples met Richard Crossman, a politician who actually listened to what she and the others living in that hospital ward were saying about controlling the shape of their own lives — and who started the bureaucratic wheels turning to make it possible for them to do so.

So there are implications in the lives recorded here for the way a whole range of people see the possibilities for others whose disabilities are severe. They are particularly important, perhaps, for all those professional workers who so often are in no doubt about what those people can*not* do, and who trap them so often and so damagingly into the vicious spiral set up by their own low expectations.[23] The workers include, as the Wymers emphasise, those who are concerned with residential care; in its inclusion of help towards more independent living among the aims of its residential homes, the Cheshire Foundation is beginning to take their point about the duty of such establishments to encourage people to discover alternatives.

But if that is one set of implications for professional workers, the other is perhaps that they should learn when to hand over to people who know more about the reality of disability than they do. The Dawes and Barbara Pestell both emphasise the importance of peer and co-counselling among people who have disabilities — the Dawes from their own experience of offering it, Barbara Pestell because she knows it to have been a lack in her own life. The shift in the balance of power and authority in the lives of people with disabilities that the approach implies has been at the heart of the growth of the Alternative Living Movement in the United States.[18] It is gradually being recognised in Britain, as people with disabilities refused to accept the 'disabled role' that other people's perceptions have imposed on them.[24] It is finding its expression in the growth of organisations of and not for people with disabilities — like the Spinal Injuries Association, the Union of the Physically Impaired Against Segregation and the Liberation

Network of People with Disabilities. But how many professional workers are still stuck with their preconceptions? And how many people with disabilities are denied the resources they need because of that?

IMPLICATIONS FOR HOUSING

The two people in this study who need the most help with every aspect of daily living get it in perfectly ordinary housing which has had hardly any adaptations at all. Two couples live in ordinary housing adapted to their specifications. Only two households are in housing especially designed for people with disabilities. And one of them seems the least convenient of all the housing described for its users.

There are implications in this, perhaps, for those experts who insist that people whose disabilities are severe must necessarily live in special housing — and who may use the lack of it to deny them access to any housing at all. It may be, as it has been for Bernard Brett and Barbara Pestell, that what makes a house work is simply a great deal of space in which to establish individual patterns of living and support. If 'special' housing there is to be, the experience of the Dawes suggests that the special elements can often come through the adaptation of ordinary property rather than purpose building. And certainly the contrasting experiences of the Dawes and the Halls suggest in their different ways that it is the people who will actually be using the housing, rather than the designers who have read the textbooks, who will often know best how houses should be designed.

Perhaps, in short, it is time to demystify the special housing business a little, and to recognise more clearly that what is needed is not so much a highly specialised environment but a space which is convenient for individuals to use as they go about the life they choose — and that that space can be created in all sorts of ways if only the people who are actually going to use it are drawn into its shaping.

All that anyone could wish to know about different design details for people with disabilities has already been comprehensively recorded.[13] So here it seems worthwhile simply to tease out four general implications from the housing that features in this book.

(a) Siting

All the people in this study live conveniently close to at least some local shops — though not all are as conveniently placed as the

Wymers, who can reach the cheaper town centre and other local facilities without transport and who have the back-up service of a sheltered housing scheme at hand without being part of it. It may seem obvious to emphasise that housing especially designed for people with disabilities should be as near as possible to where the local action is, and within easy walking distance of public transport as well so that their visitors may use it even if they can't. But to judge by the trouble that Habinteg still reports in getting sites which meet its insistence on this point, some local authorities still haven't got the message.

(b) Flexibility

However carefully designers read the texts, they can never come up with a package that suits all of the people all of the time. This has implications for individual detailing, in consultation with future users. Habinteg, for instance, has a policy of using fittings whose height can be adjusted without difficulty. (It has also redesigned the kitchen which has given the Halls so much trouble. In its subsequent schemes, the kitchen design recognises that people will most often want to eat near the place they cook, and so save, as much as they can, the possibly wearisome business of carting plates and food about.)

More generally, there is no guarantee that the composition of 'special' households will remain immutable over time. When Habinteg built its first estate, for instance, it was not often that two people who both used wheelchairs set up house together — which may have something to do with why the Halls' flat works less well for them than they would wish. There are implications here for providing housing which can meet an increasing range of possible user demand.

This throws up its own question — though not one which is directly relevant to this study. The composition of households may change if people move. But it may also change over time if they don't. Children will be born and grow up; couples may separate. Is housing to be underoccupied some of the time so that it can allow for changes in personal circumstances? Or are people with disabilities to be expected to up and move every time there is a change in the shape of their household? The question has already come up in the Spastics Society's Part III 'housing' scheme at Neath Hill.[7]

(c) Privacy

The Wymers' flat was specially adapted to meet their needs. But it still leaves them with no privacy at all as they journey between bedroom and bathroom in their hoist if there happens to be a visitor in the living room. The relationship between bedroom and bathroom may be one of the critical ones in designing or adapting houses so that they offer a normal degree of privacy to their users. But the only house among these six in which privacy is guaranteed was not designed with people with disabilities in mind at all: Barbara Pestell's personal bathroom opens off her bedroom, and there is another bathroom for the other occupants of the house.

(d) Territory

All the people in this study except the Halls have their own patch of garden — though the Wymers' is in fact commandeered from the borders round their flat rather than officially their own. For them and the Dawes at least, a garden is very important. The Halls feel the lack of this piece of territory; for them, the common patio at the front of their flat and the communal piece of grass at the back — to which they have no direct access — is not enough. It is now Habinteg's policy, wherever density allows, to provide private gardens for each of its units.

IMPLICATIONS FOR SUPPORT SERVICES

The first point to make under this heading is that the need for personal help cannot be neatly correlated with degrees of physical limitation. Professional preconceptions might say that a couple who are both tetraplegic 'must' have a great deal of personal help; the Dawes' daily life shows that there is no 'must' about it. The need that people will have for help in their daily lives will vary according not just to physical ability but to temperament; it may change over time. That has implications for flexibility in its planning.

The second point is that even when people do need personal assistance with many aspects of their daily lives, they do not need it all the time. The Wymers need personal help for 22 hours a week, not 24 hours a day. Barbara Pestell shows that attention during the night can be provided in people's own homes.

The third point is that the help people need does not have to come from special, 'expert', helpers. Bernard Brett and the Wymers recruit their helpers locally from among the ordinary members of the ordinary population; Diana Staples's helpers come from Denmark before, and not after, their professional training courses. Barbara Pestell may draw on the district nursing service to help her get up and go to bed, and to assist her with her toilet, but the rest of her daily needs are met by young volunteers who have had no special training. The particular expertise that people may need among their helpers is the kind that they themselves, not the 'experts', are most qualified to teach.

These three points together make a nonsense of the assertion that people whose disabilities are severe 'must' inevitably have 24-hour cover from specialist helpers; they show the assumption that 'only an institution can provide' the level of help that people may need to be just that — an easy justification for traditional block patterns of meeting individual needs. The question is not whether people can be enabled to cope outside a residential setting, but how.

On the evidence of these nine lives, the support service that works will be the one that is both flexible enough to meet individual needs and reliable enough to meet them. And the more personal help someone needs, the more essential that flexibility and reliability become.

For people whose needs for personal help are not great, current statutory services may be able to offer enough of both qualities. If the Dawes' home help doesn't turn up on one day, for instance, that day is not ruined for them; if Robin's district nurse comes on one day rather than another during the month, that is not disastrous. Their lives would begin to be seriously affected only if the home help didn't come for a week or more, or if the district nurse didn't turn up within a few days of the appointed time.

But the more help people need, the less the current statutory services seem able to provide it. What the Halls' ten years of reliance on those services for most of their help has shown is precisely that. Unreliability and inflexibility in official services has mattered very much to the quality of their lives. They have not always had the assurance of assistance just when they need it most; on occasion, they have not had that assurance at all. The demands of official timetables have not guaranteed enough flexibility to suit the Halls' preferred pattern of life; a great deal of their energy over the last years has gone not into living it more fully, but simply into assuring the basic structures of daily living that most people who do not happen to have serious physical limitations simply take for granted.

If people need more support than the Halls, then the inability of statutory services to respond to individual living patterns may become critical. To get up and go to bed at irregular times mostly spells only inconvenience to Barbara Pestell — though the presumption that she must fit official timetables rather than setting her own can certainly be questioned. But if she had to get to work each day by a certain hour, as others may have to do, then what is now inconvenience would soon become an impossible barrier to the effective living of her life.

From the nine lives recorded here, it seems almost axiomatic that the more personal help people need, the further they have to go from reliance on statutory services to find it. This raises its own questions for those services. Are they going to increase and streamline their own provision so that it does become capable of meeting individual needs and so express the spirit of the Chronically Sick and Disabled Persons Act? Or are they going to admit that this is beyond them? If the second, how great will their commitment be to ensuring that alternative, non-statutory services should exist for all those who may need to draw on them?

There are questions, too, about what the shape of those services should be, however they are organised. Should helpers live in? Barbara Pestell is glad that hers do; Bernard Brett prefers his principal helpers to have their own, independent homes and lives, though he has always had at least some relief helpers living in; Diana Staples wishes it were possible to have a rota of visiting helpers rather than just a single principal attendant who lives in her house.

How many helpers do people want? The Wymers and Bernard Brett have both found that having a considerable number helps to minimise the tensions of the very particular relationship that they must have with the people who give them intimate assistance. Diana Staples talks of the reality of those tensions in her own dependence on one principal helper. The Dawes are clear that any more assistance than the few hours' home help they get each week would be an invasion of their privacy.

How long do people want their helpers to stay? Bernard Brett and the Wymers both talk of the difficulties that change may bring and of the laborious business of teaching new helpers their routine. But both see the advantages of a fairly rapid turnover of at least some helpers as well; the Wymers would like there to be a standard six-month contract for local authority employees, such as home helps, renewable only if both parties agree. Diana Staples finds that her present system of six-months contracts suits her well.

People, in short, will have their own preferences. We are back to the need for the greatest possible flexibility to meet them, combined with the reliability that makes it possible for individuals to establish their own chosen pattern of life, which is not dominated by simply assuring its basic structures.

There seem to be four possible models on which that flexibility and reliability could be built.

(a) Good neighbourliness

This option is politically fashionable. The present government has made plain its own antagonism to statutory social services. It has offered its own vision of a future in which communities are freed from the sapping and fallacious promises of public support to rally round their own members, while statutory services become no more than a safety net for those whom the newly-caring communities do not reach. Disillusionment with the statutory social services is not limited to the political right. It was David Ennals who, as Labour Secretary of State for Social Services, urged people to become 'good neighbours' to those who are elderly. The political left has its own arguments against the welfare bureaucracy and its own advocacy of returning control over social provision to the people who use it.

So could people whose disabilities are most severe rely principally for the personal help they need on local networks of informal support, with or without the financial support or other backing of statutory services? The proposition has not been tested. But it seems a highly romantic one. Most of the present good neighbour schemes — and the 3000 discovered in a recent survey seems a considerable underestimate of their numbers — are geared to far more occasional help than people whose disabilities are severe may need; what they like to concentrate on is friendly home visiting, doing odd jobs and providing transport. They certainly see themselves as additions to rather than substitutes for statutory services. They suffer from all the difficulties brought about by a constant shortage of helpers and a fast turnover among those there are; the people who join them are not usually looking for a long-term commitment. They are not spread across the country according to potential need for what they provide: they are concentrated not in the deprived north of the country, but in the prosperous south-east, where there is the largest pool of middle-class women with time and money on their hands. They are not, either, increasing as fast as the huge publicity that came along with the Ennals scheme or current political emphases might suggest that they would be. A good half of them were set up before Ennals even made his appeal.[1]

So good neighbour schemes hardly meet the essential criteria of flexibility and reliability that support systems for people whose need for personal help is considerable must provide. Even if the schemes got far more of the public financial support that seems to make for effectiveness, it's hardly likely that they would change their essential nature. That's not to dismiss them; the urge to help is to be cherished, not put down. Good neighbourliness is something that everyone in this study knows about already, as neighbours, friends and relatives help out in emergencies, offer back-up to their main support systems, accompany them to the shops or run errands for them. But it is not a substitute for those support systems.

That's not to say, though, that the urge to help can't be harnessed and formalised to become an important source of the help that people may need in their daily lives. One way in which this can be done is through cooperative tenancies, which we look at later. The other way is through Community Service Volunteers.

*(b) Community Service Volunteers' One-to-One Scheme**

CSV's whole existence depends on the recognition that people enjoy helping each other. Usually, its volunteers work to bolster statutory social provision. But its One-to-One scheme, which had its beginnings in the occasional placement of volunteers during the mid-1970s with further education students who needed personal help because of severe disabilities, comes nearer to replacing official help altogether in individual lives. The name reflects the fact that it is the only CSV scheme to attach volunteers to individuals, rather than to organisations or groups; each individual will get as many volunteers as she or he needs to sustain his or her chosen pattern of life — which in practice works out as a maximum of three.

Under the scheme, which was officially launched in 1979 with a small DHSS grant, volunteers are working alongside people with severe disabilities in their own homes, where the aim is to act as 'working extensions' who do no more, and no less, than those things that people want to do for themselves but, because of their physical limitations, cannot. They are working with students in further education who need personal help. They are working with individual children in residential settings, and with families where there is a risk of children going into care. By the beginning of 1982, there were about 40 volunteers in the scheme, and with DHSS funding for another two years and an ambition to have 360

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* In August 1982 this was renamed the Independent Living Scheme.

volunteers at work in three years' time, One-to-One is looking like an idea whose time has come.

But for the idea to work as well as it should, there has to be careful organisation and support for the volunteers. Beverley Abbott, the Senior Volunteer Director, insists that CSV is primarily in the business of ensuring a valuable experience for the volunteers; she sees the scheme as being about 'reciprocal caring' between them and the people they work with. This work is far more intensive than any other that CSV takes on — which brings not just more rewards for the volunteers but a need for careful planning to enable them to find them. This is the only CSV scheme which takes only volunteers who have agreed specifically to work on it — a break with the usual CSV principle of simply sending volunteers where there is a need for them.

The volunteers work for a minimum of four months; the average placement works out at six. Local authorities are asked for a placement fee of £45 a month for each volunteer — another break with CSV tradition which reflects just how important it feels authorities' commitment to the scheme to be. They are also expected to pay each volunteer £12.00 a week pocket money and £14.50 food allowance and to find suitable lodgings.* In addition, they are asked to ensure regular supervision for each volunteer, usually from a social worker. And they are asked to find the volunteers some additional work, right away from their individual placement, for their off-duty hours.

Compared with the cost of residential care, these essential supports are cheap at the price. But even so, not all the local authorities in whose patches volunteers have been placed are as cooperative as CSV wants them to be. Some have refused to cough up the placement fee. Others don't seem to realise the importance of regular and sensitive supervision, or of that secondary project which gives both individuals and volunteers a breathing space. Arrangements for board, lodging and pocket money vary from individual to individual and place to place. About half the volunteers at the moment live in with the people with whom they are working; that's the case for Barbara Pestell and Bernard Brett, though it won't be for the Halls. All three have also chosen to, or been persuaded to, meet some or all of the costs of pocket money and board. (Theoretically, though, one volunteer can claim invalid care allowance of £17.75 a week against this; an individual whose

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* From April 1982.

income comes from social security benefits can claim up to £37.20 a week for live-in 'domestic' help,*

Barbara Pestell finds the One-to-One scheme meets her individual needs as no previous arrangement has been able to. Clearly, its potential for people who need a lot of help in their daily lives is enormous. But just how far that potential will be realised looks to depend on how seriously local authorities take their side of the bargain. And it will depend, too, on how far the flow of volunteers keeps going. CSV knows that the current rate of unemployment, especially among young people, has had its effect on that.

(c) The Association of Crossroads Care Attendant Schemes[3]

Crossroads is designed specifically to support households where most of the help is provided by 'able' families, and to relieve stress on the carers. So it is not directly relevant to this study. Nevertheless, the model of support it has developed is one which has considerable implications for people who cannot, or do not wish to, draw on their 'able' families for their regular help.

Crossroads started in 1973, when the less than accurate portrayal of the life and times of a paraplegic character in the eponymous television soap opera prompted a viewer who was himself tetraplegic to contact the producer. The television company was impressed enough by the realities of life beyond the celluloid to make a grant for the development of a prototype family support scheme. Pat Osborne, a district nurse, set the scheme up in Rugby, and the Crossroads movement has grown from there.

Right from its beginnings, Crossroads was based on three important premises — which the lives of the nine people in this book reinforce. The first was that people need help at specific times of their day and not a vague and constant presence throughout it. The second was that it is perfectly possible, by drawing mostly on married women with their own family commitments, to set up a professional service which provides that help at the time which suits the customers. The third was that the staff — whose job description falls somewhere between that of a home help and that

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* At 1981-2 rates (November to November). In July 1982, however, a DHSS ruling disqualified CSVs from eligibility for ICA on the grounds that they are gainfully employed, rather than 'friends' of the disabled person. Two months later CSV, which considers that pocket money cannot be called a wage, was still fighting what it considers a highly unjust ruling.

of a nursing auxiliary — need only the training which the customers themselves and their families provide.

So Crossroads care attendants will help people get up and off to work; they will come at the time the customers specify to help them to bed; they will sleep in overnight to give caring families an occasional break; they will come in at a regular time to allow the principal carer time for herself or himself. They will, in short, offer support at precisely the time when the statutory services are off duty, or in a reliable way that these services seemingly cannot guarantee. And because they tailor their work to what individual families actually want, they make it possible for 20 families to carry on coping for little more than the cost of a single social worker. Even if families also have the help of a district nurse and/or home helps and meals on wheels — as about half of the predominantly elderly customers have done — Crossroads makes financial as well as often sanity-saving sense.

There are currently about 40 Crossroads schemes across the country, and a good many people wish there were a lot more. Their management is drawn from health and social services and local voluntary agencies, but dependent on none of them. Funding varies, but many schemes depend on joint-financing between health and social services authorities. Some local authorities are now taking up the Crossroads idea to launch their own schemes; these, however, are independent of the Crossroads Association.

There are a whole lot of advantages to Crossroads. It is a strictly professional service, relying not on goodwill but on staff who are paid slightly more than the going rate for home helps and supported by a paid organiser. It is geared to taking people the help they decide they need, not to providing what the agency thinks they should have — and its independence of statutory authorities enables it to do this. It seems, in short, to offer both the flexibility and the reliability that support schemes for people who need considerable personal help must achieve. So it offers a model on which services to the people with whom this book is concerned could be developed.

(d) Independent options

After the nightmare of recruiting her own housekeepers, Barbara Pestell welcomes the security CSV brings by both taking on recruitment and stepping in if there are difficulties once the helpers have arrived. The Wymers would like to see established — either by statutory services or privately — a back-up 'service agency' on which disabled people could draw for helpers, either occasionally or permanently; they are, however, adamant that users of the service should still handle their own payments to its workers, and remain in control of their own system. Diana Staples wishes that it were possible for her to have control over the hiring and payment of her own attendants.

So once again there are no general rules. Some people will welcome the sharing of responsibility for their support systems; others will not. Once again, it's flexibility that's needed. This has important implications for housing-support packages and for personal finance.

IMPLICATIONS FOR HOUSING-SUPPORT PACKAGES

The legislative and bureaucratic barriers in the way of welding housing provision with enough support to meet the daily needs of people who need a considerable amount of help are not immutable. If rules can be made, they can also be remade. So the question becomes whether they should be, and if so, how?

There has been no shortage of discussion over the last decade on ways to wrap the housing-support package so that it provides the flexible and reliable support that people may need but does not, in doing so, segregate the places in which they live from the general run of housing in their communities. In his *Designing for the Disabled*, Selwyn Goldsmith looks at seven possible packages.[13]

The 'special village', exemplified by Het Dorp in Holland, offers, he finds, a high quality of accommodation and the certainty of support, but its way of life, despite its planners' intentions, turns out to be completely segregationist; certainly there is no clamour for this sort of package in this country. A quite opposite suggestion, that people could be 'boarded out' with households that would offer them the help they need, Goldsmith dismisses as 'cloud cuckoo land'. Although some current experiments with supported lodgings for people who have been mentally ill, or are mentally handicapped or elderly are beginning to challenge that outright scepticism, this particular package does seem unlikely to fit the preferences of many of the people this book is concerned with, even if the supportive households could be found.

Two other packages which try to combine the essence of independent living with the degree of support traditionally offered only in residential institutions seem to show that what results is simply a mish-mash which is neither one nor the other. The Danish Collective Houses, of which there were nine at the start of the 1970s, offer a third of their tenancies to people who need a lot of personal help because of physical limitations, together with communal and particular support. But once the nursing unit for people with respiratory polio, the hostel for single younger people and the workshops and communal restaurant are added to 170 flats to make up the largest of these Collective Houses, in Copenhagen, 'ordinary' independent living is hardly the name of the game. From Goldsmith's observations, it seems that the intended 'integration' between the tenants who have disabilities and the ones who don't hardly happens at all.

One British attempt to combine the support an institution offers with opportunities for independent living seems hardly more successful. The Cheshire Foundation's notion of siting a clutch of bungalows — designed for a couple of whom one partner is 'able-bodied' — near its Home in Crawley, Sussex, is not one that has been widely taken up.

Where do we go from there? There seem to be three possible shapes for the housing-support package to take.

(a) Fokus

For most of the 1970s, it was the work of Fokus, in Sweden, which seemed to act as the exemplar of the best that could be done if only the British rules could be changed to allow for a sensible welding of housing with support. Fokus started as a voluntary organisation, with plans to set up its particular pattern of independent living in every town in the country. By the time it was taken over by the local authorities in 1974, there were 13 Fokus schemes and the number remains the same today.

These developments provide units specially designed and equipped for people with severe disabilities within blocks of ordinary flats, together with some communal facilities. The municipal home help service meets the routine daily needs of the tenants who have disabilities; but Fokus provides its own care staff, who are on call for 24 hours in every day. The model certainly caters for people whose physical limitations are as great as those of the inhabitants of British residential institutions — and seemingly in a way which not only allows for but actually encourages their greatest opportunity of integration into their communities.

But by 1980, it seemed that Fokus was falling quite seriously short of its own declared philosophies. There was no doubt that the physical accommodation suited its occupants who had disabilities; a survey of their views in that year found that 94 per cent of them felt it worked well or very well for them. But even with the supposed advantages of the 24-hour built-in support, this was not enough to give tenants the security that most people would hope to find in their own home. A straight third of the tenants felt some or even great insecurity in their lives. There was a correlation between feelings of insecurity and degrees of handicap. But the more important link was with the scheme in which the tenants lived. Some schemes, it seemed, behaved as if the flats were no more than dispersed institutions, with staff who behaved as if tenants should jump to their notion of control and order. This defiance of Fokus's central aim, which is to give tenants unequivocal control over the shape of their own lives, was not something that had crept in since the local authorities had taken the schemes over; it had already been noticed by Selwyn Goldsmith in visits before that happened.

So the supposed advantages of Fokus's support scheme were far from proven. Not only did it fail to bring security to its tenants' lives, but on the face of it, at least, it seemed to increase their dependence on helpers rather than their self-reliance. The hoped-for 'integration' didn't amount to much, either. The study found that the tenants who have disabilities spent their time much as anyone else, which included a fair number of solitary hours before the television. Many felt isolated, especially at weekends, because of the continuing problems of getting out and about in their communities.

Fokus, Selwyn Goldsmith concluded in 1982, on the strength of this survey and of his own observations, had after all been built on an institutional rather than an independent living model; the dangers of 'latent institutionalism' were inherent in it from the start.[14] His conclusions can be backed by at least one other British observer of the Fokus scene. Philip Rathbone, in his 1980 visit to Sweden, noted that while in one scheme the communal room seemed well-used by the people for whom it was intended, in another it seemed totally unused — a contrast that he ascribed to the relative ages of the tenants in the schemes. Younger Swedes, it seems, do not aspire to feel part of a 'disabled community'; Rathbone noted a tendency among them to move on from Fokus to ordinary housing when they could. He also noted that in one of the schemes at least there were very considerble barriers to integration between tenants: the 'ordinary' flats were quite inaccessible to anyone in a wheelchair.[22]

But if Fokus does not combine the opportunities for truly independent living in the regular community with the assurance of the support that people may need, what housing-support package can? The next model is the one most common in Britain — the housing scheme which takes as it starting point sheltered housing for the elderly, and builds this either into a 'special' scheme specifically for people with disabilities or disperses it through regular, general purpose housing.

(b) 'Special' housing schemes

There are no rules and regulations which specifically govern sheltered housing schemes for people with disabilities. Friendship House in Poole, Dorset, opened in 1972, and was the first of its kind. It offers 25 dwellings, 16 for one person and nine for two, together with communal rooms and staff accommodation. But although the tenants include one young couple who have cerebral palsy, it has not attracted many others in their age-group; many of the tenants are elderly. This may have to do with the fact that younger people don't, on the whole, want to live in a 'special' scheme of this sort; if they can manage with the small amount of help that sheltered housing is able to provide, they may well choose to live in a more ordinary setting. It may be, conversely, that if the support offered by sheltered housing schemes were more intense, more people would choose this option. But there is at least some evidence to show that it wouldn't be high on their list of preferences.

'Special' housing associations which also provide some support, but in housing schemes which also cater for the 'ordinary' mix of tenants, are exemplified by Habinteg, which by 1982 was providing over 600 dwellings in 11 schemes, and was building 400 more, in seven schemes. Habinteg tries to set the stage for as much 'integration' as its tenants choose to develop. It doesn't overload its schemes with the 'special' element: although a quarter of its tenancies are reserved for people who have disabilities, they generally amount to about 10 per cent of its populations. It removes as many of the barriers to free movement within its schemes as possible: while all the flats for tenants with disabilities are built to wheelchair standards, the others are all designed to be accessible to wheelchairs as well. In its mix of 'special' housing — for families with a child or adult member with a disability, for couples who both have disabilities, with or without children, for single people with disabilities, with or without an ageing relative — Habinteg tries to go as far as it can to guarantee that no one will be excluded from its schemes because the shape of their household doesn't 'fit'. (Just how successful it is, however, may depend on how reliable the local authorities' assessment of 'special' housing need manages to be.)

But what Habinteg cannot do is guarantee to provide housing for anyone who applies, and the support they may need to go with it. The rules mean that it is strictly limited in the sort of support services it can build in. Its community assistants — one to each scheme, with a relief assistant — can offer no more than an emergency service to the tenants; the particular arrangements with their community assistant that the Halls had for a while were a one-off provision, not something that Habinteg can afford to turn into a consistent policy. It tries to liaise as closely as possible with local authority social services departments and agencies so that would-be tenants get the support it cannot provide; it is more successful at some times than at others.

So is the answer to change the rules so that housing associations and authorities — and indeed sheltered housing schemes if these are among the options that prospective tenants would choose — can offer a more thorough-going support service? With the growth of 'special needs' schemes among housing associations and the inclusion, for instance, of 'hostels' for young people under that rubric, there already seems to some in the trade to be a crack in the regulations that could be widened.

But if housing authorities were to get squarely into the support business, what would the character of their housing become? It would become more and more like Fokus — a housing-support package which is in fact founded on a dispersed institutional model rather than an independent living one. Part III accommodation is already — in the London Borough of Camden's Boundary Road and the Spastics Society's Neath Hill developments — moving nearer to that independent living model. If housing authorities were to start providing something nearer that sort of Part III accommodation, how long before the two provisions met in the middle to narrow rather than widen the range of options open to people who need personal support in their daily lives? There would certainly continue to be one crucial difference between the two approaches: people living in the housing model would have their own funds with which to construct their lives, rather than relying on the derisory and demeaning 'pocket money' rate which is all the entitlement that Part III residents have if they are not employed. But the tenants of Fokus also have control over their own pensions, if they are not working, and the rents and services are geared to swallow no more than 20 per cent of these. That has not been enough, it seems, to guarantee that they feel in control of their own homes and lives.

Once the same agency provides both housing and support services, in short, the potential for the 'latent institutionalism' that deprives people of effective control over their own patterns of living seems considerable. It is the continued separation of housing and support which seems most likely to guarantee the potential for the space people need to get on with their lives in the way they choose. The conclusion is hardly surprising, perhaps. It does no more than reflect what is normal in the way this society meets the needs of its members.

The continued separation of housing and support also leaves the way open to at least the possibility of a wider range of choice in how both are delivered. The danger of a neat housing-support package that really aspired to work for all of the people all of the time — itself unlikely — is that the place in which it is delivered becomes *the* place that is known to cater for people who need a great deal of support in their daily lives. Things being what they are, it probably wouldn't be long before that place became the *only* place where that package could be found. Yet as the Crossroads study showed, people don't lose their attachment to particular areas just because they happen to be living in housing that is grossly inconvenient for them. People may not want to live in a particular new estate in a particular area. Their work may demand that they live elsewhere; they may prefer to have older property adapted. These are choices to which very many members of this society aspire. Why should people be excluded from them just because they need more help than others if they are to make them work?

If they are to be included in, rather than excluded from, the normal range of choices, then what is needed is not a change in the rules to allow for the creation of housing-support packages. It is work on making all kinds of ordinary housing accessible to them, together with the development of the separate support services which will meet individual needs.

There is, however, one further way of wrapping the housing-support package which seems to bring the flexible and reliable support that people may need without endangering the control that tenants have over their own lives.

(c) Building in cooperation

The first approach under this heading takes as its model the Grove Road scheme in Sutton-in-Ashfield. This scheme was built by the Inskip St Giles (now Raglan) Housing Association, but the idea for it came from prospective tenants, who were closely involved at all stages of the development. The aim was to provide a building which gave these tenants complete privacy and individuality and as much control as possible over their own environment, while at the same time building in elements of the support they decided they needed. The building became a development of six flats — the three on the ground floor for tenants who had disabilities, the three on the upper floor for others. The ground floor flats were carefully designed and fitted to suit the physical capacities of their actual and potential tenants; the tenancy agreement has written in the cooperative model of support.

'Occupants of the first floor units', this says, 'will accept a "supporting family" role in respect of the ground floor occupants. It is not intended that this should be on a specific one-to-one basis, but that all participants in the scheme should accept a cooperative basis of giving/receiving assistance. Within this concept it is important to understand that if any occupant(s) of any flat(s) feels unable to continue participating in this concept the management committee of the housing association reserves the right to terminate the tenancy.'

The ground floor tenants get their help primarily from statutory services; the role of the other tenants is to supplement this. The democratically-constituted tenants' association, the St Bartholomew's Tenants Group, decides on the management of services to common parts of the building, initial aspects of tenant selection and the organisation of and payment for the internal support system. The ground floor tenants pay the supporting families at approximately home help hourly rates, for a guaranteed six hours' help a week, whether that is required or not; payment for more help than this is made pro rata. All the ground floor tenants subscribe to this system, and the supporting families divide payments equitably according to help given or inconvenience caused.

Although the housing association required that it was written into the special conditions of the tenancy agreement that a 'precondition of entry to the scheme is that disabled occupants should be reasonably independent and capable of living an independent life with limited assistance', and although it is the housing association that has the final word on the selection of tenants, all the first ground floor tenants had previously been living in institutions. Their experience of living at Grove Road reinforces their assertion that institutional living fosters dependence. They anticipated, on the basis of that living, that they would need upwards of 20 hours' help a week from supporting families. In the event, the most dependent among them needed only eight hours in the first week, decreasing to between one and two as 'de-institutionalisation' progressed.

As the tenants' group has said, the cooperation clause in the tenancy agreement provides the most important facet of the support system. 'It is flexible, and apart from giving handicapped tenants the security of knowing that there is always someone around on whom they can call in an emergency, it provides the practical daily help so supportive to their independence.'[2,5,8]

The Grove Road scheme has inspired at least one other cooperative venture. Task Force on Supported Accommodation (a development team within Lothian social work department) has initiated a 'Neighbour Support Scheme' in Edinburgh. The six flats in the scheme — three for tenants with disabilities, three for 'supporting neighbours' — are not a special block, but part of a general development of 50 flats, built by Edinvar Housing Association. All the flats allocated to the scheme are on the ground floor and adapted for wheelchair use. They are inter-connected by an alarm/intercom system and will be equipped with all the necessary special aids. Two of the three flats for tenants with disabilities will have two bedrooms, the other will have one. The 'Neighbour Support Scheme' is due to open in the summer of 1982.

Although the intention is that tenants should not need constant attendance or be fully dependent on others for their daily routine, it's anticipated that they will use statutory domiciliary services. The supportive neighbours, it's envisaged, will provide some help with dressing, bathing and toileting, and with shopping, cooking and laundry as necessary; but the most important aspect of their support will be 'as the need arises'. The scheme emphasises that this help will be neither 'professional' nor 'charitable'. There will be a cooperation clause in the tenants' contracts, and it's envisaged that the tenants who have disabilities will pay the others a proportion of their attendance allowance to drive the contract home.

The Copec Housing Trust in Birmingham offers a model for another approach to the housing-support package — this time by maintaining the separate provision of the two elements, but nevertheless making it easier for them to come together. It has adapted an older house so that a tenant who needs a great deal of personal help can live on the ground floor, while the self-contained flat with two bedrooms, kitchen and bathroom upstairs is given over to her helpers. The downstairs tenant pays the rent on the whole house; at the moment, her helpers are two CSV One-to-One volunteers.

This study suggests that some people, at least, would prefer their helpers not to live with them if the flexibility and security of support they need could be assured in some other way. The Copec arrangement allows for both the flexibility and the security — but for normal privacy and independence for both parties as well.

Beverley Abbott, who runs the CSV scheme, wishes that more housing designed for people with disabilities could make provision for the helpers they may need in this way. Significantly, perhaps, the adaptation was not dreamed up by Copec out of the blue. It was a specific response to a specific individual need.

IMPLICATIONS FOR FINANCES

The Dawes were able to move to the area they wanted to live in and have the house they wanted adapted to their specifications at least partly because they had the money to put down for a mortgage. Bernard Brett was able to buy the house that suited his chosen way of life and can sustain that pattern because he has some private means. Barbara Pestell could not, she says, go on living in her house without financial help from her brother. There is no getting away from money.

And for some people, it seems, there is no getting enough of it to meet the extra costs that their disablement brings. The different allowances introduced during the 1970s make a sometimes important contribution to the finances of the people whose lives make up this book; Bernard Brett emphasises the major improvements there have been in state benefits over the past decade or so, however inadequate they remain. But when the Halls get little change from one of their weekly mobility allowances after a single visit to the dentist, the allowance hardly offers them a sustained opportunity to move freely about their community. When the Wymers have to find more than £10 a week over and above their attendance allowances just to pay their helpers, it's clear that for some people the benefit doesn't meet the costs. Bernard Brett has had to find over £5900 a year to meet the costs of help, when his combined attendance and mobility allowances bring in just over £2000. He, like others in this book, would like a job that brings in a decent salary. But for some, it seems impossible to find work which would pay more than social security benefits. Robin Dawe emphasises how the current 'either benefits or earnings' rules act to keep people poorer than they might otherwise be.

Yet ironically, current economic policies mean that the housing opportunities for people with disabilities who can summon the necessary cash are at last becoming brighter. 'I am in no doubt at all', John Stanley, Minister for Housing and Construction, told the Royal Association for Disability and Rehabilitation conference in October 1981, 'that in the 1980s we can and should look to the private sector — to the housebuilding industry and to the building societies and banks — to make a major and sustained effort to meet the requirements of those disabled people who want to own their own homes.' He brought good news from the chairman of the Building Societies Association, who gave the assurance that his members 'readily recognise the special housing needs of disabled people and do whatever they can to help such people obtain the accommodation they require', by being willing to lend for not only adapted housing but modifications. The National House Building Council, in its 1980 advisory note on housing for people who are elderly or disabled, identifies this as a potentially growing market, as so few suitable houses are being built. The Council has since suggested to housebuilders that they should advertise their willingness to alter standard specifications for purchasers with disabilities; it has offered an award to the local authority which makes the most land available for the building of houses for sale to people who are elderly or disabled.

Mr Stanley asserts that 'many disabled people are as keen to own their own homes as anyone else'. The question is how, as their opportunities for employment get ever-bleaker, they are to find the cash to do it. Bernard Brett points out that home ownership brings not only security but an asset which more people could use to widen their opportunities if a realistic grant to help with moving costs were introduced. He suggests that housing should be provided for people with disabilities as of right, as a 'form of positive discrimination that would enable many thousands of people to find a real place within the community'. At the very least, he suggests, a special fund of the Housing Corporation might make loans or arrange mortgages for people whose disabilities are very severe.* How likely is even that second suggestion to be put into action?

The cost of housing is one thing. The cost of support is another. Statutory services look to be getting less and not more capable of meeting the needs that people may have for flexible and reliable personal help. Where is the cash for alternative support systems to come from if people are not working and do not have private incomes? The CSV One-to-One scheme offers a way round the question by expecting local authorities to meet the cost of help — which is already 'subsidised' by the volunteer status of the workers. But direct answers to the question are few.

The supplementary benefit allowance for visiting domestic help is often not what people need most. The current commercial rate for a live-in housekeeper is between £45 and £60 a week;

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* See Bernard Brett's chapter 'The Need for Housing' in *Disability in Britain*.[27]

attendance allowance at the higher rate plus the supplementary benefit allowance for live-in domestic help will buy one. But what if people don't want live-in help, or if they need additional back-up? Is it reasonable that the Wymers should pay not far short of half their weekly, state-provided, income simply to assure the basic structure of their lives?

The St Thomas' 'responaut attendant' scheme, which pays for the 60 hours of help that Diana Staples gets each week, offers a possible model for by-passing such charges for people who are now living in hospital units. Although it was carefully billed as an 'experiment' and its recipients as a 'special case', the philosophy behind it is once more fashionable. The Government's Green Paper, *Care in the Community*, is all about shifting resources from hospitals to community services, so that the many thousands of people now stuck in hospital for want of an alternative, can leave. Although it does not specifically cover people with physical disabilities, there is no good reason why its arguments should not equally apply to them. At least one of its suggestions could be helpful — an annual payment by the health authorities to local authorities for each individual they discharge to their care.[11]

Such a scheme, however, would have the disadvantage that Diana Staples sees in the St Thomas' arrangements: it would leave the financial control with the authority and not with the individual. For some people, this might not matter, as long as the local authority could be persuaded to use the money to create the support system they wanted. For other people, though, it would matter. Diana Staples would like to take full control of her own attendants; neither the Wymers nor Bernard Brett would relinquish control of their support systems.

So there is, in the end, no getting away from ensuring that individuals have the cash they need to organise their own lives. The need for greater employment opportunities for people with disabilities, and the complex business of dovetailing this with financial benefits that meet the extra costs their disabilities bring and the earnings gap that comes with reduced working capacity, goes way beyond the scope of this book. But the whole area is quite critical. It is over 15 years since the Disablement Income Group first started campaigning for a decent disability pension. It is seven since the Disability Alliance, which counts over 60 organisations of and for people with disabilities among its members, began its own campaign. But despite the pledges of successive governments, people with disabilities are still waiting.

The 1970s opened with an assertion, in the Chronically Sick and Disabled Persons Act, that people should get the help they need to enable them to live in their own homes. But if anything, the Act has deflected attention from the thing that people need most if that is to be possible for them. Lists have been drawn and drawn again of the different provisions the Act should have made, without much heed perhaps, to whether people would rather have the resources to buy them for themselves, buy others, or buy something quite different. Help with telephone charges and bath aids are of little use to people who haven't a place in which to install them. The home help service is meaningless to someone who hasn't got a home for the help to visit. If independent living is to be a real option for people who need considerable support in their daily lives, then there is no getting away from cash. As Diana Staples says, 'Give people enough money — and then let them choose for themselves.'

Useful addresses

The following are referred to in the text:

Housing Associations

Habinteg Housing Association Ltd
6 Duke's Mews, London W1M 5RB
Copec Housing Trust
(Special Projects Division), Neville House, 14 Waterloo Street,
Birmingham B2 5TX

Care Attendant Schemes

One-to-One Scheme (now renamed *Independent Living Scheme*)
Community Service Volunteers, 237 Pentonville Road,
London N1 9NJ
Association of Crossroads Care Attendant Schemes
11 Whitehall Road, Rugby CV22 5HT
St Thomas's Responaut Scheme
c/o Administrator, Phipps Ward, South Western Hospital,
Landor Road, London SW9 9NU

Neighbour Support Schemes

Grove Road Scheme
The Secretary, St Bartholomew's Tenants Group, 28-38 Grove
Road, Sutton in Ashfield, Notts NG17 4LR
Edinburgh Scheme
Project Leader, Lothian Regional Council Social Work Department,
Task Force on Supported Accommodation, 2 Cranston Street,
Edinburgh EH8 8BE

Financial and Other Benefits

The Disability Alliance, 21 Star Street, London W2 1QB, produces a comprehensive *Disability Rights Handbook* each year, as well as checklists of the different benefits to which people with disabilities may be entitled, whether in or out of work.

Citizens Advice Bureaux should have relevant leaflets about benefits, including DHSS Leaflet HB1 *Help for Handicapped People*, DHSS Leaflet FB2 *Which Benefit? 60 ways to get cash help*, and the Department of the Environment Housing Booklet No 14, *Home Improvement Grants.*

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Most people whose physical disabilities are very severe must rely on 'able' relatives if they are to live in their own homes. Others who cannot call on this 'informal' help often find that their only alternative is to move to a residential home.

The nine people whose lives make up this book are different. Their disabilities are very severe and they cannot depend on 'able' relatives; yet they have rejected the idea that the only possibility for them is a place in a residential institution and have established homes of their own. Detailed descriptions of their daily lives show the variety of help they have drawn on to make this possible and how hard they have sometimes had to work to find it. Help often started, as the architects' drawings show, with housing adaptations. Over the years, it has included elements of statutory or voluntary services, or informal networks of friendship, and occasionally all three.

These stories challenge policy makers, architects and people working in statutory and voluntary services to look again at their assumptions about what is possible for people with very severe disabilities. They challenge them to recognise that the greatest barriers to independent living may not be physical disabilities, but the barriers created by laws, regulations and services. They show that many other severely disabled people could, with support they choose for themselves, have what most of us take for granted — a home of their own in which they can live as they please.

Ann Shearer is a freelance writer and has contributed to *The Guardian, New Society* and other periodicals. Her previous publications include *Disability: Whose Handicap?* (1981) and *Handicapped Children in Residential Care* (1980).

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