

Ageing with a disability

What do they expect after all these years?

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This report details the findings from the first major study on ageing with a disability in the U.K. To be clear, this does not refer to people who experience disability as part of the ageing process, but to those who are disabled in child or adulthood and who are now ageing. Based on responses from over 200 older disabled people, the report examines people's personal experiences of ageing and the impact this has on their lives. The report focuses on the practical implications of ageing with a disability and considers how well existing supportive resources are matched to older disabled people's self-defined needs and solutions. A model for creating a supportive environment for meeting the range of needs associated with ageing is outlined, together with the practical measures required to put this into effect. Race and gender dimensions to ageing with a disability are also discussed in detail.

The main message from the study is that, many older people feel that their needs – and even their existence – have been overlooked. Many are anxious about the future and feel that their independence is being threatened by the lack of appropriate and acceptable supportive resources. There are many obstacles to older disabled people being able to articulate their needs and – most important of all – have their voices heard. These problems are often particularly acute for older women, and older black and ethnic minority disabled people – many of whom live in extreme isolation. Existing services have mostly reinforced their dependency and the report highlights the need for a more flexible range of support options which would enable older disabled people to maintain control over their own lives. It also suggests that, this will only be possible within a framework of clearly defined rights and entitlements which would empower older disabled people to remove their enforced dependency for themselves.

This report will hopefully make an important contribution to raising awareness about ageing with disability – although many of the issues discussed will also be relevant to the development of policies and services for older and disabled people generally. It should be of interest to organisations of and organisations for disabled people,

statutory agencies responsible for purchasing or providing services, policy makers and planners, and to other individuals and organisations with a personal or professional interest in ageing and disability.

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1. Ageing with disability: the forgotten dimension

Introduction

The ageing of the population in Britain is having a profound impact on social policy, professional practice and academic research. This 'ageing population' is far from a homogenous group; there are important differences between particular groups and sub-groups which need to be identified and acknowledged. One particular group which has been more or less completely overlooked are disabled people who are ageing. To be clear, this does not refer to people who may experience disability as a consequence of the ageing process, but to those who become disabled in child or adulthood and who are now beginning to age as disabled people. Indeed, it is only within the last fifteen to twenty years that there has even been an identifiable cohort of ageing disabled adults, for several reasons. First, life expectancy for many types of disability prior to this was low; second, large numbers of people who became disabled as a result of injuries received during World War II are now

entering older age; third, many children and young adults disabled as a result of the widespread polio epidemics of the late 1940's and early 1950's are now in their 50's or older. Added to this, there are an unknown number of people with various disabilities who have been disabled since as long ago as the 1920's.

Changing patterns of life expectancy brought about by advances in medical technology, treatment and rehabilitation also mean that the size of this sub-group of older disabled people is increasing. While there are no completely accurate figures, we can get some idea of the numbers involved from the two national disability surveys carried out by the Office of Population Censuses and Surveys in the late 1960's and 1980's (Harris, 1971; Martin et al, 1988). The first OPCS survey carried out in 1969 estimated that there were 97,000 'very severely', 'severely' or 'appreciably handicapped' people between the ages of 30 and 49 in Great Britain (Harris, 1971). Assuming that half of this group have survived in the subsequent twenty year period (which is a very conservative estimate), this would mean there are at least 50,000 disabled people alive today aged 50 plus who have been disabled for 20 years or more.

The latest OPCS survey, while using a slightly different classification of disability, estimates that there are now 201,000 similarly disabled people (categories 6 - 10) aged between 30 and 49 (Martin and White, 1988). These figures clearly indicate that the number of people ageing with a disability is continuing to rise. Indeed, based on these figures alone, it is quite probable that this group will double in size within the next twenty years (Zarb, 1992). In addition there are an unknown number of people who would not have been counted under the OPCS classification but who would consider themselves to be disabled. Given the increasing life expectancy for the ageing population as a whole, the true number of people who are now ageing with a disability is probably considerably higher than these conservative estimates suggest.

The number of people who are ageing with a disability is also increasing at different rates amongst men and women, and amongst different ethnic groups. Although the prevalence of some physical impairments is higher amongst males, many of the largest sub-groups of older disabled people contain more women than men. The most recent national survey estimates that there are a total of 3.6 million disabled women in Britain, compared to 2.5 million men. Amongst those aged 75 or more, disabled women outnumber men by a ratio of nearly 2½ to 1 (Martin et al, 1988).

The present population of Britain includes approximately 2/2 million people of ethnic minority origin. There are no national figures but a number of local studies indicate a high incidence of certain physical and sensory impairments

amongst African Caribbean and Asian communities; the high incidence of sickle cell anaemia and thalassaemia amongst people of Caribbean and Mediterranean origin is well known (Begum, 1992; Cox, 1984; DHSS, 1983; Keeble, 1984; Wandsworth CCR, 1978). In addition, there are an unknown number of refugees from various countries, some of whom have impairments associated with war, torture and so on. Largely because of migration patterns, the ethnic minority population has a younger age structure than the indigenous population; for example, around 4% (approximately 97,000) of the African Caribbean and Asian populations had reached retirement age by 1986, compared to around 17% of the white UK population (CRE, 1987). So, although it is not possible to state any overall figures, the prevalence of ageing with disability amongst ethnic minority communities is also likely to increase significantly over the next decade and beyond.

The current context

In 1980 the DHSS identified physical disability as one of the four priority areas for service development. Despite numerous studies in the subsequent ten years which have identified the appalling state of disability services (Beardshaw, 1988; Fiedler, 1988), critical reports from committees set up by the government (e.g. McColl, 1986) and the expressed concern of organisations like the Kings Fund, the Royal College of Physicians, the Audit Commission, British Council of Organisations of Disabled People (BCODP), and the Prince of Wales Advisory Group on Disability, almost no significant service developments have taken place. What resources have been available have often been wasted on inappropriate services which either fail to meet disabled people's real needs, or at best provide only partial solutions (BCODP, 1988; Zarb et al, 1990). Against this background of neglect it is not all that surprising that people who are ageing with a disability have been more or less completely overlooked.

Following publication of the White Paper 'Caring for People' and the passing of the Disabled Persons (Services, Consultation and Representation) 1986 and NHS and Community Care Acts 1990, the organisation of community care services is moving towards a social market model of provision with a greater emphasis on disabled people as consumers of services. It remains to be seen, however, whether these legislative changes will result in genuine improvements in the quality of disability services or enable disabled older disabled people to have greater choice and control over their lives.

While these changes place individual needs at the centre of service provision, because so little is known about the needs of people who are ageing with a

disability, it is likely that their own particular needs may get lost in the broad sweep of policy change.

The rhetoric of consumerism, efficiency and individual choice also has to be set against a background of a concerted effort throughout the 1980's to encourage family and other informal and voluntary support for older and disabled people in order to ease the pressure on public services. There is a clear expectation that public services are only intended to supplement informal and voluntary support. The ability and/or willingness of older people's families (and others in their 'informal support networks') to meet this expectation has, however, remained unquestioned by policy makers (Dalley, 1988). Obviously the longer-term impact of these policies will depend on the availability of supportive resources and, more importantly, the political will to use such resources in ways that match up to disabled people's own needs and expectations. With so much potentially at stake, it is particularly important that the needs of previously neglected groups are given a much higher profile on the policy agenda.

This report will hopefully make an important contribution to raising the profile of one neglected group - people who are ageing with a disability - although many of the issues discussed would also be relevant to the development of policies and services for older and disabled people generally.

2. A framework for understanding ageing with disability

The dimensions of support for people who are ageing with a disability

While there have been several studies which have looked at support needs of different groups of disabled people, there is very little information relating specifically to the needs of people who are ageing with a disability. What there is, however, suggests that they do not receive a very priority in the provision of supportive services. The recent study on ageing and people with learning difficulties (Hogg et al, 1988), for example, found that older people with learning difficulties and their families make very little use of what services are available. They suggest this is partly due to reluctance on the part of the families concerned, but also on the inappropriateness of existing services to meet their needs. Also, echoing the anecdotal accounts from other groups of disabled people (eg. Corbett, 1992), the present learning difficulties who are ageing have lived through earlier decades services currently available did not exist. As a consequence, they have a very high degree of self-reliance (Hogg et al, 1988, pp.280-81).

Other studies (eg. Wertheimer, 1981) have also highlighted that older people with learning difficulties are treated as a very low priority by social services. There have been several studies which make the same point in relation to the needs of elderly and social services clients (Brearley, 1975, 1978; Challis and Davies, 1980; Marshall, 1990). We also know from studies which have considered service use amongst various groups of disabled people that, they too are often treated as low priority by statutory support services (Beardshaw, 1988; Blaxter, 1980; Glendinning, 1986; Oliver et al, 1988; Owens, 1987).

Lack of flexibility in support provision obviously creates considerable practical difficulties for any disabled person. However, the problem may take on another dimension in older age if and when people find that their support needs have changed, quantitatively and/or qualitatively. As Beardshaw points out, uncoordinated and inflexible support provision will present even more acute problems for people with fluctuating or gradually increasing needs (Beardshaw, 1988, p.25).

Information is also a key pre-requisite to disabled people having genuine choice and control over how their needs are to be met. Without information about available resources, how to access services, or about their rights, it is impossible for people to make genuine choices or determine what kind of support is most appropriate to meet their self-defined needs. However, previous research has often highlighted information poverty as a major constraint on providing appropriate and adequate solutions to disabled people's support needs (eg. Beardshaw, 1988).

These various obstacles to self-determination and adequate support are thrown into even sharper relief for the majority of older disabled people who have lived most of their lives without ever using any services or often, even considering that they might do so. As Macfarlane (1991) points out, the combination of this experience and the wide ranging obstacles for people wanting to access appropriate supportive resources means that many older disabled people will simply be left with no support at all;-

"Provision of appropriate services at a time and frequency acceptable to older disabled people who have lived for a long period the lifestyle of a non-disabled person are often hard to access, or inadequate. What is on offer in the way of housing and personal support is often refused or rejected as not being suitable" (Macfarlane, 1991, p. 18).

Regarding living options, there are practically no published studies relating specifically to the environmental or housing implications of ageing with a

disability. We can, however, derive some of these from the literature relating to older people, and to disabled people in general.

There are various factors which may lead older people either to choose a change of accommodation, or to make alterations to their present home. In some cases, changes in physical capacities may create a need for adaptations (Newcomer and Bexton, 1978; Zarb et al, 1990). Changes in family circumstances - eg. the death of a partner - may make moving to smaller, more manageable accommodation a practical option (Harrison, 1973). However, due to the lack of accessible homes in the general housing stock and the long waiting lists for housing association or local authority houses and flats, finding alternative accommodation following a decision to move can be extremely difficult (Borsay, 1986; Laurie, 1991).

Also, the allocation policies of some housing associations which operate arbitrary age and/or disablement criteria for their tenancies may present further obstacles to finding suitable accommodation. Where places in sheltered accommodation are available these are often in homes predominantly inhabited by very elderly people (Harrison, 1987; Means, 1986/87). This is not an acceptable solution for people who may well be 20 or more years younger than most of their neighbours and, consequently, feel socially isolated. The vast majority of sheltered housing units are designed for single person occupancy, and so would not be suitable for many disabled people living with their partners in any case.

The longer-term consequence of these restrictions on obtaining suitable housing can be that, even if people have already made changes in their living arrangements, further moves may have to be considered (Landsberger, 1985). There is the possibility that the only option remaining for some people will be a move into residential care. However, apart from the fact that this is likely to be an unacceptable option for many people, often it is simply unnecessary as any support they need could be provided in their homes.

There are several reports on the kinds independent living options available to disabled people written from the perspective of disabled people themselves both in the U.K. (eg. Davis, 1981; Laurie, 1991; Morris, 1990; Thompson, 1983), and in other countries (eg. Ratzka, 1986; Swain, 1988). There has not been very much consideration given, however, to the appropriateness of these various options to the needs and preferences of older disabled people.

As Macfarlane (1991) points out, while some of the principles of independent living currently promoted by the disability movement as a whole may be appropriate to the needs and preferences of older people, some may not;

"Older disabled people's expectations may be different from younger disabled people Many older disabled people are content with their once-a-week outing for a hairdo and do not want necessarily to take on board or understand the issues that have prevented them from leading more independent life-styles. They just want to be able to get their own cup of tea and feed the cat" (p.18).

This also has a particular bearing on the issue of disabled people employing and controlling their own personal assistants. As De Jong (1986) points out, older people may not want to have the responsibility of organising their own personal assistants and may prefer a more structured system of support. Obviously, however, this cannot simply be assumed; whatever options might be developed, clearly these must be based on the solutions defined by older disabled people themselves.

Being able to obtain appropriate personal assistance and living options is also very much dependent on people having adequate financial resources. Yet, numerous studies have shown that a large proportion of disabled people not only have lower than average incomes, but also have a wide range of extra disability related costs (Baldwin, 1977; DIG, 1988; Disability Alliance, 1988; Durward, 1981; Hyman, 1977).

Further, many of the extra costs associated with disability will be cumulative over time. Consequently, many older people's real (i.e. disposable) incomes will be progressively reduced over time - particularly following retirement. At the same time, financial resources in retirement will obviously be very much dependent on the income people receive during their working lives. Some people will have occupational pensions and/or savings in addition to their ordinary pensions, while others who may have had restricted opportunities for employment will only have subsistence incomes made up of state benefits. Obviously, this will have a significant impact on the quality of their lives in older age.

Regarding health services for disabled people there is often a lack of even the most basic knowledge about disability amongst the medical profession and little attention has been paid to longer-term effects and the possibility of renewed or progressive physical deterioration associated with ageing.

There are also question marks against existing models of rehabilitation which fail to recognise that individual needs and goals extend beyond physical/functional rehabilitation - however important that may be - and often continue to evolve over time. In particular, there is often an alternating balance between the need for health care and social support requiring a much greater degree of flexibility than currently exists. The view of rehabilitation as a finite

process also poses problems for people wanting to re-negotiate access to services at different times during their lives. This is particularly true for older people who are likely to experience changes in both physical/health status and personal/domestic circumstances over time (Zarb, 1992).

Further, this problem is exacerbated by the way in which different groups are classified for the purposes of service provision. Specifically, within the broad category of 'people with physical disabilities', a further distinction is made between 'young (or younger) disabled adults' aged between 16 and 65, and the rest. However, as the 'young disabled' actually constitute only a minority of disabled people, and the common practice is for older disabled people to all be classified as 'elderly', this arbitrary classification does more harm than good;

'It has become common practice to identify dependent older people in terms of ageing rather than disability, so that 'the physically disabled' are, in fact, a kind of residual category Although they make extensive use of health and social services, there are usually too few formal arrangements for dealing comprehensively with their needs" (Harrison, 1987).

Gender and race dimensions to ageing with a disability

Although practically all the issues discussed above are of universal concern to older disabled people, it would be a mistake to imply that the experience of ageing is the same for men and women, or for people of different races and cultures. Similarly, there are also likely to be important race and gender dimensions to how older disabled people define their own individual needs, which need to be explored and highlighted.

Gender

Both old age and disability are dimensions of experience which are fundamentally linked to gender (Arber and Ginn, 1991; Morris, 1991). Gender is also a particularly important factor in determining whether or not individuals are supported or prevented in their attempts to live independently. Social expectations and other barriers often force women into economic and other forms of dependency. Consequently, disabled women face a particularly acute struggle to overcome the obstacles against them controlling their own lives, or even defining their own identities.

Indeed, other studies have shown that disabled women are often treated as 'invisible' by a society which fails to meet their most basic needs, and is unable to respond positively to their efforts to take control over their own lives (Lonsdale, 1990; Morris, 1989, 1992). This invisibility is fundamentally

related both to ideological factors such as ideal notions of womanhood and femininity, and to material or structural factors such as the inaccessibility of the environment, lack of employment opportunities, and an income maintenance system which systematically disadvantages women.

These obstacles throughout their lives combine to effectively force dependency on many older disabled women. At the same time, despite the obstacles to their own independence, many disabled women are still expected to provide support for others. For example, whereas the majority of disabled men have their personal assistance needs met by a spouse or partner this is much less likely for women, for whom help with personal assistance is more likely to come from other (mostly female) family members (Green, 1988).

Another important difference relates to the supporting relationship itself. It might be argued that, men often have the expectation that women (usually wives or mothers) will provide personal assistance or other support if they are disabled. However, as Morris (1989) points out, often the opposite expectation is placed on disabled women;

".... as women, part of our return to 'normal' life is often a return to the pressures of looking after other people. Aids and adaptations which are supposedly about helping us to be independent are in fact about enabling others to be dependent on us"

All of these issues affect disabled women throughout their lives and, consequently, are essential to understanding their experiences and needs in older age.

Race

Practically nothing is known about the race dimension to ageing with a disability. However, the evidence from more general studies on older people highlights the ways in which African Caribbean and Asian elders in particular are disadvantaged (in income, housing, health, and access to services) relative to older whites. As members of a minority group they also experience the particular disadvantage of racial discrimination (Hill, 1991, 1992). There is also considerable evidence of unmet support needs amongst African Caribbean and Asian disabled people of all ages (Ahmad, 1988; Begum, 1992; GLAD, 1987).

Some writers have suggested that older people from ethnic minority communities are in 'double jeopardy' (Dowd and Bengtson, 1978). Class and gender, as well as race and age, are important dimensions of inequality; the

cumulative effect of these factors have led to consideration of 'triple' or 'multiple' jeopardizes in describing the experience of different sub-groups, particularly within the black population (Norman, 1985). More recently, however, black disabled people themselves have argued that this kind of conceptualisation fails to speak to their own experience (Begum, 1992; Stuart, 1992). Rather, the emphasis should be on 'simultaneous oppression' as this avoids the marginalisation of their identities and focuses more clearly on the fact that the inequalities faced by black disabled people are shaped by racist, disablist and patriarchal structures at the same time.

It is also important to acknowledge that many older black disabled people live in extreme isolation, their existence often unrecognised even within their own communities (Hill, 1991). This, combined with the direct effects - both personal and practical - of systematic discrimination, means that black disabled people are often effectively denied even the most basic rights of citizenship;

"Black disabled people, I have found to my cost, are a discrete and insular minority. We have been unfairly saddled with restrictions and limitations, subjected to a history of purposeful unequal treatment and relegated to a position of political powerlessness and disenfranchisement in a society where even the label 'second class citizen' seems wholly inadequate to identify our social status." (Hill, 1991, pp. 45-6).

Note: The background research for this project included collating relevant information from other studies on the needs and experiences of older and disabled people from black and ethnic minority communities. A separate briefing paper which discusses these experiences in the wider context of institutional racism and the development of policies on race is available as a supplement to this report.

Disability, multiple oppression and ageism

Consideration of gender and race dimensions to the experience of ageing with a disability points directly to the need for a conceptual framework which not only encompasses the impact of sexism and racism, but also links these to both disablism and ageism. In other words, a framework which recognises that these are all forms of multiple oppression and, consequently, are all equally important dimensions to the experience of ageing with a disability.

Further, as noted earlier, the various forms of multiple oppression must also be seen as simultaneous oppressions. To be clear, this does not mean that effects of, say, sexism, racism and disablism on the lives of black disabled women can

be seen as 'additive', or even 'cumulative', as this only serves to atomise, distort and marginalise such experience. Attempting to view multiple oppressions in this way makes no more sense than asking whether a black disabled woman is 'more oppressed' because she is disabled, or because she is black.

Rather, as Morris (1992) points out in discussing the relationship between sexism and disablism, the key issue in addressing multiple forms of oppression experienced by disabled people is that they must be viewed within a unifying conceptual framework which places such experience at the centre of both political and research agendas. In the case of disabled women's experiences, she argues, this throws out a particular challenge to mainstream feminism - which has ignored the mutual oppression faced by disabled and non-disabled women or, at best, treated disability "*as a supplementary issue*" (Morris, 1992, p.162). Similarly, Stuart (1992) argues that understanding black disabled people's experiences is only possible within a framework which addresses race and disability in the wider contemporary and historical context of institutional racism.

Consequently, while this report will attempt to highlight particular concerns and experiences of black disabled people and disabled women wherever appropriate, we view such experience as being inextricably linked to the central issues which the report is seeking to address. Namely, to identify the obstacles to older disabled people being able to retain control over their own lives, and the solutions which need to be developed in order to overcome them. So, while the experience of ageing with a disability is central to the conceptual framework we have adopted, we contend that this can only be properly understood alongside the simultaneous forms of oppression linked to sexism and racism and the impact these have on people's lives.

However, while the links between multiple forms of oppression associated with disablism, sexism and racism are now beginning to be recognised (Abberley, 1987), and clear evidence of institutional discrimination experienced by disabled people has been documented (Barnes, 1991), there is little acknowledgement of how these are linked to ageism. This is perhaps surprising in view of the fact that ageism is a form of oppression which - although not completely universal - certainly cuts across and reinforces all of the others.

Elsewhere, we have suggested that, as with all "isms", disablism is fundamentally linked to the structural position of disabled people in the process of production (Oliver and Zarb, 1989; Oliver, 1990). This applies

equally to understanding the position of people who are ageing with a disability

"... the economy, through both the operation of the labour market and the social organisation of work, plays a key role in determining societal responses not just to ageing and disability but consequently also to ageing with a disability. Both old people and disabled people are forced into situations of dependency because they do not participate fully in the processes of production" (Oliver, 1992, p. 254).

Similar observations have been made in relation to ageism and, in particular, the ways in which this has become institutionalised within industrialised societies (Dowd, 1980; Featherstone and Hepworth, 1990; Minkler & Estes, 1984; Townsend, 1986). As Norman (1987) points out, the consequence of this is that older people are devalued and marginalised, treated as objects of pity or fear, and labelled with a whole range of overtly derogatory stereotypes. Again, however, it is important to emphasise that ageism and disablism are simultaneous, rather than simply parallel forms of oppression and that;

"it would be wrong to assume that old disabled people simply experience a double dose of dependency; to put the matter simply, to be old and disabled is not twice as bad as merely being old or merely disabled" (Oliver, 1992, p.254).

Despite this, while ageism, sexism and racism are now almost routinely included in any credible discussion of multiple oppressions, there has been almost no sustained dialogue on the links between ageism and disablism, even - it has to be said - within the disability movement itself;

'As a nation we are still unaccustomed to discussing disability in a way which is meaningful, constructive and which leads to a positive outcome. We are often unwilling to confront the issue of ageism and how it is likely that we all experience some form of disability purely through accepting life as a continuum' (Macfarlane, 1991, p.18).

There are parallels in this with the exclusion of older and disabled women in mainstream feminism (Morris, 1992), and with the exclusion of disablism generally from most analysis of various forms of oppression - multiple or otherwise (Oliver, 1992). Further, the long-term experience of such marginalisation often means that people who are ageing with a disability seem to be powerless to resist their exclusion, or to challenge their enforced dependency;

'Many older disabled people who have always known disability missed out completely on anything remotely resembling independent living They have also missed out on acquiring educational and social skills that non-disabled people take for granted Many will still be treated as children because when forced dependency is in operation it instills in the disabled person that they are a burden not only to themselves but to the whole community' (Macfarlane, 1991, p.16).

As this report will aim to demonstrate, acknowledging the impact of ageism is central to a proper understanding of the ways in which multiple forms of oppression impact on the lives of older disabled people. We are not necessarily claiming, however, that the conceptual framework sketched out here is in any way complete for, as we have suggested elsewhere;

"Whether simultaneous oppression offers a more adequate way of understanding disability is something that only further, more developed emancipatory research can show. Whether such a concept can cope with old, black, gay, disabled people remains an open question the work is only just beginning" (Oliver, 1992, p. 254).

We hope that this report will make a positive contribution to developing this understanding by highlighting the range of disabled people's experiences of ageing, and the implications for developing appropriate supportive resources and practical policies which would enable older disabled people to maintain control over their own lives.

Before moving on to discuss these experiences, we outline the background to this project, how it was carried out, and describe some of the characteristics of the people who participated.

3. About the ageing with a disability project

Background to the project

This study was prompted by two separate but related concerns arising out of our previous research on ageing with spinal injury (Zarb et al, 1990).

First, the earlier study suggested that the ageing process often has far reaching implications for the quality of older disabled people's lives and highlighted the lack of appropriate and acceptable supportive resources for meeting their needs.

Second, we were aware of a new body of research suggesting that people who had been disabled for 20 or more years as a result of poliomyelitis were beginning to experience a variety of physical problems which seemed to be late effects of their original impairment and which came to be termed 'post-polio syndrome' (Codd & Kurland, 1985; Laurie, 1984; Maynard, 1985). Other work provided further evidence of this and suggested the possible existence of an equivalent phenomenon to the 'post-polio syndrome' relating to late effects of spinal injury (Trieschmann, 1987; Whiteneck et al, 1992). The findings from our own study were consistent with these ideas and pointed to a need for further investigation to explore whether other groups of ageing disabled people may have similar experiences.

Identifying participants and issues

Both of these issues were increasingly mirrored in concerns being voiced by various groups of disabled people themselves. A few groups had organised seminars about issues around ageing and an increasing number of anecdotal accounts were appearing in the newsletters of various organisations like Spinal Injuries Association, the British Polio Fellowship, and the Spastics Society. Two themes in particular were consistently highlighted in these accounts. First, that older disabled people are anxious about maintaining their independence; second, that many people feel that too little attention is being paid to their concerns. Both of these themes were clearly reflected in the film - 'Survivors' - made by a producer with personal experience of ageing with a disability;

"What do we fear as we age? We fear loss of independence. That is a consensus and I do not think any of us feels very confident about what is going to happen." (Corbet, 1987, p.3)

"What are our expectations for ageing with a disability? We do not know. Most of us do not think anybody else knows either, that is a constant refrain. Being part of a newly surviving population makes us nervous. I think the message is that we would like to know more than we do now." (Corbet, 1987, p.4)

In this project the research was extended to cover the ageing experience amongst people with a wide variety of long-term (defined as 20 plus years) physical disabilities or disabling illnesses including diabetes, polio, multiple sclerosis, scoliosis, parkinsons disease, and arthritis. The research was conducted in three overlapping phases. First, short articles informing people that the project had been set up were published in the newsletters of various disability organisations whose readers were likely to include people who were ageing with a disability. In some cases, a leaflet about the project was

distributed along with other mailings to members in the areas of the country covered by the survey. Requests were also sent to clients of Medway (40) and Greenwich (30) Social Services Departments on our behalf. However, these did not produce a very large response. (See Appendix A for full details).

The leaflets and articles included a request for people interested in participating in the study to phone or write in to let us know about their own personal experiences and what they thought were the most important issues around ageing which the project should address. This eventually led to a total of 300 people volunteering to participate in the study. 237 of these were resident in the Southern half of England (the catchment area advertised for follow-up interviews). The other 63 were from all over the U.K. and 4 people from France, Australia and Canada who had heard about the project also contributed with written accounts of their own thoughts and experiences.

Even after allowing for people who lived too far away to be interviewed, the number of volunteers was still more than three times higher than the 70 or so we had expected to interview. (In fact, there would have been an even higher number of volunteers if we had not asked organisations who were still publicising the project to stop). Consequently, even though money was made available for an extra interviewer, it was still not possible for everyone to be interviewed in person.

It was very clear, then, that there was considerable interest in the project amongst older disabled people. In fact, we had not had much doubt about this at the start of the project although we did anticipate that actually finding enough people to participate might be a problem. Clearly this was not the case and the fact that so many people came forward, even from a comparatively limited range of sources, indicates the level of concern amongst older disabled people that issues around ageing need to be highlighted.

Following discussion with the project advisory group, it was decided that the most sensible option for the second phase of the project would be to take a quota sample which would be proportionately representative of the numbers of men and women amongst the volunteers and the numbers in each disability group. In the event, although the final interview sample was broadly representative, the quotas were not all completely proportional for the following reasons;- a) some groups who had been contacted early on in the project had already been interviewed and so were slightly 'over represented' in the final sample; b) because there were only a very small number from particular disability groups, it seemed more sensible that all of these should be

interviewed rather than a quota; and, c) because of this, the numbers in some of the larger groups had to be reduced.

Altogether 101 people (61 women and 40 men) from the original 300 volunteers were interviewed in person between the summer of 1990 and the end of 1991. About two thirds of the remainder contributed oral or written accounts; most of these were fairly short, but some were almost as detailed as the interviews themselves. (Full details of how the sample for the interviews was drawn up are given in Appendix B).

Outreach work with African Caribbean and Asian Communities

The project has also sought to address the race dimension to ageing with a disability. However, the membership of the local and national disability organisations who assisted with the project would appear to be predominantly white as only 3 African Caribbean or Asian people and 6 people from other ethnic minority communities were included amongst the 300 who originally volunteered to participate. Consequently, during the second phase of the project, further attempts were made to locate ageing disabled people from ethnic minority communities (primarily of African Caribbean and South Asian origin) through numerous community groups, local support agencies, community centres, and churches in areas with high black and asian populations; a circular requesting help with locating volunteers was also sent to General Practitioners throughout South East Thames Regional Health Authority area (see Appendix A). These various sources failed to produce any significant response for the following reasons.

First, most of the community groups contacted do not have the resources or the organisational mechanisms to identify people with long-term disabilities; those who did agree to help were mostly only able to do so by word of mouth contact with particular individuals who might be willing to participate. Second, the methods used for contacting members of disability organisations who did participate in the study (i.e. letters to people on membership lists and articles in newsletters) are often inappropriate for reaching people in black and asian communities; asking community groups to distribute leaflets direct to possible participants subsequently proved to be more appropriate, although this method is much more time consuming. Third, there is widespread mistrust (and in some cases, hostility) towards research amongst black and asian communities, as previous reports and recommendations are not seen as having produced any improvement in support provision. Further, a small number of people who were identified as potential participants could not be included as none of the research team spoke any of their community languages. Finally, the amount of time needed to identify contacts, follow-up

suggested leads, chase nonresponders, and generally raise awareness about the project was much greater than originally anticipated.

Because of these difficulties it was only towards the end of the original project timetable - and after switching to direct leafleting - that any progress at all had been made in locating older African Caribbean and Asian disabled people who might have been willing to participate. Also, the few positive contacts that had been made came too late for participants to be interviewed within the time remaining.

Consequently, further funding was approved in order to employ two outreach workers/interviewers to follow-up existing contacts and undertake further outreach. One of the workers was of South Asian origin and fluent in three community languages, while the other was African Caribbean. Most importantly, both had experience of community work within the South Asian and African Caribbean communities, which was felt to be an essential prerequisite for successful outreach work.

It had been hoped that, by following-up existing contacts and concentrating on more intensive outreach up to 30 people willing to participate could be located. In the event, 24 individuals (15 African Caribbean and 9 South Asian) were interviewed; also, 3 group discussions were organised (one with a group of older and disabled African Caribbean people and two with Asian groups).

Although all 24 were older disabled people, it proved impossible to locate sufficient numbers who had been disabled for 20 years or more (which was the main criteria for inclusion). There were two main reasons for this. First, the South Asian and African Caribbean populations are both younger than the ageing UK population as a whole; also, people disabled in the early part of their lives were unlikely to have travelled to the UK so those who did are mostly people disabled during early middle age or later. Both of these factors mean that there are proportionately fewer South Asian and African Caribbean people disabled for 20 plus years, compared to the indigenous population. Second, although some of the community groups contacted were able to identify individual older disabled people, they were rarely able to say how long they had been disabled. Consequently, during the early part of the outreach work there were several 'false starts' where interviewers went to see people who turned out to have been disabled for a shorter time and could not, therefore, be included.

The combination of these two problems, and the timescale for completing the project, meant that the eventual interview sample had to contain a small

number of people for whom the criterion of being disabled for 20 years or more had to be relaxed.

Dissemination

Apart from the research itself, dissemination is also an important part of the project. In addition to producing this report, the following dissemination work has been carried out.

A preliminary summary of findings and practical issues identified by the study was widely distributed to statutory and voluntary sector support agencies and other organisations or individuals with an interest in ageing with disability. Feedback was also requested from disability organisations involved in the project and other organisations such as Age Concern, some of whom subsequently contributed comments and/or wanted to discuss the implications further.

In addition, a series of briefing papers have been prepared for national organisations whose members have participated in the project so that they can hopefully utilise the project findings in their own work. Each briefing paper summarises the main issues arising from the project plus any particular concerns raised by different groups of disabled people. These are supplemented with selected transcriptions from the interviews.

Leaflets about the project were also distributed to a number of community groups working with older and disabled people from ethnic minority communities. The purpose of this exercise, apart from requesting participants for the follow-up interviews, was to raise awareness about the project and, hopefully, initiate a dialogue about ageing with disability and race. This subsequently led to meetings and discussions with several groups who expressed an interest in the project and a useful exchange of information about issues which need to be addressed.

One of the main issues raised by older disabled people was the lack of information about where and how to obtain services, benefits, equipment and so on. In view of this, an information sheet outlining what is available and listing useful addresses and contacts was produced and distributed to all of the people who volunteered to participate in the project.

Several articles and book chapters on various topics covered by the project have been written for various publications. Also, papers have been presented at three conferences on ageing. (A full list of publications/papers, and organisations contacted is contained in Appendix C).

Finally, a one day seminar to look at the practical implications for disability organisations and statutory and voluntary sector support agencies is scheduled for early 1993. It is also intended to produce a practice guide incorporating issues raised by the seminar.

About the interview participants

The interview sample included people with a broad range of impairments. The largest groups were people with polio, arthritis, diabetes, limb amputations, and multiple sclerosis (Table 1). Their ages ranged from under 40 to over 80, with over half aged between 60 and 79 (Table 2).

TABLE 1: INTERVIEW PARTICIPANTS - TYPE OF IMPAIRMENTS

	No	%
Polio	29	23
Arthritis	18	14
Diabetes	15	12
Amputations	14	11
Multiple Sclerosis	14	11
Scoliosis	9	7
Parkinsons Disease	6	5
Cerebral Palsy	4	3
Others	16	13
Totals	(125)	(100)

(Note: A full breakdown is contained in Appendix B)

64% of the sample were women; 74% were white from the U.K., while the remaining 26% were from ethnic minority communities (see Tables 3 and 4). Just under half of those interviewed had been disabled for between 30 and 50 years, with almost a quarter being disabled for 50 years or more. Women in the interview sample were more than twice as likely than men to be single, widowed or divorced; consequently, they were also around three times as likely to be living alone.

TABLE 2: INTERVIEW PARTICIPANTS – AGE

	No	%
Under 40	10	8
40 - 49	11	9
50 - 59	20	16
60 - 69	36	29
70 - 79	36	29
80 or over	12	10
(Totals)	(125)	(100)

TABLE 3: INTERVIEW PARTICIPANTS – GENDER

	NO	%
Male	45	36
Female	80	64
(Totals)	(125)	(100)

About the ageing with a disability project

TABLE 4: INTERVIEW PARTICIPANTS - ETHNIC GROUP AND ORIGIN

	No	%
White - UK	92	74
Black - African Caribbean	17	14
Black - Asian	10	8
Others	6	5
(Totals)	(125)	(100)

The structure of the report

The remainder of this report presents findings from the study and, based on the experiences and views of the people who participated, and outlines the most important measures required for meeting their needs.

The next chapter considers people's subjective personal experiences of ageing with a disability and the impact this has on their lives. In particular, we focus on how older disabled people view their own independence and their expectations for the future. In chapter 5, findings on the kinds of changes associated with the physical ageing process itself are outlined. These two dimensions - personal and physical - are often inextricably linked in older disabled people's own accounts of their experiences, so both are

essential to understanding the significance of ageing and the impact this has on their lives.

Chapter 6, focuses on the practical implications of ageing with a disability and considers how well existing supportive resources are matched to older disabled people's self-defined needs. In particular, we consider issues around dependency, the visibility of people's needs, and institutionalisation. Finally, in chapter 7 we outline a model for creating a supportive environment for meeting the range of needs associated with ageing, and consider the practical measures required to put this into effect.

As noted earlier, there are particular race and gender dimensions to many of the issues discussed in this report which need to be explored. At the same time there is a danger that, in highlighting differences in needs, we might divert attention away from the fact that all disabled people have support needs in common. Consequently, while differences in the views and experiences of men and women and people from different racial and cultural groups have been highlighted in the report, we have attempted to do this in an integrated and unified way rather than adding discussion of these issues on for extra or 'special' consideration.

This is more than a simple question of balance and presentation. Rather, it is a basic premise of the project that, all disabled people should have the right to a supportive environment which enables them to control their own lives, and to define their own needs and solutions. These definitions will obviously have important gender, race and cultural dimensions, but the important unifying factor is that all disabled people should have the right to define their own needs and identities in whatever way they choose.

Where gender and race dimensions are crucial, however, is in understanding and addressing the different obstacles which particular groups of older disabled people face in being able to define their own needs and the appropriate ways of meeting them. So, while all older disabled people need to have an adequate income, for example, the obstacles to meeting this need will clearly be shaped in a fundamental way by race, class and gender. These obstacles cannot to be tackled, then, unless these race and gender dimensions are fully acknowledged.

4. The experience of ageing with a disability

Forgotten people - forgotten needs

Although the main purpose of this report is to examine the practical implications of ageing, it is impossible to develop appropriate policies and support services without an awareness of, and sensitivity to people's subjective experiences of ageing with a disability. So, before moving on to discuss the practical issues around support needs, housing, finance and so on we have attempted to portray the range of people's experiences of ageing and the impact this has on their lives.

These experiences are vary varied, although there are also several important common issues. In many ways older disabled people feel very positive about themselves despite negative experiences of ageing as disabled people. Several people clearly feel that, living with a disability for 20, 30 years or more in a generally unsupportive environment has certainly taught them the 'art of survival' if nothing else. At the same time, the majority feel that ageing also raises the stakes as far as their continuing to survive and maintain control over their own lives is concerned. Many are very anxious about what the future has in store.

It is essential that these views and experiences are located in the context of the social and material environment in which people age with their disabilities. Specifically, the question of whether or not this environment is supportive or unsupportive is absolutely crucial. In the introduction to this report, it was suggested that the needs and even the existence of people who are ageing with a disability have been overlooked. In fact, this is something of an understatement as several people described the problem in much stronger terms;

"I was originally told that I wouldn't even live for one year. I think that we have been completely forgotten - maybe people don't even know that we're still alive."

'Really - diabetics are a lost race in this country. Vie treatment we get is completely ghastly.'

"Our needs are many and various. Services could certainly be more helpful We are fobbed off as a dying race."

"We all are experiencing the ageing process and are apprehensive of the future we wonder what the future holds for us."

"How lovely to hear that people are interested in older parkinson's. My husband has suffered with parkinson's disease for 20 years. He is getting worse - he knows this and gets depressed. Nobody seems to understand - nobody seems to care"

These kinds of views go a long way to explaining why such a large number of people volunteered to participate in the project. Several people commented that a project about this issue was long overdue and hoped that their needs would now at least start to get some recognition;

"I read your article and I thought that everything you said applied to me - I've experienced all those things. For years I've wondered whether anyone would ever bother to do something like this. So, when I saw your article, I couldn't believe it. I thought - this is great - first thing Monday morning, Fin getting on that phone."

"I think it's very important to have a study like this because, in the past, even when there has been research no-one ever seems to have bothered to find out how people with diabetes really feel about their lives and all the little ways it can effect you. You need to put the research in a wider context, so I think it's very good that you are trying to do that."

"I dread to think what life will be like in my golden years and I really don't want to think of sitting in a wheelchair and unable to do anything for myself. It would drive me crackers if I have to ask others to do everything for me - I don't think I want to live that way. I hope what I have to say is of some help in your enquiries Thank you for having an interest in us."

Changing satisfaction with the quality of life

People's perceptions of, and attitudes towards ageing cannot be understood without reference to previous life experiences. As the experience of disability will have been a major feature of the lives of all of the people participating in this study, it is not surprising that this frames their personal responses to ageing.

In our previous study of ageing with spinal cord injury (Zarb et al, 1990), we suggested that ageing was typically associated with a 'downturn' in people's satisfaction with the quality of their lives after they had been disabled for between 20 and 30 years. Also, this appeared to be closely associated with the onset of the ageing process. Often this trend was preceded by steadily increasing satisfaction in the earlier years of people's lives.

Very similar experiences were reported by people in the present study also. For some people satisfaction with the quality of life tends to rise again over time as they accommodate themselves to the physical and personal changes experienced with ageing. As shown in Table 5, for example, almost twice as many people who had been disabled for over 30 years had high levels of satisfaction compared to those disabled for under 30 years.

However, this is clearly not a universal experience as around half of those disabled for over 30 years remain dissatisfied. So, although these trends give some indication of general changes associated with ageing, it is important to consider why satisfaction increases for some individuals and decreases for others. Also, it should be noted that women were less satisfied than men with the quality of their lives, and that there were differences according to race; some of the reasons for these differences are discussed further below.

TABLE 5: SATISFACTION WITH THE QUALITY OF LIFE OVER TIME

Proportion very or fairly satisfied;-	Males	Females	White	Black/Ethnic Minority	All
	%	%	%	%	%
(no. of years disabled)					
Up to 30	31	18	25	31	27
31 to 50	51	43	43	30	47
Over 50	58	45	52	N/A	52

The impact of ageing

There are numerous factors which influence how older disabled people view the quality of their lives. First, several people feel that the effects of the ageing process itself are like the onset of a 'second disability'. In other words, they likened the impact on their lives to the kind of experiences they had when they first became disabled. Indeed, for some who had never really considered themselves to be disabled before, the main impact of ageing had been that they now recognised their disability for the first time in their lives;

"I don't know how much I will be able to contribute because, my disability isn't all that severe. But, when I heard about this (i.e. the project) it sort of confirmed some of the things I'd been starting to think about already. The thing is that, I'm not getting any younger and while it (disability) wasn't really noticeable when I was younger, it is starting to catch -up with me now - and that forces you to

recognise that you do have a disability and you have to start thinking about what you're going to do."

Other people felt that, while they had always found the physical consequences of their disability difficult to cope with, the additional effects of ageing had made the situation much worse;

'Ageing in itself is a hard enough struggle - but with the added handicap this does not make things any better.'

"It's like driving a car with the handbrake on (diabetes). It's a hidden illness, but it is a depressing and a complex illness - and it gets worse the longer you go on. It's really messing me up."

For some people, this heightened awareness of disability had been a gradual or even insidious process. Often, however, the process had been triggered by a particular problem or crisis like the death of a partner, being forced to take early retirement, or a sudden or accelerated downturn in an individual's physical well-being. Whatever particular circumstances had triggered these changes, people's initial reactions to them were often quite traumatic ;

"The pain - it's become far far worse - it gets worse and worse all the time. So, you look back and suddenly you think - last year, I could do that and now I can't do that anymore."

"It's a very slow process - it gradually creeps up on you. You deteriorate as you get older and it seems to speed up all the time. Especially at the age we are now - I can't get in the bath anymore - well, I can, but I can't get out again. Something like that though - it seems to suddenly hit you. One day you can do it and then you suddenly find you can't. And it does get to you a bit obviously - I cried the first time I realised I couldn't get out of the bath - that's how it got to me."

'A couple of years ago I had gangrene in my foot which had to be amputated. I was in hospital for 8 months. Now, it's completely finished me - my life is over. I'm dreading the future - I'm taking no chances. I don't go anywhere - I no longer enjoy life. It's a vicious circle you get into - one thing just leads to another. I don't think there really is anything that can help me now - there's no hope. I really think I might die soon.'

Emotional changes associated with ageing

Several people talked about the kind of emotional changes they had experienced as they grew older. The most commonly reported changes were increased anxiety and frustration (see Table 6). Loneliness and depression are also a problem for some people - particularly older women, who were also more likely than men to experience anxiety or frustration.

TABLE 6: EMOTIONAL CHANGES EXPERIENCED WITH AGEING

Proportion reporting increased;-	Males %	Females %	All %
Anxiety	38	42	41
Frustration	31	38	35
Loneliness	9	20	16
Depression	9	21	17
Mood swings	9	13	11

As noted earlier, the realisation that ageing contributes to a heightened awareness of physical deterioration was a particular source of frustration for many people. For some, there were also additional consequences like having to give up working, a reduction in social and leisure activities, or the impact on personal and sexual relationships;

"Unfortunately in 1985 (53 years after onset), I developed very bad osteoarthritis in the shoulders and arms which was caused by the wear and tear placed on them by using crutches for so many years. So, I had to give up working for a living. Since then I have become practically housebound and suffer from terrible depression, missing my colleagues, and frustration at not being able to do normal everyday jobs."

"It's been a bloody bore quite honestly (since retirement). That's mainly because, although I have a lot of mental energy, I can't do things that I want to. It's been really frustrating."

Several people emphasised that their physical and emotional well-being were inextricably linked, and that this had always been the case throughout their experience of living with a disability.

Consequently, one of the most common effects of physical decline experienced with ageing had been to reduce people's general levels of motivation. This can become a vicious circle; emotional strains meant that they felt less able to cope physically which, in turn, contributed to a further drain on both their emotional and physical reserves;

"My major disability is lack of energy - will power just isn't enough anymore. I deal with it by - when I'm better - I shut it out of my mind and forget about it. But, when I'm down I get depressed. It's unpredictable sometimes."

*"We are always so tired, so after 20 years - you're just completely knackered."
"I still find it very difficult to cope, but it's much harder now that I'm 50. You talk about the quality of life - it's getting poorer all the time."*

On the other hand, some people reporting similar changes, did not necessarily view these in exclusively negative terms. In particular, changes like increased frustration, impatience or aggressiveness were sometimes seen as having positive benefits, particularly in avoiding depression or apathy and dealing with an unsupportive environment;

"Everything seems to be geared towards making life more difficult for disabled people. Obviously, the longer you go on the harder it's likely to get. It's this constant fighting you have to do - no wonder we're all so stroppy."

Further, several people felt that they were so used to dealing with problems like physical pain that they did not have much doubt about being able to cope with any additional problems they might face when they were older;

'Having a disability can be good for you in some ways - it depends how you approach it. It makes you grow up as a person. You learn a lot about yourself and how to deal with life - as well as all the practical things, like being able to put up with a lot of pain. You learn how to deal with that sort of thing over the years.'

Perceptions of mortality and life expectancy

Several people felt that they were ageing faster than their able-bodied contemporaries. Others, who had not yet experienced this, nevertheless anticipated that they would be similarly effected in the future;

"I grew up with my disability and therefore never felt it a handicap when I was young. I maintain a disabled person ages quicker than an able bodied."

In some cases, this knowledge had given rise to the feeling that 'time is running out'. On a practical level, this had also influenced people's plans for the future; for example, planning to retire early. Closely related to this aspect of the experience of ageing is the issue of people's perceptions of their own life expectancy. Some people anticipated, not only that they would age quicker, but also that they would die younger than their contemporaries. Interestingly, most people's attitude towards this was quite accepting; often, the anticipation of dying seemed to be less traumatic than dealing with the effects of the ageing process itself;

"They told my mother when I was born that I wouldn't live - that I wouldn't survive infancy. Because, in those days people with Spina Bifida often didn't live. So then they said - no, she won't reach 10, and then they said 21, and then they gave up - because they were fed up of me by then."

'I was employed in manufacturing for 47 years. I started at age 14 as the doctor told my father when I was 13 that I would not see my 14th birthday. He decided I was to leave school and start as an apprentice. As you can see, that was my first experience of how wrong the experts can be.'

"Society, by which I mean adolescents of 50 or younger - which is how I perceive it - seems to have a lot of difficulty coping with ageing. Our culture discourages us from talking about something which involves everyone. Take dying, for example. We have bereavement counselling, but not bereavement preparation. It's as if we're not supposed to think about it - but you do, you need to. It's not just an emotional thing - there's practical considerations as well."

Older disabled people's attitudes towards their own mortality also need to be understood in the context of perceptions of life expectancy formed in child and early adulthood. As the above quotes illustrate, at the time many of the people participating in this study became disabled, life expectancy for people with various disabilities was low. Several people related how they had either been told, or simply assumed, that they would not survive adolescence, or would only live for maybe 20 or 30 years; consequently, they had always had a heightened awareness of their own mortality. This can have a significant influence on people's outlook on the future. For example, some said that, while they were aware that they may face an early death, they also felt fortunate that they had lived as long as they had.

The art of survival

While the kinds of changes described above are often a source of considerable frustration or anxiety, some people also emphasised that they would be much

easier to cope with if they had appropriate support (personal and practical). However, given that so many people participating in the study have lived most of their lives without any support outside of their own family and friends, several felt that they were well equipped to develop their own positive coping strategies; indeed, they would not have been able to survive without them;

"32 years ago the assistance you could get was primitive to say the least. When I left hospital the follow up was negligible. When I came home, I didn't even have a wheelchair. There wasn't a spare respirator if anything went wrong. You just didn't have any of those things. At the time, the medical profession were totally aghast at the idea of me coming to live at home. They said I'd be dead inside a month - to try and dissuade me. Of course, the situation has changed considerably since those days but - when you've been through that - you do learn a thing or two about how to survive."

"The funny thing is that the way I feel about it has just got better and better over the years because I never let it get in my way. I knew right at the start I had to motivate myself to make something out of my life - because, you can be sure as hell that no-one was going to do it for you - and that's the way I've always gone on. So, even now that I'm deteriorating the way I am, I still never let that get me down. It's as if the two things sort of go in opposite directions. Physically you are going downhill - and fast - but, mentally, you get stronger and more determined."

As the experiences described above illustrate, many older disabled people become fairly expert in the art of survival over the years. But, this can sometimes be a two edged sword for people who subsequently find it very difficult to accept needing or asking for any extra help in dealing with some of the problems they experience with ageing. This has far reaching implications for how older disabled people define their own independence, and what they consider to be appropriate and acceptable forms of support.

The consequences of invisibility and isolation

Because of the invisibility of disability (particularly earlier in their lives), many older disabled people feel very isolated and unable to get anyone to understand their anxieties about ageing. For some, participating in the study had been the first opportunity to discuss this for maybe 30 years or more;-
The experience of ageing with a disability

"It's difficult because no-one seems to understand - even my family, and they've been used to me for all these years - it's good to talk to someone who understands what you're on about."

"I have for over 70 years tried to hide my disability. It now seems to do me good to talk about these things. I was the 7th child in a family of 14 - all the others quite normal - and I was brought up to - pull yourself together and stop complaining."

"I do try to tell myself that it's other peoples problem, not mine but when I feel angry, a lot of the time, I cry and people don't know how to deal with that - they just look down and try and ignore you. It's there all the time but I hardly ever get the chance to talk to anyone about how I feel - well, no one who's going to listen anyway."

"I really suffered when I was a child. My mother was very proud and so she wouldn't tell anyone about me the social services didn't ever know about me. And, of course, because of that I have never been able to get any help - my disability has never been recognised."

As this last quote illustrates, there can also be very important practical consequences of this kind of invisibility and isolation as people may be unable to get others to recognise their needs. Also, the cumulative effect of this kind of experience may be that people do not have the confidence to articulate their needs. This often tends to be a more common experience for older disabled women who, as suggested earlier, are more often treated as invisible by society than men;

"I still feel very hurt and angry about the way people treat me. It hasn't really got any easier. It's got worse if anything because I get so frustrated when I see that it's practically no better than it was 40 years ago. It's taken me this long to get the confidence to start to complain, although I still feel very unsure of myself. I don't agree that you get used to it over the years and it doesn't bother you any more. You learn how to cope with it better, but deep down it does bother you. It's the same as people talk about people who are black or anyone who's slightly different. There's a lack of understanding."

Several women in the study also talked about the isolation they had experienced as disabled wives and mothers. Because they had become so used to subordinating their own needs to those of their families and partners, they felt unable to express their anxieties about ageing, or to ask for any support for themselves. Indeed, some women went as far as saying that they felt 'guilty' or 'a fraud' for even thinking that they should ask for any help from their partners;

"The first thing is I won't accept growing old and that makes life even more difficult. If I didn't mind growing old and if I accepted the fact that I was

growing old, it might make my life easier. Number two is that - I used to adore my children. Now, I suppose I still do, but I want them to go. They're too much trouble - and that makes me feel horrendously guilty I think I've gone rapidly downhill from the age of mid thirties. It's been a slow degeneration from the age of 25 and a rapid deterioration from the age of 35 and now, my children are just too much trouble, which is awful really. And the fact that my children are used to seeing me flopped out here with my legs up on the settee lying flat. It's a common state, but other people's mothers aren't in that state. I don't feel like a good mother."

Isolation amongst older African Caribbean and Asian disabled people

Isolation and invisibility were major issues for most of the African Caribbean and Asian people who participated in the study. There are several dimensions to this which need to be highlighted.

Both African Caribbean and Asian people felt that they were very isolated within their own ethnic and cultural communities. People in both groups talked about a lack of sensitivity to the needs of disabled people in their communities and the ways in which this affected all areas of their lives;

"I think disabled people are discriminated in the Asian community. Personally, I do feel that. In my experience anyway, they are discriminated in the Asian group."

"You hear this again and again. Asian disabled people saying - we are here now, but we don't fit in to the white society, and we don't fit in to the Asian society - we're in no-man's land. Like I say, personally, I think I can fit in easier with the white groups. But, being in your own community - if you say you want too much, or you are expecting too much, then they wouldn't understand you. So, you don't fit in there - they don't take your word. They think, you know, all you disabled - you just keep oil one side."

"I feel very isolated. It would be good to have more organisations or some kind of local group - so you don't have this feeling that it's just you. In a way, it would be good to know that other people have the same kind of problems."

"I felt very ostracised by the black community I went through a stage where I didn't belong anywhere. I felt left on the shelf - but my sisters always dragged me out."

One very important consequence of this isolation is that some people feel cut off from their own culture and/or religion. This was a particularly acute

problem for some of the older Asian disabled people who emphasised the importance of participating fully in cultural and religious life.

Indeed, for some, not being able to do this was possibly the most disabling feature of their lives;

“As a practising Muslim, being in this country I don't think my community has been helpful to me. But, my family has always been very helpful. They pray 5 times a day - they're always there to pray for you - for your good health. But, the religious community - I don't think they are really there to help. They say prayers for all the disabled and sick people, that's all - just general prayers. ”

“Like, when I go to the mosque, I have to sit on a chair. So, it's always - she's got a problem, why is she sitting on the chair. But, you know, I don't want to have to tell everybody every time what is my problem. It's just that when you sit on a chair it looks like you've got a lot of problems - you feel a bit left out. You're made to feel that, you know, you don't belong to the group you feel a bit inferior.”

“There's a breakdown of religion and culture. Muslim people - they go to the mosque, but there isn't a Muslim interpreter. What about speaking. What about an interpreter. We need more interpreters in our culture and religion. It's not fair. We don't want deaf people to be left behind. ”

The experience of most of the African Caribbean people in the study was slightly different. While they talked about being isolated from or, in some cases, ostracised by the African Caribbean community in general, most still felt that they could draw on the strength and support provided by their churches. For those who felt cut off from the church, this was usually more to do with practical difficulties (eg. lack of transport), than social isolation as such;

“I would like to be able to go to church, but there is no-one to take me. Before I was sick, I used to go to church every Sunday - I was in the choir. But, one friend (from church) still comes to look for me every week.”

Religious devotion also plays an integral role in determining 'worldly' aspirations amongst older African Caribbean disabled people. People's answers to questions about how they felt about the quality of their lives almost invariably carried religious connotations;-

“I was sick for one year, you know, and I never get depress or anything - and I was in pain you know, but I satisfy and I always have a smiling face because

what's the use of being depressed. All I do is ask God everyday to touch you and keep you tip"

"What's the use of getting depressed it doesn't help, it brings you down - I just leave it up to God"

One or two older Asian women, also emphasised the problem of being isolated within their families and the expectations and pressures placed on them as wives and mothers. While they accepted these expectations as an element of their culture which should be respected, they nevertheless found it very difficult to meet them due to the lack of understanding and support from their families and the wider community. As with some of the white women who discussed these issues, they also felt guilty about not being able to live up to the expectations placed upon them, and this added to their sense of isolation;

"I stay at home, do the housework, look after the husband - it's a boring life. So, I started a group here - an Asian Women's Group. I used to go to a (white) club. But, white people don't understand our culture. I mean, if I go home early - they say - why are you going home early, you're a baby, and all that. I say to them, I have to follow my own mother and my culture - I don't want to break my family. It's very difficult."

Others (both men and women) also expressed the view that some Asian families - depending on their religious faith or culture - are 'over protective' of disabled family members and that this also increases their isolation and invisibility within their own communities;

'Asian people are very caring people, we have a caring attitude so sometimes they can be too caring and over protective. Especially disabled members of the family. But there are some positive sides to it and there are also quite a lot of negative sides to it. If you over protect disabled people, you see you are depriving the disabled person from learning about some of the things, some of the facilities which are available within the mainstream that could make life easier for them. So we come across cases like that in our work. People, disabled members being over protected, and they are resulting in the disabled member - also the relatives - not being aware of the most basic facilities which would make life easier for all of them. The whole family. So like I said, the negative side is that. It can bring additional problems, not just for the disabled member but also for the families."

One or two suggested that, this problem of 'over protectiveness' may also be compounded by a wider tendency for some Asian communities to view disabled people purely as 'objects of charity'.

This in turn may be related to the fact that, in some Asian cultures, disability is viewed as the result of some form of divine intervention which makes the need for 'worldly' intervention (eg. practical and material support) unnecessary, or even undesirable;

"I think a lot of Asian families are embarrassed about disabilities because - they don't know - back home, the education is very bad Let's say I have a disabled child - the mother will blame me. They don't know. Who did wrong? It's God - you can't blame me."

However, this is a very difficult issue to evaluate on the basis of the experiences of only a handful people and without a proper understanding and sensitivity to all of the cultural and religious dimensions involved. Also, there is always a danger that these views may be interpreted in a stereotypical way and/or used as a justification for non-intervention (particularly by service providers). Clearly, this would be unhelpful to say the least and would only serve to perpetuate the isolation of older Asian disabled people.

Another dimension to the isolation experienced amongst older Asian and African Caribbean people is that, apart from being isolated within their own communities and society generally, some also feel cut off from their countries of origin. Most first generation elders came to the U.K. with the intention of finding work and, hopefully, establishing a better quality of life for themselves and their families. The majority did not necessarily have the expectation of spending the rest of their lives in Britain.

One or two of the Asian people we interviewed did talk about wanting to return to their home countries for a visit, but no-one discussed ever having wanted to go back on a permanent basis. Nearly all of the African Caribbean participants, on the other hand, talked about this issue. For some, the hope of returning to the Caribbean had perhaps been the most important goal they had for their later years.

However, this desire has only been realised by a few. Also, many recognise the fact their homelands have changed greatly from the time they left, or that they had few relatives remaining, and were reluctant to go back for this reason;

"Where would I go, who would look after me, I only know here."

Others who expressed a wish to visit home before they died, had not had the opportunity to build up any savings. So, although not everybody wanted to home, most felt they would at least like the opportunity to visit.

Ageing and independence

Many older disabled people expressed significant concerns about independence, which they saw as being threatened by physical and/or personal changes experienced with ageing. In some cases, this only extended to personal or physical independence, but for many people ageing represents a threat to their independence in the much wider sense of losing control over how they wished to live their lives.

Concern about independence was the most common reason people gave for why they felt more anxious as they grew older. Further, this anxiety tends to keep on increasing as people perceive their independence to be threatened, either by further physical decline or, more often, by the lack of appropriate and acceptable support;-

'Maybe with all the changes that are coming through now things will get better - we'll just have to wait and see. But, I can see why some people might be cynical - especially when they say they're going to give people more choices. There aren't that many choices - all that we have seen is that there are more and more nursing homes opening up. Maybe that's what they mean by giving more choice - I don't know.'

"My mother always had to go out to work just so we could get by - and she had to look after acs as well But, do you think there was any help from the state - there wasn't any. So, I think that's always stayed in my mind and I do feel very lucky that I didn't end up like that in my own life. But, what really worries me now is that we seem to be going back to those days. We seem to be becoming a very uncaring society - especially the government - but it goes all the way through I think. That frightens me because - what kind of prospects do you have if you need any help?"

'I've always done everything myself and I haven't asked for help a great deal. Then, when I did - it wasn't there. 77iat's what concerns me.'

Several people were concerned about the possibility of having to make major changes in lifestyle, such as seeking more personal assistance or changing their living arrangements. Anxiety about the possibility of having to move into institutional care had a particularly strong influence on these perceptions;

"When I was first in hospital, everything was done for me - bottom wiped and John Thomas stuck in the bottle and all that sort of thing. Because it was at the start of the illness, you accepted it. But, how I would feel as a crusty old man having that done for me - I don't honestly know. I think this is why I want to make the alterations I can - to put that day off as far as possible. Obviously, I hope I'll never reach that stage. I don't know how far the deterioration is going to go. This is the thing - nobody can say. To me, to be in a situation where I'm totally dependent on other people how I would cope with that - I don't honestly know. I suppose, obviously, I just hope that situation never arises. If it did, and I found that I thought my quality of life wasn't worth it, you know, I would then possibly think about doing something about it. I don't know if I'd have the nerve or the guts to carry it through, but I think it is something I would seriously think about."

"I live alone since my wife died three years ago and have no living relatives. I have a flat in this McCarthy and Stone establishment where, of course, no nursing care is provided. I am able to manage as I am at present, but if I get much worse my fear is that I will have to go into some sort of nursing home."

Similarly, while some people recognised that they now have a need for additional support (either physical or emotional), they still found this difficult to accept;

"Independence for me - even though a lot of people would say the opposite. It's all about choices isn't it. I'm sure a lot of people would say that being in a hostel like this, or in sheltered accommodation, isn't living independently - but that's not the way I look at it. It's not a question of doing everything for yourself, it's having the choice about how you do things. This is my choice - that's all there is to it really."

A small number of people, on the other hand, had either never placed much emphasis on independence in their lives, or, had never felt they had that much independence in the first place. Consequently, they did not necessarily perceive ageing as representing such a potential disruption to their lives as some of the others.

These perceptions of the possible impact of ageing on independence have to be understood in the context of attitudes towards independence, autonomy and responsibility developed throughout people's lives. For example, several people perceive achieving their independence (however, they defined it) to be one of the most significant features of their lives. This was particularly relevant in the early years, when there was often no support or guidance

available. Achieving this independence had often taken many years and certainly involved a great deal of effort.

This determination to maintain their independence in older age is often accentuated even more amongst people who had spent their youth in special schools and institutions;

"When I was a child, I was in and out of hospital and convalescence homes for years. I went to a special school for disabled children - it was appalling. The attitude was that we weren't going to do anything with our lives in any case, so they just didn't bother ... There was one time - I'll never forget it - when I was seven, I was sent to this convalescence home. They were very strict and I suffered from incontinence - I always have - but they just didn't understand and so they used to punish you. Whenever I wet myself, they used to make me rub my nose in it. That was the sort of thing you had to put up with. It has changed a lot since then, but there is still a long way to go. Anyway, all of that just made me very determined to be independent - I wasn't going to let them break me."

Also, it is important to recognise that 'independence' is not a fixed state; both people's practical needs, and what they consider acceptable means of meeting them, are likely to change over time. Many people also talked about the efforts involved in maintaining their independence and how this had become harder as they grew older. Consequently, it is easy to see how the possibility of having to give up some of their independence was a source of great anxiety. The fact that some felt that losing their independence would be totally unacceptable and that death would literally be a preferable option shows just how important this can be.

Independence and gender

The general anxiety about lack of support is often much more acute amongst older disabled women (see Table 7). The factors taken into account when asking people how they felt about their overall support included satisfaction with personal and domestic assistance, as well as material support in terms of housing and financial resources. It is likely, therefore, that gender inequalities in the distribution of such resources are reflected in women being even more anxious than men about the future generally, and about maintaining their independence in particular.

TABLE 7: ADEQUACY OF OVERALL SUPPORT BY GENDER AND RACE

(Percent)	Males	Females Black/Ethnic Minority	White	All	
Very good	5	1	0	3	2
More than adequate	18	10	6	15	13
Adequate	21	11	9	17	15
Minor inadequacy	30	39	31	37	36
Marked inadequacy	23	29	34	24	27
Severe inadequacy	5	9	19	3	7
Base Totala	(N=44)	(N=79)	(N=32)	(N=91)	(N=123)

Further, many older women (disabled or not) are also supporting others. This can also increase their anxiety about the future. For example, some of the men in the study felt sure their partners would be both willing and able to continue supporting them indefinitely, so had not considered any other possibilities. Women were more likely to question whether their partners would be able to do the same. At the same time, some women felt that, having to support their partners and families meant that they were also better equipped to manage with minimal support for themselves when they are older although, again, this was usually more out of necessity than choice;

'You have to look after yourself I worked part time 'til I was 60 in any case. But before that I had the house and family to look after so you need to keep going.'

Similarly, some women's experiences of supporting others had made them all too aware of the lack of support for older people and their families. Consequently, they felt they had little reason to be optimistic about their own needs being met in the future;

"I have started thinking about getting older - what it might be like. You can't help thinking about it and I think - in my case - the experience of looking after my mother for all those years made me more aware of the sort of problems you can come up against."

This is not to say that older men do not provide support for their partners or others, nor that the perceived threat to independence is only an issue for women. However, both of these issues are likely to be particularly acute for women throughout their lives and, consequently, crucial factors shaping their experience of ageing also.

Given the kinds of obstacles and pressures they face, it is not surprising that older disabled women tend to place an even stronger emphasis on maintaining their independence in older age than men. Several of the women in the study talked about their ongoing struggle to maintain their independence throughout their lives. In particular, the ways in which other people's low expectations of them had only made them even more determined to maintain their independence as they grow older. This general point is illustrated very clearly by the following comments about the hostility one woman had experienced as a disabled mother and the continuing influence this has had on her whole outlook on life;

"When I was pregnant I had some really weird things said to me. It was disgusting - they didn't think it should be allowed, and that I wouldn't cope - that made me damn sure that I was going to cope. In fact, I probably coped better because I always had in the back of my mind that people were looking for me not to cope With those sort of attitudes now - I've got much harder unfortunately. I don't think it's a good thing, but it's other people who have made me like that. "

Independence and race

Although most of the Asian people in the study expressed concerns about their future independence, this was not discussed at all by any of the African Caribbean participants. This is not to say that they considered the issue to be unimportant. However, most were much more anxious about immediate issues around basic day to day survival; in this situation, worrying about their independence in the future seemed almost a secondary consideration;

"I am never in good spirits. I want to die, I feel depressed and frustrated at everything. I don't talk to anybody I wouldn't commit suicide - I just carry on. I just wish I had someone to cook for me."

"They cut off the heat you know. So, when I am cold I have to bum electric fires. They say to me I owe them eighty odd pounds. Where am I going to get it out of my little pension I said to my social worker - I think I wouldn't be so ill if I didn't have all these worries."

These experiences must be understood in the context of the low expectations older African Caribbean disabled people have of a society which they have only ever experienced as unsupportive or even hostile. It is also clear that, the legacy of colonial domination in the Caribbean still has a strong influence on first generation African Caribbeans who are now ageing in the UK. For example, some of the participants recalled stories of how they were *"taught their place"* as servants in the white master's house;

"In Jamaica if you don't have to work with them you don't have to mix with them. It's only if you come in contact with them - then otherwise you don't mix with them. You don't find prejudice like here, everybody - knows their place."

'Y was amazed, I remember when I came here and the first thing I noticed was a white woman scrubbing her steps, I said to my brother - what is she doing there, hasn't she got a maid? No, he said, only rich people in England have maids. You know in Jamaica they leave from England in their poor state but when they reach there, they get the best jobs, you have to be on their every beck and call."

On arriving in Britain hoping for a better life, most people then encountered racial abuse, discrimination and general hostility from the host country;

"When I came here conditions were bad. You weren't looked upon as anything. You get the worst jobs. When you go to look for somewhere to live and it was a white persons house, when they open the door they nearly jump out of their skin like you gonna eat them up. Things don't change much because you still have prejudice around."

As the last quote illustrates, most of the people who discussed the issue of racism also felt that the reality of their lives had changed very little as they grew older. Apart from general comments about white society's attitudes towards black people, there were also several examples of specific instances of racial abuse, or discrimination in employment, housing, or in obtaining access to services;

"In the hospital, I wasn't being treated properly - I think it was because I was black. One nurse tell me that if I don't shut up, she will box me. One push me off the chair. And, if you could feel the bump on my head - that's what she did to me in the hospital."

Years of living in a hostile environment, coupled with the legacy of colonialism, has denied older African Caribbean disabled people the confidence or motivation to either demand or expect a life of independence,

autonomy and control. Further, this lack of confidence often prevents them from being able to articulate their needs now they are growing old.

Although most of the older Asian disabled people in the study did not interpret their experiences in terms of discrimination or racism, several did talk about the issue of "injustice" and the obstacles this presented in their lives;

'I do not want to be a burden on the public services but it is your right and if there are services that you should get. There should be justice, but one should not be a burden on public resources. I do not want to force anyone, I only request.'

Some, however, believed most of the restrictions on their independence came from attitudes towards disabled people in their own communities, rather than society as a whole;

"These Asian older people groups, they are not all very supportive. If you are good friends with a member of the committee or if you are related to any committee member, you get good service. If you are a general member of the community then, in my opinion, you do not get good service. So, having Asian community groups is not a guarantee that people with disabilities will get services. Sometimes there is a sense of betrayal if people are from the same cultural grouping. "

"The Asian community has not got a good view about disability. I hope you do not mind me saying this but it is my personal experience. There are great injustices done. There is also discrimination between different cultural groups within the Indian community. I do not want to complain about anybody, I just want justice to be done - justice not more than that. But, Asian people are treating other Asian (disabled) people unjustly."

In similar ways to older African Caribbean people, these experiences meant that many older Asian disabled people not only had very low expectations about their needs being met, but also felt powerless to do anything about this;

"I am aware that I am getting older and will be getting more dependent on others. This is a worry to me because, if you make more demands or are more dependent on others they will step back. So, it is a worry about getting more dependent on others. I would like to maintain my independence."

"My wife had a stroke and now she should get one injection a month at home. Last injection she had was 3 months ago. When I ring them to ask why she has not had injection each month, nobody is taking any action. They do not listen to me. What can I do."

The most important common denominator between the different experiences and views discussed in this chapter is whether or not changes associated with ageing are compatible with how individuals wish to live their own lives. It is very difficult to understand the significance and meaning of ageing without close appreciation of this crucial factor. Clearly, how people view their own independence and their hopes and anxieties about the future will be shaped in very fundamental ways by their previous life experiences which, in turn, are shaped by their experiences of ageism, disablism, sexism and racism. Any supportive resources aimed at addressing the needs of older disabled people must be sensitive to these differences in experiences and needs, the different ways in which people wish to control their own lives, and the obstacles which have prevented them from doing so.

In particular, it is essential that the sources of the simultaneous oppressions faced by older disabled women or older African Caribbean and Asian disabled people are recognised. In subsequent chapters, we outline the practical implications of these experiences for developing appropriate supportive resources. Before this, however, it is also important to examine the other crucial dimension to people's experiences of growing older with a disability - namely, the physical ageing process itself.

5. Physical changes and problems associated with ageing

The significance of the ageing process

In addition to understanding older disabled people's subjective experiences, it is also important to summarise the kinds of problems and changes typically associated with the physical ageing process itself. These two dimensions - the physical and the personal - are often inextricably linked in older disabled people's own descriptions of the significance of ageing, so both are essential to understanding the experience of ageing with a disability and the practical effects on people's lives.

Given the broad range of impairments covered, there is a surprising degree of similarity in the kinds of physical problems/changes reported. Although the specifics obviously vary between and within different impairments (see

separate briefing papers), two general themes have been consistently reported.

Premature ageing?

First, many people's experiences are consistent with the notion of 'premature' physical ageing which is characterised by a process of 'general deterioration' rather than any specific medical or health problems as such. This is reflected by the kinds of physical changes most commonly reported (see Table 8). Just over half of the sample reported a decrease in agility and/or mobility and 40% were experiencing difficulties with walking as they grew older. The proportions experiencing this kind of change were similar amongst all disability groups with the exception of people with diabetes, a smaller number of whom were having problems with their mobility.

TABLE 8: PHYSICAL PROBLEMS/CHANGES EXPERIENCED WITH AGEING

	Proportion reporting problem /change (%)	Average age when first noticed	Average years disabled when first noticed
Decreasing agility/mobility	51	54	30
Difficulties with walking	40	58	25
Arthritis/Rheumatic problems	29	54	33
Increased pain	27	51	35
Changes in energy levels	27	51	31
Problems with vision	22	59	32
Weight gain/loss	21	57	34
Problems with shoulders, arms or hands	18	55	30
Problems with circulation	12	62	34
Heart problems/angina	12	58	37
Drug dependency/side effects	12	51	27
Respiratory problems	11	55	40
Asthma/breathing problems	10	49	34
Fractures/dislocations	9	64	32
Problems with transfers/turns	7	49	26
Bladder or kidney infections	7	37	26
High/low blood pressure	7	54	31
Limb deformity	7	54	27
Contractures/muscle wastage	6	70	50
Problems with hearing	6	68	34

(Table 8 continued)	Proportion reporting problem	Average age when first noticed	Average years disabled when first noticed
Stroke(s)	5	65	25
Spasms/spasticity	5	57	32
Brittle bones (osteoporosis)	5	50	41
Speech/communication problems	5	57	30
Edema (swelling of joints/limbs)	4	68	29
Spondylosis	4	48	28
Balance/co-ordination	4	57	49
Incontinence	3	47	25
Viral infections	3	56	28
Muscular atrophy	3	38	25
Thyroid problems	3	51	29
Scoliosis	2	26	10
Ulcers	2	55	32
Headaches/dizzy spells	2	57	36
Pressure sores	1	85	58
Epilepsy	1	56	12
Other(s)	13	55	37

The long-term effects of physical disability

Second, this process of general deterioration appears to be more closely associated with how long people have been disabled than with age itself. Over three quarters of all the different kinds of physical problems or changes reported had first become noticeable between 25 and 35 years from onset of disability, regardless of either current age or age at onset. The only notable exceptions to this were osteoporosis (brittle bones) and respiratory infections, both which typically become noticeable after 40 to 50 years.

This finding is also indicative of the fact that, many of the physical problems/changes experienced are perceived as being long-term effects of people's original impairments. A large number of people participating in the project confirmed the indications given by previous work on ageing with spinal injury and on 'post-polio syndrome' that, ageing with a physical disability almost inevitably means that people's bodies will wear out quicker than their able-bodied contemporaries; also, that this process of general 'wear and tear' will often be associated with a variety of more specific physical and health problems such as arthritis, increased pain, reduced energy levels, weight gain, and contractures;

"I have had terrible pain with arthritis in my wrists. That started about 8 years ago (35 years after onset) and it does seem to have spread to my shoulders as well. It's rheumatoid arthritis and I think that that's much more likely to affect me when I'm older than the polio really. If I'm crippled, I will be a rheumatoid cripple, not a polio cripple. Mind you, I have heard about arthritis affecting lots of disabled people - you see it all the time. They say that your shoulders last about 30 years and I'm sure that's right."

"I get arthritis. That might be to do with the scoliosis - it might not. I mean, my mother has that as well, so I don't know. I've got it at the top of my neck and shoulders and, also, across the hips now. ... Talking to other people - a lot of people with scoliosis do have it because of the pressure on the hips. So that probably is to do with the scoliosis."

"Pain is my biggest problem. I mean, Spina Bifida and Scoliosis are both painful things. But, it's become far far worse. Certainly, when I look back - I mean, I didn't need a wheelchair until 15 years ago, and the pain has certainly got worse - it gets worse and worse all the time. So, you look back and suddenly you think - last year, I could do that and now I can't do that anymore."

These kinds of problems are not restricted to wheelchair users however; for example, nearly all of the limb amputees had experienced similar problems which they believed to result from the extra strain on their remaining limbs; similarly, people with polio reported experiencing arthritic problems in limbs which were not originally affected by polio, and people with scoliosis often report that curvature had led to the same kind of problem.

For some groups, there are also common secondary impairments caused either by the original impairment, or the long-term effects of medical or rehabilitation strategies employed by the medical profession. For example, blindness and neurological problems associated with long-term insulin dependence (diabetes) and chronic pain resulting from building up immunity

to certain drugs like morphine (various groups, but particularly people with long-term arthritis);

"During the last 5 years my life has been a living hell. It all comes back to this so called wonder insulin - this human insulin. It may be alright for younger people, but older people like me are suffering unnecessarily. You see, new diabetics don't suffer the side effects, but the older ones do. I've been 58 years on soluble bovine insulin - when your body has been used to that for so long, it doesn't take kindly to the change."

"They put me on penicillin because my temperature was going to 104 every day - that was 8 injections a day. But, it didn't do a bit of good because, once you've had the smaller doses and increase to the bigger doses later, you were immune. So, by the Christmas I weighed about 5 stone - I developed a heart condition and got rheumatic fever - I was all purple. I was just laid flat out. I couldn't bend because the bones had grown so much and the cartilage had just all disappeared, so the hip joints had no room to move whatsoever. Then, it took about 6 months to get the temperatures under control."

".... the drugs they put me on upset my stomach and my bowels so after that I didn't have any medicine. I said that I preferred not to have any drugs. But, the rheumatologist was very good. He still used to see me regularly and I had hydrotherapy and different kinds of splints for joints, injections in the knees and things like that. But, he was very good - he didn't force medicine on me anymore after that - except when the trouble flared up in the spine. It was very bad, and he put me on a drug called Methrazone - an anti-inflammatory drug. But, I'd only taken it for a few days when I had very bad side effects - including waking up in the middle of the night and struggling for breath and having a rash all over me and feeling ill and having more pain. So, I just said to him - I prefer the devil that I know thankyou very much - and he said - you're probably right."

People with long-term scoliosis and other muscular-skeletal impairments reported chronic respiratory problems caused by spinal deformity;

"I started having very serious problems with my breathing three years ago (50 years from onset). That's really my only disability now - it changed my life more or less overnight. It had been building up for a while I suppose, but it didn't really cause any serious problems up till then. Then I started having these terrible pains - I thought I was going to die - I ended up in hospital for two or three months, and I've been under more or less permanent treatment ever since."

"It's all to do with the transfer of blood gasses to the lung. With scoliosis, the lungs and rib cage tend to get deformed so it gets harder - it takes more energy than your body has got, and the blood gasses sort of get diluted. But, it doesn't stop there because, it turned out I've got asthma as well."

For people with polio, there were also a variety of physiological problems coming under the heading of 'post-polio syndrome';

"I have deteriorated physically - there's no doubt about that. I think it is this thing they've been on about - this late polio syndrome or whatever it's called. I have collected some articles on it to see what it was all about, and most of what they were on about fitted in with what I've had happen to me. The main thing I put it down to is just wear and tear from all the years of humping myself around in this thing (wheelchair). Also, now I'm getting a lot of trouble in my shoulders. I've always had some residual effects in my shoulders from the illness itself, but it's got a lot worse now."

"I had polio when I was 41 years old and I am now 56. I find that now, I feel old. I'm very sleepy in the mornings and the afternoons. I had to stop work last year because of back trouble and being breathless all the time. My back, my legs and my spine are all very painful and I can only walk slowly with two sticks. You want to be very quiet and left alone all the time. The doctor said I have polio so it is all part of the post polio syndrome, and that I have got to try and live with it."

Variations in the ageing process

Obviously, there are certain kinds of physical or health problems which only effect people with particular impairments, or which have a much higher/lower incidence amongst particular groups. Apart from those already mentioned, other examples are given below.

The incidence of osteoporosis appears to be restricted almost exclusively to people with scoliosis or arthritis, while heart disease was almost exclusive to people with limb amputations and those with diabetes; both of these groups also reported a noticeably higher incidence of circulation problems, while people with limb amputations were the only group to report having ulcers and headaches/dizzy spells. Similarly, people with polio had a noticeably higher incidence of respiratory infections. People with impairments connected with the nervous system (eg. multiple sclerosis and parkinsons disease), not surprisingly, reported a low incidence of most of the physiological problems, but a higher than average incidence of increased

hearing or communication problems and problems with balance and coordination.

Regarding the pattern of the various physical changes over time, different kinds of disabilities appear to have different 'trajectories', although there is also a certain degree of overlap in this. Four main patterns or trajectories are indicated by the findings.

i) 'Progressive deterioration since onset': This appears most characteristic of the process of 'burn out' reported by some people with multiple sclerosis and, to a lesser extent, the experiences reported by some people with long-term arthritis.

ii) 'Onset of gradual deterioration after 20 plus years of relative stability': This pattern is characteristic of the experiences of many people with spinal injuries and also fits the experiences reported by people with polio, limb amputees, and people with long-term diabetes who also have physical impairments.

iii) 'Onset of increasingly progressive deterioration after either a period of relative stability or only gradual deterioration': Although the numbers are too small to make any conclusive generalisation, this pattern seems to be characteristic of the experience of long-term scoliosis.

iv) 'Intermittent change with underlining pattern of gradually progressive deterioration': This was most often reported by people with parkinsons disease and people with multiple sclerosis. While both groups typically experience intermittent 'remissions' and 'relapses', people have reported that they never regain quite the same levels of energy or strength after successive relapses.

(Note: Space does not allow a full discussion of these variations here, but further details are contained in separate briefing papers which are available as a supplement to this report.)

Ageing or disability?

Many people were concerned about the wide variety of physical and health problems they had experienced with ageing and felt that little or nothing is being done to investigate why these problems are occurring and what, if anything, can be done to remedy, or at least minimise, the effects. There is also concern that some of these problems may have been avoidable; therefore, younger generations who are yet to experience the ageing process

may also benefit from such investigations. Related to this, there is concern that there is very little research on separating out the effects of ageing and the long-term consequences of people's original disabilities;

"I do think that the medical profession should be looking into these things more. Alright, I know that - if you have a tin leg - you're bound to get problems with arthritis and things like that. I know that mine is to do with my disability because you do put an extra strain on your good leg to compensate - so it's bound to wear out. But, you don't know if there is anything that could have been done to alleviate some of that strain. Maybe there isn't - but if nobody tries to find out, you're never going to know for sure are you."

"There are so many things that you can go wrong when you're older in any case, but nobody seems to be trying to find out what's connected to the disability and what might just be old age. Unless you have some idea, you don't know if there's anything you can do about it - if there's any treatment that they ought to be trying out people should be told so that they can decide if they ought to be doing anything about it themselves. I mean, perhaps you wouldn't tear about so much when you're younger if you know you're going to suffer for it later - I don't know. Obviously, it's up to the individual - but, they should be advised of the situation so they can decide for themselves."

How ageing with disability is defined is also an important issue. Some people felt that they had had what they subsequently recognised as a disabling impairment or condition for many years, but that this had only recently been 'officially' diagnosed. A few people described long running conflicts with doctors about this. For example, some people reported that they had had scoliosis for many years, but that their doctors had only been prepared to confirm this once a certain level of severity had been reached. At the same time, other people who had had similar experiences to this were in agreement with their doctors about when their disability should be described as such;

"I had it (Scoliosis) when I was born, but I only found out when I was 29. I had severe pain and I kept ending up on the floor all the time curled up with very very severe pain."

Some people were unsure if we would want to include them in the survey, but had contacted us because they wanted to participate; also, some were unsure if they met the criteria for inclusion because they were not 'Registered Disabled' with their local authority. These doubts were voiced, despite our explicit message that anybody would be included as long as they considered themselves to have been disabled for 20 years or more.

Although the numbers are too small to make any definitive generalisations, there also appears to be a cultural dimension to this issue. A noticeably higher proportion of African Caribbean and South Asian people in the study said they either did not recognise any conventional medical label for their impairment, or that this was unimportant to them. For example, impairments such as arthritis were described in non-specific (although more direct) terms such as *"a pain in the bones"* or *"a bad back"*, even though the individuals concerned were aware of their doctor's definitions.

Clearly, these experiences reflect the pervasive influence of professional control over the definition of disablement (particularly by the medical profession), but they also give some indication of resistance to this by older disabled people themselves. On a practical level, this also has important implications for people's chances of getting access to services (this is discussed further in the next chapter).

While disputes about being able to have their disability recognised is an issue for some people, there are others who reported almost the opposite experience. As discussed in the previous chapter, some people felt that, while they had known about their disability for many years, they have not wanted to acknowledge this until now. Their experience of ageing, however, has changed this, so that they now (reluctantly, perhaps) consider themselves to be a disabled person. At the same time, some people mentioned the converse problem that, while they consider themselves to be ageing, they cannot get other people to recognise this because they are still relatively young;

"... they just don't know how bad it can be - especially when you are ageing, because you do suffer a lot more as time goes on - it's just that it might not be so noticeable."

"I'm 38 but, I wouldn't say I've got the health of a 38 year old. I would say that my health - compared to a 38 year old - is not very good. I am very aware that I'm ageing faster but you can't tell anyone - they don't believe you."

The experiences reported in this and the previous chapter highlight the various ways in which ageing disabled people's needs and, in some cases, their very existence have been overlooked. Further, it is clear that disablism, ageism, sexism and racism all have an affect on producing this situation. Apart from the personal consequences in terms of people's emotional and physical wellbeing, this also creates a whole range of practical obstacles to their being able to access appropriate services and other supportive resources. These are examined in the following chapter.

6. Dependency creating services

The dimensions of dependency

So far, this report has highlighted two key themes. First, that many older disabled people feel that their needs - and even their existence - has been overlooked. Second, that many are anxious about the future and, in particular, about maintaining their independence which they see as being threatened by a lack of appropriate and acceptable supportive resources.

Obviously, these two themes are inextricably linked. Further, as the rest of this chapter will demonstrate, the statutory services that are available mostly create and reinforce older disabled people's dependency and frustrate their attempts to maintain control over their own lives. This general problem is manifested in several ways. First, there is a lack of recognition of the needs of people who are ageing with long-term disabilities in the organisation of service provision. Second, there is a lack of understanding of the medical and physical consequences of long-term disability. Third, there is a lack of suitable or acceptable living options. Fourth, these problems are compounded by inadequate benefit and pension provision and the lack of recognition of extra financial costs associated with ageing with disability.

All of these dimensions of dependency creating services are themselves closely linked. In what follows, we attempt to demonstrate these links by focusing on some of the key issues raised by the people who participated in the study. In particular, issues around financial dependency, lack of information, the limited range of living options, the ways in which older disabled people's needs are made 'invisible', and the inappropriateness of existing services are discussed. Finally, we look at the ultimate form of dependency creation - institutionalisation.

Enforced dependency

A constant theme running through the views expressed by older disabled people is that the last thing they want is to 'become a burden', either on their families or on support services. In fact, it is striking just how little support most people say that they need. Being able to get this support, however, is often virtually impossible. Rather, the present organisation of services and, in particular, benefit and pension arrangements, means that many older disabled people find themselves becoming more dependent even though they are well aware that this is completely unnecessary. Several people gave examples of various ways in which they feel they are actually penalised for trying to be self-sufficient in older age;

'In my experience - but, I have been disabled for an awful long time - you just cope each day as new things occur. But then again, it depends on the individual. I mean, I'm married and I've got the support of a husband. Not everyone is in that situation. If they were alone, then obviously it's a very different kind of thing. I mean, my husband has to do a hell of a lot of housework in addition to going to work - the things that, physically, I'm just not able to do. We did try to get a home help a couple of years ago because I got worried and I thought - it's just not fair, he's knocking himself out. The borough said that I qualified for a home help but, because my husband was working - even though he's in a low paid job - we'd have to pay. In fact, we would have had to pay more per hour than my husband earns. You know, we thought - that's got to be a joke. So, we just said - no thanks, we'll carry on. So, in that respect, there's not a lot of support when you're older. I can understand it in a way - economically. But, all the time you're coping they don't wonder why - they're just damn glad that you're not bothering them. It's those that can't cope - for whatever reason - that are helped. Those that are prepared to struggle on don't get any help at all. I've always said that the system has been geared not to those who help themselves but to those who, for whatever reason, don't. In a way, that's sad. But then again, I'm the sort of person that doesn't really like asking for help anyway - and I'm sure there's a lot like me.'

As this quote illustrates, many older disabled people have managed with little or no support outside of their families and friends, in some cases, for more than half a century. Precisely because they have managed so well, however, what needs they do have in older age are overlooked. When this is coupled with low expectations of community services and a reluctance to request outside help, the end result is often total isolation from whatever resources might otherwise be available. For the majority of older disabled people, the relationship with existing community services is, quite literally, 'out of sight - out of mind'.

The widespread feeling amongst older disabled people that they are being penalised for being self sufficient is not restricted to the issue of personal assistance or domestic support. Others made similar comments about frustrated attempts to find suitable living options which would enable them to maintain their independence and - in their terms - avoid dependency on their families or community services;

"It's difficult to say how we might feel about (moving into sheltered accommodation). You can't break away from old habits. You shouldn't have to anyway if it's at all possible to avoid it. But, sometimes, beggars can't be choosers. If I died and (my wife) was on her own - the situation would change

overnight. But, apart from that, it's hard to know exactly what we might do. We're too proud you see - we wouldn't want to impose. So, if we haven't got that much time to go anyway I suppose it would be some kind of charitable home. At least we wouldn't have imposed on our daughter that way."

"Our culture tells us - stand on your own feet, be responsible, and don't be a burden to others. Well, I am standing on my own feet, I'm responsible for deciding to stay alive, and I make it easy for others by trying not to be a burden on our families or anyone else. But society makes this very difficult because I can't find a home that I can afford to live in."

The most clear cut and tangible examples of older disabled people being penalised for their self sufficiency relate to financial resources built up throughout their adult lives which many now see as being threatened by punitive means testing, charges for home help and other support services, and anomalies in pension and taxation systems;

"Pie allowances you get are some help - but it's nowhere near enough. It's like when they told me I could have the Invalid Care Allowance. I thought - this is wonderful, it would be a great help. What they didn't tell me, of course, was that - because of my pension - I'd be taxed. So, they take it away again. It's always the same. We've saved and worked to look after ourselves but you are forced to be more sort of dependent. There's no reward for trying to be self sufficient. "
"I wouldn't say they (social services) haven't ever helped at all - that wouldn't be fair. But, there's always this thing about - if you've got any money of your own, you never get so much help. These days, there's always this means test which isn't really fair. It's as if you're getting penalised for trying to look after yourself - the more you do, the less help you get. It's not as if I've got all that much. I did work, so I've got a small pension on top of my old age pension - but it doesn't come to all that much - you need that little bit extra. Mind you, I'm lucky compared to a lot of people. Some of them hardly have anything at all - I just don't know how they manage."

Obviously, the practical consequences of this situation in terms of increased expenditure and the dwindling of their savings is of critical importance to the quality of older disabled people's lives.

It is equally important to consider the emotional impact in terms of increasing anxiety about the future and the general disillusionment which many people felt;

"They don't look after the disabled - not one bit. I wrote to the council - and they want £400 to do that run in and ramp at the front. I haven't got E400 to do

that. I can't get a penny - I don't get a penny off nobody. Everything I've got, I've had to work for. I've had nothing off of the State - I've had nothing at all. I mean, I'm a very independent sort of bloke - but I would like a bit of help now and again if I need it."

Faced with the financial and other insecurities created by the punitive obstacles to self-sufficiency some older disabled people find that they are left with little else to fall back on other than the choice between depending on their families or on charity - both of which they had actively resisted for so long in their lives.

No information - no choice

Many people reported that they had been frustrated in their attempts to get advice and information about the range of supportive resources they might need. More often than not, these problems arose because people simply did not know where to go for information, or because appropriate sources of information or advice simply do not exist. In other areas, professionals who act as gatekeepers to information are either unwilling or unable to provide the kind of advice people need.

This was particularly likely in the case of advice about medical matters. As noted earlier, many older disabled people feel that more should be done to investigate the physical and health consequences of ageing with a disability. The present dearth of understanding not only creates practical problems in accessing appropriate health services when they are needed, but also hinders older people's own efforts to make responsible choices about their own health;

"There are things that would have been useful to know about in advance so that you have some warning about what to expect. With me, everything has really come to a head in the last 3 or 4 years. I've had really chronic bronchial problems - it nearly killed me to be honest but nobody ever said to expect that, so I didn't have any warning at all. It would have been much better if I had because I could have organised my lifestyle in a different way - taken things a bit easier. Also, I would have done more exercise, and different kinds of exercise - that sort of thing."

Even amongst the minority of people who had eventually been able to find out what they needed to know, this had usually been despite of, rather than because of the medical profession;

"I have come to get satisfactory help from the medical profession through helping myself and keeping my own eyes and ears open first. For example, I had never heard of a pain clinic until I heard something mentioned on television. I then went to my GP and said - please can I go to a pain clinic. Then, I was sent to a pain clinic - and I've gradually gone sort of up and up in medical circles through keeping my own eyes and ears open. For example, joining this self-help group. A friend of mine heard about it on the radio and put me in touch with it. Through them, I've heard that other people of my own age have had operations and therefore I've looked into the possibility of having operations - which were not suggested to me originally by the medical profession. So, any kind of medical help - and it's very competent help I think I've had in the long run - I have eventually come to it through my own initiative."

Several people also reported not being able to get adequate advice and information about benefits and pensions. Some were not receiving benefits which they would almost certainly be eligible to claim. Some people had found out about eligibility for benefits completely by accident (eg. from friends and relatives or, as in the following example, from a war pensions welfare officer who just happened to notice that this woman was virtually unable to walk while he was visiting her husband);

"My wife gets this Mobility Allowance now, although we only found out about that quite by accident. My welfare officer (War Pensions) came on a visit one day and she said - I couldn't help noticing that your wife is having difficulty walking are you claiming for Mobility? Well, I didn't even know what it was then, so she gave us the form and said to take it along to our doctor. So, she went to see the doctor and he told her he'd fill it in as soon as she walked in practically. He said - it's obvious you should be getting it Mrs. xxx ~ so that was that. But, you see, we only found out about that by chance - she could have been claiming it for years, but we just didn't know."

As a result of this lack of information, some people realised (often too late) that they could have been claiming these benefits for many years if they had known about their eligibility before.

Again, this means that they had been forced to be more dependent than they might otherwise have been. While they were, not surprisingly, disappointed most people in this situation were in no doubt about where to lay the blame;

"We cope with difficulty and with little help. It was purely by accident that I found out I was eligible to claim for attendance allowance. This I did, and it took me 17 months and two medicals and God knows how many phone calls to London, Blackpool, my MP, the Health Minister to get it. I'm independent and

have an active mind and would not give in. But, how many other people have given up. We keep reading in the papers of the £9 million per year of unclaimed benefits - that's why it's unclaimed. It is also a fact that no doctor will tell a patient that they can claim anything at all, and during my spells in hospital I was never visited by, or put in touch with, the DHSS for any benefits whether financial or aids."

Another area where lack of information creates dependency is in finding suitable living options.

Although they were able to describe what kind of living options they were ideally looking for, most people who were looking to change their living arrangements had no idea whether or not they would be available and, if so, where they could go for appropriate advice and information.

This was a particularly crucial issue for people considering a move into a residential or nursing home. Because of this lack of information, making such an important change in their lives can literally be like stepping into darkness;

"I think I will be staying here now - unless they take me out in a can't stay here I would go to a private nursing home. There's one I have visited. It's small - about 8 or 9 people - and the staff are very caring. Obviously you prefer to stay at home - but somewhere like that would be a fairly sensible choice if you did have to move. The only trouble is that, you need to have all the information, which is pretty difficult. It's pot luck really with picking a home. A lot of them seem fine when you get the glossy brochures - but you don't really know until you're actually living there."

As the above examples illustrate, people often find themselves in a 'catch 22' situation when it comes to obtaining information about services they need, as professionals who do have access to information often do not pass this on unless they are asked. However, without any guidance or advice, it is unlikely that the majority of people will even know what questions they should be asking in the first place;

"I tried acupuncture. I saw an advert in the local paper for an acupuncturist. I asked him to come and see me, and he came about 6 times altogether. It really helped some of the time, but it was very expensive - £20 a go. I couldn't really afford to keep paying that - although I would have done if I could. So, I went back to the pain clinic and then I discovered that the doctor there was already doing acupuncture on the NHS. I was amazed when I found that out. I said to him - why didn't you say? He just said - why didn't you ask." (our underlining)

Financial dependency

As noted earlier, some people felt that they were being penalised for trying to be financially self-sufficient. Indeed, for many older disabled people, the level of financial resources they have at their disposal not only means that they are forced to be dependent but, in many cases, to live at bare subsistence levels;

"Believe me - it's hard to live - it's hard just to scrape through. I mean, we don't have no luxuries. We don't get no clothes. As a matter of fact, we get our clothes given to us."

"We get almost £200. But, that's for two of us mind. By the time you've paid your mortgage, your water rates, your insurance, your gas, your electricity - by the time you've finished all that, believe me there's not a lot left over - we got about £30 a week to live on, and that's it. That's with attendance allowance, mobility allowance, my pension, and her old age pension - everything together - it's not a lot."

As shown in Table 9, over a third of those who gave details about their financial circumstances had a total household income of under *£100* per week, while three quarters had incomes below the national average for the general population. Further, it is important to note that, for many disabled people, ageing is also associated with an increase in expenditure on household maintenance, domestic support, personal assistance, transport and so on. Standardising the data to take account of reported outgoings and household type shows that over two thirds had incomes which were rated as inadequate, with almost half of these having marked or severely inadequate incomes (see Table 10).

TABLE 9: GROSS WEEKLY HOUSEHOLD INCOME BY GENDER AND RACE

(Percent)	Male	Female	Black/Ethnic Minority	White	All
Under £50	0	2	0	2	1
£50 - £99	14	46	59	26	34
£100 - £149	39	30	29	35	34
£150 - £199	11	2	0	7	5
£200 or more	36	20	12	30	26
Base Total	(N=32)	(N=54)	(N=18)	(N=68)	(N=86)
Average	£170.00	£130.16	£105.96	£155.31	£144.98

TABLE 10: ADEQUACY OF HOUSEHOLD INCOME (STANDARDISED)

(Percent)	Male	Female	Black/Ethnic Minority	White	All
Very good	8	3	0	7	5
More than adequate	24	10	10	17	15
Adequate	16	12	10	14	13
Minor inadequacy	22	27	35	22	25
Marked inadequacy	22	30	15	30	27
Severe inadequacy	8	15	25	9	12
Non-classifiable	0	3	5	1	2
Base Totals	(N=37)	(N=60)	(N=20)	(N=77)	(N=97)

There were also marked gender and race differences in the financial resources people had at their disposal. For example, women had lower incomes (from all sources) than men - £130 compared to £170 per week and were also more likely to be rated as having inadequate incomes (72% compared to 52% of men). Amongst black and ethnic minority households the differences were even more marked. Almost 60% had weekly incomes below £100, compared to only a

quarter of white households and average incomes were more than 30% lower overall (£106 compared to £155).

Changes in personal or domestic circumstances commonly associated with ageing can also have a significant impact on disposable incomes; for example, a member of the household becoming ill, or entering institutional care. Similarly, because of the various health problems and physical changes discussed in the previous chapter some older disabled people feel the need to take early retirement. Amongst the early retirees interviewed for this study, two thirds said that this was for health reasons. Obviously, in most cases, this meant that they had reduced pension benefits and savings;

"I get a very small pension from my last job. That's another thing I had you see - because I had to stop work early, it's a lot less than I would have got if I'd stayed on. And then, because I get it, it means that I can't claim income support because it just takes me over the limit. That's really stupid because if I could get income support I could probably claim for the disability allowance. So I'm definitely worse off."

Apart from those who were forced to stop working altogether, some people reported that they were only able to work part-time, which also meant that they had reduced earnings. On the other hand, a few people who were finding work very difficult physically, could simply not afford to give up even though this was clearly having a detrimental effect on their health;

"I can only work part-time because of my back. That has definitely marred my career prospects. Not from the outside - nobody's ever said you can't promote her because she's got a bad back, but I know my own limitations and I can only work part-time."

"I can only work part-time because I just get so tired. I have the family to run anyway, so that keeps me pretty busy - and you want to leave yourself some energy to do other things in your life besides working. I did work full-time for a while when I was younger, but not any more. But, where I work, they are not very understanding. You see, I said that I wanted to spread my days out - work one day, and have a day off, then work. That way, I can get my energy back so I'm able to put everything into the job. But they said - Oh no, you can't do that. So I have to work 3 straight days, which means I'm completely knackered by the time I've finished."

The level of financial resources they have at their disposal is obviously a crucial factor in determining whether or not older disabled people will be able to maintain their independence. For some, the combination of reduced incomes

and increased costs meant having to go without some of life's essentials, simply because they could not afford them. Again, several people felt particularly resentful about the lack of any allowance for this within existing social security and taxation systems;-

"The council should help. I mean, I do a lot of things here. I mean, I strip walls and everything. And, when you're getting old - I'm 70 now - it does get too much for you. I mean, we can't afford to keep paying out for people to do it."

"The thing that really bothers me is that people just don't seem to recognise how much it costs you to be disabled. And, it probably costs you even more when you're older. But you don't get any allowance for that at all, which I think is all wrong. And if there are any benefits you might be able to get, they're always means tested and that's not right in any case because it should be obvious to anyone that you need the extra if you are disabled."

The availability of financial resources to meet the extra costs associated with ageing is obviously linked to employment opportunities throughout people's lives. This, in turn, is strongly associated with both race and gender in a number of ways.

First, we have already noted that women had lower household incomes than men in the study, and were more likely to be rated as having an inadequate income. Second, men were more likely to have an occupational pension in addition to their state pension and other sources of income.

This in turn is a reflection of differences in occupational careers between men and women.

Women were less likely to have worked since becoming disabled, were more likely to have worked in lower paid occupations, and were more likely to have stopped working early in order to provide personal assistance or other family support (see Tables 11 and 12). At the same time, those remaining in employment were more likely to carry on working past retirement age. In most cases, this was not out of choice but simply because they could not afford to stop. Also, there were a few women in the study who, although they would have liked to work less hours or cease employment altogether, were carrying on because they did not want to be financially dependent on their husband's or partners;

"I have somebody to come in once a week because I can't Hoover, so somebody comes in once a week to do the cleaning. That's a private arrangement. I was told I couldn't have a home help. I was told I wasn't eligible because my

husband earns a lot of money and I'm never counted as being financially independent - even though I have to be regarding our own domestic arrangements. My money is my money, and his money is his money. From the point of view of anything else, we have to be counted as a married couple and I'm not eligible for anything. So, my domestic comes in for one afternoon a week for 3 hours, and I pay her out of my own salary. "

"I think, inevitably, it depends on the partner you live with as well. Now, I live with somebody who is very un-understanding - who is not understanding - who lives for his job, his garden, and that's about it - his food, his television. Someone who is not very sympathetic and I feel that, if I'm going to stay with him for the time being anyway, then I've got to carry on and have a meal ready at the end of the day and have done the shopping and, you know, whatever. Also, I've got to have my own financial independence - life would be hell without my own financial independence. "

There was also a marked disparity between the financial resources available to older disabled people from black and ethnic minority communities compared to white people in the study. At the same time, a larger proportion of people in these groups were still working (Table 11), but were disproportionately represented in lower paid occupations. Secondly, the combination of these factors meant that they were almost five times as likely to be dependent on income support as older white disabled people.

Consequently, opportunities to secure additional necessities were extremely limited for the majority of people from black and ethnic minority communities. In the same way that the financial circumstances of older disabled women can be linked to gender inequalities in employment, the low incomes of older black disabled people can be traced back to the restricted employment opportunities they had experienced throughout their lives, and to the fact that they were mostly restricted to working in lower-paid occupations. Obviously, this will have a major impact on the general quality of their lives in older age and, in particular, on their ability to maintain their independence.

TABLE 11: EMPLOYMENT STATUS BY GENDER AND RACE

(Percent)	Male	Female	Black/Ethnic Minority	White	All
Working (full-time)	7	13	16	9	10
Working (part-time)	5	5	0	7	5
Retired (age 60/65)	75	53	61	61	61
Not working (incl. early retirers)	14	29	23	24	24
Base totals	(N=44)	(N=79)	(N=31)	(N=92)	(N=123)

TABLE 12: AGE LAST WORKED

(Percent)	Male	Female	All
Under 30	0	14	8
30 - 49	8	17	13
50 - 54	8	3	5
55 - 59	10	15	13
60 - 64	36	14	22
65 or over	21	3	10
Still working	13	17	15
Never worked disabled since ₅		17	12
Base totals	(N=39)	(N=59)	(N=98)

Restricted living options

Another key issue in the production of older disabled people's dependency is the very limited range of alternative living options for those who want or need to move. This problem, coupled with difficulties in obtaining adaptations to existing housing and limited financial resources means that a significant proportion of older disabled people are forced to live in unsuitable or unsatisfactory housing conditions. Almost one third of the people participating in this study reported that they either wanted, or were actively planning to

move from their present homes. One in ten had already moved within the last few years.

There were a number of reasons why people wanted to change their living arrangements when they were older, and these were often interconnected. Some people found that their living environment needed to be adapted to suit physical changes they had experienced with ageing, but had experienced difficulties due to the unavailability of the kind of adaptations or equipment they wanted, lack of advice and information, or - most common of all - inadequate financial resources.

Consequently, amongst those who wanted to move, three quarters said this was because their present accommodation was unsuitable, while just under a third added that changes in their, or their partner's, health status was also a factor. A similar number mentioned lack of appropriate support (service based or informal) in their local areas as one of the reasons they wanted to move. Amongst the interview participants as a whole, well over half felt they would be likely to move if their spouse or partner became ill, or died.

Whatever their precise reasons for wanting or needing to move, many people stressed the importance of planning ahead for changes in personal or domestic circumstances which they anticipated having to face in the foreseeable future;

'You do have to think ahead because, when you get older, there's bound to be some kind of problems and it's best if you've thought about what you might want to do. Alright, you might not need a lot of extra help but, on the other hand, you might - you don't know for sure. So, in my case, when I was thinking about going to live away from my parents, the main thing on my mind was - it's important to get the right place to start with so that you have the help you might need when you're older - if you need it.'

People who were not planning to move, also stressed the importance of being able to adapt their present homes to suit their changing circumstances and needs in older age. Some also pointed out that it would be much better to plan ahead and make any changes to their living environment before problems actually occurred, to avoid being faced with the choice between living in unsuitable housing, or being forced to move against their wishes;

"This problem with the arthritis has made me think a lot about the house and getting it fixed up so that I can manage everything with the minimum discomfort and inconvenience. I'm having the bath changed to one of those ones with the built in seat so that I don't have to stretch too much to lift myself out. Similarly, a raised lavatory to make it easier to stand up - this sort of thing. Also, I shall

be having all the plug sockets raised and I will probably need to have the door handles altered so that I can get at them from a wheelchair. You see, I might not end up needing some of these things - or any of them for that matter - but, it's best to be prepared if you're able to."

"I envisage that, in a few years, if I've got to give up driving myself I'm going to be at home more often. So, I want to have a home where I'm as fully independent and capable as I can be. You know, to look after myself - cooking washing ironing - all this sort of thing. As my physical capabilities reduce, I want the fitments in the bungalow to be able to fit and meet that reduction in my physical capabilities. That way, I feel that I'll still have a chance of having a quality life."

Being able to plan ahead, and make any changes wanted is obviously very much dependent on having adequate financial resources. Nearly 40% of those who wanted or planned to move included financial considerations amongst their reasons. In some cases, they hoped to release some of their capital in order to obtain more suitable accommodation and/or purchase additional personal or domestic assistance. Others were finding it difficult to maintain their present homes and were hoping to get cheaper accommodation. In a few cases, money was required for a planned move into sheltered housing or residential care. At the same time, some of those who wanted to move doubted if they would actually be able to afford to do so;

"I'm not planning on retiring for a while yet, but we have thought about moving when the time comes. Ideally, what you want to be able to do is sell up and either get a cheaper place, or rent, so that you have the money that's left over to live on - that's the basic plan. Preferably, a two bedroom ground floor retirement flat with all the services on hand (i.e. sheltered flat). That would suit us very well if we could get somewhere like that. That is a problem though. the housing associations don't have enough places for people to rent. There are a lot more private developments - but, buying is alright if you've got cash to spare, otherwise you really want to rent so you can have the money from the house to live on. It defeats the object if you don't actually have enough to live on when you move."

'You do have to think very carefully about what kind of home you're going to need when you're older. We were lucky - we had a big house to sell, so that did make it a lot easier. But, a lot of people don't have the choice, and I'm sure they sometimes get stuck living in homes which aren't really suitable - they just haven't got the money to get out of it.'

These quotes also illustrate that, even if they have adequate financial resources, people's plans are often frustrated by the very limited range of alternative living options available to older disabled people. As shown in Table 13, the vast majority of people wanted to live in their own home (even though this may involve moving to cheaper or more suitable accommodation). Very few people would freely choose any other living option, although around 1 in 5 felt that a move into either sheltered accommodation or a nursing home might be an acceptable alternative. Even then, several added that this would be more out of necessity than choice.

TABLE 13: IDEAL LIVING OPTIONS

(Percent)	First Choice	Second Choice
Own home	85	11
Supported tenancy (eg. Grove Road)	0	5
Sheltered housing (warden)	8	22
Group living unit/hostel	2	12
Nursing home	3	23
Residential home	2	14
Disabled village (eg. Het Dorp)	1	2
Core/cluster housing (CIL model)	1	4
Other	0	9
Base totals	(N=123)	(N=56)

However, there were a number of problems with getting access to even this very limited range of choices. First, there are general problems like the shortage of suitable homes, and lack of information. Second, even housing which is supposed to be specifically adapted for disabled people is often inappropriate because of problems such as lack of space and assumptions about restricted lifestyles and single occupancy which are reflected in housing design itself;

"Ideally, you need a little kitchenette and a separate bedroom - something like a small flat. Also, you don't really have enough room to put all your things - as you can see. That's why I have to keep the electric

wheelchair outside - there's just nowhere to put it in here. If there was a bit more space, I could get straight into it when I go out, instead of having to transfer when I get outside. It's little things like that. That's the problem with adapting somewhere instead of having a purpose built place - you have to work with what's already there so you can't always have everything just right. Mind you, having said that, what suits one person might not be ideal for someone else - so you need to have the design as flexible as possible. Anyway, you don't know if you're going to stay in the same condition yourself so you might even want to change things around later on in any case."

"It was put to me before I came here that I might be able to live independently in a sheltered flat or something like that. But, when it comes to cooking and things like that - it would have been too much of a risk The only other thing that I thought of was - you could have a home like this, but have an annexe built on. That way, you could live there on your own but you'd always have someone to call on if you got into difficulties. I have heard that there are some places like that - but there wasn't anything around at the time."

Similarly, while some people view sheltered accommodation as an acceptable compromise between struggling to stay at home and moving into a residential or nursing home, this option is not without its problems either. First, there is the general problem that sheltered accommodation is often unsuitable for wheelchair users and others with restricted mobility. Second, sheltered accommodation is essentially provided on the assumption that residents will be living on their own; some couples who were actively seeking a place in sheltered accommodation found that this option was effectively closed to them. Third, moving into sheltered accommodation may not be the last change people will make in their living arrangements - even though this is usually what they anticipated when they first moved. This is because of the lack of flexible support options like occasional personal assistance available to people in sheltered accommodation; similarly lack of space for people wishing to have live-in helpers;

"I can't climb the stairs now and so we are going to have to move as soon as we can get something fired up. I have applied to the council for a place in sheltered accommodation. They sent us to view the first place they had but it put me right off. For a start, there wasn't enough room to swing a cat in there. There wasn't even enough room for one person let alone the two of us. Actually, I'm pretty sure it was only meant for one, but they were just trying to fob us off that it was meant for two - I was thoroughly disgusted with the place in any case. It was very badly designed all the way through. It just didn't make any sense for someone who has a problem with mobility On top of all that, I didn't think

too much of the warden either. She didn't seem at all interested and you could see that they didn't do much checking up or nothing - which defeats the object in any case."

"I wouldn't want to change where I'm living now - no way. I hope I'll be here until they carry me out or throw me out. I mean, if I go doolally I might have to go. Hopefully I'll be staying here but, if it became necessary, I might have to move into a home. I mean, then, there's just no two ways about it because here you've got to be able to look after yourself - there's no nursing attention and people have had to go into homes from here because they got to a stage where they couldn't look after themselves You do get nurses come in sometimes to help with washing and dressing people and putting them to bed - and home helps - and that's it. If you really need looking after all the time, then that service is not available Anyway, you've only got one bedroom so you couldn't have somebody living in in any case."

Several people voiced concerns about the growth in the private residential home sector. Some were concerned that, due to the high costs involved, the increasing number of private homes effectively reduces choice for older people. Others were concerned that there is no check on the quality of support provided; also, that private homes are able to operate discriminatory admissions criteria to exclude people on the grounds of disability, race, or any other criteria they may wish to adopt;

"I suspect part of the problem is that most of these homes are privately run now. Maybe if there was more of a mix with the county council homes as well, it might be easier to get in. But, I don't really know - I don't even know where to ask."

"There are lots of homes - especially round here (south coast), but we can't afford the sort of prices the private homes are charging. It's a bit of a sham really because the government says we're supposed to have more choice but, if you can't afford it, there is no choice. Anyway, some of the ones we've looked at, I couldn't possibly live in them. They're homes for vegetables, not for old people. There are a couple which would be suitable. In fact, we are on the waiting list for one place and, hopefully, we might be able to get in there. The other, there is quite an amusing story about that. My wife is West Indian and I'm Jewish. She rang them up to enquire about places. She put on her best middle class accent and everything was going along until she mentioned that her husband was Jewish. Then, they said - oh no, we couldn't possibly help. Maybe she should have told them she was black as well - then they really would have had a fit, wouldn't they."

The restricted choice of living options for older disabled people is often compounded by the financial obstacles which many face. For example, some people on low incomes cannot even begin to consider purchasing suitable accommodation; others may find that their existing homes would not raise enough capital for the kind of accommodation they are looking for (eg. a bungalow); even people with savings may find that their financial reserves are needed to meet other additional costs associated with ageing (eg. purchasing personal assistance or domestic support).

Not surprisingly, these obstacles also contribute to older disabled people's anxiety about having to rely on their families and the possibility of having to move into residential care. Because of this, some people were very concerned about being forced into accepting unsuitable or undesirable living options - simply through lack of choice;

'Ageing does worry me, although I try not to think about it because it's quite depressing. I mean, here there are stairs - and I haven't lived anywhere where there was stairs since I was a child and I didn't know if I could cope physically I tried for a stair lift, but the ceiling is too low, so that's out of the question. The social services did put a downstairs loo in for me, which with my disability, I do need. So, that's great - but there is still the stairs. I mean, I can climb stairs But, when my husband retires, we've got to move out of here anyway. So, in the back of my mind there is a little niggle - am I going to make it till he retires, or am I going to reach the stage where I cannot go up them There's always these things at the back of your mind In the end, it all comes down to money doesn't it. My dream has always been to have my own little bungalow - but, that's never been financially possible, so that's just a dream - you can't live on dreams.'

"Having seen the council place, I think I'm going to have to look for something else. It's tricky anyway because, they only offer you three places and then that's it. So, you think to yourself - the other ones might turn out to be even worse, so maybe I should take it - so you're sort of forced into it a bit."

Invisible needs - invisible people

The experiences reported above illustrate that, because of their isolation and enforced dependency many older disabled people effectively become 'invisible', and their real needs go unrecognised. Further, this often becomes a vicious circle; as their needs and experiences are not acknowledged, many people simply carry on, and do not even attempt to articulate their needs because their experience has always been that no-one would listen to them

anyway. Consequently, what needs older disabled people do have often remain unmet.

In fact, there were a wide range of unmet support needs reported by people participating in the study, and levels of contact with most community services were very low (see Table 14). Further, existing services which were being used were often inappropriate to older disabled people's self defined needs. Indeed, several people had either declined or stopped using particular statutory services (mostly social work support or home helps), because they had found them so unsatisfactory and preferred to manage without them.

There were also some noticeable variations in levels of contact with various services according to both race and gender. Women had higher levels of contact with most services than men. This was particularly the case with domestic assistance, community nursing, occupational therapy and day care services. This reflects the fact that the older women in the study were not only more likely to be supporting others, but were also less likely to be able to rely on informal sources of support, or to purchase additional support privately compared to older men.

Similarly, older disabled people from black and ethnic minority communities were more likely than their white counterparts to face problems like extreme isolation and very low incomes. Consequently, they were forced to rely on statutory services to much greater extent. For example, levels of contact with social services and use of day care services were both twice as high amongst this group, while they were nearly three times more likely to be using the community nursing service. At the same time, levels of contact with alternative sources of support from disability organisations or other voluntary agencies were lower.

TABLE 14: CURRENT USE OF COMMUNITY SERVICES

Proportion using each service:	Male	Female	Black/Ethnic Minority	White	All
Social Workers	27	19	36	16	22
Home Helps	13	25	27	19	21
Community Nursing	11	19	30	11	16
Day Care Centres	11	18	24	12	15
Occupational Therapists	11	18	9	17	15
Local Disability Organisation	13	15	9	17	15
Voluntary Welfare Services	18	14	12	16	15
Chiropody	9	15	3	16	13
Dial-A-Ride	7	6	9	6	7
Meals on Wheels	7	4	12	2	5
Good Neighbours/Befrienders	0	7	6	3	4
Health Visitors	0	4	0	3	2
No services used	20	14	9	18	16

TABLE 15: COMMUNITY SERVICES WANTED

Proportion wanting to use the following;-	%
Information on services/living options	24
Transport services	24
Domestic assistance services	17
Aids/adaptations	16
Financial advice	14
Advocacy services	14
Leisure/education services	9
Personal Assistant Schemes	8
On-call support service	7
Self-help groups	7
Respite services	6
Companion service	5
Decorating/repair service	4
Chiropody	4
General counselling	3
Sexual counselling/relief	2
Gardening services	2

Note: These percentages are based on the number of people mentioning each type of service when asked if there was any type of support they wanted but did not have already.

Over 60% of the people interviewed wanted some kind of support service which they were not currently receiving. Common needs included transport services, aids and adaptations and domestic assistance (see Table 15). Underlining the issues discussed earlier, the highest demand of all was for information about services and/or advice about benefits - wanted by just under 40% of all the people interviewed. A further 14% also felt that they needed to use some kind of advocacy service. In some cases, this was combined with a

need for information and advice, while others had specific grievances related to being refused particular services or benefits.

For most people, the actual amount of additional support they wanted when they were older was fairly minimal. For example, almost 60% of those interviewed felt they could manage without any additional personal assistance, and most of those who did want more help said that this would usually be for no more than two hours a day. Similarly, the average amount of domestic assistance people wanted was less than an hour and a half per day. Given that most people were making such small demands on services, they were - not surprisingly - disappointed and disillusioned that their needs were not being met;

"I do miss being able to have a bath. What I really need is an electric hoist because - I can't sit in the bath because of my balance, with a hoist I could sort of suspend myself in the water. We tried to get some help before we had the shower put in but, like my husband was saying, the district nurses could only promise to come once a week. I didn't think that was very good - I'm not making a great demand on the world, it's not too much to ask to be able to have a bath."

"I am a very independent sort of bloke. I suppose that I don't really want all that much but, the way I feel about it, you like to know that there is a little bit of help if you need it."

Amongst those for whom ageing was associated with an increased need for personal assistance, the most common needs were for help with having a bath or shower, dressing and undressing, and help with going to the toilet (all wanted by between 20 and 40%). A small number of people also mentioned wanting help with transfers in/out of wheelchairs or cars, or that they needed help with turning at night. Several people had found that existing services were unable or unwilling to respond to these needs because they did not fit in with how services are organised, or because the times they wanted help did not match the times services were available. However, these kinds of problems, which are faced by many disabled people of all ages, were often compounded by the lack of recognition of additional needs associated with ageing, however small these may be. Even the minority of people who were using existing personal assistance services typically found that it was very difficult, if not impossible, to get service providers to recognise that their needs may have changed;

"I need help with getting dressed. The district nurses didn't actually do that - but I still need someone to help me - it's just physically impossible now. You need help with these kind of things so you can live a normal life and do all the

things you would normally do. But, trying to get that across to people - it's impossible."

Similarly, although just under half of the people in the study needed some additional domestic assistance, less than 1 in 5 people received any support from the Home Help service. Some people had used the service in the past but had since stopped. In a few cases, this was because charges had been introduced which they could not afford. For others, unreliability and inflexibility meant that the service was not appropriate to their needs. Several people also complained about the very limited home help hours they had been offered.

Given that many people's disposable incomes were declining over time, the trend towards charging for home help services was particularly hard on some. But, in the absence of any acceptable alternative, they had no choice but to pay. Others had been forced to reduce their home help hours to what they could afford, and those who could were actively seeking alternative means of meeting their domestic support needs.

Most of the Asian and African Caribbean participants who were using the Home Help service made exactly the same sort of criticisms as everyone else. Although a few specifically expressed a preference for Home Helps from their own ethnic or cultural communities, this did not seem to make very much difference to whether or not they were satisfied with the service; most were dissatisfied with the service - whoever the workers were;

".... some of them don't want to do nothing. They come, they want to smoke, make cups of tea, they don't want to do anything."

"I wouldn't have a home help. They can't cook, when they come they don't want to do anything. When she feel like coming she come - no one ever come to check. For the one year she ^shad been with me she sweep the bedroom twice - can you believe that. I couldn't live in a room where it only sweep twice, I try and keep my place clean and tidy and that's how we were brought up in Jamaica."

For those who did want to be allocated African Caribbean or Asian Home Helps, this was usually because of problems they had experienced with workers doing their shopping. Specifically, they wanted Home Helps who understood what kind of food they wanted and where to get it, rather than having to put up with whatever they were given;

'It's no use using the council services. I mean, I can't send someone out shopping because she don't know my culture. She don't know what food to get. I

need to be able to leave instructions and know that they can do it right away. But, all of this is lost on the social services. It's not enough to just send round a black woman. She has to have the same background. It's no good otherwise. "

Similar comments were made about the meals on wheels service. Those using the service, often complained about having no option but to eat food which was completely different from the type of meals they previously cooked for themselves. The popularity of weekly luncheon clubs amongst older African Caribbean people, for example, stands as testimony to this as most people felt that Caribbean food was not only more nutritious, but also more 'humanising'. Having to eat English meals, on the other hand, was felt to be tantamount to being stripped of their cultural identity;

"I get meals on wheels and I don't like it. I don't eat it. They can't cook rice and peas and nice chicken and make carrot juice or even pudding."

People who lived on their own were particularly likely to report needing more domestic assistance.

It was also noticeable that; women had a greater need for domestic assistance than men as they were more likely to have a domestic role within the household. For some, this was a source of considerable strain and anxiety and difficulties they had experienced with accessing domestic support only served to increase the pressures which they felt were placed on them as disabled women;

"I worry myself silly about letting the family down and, if there was someone to call on, I wouldn't worry so much You see, if I have to be in bed I can never really relax because I'm always worried. I worry about if it's too much for (my husband), and all the rest of it I can think of several instances where my GP has said - you shouldn't be doing such and such and I've thought - well, there's nobody else to ask."

"Here I am with a husband who's disabled - who's worse than I am, a family to run, and I wasn't getting the help that I needed when I needed it to be able to cope in that sort of situation. I've always done everything myself and I haven't asked for help a great deal. Then, when I did - it wasn't there. That's what concerns me."

This kind of experience also highlights another very important dimension to older disabled people's support needs. Although the amount of additional assistance people needed was usually fairly minimal, several found that the

times when they needed this help tended to become more variable as they got older. There were several reasons for this.

First, in some cases, the kinds of physical problems or changes people had experienced with ageing meant that they sometimes required additional personal assistance which they did not need at other times. Second, several people found that their usual sources of support were increasingly prone to breaking down or coming under strain; usually, this was because they were almost completely reliant on friends or relatives - most of whom were themselves ageing - without any back-up from community services. Third, some people had chosen not to use service based support on a regular basis because they felt that this would compromise their independence, and only wanted personal assistance on the occasions they believed it was absolutely necessary. Finally, some people had been forced to reduce the amount of regular assistance they had for financial reasons; while they managed in this situation for most of the time, there were inevitably occasions when they could not cope, or could only do so at considerable physical and/or emotional cost.

For all or any of these reasons, several people wanted to be able to access temporary assistance on an occasional basis, or wanted services to be organised in a more flexible way so that they were not forced to choose between having no help at all, or being dependent on regular services which they may not really need;

"... it would be useful to have something like that occasionally. Like, for instance, when one of us goes into hospital, or if I'm suddenly smitten with a bug or something or unable to move. It doesn't happen very often but, I mean (my husband), he tries very hard but he is quite disabled and it's not easy for him if there was someone to call on, I wouldn't worry so much."

"There are days when I could use some extra help My wife works, but there is her niece and I have some good neighbours who I can call if I'm in trouble - you're never completely alone whatever happens. But, there are some days when I feel very tired and I can't even manage to make a cup of tea. Usually, I just stumble around the place. I suppose, times like that it would be good if someone could call round - maybe get some lunch and things like that. It would certainly be good to know there was that extra help if you needed it."

As with their regular support needs, most people did not anticipate wanting a great deal of temporary additional assistance. Rather, they simply wanted the security of knowing that the help would be there if and when they needed it. However, the inflexibility of existing services combined with the experience of managing without any additional assistance for so long meant that most

people did not have access to this kind of support and, in most cases, did not believe that they ever would. Instead, they just carried on making the best of whatever arrangements they had. Again, the consequence is that their needs effectively remain invisible.

In view of the various problems with existing community services, many of those who were able to had obtained private help instead. The costs involved (an average of £4.50 per hour for private domestic assistance, for example) meant that several other people who would have liked to take this option could not afford to do so. Most people who needed extra support were simply having to manage without or, if they were able to, rely on friends and relatives.

This was a particular problem for older Asian and African Caribbean people in the study, none of whom were able to purchase private domestic support (although one woman did use Independent Living Fund money to pay for personal assistance, and another two Asian people had regular domestic help provided on a voluntary basis). Some of the Asian people interviewed did talk about the possibility of employing private help, but none of the African Caribbean participants had even thought about this option. This is partly a reflection of the fact several were struggling to meet the financial commitments they had already, so thinking about paying for extra help would be pointless.

Another area where existing services fail to respond to older disabled people's needs is in the supply of aids and adaptations. One of the most common consequences of the physical ageing process is reduced mobility. Because of this, coupled with the unsuitability of some people's accommodation, there is an increased demand for various aids and adaptations to offset some of the problems experienced with ageing. Most of those who needed structural housing adaptations had experienced considerable difficulties in obtaining the co-operation of their local social services and housing departments. In some cases, the main problem had been that they were unable to agree an acceptable share of the costs. More often, people found it very difficult to get social services to even agree a need for adaptations in the first place. Some people who had experienced one or both of these problems had simply given up in desperation;

"The social services weren't a lot of help (with the bathroom). First of all they said we couldn't have the hoist because it couldn't be fitted in that space in the end, I persuaded them to give me the hoist and I fitted it myself. The other thing which they did give us was a closomat toilet but its completely useless - she (my wife) can't use it unless there's someone with her. What we really need

is for the wall separating the bathroom and toilet to be knocked through so we can move the bath over to the other wall the occupational therapist they sent round to have a look agreed it would be the best solution as well. But, the social services said they'd only do it if I paid for it. It would cost £4,000 - I just haven't got that kind of money It doesn't make a lot of sense does it. I mean, all this money has been spent - but none of it is any use. Then, they refuse to pay for what we really want. Plus the fact that, it would probably save a lot of money because you wouldn't have to have three nurses to give her a bath."

Several wheelchair users also found that they needed to switch to lightweight wheelchairs when they were older. Most had not been able to do so, however, because of the prohibitive costs and the lack of suitable alternatives available through statutory provision. There is also a demand for a variety of (mostly minor) aids like hand rails, hoists, bottle/jar openers, pick-up aids, trolley trays and adapted telephones. Several people reported having difficulties getting these aids supplied, or finding out where they could buy them for themselves. A few people had managed to get aids or adaptations supplied by statutory agencies but not the ones they actually wanted;

"What I do need is something to undo jars. Something to hold the jar still while I undo them. I've been looking around but I can't actually find anything suitable. If I could find it, I'd buy it. I haven't found the right one for what I need."

"We had the shower and the hand rails supplied by the council and they met 85% of the cost But, we could still really do with a hoist as well It's been over a year now but we still haven't heard anything. We have thought about trying to get one for ourselves - although, it would have to wait because we can't really afford it just at the moment. But, I don't really know where you go to find out about these things."

Another area in which older disabled people's needs are often more or less completely overlooked is in the organisation of health services. We have already seen, for example, that older disabled people often find themselves in conflict with the medical profession over defining the nature of the physical problems and changes they experience with ageing. Consequently, many had faced obstacles to obtaining the kind of health services they believe they needed. These conflicts are largely due to the medical professions lack of knowledge about the long-term effects of physical disability and, at the same time, their refusal to recognise the value of disabled people's own expertise and knowledge. This problem is compounded by a very narrow view of rehabilitation which largely fails to take account of longer-term needs and, in particular, the fluctuating balance between health and social support over the life course.

This is reflected in the kinds of improvements to health services people wanted to see. For example, the lack of confidence in existing services is reflected in almost a third wanting access to 'specialist' disability services, while a similar number wanted services generally to be more responsive to the needs of older disabled people (see Table 16). Similarly, the lack of interest in, and knowledge about disability amongst the medical profession is reflected by over a quarter of people in the study wanting access to advice and information. There was also a significant demand for practical services like physiotherapy, wheelchair clinics and pain clinics. However, most people needing such support had been unable to get it.

TABLE 16: IMPROVEMENTS IN HEALTH SERVICES WANTED

Proportion wanting improved/new services	(Percent);
Specialist disability services	32
Make services more responsive to needs of disabled people	29
Information/advice about treatment	27
Physiotherapy/hydrotherapy	23
Long-term follow-up	19
Wheelchair clinics/Prosthesis services	16
Hospital transport	13
Alternative/homeopathic treatments	13
Improved waiting times	9
Pain relief clinics	7
Make services more responsive to needs of black disabled people	5
Others	12

Note: Others (all 3% or less) - Dental care; Ophthalmology services; speech therapy; Well Woman clinics.

There were several reported examples of people who had received inappropriate or even harmful treatment as a result of the poor understanding of long-term disability. These include orthopaedic surgery like fusion and tendon operations which had left people more physically impaired than before. Similarly, some people reported instances of radiotherapy causing nerve damage and increased physical impairment. Others also highlighted the apparent confusion amongst the medical profession between neurological and orthopaedic complications, and the effect this has on inappropriate investigations and/or interventions. Similarly, a few people reported that their doctors had tried to dismiss their problems as being purely psychological or, in the case of older women, to 'explain' them away as being due to the menopause;

"Regarding long term health problems - half the specialists in my own case are useless, and I no longer attend a diabetic clinic. One instance - when I reported for a check-up I told my specialist that I had hypoed 10 times in 14 days. He then referred me to a psychiatrist - who's cuckoo? I told my GP of this and he said it's the stock answer when they don't know the answer to a problem. I was also told by another doctor that I was lucky not to be in a wheelchair and, by another, that I was - too old and a diabetic. Maybe this answers your question about the attitudes of the medical profession."

"I was once sent to see a behavioral psychologist in Guys Hospital Pain Clinic - she really got under my skin and seemed to me to be implying that a large part of my pain was psychological. That just makes me so boiling livid - because it just isn't true. My pain can be just as bad when I'm perfectly happy. It doesn't bear any relation to my state of mind - it's physical. So, it might be true of some people, but it certainly wasn't true for me. But this young woman just annoyed me intensely."

"I've given up as far as doctors are concerned - it's just not worth getting my blood pressure up any more than it is already. I mean, it really is pretty galling when you go to your GP and all you get is - 'it's just the change my dear' - it makes my blood boil. The attitude seems to be that you just have to put up with it and that's that."

As a result of such indifference to the problems associated with ageing, some people – not surprisingly - found it very difficult to get access to treatment if they needed it. A few people believed that the delays and obstacles they had faced had actually contributed directly to further physical deterioration or ill-health;

"I'm almost completely blind now. I had an eye operation in October this year (1991). It didn't work, so I probably lost the sight of this eye for good. I'm not at all happy about it because they should have really done the operation in 1983 when the problem first started. They kept putting me off. You know - come back in six months - all this kind of rubbish. If I'd had the operation earlier, I'm sure it would have worked - or at least there would have been a better chance of saving some of my sight."

"I've been under (the consultant) for 8 or 9 years now and he's done absolutely sod all - he's not interested, he doesn't want to know the thing I want is the operation. That's what I've fought for for the last 10 years. Now, I've got one of the best surgeons in the country. But, for all those years before I couldn't get anywhere - they told me they wouldn't do it. They thought it wouldn't help me - but I disagreed with that. So, they just refused point blank I intend to take them to court for the 8 years of pain and suffering they caused. But, I can't do that until I've had the operation so that I can prove I was right. So, perhaps a year after the operation I'm hoping that I can take them to court."

Ageing and sexual needs

All of the problems discussed above are brought sharply into focus when associated with subjects which, because of stereotypical beliefs about the needs of older people, are considered taboo. In particular, some of the people in the study - almost all of whom were men - talked about the virtual impossibility of getting any advice or help with sexual problems;

'Your sex life changes when you get older. You can't get on top - your limbs won't take your weight any more. You see, you need advice for something like that. But, most older people are afraid to ask - it's taboo isn't it? But, you do need that - it should be talked about more openly. "

"In 1971 I became impotent almost overnight. I went to my GP whose only reaction was to ask me how old I was, and to say that at this age (51) it was to be expected and to be thankful for what I had had. On my next appointment at the clinic I informed the doctor I was a bit off balance at the time and all he said was - we will have to get you OK again, and then we will see about that. Another three months and the next time it was another doctor, with a young nurse standing at his side. This time I did not mention my problem because of her presence. Three more months, and another doctor. This time I had written it down and handed my note to him after he had finished. He handed it back to me with - nothing we can do about that - written on it, that was that. Now, in spite of continued frustration, I had to accept it. In 1982, after reading an article on

the subject, I wrote to the Diabetic Association of which I was now a member. I was put in touch with a clinic - this turned out to be a family planning clinic I then attended the other clinic several times, getting nowhere. Although my wife attended with me she was not invited in to also see the doctor. I was then asked if I wished to attend further. I took the hint, and terminated my appointments. Just over a year ago, a lady doctor at the diabetic clinic asked me about this subject, and I told her of my experience. She was the first person in all those years who was willing to discuss this subject - too late."

These experiences highlight the dehumanising effect of denying older disabled men's anxieties about their sexual relations. In effect, denying their existence as sexual beings is another aspect of making their needs invisible. Other writers have noted that this is a fundamental part of women's experience of disability (Morris, 1989; Lonsdale, 1990). However, very few of the women participating in this study were prepared to talk about this aspect of their lives explicitly, although some did touch on problems with personal relationships in more general terms. Although we can only speculate about the interpretation of this finding, this may, in part, be a reflection of the invisibility of their sexual needs in the sense that living for so long in a society which treats them as asexual beings has led them to internalise these negative images. (Most of the women were interviewed by female interviewers, but the fact that some were interviewed by men is also likely to have been an important factor). Those who did discuss this issue emphasised that their feelings of being stigmatised, or unfulfilled, tended to become even more acute in older age;

"It is very difficult to meet men when you are disabled. My husband did love me, but he couldn't give me what I needed. It gets even more difficult when you are older - you just want to be loved and feel attractive just like anyone else."

None of these women felt that there was anywhere they could go for support or advice. A few of the men in the study had been able to get some advice about sexual problems, although this was invariably inappropriate and grossly insensitive. Further, as the following quote illustrates, the issue is as much about practical difficulties as emotional concerns;

"The biggest problem for me is lack of female company. That really bothers me, but I don't see that there's a lot I can do about it. There's barriers to sex which disabled people have all the time. You have these groups like SPOD - I've been to them, but it wasn't much use. What I really want is some sort of club you could go to. I mean, an able bodied man can go up to London - go up to Kings Cross or somewhere like that and get a woman. But, for an older disabled man - you're out of all that. Then - if you go to the doctors for advice - they

won't give you an answer. That's the most frustrating thing. They just say - talk to your social worker. But, that doesn't do me any good at all at my age. I mean, here I am with all this sexual frustration, and they tell you to go and talk to a 21 year old girl - that's really clever isn't it. That is a problem with living in a place like this as well. Most of the staff are women, and a lot of them are quite young. I'm not saying it's their fault, but when you get these young girls coming in the rooms all the time - it is provocation. But, even if I could get a prostitute, I haven't got the money to pay out for it anyway. I think there should be some kind of organised sex for older disabled men. They should have something like that available so you knew where to go. There must be a lot of people who feel like that - but, what do you do?"

Institutionalisation

Many older disabled people's previous experiences of using community services had been so negative that they had long since given up asking for what they need. For some people, however, problems like the death of a partner, poor incomes, or unsuitable housing - perhaps combined with physical deterioration - meant that they were forced to depend on unsatisfactory and inadequate services.

For some people, challenging this enforced dependency becomes virtually impossible because they are drawn into a dehumanising spiral of frustrated expectations, an ever increasing sense of desperation, and isolation from the personal support of friends and relatives. This is most clearly highlighted by the experiences of older disabled people who find themselves in residential institutions against their will.

The following quote, for example, is from a woman who had been living in a sheltered hostel but had recently been transferred - literally against her will - to a private nursing home sponsored by her local authority;

"I loved it there and I didn't want to leave. They never gave me any warning. I was there on the Thursday, and on the Friday I was gone - I just came here. If they'd asked me I would never have agreed to go. They said it was because I was getting worse and I needed more help. But, I think they just didn't like me The only difference here is that I have my tea made for me - that's the only difference that I can see. I hate it here. The atmosphere is just horrible. The care attendants are so rude - I'm very depressed. I haven't been out once - they don't take me out. I can't even get to the telephone, because I can't fit in the booth. When I was in my own room, I had a phone - now I can't even talk to anyone. I only needed a little bit more help - they didn't need to bring me here."

As this woman's experience highlights, when support services are unable to meet older disabled people's needs, the only 'solution' offered is to force people into accepting dependency creating services - of which institutionalisation is obviously the most extreme example. In this case, as with many others, making existing services more flexible would not only have been more effective in meeting real needs but, perhaps even more importantly, would avoid the dehumanisation which such enforced dependency creates.

Once older disabled people find themselves in institutional care, many are likely to find that they have lost control over almost every aspect of their lives. This is very vividly illustrated in the following quote;

"What I would ideally like is my own bathroom and toilet. The place (nursing home) is very well equipped - but I could use a (wheelchair) shower unit. You can get them put in, but you have to pay for it yourself. If I had a bit of help from the staff, I could manage with one of them. I do find this whole bathing business very distressing. It makes you feel like you're losing your dignity. The whole thing bothers me. They undress you and just leave you there - half the time, the door's open so everyone can see. You don't have any privacy. And then, when they're washing you, they're just standing around chatting amongst themselves as if you weren't there. They just seem to take over. They say this is what you want, not is this what you want."

Although institutionalisation is at the extreme end of the continuum, and accepting that not all older disabled people will experience residential care in this way, it is nevertheless indicative of the endemic dehumanisation which lies at the core of existing support provision for people who are ageing with a disability.

It is equally clear, however, that the dependency which this creates is as unnecessary as it is undesirable. As the following quotes illustrate, older disabled people themselves are often in no doubt that their enforced institutionalisation could easily be reversed if appropriate supportive resources were made available;

"If the right care attendant came up and I could get a place of my own - I'd grab it straightaway. You can get very lonely here. Sometimes you feel isolated."

"If I had someone there who could help me - someone who listened to what I wanted - I don't see why I couldn't manage outside. You've seen what they're like - they just come in and give you some tablets. Well, I can tell somebody to give me the tablets just as easily."

This chapter has highlighted the various ways in which older disabled people's needs become invisible. When this is coupled with the state of enforced dependency which many people find themselves in, the end result is that people are often faced with the choice of having to accept inappropriate services, or simply manage without any support at all.

Many of the problems experienced with existing services are the same as those faced by the majority of disabled people of all ages. However, what is of most concern here are the additional consequences which follow from the lack of recognition for needs associated with ageing. In particular, the experiences reported by people participating in the study indicate that existing services almost invariably fail to respond to the ways in which people's support needs may increase, or change, when they are older.

Consequently, people who are ageing with a disability often fall through the net of existing service provision. This is partly due to the inadequacy of disability services in general. But, is also related to the way in which services are organised - i.e. either services for 'younger disabled' or services for 'older people/over 65's'. As people who are ageing with disability do not fit neatly into either of these groups, their needs are often overlooked. This is reflected in the very low take-up of most community services by people participating in this research. There is also the added dimension that, because of lack of knowledge and understanding about ageing with disability, existing services and welfare provision in general fails to meet their needs - even when an attempt is made to do so. Examples of this include the lack of suitable living options; the unnecessary obstacles in access to sheltered accommodation; offering day centre places to people who have little in common with existing users; refusal of certain benefits and allowances for people whose physical or health status fluctuates; similarly, offering fixed amounts of regular support to people who are more likely to only need short-term flexible support on an occasional basis. Further, while many people found that their need for personal assistance tended to increase when they were older, most services are only able to provide assistance on a very limited basis.

In the final chapter of this report we outline what kind of supportive resources should be developed to counter the enforced dependency and isolation faced by many older disabled people, and consider some of the most important measures required to put this into effect.

7. Building a supportive environment

Defining the components of a supportive environment

This report has highlighted a whole range of problems associated with the experience of ageing within a unsupportive and disabling environment. In this final chapter we outline the opportunities for building a supportive environment for meeting the needs of older disabled people, and the 'building blocks' required for change. We also consider some of the key implications for current policies on service provision.

We are not, however, claiming that this is a definitive model for support, or that every person who has participated in the study would necessarily agree with all of our conclusions without at least some qualification. Indeed, given that each individual having the right to define his or her own needs and solutions is a central principle of the model outlined here, it could not be any other way. Further, it is clear that no single model could possibly cover the range of needs and experiences associated with ageing. Rather, what we are proposing is a set of principles for developing an ideal model - support against which existing policy and practice can be evaluated.

In outlining a model for building a supportive environment, it is important to keep in mind that there are important psychological as well as material dimensions involved. Clearly, issues like low incomes, inappropriate services, lack of suitable living options and the lack of practical advice and support have a direct and observable impact on older disabled people's lives. However, it is equally important that any strategies aimed at tackling these problems also take account of how people feel about their own situations. In particular, they must take account of how their previous experiences (including the class, race and gender dimensions to such experiences) shape older disabled people's definitions of their own needs and what they consider to be appropriate and acceptable solutions for meeting them.

This is not simply morally desirable, but is also a much more rational way of organising services as only older disabled people have specific knowledge of their own needs and how they could most effectively be met. Following on from this, apart from individuals being enabled to define their own needs and solutions, there is also a considerable amount of collective expertise and knowledge amongst older disabled people. Unfortunately, however, this expertise has not been viewed as a positive resource by policy makers or service providers in the past; further, there is little evidence that this is about to change in the foreseeable future.

A fourth element of the supportive environment model is that support should be provided on a pro-active rather than reactive basis. What this means is that, rather than simply waiting for a crisis to occur due to lack of appropriate support, supportive resources should be organised in such a way which would enable people to plan ahead for possible changes in their circumstances. To be clear, this does not mean that case managers, social workers and so on should make decisions on behalf of older disabled people. Rather, that older disabled people themselves should have a sufficient range of supportive options available to them, together with appropriate information on how to access them, so that they can make informed decisions about their future support arrangements.

The need for a pro-active approach to support provision is very closely tied to the fifth element of a supportive environment model which is that supportive resources should give older disabled people genuine security. This report has highlighted very clearly that many people's experience of ageing with a disability is characterised by anxiety - not only about ageing itself, but also the lack of appropriate and acceptable resources to meet their changing needs. Most older disabled people do not want to make any great demands on support services. Rather, they simply want to get on with their lives secure in the knowledge that what little support they might need will be available if and when they need it.

The present organisation of support services, however, very rarely gives people the kind of security which a more pro-active approach would guarantee. Instead, older disabled people and their families are forced to play a kind of 'russian roulette' - simply trying to keep one step ahead of the next crisis;

"I lived upstairs in a one bedroom (council) flat and I couldn't get any help living there because they only live in. You try and try to get somewhere to live, but it wasn't until I was in a state of collapse last November and I couldn't go on, that they suddenly thought - oh, there's something wrong with this guy and they gave me this two bedroom flat"

'As far as I'm concerned, social services are none existent. I mean, you can imagine my dilemma when my wife fractured her ankle. She needed to go to the hospital, but there was no way I could be left on my own. That was on the Saturday, and we went through all the Sunday with neither of us having a hot drink. We had nothing cooked or anything. Anyway, on the Monday my carer came to bath me - she comes in twice a week - and she said - no, you can't go on like this and I said - what can I do about it, I haven't got a social worker any more so, she rang through to the social services and she told me to speak to

them. First of all, the woman I spoke to said - well, I'm sorry, but we're so short staffed it might take weeks before a referral comes through. I said - you what? I said - we want help now, not in weeks time."

"I'm so used to having to buy reliability. You know, reliability above all is what I have to have. You know, I can't lie in bed and somebody just not come - which is what has happened. I mean, I've laid on the floor all night I don't want to go through that again - you know, lying naked on the floor."

Sixth, building a supportive environment calls for the development of creative solutions for meeting older disabled people's needs. Existing supportive resources, even at best, only provide partial solutions (Zarb, 1991); more often than not these are rejected by the very people they are intended to assist. Further, it would clearly be impossible to develop creative solutions unless these are based on older disabled people's own definitions. However, this report has highlighted that there are several obstacles to older disabled people being able to identify their own needs and - more important still - have their voices heard.

These obstacles not only create very real practical problems, but also have the even more damaging effect of wearing down older disabled people's ability to keep fighting for what they need. From their perspective, the services which are supposed to make their lives easier often become the biggest obstacle of all;

"The home help we employ is marvellous really. We used to have a council home help. They were so irregular - you never knew what time she was going to come, or even if she would come at all. She always used to come at different times - Interrupting lunch and things like that. She'd say - I'll see you next week - but you never knew for sure if you would. Then, when she did come in, it was only for 2 hours a week in any case. Eventually, the home help organiser rang one day and said that she wouldn't be coming in because they were short of staff. We were so fed up by that time that I just said - well, don't bother coming back at all."

"I had endless battles. It's very wearing and - I'm deeply disillusioned and bitter at the way the so called health service can do this to people. You know, I find that disabled people's problems, particularly with me, you ask so many people it isn't with their own physical problem - it's dealing with people who are there to help them, and it's dealing with the bureaucracies."

Disabling Services

- Dependency
- Fixed options
- Discretionary services
- Reactive
- Service led support
- Anxiety
- Partial solution

Supportive environment

- Independence
- Choices
- Rights and entitlements
- Proactive
- User led Support
- Security
- Creative solutions

Building blocks

- Information
- Knowledge
- Confidence
- Personal support
- Financial Resources
- Recognising difference
- Empowerment

This, in turn, points to the most important component of a supportive environment - namely, a framework of rights and entitlements. All of the problems which define the disabling environment are fundamentally linked to the basic issue that, services are mostly provided on a discretionary basis and that older disabled people have very few rights. Still fewer have sufficient knowledge or confidence to demand what little rights they do have.

The practical result of this state of affairs is that, while they might recognise they are missing out on the kind of support they need, many older disabled people do not feel able to translate this into making explicit demands for having services as of right;

'I'm very independent - I've never been one of these people who goes on about my rights - you know, saying I'm entitled to this that or the other. Probably, I don't ask for as much as I should - but that's just the way I've always been. I just get on with it.'

Implications for current community care policy

Establishing a supportive environment clearly implies providing a range of support options based on choice. This would mean giving older disabled people rights to the full range of resources discussed throughout this report and, most importantly, the right to choose how their particular needs should be met. This would facilitate older disabled people having the degree of control over their own lives which dependency creating services have previously denied them.

As suggested earlier, this would require much further reaching changes than those envisaged by current community care reforms (DHSS, 1989; Griffiths, 1988). For example, while the idea that users will have a greater say in the planning and delivery of services is firmly lodged in popular perceptions of these reforms, the organisational changes actually taking place clearly point in quite different directions. Further, there is little evidence that the particular obstacles to involving older disabled people are being addressed (Parratt, 1991). Specifically, rather than providing a framework of rights and entitlements, it is quite clear that the choices for people wanting practical support will still be determined by - a) what needs purchasers are prepared to recognise (and pay for) and, b) what services the providers (particularly in the independent and voluntary sectors) are able and willing to offer.

Of course, the NHS and Community Care Act 1990 places an obligation on local authorities to ensure that 'unmet needs' identified by assessment procedures and service audits should be fed into the planning process so that

appropriate services can subsequently be developed. However, this process will still be dominated by professional decisions about disabled people's lives and does not, in any case, offer any guarantees about changes in the content of services being made. An alternative scenario is that unmet needs (regardless of whoever they are defined by) will simply be 'recycled' between the processes of assessment and planning. At present, there is no clearly defined mechanism for breaking this cycle. Instead, it is assumed (perhaps too optimistically in view of past experience) that, as long as the appropriate financial and organisational infrastructure is put in place, there will be sufficient incentives for a demand led welfare market to respond. These limitations to current policies are most clearly illustrated by proposed arrangements for case management and assessments of need, which will be the linchpin of the reforms. While it is accepted that users must have an input into this process, it is by no means clear what procedures will be adopted to guarantee that their own assessments of needs and solutions will be reflected in any support packages which may follow. If genuine user involvement is to become the 'cornerstone principle' of the present community care reforms (as envisaged in 'Caring for People'), this would surely have to include users having the right to define their own needs and solutions and, if necessary, to challenge any denial of this right by care managers through procedures laid down by statute.

Further, the issue of who care managers will be, and to what extent they will have sufficient autonomy to represent the best interests of users needs to be addressed (Parratt, 1991). The history of relations between disabled people and statutory support agencies has been characterised by distrust and disillusionment. This report has also given examples of people who clearly feel they have been badly let down by doctors, social workers, community nurses and others. Given this climate of lowered expectations and mistrust, it is likely that care managers drawn from within statutory agencies will still be perceived as being more closely aligned to the interests of purchasing (and providing) agencies than the needs of users. Indeed, the Department of Health's implementation guidance on assessment and case management clearly indicates that the final decision on individual support packages will be based on cost and the availability of resources (Department of Health, 1991). Disabled people could be forgiven, therefore, if they see their needs as coming a poor third in the assessment equation.

However, as suggested earlier, there are alternative opportunities offered by the increasing number of disabled people who are seeking their own solutions to for meeting their support needs by using the resources of Centres for Independent and Integrated Living, and other organisation of disabled people. If genuine user involvement is to become a major part of future

community care plans, what better way to start than by directly involving such user led organisations in formal planning and assessment procedures. Again, while there are qualified moves in this direction in the current reforms (through, for example, consultation with self-advocacy groups), the new legislation specifically rules out the possibility of contracting out the role of care management/assessment to any independent organisation.

This would appear to be a short-sighted policy, as it not only fails to recognise the considerable expertise which such organisations could offer, but also misses an opportunity to ensure that individual users have effective representation from an independent body if they should want it. Further, although the Disabled Persons (Services, Consultation and Representation) Act 1986 would have given disabled people some of these rights, only six of its eleven sections have been implemented to date.

The building blocks for change

In order to move from a disabling to a supportive environment there are a number of prerequisite 'building blocks' which would need to be put in place along the way. The establishment of a framework of rights and entitlements would be central to this process. However, simply establishing such a framework is only part (although, obviously, the most important part) of the answer. It is equally important that older disabled people have the resources (both practical and personal) to exercise these rights.

First, one of the most important resources older disabled people need is information and knowledge - along with the confidence to use it effectively. As this report has demonstrated, whether or not people feel secure about their future independence is critically dependent on them having the appropriate resources to enable them to plan ahead for possible changes in their circumstances. These resources refer to finance, personal support (if needed) and, most importantly, information about what support and living options are available.

While Local Authorities already have statutory obligations to provide information about services under both the 1970 and 1986 Disabled Person's Acts, the experiences highlighted in this report demonstrate that they are clearly failing to do so. Several people talked about how difficult it is to find out about alternative living options, for example. Although they were able to describe what kind of living options they were ideally looking for, most had no idea whether or not they would be available and, if so, where they could go for appropriate advice and information. Similar problems were encountered with finding information about obtaining personal assistance or

other forms of practical support. Consequently, people's attempts to take responsibility for maintaining their future independence were frustrated by lack of information and advice, creating avoidable anxiety and uncertainty and enforcing, rather than challenging, their dependency;

"This is a problem though isn't it - you have to dig and probe to find out what's available. Apart from taking up a lot of time, it can be a pretty hit and miss affair whether you actually find what you're after. I think that there should be somewhere you could go for this sort of thing - it should come from the social services, they should be doing that. But, the trouble with the social services is that - if it's not on their books, it doesn't exist. They don't really bother to find out about what else might be on offer."

Second, older disabled people need access to practical support and advice as well as financial resources. The key issue here is that, such support would need to be flexible enough to match people's changing needs, and allow them to plan ahead and make informed choices about how their needs should be met;

"I am finding it a lot more difficult to transfer myself on and off the bed so the one thing I am definitely going to need is a hoist over the bed. I'll probably have to have one in the bathroom as well, if I'm going to be able to stay living independently without having to have someone in to help me. I did make some enquiries with the Social Services, but I don't think they're going to be able to help, so I'm going to have to find the money from somewhere myself. Having said that, I think they should help at least with some of it, because it does mean I'm going to be independent hopefully. But this has always been the problem when you go to the council for help. When we moved in here, we got a bungalow because I knew then that I was probably going to deteriorate more as time goes on, so I was trying to get myself organised for when that happened sort of thing. So, we went to the council about a grant, but they said you can't have one because you haven't moved in yet. It's stupid isn't it because I needed the adaptations doing so I could move in - but they wouldn't have it. We got it sorted out between ourselves - with the family."

Third, the principle of recognising and respecting the ways in which needs are shaped by race and gender is also a crucial pre-requisite for enabling all groups of older disabled people to exercise their rights fully. More important still, building a supportive environment is fundamentally dependent on recognising - and challenging - the ways in which ageing with a disability is experienced as multiple oppression. As we have seen throughout this report, there are a whole range of obstacles to older disabled people having the right to control their own lives. This is not to say that all disabled people will

experience ageism, racism or sexism, although these are all forms of multiple oppression which would need to be addressed;

'As far as I'm concerned care in the community is a life long sentence of looking after someone else. It's not really about people being independent at all - it's just about looking after one's spouse, or children, or your parents - especially if you're a woman. I looked after my mother for 8 years after she had her stroke and I know of lots of people who do that and, obviously, a lot of them are either old or disabled anyway. So, when you're in a situation like that - both of us were disabled - you couldn't say we were independent at all. You have to take this care in the community business with quite a big pinch of salt if you ask me.'

"It has been a continual fight, I feel I have a lot of things going against me, I am disabled short, black, a woman, a single parent - but I am determined to be optimistic."

Only with all of these building blocks in place will older disabled people be able to empower themselves, thereby ensuring that they are able to retain control over their own lives. In the remainder of this chapter, we outline some of the practical steps which are required for turning these principles into a practical reality.

Developing appropriate supportive resources

The majority of older disabled people simply want to get on with their lives with the minimum of disruption, and without making any significant demands on their families - or even statutory support agencies. Unfortunately, however, it is equally clear that the lack of appropriate supportive resources not only detracts from the quality of older disabled people's lives but, as we have argued in the previous chapter, also increases rather than reduces their dependency.

Obviously, this has important implications for statutory agencies who are charged with responsibility for providing services and information about services. At the same time, there is perhaps an even more important role to be played by disability organisations, to whom older disabled people are usually more likely to turn to for information and advice. Also, it is essential that much more is done to support the development of organisations of disabled people who already have the expertise and knowledge which older disabled people are looking for. In the present situation, the majority of older disabled people do not use these resources simply because they are unaware that they are available. Rather, they turn to statutory agencies or traditional disability organisations as these are perceived to be the only options available.

This is particularly relevant to people who may wish to explore personal assistance options. Although very few people participating in the study were using personal assistants currently, more than 1 in 5 intended to do so in the foreseeable future; a similar number felt that they might use personal assistants - depending on what changes (if any) they experienced in their circumstances. However, despite the increasing awareness of this kind of support option, only a handful of the people participating in the study were aware that other disabled people actually recruit and/or employ their own personal assistants. Fewer still were aware of the support and advice offered by Centres for Independent Living which might give them the opportunity to explore the appropriateness of this option for themselves. Consequently, several people said that they would be reluctant to use personal assistants because they felt this would actually reduce the level of control they would have over their own lives.

This is ironic in view of the philosophy of independence and empowerment which CIL's and other groups are promoting. However, considering that most older disabled people's experience and perceptions of personal assistance services are based on options provided by statutory agencies or traditional care attendant agencies, it is not particularly surprising that they take this view.

This situation is also reflected in the comparison between existing personal assistance arrangements and those which people would ideally like to have in the future. For example, while very few people currently use personal assistants for anything other than personal care, preferences for future use involved using personal assistants for a much wider range of personal, domestic, and other kinds of support (Table 17). Similarly, most of those currently using personal assistants, have this support on a regular basis only; preferences for future use reflect a much greater demand for flexible personal assistance schemes which would combine regular support with occasional use as and when required (Table 18). Further, there is clearly a much higher demand for self-recruited personal assistants (Table 19).

TABLE 17: PERSONAL ASSISTANCE OPTIONS – TYPE OF SUPPORT

(Percent)	Current Users	Intended Users
Personal assistance	100	83
Domestic assistance	50	67
Social/leisure activities	31	52
Other	31	34
Base totals	(N=18)	(N=53)

TABLE 18: PERSONAL ASSISTANCE OPTIONS – SUPPORT ARRANGEMENTS

(Percent)	Current Users	Intended Users
Permanent (live-in)	12	14
Permanent (live-out)	41	33
Rota System	35	21
Occasional use only	0	25
Others/combinations	12	8
Base totals	(N =18)	(N = 53)

TABLE 19: PERSONAL ASSISTANCE OPTIONS - RECRUITMENT

(Percent)	Current Users	Intended Users
Self-recruited	24	58
Crossroads	24	12
Other voluntary	24	12
Local authority	17	4
Private care agency	6	0
Others/combinations	6	15
Base totals	(N=18)	(N=53)

Clearly, more could be done to promote a more creative and flexible approach to personal assistance schemes which would enable larger numbers of older disabled people to tailor their support arrangements to their own needs, circumstances, and preferences. Again, these kinds of creative solutions are already being developed by organisations of disabled people themselves (Oliver and Zarb, 1992). However, these schemes are typically under resourced and under valued by statutory agencies who, instead of building on these initiatives, continue to develop their own much more limited personal assistance services or fund traditional care attendant agencies. Unless this situation is reversed, it is very unlikely that the majority of older disabled people looking for alternative support options will be able to take advantage of the benefits which controlling their own personal support can offer.

While there is considerable scope for developing flexible personal assistance schemes which would meet the needs of older disabled people, these would also have to be varied enough to suit different needs and preferences. It is clear, for example, that employing their own personal assistants (even if they have the financial resources available) will not be an acceptable option for many older disabled people. When this option was discussed during the interviews, several people commented that, taking responsibility for employment, insurance, and so on is the last thing they want to do. Rather, they are looking for options which - in their terms - would give them less to worry about and not more;

"When you can't dress yourself anymore, or you need any kind of physical help in that way, you're in care - whether you're in a home or anywhere else. As far as I can tell, having people go into people's homes to do that sort of thing - you're basically just providing a hospital facility, except that you're providing it

in everybody's home at the same time. I don't know that having the money to employ your own helpers instead is really the answer. You've got all the responsibility for their salaries and all that sort of thing which is the last thing you want."

Another important issue is that, for people who have been used to living on their own and managing their own lives without any outside help for so long, having a personal assistant is simply too much of a change - regardless of whether or not there is a practical need. Some older disabled women had particularly strong views about this. For some, the issue is that they feel responsible for running their own homes and families; having a personal assistant (or a domestic helper for that matter) would make them feel as if they were failing to meet these responsibilities. More generally, given that older disabled women tend to have a particularly acute struggle to maintain their independence, some feel that having personal assistance would compromise rather than enhance their independence;

"I would say that, at the moment, that wouldn't suit my lifestyle. There may come a time - if I worsened - that I might have to consider that. But, it's not my ideal choice. But, if I didn't have my husband then certainly I would have to think about it more seriously. That really frightens me because, without my husband, I couldn't cope. I can only cope as well as I do because of him because he's so supportive. We've been married for 28 years and he knows the things that I can't do. So, automatically, a system sort of evolves and you don't really need to worry about it. I mean, I know that the care attendant system is marvellous for people that do have carers. But - I know it sounds silly because it's meant to give you independence - but, to me, that would be taking away my independence. I know that, logically, that doesn't make sense but - emotionally - I would fight against that. I'd think - oh no, a stranger coming into my home - it's silly I know but that's how I feel."

'Really, what it comes down to is having control. Because, when you're disabled, there are certain areas of your life that you don't have so much control over - then you fight very hard to keep the amount of control that you do have. I mean, although emotionally I can allow my husband to do all these kind of things, I would find it harder to accept that from somebody else. I'm fortunate that I don't need help in very personal matters like dressing and feeding or whatever. I would find it very difficult to accept that kind of help should I ever require it."

Obviously, these kinds of concerns will mean that some older disabled people may never take up the option of using personal assistants under any circumstances. At the same time, these doubts have to be evaluated in the

context of perceptions of existing personal assistance schemes, most of which were not initiated by disabled people themselves. Where personal assistance services are run by statutory or voluntary organisations, it is perhaps understandable that people should view these services as reducing their level of control over their own lives. If they were to have the opportunity to try employing their own personal assistants, it is quite possible that - for some people at least - many of their concerns about lack of control would be removed;

"My husband does need a little bit of help getting out of bed, but I can still do that at the moment. But, if I wasn't able to help him, he would need help and, if I wasn't able to help him - that would probably mean that I would need help myself. So we'd be looking for someone for both of us. I'm the sort of person that's, if I can do it I will. If there's a way round it then I'll manage. But, that's not necessarily going to work forever so I do accept that there's going to come a time when I might need somebody to help. That's why I would feel happier if I was employing somebody myself. That would help to ease some of my reluctance to have help. You see, one of the things with the home care service is that, they report back and you wonder what is said about you. I think that privacy is a big thing and, if you employ someone yourself, you're more likely to have a bit of privacy than if you're having someone from the home care organisation. Privacy is a big thing - particularly when you're disabled and all the things that go with that. You don't want the whole world knowing about you in great detail. So, you're more likely to have that privacy if you have someone who's just employed by you instead of being part of an organisation, or Social Services, or whatever."

"It's not enough having to rely on the District Nurses or the Crossroads people. You need more money to be able to do what is best for you. Then you wouldn't have to just put up with whatever other people think is best for you."

Further, it is important to emphasise that the 'hiring and firing' model for personal assistance schemes is only one amongst a range of options which could be developed further in the future. Whatever particular arrangements older disabled people might choose, however, it is clear that there is a common demand for options which would enable them to maintain their independence.

As the following statement from the United Nations World Programme of Action concerning Disabled Persons highlights, the fundamental issue is that all disabled people should have the right to control how their needs should be met;

'Member states should encourage the provision of support services to enable disabled people to live as independently as possible in the community and in so doing should ensure that persons with a disability have the opportunity to develop and manage these services for themselves.' (UN World Programme of Action)

Addressing the race dimensions to ageing with a disability

There are also important race and cultural dimensions to the issues discussed above which need to be addressed. First, it has to be said that the concept of 'personal assistance' is essentially a product of a disability movement in which - although bridges are now being built - black and ethnic minority disabled people have not been fully represented in the past. Most of the African Caribbean and Asian people participating in the study had never heard about personal assistants and were not particularly interested in exploring this option during the interviews. This is not to say that personal assistance schemes for older African Caribbean and Asian disabled people are irrelevant. However, it should not be assumed that they would recognise such schemes in the same terms described above. Rather, because of their isolation - both from statutory services, and the kinds of alternative options developed by disabled people themselves - many older African Caribbean and Asian people simply do not know about the possibilities which personal assistance schemes might offer. As one of the Asian People with Disabilities Alliance Members who participated in the study put it;

"They're not even aware of the disability, how can they be aware of the services? that is the sort of things that people go through when they come in the west. You know, to a new country. Completely unaware of the mechanics of, the way. So, I'm sure there may be lots of other people in similar situations or in a worse situation than I am, who will not even be aware, even now after many years there are some people who are not aware of the available mechanics of the services, facilities and things like that. You know, in the course of our work we come across people like that who have difficulty with the, you know, to disseminate, understand the available information. So they're missing out on a lot of things, a lot of opportunities, a lot of things to make life easier for them."

Also, it must be acknowledged that, for many older disabled people from ethnic minority communities, there are even more basic problems of daily survival which need to be addressed before they would be in a position to consider longer term options which personal assistance schemes might offer. For example, the possible options for future personal support arrangements are largely irrelevant to someone who has much more immediate concerns

about unstable housing tenure, or someone attempting to cope with extreme financial insecurity.

As noted earlier, this kind of situation makes planning ahead virtually impossible for any older disabled person. But, it is also apparent that this is a situation which older African Caribbean and Asian disabled people are more likely to face (proportionately) than older white disabled people. Consequently, this needs to be acknowledged and addressed as a prerequisite to developing appropriate and acceptable personal support options. Even more important still is the need to address the extreme isolation in which Asian and African Caribbean disabled people find themselves as they age. There are several dimensions to this isolation, requiring appropriate responses on a variety of fronts.

First, it is clear that older Asian and African Caribbean disabled people often face significant difficulties gaining access to support services. While levels of contact with statutory services were higher than amongst other groups participating in this study, the support they actually received was minimal, and most did not have access to any alternative supportive resources at all.

Second, most of the older Asian and African Caribbean people participating in the study were cut-off from the support and advice networks provided by local and national disability organisations. A study in three London boroughs carried out by GLAD, for example, highlighted *"how little work has been done to examine the effects of ethnic origin and cultural background on the needs of disabled people. Disability groups had tended to focus on the common needs arising from disability, while ethnic minority community groups have given priority to fighting racism in many areas affecting the lives of their community"* (GLAD, 1987). The report also suggested that, both established voluntary organisations and African Caribbean and Asian community groups themselves are failing to address the needs of older disabled people. For some of the people in this study, alternative support was available from local church groups or, for some older Asian disabled people, groups like the Asian People with Disabilities Alliance - although such groups are typically under resourced and consequently unable to provide the level of support they would like to.

Third, the system for funding voluntary sector initiatives also places considerable constraints on the support such groups are able to provide. Funding is usually provided on a temporary basis and may also have to be obtained from multiple sources. This makes long-term planning and development extremely difficult, if not impossible. At the same time, it has been suggested that, despite these constraints, self-help initiatives have at

least raised awareness of the needs of African Caribbean and Asian elders amongst statutory agencies; also, that, potentially at least, they have an important role to play in establishing ongoing lines of communication between the local communities and statutory authorities. Ahmad (1988) points out, however, that the potential for such self-help initiatives will not be realised in practice unless the issues of control and power are fully addressed;

"The voluntary sector should not be seen as the only means of communication with Black people. The voluntary sector is traditionally seen as being able to represent Black people, but this ignores issues relating to the relationship between the local authority and the voluntary organisations. This is often patronising, and fails to take into account the real power relationship between them. The purse strings of the organisation are held by the statutory sector. The organisation is also subject to continual monitoring by the statutory organisation, often in a directive way." (Ahmad, 1988:37).

Fourth, the longer-term consequences of restricted immigration mean that many older Asian and African Caribbean disabled people are also cut-off from wider family networks which might have been able to provide personal and/or practical support. For some, the combination of these various forms of isolation may mean that institutionalisation is the only option remaining, thus making their isolation complete;

"I come in this country to work and buy things that I can send down home like a human being. Now I am inside a horse stable, I never live nowhere like this up until now, I don't even know where the hell I am. I live in here all alone. I got one white friend, otherwise I don't talk to anybody, I don't see any reason to have friends in this place. Every day is the same."

It is also important to consider the psychological impact of this objective isolation and the effects on people's ability to articulate and demand the kind of support they need. Further, this cannot be divorced from their experience of racism. For many older Asian and African Caribbean people, living through years of prejudice and the legacy of colonialism has denied them the confidence, or the motivation, to demand or expect a life other than the one handed to them by their 'colonial masters'. Also there is a great distrust in giving personal information to what is perceived as an impersonal "white social system". This only adds further obstacles to older black disabled people articulating their needs;

"What's the point you fill in form after form, tell them all your business then they turn you down. I would rather go without."

'I started this club because people were in their homes doing nothing. White people in the system had their own clubs and the black people wouldn't go to them. So a lot of black people were inside their homes suffering cause they wouldn't tell social services how much money they had in the bank or the post office.'

The failure to recognise or understand these experiences means that older Asian and African Caribbean disabled people often feel that they are treated as 'simpletons' who have no grasp of the world they live in. However, a more realistic portrayal would be one of people, hampered and bogged down by a welfare system which has never shared the rules of the game. As one of the women in the study put it;

"... we simply don't know what to do - they should send people to tell us - we just don't know."

These experiences suggest that there are a number of obstacles preventing older black disabled people from receiving appropriate and acceptable support services which need to be overcome. These, in turn, have important implications for existing strategies and point to the need for fundamental changes in approach.

First, one of the main criticisms levelled at statutory (and some voluntary sector) agencies is that, they do not have structures in place for giving black disabled people a voice in how services are planned and delivered. Clearly, having representatives from ethnic minority communities on planning groups, service committees etc. would help to counter this. However, this strategy has been employed in the past (albeit patchily) and has not led to any significant improvement in service provision. Such formal structures can never be an adequate substitute for service agencies dealing directly with individual users and, most importantly, listening to what they have to say about their own individual needs and circumstances.

Second, existing strategies which attempt to address the needs of older and disabled black people are mostly of two kinds. On the one hand, policies and services are developed as part of a general policy on services for older people and/or disabled people. On the other hand, some authorities and agencies have tended to adopt a more 'separatist' approach whereby services are developed and targeted on specific ethnic or cultural groups. Both of these basic approaches have been criticised for either ignoring the particular cultural/religious dimensions to people's needs, or for marginalising ethnic minority groups by placing them at the periphery of the policy agenda.

This report has highlighted that there are important similarities and differences, both in the needs of different groups of older disabled people and the particular obstacles they face in obtaining access to appropriate and acceptable support. This suggests that a more creative approach to developing services is required. This would involve establishing clearly defined rights to support for all older disabled people while, at the same time, recognising different needs and preferences. Rather than continuing to make a false and arbitrary distinction between the 'integrationist' and 'separatist' approaches, the way forward surely lies in taking difference as a starting point for developing services at both a collective and individual level.

In particular, much more needs to be done to maintain and extend the work already started by numerous local groups of older and disabled black people. This issue is partly dependent on facilitating much closer cooperation, on an equal footing, between such groups and local statutory support agencies. Developing a closer understanding of why such groups develop (ie. the gaps in provision they are attempting to meet) and an appreciation of their value to local communities are also important pre-requisites. However, no significant progress will be made unless the crucial issue of resourcing is addressed directly. As the Social Services Inspectorate pointed out in 1987 - *"meeting the needs of a section of the community cannot be left to chance or the goodwill and enthusiasm of a few members of staff who do their best, but who have no (SSI, 1987).*

Unfortunately, however, this is exactly what is happening and valued local groups are unable to meet the needs which they have accurately identified within their own communities. At the same time, statutory agencies are spending much larger sums on providing services which most often fail to meet the needs of older black disabled people. Clearly, the most important issue here is that older disabled people from black and ethnic minority communities should have the right to the kind of support that meets their self-defined needs. Further, if funding existing services cannot fulfil this requirement, there is a clear case for switching it to organisations who can. As one of the workers at Asian People with Disabilities Alliance explained, this is precisely the challenge which needs to be addressed;

"It is very tragic because when you come to think of it these first generation elderly people are the ones who have contributed a lot during the good years of their lives But now when the time has come for them to enjoy some of the services which they need now in their old age they are unable to do so. Because there are no available information to tell them about these services. So that is why we, because we have become fed up, you see, we're highlighting the needs and nothing has been done that's why there was a need to provide support

services and again we could not get any constructive support so we had to set up the project ourselves."

"Services, what services? The available services? It's only used by a handful of Asian people. What about hundreds of people that are not using it? Because the services are not appropriate. Not culturally sensitive to their particular needs So that is one of the things that we are advocating, that we are highlighting, that the services should be appropriate to our needs. Ok, again, because of the lack of expertise, or no expertise at all, and the authorities are unable to provide them, let us provide them ourselves to our community. That's what we are telling them and that's what we will be going around telling the authorities, so either they provide it or let us do it."

One of the main explanations put forward for the low take up of community services by older and disabled people from ethnic minority communities is that, information about service availability is not provided in appropriate forms. The findings from this study indicate that, although this is certainly true, it is only a partial explanation, as take-up of existing services is also very low amongst older white disabled people. The common denominator is, quite simply, that services do not match older disabled people's own definitions of their needs. Clearly, there will be important ethnic and cultural dimensions to the variety of needs which different groups and individuals define for themselves. However, this will remain fairly academic as long as service providers continue to ignore the basic principle that services should be based on disabled people's own definitions of their needs. Unless this principle is adopted, it is unlikely that tinkering with trying to make services more 'culturally sensitive' will bring a solution any nearer.

Notwithstanding the earlier comments on establishing universal rights to support, one issue where the cultural and race dimensions to ageing with a disability will be of paramount importance concerns the appropriate use and understanding of language. To be clear, this goes far beyond the simple question of whether or not information is provided in community languages.

For example, some older African Caribbean and Asian people participating in the study do not necessarily recognise the terms 'disability' or 'disabled person' rather, their own definitions of what disables them are much more to do with obstacles they face in their relationships with others, in employment, housing, and in obtaining financial security. Further, most of the limited information sources which are available are developed within formal statutory agencies which are, by their very nature, whose needs they are seeking to address. Much more creative solutions need to be developed in order to overcome these problems. In particular, much more use should be made of

existing networks of communication within particular (and local) ethnic minority communities (eg. community language radio stations and newspapers, churches, mosques, social groups, luncheon clubs and so on).

In the case of older African Caribbean and Asian disabled people, in particular, appropriate approaches to developing effective sources of information also need to take account of the isolation which characterises many people's lives. In practical terms, this means that the provision of advice and information needs to be a much more pro-active process in order to overcome the obstacles created by people not even knowing what kind of information they need in the first place. Without appropriate information to raise awareness of what services are available, older disabled people are powerless to take any control over how their needs will be met. Consequently, several of the older African Caribbean and Asian people in the study felt that there was very little they could do to improve their situations;

"I am aware that in this country they provide services to disabled people. But, why are my family not getting any services. I am not aware of the services."

"I do know that there are two Asian organisations that provide some service to the community. There is Asian older people's groups and I have heard of disabled people groups which is run by white people. I have not used them because I don't know the address."

Establishing a framework of rights and entitlements

All of the practical measures discussed above would be of crucial importance to building a supportive environment which would enable older disabled people to have real choices in how their needs are met and, thereby, retain control over their own lives. However, none of this will ever be enough to guarantee such independence unless the essential components of the supportive environment are underpinned by a clearly defined framework of rights and entitlements.

To be clear this implies far more than simply allowing older disabled people to have a wider choice of services and other supportive resources which are defined and distributed at the discretion of 'caring' professionals. Rather, the issue is about genuine political citizenship which would empower older disabled people as full and equal members of society. As Ignatieff (1989) puts it;

"The practice of citizenship is about ensuring everyone the entitlements necessary to the exercise of their liberty. As a political question, welfare is

about rights, not caring I do not want to live in the 'caring society' a nanny state in which the care we get depends on what the 'caring professions' think fit for us to receive. I would much prefer to live in a society which struggles to be just, which respects and enhances people's rights and entitlements." (Ignatieff, 1989)

We emphasised earlier that, the experience of ageing and the obstacles to older disabled people's self-determination must be located within a framework which acknowledges the existence of ageism and multiple oppression. Although it is clear that older disabled people have no wish to demand any more than they need to maintain control over their own lives, the combination of ageism, disablism and the various other forms of oppression illustrated in this report, means that many are forced into a life of dependency and denied even the most basic rights of citizenship. More than two years after this project started, we are still receiving letters from disabled people for whom these are the real issues which they have to face in their daily lives. It is perhaps fitting, then, to end with an extract from one such letter which sums up both the dependency which characterises so many older disabled people's lives, and the hope that they might one day have the right to the kind of supportive environment we have outlined;

"Why is it that age, more so old age, is now treated with contempt by authority both government and local. We work hard all our lives, whether fully fit or not, to save a little to both enjoy our retirement and retain our independence. However, if you are taken ill or an illness you have suffered from all your life flares up or develops then you are penalised, because of age or thrift. Personally I wish to retain my independence and do not wish to be a burden to my family or a drain on the community, but like so many thousands of like people, we do not wish to, neither will we beg for help I do hope the above will give you a little guidance to the needs of the aged and to which category you will one day become a member. I do hope that by then, there will be a little more care and attention paid to the over 65s."

Finally, the title of this report poses the rhetorical question - what do older disabled people expect after all these years? The comments above underline that they certainly expect far more than the life of dependency, frustration and anxiety which so many have experienced. The only question left to ask is - do they have a right to expect more in the future? We hope that this report has not only made it clear that they do, but also pointed the way forward to turning this ideal into a reality.

Appendix A: Sources for project participants

Response to requests for survey participants (Stage 1)

<u>Source:</u>	<u>Contact:</u>	<u>Response:</u>
Arthritis Care	Details circulated to London branches	16 volunteers (plus 1 refusal)
British Limbless	40 letters to	13 volunteers
Ex-Serviceman's Assoc.	named individuals	(plus 2 refusals)
British Polio Fellowship	Article in BPF Bulletin	62 volunteers
Cheshire Homes	Requests for 2-3 volunteers from 10 selected homes	10 volunteers (plus 10 refusals)
Chest Heart & Stroke Assoc.	Details circulated to London branches	7 volunteers (plus 1 refusal)
Diabetics Association	Article in 'Balance'	97 volunteers
DISC	Letters to 6 named individuals	6 volunteers
Greenwich SSD	30 letters to named individuals	4 volunteers (plus 1 refusal)
Medway/Swale SSD	40 letters to named individuals	11 volunteers (plus 2 refusals and 2 not disabled)
Multiple Sclerosis Society	Insert sent out with quarterly newsletter	37 volunteers
Parkinsons Disease Society	Article in Newsletter	14 volunteers
Scoliosis Association	Letters to named individuals	14 volunteers

SEQUAL

Letters to 10 named individuals

8 volunteers
(inc. 6 outside SE)

Appendix A: Sources for project participants
(Other organisations contacted)

Response to requests for survey participants (Stage 1)

Source:	Contact:	Response:
Arthritis Care	Details circulated to London branches	16 volunteers (plus 1 refusal)
British Limbless Ex-Serviceman's Assoc.	40 letters to named individuals	13 volunteers (plus 2 refusals)
British Polio Fellowship	Article in BPF Bulletin	62 volunteers
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Parkinsons Disease Society	Article in Newsletter	14 volunteers

Scoliosis Association	Letters to named individuals	14 volunteers
SEQUAL	Letters to 10 named individuals	8 volunteers (inc. 6 outside SE)

(Other organisations contacted)

Organisation	Response
Afro-Caribbean Community Association, Brixton	No reply
Age Concern, Lambeth	No reply
Age Concern Newham	No reply
Apna Ghar Housing Association	No reply
Asian Centre, Haringey	No reply
Asian Community Action Group	No reply
Asian Pensioners Group	No reply
Black Elderly Group, Southwark	No reply
Black over 60s Workshop, Tottenham	No reply
Brent Asian Elders	No reply
Brent Indian Association	No reply
Brent and Harrow FHSA	Put in touch with several local contacts
British Epilepsy Association	Reported that very few members have long-term disabilities
Calabash Lewisham	No reply
Crossroads Care Attendants Schemes (Seven London Boroughs)	Distributed leaflets to Black and Asian clients – 1 volunteer replied
Dial A Ride (seven London Boroughs)	Leaflets posted – no replies received
Downs Syndrome Association	Unable to help
Evangelical Alliance	No reply
GEMMA	Details circulated to monthly meetings but no volunteers identified
Hackney Muslim Womens Council	No reply
Hackney Pakistan Women's Welfare Centre	Unable to help
Haringey Black and Minority Ethnic Consortium	No reply
Indian Muslim Federation (UK)	No reply

John Grooms Association	Offered to ask for volunteers, but not taken further due to large response already received
Lord Roberts Workshop	Unable to help
Markfield Project	No reply
National League of the Blind and Disabled	Letter circulated to London branches but no volunteers
North London Bengali Association	No reply
South East Thames Region FHSA's	Requests for GP's to identify potential participants – no replies received
St. Hilda's East Community Centre, Tower Hamlets	No reply
Standing Conference for Ethnic Minority Senior Citizens	Offered to contact member organisations in London area but no replies received
Wandsworth Disablement Association	No reply
Wandsworth Black Elderly Project	No reply
West Indian Ex-Servicemen Assoc.	No reply
West Indian Self Effort Project	No reply
Willesden Asian Community Centre	No reply

Outreach work in African Caribbean and Asian communities (Stage 2)

Organisation	Outcome
Age Concern Brent	Unable to help
Age Concern Camden	Expressed interest in project and offered to try and arrange group interviews
Age Concern Tower Hamlets	Interviews with 2 local clients
An-Nisa Society	Expressed interest in project. Not followed up due to lack of time
Apna Ghar Housing Association	Expressed interest in project but unable to identify potential volunteers
Asian Elderly Group	Unable to help
Asian People with Disabilities Alliance	Very interested in project but unable to identify volunteers
Asian Resource Centre, Islington	2 people interviewed
ASRA	Unable to help
Association of Blind Asians	Very interested in project. Offered to help further identify volunteers, but not taken further due to lack of time

Bangladesh Womens Association	Unable to help
Barnet Elderly Asian Group	Expressed interest in project but unable to identify potential volunteers
Brent Association of Disabled People	Distributed leaflets and suggested other local contacts
Brent Community Relations Council	Put in touch with other local contacts
Brent Indian Association	Expressed interest in project but unable to identify potential volunteers
Harrow Asian Womens Association	Put in touch with three potential volunteers, 1 interview and 2 refusals
Lambeth Accord	Interviews with 4 members
Mission Dine Luncheon Club, Brent	Meeting with organiser
Moonshine Club, Brent	No disabled members, but put in touch with other local contacts
Mount Calvary Club	Put in touch with local contacts
Newham Deaf Asian Womens Group	1 volunteer plus organiser interviewed
New Testament Church of God Community Project	Group interview with 25 members (mixed group of older and older disabled people)
Parkside Community Health Council	Article in newsletter requesting volunteers – no replies
Patmos Lodge (LB Lambeth Home)	Interviews with 3 residents
Southwark Social Services	Put in touch with local contacts
Stonebridge Asian Elders Group	Expressed interest in project but no volunteers identified when followed up
Welcome Senior Citizens Club	1 person interviewed
Welldon Community Centre	Unable to help
West Indian Senior Citizen Group	1 luncheon club member interviewed
West Indian Self Effort Project	Group interview arranged with 5 members of luncheon club

Appendix B: Details of project participants

Breakdown of impairments (by gender)

<u>Disability/impairment</u>	<u>Total</u>	<u>responde</u>	Total	<u>Interview</u>	<u>sample</u>	Total
	Male	nts Female		Male	Female	
Polio	25	40	65	9	20	29
Multiple Sclerosis	7	30	37	2	12	14
Scoliosis	4	10	14	2	7	9
Arthritis	3	16	19	1	17	18
Amputees	13	1	14	13	1	14
Diabetes	43	54	97	6	9	15
Parkinsons	10	4	14	3	3	6
Coronary disease	3	2	5	1	2	3
Muscular Dystrophy	3	0	3	3	0	3
Freidreichs Ataxia	1	0	1	1	0	1
Cerebral Palsy	2	2	4	2	2	4
Stroke	0	3	3	0	3	3
Asthma	0	3	3	0	0	0
Hearing impairment	0	1	1	0	1	1
Others/not-specified	16	28	44	2	3	5
TOTALS	130	194	324	45	80	125

Current age by gender and race (interview sample)

	Males	Females	Minority Black/Ethnic	White	All
Under 40	4	10	15	5	8
40 - 49	2	13	3	11	9
50 - 59	13	18	12	17	16
60 - 69	33	26	30	28	29
70 - 79	33	26	27	29	29
80 or over	13	8	12	9	10
(Base totals)	(N=45)	(N=80)	(N=33)	(N=92)	(N=125)
Average age	67	61	62	63	63

Appendix B: Details of project participants

Number of years disabled by gender and race (interview sample)

	Males	Females	Minority Black/Ethnic	White	All
Up to 30 years	24	45	70	26	38
31 - 50 years	51	40	30	49	44
Over 50 years	24	15	0	25	18
(Base totals)	(N=45)	(N=80)	(N=33)	(N=92)	(N=125)
Average years	42	34	24	42	37

Marital status by gender (interview sample)

	Male	Female	All
Single	22	25	24
Married/Living partner	with 73	43	54
Widowed	4	24	17
Divorced/Separated	0	9	6
(Base Totals)	(N=45)	(N=80)	(N=125)

Household composition by gender (interview sample)

	Male	Female	All
Living alone	11	29	22
Living with spouse/partner	73	44	55
Living with relatives/friends	0	15	10
Living with personal	4	0	2
N/A-living in residential institution	11	13	12
(Base Totals)	(N=45)	(N=80)	(N=125)

Appendix C: Dissemination and consultation

Publications and Conference papers arising from the research

Zarb, G. (1990) 'Ageing with Polio' British Polio Fellowship Bulletin, Vol. 28 (5)

Zarb, G. (1990) 'Ageing with Diabetes' Balance, No. 119,

Zarb, G. & Oliver M. (1991) Ageing with a Disability: The Dimensions of Need - Preliminary Findings, London: Thames Polytechnic

Zarb, G. (1991) 'Creating a Supportive Environment: Meeting the Needs of People who are Ageing with a 'Disability'', in Oliver, M. (ed) Social Work: Disabled People and Disabling Environments, Jessica Kingsley Press

Zarb, G. (1991) 'Forgotten but not gone: the experience of ageing with disability', paper presented to British Society of Gerontology Annual Conference, UMIST, Manchester, 20th to 22nd September 1991

George, M. (1991) 'Unmet Needs', Nursing Times, Vol. 87 (21)

Zarb, G. (1992) 'Changes in health care: a British Perspective', Chap. 25 in Whiteneck, G. et al Aging with Spinal Cord Injury, New York: Demos Publications

Oliver, M. (1992) 'Societal responses to long-term disability', Chap. 20 in Whiteneck, G. et al Aging with Spinal Cord Injury, New York: Demos Publications

Zarb, G. (1992) 'Changes in health care: a British Perspective', Paper presented to International Aging with Spinal Cord Injury Conference, Regency-Hyatt Hotel, Denver, USA, March 23rd to 25th 1992

Oliver, M. (1992) 'Developing an understanding of societal responses to long-term disability', Paper presented to International Ageing with Spinal Cord Injury Conference, Regency-Hyatt Hotel, Denver, USA, March 23rd to 25th 1992

Zarb, G. (1992) 'Forgotten but not gone: the experience of ageing with disability', Chap. 2 in Arber, S. and Landrou, M. (Eds) Elderly People. Independence and the Life Course, London: Jessica Kingsley Press

Zarb, G. (1992) 'The dual experience of ageing with a disability', in Swain, J., Finkelstein, V., French, S. and Oliver, M. (Eds) *Disabling Barriers: Enabling Environments*, London: Sage/Open University Press

Zarb, G. (1993) 'Ageing with a disability: A biographical approach', in *OU Course Reader K256: An Ageing Society*, Milton Keynes: Open University Press (forthcoming)

Briefing papers

'Ageing and Diabetes: Briefing Paper' unpublished paper prepared for British Diabetics Association, February 1991

'Researching ageing with disability amongst ethnic minorities', unpublished discussion document prepared for Project Advisory Group, March 1991

'Ageing with Polio', University of Greenwich, Autumn 1992

'Ageing with Multiple Sclerosis', University of Greenwich, Autumn 1992

'Ageing with Arthritis', University of Greenwich, Autumn 1992

'Ageing with Scoliosis', University of Greenwich, Autumn 1992

'Ageing with Parkinsons Disease', University of Greenwich, Autumn 1992

'Ageing with a disability: The experience of long-term amputees', briefing paper prepared for BLESMA, Autumn 1992

Other organisations sent summary reports of briefing papers

Age Concern (various London branches)

Association of Jamaicans Bristol University

Dawson UK Limited, Book Division

Department of Health and Social Security, Library Disability Now

Disabled Living Foundation Gazette International (USA) International Polio Network, St. Louis, USA

Leicestershire County Council, Elderly Persons Services

Leonard Cheshire Foundation

London Borough of Tower Hamlets, Library

Nuffield Institute for Health Services Studies, University of Leeds

Open University

Post-Polio Syndrome Group, Calgary, Canada

RADAR, Information Department

Rehabilitation Research and Training Centre on Ageing, University of Southern California, USA

Royal College of Nursing

University of Hull, Department of Social Policy

Other organisations contacted or consulted during the course of the project Age

Concern England/Greater London Age Concern

Chartered Society of Physiotherapy

Department of Health - Advisory Group on Rehabilitation

Department of Health - Priority and Health Services Division

Multiple Sclerosis Society (various local branches outside SE of England)

Muscular Dystrophy Society

National Asthma Campaign Spastics Society

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