

# **AGEING WITH A DISABILITY IN RESIDENTIAL CARE**

**Briefing paper prepared for  
The Leonard Cheshire Foundation**

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## ABOUT THE PROJECT

The research project - 'Ageing with a Disability: The Dimensions of Need' - commenced in March 1990 and was completed at the end of September 1992. Funding for the work was given by the Joseph Rowntree Foundation. A full report - 'Ageing with a disability: What do they expect after all these years?' - will be published shortly (see Appendix for full details).

The project has examined the experiences of people with long-term physical disabilities or disabling illnesses who are also experiencing the ageing process. The findings are based on responses from over 300 men and women with a variety of disabilities, including Diabetes, Polio, Multiple Sclerosis, Scoliosis, Parkinsons Disease, and Arthritis. 125 of these have also been followed up with in-depth personal interviews; of these, 15 were living in residential or nursing homes, or in sheltered accommodation.

The project has also attempted to highlight the race dimensions to ageing with a disability. Attempts to locate older disabled people from black and ethnic minority communities through the membership of established disability organisations proved unsuccessful. Consequently, additional outreach work has been undertaken to consult with local community groups, identify older African Caribbean and Asian disabled people, and to discuss their experiences and needs.

Apart from the research itself, dissemination is also an important part of the project. The specific aims of the dissemination can be summarised as follows:-

- i) to raise awareness of the existence, needs, and experiences of people who are ageing with a disability amongst voluntary sector organisations, organisations of and for disabled people, and support agencies;
- ii) to initiate on-going dissemination and debate on the practical implications of ageing with disability, and to document proposals for future action aimed at addressing the needs of older disabled people;
- iii) to suggest some of the key practical measures which older disabled people would like to see taken;
- iv) to highlight any particular concerns of different groups of older disabled people who have participated in the project.

We are also planning to organise a seminar/workshop to discuss the practical implications of our findings. This has been provisionally scheduled for Spring 1993. We are also planning to produce a practice guide for disability organisations and statutory agencies based on this seminar.

Although most of the issues raised by the project are of universal significance, it is important that the findings are made available to the various disability organisations whose members have participated in the project so that they can utilise this information in their own work.

This briefing paper is based on information given by a small number of Cheshire Homes residents who have contributed to the project. Requests for two or three volunteers were distributed to 10 selected Cheshire Homes in the Southern half of England. The response to these requests produced 10 volunteers and 10 refusals. A total of 8 residents also participated in the follow-up interviews. The average age of this group is 67; they have been disabled for between 20 and 62 years, with the average being 35 years. 5 are women and 3 men. Main impairments are Multiple Sclerosis, Muscular Dystrophy, Scoliosis, Friedreich's Ataxia, and Asthma.

Following an overview of some of the main background issues to ageing with disability, participants views on specific topics covered by the research are outlined. Each section contains a summary of the main issues raised and (where appropriate) the possible implications for Leonard Cheshire Foundation and others. The briefing paper is organised around the following topics:-

- # Concern about ageing and the need for research;
- # The experience of ageing with a disability;

- # Physical and health problems associated with ageing;
- # Health services/health care;
- # Practical/personal support needs;
- # Views on residential care.

## **BACKGROUND ISSUES**

The ageing of the population in Britain is having a profound impact on social policy, service provision and professional practice. However, the 'ageing population' is a far from homogenous group; rather, there are important differences between particular groups, sub-groups and age cohorts, which have to be identified, acknowledged, and responded to, if appropriate services are to be provided and individual personal needs adequately met.

One particular sub-group which has been more or less completely overlooked are people disabled in child or early adulthood who are now beginning to age with their disabilities. Changing patterns of life expectancy brought about by advances in medical technology, treatment and rehabilitation mean that the size of this sub-group of 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 OPCS in the late 1960's and 1980's (Harris, 1971; Martin et al, 1988). These surveys indicate that there are just under 100,000 people aged 50 plus and disabled for 20 or more years alive today, with around another 200,000 who will reach this age within the next 10 to 20 years.

This increase in the numbers of people who are ageing with a disability is also differentially distributed according to both gender and race. First, although the prevalence of a few types of physical impairments is higher amongst males, nearly all the largest sub-groups of older disabled people contain far more women than men. Second, largely due to immigration patterns, most ethnic minority communities are younger than the white ageing population; thus, the prevalence of ageing with disability is likely to increase at an even faster rate amongst these groups over the next decade and beyond (CRE, 1987).

Despite the growing number of older disabled people, next to nothing is known about the experience of ageing with a long-term disability. It is important to consider that, while there may be some overlap between the interests of ageing disabled people and other groups in the ageing population, each group will bring its own perspective to the ageing and disability experience. Within the population of people who are ageing with a disability, there are also likely to be differing experiences and concerns structured around race and gender. These contrasting perspectives may, in turn, influence expectations and preferences about what kind of support may be required, and how it should be made available. Furthermore, the present structure of support services fails to meet the needs of the majority of disabled people, let alone those who may be experiencing the additional problems often associated with ageing (Beardshaw, 1988; Fiedler, 1988). Almost inevitably, this means that many people in this group will fall through the net of existing support provision.

## **CONCERN ABOUT AGEING AND THE NEED FOR RESEARCH**

The response we have had from many people with long-term disabilities indicates concern about ageing and the need for more research of this kind. There are several dimensions to this concern:-

- \* Some people who have contacted us are concerned about the wide variety of physical and health problems they have experienced with ageing and feel that more should be done to investigate why these problems are occurring and what, if anything, can be done to remedy, or at least minimise, the effects. Related to this, there is concern that there is very little research on separating out the effects of ageing and the consequences of long-term disability itself.
- \* Even where people have not yet experienced any significant problems, some are anxious about what may happen when they are older. Apart from the implications for their own lives, some are also concerned that future generations of ageing disabled people should not have to face the same kinds of difficulties.
- \* While medical research is obviously important, many older disabled people clearly feel that there has been a marked lack of attention paid to the long-term implications of living with a disability in terms of quality of life issues and practical/personal support needs. Some people stated that they have been waiting for a long time for someone to undertake a study of this kind. We are very conscious of the fact that, in undertaking the study, we have raised people's expectations that the issues they are concerned about will now be given a higher profile. While the project will hopefully be able to meet some of these expectations, there is a clear need for organisations like Leonard Cheshire Foundation and others to take this further and incorporate these concerns about ageing into their own work.

## THE EXPERIENCE OF AGEING WITH A DISABILITY

Although the main purpose of the project 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 the subjective experiences of ageing with a disability and the impact people feel this has on their lives.

The experiences reported by people participating in the study are very varied, although there are also several important common issues. In many ways older disabled people feel very positive about themselves despite, or more often because of, negative experiences of ageing as disabled people. Several people clearly feel that, living with a disability for 20 or 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.

Some of the main issues identified are summarised below.

- \* Many of the people we contacted felt that their needs, and even their existence, have been overlooked.
- \* These feelings of having been forgotten go a long way to explaining why such a large number of people volunteered to participate in the project. Several commented that a project about this issue was long overdue and hoped that their needs would now at least start to get some recognition.
- \* 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 20 years or more.
- \* 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.
- \* This is illustrated by people's level of satisfaction with the quality of life. The findings indicate that, ageing is typically associated with a 'downturn' in people's level of satisfaction after they had been disabled for between 20 and 30 years. Also, this appears to be closely associated with the onset of the ageing process. About half of the people in the study reported that their satisfaction with the quality of life had risen again over time as they accommodated themselves to the physical and personal changes experienced with ageing. Others, however, remained dissatisfied.
- \* There are numerous factors which influence how older disabled people view the quality of their lives. First, some 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. Other people felt that, while they had always found the physical consequences of their impairments difficult to cope with, the additional effects of ageing had made the situation much worse.
- \* 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. In a few cases, the main precipitating factor had been moving into residential care.
- \* 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. 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.
- \* 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.

\* At the same time, 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.

\* 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.

\* Faced with this situation, 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.

\* A related problem is that, because many older disabled people have been isolated for so long, they are often unable to get others to recognise their needs. Also, the cumulative effect of this kind of experience may be that some people do not have the confidence to articulate their needs. This often tends to be a more common experience for older disabled women, many of whom are particularly isolated.

\* Older disabled people from black and ethnic minority communities were also particularly isolated and most did not have access to the support and advice offered by established disability organisations (either nationally, or locally). The fact that less than 3% of our original sample drawn from members of various disability organisations were people from black and ethnic minority communities gives some indication of the scale of this problem.

\* Many of the people we contacted expressed significant concerns about their independence, which they saw as being threatened by physical and/or personal changes experienced with ageing. In some cases, this only extends 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.

\* These anxieties are often closely related to the lack of appropriate and acceptable support for people who are ageing with a disability. Several people were concerned about the possibility of having to make major changes in lifestyle, such as seeking more personal assistance, or making further changes to their living arrangements.

\* For some, such changes simply represent an unacceptable degree of compromise with how they wished to live their lives. There were others, however, who took a more philosophical view and felt that, having extra help was probably the best way of maintaining their independence, or at least avoiding any further loss of independence - even though they would still resist such changes in their lives for as long as they possibly could. A small number of people, on the other hand, had either never placed much emphasis on independence (either physical or emotional) 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.

\* While most of the Cheshire Homes residents who participated in the project shared some of these concerns, their experiences of ageing were often more specifically framed by their experiences of ageing in residential care. This is discussed further in a separate section of this paper.

### **THE EXPERIENCE OF AGEING WITH A DISABILITY (Quotes)**

*"It has been difficult. But, I don't spend too much time thinking about it (ie. physical ageing) to be honest. With me, I say it's life first and disability second."*

*"Life is what you make it. Nothing is impossible - I've accepted my disability."*

*"Anything I do - I'd rather have six months of happiness than 10 years of misery so, I don't need to hang on to*

*the hospitals - I can look after myself."*

*"On the whole, I'd say I'm very satisfied. Although, there are some things that are sort of slipping out of my reach. But, people say you're getting old - what do you expect? But, I say you're only as old as you feel."*

*"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. It certainly confirmed my ideas about living on my own. It just doesn't seem practical - you have to worry about things like not having any transport and being stuck there on your own. That's really important - and there's the lack of company as well so, it brought it home to me that I had to try and make sure I didn't end up in the same situation."*

*"They discovered I had it (Multiple Sclerosis) in 1983. They sent me to (a nursing home) and after that they just sent me from place to place. I was pushed around for 10 miserable years until I ended up here - that was about 5 years ago."*

*"When I was eleven I was diagnosed as having muscular dystrophy - that's all I know. I was told that I wouldn't last 'til I was twenty - or at least that's what my parents were told anyway. But, I must say that it hasn't been anything like as bad as we were told to expect. When I was younger, I did have very bad curvature of the spine and, I know from what's happened to other people I know that that can lead to a lot of problems if you leave it. But, I was lucky because my parents were very very supportive, and they went and found this chiropractor and, really, that changed my life because he was able to work on it and get it straightened out. So, that's been very beneficial for me and it's meant that I've had a better quality of life than I would have done if we'd just accepted things as they were. I only started using the wheelchair in 1979 (ie. 19 years after onset), so that gives you an idea of how beneficial it was. But, apart from that, I'm convinced that - with being generally fitter - it's greatly improved my resistance to infections as well. I was always going down with something when I was younger - but I hardly ever get ill now. ... I don't go anymore (to chiropractor), I stopped going quite a few years ago. But I still keep myself pretty fit. Like, I go swimming once a week - a friend takes me - and I go in the hydrotherapy pool - that does you a hell of a lot of good as well. So really, I think I've done quite well. I can't say that I'm completely unaffected by ageing because you do get aches and pains you didn't have before and that sort of thing - and I know there will probably be more of that when I get older. But, on the whole I'm pretty fit - I look after myself."*

*"I've never had a job. I did have some work experience at the local council offices but I didn't keep on with it. It's not being able to concentrate as much as anything - I found that I just wasn't able to concentrate for very long at a time. They did offer to let me stay on to see how it went, but I decided it wasn't for me."*

*"I had always worked right up until when I was diagnosed but I had to stop on health grounds - I just couldn't cope with it physically. I would have loved to go back to work, but it's just never been possible."*

*Researcher: Did that effect your pension at all?*

*"Yes, I had to throw in my pension, so I don't get any superannuation. It probably wouldn't have been all that much, but it would have been handy all the same."*

*"I wasn't all that worried about using a wheelchair. It made life easier in many ways. In fact, I felt I used to get much annoyed staggering about everywhere with my walking stick - that was much more frustrating."*

*"When I was younger I used to bash about the place and get all het up but, you learn after a while that it's just wasting energy - so why bother. In any case, even though I've got this disability it's never been as bad as I thought it would be. I mean, after I first found out I wondered whether it was worth going on. I thought - what's the point. But, as you go on you find you can just get on with it and it doesn't have to be as bad all that it's made out to be. It's up to you really isn't it. Some people are always moaning - oh, I can't get to the shops very easily, or that sort of thing. But I always say - why worry. If you learn how to get rid of your impatience and life seems a lot easier."*

*"I'm about the third youngest here. I'm always talking about the old dears, but then I remember that I am one myself which is quite funny really. But when I look around and see how most of them are going on I don't think*

*I'm doing too badly. Really I'm much more active than most of them here - that makes you feel younger in a way."*

*"It's probably true that - if you have been disabled for a long time - you have to look after yourself. Some of them here just seem to stop and wait for people to do things for them. I've always had to be fairly active. I worked part time till I was 60 in any case. But before that I had the house and family to look after so you need to keep going. It always amazes me how little some of the older ones do - they just sit around most of the time."*

*"I had a house of my own before I came here. But I had to move - I couldn't manage the stairs. Maybe if I hadn't been on my own I could have stayed on, but it's very difficult when you haven't got your husband around to help."*



## PHYSICAL CHANGES/PROBLEMS EXPERIENCED WITH AGEING

People participating in the project have reported a wide variety of physical and health problems/changes experienced with ageing. Some of those commonly experienced (eg. decreasing mobility) may well be associated with the 'normal' ageing process (although there is no universal agreement about what normal ageing actually entails); at the same time, there are a small number of problems/changes which seem to have a slightly higher prevalence amongst people with particular impairments (see separate briefing papers for further details). As mentioned earlier, several people felt that there is a need for more work on separating out the consequences of ageing and disability with a view to (hopefully) being able to prevent or mitigate some of the problems experienced. Clearly, until more is known and understood about the long-term consequences of ageing with a disability, it will be difficult for the medical profession to develop appropriate medical interventions.

Some of the most common problems/changes reported are also very prevalent amongst the general ageing population. However, the effects of these when combined with pre-existing disability related conditions are often cumulative, and can have significant consequences for the quality of individual's lives. There are also implications for the provision of practical support which are discussed further below.

A breakdown of the kinds of physical problems and changes reported by people participating in the interviews is given in Table 1 below.

## PHYSICAL PROBLEMS ASSOCIATED WITH AGEING (Quotes)

*"It takes me longer to do things than even a year ago. It's completely progressive - there's no remissions like you get with MS."*

Note: Respondent has Friedreich's Ataxia.

*"The biggest affect has been my speech. That started to go about 1981 I suppose (ie. 36 years after onset). It's affected my hearing badly as well. I can't separate background noise so I have a lot of trouble understanding what people are saying. I stopped work years ago - about 1965 (20 years after onset). It was getting too much and I was having quite a few accidents. It was embarrassing - that side of it - because people think you're blind drunk when you're falling about all over the place. So, it was best to pack it in. Anyway, that was about the same time I started using the wheelchair - so I wouldn't have been able to carry on very easy in any case."*

*"It's difficult to know whether it's got any worse. Possibly, it's not that bad but - I've got Addisons disease as well, and Asthma - it's really the combination of all three sort of ganging up on me. I'd say it's not so much a case of steadily getting worse. It's more like things just get a little bit more unpredictable. I need to take steroids and, these days, I find I have to keep adjusting them - which is a bit of a nuisance."*

Note: Respondent has had Mycaemia Gravis for 20 years and also has Addisons disease and Asthma.

*"With my MS, I've never been up and down like a lot of people I know. After about the first six months - I did deteriorate quite quickly at first - but after the first six months it levelled out and it's been more or less the same since. You do worry at first because you don't know how you're going to end up, but, touch wood, this is about as bad as it's going to get."*

*"Since I had the fall - I was in hospital for six months off and on - since then, I really can't walk at all. I can just about get to the bathroom on the frame, but that's definitely my limit."*

*"That's something that does get you when you're older. I have become slightly incontinent. You do need to go much more - I used to be able to hang on all day when I was younger but I usually manage to make it in time - I've just had one time when I had to lie in a wet bed, so it's not too bad."*

*"I've got rheumatoid arthritis in my hands and all up this shoulder. That can be very painful but the main thing is that it means I can't really lift anything. I have to have everything made very light, otherwise I can't manage."*

**TABLE 1: 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
Stroke(s)	5	65	25
Spasms/spasticity	5	57	32
Brittle bones (osteoporosis)	5	50	41

/Cont...

(Table 1 continued)

Proportion

Average age Average years

	reporting problem /change (%)	when first noticed	disabled when first noticed
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

## **IMPLICATIONS FOR USE OF HEALTH SERVICES/HEALTH CARE PROVISION**

The experiences reported to us suggest that the provision of health care for people with long-term disabilities is erratic and that, in general, there is a lack of appreciation of the problems they face amongst the medical profession;-

\* Some people felt that there is a lack of routine check-ups for older disabled people, and that this aspect of long-term health care has declined over recent years. On the other hand, there were a few individuals who felt that check-ups were unnecessary. Nevertheless, it seems clear that routine check-ups (in specialist clinics where necessary) should be available if/when they are needed.

\* Some people expressed the view that there is very little treatment offered to people with long-term disabilities, and very little understanding about the long-term effects of disability amongst the medical profession. This, in turn, is a reflection of the concern about the lack of research discussed earlier.

\* Similarly, several people expressed varying degrees of concern about the lack of advice from doctors about problems they had experienced with ageing. In some cases these were problems specifically related to their particular impairments; in others, these were more general problems (eg. impotence). Whatever the specific nature of these problems, it does appear that the medical professional are not as supportive/understanding as people would like.

\* A few people also mentioned specific problems they had experienced with getting adequate GP support for residents in residential homes.

## **HEALTH SERVICES/HEALTH CARE (Quotes)**

*"When you are in a place like this (nursing home) you don't get the attention you would outside. They (GP's) think - well you're being looked after, so they don't bother. I had to ask for him four times the last time I wasn't well. They used to have a surgery in the home but they stopped the weekly visits - so we don't have that anymore."*

*Researcher: When you say you don't get the attention you need, what sort of things are you thinking of?*

*"I can't say exactly - it's just a feeling you get - what if anything went wrong, you know."*

*"You go into hospital but there's no-one there to look after you. I should have a check-up every year at the national hospital (for nervous diseases) but it's a bit too much for me to go up there. But if you went now, it probably wouldn't be the same. Still, I suppose I've got used to it now - so I just manage the best I can. Probably it's not so important to me now (check-ups)."*

*"Another thing you could bring up is - they're very careless about things like your medication. When you move into a home - or move anywhere really - you're medical notes take about 12 months to get to your new doctor. But, when you're disabled, speed is of the essence. I mean, with medication, it can be very dangerous. Most people in here - I'm sure they don't know what tablets they're taking. So they can't tell anyone if they're not getting the right kind of medication. I think that's a really major point."*

*"I do think that doctors seem to have great difficulty with you if you have more than one thing wrong with you at the same time. Whatever you get it's always put down to your disability and - unless it's life threatening - that's the end of it as far as they're concerned. This is a problem isn't it. People say - you can't expect to get away without any problems. I know I can't do the same things I did 20 years ago, but I know it's not just that. Whenever I go to the doctors, their general approach seems to be to just tell you to rest and see what happens. Well, I know that isn't enough of an answer but that's all they ever seem to tell you."*

*"I get tired of chasing him (GP) up. I don't bother with check-ups to be quite honest. I shouldn't think they'd give me one even if I wanted to. I'm sorry to be so clinical about it, but I don't think the doctors are all that interested in someone in my condition. Anyway, you shouldn't have to chase them up. I think - if you're going to have check-ups - it should be automatic."*

*"I think there is a general problem with the health services - they treat the patient and not the whole human being. Obviously, that's a problem for everyone but it's probably even more important if you've got some kind of disability because that's always in the background even though you get the same things wrong with you as everyone else. It tends to make things more complicated - well at least some of the time - but, the doctors don't seem to be able to deal with that."*

*"I haven't seen a doctor for years. I never really wanted to bother with having any (check-ups) - I was too busy enjoying myself. I won't be doing any of that here, but I don't really care about that anyway."*

*"I have a general check up with my GP - he's pretty well up on my situation, so I've got no complaints about that. But, as far as things like access to the surgery goes, there's plenty of room for improvement. Whenever, I go I ring up first and they get the ramp out so I can get in. But, you shouldn't really have to do that - you expect somewhere like the doctor's to be accessible. And, I don't just mean not having steps - there's other things like those little sills they have in doorways and things like that - it's just as awkward for people who aren't in a wheelchair a lot of the time. ... There ought to be some kind of rules about surgeries and health centres so you can be sure they are completely accessible."*

*"The medical care here (nursing home) is very very good. The doctor comes in to check on me very regularly but I always get hold of him whenever I need to. Someone would come out right away if necessary - I only have to call or ask someone to call them."*

*"I was a bit stuck when I went into hospital. They put me in plaster of course, but it was so heavy that I just couldn't do anything myself. I was completely incapacitated. What they'd done was, they used the heavy plaster - it was the wrong one. The specialist said - even a normal person couldn't lift that leg, you need the lightweight plaster. So it was all right after that. The treatment was really good apart from that. But I didn't like being put on a geriatric ward. They were all a bit gaga - it wasn't a lot of fun. There was a young chap who came in for a couple of nights - he was the only person I talked to really. They (family) brought my wheelchair in after a couple of weeks so I could get around and talk to other people - it wasn't so bad after that. The only thing that did annoy me was the way nurses would make you wait so long when they took you to the toilet. They just used to leave you hanging around there. I didn't like that."*

## **PRACTICAL AND PERSONAL SUPPORT NEEDS ASSOCIATED WITH AGEING**

Like many other groups within the ageing population, people with long-term disabilities are often likely to require some additional practical and/or personal support when they are older. In some cases this follows from the physical problems/changes experienced with ageing (eg. reduced mobility); usually, however, the kind of support needed will ultimately depend on the personal, financial and practical resources already available. For this reason, support needs should always be evaluated on an individual basis, although there are some common concerns reported in the study which are summarised below;-

\* Older disabled people may need additional practical support in the form of assistance with transport; domestic help with cleaning and shopping; provision of mobility aids; and, in several cases, personal assistance. Often, people's decision to enter residential care had been directly influenced by difficulties with getting this support in the community.

Some also highlighted difficulties in obtaining information on alternative living options which may be available. While statutory agencies should be providing such information, they often fail to do this so there is a potential role for Leonard Cheshire Foundation and other voluntary organisations to act as 'information brokers'.

\* Regarding the practical assistance available in the various Cheshire Homes where participants were living. This was mostly felt to be adequate although there were particular concerns about lack of flexibility and the restrictions this placed on people's independence. In particular, there is a clear demand for more flexibility in the arrangements for providing personal assistance outside of the set hours when this is normally available. Also, for such support to be more closely tailored to individual needs and lifestyles.

\* A few residents also commented that the design of their particular homes were not ideal - particularly for people whose physical or health status may change when they are older.

\* Some individuals specifically mentioned the need for more local self-help groups which would give members the opportunity to discuss matters of mutual concern, and learn from each others experiences. This was most often discussed in relation to the need for practical information on matters such as obtaining equipment and benefits, but also in the context of mutual support in discussing anxieties about health matters and ageing in general. This also reflects a wider issue which the study has highlighted; people who have lived for 20, 30 or more years with a disability or disabling illness have a vast amount of collective experience which can be an extremely useful resource to others. At present, however, these resources are not being fully utilised. Those who were regular members of local disability groups on the other hand, had mostly found this to be very helpful.

\* There is also a clear need for organisations like Leonard Cheshire Foundation to engage in a more pro-active strategy for responding to the needs of older people from black and ethnic minority communities. Many people in these groups are not even aware of what support and advice may be available or where to go for information. Consequently, they are often extremely isolated. However, tackling this issue would involve far more than simply providing information as the long-term consequences of this isolation often means that people do not have the confidence to articulate their needs. Clearly, these problems cannot be solved by any simple means. However, we would suggest that closer alliances with existing black and ethnic minority community groups would be a useful starting point.

## PRACTICAL AND PERSONAL SUPPORT NEEDS (Quotes)

### (1. Personal and domestic assistance)

*"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 doors 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."*

*Researcher: Before you moved here - when you were living at home - did you have any help from the community services?*

*"The district nurses came once to help me with the bath - but that was the only time. They said they couldn't do it when I had my son and daughter here. But, it shouldn't be their job - it's embarrassing. If it's someone coming in from outside it's easier to accept."*

*"Basically, I think that choice and transport are the two key things you have to think about when you're getting older. The set up we have here (residential hostel) is pretty secure on the whole, and I can't say I have any real worries on that score. But, it would be very useful to have something that's a little bit more flexible some of the time I mean, we have the care attendants and they come in every day but, if you deteriorate a lot and they can't manage you, the only other thing really is to go into a nursing home. It probably won't be an issue for me personally, but we have already seen this with some of the others who have been here. So, what you really need is something else inbetween so that you have just that little bit extra flexibility. Something like this on-call support sounds like just the sort of thing we need."*

*"The staff here (nursing home) - a lot of them don't have no basic training - that's what gets me. Anyone can apply to work here without proper training. It's no good when they're doing things like lifting - it's asking for trouble. And, because they're not properly trained - I don't mean all of them, but the ones who aren't - they get you all muddled up. When you're getting dressed or having a bath, by the time they've finished - you feel pretty disorientated."*

*"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 - especially if you only see people at mealtimes."*

*"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."*

*"I'm glad to see that the authorities are beginning to take more notice of disabled people. I don't think of myself as a militant, but I do think you have to go on at people and make them listen - because it's true that we know best what we need in the way of services and transport, and things like that. I don't just mean going on about having more money. I know money doesn't grow on trees, but there is a lot of wastage because people just don't think what they're doing. But, it is changing - or at least it is round here. I know, because I'm on different committees with the health authority and the county council and I've seen the changes in their attitudes over the last few years. Before, it used to be just one or two of us and - because you're on your own - they just think you're being a nuisance. Now, they see that there's other disabled people who think the same, so they know there must be something in what we're saying. These days, they invite me to join these things so you feel a lot better about it - it doesn't feel like I'm the only one. But, that doesn't mean everything is sorted out just like that. You mustn't compromise - you can't let them spend all their time talking and not actually doing anything - there's too much of that."*

*"It would be better if I could at least pick what time I go to bed. You don't have any say about things like that - you just wait your turn."*

*"That sounds like a wonderful idea (having a personal assistant). 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."*

*"We have the care attendants (District Health Authority) coming in in the mornings and at night. I need a bit of help getting in and out of bed and they do that, and help me get dressed, a bit of help going to the toilet - that's about it. ... They come between 9 and 10 at night, so I do have to go to bed a bit earlier than I'd like sometimes. I suppose, I've adjusted to it, but it is a bit early for me really. So, I usually listen to some music or something like that until I want to go to sleep, but I have to do it in bed. It's not a problem all the time, and they are very nice people - I must say that - but, it is a bit restricting because, if you wanted to go out to the theatre or something like that, it's all a bit awkward".*

*"The care attendants only come in the morning and when they come back at night. During the day, we've got the warden if anything comes up. There's always someone here during the day, plus we get emergency night cover, so the back-up is pretty good. Yes, I'd say I'm confident with the back-up. The only thing we lack, I suppose, is - with the care attendants, they only come at the set times, and they're not around during the day. If you could have a slightly more flexible arrangement it would be better for everyone because you can't expect the warden to do everything for you and there's bound to be the odd times when you might just want a little more help than usual. So, we could do with some back-up - but, it's not too bad really."*

*Researcher: If you could get extra help from a care attendant or helper, would you prefer to organise them yourself? Maybe even employ them directly instead of the health authority?*

*"Well yes, if you're paying them it would give you a sense of authority wouldn't it. Anyway, if they're (ie. ILF) going to pay for you to do it, then I'm all for it. I don't know how it would work out though, with doing all the paperwork and that sort of thing. I suppose I could get the hang of it if someone showed me the ropes. I have heard about disabled people doing this - employing their own care attendants - it's got to be a good idea because, you're bound to have more control of the situation like that. So, if other people can do it then maybe I can as well. ... Maybe we're not as powerless as we sometimes think we are."*

*"In a place like this you need to be able to look after yourself. They are all very helpful, but they don't really understand that everything takes longer. You need more time just to move about from one part of the room to another - every little thing just takes more effort."*

*"I have to have help with having a bath. It's not too safe for me to try on my own and I can't use the shower they have here at all. I didn't need help with the bath when I was at home though, because I knew my way around my own bathroom, and there was a bit more space anyway."*

*"I haven't heard about anything like that before, no. It sounds marvellous (ie having own flats with personal assistance) but I think finding someone compatible would be the main problem. I'm sure I would try it if I had to, but some people are impossible to get along with aren't they. Anyway, apart from that you get used to your own company - being on your own - you get to like it after a while. I'm not sure if I could get used to having someone else around really. Maybe I would consider it - if I couldn't walk at all, I might."*

## **(2. Aids and adaptations)**

*"I used to have a manual wheelchair when I didn't need to use one all the time. But, these days I only use an electric. It's so much easier for getting around but the only problem is finding an electric wheelchair that's good for indoors as well as when you're outside. The outdoor ones are too big and too heavy - especially when you're in a small place like this, and the indoor ones aren't really up to dashing about all round the town. This one I've got now is an indoor/outdoor one but it's just about streamlined enough for me to use indoors. I was lucky really because I tried several different ones before and none of them were quite right. When he brought this one round for me to look at I knew it was what I was looking for as soon as he brought it through the door."*



*I had it on loan for 24 hours so I could give it a good try out - I think you should be able to do that anyway, especially when you're spending so much money."*

*"When we first moved in here (Spencer Lodge) we couldn't use any of the toilets. We had actually seen the plans before, but somebody must have decided to change them. When they were finished, all the toilets were on raised plinths and none of us could use them - they all had to be taken out so they could start again."*

*"You see this wheelchair - look, it's broken. I can hardly move in it anyway - it's such an awful squeeze but, nobody's been to see about it. They come in and out all day long - but nobody's asked me about it."*

*"The thing about the design of a place like this, it's the difference between adapting a house and something that's purpose built for disabled people to live in. You see, these room at the front were just adapted but the others were added on when the place opened so, the new rooms have more space. In here, it's all a bit cramped. 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."*

*"All your muscles get very weak with MS - you need to have everything very light. I couldn't use my old wheelchair anywhere, but since I got this stowaway it's so much better. I can even get in a car with this one - I couldn't do that before."*

### **(3. Transport needs)**

*"Transport is so important wherever you live. We do have a Dial-A-Ride here and that's been a great help to a lot of us. The only problem is that, in an area like this (ie. rural area) the distances you have to cover are so big. It can easily be 60 miles between one person and another in the same area. So, what they're doing here is splitting it up into smaller units so each one will have a radius of about 5 miles - it's the only way you can do it really."*

*"Personally, I wouldn't want to live alone, and that's mainly because of transport. If I had my own place I'm sure I'd be a lot less independent than I am now because, basically, I'd be stuck at home most of the time. Whereas here (residential hostel) the transport's nearly always available so I can get out more or less whenever I want to - that makes a big difference to me because I like to be active."*

*"Dial-A-Ride is better than nothing, but it's obviously not the whole answer."*

*"Transport - that's something else that is so important. I don't drive myself, so I totally rely on other people if I want to go anywhere. It's alright around the town because I can get about in my electric wheelchair, and we're very lucky here because we've got the minibus through the League of Friends. They have a bank of volunteers - you ring them up and tell them where you want to go. Alright, sometimes they might not be able to make it, but generally they are very good".*

*"I used to have my scooter, which was marvellous for getting down to the shops and that sort of thing. But when I moved here, I had to get rid of the scooter mainly because I just didn't have the room to keep it here."*

## **OLDER DISABLED PEOPLE'S VIEWS ON RESIDENTIAL CARE**

Compared to the experiences reported by people in other residential establishments. Most of those interviewed were fairly positive about living in a Cheshire Home. (Although we do not know if this is true of those residents who declined to participate in the survey).

At the same time, there were a number of important concerns which need to be highlighted. These are summarised below:-

- \* First, some people were concerned that they may not be able to remain in their present home if they should experience any further physical deterioration with ageing.
- \* Second, these concerns also need to be understood in the context of why people had moved into residential care in the first place. Often this decision was closely related to the lack of appropriate support services in the community. Faced with this situation, moving into residential care would have been seen as the only option available for providing the level of support and/or security which people wanted. It is not surprising, therefore, that any perceived possibility that such support may not be available in the future was a source of considerable anxiety for the individuals concerned.
- \* More generally, some people commented on the importance of having access to a range of living options which would enable them to plan ahead for any possible changes in their circumstances when they are older. For some, moving into a Cheshire Home was seen as the most acceptable option - mainly because continuing to live at home was considered impractical. On the other hand, a few people felt that - while such a move may have been appropriate in the past - they would now actively consider moving back into the community providing, of course, that appropriate support options would be available.
- \* Regarding support within the residential homes. Some people felt that there is a tendency for the homes to be over-protective, thereby fostering unnecessary dependence. This is also related to the issue of lack of flexibility in arrangements for personal assistance and other support which was discussed in the previous section of this paper. This suggests that there is clearly scope for creating a more flexible range of support options which would enable residents to have greater independence and choice.
- \* The specific change most frequently mentioned related to greater flexibility in the times when care attendants (or their equivalent) are available to provide assistance with getting up and going to bed in particular. Also, to provide personal assistance on a more flexible basis at other times so that people can call on such support as and when it is needed.

### **OLDER DISABLED PEOPLE'S VIEWS ON RESIDENTIAL CARE (Quotes)**

*"The design of this place is good. But there are problems with some of the older Cheshire homes - they're not purpose built and, from what I've seen, there's not enough thought put in to the adaptations. So, probably some people would be able to do more for themselves if the design was more suitable for them."*

*"I came here for a three month trial period. It's much better doing it that way because - with me anyway - I need time to settle. But, the biggest drawback here is the changeover in the staff. They get to know you, and you get to know them - but a lot of them don't stay around for very long, so you're always having to start all over again. If I was living independently and then you had someone different coming in every day - it would kill the situation. Everybody's entitled to their own life. But, a lot of people get things they don't need. I meet a lot of people and they say - you're disabled, you're not part of the community. But, when it comes to the poll tax and rates - we're part of the community then aren't we."*

*"We have a residents committee. They have to consult the residents before they make any changes. So, we do have a say in how the home is run. I think, with most of us, we mix quite well socially. We don't hold no age barriers but, sometimes, disability does make a barrier. But on a day-to-day basis, I don't really have no-one to talk to all that much. My wife does visit sometimes and, like I said, I go home some weekends. 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 look in the windows 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?"*

*"It hasn't been easy making this place (Spencer Lodge) exactly how we originally envisaged it would be. It's always been a little bit unclear - especially to the staff - because it was meant to be something between a hostel and a home. I think, with the staff, they're not always clear about exactly what their job is. It is difficult to define in some ways, but they often worry more than they need to. I mean, they worry about people - new people when they come in - if they think they're going to be too much for them to handle. I think that has probably got something to do with how we set up originally because the first lot of us who were in here did need quite a lot of help at the beginning. Now, it's moved the other way and, really, we need to have something with a greater mix so that we can take on people who might need more assistance. Otherwise, it's going to end up with only people who can basically look after themselves - which wasn't the original idea exactly."*

*"By the time I decided to move here, I didn't really have that much choice it was the environment as much as anything else. Physically, I'd been getting progressively worse. There was no way I could have had a helper - there just wouldn't have been room. There was all these kinds of problems - which I didn't have when we moved in there. I don't know how I'll be fixed in 12 months from now - I might need a lot more help. But, I want to stay as independent as I can for as long as possible."*

*"I've been here three years now (nursing home). I'm still independent but the main problem you have in a place like this is being able to maintain your dignity. I think it's very important to try and keep your dignity for as long as possible. There are things they (staff) could do - like, you only really need one person to help you with a bath not three - especially when they're just standing around chatting while you're sitting there without any clothes on. Then, when they have new staff, they don't always bother to introduce you. So, you just have this stranger come in and take you into the bath. They're over protective really. Perhaps it's not fair to criticise - but I think there should only be the minimum of help that you need. You don't have to have help all the time - it's too much. I have told them that I don't like the situation. Some respect your wishes, some don't. If they ask you - can we take you to the bath now - then I probably wouldn't mind. But some don't - that's what gets me. I think part of it is because I'm more independent than most of them here - that probably makes a difference."*

*"When I was living at home with my wife - it wasn't working out very well. We were getting into marriage problems, and it was hard for her keeping up with the help I needed. The biggest thing was - I couldn't get the privacy I needed at home. There wasn't enough space - especially when the mother-in-law came to stay - that was the last straw. So, I saw a social worker and they got me into this place. But, I had to come all the way out to Kent because there were no places in Berkshire. They've got all these old people's places, but nothing for disabled."*

*"I do plan to stay here now - I'm quite happy. I would have preferred to stay at home, obviously, but it just wasn't practical. Apart from the lack of space, there was all sorts of problems with the help I needed. Like, transferring onto the stairlift - my wife really couldn't manage it by that time. You get to the point when you just feel like you're in the way. As far as getting help goes, this place (nursing home) is ideal. You've got to have the facilities, and that's what you get. It would be nice to have your own bathroom. When I was at home, my wife used to help me getting into the bath with a hoist. But, she was getting back trouble - that contributed to me going as well. She more or less worked herself to death."*

*Researcher: Did you think about any of the possibilities for you living independently in your own place before you decided to move here?*

*"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. All the*

same, it would have been quite nice. What I wouldn't have minded was finding an ex-nurse and have her living with me. That would have been an ideal situation for me - but would my wife have like it? 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."

"I wouldn't give a fig for living in a flat on my own. I don't think of that as being a very practical option and, in any case, I'm sure I'd just get lonely being on my own. This sort of set up (residential hostel) is ideal for me. Obviously, it could be improved in some ways - I think they should have slightly bigger units for a start - but, on the whole, I'm really quite happy here. The only thing that does worry me a little bit is - the age limit here is 55, so that means that gradually there's going to be a bigger and bigger age gap between the new residents and the older ones. I'm already the oldest one here and it's quite possible we'll end up with a 30 year age gap before I'm finished. But, I suppose you're going to get that wherever you go."

"I can understand why a lot of people want to stay in their own homes - however difficult it might be. I'm sure a lot of people think they've failed in some way if they don't do that and, although I think that's sad personally, it's easy to see why they feel like that. But, for me, struggling to live in a flat on my own just wouldn't appeal. The way I feel about it is - I've got other talents and I don't want to waste my time cooking and cleaning and struggling over every little thing. I'd much rather be spending my time out and about doing things and seeing people, and being here means I'm free to do that. So, what I'm saying I suppose, is that this is 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."

*N.B. The following quotes are from a former resident at a Cheshire Home who was moved (against her wishes) to a nursing home while the interviews were in progress.*

"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."

*Researcher: What kind of extra help did they say you needed? Do you get any different kind of help here?*

"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."

"It's all old people here - I can't stand it. But, I wouldn't take the risk of going anywhere else. If I can't go back (to previous home) I'll stay here. I want to be somewhere with people I know. If I went anywhere else I wouldn't really be any better off."

"I've been here since 1985. I was living with my parents before that, and I'd never been able to have any real independence. When this place started, it was my chance to branch out on my own. It was a good move for me because my parents - they were great, but they were doing everything for me. Here, I'm free to come and go as I please, but I've got the back-up as well."

"It's very handy being here, because - although I'm on my own - my friends and family are close by. I've lived in the area all my life you see. And, if I want to go to the shops or something like that, you're right next to everything you need. I think that's a very important thing - the locality. It's good to merge with the neighbourhood. Some of these places (ie. other Cheshire Homes) are very nice, but they're cut off from the community. I wouldn't like that at all personally."

"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. That's why a Cheshire Home seemed to fit the bill - because it's a home for life. I don't think I'm likely to move anywhere else. Apart from the space, this is my ideal living arrangement really - it is for me, because I like to know the backing is there. I suppose that, if I could find somewhere with the same kind of arrangements but with more space, I might be tempted (to move). But, it would have to be in this area - there's absolutely no way I would leave here because I've been in the area practically all my life - it wouldn't make any sense to go somewhere else."*

*"To be honest, the possibility of going to live somewhere else never crossed my mind until recently. As you know, the whole philosophy of the Cheshire Homes is that it's supposed to be a home for life. Well, I never considered that that might not always be possible. It was (other resident) having to move that put the idea in the back of my mind. The thing about that was - she was deteriorating and they said the couldn't manage her here anymore. So, it makes you think doesn't it - because that could happen to any of us in the end. If the day comes when you deteriorate like that and then you have the thought that you might have to move as well - it seems wrong somehow. I mean, if you're deteriorating physically, that's bad enough - you don't want all that extra worry on top of everything else. You don't know - hopefully it won't happen to me. But, ever since she went it has been nagging away at me a bit."*

*Researcher: So, if you ever found yourself in that situation, you would prefer to stay here and have any extra help you need come to you would you?*

*"Yes, that seems the most sensible way to do it. I mean, the help should be there to help you live your life. But, I think that - if I ever got to the point where I was being forced to make those kind of choices - I don't think I'd just accept it. Having to leave your home should be absolutely the last resort, so I think I'd try and make some other arrangements - maybe trying to get a care attendant or something - so I could stay. That was the whole point of coming here in the first place - to be more independent. You can't just let things happen to you - you have to try and work out what's right for you and stick to it."*

*"When you're living in a house, at least you have neighbours who might be able to help out with a bit of shopping or something like that. Here, they're all too old really."*

*"I'd been in the nursing home for six months when they eventually let me go home. I say eventually because they were a bit reluctant at first. But I told them that - as long as the kitchen was adapted properly - I would be able to manage. So, once they'd finished the work I was able to come back."*

*"It's much easier for me here. There wouldn't have been much point trying to keep on the house on my own. It would have been a lot of extra effort. The only thing I miss is, I would like to have just a bit more space, but on the whole, life's much easier here."*

*"I would have moved even if I could have had a helper I think. Actually I did have a girl coming in twice a week to clean round but - no - I wouldn't have been able to stay, not with the stairs. I'm sure it was the right decision. I'm perfectly comfortable here and I can be pretty self-sufficient in my own way."*

## **THE NEXT STEP**

In highlighting the needs and experiences of people who are ageing with a disability, we have not tried to be particularly prescriptive about how organisations like the Leonard Cheshire Foundation should respond. Rather, we have simply pointed out some of the most important practical implications and highlighted the key issues which older disabled people themselves are most concerned about.

Clearly, then, the onus is on all organisations of and for disabled people to consult with their own older members and to work out whatever strategies they feel are most appropriate to their own needs. However, we hope that we have at least made a contribution by raising the profile of people's concerns about ageing with a disability and pointing to some of the practical measures which are most urgently required.

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## Appendix A: Details of project participants

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### Breakdown of impairments (by gender)

<u>Disability/impairment</u>	<u>Total respondents</u>			<u>Interview sample</u>			
	Male	Female	Total	Male	Female	Total	
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
Friedreich's 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
<b>TOTALS</b>		<b>130</b>	<b>194</b>	<b>324</b>	<b>45</b>	<b>80</b>	<b>125</b>



## Appendix A: Details of project participants

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### Current age by gender and race (interview sample)

	Males	Females	Black/Ethnic Minority	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

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

	Males	Females	Black/Ethnic Minority	White	All		
			%	%	%	%	%
Upto 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

## Appendix B: Dissemination materials produced

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### Publications 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

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 Ageing with Spinal Cord Injury, New York: Demos Publications

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

Zarb, G. (1992) 'Forgotten but not gone: the experience of ageing with disability', Chap. 2 in Arber, S. and Evandrou, 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)

### Main project report

Zarb, G. and Oliver, M. (1993) Ageing with a disability: What do they expect after all these years?, London: University of Greenwich

ISBN 0 900822 04 X

Price: £8.50 plus £1.50 post and packing (Available February/March 1993)

### Briefing papers

## Appendix B: Dissemination materials produced

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`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

`Ageing with a disability in Residential Care', University of Greenwich, Spring 1993

N.B. Copies of all briefing papers and the main project report are available from:-

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