

# **AGEING WITH POLIO**

## **Briefing paper prepared for the British Polio Fellowship**

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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.

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 members of The British Polio Fellowship who have contributed to the project. A total of 65 people who are ageing with Polio have participated following a request for volunteers in the BPF Bulletin. 29 of these have also participated in the follow-up interviews. The average age of this group is 57; they have been disabled for between 27 and 81 years, with the average being 47 years. 40 are women and 25 men.

Following an overview of some of the main background issues to ageing with disability, the views of people with Polio 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 The British Polio Fellowship and others. The briefing paper is organised around the following topics:-

- # Concern about ageing and the need for research;
- # The experience of ageing with Polio;
- # Physical and health problems associated with ageing;

- # Post-Polio syndrome;
- # Health services/health care;
- # Practical/personal support needs;

## **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 people with long-term Polio indicates considerable concern about ageing and the need for more research of this kind. There are several dimensions to this concern:-

\* Many 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 long-term consequences of Polio 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 The British Polio Fellowship to take this further and incorporate members concerns about ageing into their own work.

## CONCERN ABOUT AGEING AND THE NEED FOR RESEARCH (Quotes)

*"I'd just like to say that I appreciate you doing what you are doing. I think that the approach you are taking is the right one."*

*"I read with great interest about your study on ageing with polio. If I can help in any way at all, I'd love to."*

*"If there's anything else you want to know, give me a ring or pop in whenever you like. I've enjoyed it - it's not very often you get the chance to discuss these things with someone and get any sort of intelligent response. 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 hope that this brief account may be of some use to you. It is gratifying to find that there is somebody interested in the long-term disabling effects of polio, and to that end I should be happy to try and provide you with any further information you require in your research"*

*"I was interested to read in the polio bulletin that a survey is being carried out into ageing with polio. I think this survey is long overdue."*

*"I would be most interested in taking part in your survey. If you feel my experiences could benefit your survey I will write more fully in line with the guidelines in the article or volunteer for a personal interview - both if you prefer. I would also be extremely interested in your subsequent findings."*

*"I recently read an article in the polio bulletin that you are conducting a research project concerning old polios. I am very interested to read this, especially as one hears very little these days of polio but no there are many polios around who have had the disability many years, and some are very severely disabled. I would very much like to take part in your survey."*

*"I have found that my shoulders are going - that happened at about 25 years as well. I'm fairly sure that it's arthritis because, as you say, I've just been wearing my shoulders out and I do think that causes arthritis for a lot of people like me. I have a good GP, but I rather think that if I go to him he puts most things down to wear and tear and sometimes I think - well, if someone else came in with the same thing, what would he say? He can't say wear and tear to them. So, I wonder sometimes if these things are just being overlooked because they*

*just think you're bound to get this because of your disability - it's just wear and tear. Obviously you can't have every single ache and pain investigated but I do think they ought to check more. Maybe if they did a check on say all polios who'd had polio for X number of years. They should check up to see whether there's a pattern to what's happening - whether it's the normal ageing process, or whether it's exacerbated by the fact they've had polio."*

*"I don't think the NHS would spend money on this sort of thing for polios because, it's not like spinal injuries where it's ongoing. Polios being wiped out and so that's the attitude that seems to be taken. But they do it in America. There's an argument that, it's done there because people have to pay for their treatment anyway. But, I think they should regardless of whether it's an ongoing thing or not because, we all hope to live to a fairly ripe old age and we'd like it to be as easy as possible."*

*"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 and, by the way, most of the polio victims I know in this area feel the same as I do. Thankyou for having an interest in us."*

*"The main effect on my life is a fear of being older and unable to express oneself as well as being paralysed - especially when you are in the hands of people who don't understand the special needs of polios. It is difficult to say what support I need because I have no knowledge of existing services in that respect. My carer - a housekeeper/companion/friend - is also ageing. We do wonder about the future."*

*"I live alone and do most things for myself and want to be as independent as I can. I do get very tired and frustrated. I used to cycle and walk for miles, which I miss very much as I have to go out in a wheelchair now. I think the medical profession should realise the difficulties of post polio. Doctors do put a lot of the problems down to age which is also very frustrating - at least it is to me, and to some of my friends who have other disabilities. Thankyou for taking an interest."*

*"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."*

*"I read your article (in BPF Bulletin) 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, I'm getting on that phone."*

## THE EXPERIENCE OF AGEING WITH POLIO

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 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 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. This was a particular issues for some of the people with polio who, because polio has been almost completely eradicated, feel that they have been forgotten about completely. However, there were others who felt exactly the same, so this is clearly a more general problem.
- \* 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 30 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, 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. 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 individuals physical well-being.
- \* 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.

\* 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. 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. At the time many of the people we contacted became disabled, life expectancy for people with various disabilities was low. Several 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. Obviously, 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.

\* 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, changing their living arrangements, or having to move into institutional care.

\* 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.

\* 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.

\* 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 loss of independence would be totally unacceptable and that death would literally be a preferable option shows just how important this can be.

## **THE EXPERIENCE OF AGEING WITH POLIO (Quotes)**

### **(1. Early experiences)**

*"I am 60 years of age and had polio at 22 which effected my right leg, arm, shoulders and neck. I was in what was called then an iron lung. I spent 2 years in hospital on and off and then went to what was called the MRU unit 4 times a week - it's now called a physio unit. I was in a wheelchair and was told I would not walk again, and for some reason, would not be able to have children. After 5 years of treatment and ups and downs, I walked with a walking aid. Over the years I had 6 children - and apart from the last 2 they all weighed in at 2.1/2 lbs or 3 lbs in weight, but are all very healthy."*

*"I have had polio since the age of 15 months and I am now 70 years old. I wore a calliper for 6 years and was then put in a surgical boot as my right leg was quite a bit shorter than the left. I attended hospital every morning for a number of years for electrical treatment, so I lost quite a lot of schooling. I learnt to swim and also joined a physical exercise class and used to jump over vaulting horses and use parallel bars. I started work at the age of 14 years old in an office and during the war I was put in a factory examining aircraft parts day and night. I went back to office work after the war."*

*"I contracted polio in 1932 at the age of 18 months - it effected my legs and spine. Because of the determination of my mother, I received an ordinary education and went on to do shorthand and typing and worked at this for 20 years. Then, at 34 years of age, after various hip operations I had to take a sedentary occupation (telephonist), where I spent another happy 20 years working."*

*"It is a long time since I had polio and things have changed, but I was kept inactive in bed for over 4 months with no physio at a time when Sister Kenny was in England with her revolutionary treatment but not many people had the chance to be treated by her."*

*"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."*

*"It was 1918 when I got polio. It was a very rare event in those days - so much so that the doctors didn't even know what it was for quite some time. I was going to hospital for about six months before they decided to send me to Great Ormond Street, and that's where they discovered I had polio. I was very lucky actually because, although I was badly affected and could hardly move a muscle, fortunately my lungs were not affected. Of course, that was before they had developed artificial lungs, so I was very lucky not to die - which is what would have happened otherwise, I'm pretty certain."*

*"Anyway, I went to Great Ormond Street as an out-patient for two years. Then, when I seven, they just said - 'well, there's nothing more we can do for you'. In fact, one of the doctors told my mother that I wouldn't even ever walk again. But, then my mother got me in to St. Vincents at Pinner. It was a very different situation there. The hospital then was run by nuns and they were also great believers in self-help - I think that's probably where I got it from. They were very good on physio in particular. They didn't wrap us in cotton wool - they just gave you your freedom and let you build up your strength in your own time. So after two years in a*

wheelchair, a year later I was walking about with my callipers, so I was ready to go out into the world and make my own way."

"I don't really think of myself as a pioneer, but I can see why some people might think that. No, with me, I think it's just the way I am - I would have been just as determined to get on whether I had a disability or not. I've always known what I wanted to do with my life, and the disability has never been more than an occasional nuisance. By far the most important thing for me is the fact that I've been able to work - I can't stress that enough. I made up my mind very early on that I wanted to have my own business and that's what I've done. In any case, you had to be prepared to look after yourself because, in those days (ie. 1920's and 30's) there wasn't any help - you had to look after yourself whether you liked it or not. So, I suppose it's likely that many of the people who have survived as long as I have with their disabilities have got on because they more or less had to. But, then again, you don't know about those who didn't make it - you don't know what went wrong."

"There wasn't any rehabilitation as such in those days. It was very difficult to know what to do and, anything that I could get jobwise, I had to sort out for myself. I decided that I wanted to work as an engineer and I did find a course. But, when I first went there (to college), I couldn't get anywhere at all. There were steps everywhere - they were only small steps, but they might just as well have been ten foot high as far as I'm concerned because I just can't handle any sort of step at all. So, I had to be carried everywhere - which was a bit of a lark as you can imagine, but I got through it in the end. The funny thing is though, even if it was difficult for the disabled to get a job in them days, I think it's even more difficult for the kids now. Alright, there wasn't many employers who would take you on if you were in a wheelchair - there isn't that many now - but, the ones that did, I think you could rely on them to give you a fair deal more than the employers today. I suppose I was lucky also because I got on the tail end of the Disability Resettlement thingy, so that was help."

"I do think that it makes a hell of a lot of difference what your family situation is - I mean how well off you are. If you take my case - but the same thing applies to a lot of people - we were a poor family, so there was no extra money to get any help. My mother always had to go out to work just so we could get by - and she had to look after us as well. I can remember when I was a nipper, my mother used to get the clothing cheques off of the man from the co-op, and that was how she could manage to get clothes for me and my brothers. I thought even then that it was no way to live. So you've got no money, and you have to work all the hours there is - how can a family be expected to cope in that situation? 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 really suffered when I was a child. My mother was very proud and so she wouldn't tell anyone about me. The polio wasn't even diagnosed until I was over a year old. Then I went to a private school so 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. But the worst part was that I went to a school where they had never even seen a handicapped child before and they just didn't have any idea about how to handle me. For a start, I had to put up with the usual thing of being called a smelly cripple - although most of the other kids just ignored me most of the time. In the end they ended up reporting that I was mentally subnormal because I wouldn't talk to any of the other children. But, do you know why I wouldn't talk to the other children? It was because I was frightened of being knocked over. I couldn't stand very well and I was scared that I would get knocked over in the playground. So, when it was breaktime, I used to wedge my callipers in the sandpit and just sit there - it was the only way I could be sure I would be safe. I didn't want to do it because I used to have open blisters when I wore callys (callipers) and I knew I wasn't supposed to get sand in them - but I still did it, there wasn't anything else I could do."

Researcher: Do you remember much about what you were told about the nature of your disability?

"Not much. I was in isolation for a month and then I was brought onto the children's ward, and I was in a plaster bed for a year. Then after that I went over to the (Nuffield) orthopaedic centre and I was there for another 9 months before I went home. I went back again in '47 (6 years after onset) for spinal surgery. But, you know, in those days there wasn't any preparation for discharge whatsoever then. After 17 months I had some callipers made and they started me walking on callipers and crutches. The emphasis in those days, of course, was very much on walking. There wasn't any thought given to whether ones home was convenient, or aids to daily living."

*"I didn't have any real rehabilitation as we know today - not at all. I went home with the callipers and crutches but there wasn't a wheelchair provided. In those days, one hired a wheelchair locally sometimes but, really, if you didn't walk you stayed in bed. There wasn't anything wheelchair orientated. I did need a wheelchair for distances. I had one for going out. In those days, physio was just muscle massage and general exercises, and OT was just basket making really. That was it. It sounds like the dark ages now, but that was the set up."*

*"Giving birth was a really bad experience for me. With each of my three pregnancies, I was very ill afterwards. I don't mean medically - just totally washed out if you know what I mean. But, you see, it was the same thing again - I was sent to an ordinary hospital and there wasn't any other disabled women there and they didn't do anything to help me. You should be able to go somewhere where the staff know something about disability so that they can advise you on how to cope. I can't believe that my pregnancies had to be as bad as they were - but there just wasn't anyone I could turn to. It wasn't any better when I got home either - just one visit from the district nurse after each one, and that was it. I'll never forget the nurses when I left hospital with my baby. They all stood there watching me walk out with that sort of spaniel look on their faces. You could see they were thinking - look at that poor crippled woman, how is she going to cope. God, it was an awful experience."*

*"When I used to work in a factory (1950s), the attitudes there to disabled people was very nasty - with the employers I mean. To give you an example. We had toilets upstairs for the workers and the managers had theirs downstairs. So, although I used to climb up there it was getting very tough so I asked the Personnel Officer if I could use the toilets downstairs. But she just told me - if you can't get up the stairs you shouldn't be here. That's the kind of thing you have from people - it is very unfair."*

*"When I was seven, I remember my mother pushing me along the Strand and we passed the Pitmans offices; I said to her - what's that place? - and when she told me what it was, I told her - that's where I'm going to go. So, while I was at the boarding school I used to come out one day a week to do this course in commerce at Pitmans until I left there when I was 17. From there I went into a large engineering company and eventually worked my way up to become a director. I stayed there until the end of the war and then I thought it was time I did some public service. I think that, every man at some point in his life feels the need to do their public service, and I wanted to do that. So I became a councillor which was a real education in itself and I stayed on the council until I started up my own business. You see, that was the best thing I could have done because, I had had a thorough grounding in all aspects of business practice which I was able to put to good use. I've been all over the world and made so many friends and I've enjoyed every day. So, I have always had this belief that I was going to make my way in the world and - to be honest - I should say that my disability has been more or less irrelevant. Obviously, I had it in mind that I could make my disability much easier to deal with my being resourceful, but I am pretty certain that I would have done the same things whether I had had polio or not - that's just me, it's the way I've always been."*

*"My mother told me that I had it when I was about five - I'd had it since I was two (polio). There wasn't any rehabilitation - the doctors just told my mother I wouldn't live to see my fourteenth birthday, and that was that. I couldn't walk at all until I was five. I just used to crawl about, but I dragged myself up and taught myself to walk. There wasn't anything else, they didn't even have callipers then (in Ireland in 1930s)."*

*"In the early days, as I've said, disability wasn't really discussed. So, for a long time I almost felt sort of, you know, if you persevered enough with your walking, you almost felt as though you might be - not altogether complete again but, you know. This was the whole thing - you must persevere with your walking. So, for a long long time I thought that, if I tried really hard then one day I might not have to use crutches, or maybe only get away with one calliper. It was a very gradual process that sort of learning that it wasn't going to be like that."*

## **(2. Later experiences)**

*"I was very lucky really in my 20's because, when I had polio I was at least fully grown. It was really strange for some few years. I could almost forget polio. In fact, unless someone asked me if I had a fall or something it did not really effect me and I did not think about the bad limp. About the time I was in my late 40's I started having problems with my wrists, arms and hips. I went to the doctor who said - well of course, it's your age (I*

wasn't even 50 years old) and a bit of arthritis. I looked at him and said - do you think it could be anything to do with having polio and putting a lot of weight on one side. He looked at me as if to say - well I'll just humour her. He said - well dear, you had polio but that was many years ago. But, I was told by my consultant - you haven't had polio, you have polio and you have to live with it. Some days I get up and feel as if I have been at work all night. My leg hurts, my arm and shoulders feel like a ton weight. I'm tired, and I'm still only 60 years old. My mother was still working at 70 years, but I worked until I was 58. I had a stroke - again on my right side."

"I contracted polio in 1940 at the age of 6 months. I am partially paralysed down the right side and wear a full leg calliper and a built up surgical shoe. Although my illness made me slower than other children, when I was young it did not keep me back from participating in most of the games we played. When I became a teenager I would have loved to have been able to jive and do the fast dancers, but alas my leg would not go the way my heart and my head wanted it to. But again, I enjoyed the slow intimate dancers and I met my husband in this way. I married when I was 20 years old and by the time I was 25 I had 3 beautiful sons whom I simply adore to bits. As the years pass I now find in my 50th year I have odd aches and pains in my back, hips, knees and feet which, really, on some days are so painful I just cannot do much at all. Walking is getting more difficult as I tire very easily. I also get awful sore if I sit for too long. My breathing is also causing lots of bother. Going up or down stairs and up or down hills leaves me without a puff - although my heart is sound."

"I have experienced greater tiredness but I wouldn't say I get frustrated about this. I don't think there has been any difference to my lifestyle other than what is common to all ageing people."

"I contracted polio in 1952 3 weeks after having my first baby, my son, who was also affected. I have been wheelchair bound ever since, but wear a calliper on one leg and, with a frame, walk a few yards several times a day."

"I am now 76 and contracted polio at the age of 18 months - left leg. In my experience I have lead a very active life. From a very early age I was encouraged to cycle and swim. I don't think ageing has changed this very much."

"I contracted polio in 1944 while working abroad. After surviving the acute stage, I was shipped home to UK in an iron lung around Christmas of that year. I was weaned from the respirator and spent over a year of intensive physiotherapy at the Royal National Orthopaedic Hospital in Stanmore, by which time my improvement had levelled out leaving me with no use of my legs, weak trunk muscles, scarcely any shoulder muscles, weak biceps, negligible triceps, but nearly normal hands. I have lived in a wheelchair since and continued my profession full-time for 30 years, driving a car with hand controls, and now maintain nearly half an acre of garden single handed with occasional help. I am now 64. Unlike, apparently, many polios I have not yet, thankfully, noticed any deterioration in muscle power since I left Stanmore. No doubt I was lucky in my constitution. It may be relevant that my mother is still living and well at 101. The only negative aspect of passing time that I have encountered so far - but a major one - was the death of my wife 3 years ago after 32 years of outstanding devotion and help. On the positive side, now that I am virtually retired and alone, I am able to devote much time to previously neglected interests and talents, attending adult education classes twice a week and making a serious attempt to improve my painting. I have recently got involved in training schemes for trainee physiotherapists, OT's and social workers, helping with demonstrations and discussions on the problems of disabled living."

"I'm not really a very good representative of disabled people anymore. I did help to get our local organisation started and I tried to stay actively involved for a number of years. But, I haven't been able to keep it up."

"One of the great advantages of polio - if it makes sense to call it an advantage - is that, you get the worst of it over on day one. That does put you in a different state of mind than it would if you knew things were only going to get worse. It must be very different for people who have some kind of progressive disability but, now that I am starting to crack up myself, I suppose I am beginning to feel like that about it. But, then again, I've always felt that I've been living on borrowed time. It's a fairly unnatural way to live like this, and there have been several times when I've almost ceased to exist. So, having gone on so long, I wouldn't mind all that much if I stopped now. I'm certainly not afraid of dying. You see, the medical profession now are beginning to say that they won't give certain types of operations - like, say, a transplant, to people who aren't going to live for very long in any case, or who won't live as long as somebody else who could have the same operation. If that happened to me now - if they said we can give you a transplant and you might live another few years - I would

*say no, I don't want it. I wouldn't see the point in going through that just to extend your life for a short time."*

*"I think that people's attitudes towards disabled people have changed considerably. When I was younger, people just didn't know how to deal with somebody like me, but they are a lot more accepting these days. There is much more goodwill around."*

*"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 do try to tell myself that it's other people's 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 do think a lot of it is because people don't understand about disability, It's alright if you're in a wheelchair - people know how to deal with that. Then they can be all patronising and pat themselves on the back for being kind to you - or feel guilty if they don't. But, what gets me is that, most people with a disability aren't in wheelchairs and so other people can't see the difficulties you have. But when you tell them, they either don't understand or just don't take any notice. I've always said that there should be a national disability week in schools because then, if kids can get used to disability they can take that understanding with them when they leave school - you've got to start to change people's attitudes and I think that would be a great way to do it. But I'm really fed up with the total lack of consideration. Now I want to register as disabled. I know about the problems with labelling people, and I have been against that in the past, but - for me - I want to be registered so that I can make people recognise my disability and get some support. I feel that it's about time I got some help. I've had nothing - just medical treatment when I was a child and boots - that's it."*

*"I have only recently joined the (polio) Fellowship as 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 consider myself lucky in many ways. I enjoy good health although it is a constant battle against overweight. It is not easy to exercise in a wheelchair. I long ago accepted my limitations and have adjusted to each set back. I have had a very interesting career and have taken part in lots of leisure activities. I have travelled abroad and still hope to do so again in the future."*

*"I contracted polio at the age of 6 in 1945. I walk short distances with the aid of two full length callipers and two sticks. I drive a hand control mini and make much use of a wheelchair. I have many thoughts on the ageing process of polio, especially on positive mental approach. The ageing process is with us all, but it should be faced in a positive light. There are many compensations."*

*Researcher: Has the way you feel you cope with your disability changed at all over the years?*

*"That's a very difficult question to answer. I find that, if you analyse the situation too much it becomes counter-productive. It becomes secondary to what you are trying to do with your life, and I think that as long as you stay productive there is no real need to think about it too much. Even so, I do wish I had more energy and more stamina than I do now - those are the biggest problems I have personally."*

*"You think that you are fine and it doesn't bother you any more, but then something happens that makes you think - I'm not so sure. It does still upset me the attitudes some people have. Like when I hear people talking about being a cripple - that does hurt. I can't understand people who say it doesn't bother them. I've always felt that I have to try and prove to people that I'm just as good as they are and I don't think that's really changed - I still feel like that. So there's that side of it. But probably, the worse part of it is the way that a lot of people still treat you as if there was something wrong with you mentally. I do cope with that better than I used to in the sense that I don't let people know that I'm upset - but it does hurt. So, I have become a lot harder over the years because of that kind of thing."*

*"The thing is that, you see, I have never known anything else apart from being disabled. So it never really enters into my way of thinking if you know what I mean. So I can't say I cope any different. There are restrictions, there always have been, but the problems I have now are much more to do with getting older - they're not really things to do with my disability at all."*

*"Health visitors used to appear when the girls were babies because we're both disabled so, immediately, the children are at risk. They soon realised that they weren't of course so that all fizzled out. It's a bit much really. I used to say - what are you doing here? We're not at risk. I mean, I could only take it up to a point. People say some funny things sometimes - particularly when you're both disabled. 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. But then, (my youngest) had this asthma and she looked quite white and a woman stopped my in the shops and said - your child is ill, are you sure you're looking after her properly. I mean, that sort of thing - she wouldn't have said that to anybody else. But, the fact that I was in a wheelchair made her say that. At the time, I couldn't think of anything to say - I was a bit over-sensitive. My daughter said to me later - why didn't you bite her head off and I said it was because she actually upset me and I couldn't answer her back because I probably would have cried and I didn't want to do that because it would have given her some sort of satisfaction. 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."*

*Researcher: Do you think you've got used to dealing with that sort of thing now?*

*"Well, I think I have but then some smart Alec says something and it goes home. You think that people are moving forward as far as disabled people are concerned, but then you think - no they're not. Sometimes, people are quite surprised to find I can actually think for myself, that I can actually talk, that I can actually put forward a good point of view. I can see them thinking that - I'm not imagining it. I do find that a bit galling even now - it's hard to get used to it. I don't agree that you get used to it over the years and it doesn't bother you any more. Obviously, it depends on the type of person you are. You learn how to cope with it better, but deep down it does bother you. It's like the constant use of the word cripple - I find that absolutely awful, I hate it. Sometimes I can even find myself laughing about it until, like the other day - I was in the checkout line at Sainsburys and I heard somebody say - what do you have to do around here to get through, pretend you're a cripple? You know, I immediately froze and I thought - there's no need for that sort of attitude. It's the same as people talk about people who are black or anyone who's slightly different. There's a lack of understanding. I don't think you can ignore it but I do think you learn to cope with it over the years. I mean, I've always been disabled but I don't think that, as a child, I noticed it as much. It's only from my teens onwards that I noticed it."*

*"When me and (my husband) have discussed it, he says it doesn't bother him - which is odd because he hasn't been disabled as long as I have. We came to the conclusion that I get more of it because I've got the children. I meet other mothers and I get odd comments from them which, perhaps, men wouldn't say to each other. Yes, we did come to that conclusion. When the children were little and we used to go out together we used to have the most extraordinary comments, but you have to just try and ignore it and get on with it. But, I'm always conscious of being rude to people so I don't usually answer back. I think of what I could have said afterwards, but at the time I'm so astounded that anybody would have the gall to say some of those things to me that I can never think of a suitable retort. But, it does go on all the time. But, whatever people tell you, I'm positive that it does go home. I mean, I have a friend who's had polio since he was two. He's a very clever man and although, outwardly, he will tell you that it doesn't bother him what people say to him, I know jolly well that it does. I think that it's because he's trying to prove that he's as good as the next person and that's probably true for all of us. This persistent idea that your intelligence is lower than everybody else's - it's really awful."*

*"We carry on working, housework, bringing up a family on weak muscles. I do worry about this as I still have a young son and my husband, and wonder how long I can cope. When I am sitting or even standing against something, I look normal. People tell me how well I look. Of course, I am glad I do but again, the aches and pains do make life hard. You think - if I could run for a bus, or even get on a bus and go shopping on my own without help, walk along the beach - all the stupid things that normal people do. I worry when I keep reading about the water problem. After all it was dirty water that caused a lot of the polio wasn't it. It happened in 1953 and it could happen again. Unless you went through it all you honestly don't know the pain and suffering that goes with it (polio). Your life takes a tumble. I was a manager of a catering firm when I was 21 years old. 6 months later I was at death's door. So, believe me, people don't know what it's all about. To top it all, I got epilepsy 2 years ago so of course I'm not allowed to drive as my fits are not controlled. So again, I ask myself is this to do with the brain cells. Could the weakness and all the falls when I was trying to walk years ago have caused the epilepsy. Before you say no - I have fallen down stairs a good many times trying to walk, and split my head open and had stitches. Why, you may well ask - because I wanted to be normal. I have a*

*wheelchair of course, but I hate it. Life is a challenge isn't it?"*

*"I had polio as a small child in 1943 (age 2). Since 1988, I have much greater muscle weakness and pain. I went to see an occupational therapist. She advised me about doing exercises in my chair and also about all sorts of small aids to make everyday life a bit easier. But, here in France, the social services are the worst in the World. The Occupational Therapist was a voluntary worker working for an organisation like the Disabled Living Foundation but, for my arms I had to see the Occupational Therapist at the Military Hospital. When my muscle weakness started I had a breakdown which lasted for nearly 2 years I felt helpless and got afraid to be at home. Then I went to England for the summer and I came home OK. I think now, that I have to do as much as I can to help myself. I do think that the medical profession should be more aware of some of these problems. I do get very tired and at the end of the day, because things are so difficult - like tidying, cleaning, and making the bed. I have to try and do it all in the morning when my muscles are fresh. Then, in the afternoon, I rest. My quality of life is not very good and it is hard to cope - especially with the attitudes of normal people. What do they think they know about it?"*

*"I've seen something on telly recently about employing your own care workers - advising people about employment law, National Insurance, and all this sort of thing. I think this is something that could be needed to some degree. It's certainly something that I might want to consider one day. The other thing I've been looking at is these home delivery services for frozen foods and things like that. I've discovered that, with a telephone and a credit card I can get virtually anything I need delivered to the door - my clothing, books, records, drink. I think it's good that it's there if needed. I don't want to use it now, because I feel that that would make me virtually totally isolated. I'd become a hermit - I wouldn't get the social contact. But, I feel that when the day comes when - for whatever reason - I can't get out, if these sort of facilities are still about and I can afford it - then fair enough. So then, if I could get all my food and everything delivered, it would just be a case of someone coming in to help keep me and the place clean sort of thing. I feel that this is going to happen, or certainly could happen so if I make all the preparation now - as far as I can do - I think I should be able to stay here longer than otherwise - with the possibility of going away for what they call respite care occasionally, if the situation warrants it. I think that, if you've got the right mental attitude to it and you're mentally stimulated every day, the rest of it is OK. Having said that, you are dependent on neighbours - I've got very good neighbours - and, I think I've got a very understanding doctor. So, it's not too bad, but money is constrained. I mean, any money you can get from public sources is obviously constrained by what they've got. So, all of these things depend on the money as well. What I'm really looking at in adapting the bungalow further all the time is to make self-care in my own home a lot easier for me, and to make caring for me in my own home easier for other people - if it comes to it. This is how I visualise using any capital along those lines. You have to plan for these things. You can't just wait for it to happen because it's too late then. I think that so much of how you react as an individual is down to what's happened to you in the past, what you see around you happening to others - to other older people. You take that on board. You can either shut it out and say it's not going to happen to you, or you can think about it. One thing I have learnt in life is that sods law operates so much - the bread and butter always ends up butter side down on the carpet sort of thing. So, I wouldn't be happy in my own mind if I wasn't trying to take some preventive action to ensure that I can stay here as long as I can. I mean, you can't cater for the unforeseen but, what I'm talking about, is catering for my continuing physical deterioration through the ageing bit. And you've also got to take on board the possibility - although I don't know what you could do about it - of having a stroke or something like that. I mean, if that happened, it's a whole new ball game. So, I don't think you can really consider that - if it's not part of the my normal expectancy. If something like that happens, you have to put everything back into the melting pot. So, with those sort of things, you do have to wait and see. But, in my present situation, I am trying to plan for the future. I've had the opportunity to because - it's like my mother - although she worked all her life she was never in a position to secure a pension for herself or anything like this. She didn't have any financial security for her old age. Then, as a child money wasn't plentiful. I mean, I'm thinking back to the days when my mother had to bring up three boys on next to nothing. I remember when the man used to come round every Saturday afternoon for his money - she used to get the clothing cheques off of him so that she could go down to the shops and exchange them for clothing. You know, I thought even then, there's got to be something more to life than this. So, then to see her when she did retire and she had next to nothing I thought - that's not going to be for me if I can do something about it. This is one of the pay-offs for having worked for one company for all that time, because I've benefited financially from the pension scheme, but, people who chop and change their jobs - they don't benefit to the same degree."*

*"As regards quality of life, I now have to consider carefully where I go. eg. shopping, theatres, places of interest and holidays. I have to think about access and proximity, and find many activities now out of my reach*

*which were not before. I have always swam regularly and continued to do so by starting a special local group."*

*"Anxiety and tiredness - things like my car getting broken into and not being able to get around. These things upset me a lot more than they used to and, the other thing is that I get frightened living on this estate with all the kids always smashing things up and all."*

*"I lost my mother in 1978 and I'm the only one because she was a widow at the time I became disabled. I was living with my mother, so I lived alone after that."*

*"I can't really think about sex or anything since my wife died. I suppose I do still miss that, but it doesn't upset me or anything."*

## PHYSICAL CHANGES/PROBLEMS EXPERIENCED WITH AGEING

Members have reported a wide variety of physical and health problems/changes experienced with ageing. Some of those commonly experienced (eg. arthritis) 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 number of problems/changes which seem to be related much more specifically to long-term Polio. As mentioned earlier, several people felt that there is a need for more work on separating out the consequences of ageing and Polio 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 Polio, it will be difficult for the medical profession to develop appropriate medical interventions.

A breakdown of the kinds of physical problems and changes reported by people with Polio is given in Table 1 below; those reported by other groups of older disabled people are also shown for comparative purposes.

\* While it would be unwise to draw anything other than very tentative conclusions from a sample of this size, there are a number of problems/changes which appear to be closely associated with Polio which should be highlighted for further investigation. For example, respiratory problems, contractures or muscle wastage were noticeably more likely to be reported by people with Polio. There were also a number of problems/changes which appear to have a higher prevalence amongst this group. For example, decreased mobility, arthritis and rheumatic problems, pain, reduced energy levels, problems with shoulders or arms, and fractures.

\* On the other hand, there were some problems which have a lower prevalence, or are even non-existent amongst people with Polio. These include difficulties with walking, sight impairments, coronary disease, drug dependency, bladder or kidney infections, and strokes.

\* Some of the most common problems/changes reported are also very prevalent amongst the general ageing population (eg. arthritis, hearing impairments and reduced mobility). However, the effects of these when combined with pre-existing Polio related conditions are often cumulative, and can have significant consequences for the quality of individuals lives. There are also implications for the provision of practical support which are discussed further below.

\* Several people specifically mentioned the issue of Post-Polio Syndrome. Most who did raise this issue were fairly convinced that Post-Polio Syndrome is a reality, while others felt that their experiences were at least consistent with the possibility of Post-Polio Syndrome. Most importantly, the vast majority of people who had experienced these kinds of problems felt that much more should be done to investigate the late-effects of Polio. Also, that they had had great difficulty in getting others (particularly the medical profession) to take the issue seriously.

**TABLE 1: PHYSICAL PROBLEMS/CHANGES EXPERIENCED WITH AGEING**

Proportion reporting problem/change (%)	Polio	Total sample
Decreasing agility/mobility	57	51
Arthritis/Rheumatic problems	36	29
Increased pain	36	27
Changes in energy levels	36	27
Weight gain/loss	33	21
Problems with shoulders, arms or hands	25	18
Respiratory problems	25	11
Difficulties with walking	21	40
Fractures/dislocations	14	9
Problems with vision	11	22
Problems with circulation	11	12
Asthma/breathing problems	11	10
High/low blood pressure	11	7
Limb deformity	11	7
Contractures/muscle wastage	11	6
Heart problems/angina	8	12
Problems with hearing	7	6
Balance/co-ordination	7	4
Brittle bones (osteoporosis)	4	5
Speech/communication problems	4	5
Edema (swelling of joints/limbs)	4	4
Drug dependency/side effects	4	12
Problems with transfers/turns	4	7
/Cont...		

(Table 1 Continued)

Proportion reporting problem/change (%)	Polio	Total sample
Bladder or kidney infections	4	7
Viral infections	4	3
Muscular atrophy	4	3
Thyroid problems	4	3
Stroke(s)	0	5
Spasms/spasticity	0	5
Spondylosis	0	4
Incontinence	0	3
Scoliosis	0	2
Ulcers	0	2
Headaches/dizzy spells	0	2
Pressure sores	0	1
Epilepsy	0	1
Other(s)	18	13

## PHYSICAL PROBLEMS ASSOCIATED WITH AGEING (Quotes)

*"At the age of 6.1/2 I contracted polio which left me completely paralysed and in an iron lung for 2 years. Eventually I got the use of my limbs back with the exception of the right leg, and also have scoliosis and arthritis in my joints. However, I have been able to overcome my disability and manage to have a reasonable standard of living but naturally not without much hardship. I work a full day, but in the last few years have incurred various medical problems."*

*"I had polio when I was about 13 months old and I am now 52. My disability has got worse over the years and I have been fighting cancer for the last 11 years which makes the disability a lot more difficult to live with. I am married and have two grown up children - but they're not living at home now. My husband is still at work but spends a great deal of his time looking after me. I am in a wheelchair now."*

*"At the moment, I am somewhat housebound, endeavouring to regain the power in what muscles I have left following a fractured femur. I contracted polio in 1949. I am now 72 years old and I am having considerable problems with ageing. As I say, at the moment I am in a nursing home following a fall. I hope to return home fairly soon but it is difficult to say when as I am waiting for a cracked tibia to heal."*

*"I have had this metabolic change about 18 months ago (41 years after onset) which means I have put on a lot of weight and there doesn't seem to be anything I can do about it. It does concern me because I'm pretty sure it will affect my mobility later on. I have found it increasingly difficult to walk or stand for very long in any case, so it certainly won't help very much will it."*

*"With polio, it does affect your breathing because it affects the intercostals, although I have always been asthmatic even before I got polio. The trouble with that is that, I can't lift my arms up above my shoulders otherwise I stop breathing so reaching up for things is a problem. I still do it - because you have to - but I have to stop and catch my breath for about a minute and a half."*

*"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. But, in my case, I'm not sure if it could be connected (to polio) because I am walking. Anyway, I can't lift things - or I can only lift things one at a time, very slowly."*

*"I have been under a faith healer for my arthritis. I believe that something like that is caused by anger coming through your body - well, nobody knows for sure. But, the thing is that, if your body attacks its own tissue - which is what happens with arthritis - then I believe it should be able to heal itself as well. It's not quackery - I've always been very wary of that. But, I believe we have a lot of power to deal with pain, but we don't know enough about our own pain control centres. Anyway, this faith healer - she certainly helped me a tremendous amount. I could feel the difference - there was a definite improvement and I haven't had any deterioration."*

*"It (arthritis) has the most unfortunate effects because I need my arms to pull myself about on my sticks and up and down the stairs and, of course, it's very painful so you don't do as much as you would. It has a cumulative effect because - you use your sticks more and that hurts more, so you walk less and then you get less exercise. So, it's a vicious circle. Also, you have to avoid crowds - unless you have a good strong arm. I just can't manage in crowds anymore - it's too dangerous and I just don't feel confident anymore. So that affects the things you can do in all sorts of ways. For instance, I hardly ever go to the theatre now, which is something I used to enjoy very much."*

*"I have, for the last 4.1/2 years (45 years after onset), had a weakness in this right arm which I'm not able to lift very high now. I did see my GP when it first started, and he just said it was a frozen shoulder. Then I had some physio, which didn't help. I did ask the doctor if he would refer me to someone else, but he wasn't happy although, in the end, the physio did refer me to the consultant in rehab who said - was I sure I'd had polio, was it not an injury? I said that I'd definitely had polio so then he referred me to a neurologist at the Radcliffe and he said that, in his opinion, it was a trapped nerve and it may recover and it may not. He said that, in his*

*opinion, it was nothing to do with disability whatsoever. So, then he referred me to the neurophysiologist who wired me up to all those little machines and things and he said - well, in my opinion, it's an ageing process. It's just the years have taken their toll and no treatment would help. In fact, he said, treatment might make it a lot worse. So, that's been the main change which I noticed very much at once. But, I suppose when one looks back at it you think - was it more gradual? You do something day after day, year after year. I mean, now, I have to have a raised toilet seat. At one time I would never have dreamed of having such a thing - I didn't more or less get help from anything."*

*Researcher: Have you had any other symptoms of ageing?*

*"No, not really. I don't do the walking I used to but I think that, you know, attitudes have changed. I still walk with my crutches, I wouldn't want to not walk. But, having said that, I walk more for practical purposes not because I don't want the wheelchair. I think that attitudes to that have changed a lot. You used to have this emphasis that - you must walk, almost to the point of even if you die in the attempt. This was the attitude in the old days of course. There was such an emphasis - you must walk, it was all walking."*

*"I am now 67 and contracted polio at the age of 32, resulting in weakness in the left foot, right knee, left hip, and right shoulder. However, I was one of the lucky ones and over the years my lifestyle has not been seriously restricted except that I am unable to dance (which was a blow initially) or run. But now I am finding I get far more tired than I should and the polio effected muscles are much feebler than they were with the left hip, in particular, causing a lower back problem which I never used to have. I have great difficulty now in standing up straight. My excellent GP gave me a thorough MOT to see whether there was any special cause for the tiredness, but came to the conclusion that as the weakened muscles are effected by age everything is that much greater an effort. I am not able to walk as far as I could and have had to revert to a walking stick, but otherwise life is much the same. Thankyou for your interest."*

*"I contracted polio when I was 20. I was paralysed in most limbs except the left arm but I made an extremely good recovery and was eventually able to walk without the aid of a stick, but my right side remained weak and I have never fully recovered the use of my right arm and hand. About the age of 50 to 52 I began to notice a deterioration which has been steadily increasing ever since. I have and can still manage on my own, and drive a car but now have an extra brake fitted. I now have to wear a knee support all the time. I mostly use one stick but sometimes - increasingly - I need two sticks. I experience much greater tiredness and frustration and find it difficult to stand for too long, and I find my back needs increasing support."*

*"Although I am not sure how relevant my information will be, I felt I had to tell you what ageing with polio has meant to me. I contracted polio at 20 months and after my early paralysis I became very strong and was able to do everything for myself. All my early life I wore a full length brace and callipers during the day and lay in a plaster cast at night. Until I was 13, when I was in hospital for surgery on my spine. When I was home I still wore callipers for walking, but never wore a brace again. I worked and drove and did everything anyone else would do, until I got into my thirties and I started having trouble with my neck and my right shoulder. Progressively the arm has just got worse and although the shoulder has not moved for the last 6 years, you would never think there was anything wrong with it to look at it. The trouble moved from the shoulder to the elbow, and then to the wrist and hand. Naturally I had to stop working. I am unable to drive my car and I am unable to push my wheelchair, so I use a powered chair. I have had all the neurological tests done this past few years but no-one can tell me what's going on."*

*"Unfortunately in 1985 (53 years after onset), I developed very bad osteo-arthritis 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."*

*"I have been a polio survivor for 48 years and I am now aged 59. I am now virtually compelled to take early retirement. I am in a wheelchair fulltime and live in a local authority bungalow. I drive an NHS invalid tricycle and have been doing so for over 40 years."*

*"I had polio at the age of 14 months, 45 years ago and spent 16 years of my childhood in and out of hospital. I married - my husband has another disability and we are both wheelchair bound - and had two children who are now 18 and 15. Since the birth of our children, I have done everything - housework, shopping, bringing up the girls etc. etc. A few years ago I started experiencing severe pain in my neck, arms and shoulders and for 3*

*years have had to have physiotherapy, which actually has not alleviated the problems a great deal. I have also had problems with numbness in my fingers and have started dropping things. When I present my problem to my GP, though extremely caring, he is obviously quite at a loss to know what to do. He doesn't tell me it's - just old age - I'm only 46. I also find that I have difficulty in breathing and this has been attributed to asthma. I used to have similar breathing problems as a child, but wasn't diagnosed as being asthmatic. Though obviously the doctors should know best, I am convinced that the scoliosis I have due to polio is worsening as I get older and consequently making my breathing worse."*

*"I had polio over 50 years ago and have had to accept early retirement due to failing health - not really the polio - but due to the onset of arthritis, and a hernia."*

*"I am 69 - male - and contracted polio in 1957, that is to say, over 33 years ago. I am lame in the right leg where the muscles above the knee were destroyed, or rather, they were never really there. I cannot run. I walk slowly. I should wear an iron going right up the thigh but, really, it was so uncomfortable and impractical in use and wore out my clothing a lot. I did away with it and somehow managed without. I do fall a lot. For example, recently I crashed - bottom first - into two doors in my home which had to be replaced. For the last 20 years I have suffered from a nervous condition - neurathonia - and have been in two different hospitals. It was a terrible experience - if only that one was thrown into the company of others whose background was so different to one's own."*

*"When you're totally paralysed in the first place, it's difficult to say that anything has changed physically. The major change, I suppose, has been that my energy has been progressively reduced. Also, the other thing is - I have definitely experienced a mental deterioration. It's my memory - my memory is definitely going."*

*Researcher: Have there been any other changes like that?*

*"Well, I've always had problems with my breathing as you can see (iron lung) but I have had a tracheotomy in the last 5 years. The other thing, I suppose, is that I do find I get very sleepy. I usually have to have a sleep 2 or 3 times during the day although - until recently - I could wait until the evening before I had a rest. It's hard to describe really, I suppose it's just a general feeling of depravation - energy depravation."*

*"Over the last few years I have started cracking up - physically, I am starting to deteriorate. I was in hospital in 1985 (26 years after onset). I had septicemia and I was in a bad way. But, I had been having increasing problems with various blood disorders over the last 10 years. The doctor said - we're not sure if we're doing the right thing, but we're going to remove your spleen and, hopefully, that will help. Fortunately, there has been an improvement since then but - with my kind of respiratory problem - the situation is never going to be very stable."*

*"My blood pressure has got bad over the last ten years. Also, I've got fluid in my lungs and that's not helping much with this breathlessness now."*

*"I had a very bad fall three years ago and broke my hip. They had to put a steel plate in the hip. It's all healed up all right now, but I've never been able to walk the same since. It was getting much worse for longer than that, but it got really bad after the fall. I'm forever falling over now - all the time I'm doing that. So I really can't get about very much at all."*

## POST-POLIO SYNDROME (Quotes)

*"I had polio when I was 4.1/2 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. But, I find it very hard to cope. If we could find out more about it (PPS) it would be a help. I think it is very nice of the Joseph Rowntree Foundation to be doing this."*

*"I had polio in 1938 when I was 9 years old (my immunity being low following an operation for appendicitis). Fortunately only my left leg was permanently effected, which hasn't stopped me living a normal life but has made it more difficult. Now, however, with increasing age I have had to curtail my lifestyle. I do not think this is because of the post polio syndrome but consider the deterioration to have been a gradual process caused by falls over many years which have damaged the kneecap and ankle, etc."*

*"I do feel that doctors equate this deterioration with old age. But, watching my contemporaries I find this hard to accept as a valid reason."*

*"Unfortunately my left leg started to go wrong and I had to have the cartilage removed and then the kneecap. In 1976 (55 years after onset) I had a knee replacement, and my sciatic nerve was twisted in the operation and had to be straightened the year after. In 1980 I had to have another knee replacement and am now waiting for a hip replacement. I am in pain all the time for the past 2.1/2 years and my polio leg is getting weaker and things are getting very difficult."*

*"I contracted polio in 1947 at the age of 1 year, resulting in paralysis of my right side from the waist down. I have read several articles on PPS and have even taken them to my GP for her evaluation in relation to my now worsening condition, but was not met with anything more constructive than - it is your age dear and wear and tear. I was advised to learn to live with it which seems to be fairly common advice to polio victims in much the same position as myself."*

*"Although I am only 42 years old, I had polio just before my 9th birthday. Therefore, I have 33 years experience. Because of the damage to my muscles etc., the ageing process seems to start earlier. Also people tend to forget younger polio victims. On returning to my orthopaedic hospital after some years I was told that people who had polio are no different to anyone else in later years. This was told to me by a young doctor who dismissed my aches and pains as normal. I feel that I am experiencing Post Polio Syndrome but it is difficult to prove."*

*"I contracted polio at the age of 16 in 1947 it affected my left side from the waist down only. I say - only - because, lately I have had tests and seen a consultant about wastage of muscles and tiredness in my arms - the left side especially. I was told I must have had polio in these areas and not noticed. When I mentioned PPS I was made to feel like a time wasting hypochondriac. I pressed the point that - if it was wear and tear would it not likely affect the right arm and leg which have done twice the job they were meant for? I use a stick in my right hand. I was told that this was not necessarily so. But, I can no longer unscrew bottle tops, fasten buttons, etc. - and I frequently drop dishes. So, if I can be of any help to you as a volunteer, I would be quite willing."*

*"I am now 62 years of age and have had polio for 48 years. Over the past 3 years I feel I have aged more rapidly than previously, including a prostrate operation and a trembling in my right forearm - both of which were suggested as being the result of having had polio."*

*"I know a number of polios who are experiencing deterioration with their breathing. Having lived with the same kind of problem for so many years, it doesn't surprise me that things are starting to go wrong."*

*"I had this operation in 1986 because I was suffering from carbon dioxide deprivation. I don't really know what caused that. Since then, the only movement I have left is a little bit of movement in my left thumb and that's it. It's like having a stroke - that's probably the best way to describe it. It wasn't a stroke - it was just like I would imagine having a stroke would be like. But, the question of post polio syndrome is very difficult to establish. As far as the medical profession over here are concerned - you'll find that the idea is generally dismissed. It's a fine line between what is ageing and what might be the effects left over from the polio. So, it is*

*very difficult to answer but, I suppose, it's only logical that there will be an acceleration in the way a person will deteriorate physically - if they do deteriorate."*

*"Whereas I am 67, I do not feel old. But I can comment on the process of becoming older. I got polio when I was 16, in 1939. I spent several months at the Royal National Orthopaedic Hospital until well enough to go home. There was no follow-up except for a 6 monthly check-up with the surgeon. So, my family arranged private physio and in due course I became able to walk with two sticks. My right leg regained some strength but the left has always been flaccid. I don't use callipers, as once up on straight legs I can walk with a swinging movement. I eventually went to train for social work. I got a diploma and worked for 31 years as a medical social worker. I retired aged 55 on health grounds - the corridors of the hospital got longer and longer. By then, what is known as PPS had caught up with me and my muscles were getting weaker or giving up altogether, and limbs which had seemingly been unaffected became painful and weak. About 5 years ago I gave in and accepted that I would be better off with a wheelchair. I already had a Ministry of Health Invacar which I still use. I now use the wheelchair all the time, although I can still get around on sticks if necessary."*

*"I have read about this post polio syndrome in the bulletin, but I can't really say if it applies to me. The only thing I have noticed is that, I have become a lot less mobile in the last 5 years (ie. 76 years after onset). My wife noticed it first actually - then I started falling all the time. I had a calliper fitted. That solved the problem with falling but, as far as being able to walk, it probably made matters worse. Now, I can only walk a few yards with a stick, and that's as far as I can go. I would imagine that's indirectly connected to polio because my left leg was always weaker because of that and now, it's even weaker still."*

*"I certainly have experienced more physical problems with age and I do think that these must be related to having had polio for so long. But, whether there is a need for more medical research, the answer to that is - I don't know."*

*"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 was on these cortisone injections for some time because of the pain in my shoulders, but I've stopped them now. I do my own exercises instead and that seems to do me a lot more good. I mean, it's more painful at the time, but I do feel better afterwards - so I'm going to keep that up as long as I can."*

*"I am now a widow 67 years of age and living alone. I contracted polio in 1953 when I was 30 and was married with 3 young children. I was initially paralysed from the waist down but was ultimately left with one fairly strong leg, the other partially paralysed. I also lost the use of half my abdominal muscles. I have had two operations on my foot to help to alleviate problems of dropped foot. These have helped in some respects, but not others. I have had a number of falls over the years and this results in reducing the confidence in walking and appears to increase the weakness already present. I believe that the normal ageing process leads to muscle weakness, and where these muscles are already weakened by polio, the ageing process is very much more apparent. But, the loss of my abdominal muscles, I feel, has been a greater handicap than the leg weakness. It is now causing me greater fatigue and difficulty in holding my back erect."*

*"I have had numerous X-rays to see if I have any bone problems. But personally, I think it is more like muscular problems. Doctors seem to excuse everything as being either in my head or exaggeration. But, I have never been one to complain about my having polio and have always fought to keep as fit as able bodied people and I know that I am definitely getting weaker as I get older. I definitely think there is a post polio syndrome and I do not think doctors take enough notice of what post polio victims tell them of their symptoms. Doctors in my area seem to think that, because I have had polio all my life I should just get on with it and make the most of what I can do, but I think more help should be given to us. If we had suddenly caught something like Muscular Dystrophy it would be different. These victims seem to get all the help and aids they ask for and, to my mind, there is not much difference in the illnesses and how they effect people. But, because MS is a relatively new illness more attention is paid to them."*

*"I think it's true that the doctors don't seem to take the idea about post-polio seriously - well here they don't anyway, because they do in America and Canada. I don't know, maybe they just don't understand it, so they*

*pretend it doesn't exist. But, I did show these articles I had to my doctor and he did at least say he'd have a look. Also, the other thing I did was, I took a photocopy down to the osteopath I was seeing and he put it in their files for reference."*

## **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 Polio is erratic and that, in general, there is a lack of appreciation of the problems they face amongst the medical profession;-

- \* Some people complained about the lack of specialist clinics for people with Polio. As many disabled people find travelling more difficult when they are older, getting to clinics is also a problem (particularly for people who do not live near large general hospitals, or the teaching hospitals and specialist units in London).
- \* Some members felt that there is a lack of routine check-ups for people with Polio, 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 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 Polio, and very little understanding about the long-term effects of Polio 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 Polio; 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. It is also significant that some individuals had actually volunteered to participate in the study in the hope that we may be able to advise them on the problems they had experienced because they had been unable to obtain this support anywhere else.

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

*"The whole problem is doctors and consultants don't really know what polio is all about. I also have a bowel problem which over the years I have coped with (again caused through polio) but now I have a lot of pain and problems. It isn't old age - it is caused through polio."*

*"I think that, if you have not already done so, you would find that getting in touch with Dr. Geoffrey Spencer of the Lane Fox Unit at St. Thomas's Hospital would give you valuable information. Though nominally a respiratory unit, it does deal with polios problems of all kinds - physical, mechanical, and social, and is beyond praise."*

*"My doctor has been co-operative in that I am now waiting for an operation on the ankle. I was able to be referred to the specialist of my own choice in a different city."*

*"Our needs are many and various. Services could certainly be more helpful. The medical profession is totally out of touch in being able to alleviate our predicament. They do not understand it - I have met only one doctor in the last 15 years who knows how to test a polio. We are fobbed off as a dying race. Far more incentive is needed in this sphere."*

*"I have nothing but the highest praise for the health services. I've always found that there has been very good links between the hospital and the local nurses - and the social services. You see, anything we need, it's always on the end of the telephone line. That's the key really - if you can get advice when you need it, and any assistance you need - then you don't have to worry. But, I do appreciate that it's not always like that for many people. You do need to have the get up and go to make the system work for you. I do think that a lot of disabled people nowadays - especially some of the younger ones - they perhaps expect too much to be done for them. But, then again, it takes a while to get on top of the situation and find out how to get all the information and help you might need."*

*"What I would really like to see is a national polio hospital. I wouldn't mind how far I had to travel. I do think you need somewhere you can go where there are doctors and nurses who know about polio. I don't just mean for treatment of polio conditions - if I need to have an operation or anything like that I want to be able to go to a hospital where I don't have to worry about the staff not knowing what to do with me, which is always the*

worry you have in hospitals. I've always wished there was somewhere like that."

"The only thing I would worry about is isolation. I think we should have been informed about the possibility of passing it on (polio). I suppose they didn't know enough about it then (1910) but, all the same, it makes you wonder how many people have passed it on to their families over all these years."

Researcher: Are there any ways you think the health services could be improved - either generally or if there are any specific services you would personally like to see?

"Oh, most certainly. The first thing is that, you need to have a policy for the health services which is directed much more towards helping disabled people to lead productive lives and to be able to help themselves. I think this is relevant in various fields. There has to be a way to make it easier for severely disabled people to get out of hospital - to make it more realistic for them to live at home. What's needed is more motivation and encouragement to people to find work and have a productive life. And, you know, there is so much in the way of technical equipment which can help people to do this - but it needs to be more widely available. The most important thing is that, there should be employment legislation to replace the present system - the 3% quota - was something which has teeth in it. The present system - employers just laugh at it. Also, I think it would be a good idea to have an extension of the disabled workshop schemes, setting out more opportunities for employment. Above all, there is a need to get disabled people to be productive, self supporting, and tax paying - to give them self respect. And dignity."

"I haven't really had any contact with the health services apart from the odd visit to my doctor (GP), so I can't really comment. The only comment I could make would be about the unfortunate attitude of some of the staff at Highfields (hospital) where I used to go to get my splints checked. The problem I had there was that they didn't have any disabled parking bays near to the main hospital itself and that used to worry me because I couldn't get in very easily. So, I used to have an arrangement to pick up my splints at the porters lodge until they told me I would have to go in to the hospital and get them myself. I explained my situation but they would just say the had to follow rules - there wasn't any common sense at all. So, I eventually stopped going there. It's just lack of consideration isn't it - it's very distressing."

"The doctors don't realise what a strain it is. The hospitals are not equipped to look after long term disabled without hoists, beds, and toilet facilities. No matter whom I see they all say - but you're young, you're not old. I wish they knew how I feel."

"I haven't consulted doctors for perhaps 60 years for specific polio problems. But lately, when I have mentioned any such weakness I have invariably met the - that's the cross you have to bear - response. As if I didn't know."

"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."

"I don't have much need to go (to hospital) but I would go to some physio if I could get such a thing. I'm thinking, maybe if I could have some kind of exercise it might strengthen up my legs so I could walk a bit easier without getting so breathless."

"We have physio three times a week (at home). We do it ourselves - my wife and the helpers - just moving my arms around and things like that to stop all the joints seizing up. It was organised by the community nurses."

"I go whenever I need to, but I don't see that there's any need to have a check-up on a regular basis. If there was anything wrong with me I'd know about it."

"I go to St. Thomas's for a check-up whenever I need to. I suppose I do go fairly regularly - but it's only when something is wrong."

Carer: "It's an ideal arrangement - we just ring up and they always see him right away. It certainly is very important that you know they're there when you need them."

"We're very lucky here. We have this wonderful clinic for over 55's I think it's quite a unique set-up. It was the

*brainchild of this doctor - Dr. Madison. He was the medical officer of health for the district, and it was his idea to get the clinic going. It's run at the (local) hospital. They give you a thorough check-up every 15 months or so, but if you're older, like in my case, you go more often - maybe every three months. They give you a really good check over and, if there's anything worth noting, they get on to your own doctor or whatever. We both go actually. It's really good because, even if there's nothing actually wrong, you know you are being looked after so you don't have anything to worry about."*

*"I don't really want them (check-ups) not unless I had some particular problem."*

*"I've got a very good doctor, but she knows very little about polio - nothing at all really. But, she is pretty good - not that I ever need to see her all that much. Now, they're supposed to do these check-ups for everyone over 75. She knew I couldn't get to the surgery, so she came to the house instead. I didn't even ask - she just came anyway."*

*"Doctors - they've got no idea. Most of them are too young to even remember polio - they don't know a thing about us. We don't get anything - I really need physiotherapy, but I can't get it."*

*Researcher: Have you ever used the district nursing service?*

*"I used to - but they always wanted to work at their hours, and that wasn't very practical. If I wasn't working and having to keep to a timetable, I would probably ask them to come in. But, they take so much time when they're not used to you, so it wouldn't work very well in my situation."*

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

Like many other groups within the ageing population, people with long-term Polio 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 people with Polio may need additional practical support in the form of assistance with transport; domestic help with cleaning and shopping; alarm calls (particularly for people living on their own); provision of mobility aids; district nursing services; day care facilities; and, in several cases, personal assistance.
- \* A few people had, or were considering, making changes in their living arrangements and this most often meant moving to warden controlled sheltered accommodation; along with other groups of older people, however, there is often a problem in finding sheltered accommodation at an affordable price; also, the standard of back-up cover available is extremely variable. Some people were very concerned about the possibility of having to enter institutional care if they could not obtain appropriate support at home. 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 The British Polio Fellowship and other voluntary organisations to act as 'information brokers'.
- \* Some older people with Polio (particularly women) are themselves giving personal support to other family members (who may also be disabled). This is always likely to become more difficult over time - even without the additional problems which may be associated with ageing with a disability. Some people have also highlighted a need for practical support to families and back-up for informal helpers; several are concerned about the additional strains being placed on their families by the lack of such support.
- \* Some people highlighted various problems relating to information about, and eligibility for, disability benefits. There appears to be a lack of accessible advice on benefits and it is quite likely that some members are not receiving benefits to which they may be entitled. Obviously, this is an area where additional support and information could be given to members by The British Polio Fellowship.
- \* There are also problems with claiming benefits and some individuals reported having experienced considerable difficulties in establishing their entitlement to benefits such as Attendance Allowance and Mobility Allowance. Delays of several months are not uncommon and one or two people reported struggling over several years in order to establish eligibility to benefits. While this is a common problem for many groups of people, the situation is also a reflection of the lack of knowledge about the long-term physical/health consequences of ageing with Polio discussed earlier.
- \* Some individuals specifically mentioned the need for 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, not just for people with Polio but many other groups also; 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.
- \* There is also a clear need for organisations like the British Polio Fellowship to engage in a more pro-active strategy for responding to the needs of older people from black and ethnic minority communities. As mentioned earlier, 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)**

*"As to your question about the practical implications. I do anticipate that I will be using a wheelchair within the next two years. I don't mind all that much because at least it will improve my mobility. Having a wheelchair will widen my horizons in some ways, and narrow them in others - you have to make some compromises. The other thing I am doing is that, I have applied for a permit to have a lift put in the house. I already have one for the office - I've had that for a year or two now - but the house is listed, so I need to get permission for that. I have all that in hand at the moment.*

*So, I am planning ahead. I think that is very important - I've always done it all through my life. It is essential, I think, to try and anticipate the changes that might come along - and to accept what is likely to happen."*

*"I don't really need any help. I do have somebody come privately for 2 hours on a Saturday morning, but that's all the help that I have."*

*Researcher: Do you see a time when you might need more help - as you get older?*

*"Well, I am a great one for independence but I suppose the day could come later. I haven't thought about it very much - I don't want to really."*

*"I think I would be very reluctant to lose it (my independence)."*

*"I do have a home help for one hour a week since the PPS came on. I only have one elderly sister who lives near and she is now finding it very difficult man handling my wheelchair - hence, I don't get out much."*

*"I do get tired quickly and frustrated - even in the house, as I must always remember that my ankle is liable to give way much more easily now and so I am always under stress when doing housework etc. A few years ago I was given a calliper but, for it to be even a little successful it has to be worn very tight which interferes with my circulation, so it has been discarded. Stairs - or even single steps if they are high - cause problems but can be coped with if there are good hand rails as I use my arms much more than an able bodied person. Getting in and out of the bath gets more difficult and is sometimes impossible when away from home in a strange bathroom. At the moment we live in a house but perhaps in the future I shall need a bungalow. When going out socially I do have to consider whether I shall be able to cope with any walking etc. but small things can be a nightmare though normally my husband is with me."*

*"I contracted polio in 1916 at the age of 4. After a childhood of hospital, surgical boots and callipers - when I left school I refused to wear the orthopaedic gear and have since lead a normal life. I am almost 79 now, recently widowed, with 5 married daughters. I live alone in a largish house and have always done my own chores. Since April last I have an official home help for 2 hours weekly. I have never received any financial help or grant from any source. In very recent years I certainly have had great difficulty in walking. I forgot to mention that polio left me with my left leg wasted. I have arthritis in both hips and very bad circulation. Footwear is my greatest problem. NHS surgical shoes are unwearable and the one time I had a pair made to measure they cost in excess of £100. My idea of bliss is a pair of shoes that don't hurt. At the end of a long life being independent, I now feel that I would like, say, an electric scooter and have been taken by a daughter to look at some. To a little old lady of 78 - who finds changing a fuse or putting together a mincing machine too technical - the scooters are a bit forbidding."*

*"The greatest thing in life for a disabled person - if it's a disability of the lower limbs - is mobility. The most significant change in my own life was getting a car. People used to laugh at the idea of disabled people driving, but I was determined I was going to because I knew that I wouldn't be able to lead any kind of life without my mobility. And, apart from that, it makes you feel more confident - when you get behind a wheel, you're equal to anyone else aren't you."*

*"Things have improved since the 1930's - you do have parking bays for disabled drivers and things like that which weren't heard of before. But there is still room for improvements - people should never be complacent."*

*"I think it should be pushed across that there are still no concessions for disabled parking in the City of*

*London and the West End, which I do think is discriminating unnecessarily. Because of my business activities I need to visit the City quite often, and I still have to get a dispensation from the police every time I want to park - I do think that is unnecessary. But, as for the West End, I just don't bother anymore unless I absolutely have to because I need to be able to park right outside wherever I'm going otherwise I'm in trouble."*

*"I do get adequate financial help but I could do with more practical help. Also, there are no social activities for a person of my age group."*

*"I live alone and cater for myself but I do have someone to do for me once a week. I do my own shopping where it is physically possible. I have to ask a friend to shop where there is no easy access. Holidays now need careful planning. Access information is essential. Our needs as disabled people are not yet all satisfied but, when I look back, I see that we have it much better now."*

*"All my present independence and the activities that go with it are totally dependent on two things. Firstly, the various social services and especially until recently, the district nurses and now, the home care people. Secondly, improved technology - electric wheelchairs and ceiling hoists, and my car - which I can drive from my wheelchair, and of course such common place things as microwave ovens, automatic washing machines, tumble dryers, and deep freezers. Not forgetting security lights, remote control doors, and cordless phones. But, all this costs money - from whatever source. Although reason tells me that the sands are inevitably running out, present circumstances leave me to anticipate an expansion rather than contraction of my life - at any rate, for some time to come."*

*"I have to take several tablets a day. Were it not for the punctilious attention of my wife, who sorts them all out in egg cups, I don't think that I could manage. I have a very good wife. It is a trial for any women living with a limping man who is now also doubly deaf, but somehow she seems more resilient than ever. Maybe she has gained an insight into the troubles of life."*

*"Since I couldn't get about so much I have had problems getting out of the bath - it's just too dangerous for me because I'll fall and split my head open. The social worker recommended that I should have a shower unit put in so I could manage on my own. The OT was supposed to come and see about it but she hasn't even been round yet. I've been waiting for two years now, so I don't know when I shall get it."*

*"All this obviously makes me very frustrated. I am slowing down and I don't want to. If I hadn't had polio I would be considered a fairly young middle aged. I do get extremely tired and have just had to agree to having a home help, who comes 1.1/2 hours a week to do the floors. I do not want my children to have to look after me. The eldest has just done extremely well in her A levels and is trying to get into college. They must have the chance to lead their own lives. I have an active mind and become very frustrated if I cannot keep it occupied. This is helped a little by the fact that I work voluntarily for the local disability organisation (DIAL)."*

*"The Polio Fellowship is a great strength and encouragement to me, especially the bulletin. As you can imagine I get very lonely at times now I'm on my own, with my relations quite a distance from me."*

*"I did ask if I could have an intercom, they told me I couldn't have that because I can still walk. But, I didn't just want it for that - it's just that I'd feel much safer if I had something like that there. But I don't think they understood that."*

*"I don't need any extra help at the moment but I will later on. I know that I won't be able to manage the stairs indefinitely so I will want to get a stair lift. I think that would be easier than moving house. I might want an alarm call, but that would depend on the situation when I'm older, and it's quite possible I might need to use the Home Care service. I already have a home help, but that's from a private agency at the moment. It costs me £26 a session (3 hours) and I don't get any assistance for that. The trouble I have with home helps is that, when one leaves, you get this great gap before you can get another one sometimes. I would prefer to have a social services home help, but of course they say I don't need one because I've got my daughters here. But, when they're gone, I think I should be able have that. The other things - although I don't want it myself - is that I think we do need a lot more day centres and luncheon clubs - there is nowhere near enough and they are badly needed."*

*"There are more and more places these days where people are getting together to find out about what help is available so that can be passed on. I mean, there's organisations like DISC (Disabled in Camden) and that's a*

*very positive step. But, I don't think it's always so easy for people to find out about them and, with a lot of people, they don't necessarily have the confidence to go looking for themselves - so they just put up with it, they don't have very high expectations. But, the worst part of it all is that the social workers and OT's - who should be helping people - they are the most ignorant of all when it comes to the needs of disabled people. In my job the people I work with don't have a clue when it comes to disability - and they don't want to know either. Just about everything I've had to find out about myself - or it's things I've found out from other disabled people. But, if there's just you, you can't possibly know everything that's available so people are missing out."*

*"All of the things we used to think about social workers - they're all true. They don't understand disability and most of them don't want to either."*

*"I have a lot of trouble finding shoes I can wear, but the orthopaedic services these days - they don't seem to have a clue. You used to have people who understood the problems but they're all ancient now, and the new ones don't seem to be trained very well. You'd think you could get a decent pair of shoes or boots wouldn't you. I mean, that's what they're supposed to do but they are pretty useless on the whole."*

*"About 5 years ago, my right leg got broken. I was in plaster for 10 months and then in a night support for another 6. I was diagnosed as suffering with osteoporosis and the leg is still extremely painful. My left arm is weakening and I am experiencing much the same pain and discomfort with it as I did with my right. Much of this year I have spent in hospital unable to breath. I am on oxygen every night and have to have night nurses and day care 7 days a week. The slightest exertion leaves me in fits of coughing and some days it is so difficult to breath. I am unable to do anything at home and on top of everything else, I wonder if it is all worthwhile. However, the struggle I am having with my health seems nothing in comparison with trying to provide care to keep me in my home. I use an agency to provide care. I receive some help from the Independent Living Fund, and between them and the home helps, I have to pay £80 a week from my benefits to enable me to stay at home. The financial strain is terrible - robbing Peter to pay Paul - every week just trying to pay your way and keeping your head above water."*

*"He (caretaker) is really good looking after me. He's always popping round to see if there are any odd jobs that need doing. It's not his job to do that but he's just very friendly - everyone knows him and he'll always come if I need anything."*

*"I'm helped mostly by my wife, and we have three local people at the moment who help her with getting me up and all the personal bits and pieces. I am extremely fortunate because, in addition to my attendance allowance, the District Health Authority pay for 36 hours a week so we can have the extra helpers. It is rare for a health authority to make that kind of arrangement I know. Actually, when we started I think it was unique at the time. But, the thing is, I think they realised that they were saving money because, otherwise, I'd have to be in hospital and that would mean being in an intensive care unit all the time. So, it's saving them money and, of course, being able to stay at home means we have a vastly different quality of life."*

*"The back up is absolutely vital. But, there is hardly any support available at anything like an affordable price. I have to have two care attendants all the time. Now, St. Thomas's supply one worker - that's no way near enough, but it's a lot better than nothing. Also, it's hard to get people because the pay is totally unacceptable for the hard work they have to do."*

*"The lady I have living with me has been here for 25 years now. So, the arrangements I have are pretty permanent. The only additional help has been when I employed the daily part-time helpers - that's only been in the last few years."*

*"It's all the rage now - to have people stay at home. I think it's right that that should be a priority. Whatever can be done to make it possible, then that's all the better. There is a lot of goodwill to draw on, and people should try and use that. But, you have to recognise that it's not always the easiest option. I mean, here they have been closing down homes for the past few years. I'm not sure if that's necessarily the wisest thing to do - especially with the number of older people rising all the time."*

*"They (health services) don't help you. When I was going into hospital, I needed an electric wheelchair for when I came home because I wasn't going to be able to use my hands. I couldn't get one and we couldn't afford to buy one, we couldn't even afford to rent one. We didn't know what to do. We're quite close to (local)*

college and we used to have some of the boys from there come and help do the garden and a bit of decorating - we've had them for years. It was only through them taking back this problem to the college - they came back and said, we'll pay for you to have this chair for the time you need it, that I was going to be helped. Otherwise, goodness knows how I would have managed. I'd have had the indignity of having a home care person coming in to lift me off the loo and into the bath, and all the rest of it. I didn't need that. I needed to be able to do things for myself, with the right sort of chair. As it happens, I didn't need it in the end. But, it was nice to know that somebody was willing to help when I was so stuck because the powers that be weren't."

"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."

"The help there is - there isn't much of it anyway - but, it doesn't really seem to be set up to make your life easier. I mean, there's an example where I just needed help for six weeks. There should be a system whereby you can get the help just for a temporary time."

"I believe in the gospel of self-help. I'm a firm believer that - these days more than ever - the opportunities are there for disabled people to make their own opportunities instead of waiting around for hand outs. Unfortunately, the difficulty is getting the right attitudes in people. I'm afraid too many of the younger ones today are too keen to take the soft option. I've never wanted to know what somebody can do for me - only what I can do for myself. That's one of the reasons I left the Polio Fellowship actually. They always seemed to be saying - now, what can we get? - they weren't really promoting the idea of self-reliance."

"People are very kind in my experience - as long as you are not awkward, which I'm afraid to say a lot of disabled people are."

"I'm very lucky with the help I get from my neighbours especially. She (neighbour) call round at least once a day to see if I'm alright and to check if I want anything from down the shops, and all this kind of thing. That's one of the most important things when you're disabled actually - so much of it is down to the help you get from your friends and neighbours - and your family of course, although that doesn't apply in my case. I am very, very lucky like that."

"We have our helpers for 36 hours a week. So, that means that my wife has to be around for the other 130 hours a week every week. Of course, that used to be impossible for one person to manage on their own because the respirators used to be so unreliable and it just would have been too dangerous. But, even so, she's had to do that for 30 years - she's always had that constant pressure. It really is the great if in our life - my wife's health. Provided she keeps it, we'll be alright."

"I've never been afraid to ask for any help if I needed it, and I am lucky that I've got such good neighbours. But, at the same time, I don't think you can expect people to do something for you if you don't try and give them something yourself. Alright, I can't do a lot of things like they do for me, but I like to think I can give my time and my friendship. So, if nothing else, I do try and make sure that I am good company to be with, and we do get along very well."

Researcher: Have you thought about the possibility that you might want some help with your personal care, or has that not crossed your mind?

"I have thought about that, but I don't quite know how I will respond to that. 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, I don't think I would be able to stay here unless I could afford - or, unless between us the State and I could afford - for 24 hour nursing. I don't know what my reactions would be to that sort of situation. It would really have to be 24 hour care, because, if I got to the point where I was totally dependent that would mean - alright, you've gone to bed, but you might still want to have a pee or have a bowel evacuation, you know - how do you do that? To me, I think the most demoralising thing that's ever happened during my lifetime is accidents like that - you know, where you have to sit in your own mess or something like that, or lay in it. To me, that is -

*I find that highly indignant that I should be put in that situation. But, 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."*

*Researcher: Would that be in preference to going into a home or something like that?*

*"That would depend on the home. If it's just going to be a place where you're sent. I mean, can I ask you a question - have you ever been recently in a general purpose geriatric hospital? They stink - don't they. The people who work there - they're caring people, and they want to help - but, quite honestly, I don't think I want to end my days in a situation like that. I don't think that people should have to. What you can do about it, I don't know because - a lot of that, what's happened - has been due to the breakdown of the family unit in the last 40 or 50 years. I mean, whereas before your family units used to stay together more, they don't now. So, you've got that, and the fact that - through medical science - the disease and illnesses that used to carry you off so you only lived to your three score and not your three score and ten, have been defeated - but you're faced with another set of diseases which are possibly more disabling. You know, I mean things like this Alzheimers disease and people who suffer strokes. I personally feel - what I'm trying to say - is that society tends to forget that the partner of anybody that's suffering from anything like that suffers just as much, or if not more. They've got all the additional worry and all the additional physical demands as they're getting older and their strength is fading. Some of these people virtually end up killing themselves looking after their partner. I don't know what the answer is quite honestly."*

*"Unfortunately we're not eligible for the Independent Living Fund. But, if there was some kind of system where we could employ someone ourselves - something like with the Independent Living Fund - that would be a great weight off my mind. Because, obviously, the girls (daughters) won't always be around. We want to be independent when we're older and we wouldn't want to have to rely on them in any case. Personally, I wouldn't worry about the responsibility of being an employer - I could handle that if it meant having the right kind of help. It is something we've talked about for the future, but whether or not we'll be able to depends on the money really. We'll just have to see what happens."*

*"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 wouldn't bother me at all if I had someone living in. Well, up to a certain extent. I mean, it would be difficult for the helper because, obviously, they need a certain amount of time off themselves. So, in some ways, you need two people who could rotate if we needed that much help. So, in a way, it would be better if they lived out and you had two or three on a rota. But, whatever you do you've got to have privacy. I've got a thing about privacy - I think you need it, everybody needs it. So, in a way I'm going back on what I just said because if you've got somebody living in you don't have the same amount of privacy. So, I don't know what's the answer to that."*

*"I have a theory that, if you're going to live at home and you need to have helpers to allow you to live at home, then you have to do the hiring and firing - even if the money is coming from the health authority or anywhere else. I don't want to have to be ringing up some nursing organiser and always asking - can they come then, will they be able to do this or that. With the arrangements we have now, the buck stops here - and that's how we like it. All we need is the financial assistance and we're alright. In any case, for someone like me, a respirator dependent polio, you do need to have people with very specialist skills. Now, the local people we've had have come in with very little experience usually. But, they turn out to be very highly skilled by the time*

*we've finished with them."*

*"It does take quite a bit of arranging because I need to have someone here every moment of the day and night, mostly in case something goes wrong with the respirator. But, if I have people helping me at home, I don't want them sitting around reading a book or whatever just waiting for me to call. So, the helpers we have now - they all have specific jobs but, whoever we get, we always stress that they need to have a high degree of flexibility because things have to be done in a particular way. Whoever is here at the time needs to be able to deal with whatever comes up. So, although it's organised so that everyone has a particular job, all of them are interchangeable as well. If my wife wasn't around to arrange everything, it might be very difficult. If I was on my own for any length of time, I would need to have three people here during the day and two at night. If I had to organise all of that myself and take care of the employment arrangements -I'm not sure whether I'd be able to cope with all of that. I think I'd have to say that, if I was in that situation, I would try it - at least for a while. But, if I felt it just wasn't practical then I would go and stay in hospital."*

*Carer: "We've been lucky that we've been able to find such good people locally. But, this is actually the first time that we've been able to get all of the helpers actually living in the village. In the past, we've had to do quite a bit of work finding people - you ask around with your doctor, the community nurses, and other people that you know. But, it's not just a question of finding enough people. They've got to be the right kind of people. It takes a certain sort of person. You know, when you say - if something goes wrong with the respirator you've only got 50 seconds to do something about it - not everyone is able to deal with something like that."*

*"You need to have more funding more care attendant schemes to ease the burden on people's families. Also, it would be a great help to people without families so that they can get on with their lives. That's why it's so important."*

*"I have three helpers plus another two for back-up. So, although I'm lucky enough to be able to afford it, it is a considerable expense."*

*"That (on-call support) sounds like an excellent system - it would be ideal. Even now, 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. I worry myself silly about letting the family down and, if there was someone to call on, I wouldn't worry so much. So, yes, I think that would help a lot. 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. Certainly if there was some backup you wouldn't have to worry so much. I've got some very good friends who have helped me once or twice when that sort of thing has happened. It doesn't happen very often, but they have their own families to cope with and you can't keep asking the same people over and over again. So, with a backup, 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. So, that would have helped. It sounds ideal - something that is very much needed. If I thought there was something like that round here, then I certainly wouldn't worry so much."*

*"She (home help) really is very good. We get on well and she looks after me. She does a lot of things sometimes that she's not really supposed to do but she likes to help. They're not supposed to go to the supermarket you see, because it's too far. So she takes our order and gets what we want when she goes for her own shopping."*

*"The only problem I have is when my regular home help is away on holiday because you can't always be sure you'll get the cover to replace her."*

*"There are rules about things they're not supposed to do for safety reasons. Like climbing or lifting, in case they have an accident. But they usually just use their own common sense. Like, there was one time when my light went. Now, she should really have left it for the caretaker, but that would have meant me sitting in the dark for hours - so she got up there and changed it for me. I mean, they do that sort of thing off their own bat - but it's just common sense isn't it."*

*"My home help is very good. But, when she goes on holiday, out of all the people she covers I'm the only one who doesn't get any cover. It's because they feel that I could manage when the girls (daughters) are here - regardless of whether or not the girls are actually here. As far as they're concerned, they are. So, I'm very frightened that they expect the girls to take over. It's not fair. They've got to lead their own lives. They can*

help a little bit, but when both their parents are disabled they shouldn't have to be expected to take over and I'm determined that they'll be able to lead their own lives and do what they want to do. So, there should be some help available. I do get this impression that families are expected to help more. In a way, that's fair - to help a little bit. But, not to take on the whole lot lock stock and barrel. We thought about having a private home help but we can't afford that. Anyway, here if you're in receipt of attendance allowance you have to pay ,9 a week towards your home help however many hours you are getting. Now, I don't get the attendance allowance, but (my husband) gets the small one. So, I thought - do they categorise the home help as being to help me, or to help the whole family. I got onto the home care person. They didn't have anyone else in the same sort of situation, so she had to go to her supervisor. She said - we're not sure whether you'll have to pay or not - and I said that, if we do, I can't have her because we just can't afford ,9 a week just for two hours. We couldn't afford it if we had twenty hours. It's so difficult. Anyway, I don't think the attendance allowance should be used for that sort of thing. In the end I got a letter asking if I was in receipt of attendance allowance. Well, it's my husband who gets the attendance allowance so I wrote back and said I am not. I haven't heard anything since so I'm assuming that they're not considering (my husband's) attendance allowance in the assessment. I don't know. The (local) Council of Disabled People are fighting it anyway because it doesn't make any sense. Some people might have 5 or 6 hours a week and they're paying a flat rate, so people like me would be subsidising other people - it just doesn't make any sense. If I had to pay that - and if I could afford to - then I'd insist on having more hours."

"The home helps we've had in the past were absolutely terrible. There was one in particular who I know was talking about me to other people she went to - half of it was made up. But, I think that is a general problem with the home helps anyway. What I can't stand is that they can report on you and you don't know what they're saying about you. I'm a very independent woman and it's hard enough for me to accept having them here in the first place. But I really do value my privacy so that's got to be the worse part of all for me - the lack of privacy."

"Shopping is one of the biggest things. That friend who was here just now, she helps me sometimes but she's getting older as well. I have been to do the shopping on my own in Sainsburys sometimes. I park the trolley near the checkout and take a basket round and tip it all into the trolley. But, it takes so long. They did tell me - Sainsburys told me - that, if I did my shopping on a Tuesday or Wednesday they could get someone to help me. But, it's just not practical for me to do my shopping at the beginning of the week. I need it at the end of the week, I've tried it the other way and it didn't work. So, that's something that's always a problem. It's very difficult to find someone to help me."

"We haven't got the storage space to do a big weekly shop in any case. There's always the possibility that the home help could do some shopping for us, but they'd probably say she could do it up here at the local shop - but that's not good because it would be too expensive. So, that's not much help."

"She (domestic helper) does all the cleaning in the flat. And, being a private one, she'll sometimes come round and clean the windows and things like that when I'm out."

"There are (restrictions). I can't get about. I can't just decide to get up and go somewhere whenever I want to like you could. I don't see that there's much that would help in my situation now."

"The social services lady told me I could get ,350 towards a holiday because I dearly wanted to go back to Ireland to visit. But, because I was staying with my sister, they wouldn't pay up after that. They said it was to pay for hotels and spending money but I didn't need it because I was with my sister. So, they gave me the fare but I ended up paying the rest myself - and I haven't got it. So, that was the only holiday I've ever had and I won't be able to have another."

"I don't care about where the help comes from. I don't have any problem with taking help from the social services - it doesn't concern me at all. I think that is a generational thing. Older people always say - I don't want any charity, I don't want that. Quite honestly, I couldn't care less - take whatever you can get out of them, that's what I say."

"I'm sorry, but I've got a thing about social workers. I haven't got any time for them - I've never met a good one and their attitude to disabled people is pretty poor judging from the ones I've met."

*"I did have a lot of help from the social worker when I moved to my new flat (after mother died). It was a time when I was having a depressive illness as well, so she was a great support at that time."*

*"The social worker I usually see is usually very helpful. But they're not all like that. Sometimes when you try and tell them what you want, they just look at you as if you're senile or something."*

*"There isn't enough information advertised about services. A lot of people don't know about what's available. You need to get a system for advertising to people so they know where they can go to get the information. You know, advertising in post offices and in chemist shops, that sort of thing."*

## **(2. Housing/Aids and Adaptations)**

*"I'm very happy here really. I like this flat. The only thing I don't like is the vandals we get all the time. I get frightened, especially when the lights outside the flat go out and they don't fix them for days on end. I've been onto the council about it, but they don't take all that much notice do they."*

*"This flat is designed for disabled (mobility housing). It's very good really except for the shelves in the kitchen. I can't see how they are meant to be designed for a disabled person. I can only reach the bottom shelf of those cupboards, but I don't even use them because I still have to stretch and I can't balance properly. So I don't know what someone in a wheelchair would do. I just leave all my food out on the work tops."*

*"I bought this house in 1930, so I shouldn't think we'd ever be in a hurry to go anywhere else - certainly not as long as my wife and I were still together."*

*Researcher: Have you thought about what you might do if there was any change in the situation?*

*"I've not really visualised that one, so I couldn't say. I don't expect it's very likely that we'd have any major problems now. After all, I've been disabled for over 80 years and I'm still remarkably healthy. No, I think we'd be alright as we are."*

*"I do think it makes a lot of sense to stay where you are when you are older, or at least to stay in the same locality. You see, when you stop to think about it, you become tuned in to your environment. You know the easiest way to get around everywhere you need to go, and you have people around who you know and they know you. That's probably the most important part of it actually because there are all the people who can do little favours for you like when you go to the shops - I know all the shopkeepers around here. You see, you take all these things for granted and you probably wouldn't even notice until they weren't there anymore. I'm sure that most people who retire to the coast and places like that, I'm sure they end up regretting it because they realise they've cut themselves from a familiar environment. No, I don't think moving is a good idea - it's very impractical."*

*"I lived in a maisonette locally before I moved here (housing association sheltered accommodation). That's where I lived with my mother. But, it wasn't so convenient for me disability wise and I moved also to have more people around me."*

*"I don't have any objection to residential homes in principle. There's some good ones and there's some bad ones. It's not a thing that I think most people would choose though. The emphasis is very much on one remaining in your own home now."*

*"The possibilities where they might be able to develop some alternatives, would be something like sheltered accommodation. But, the thing that worries me a bit with anything like that is that, I've always felt that if you ever get private enterprise in on a caring aspect, there's the profit motive comes into it. I think that the times when the profit motive is introduced, total care goes out the window. Again, I don't know what the answer is to that. I think successive governments have never funded the health service sufficiently. I mean, when you look at when it started at the end of the Second World War and you look at it now - I mean, there's so few new hospitals being built and all this sort of thing. They started off with a lead weight round their neck in terms of maintenance and all this sort of thing - all that money. I suppose it depends, really, what society is prepared to afford."*

*"I feel that with my disability as it is, and if it gets worse, what I think of as normal sheltered housing is not going to be sufficient. But, having said that, I don't really know for sure what is available in sheltered housing. So, I'm thinking in terms of - in the worst case - ending up in a mental institution like the ones what they're trying to close now. Or, if I was still presentable and having got some money, maybe somewhere like the Cheshire Homes. I like the Cheshire ideas - and the Sue Ryder homes - this idea of trying to promote independence in a home environment. I'd like to think that they are basically happy places. I suppose, his (Leonard Cheshire) ideas - they come from the heart, and I think that permeates itself all the way through his structure of his organisation, and I feel it's a more caring organisation than something which is council run or something like that. I don't know if I'm right or wrong, but this is just the feeling I have. It's a non-profit making organisation and everything they make is ploughed back into the homes. So, I think that in a way, that's the good side of private enterprise, if you know what I mean. And another thing, obviously you've got to be honest*

*with these people about your financial situation, but - for the same level of care - there's a complete range of payments ranging from nothing if you don't have the facility, to the other person who would be paying more. You know, a full scale of charges depending on individual's ability to pay. So, to me, everything I've ever heard about them has always been good. But, whether you get small personalised local nursing homes or whatever, the people running them - the main reason they're running them is for the profit motive, isn't it. I think there is a subtle difference between that type of establishment and something run by somebody like the Cheshire Homes. So, to me - if I've got to go somewhere like that - I think I'd much rather go into a Cheshire Home. Really, what you're looking for is an establishment that's run by a caring management where - within the constraints of living in a organised home, I mean a home in inverted commas as such - that, alright, the freedom's of the individual are curtailed a little bit, they have to be - but, within that all embracing caring environment you can live a much better quality of life than what you could under your own steam outside. So, that is a definite possibility. Again, I'm hoping that possibly the bricks and mortar would pay for that if I was going to go into that."*

*"I think that anything has got to be better than ending up institutionalised - anything has got to be better than that. Then, after that, so much of making this kind of scheme (ie. Grove Road) work is down to the personalities of the people involved. I mean, you've got to keep your demands or your requirements in bounds. You don't ring them up at 2 o'clock in the morning because you want a cup of tea or something like that. You know, I think it's a case of - you've got to be realistic about what is available to you, and how you use it. So, I think it depends on what the persons attitude to life is. You know, there are disabled people who wouldn't necessarily make the best use of that kind of facility. Put it another way - when I was coming to terms with my disability in the early days, I went down the road of self-pity. But, I was fortunate enough that, when I got down to the bottom, I recognised it and I woke up one morning and realised that no bugger wanted to know me - which is rightly so, because I wasn't a nice person to know. I'd like to think that I'm a bit better now. It's true that old saying - you know, laugh and the world laughs with you, cry and you cry alone. You can have disability sort of improving people's character but, in some cases, it doesn't. You can have individuals who'd be a disruptive influence in any situation and upset everything for everybody. So, you have to have some kind of trial period or selection board or something like that - have some detailed personal interviews carried out, or something like that."*

*"If it wasn't possible for me to stay at home, I would try to go to St. Thomas's (intensive care respiratory unit). It wouldn't be my first choice - it's my only choice. But, I've been going there for over 20 years now and so I'd feel confident that they would be able to see to all my needs. That security is very important, yes. Obviously, I would prefer to stay at home if it was possible. But, I'd have to have all the trained helpers so that they could provide me with the same level of care that I would have in the hospital."*

*"I've got to do some major alterations in the bathroom - having this hoist installed is a major priority. In the kitchen - again, with this problem of lifting my arms up and this sort of thing - I'm going to have to get that reorganised and redesigned so that, while I want to keep it as normal as possible for anyone else whose got to come in and work in the kitchen, I want there to be low level pull out surfaces that I can use. You know, I want to be dual purpose - the working height, the oven, and the hobs, and things like this that I'll be able to use so that I can cook for myself and that sort of thing. What I've got now is just standard fitments - so this is something where I have got to spend some money."*

*"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."*

*"When we came in here, as you can see, all the power points are 2.1/2 ft of the ground - things like that. I know the electric light switches aren't, but when you're sharing a home - like I was in those days with my mother - you can't have everything wheelchair orientated."*

*"The kids keep breaking my car. That does upset me. But I don't know what can be done about it unless there was a garage or something where I could lock it up."*

*"Oh, I don't think I could think about moving at my age. If I had to go into a home or anything like that I don't think I would want to go like that. I'd be better off dead if it was that bad I think."*

*"We were very lucky to be able to buy such a large house at a time when property was so cheap compared to what it is now. But, really, we're grossly overhoused - although the space is wonderful. With these Victorian houses, all the doors are wide, the rooms have all got plenty of space, and - with this place - we were lucky that there wasn't a single step anywhere. The space we have has enabled us to live our lives the way we do. You can appreciate that, with the arrangement we have for looking after me, life could be very claustrophobic. Fortunately, we haven't had to worry too much about that."*

*"I have thought about what I would need in the way of housing when I'm older. The main thing is that we would have to have a lot of levelling out done - especially outside - and possibly some rails, so I've got something to hang onto. So, then I might be able to get about without help - even if it is a bit of a struggle."*

*"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."*

*"The Possum system is of tremendous benefit. It gives independence to me, but it also gives a great deal of peace of mind to the people who look after me."*

*"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."*

*"I've got arthritis in my hands and that causes me a few problems with things like doing up buttons - but I still just about manage without any help. The only thing I use is a board for when I'm getting in and out of the bath. I sit on that and lower myself in - I couldn't manage without it now. I got that officially from the social services after a health visitor came round to see me. Actually, they gave me a stool for the bathroom as well - but I never use it. I think the only other thing we have like that is - my son and his wife bought us some of those extensions you fit on the tap so I can turn them on and off myself. That's about all really."*

### **(3. Transport/Mobility)**

*"I do not travel on buses anymore or go away on group holidays abroad - any travelling is done in our family car and I can walk short distances using my walking stick together with someone's arm. My disabled sticker for the car, which I applied for last year, has been a boon and we are well catered for here. However we did not find this the case when we went to North Devon on holiday last year."*

*"I no longer have a car. I used to have one adapted for the use of the left leg only but now, I use public transport - buses and trains. I am a dodderer with a stick, but people seem to think you are better, physically, than you are. I suppose this is a compliment of a kind, but it can be somewhat awkward."*

*"My care attendant carries me in and out of the car and, some of the time, does the driving. But, with all the looking after me there's not usually enough time to drive as well. The ideal would be to have a resident driver. I think it would be a good idea if there was a local transport service so that you could ring up and book a driver when you needed one - but it would have to be at an affordable price of course."*

*"What I really do need is to have a new car for when the Invacar runs out so I can make sure I can still get out a bit when I need to. But, I don't know how I'm going to do it for I have no money. There is the motability, but I don't think it will really give me enough to run a car even if I get one. With the Invacar you see, all the repairs and anything like that - they pay for all that."*

*"My biggest problem is driving. There just isn't anywhere you can go to get information about what kind of car might suit you, or somewhere you can try out different models. There is Crowthorne and Banstead Place but, with Crowthorne, all they can do is advise you about what they've got there. If they don't have what you want, that's it. Everybody know has this problem. But, the thing is that there are lots of people around who probably already have what you want but how are you supposed to know that. There should be some sort of central register so that you can see what there is and go and try it out before you commit yourself to something which might not be suitable."*

*"I am really scared about going on trains. It's getting off that's the problem because I'm always worried I might fall when I'm stepping down onto the platform. So, I very rarely go on a train unless I can take someone with me. And, I don't accept British Rails argument that they can't do anything about it because the platforms at different stations are all different levels. That's just an excuse because they could do something about that - it wouldn't be all that difficult. Anyway, they do it in other countries so that proves it's possible. I did think of one answer. If they could have some portable steps you could wheel up to the train - and, if you had it so that it was always the same carriage at every station, you know, say it was always the third carriage on every train, then you'd know that it was there. Alright, I accept that it wouldn't work if there aren't any porters - but at least they could do it at all the main stations."*

*"Because I have such difficulty using the trains, of course that means I can't always go places with the children. That's the thing - I always say that, if you're disabled, then your family is disabled as well. I mean, the girls have never been up to London with me just on our own."*

*"That (increase in petrol prices) would effectively mean that I wouldn't be able to run the car. I just couldn't afford an extra £3 a week. So, that would take away my independence - how would I do the shopping and run the girls around? I really think they should give more consideration to the effect on people who rely on their cars the way I do."*

*"I think the motability scheme is very good. The only problem I have though is finding the deposit every three years when it comes to replacing the car. That is a real struggle financially."*

*"I used to drive a trike many years ago, but I've never driven a car. I use taxis to get to work - I pay for that out of my mobility allowance. I don't use the Fares to Work Scheme. I knew about it but, I felt that - I was happy with the taxi firm I was using, which may not be the one I'd have got - I think they just accept the one with the lowest tender don't they. So, that's one of the main reasons I haven't."*

*"I've never had a very wide circle of friends. A lot of that was to do with the fact that I was looking after my mother for the last 10 years of her life, so I couldn't get out much and you sort of get out of the habit, if you know what I mean. So now, even though I've got plenty of time since I packed in work, I don't have as many*

*friends as I would like. But, the other thing about that is not being able to get about in the car like I used to. I do still drive, but it's getting really difficult with transferring in and out on my own, so that limits you as to how much you can go out anyway. I have just decided to try out the Dial A Ride to see what that's like, so that may be one way of doing it. But, what I really need is one of those vans - like a transit van - so I could get straight in my wheelchair, without having to transfer. Having said that, of course there's no way I could afford one of those things - but that would be the best way If I could do it. I do think that it's very important to keep mobile and active - especially keeping mentally active. It's the only way to keep your independence - to be able to stay living with some dignity - because you can get about under your own steam sort of thing."*

*"Mobility - that's the number one thing. That's why I think it's very sad that people have to go cap in hand to get mobility allowances and the like. It's essential to have your mobility, so there shouldn't have to be any debate about it. It's the same with the Motability scheme. Obviously, it's a very useful set up - much needed I'm sure. But, then why do they have make it a charity - it shouldn't be on a charitable status."*

*"I did have a wheelchair from the ministry - but I never used it. It was far too heavy for me to propel myself, and my wife couldn't manage it either. We had to change it for one of those with smaller wheels but - that one - that's only for someone else to push. I don't actually wheel myself round in it. So, we use that occasionally but it's not very practical most of the time. If I could get a lighter one that I could propel myself that would be a lot better. I wouldn't really use it all the time, but it would be handy if I wanted to pop out for a while on my own."*

*"When I was coming out of hospital and I wanted an electric wheelchair, one of the things they said to me was that - the trouble is that a lot of disabled people do not have the know how to be able to control an electric chair and so you need a proper assessment. I couldn't believe this. I mean, it's only disabled people who know how to control an electric wheelchair because only they have had the practice. It was quite ridiculous as far as I was concerned. I mean it only takes a week or two to get used to it."*

#### **(4. Finance and employment)**

*"There is one tax anomaly. Invalidity benefit is not taxable but retirement pension (compulsory for a woman age 65) is, so that one's tax burden increases, as does private health insurance - by a considerable amount. Another small anomaly is that a widow is given a tax allowance for a housekeeper but a single woman is not."*

*"Because I get a superannuation pension to which I paid into, I get no financial help apart from Invalidity Allowance and Mobility. I live in a council bungalow and have to pay full rent and poll tax."*

*"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. I mean, there's got to be some sensible way you could handle that - you could have some kind of disability allowance which everyone got if they was disabled, or - if you're working - you could have some kind of allowance on your tax. It shouldn't have to be too complicated to organise it, but you've got to get more people to accept that the need is there first - I don't suppose that's very likely at the moment."*

*"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."*

*"I retired in 1969 (age 65), and I'd been working since 1927 so I had a fair pension by then. Actually, I've got two pensions because I've got the state pension on top. It doesn't work out at all that much - not at today's prices - but I'd say we were fairly comfortable. We haven't got any money to splash around or anything like that, but we don't go without anything important. Anyway, when I retired I didn't want to pack it up altogether, so I still did the books (accounting) for one or two local people - the money from that was a bit extra on top, even though the tax people were always trying to get their hands on it."*

*"I don't go out to work. If I worked you see - this is a council house and (my husband's) wages are low so we get housing benefit for a rent reduction, and we also get a reduction on our poll tax. If I worked, up would go our rent, our poll tax, and we'd probably have to pay the fees for school, which would mean that we'd be worse off. So we're caught really in a trap. I do work at Dialability, but that's completely voluntary."*

*"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 anymore. 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 do 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."*

*"I'm well into my 70's and I'm still very active - although not as much as I might like ideally. I still go into the office every day even though I have now given over much of the day to day running of the business to (my son). I'm sure that makes a big difference to how well you get on. One of the things most likely to keep you mentally and physically fit is to keep working for as long as you possibly can."*

*"Even when I was a young boy I made up my mind that I was going to work and eventually to run my own business. I can't stress enough how important that has been, not just to me, but for anybody who has a disability. It's the only way to make sure that you can look after yourself. It's so much better than relying on handouts. I was very disturbed to discover that so many disabled people have to rely on state handouts these days. There is no reason why - except in the most extreme circumstances - why any disabled person should be without work these days. Technologically, there's never been more opportunities - especially for working at home with computers for instance. There obviously isn't enough being done to encourage people to do this, which is a big mistake."*

*"I started working in 1951. It was important to me that I had been able to get a job. There again, I think that perhaps employment for disabled people was stressed more in those days. I mean, things like benefits were not*

*very good in those days. So, I don't know what the comparison is in numbers. But, when I think of all the old ones, they've all worked - well, many of them were years and years in their jobs. I think that, probably, a lot of the younger element - their lifestyle is different now."*

## **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 British Polio Fellowship 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
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
<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

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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

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

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