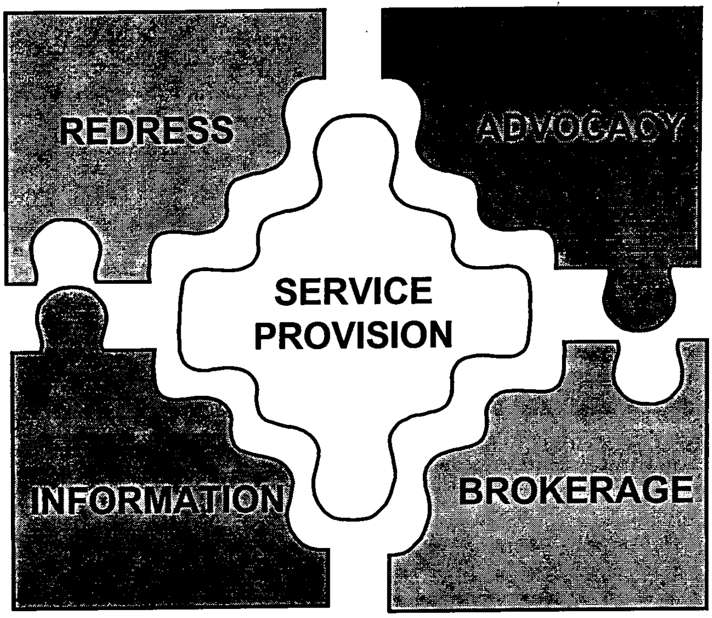

Developing a Long Term Care Charter

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DEVELOPING A LONG TERM CARE CHARTER

CONTENTS

SUMMARY

1. This report has been prepared for the Department of Health by the King's Fund, to assist in the development of a proposed 'Long Term Care Charter'. The findings are based on an analysis of focus group discussions held in three different parts of the country involving service users, carers and front-line staff with experiences of health, housing and social care services.

2. Main themes emerging from focus groups

- **Ordinary lives**
  Choice, influence, support and security were identified as important ingredients of independent living. Issues included:
  - ***Choice*** about daily activities, about where to live and about the kinds of services that are available and can be delivered.
  - ***Having a say*** in one's own treatment, care and support, and in the type and timing of services being provided for individuals and for local populations.
  - ***Support*** in developing and sustaining social activities and in dealing with the practicalities of everyday life.
  - ***Safety and security*** in the neighbourhood and in the home
- **Services**
  The main concerns centred on obtaining appropriate provision when needed and having ways of co-ordinating services to ensure ease of access and continuity of care. Issues included:
  - ***Responsiveness and flexibility*** where rigidities in the service system can lead to people waiting for long periods of time for assessments and appointments and then receiving provision ill-suited to their requirements
  - ***Quality*** relating to standards of workmanship and to basic and specialist skills among care staff and medical practitioners
  - ***Service integration.*** Importance was attached to having workers who co-ordinate provision for individuals, a single point of access to a range of services and having agencies that work together to plan and deliver services
- **Communication**
  Information was seen as the key to the provision of good services and the way disabled people are treated by professionals and the public at large can make all the difference between feeling respected or rejected as an equal citizen. Issues included:
  - ***Information*** about health and treatment, about social services' eligibility criteria, assessments, complaints procedures and help available, and about housing options.
  - ***Access*** to houses, public buildings and other aspects of the built environment facilitates participation in community life, and the capacity to take advantage of community services. Poor telephone and reception services, combined with complex forms used when applying for help can create unnecessary barriers to services.
  - ***Attitudes*** among some professionals are experienced by disabled people as discriminatory, patronising and demeaning

- **Resources**
  People talked about how they used their own money to meet costs associated with disability, how they were affected by current expenditure constraints and how they felt about the way public money was being distributed. Issues included:

  - ***Public and private finances***, where there was concern about the level of charges being levied and the fairness of charges.
  - ***Pressure on resources*** directly affects users and carers who are experiencing reductions in services and lengthening waiting times.

- **Views about the Charter**
  Cynicism about charters was evident, together with ideas about their potential value in changing attitudes and improving access to services. Issues included:

  - ***Suggestions about the philosophy and content*** of the Charter, including values and principles, types and standards of service.
  - ***Suggestions for presentation and dissemination of the Charter***, including target audiences, media formats and promotion through key networks.

3. Developing the Charter

As the Charter is developed by the Department of Health, we recommend that account is taken of:

- the current political and social climate within which the Charter will be launched, received and implemented;
- the aspirations of disabled people to lead an 'ordinary life' and their common experiences of disadvantage, disconnection and social exclusion;
- the need for a distinctive cultural shift in community care so that services can develop to meet modern day expectations of users and carers.

Having identified what users, carers and front-line staff regard as important components of good practice in health, housing and social services, we suggest that the following be built into the 'Long Term Care Charter':

- ***A statement of values and principles***, emphasising honesty, user and carer autonomy, partnership and a positive 'can do' approach.
- ***A framework*** showing users and carers what they can expect in terms of information, brokerage, advocacy, service performance and redress across the health, housing and social care sectors. Particular attention should be paid to the performance of services providing specialist healthcare to people with chronic conditions, personal care in the home, aids and adaptations, respite for carers, and suitable housing.
- ***Guidance*** on the involvement of users and carers in decisions about their own treatment, care and support, in planning and standard setting; on knowledge and skills required for working with people with complex and chronic conditions; and on the co-ordination of resources deployed across health, housing and social care

INTRODUCTION

The charter movement in the United Kingdom and indeed, in the two other European countries which have them, has a chequered history. On the one hand, charters are seen as useful for helping consumers become more aware of their rights. On the other hand, they are seen as a management tool to help deliver more consumer oriented services. The original movement which began in the United States was directed at consumer goods and services. The shift to using charters as a method of raising standards in public services happened, in this country, during the late 1970's/ early 1980's. In spite of the scepticism expressed by the public about the value of charters for the promotion of quality standards in public services [Bynoe, I (1996)] , the Labour Party manifesto of 1997 contained a commitment to reviewing the Patient's Charter, to introducing a new charter for people using health, housing and social services over long periods of time and a new commitment to up-dating the Citizen's Charter principles. The review of the Patient's Charter was set in motion in October 1997 and the Citizen's Charter principles were revised and published in June 1998[Cabinet Office (1998)].

In its manifesto, the new Labour Government made a commitment to develop a new long term care Charter. Community Care Charters had been introduced by the previous Government in 1994 [Department of Health (1994)] requiring local authorities to produce them in co-operation with health and housing authorities. These charters were intended to be local charters, with the Government setting out a framework to guide their development by local agencies. While local charters were expected to contain information about service standards, no attempt was made to set out national standards and monitoring of performance against locally determined standards was undertaken by local agencies.

The whole Community Care Charter exercise was criticised by some as being a 'top down' initiative, with little or no opportunity for users of community care services to influence the framework handed down by Government. With this in mind, the new Labour Government determined to approach the preparation of a long term care charter by involving users, carers and front line staff in early discussions about their use of services and their views about what such a charter should contain.

The report is in six parts to reflect the topics and issues raised in the focus groups. The first talks about the way in which these people live their lives and the issues that are important to them. The second deals with the services they receive; what they find helpful and where there are problems. The third part is concerned with communication; the way information is provided and attitudes which promote or prevent good communication. The fourth section discusses resources. Section five presents people's views of charters and the kinds of things they wanted to see included in a new charter; and a final section sets out our recommendations for the development of the new Charter.

This report presents the outcomes of those discussions. It is based on the analysis of 15 focus groups in three geographical areas of England. These areas were chosen to reflect the views of people living in rural, inner-city and metropolitan parts of the country. Thus three groups with older people, three with people with learning difficulties, three with people with physical disabilities, three with carers and three with front-line staff were arranged during September 1998. Sampling details and the characteristics of the people who participated in the groups are contained in Appendix 1.

Focus groups were chosen as the most appropriate method for this enquiry because they are open-ended, provide a useful forum within which people can share views and experiences and are a particularly effective method for generating ideas about improvements. They also gather together a range of viewpoints quickly.

The findings from this work are substantiated by other recent work in this field [Henwood, M. Lewis,H & Waddington, E (1998); Help the Aged (1998) Nuffield Institute for Health 1998]

ORDINARY LIVES

Choice

Choice was identified by users and carers as an important ingredient in their lives. Although their circumstances meant that they could not have as much choice or control as they wished, they did want to have some degree of choice about the way in which they led their lives. Specifically they wanted to be involved with decisions about their daily activities, where they lived, and since they were often reliant on at least some public services, they wanted to have some choice about the way in which services were delivered to them.

Choice about activities

Choice about day time activities was important to all users and since some of them spent a lot of their time at day centres, what they did there was especially important. There was a fair amount of criticism from some quarters about the limited nature of the activities offered.

I'm sure they could do a lot more activities (in day centres) like take us out in the bus and things like that, but as far as what they do at the moment, I mean they're making bloody plant pots....that's not my idea of a day centre. If I had my way I'd close the day centres down and start again

In contrast, older people in particular enjoyed going to the day centre and complimented staff on the way they made special efforts to provide entertainment, including lunch on Christmas day, and to offer support. One small group of users had led a protest when they heard a rumour that 'their' day centre was threatened with closure at the weekends;

We were out with the flags and banners cos they were thinking of closing it for the weekend.

Trips out and visits to places of interest were also appreciated.

People who lived in residential care wanted to be able to do ordinary things for themselves like making a cup of tea, sitting quietly by themselves or going for a walk. Sometimes they said even these basic choices were not available to them. One person said that she felt like a prisoner and had to ask every time she wanted to do these things. Other people felt 'trapped' because they lived with relatives or because their disability prevented them from doing what they used to do.

Choice for carers was constrained by the daily responsibility of looking after their relatives. Respite from caring was essential to these people and often their choice of when they could get 'away from it all' was limited because there was no one to relieve them. Occasionally, the attitude of the cared-for relative stopped them from having choices by insisting that only the 'family' should do the caring, but more often it was the lack of availability of 'respite care' services at weekend/evenings when the carer wanted to go out.

Choice of outings and holidays was also felt to be limited. Day centres were sometimes criticised for failing to provide choices about outings and visits and the range and choice of supervised holidays on offer had clearly been limited by resources and by the fact that people wanting to go on these kinds of holidays could not afford to pay for their carers' holiday. Choice of holidays was especially restricted for people using wheelchairs.

In contrast, some people wanted the choice **not** to go to the day centre every day and **not** to go on day trips.

People who had jobs, mainly younger people with learning and physical disabilities, were largely happy to have them. The range of jobs they did included gardening, sewing, carpentry, sorting mail and farming. Some of them were paid for the work but at very low rates and most were unpaid. Some people regarded this as 'unfair' but others were happy with what they were doing. Their choice about the jobs they did was limited by their disability and the attitudes of employers.

Many people with learning difficulties went to college several times a week but they were sometimes critical of the range of courses open to them and the way in which they were not included with mainstream college activities. This was true too for some physically disabled people who were enrolled on college courses. Choice of subjects and courses made available to them by colleges did seem to be extremely limited in some places with computing as the most common component. Users wanted more choice and to be part of the wider college community.

Most people that go to our college have 30 or 40 courses to choose from but we are given two courses to choose from. Well that is obviously not fair is it ? (We would like) more integrated courses with other people that use the college, not just people that use centres

There was praise too for some of the college and course opportunities offered to users. One example provided for people with physical disabilities was a collaborative venture between a voluntary organisation and local colleges.

They (the voluntary organisation) have linked up with local colleges and they send teachers in to run the courses at the centre, which is great because it's often a big barrier to go, as a disabled person, into colleges

Choice about where to live

There were some differences between the groups in respect of choices about where they lived. People with learning disabilities were happy with their choices on the whole, living mainly with relatives or more independently. One or two wished to move away from their families but had been prevented because of lack of availability of appropriate accommodation.

Older people who had chosen to live in supported /sheltered housing were also content because it enabled them to choose when to be in the privacy of their own space and when to join others in communal lounges. Other older people living in residential homes or unsuitable property with too many stairs and insufficient space, did not want to be there but felt they had no choice or alternatives.

Choice of location was also important for some people. Whilst many people were happy with where they lived, others wanted to move to another location but had not been able to. This usually applied to people living in areas where they felt threatened and insecure but could not move to a 'safer' area because suitable accommodation was not available or they could not afford it.

Staff agreed that choice of housing was limited by the availability of appropriate accommodation and its location. They also recognised that ' vulnerable' groups felt threatened when they lived in 'problem' areas.

The lack of choice about housing adaptations and equipment was the cause of a considerable amount of frustration to the physically disabled and older people.

We're not asking for things free, we just want some assistance...I have a lot of problems with being so big and with brittle bones and getting out of the bath is impossible If I sat down in the bath there's no way I could pick myself up again.

The OT came and said 'Well, I can't give you a lift or bath stool but I can put rails on the walls...stand in the bath and the showers' overhead so you can hold on'. Great. When they came I wasn't there but my mum explained where I wanted the handrails and the gentleman said 'Oh no, no we can't put them there, it's dangerous to put a rail by the bath.' So they fitted two rails, one on the other side of the room to the bath; (useless, we hang towels on it now) and the other for getting in and out. Instead of putting it horizontal so that I could lean on it, they put it vertical, so when your hand's wet it's useless, you just slip down the pole.

Choice of services

A major frustration for service users and carers was the lack of choice with the way services were delivered. The main areas of difficulty were with home care and aids and adaptations. Choice about home care arrangements was limited by inflexible provision and sometimes by the unreliability of the carers themselves.

The provision of aids and adaptations was also an area where people felt their choice was severely restricted. Firstly, the length of time they had to wait for assessments sometimes stopped them from making other arrangements because they did not know what choices would be available to them. Secondly, when assessments were completed, their choice of equipment or adaptation was restricted to that provided by the service. Many people, particularly physically disabled and older people had discovered that better quality equipment and adaptations were available from other suppliers. They felt that if they had been given better (and more) information they could have exercised their choice and got more suitable equipment or more appropriate adaptations. Mostly they had no objection to paying for or making a contribution to services and equipment, but felt angry when this choice was not offered to them.

These issues are discussed in more detail below.

Staff reinforced these frustrations and lack of choice for clients. Independently they made similar points and were critical of the services they delivered in this respect. In fact, they were often more critical than the clients. Some staff felt that all services limited users' and carers' choices in the way that they were provided, by eligibility criteria and cost; and by the lack of flexibility in the way they were allowed to work between services.

Staff itemised ways in which services limited client choice. Restricted resources and budgets were identified as the most common reason for choice limitation. Examples were given of the way in which home care packages were restricted by budgets and the long waiting times for OT assessments for aids and adaptations. The resource/ demand/ choice issue was felt to be intractable although some staff felt that one of the few ways round this problem was to inform, involve and empower clients.

Provider attitudes were also said to limit choice

People are not necessarily given the full range of options so they're denied choice. They're not told perhaps that there are alternative solutions because perhaps there's a fear that they'll demand those solutions from the statutory authorities. Perhaps we're a bit too shy about saying 'There are all these other alternatives but the only alternative I can offer is this, if you want any others it's going to cost you' but perhaps we're afraid of upsetting people and increasing complaints.

Both clients and staff identified several factors which encouraged and prevented users and carers exercising choice and control. Charts 1 and 2 below show what these factors were.

Chart 1: Factors preventing choice and control

- attitudes of society, providers, professionals, clients, carers
- resources
- appropriate information
- benefits, charges, payments
- inflexible assessment

Overall, there was a general view from staff that better information about services and the involvement of users and carers in decisions about care and service delivery would increase choice and improve the quality of their lives. This kind of involvement both at individual client level and in local policy making was also seen by people in the groups as one way of extending choice and the level of control over their own lives.

Chart 2: Factors supporting ordinary living

- choice
- having a say in own care and activities
- social and practical support
- collective or shared decision making
- partnerships with professionals/providers
- provider honesty and information
- independent advice and advocacy

Some of the suggestions for ways in which choice could be broadened would cost very little; more creative thinking and flexible management styles for example; offering grants equal to the amount of the cost of a wheelchair so that clients could contribute to the cost but get a chair which met their needs.

Other suggestions made by users, carers and staff would increase expenditure but if people were involved in policy discussions at an early stage their understanding of resource limitations would increase and their complaints/dissatisfaction reduce.

Having a say

As indicated above, people did feel strongly that they should, at least, have a say in their own treatment, care, support and service provision. Having a say in the kinds of activities offered at day centres and in colleges was something that many clients wanted. Because some of these people went regularly and often to day centres this was a particularly important aspect of life for them. However, some clients were more than satisfied with day centre activities and services and many compliments were offered to the staff who provided them.

Other centres were clearly not providing stimulating or challenging activities or courses which was especially important for young disabled people. There were several centres where clients had attempted to influence the provision but had failed either because of staff attitudes or resource constraints. There were enough examples of centres where clients needs were being met and stimulating activities offered, often in the same areas as the poor provision, for this to be an issue of management style which needs to change rather than just a need for more resources.

Services

Not being able to have a say in when and how home care was delivered was clearly a major issues for users and carers. Some of the fear, humiliation and pain caused to people because of the failure of providers to listen to what users and carers had to say about their needs in this respect, was awful to hear. This was particularly true for physically disabled people who needed intimate care.

I had as many as 18 different carers per week coming into my home and as far as my personal care was concerned, well I felt as if I was being raped in the sense that my body was on show to anybody and everybody. When I questioned this I was told 'Well, if you don't have your personal care then you don't get your care hours".

Carers too were angry that their experience and knowledge of what their relatives and they needed, often went unheard. They felt this especially in relation to home care, respite care and health care. Hospital doctors were said to be particularly remiss in this respect.

When opportunities were offered for people to be involved in decisions they were much appreciated. One person said that her life had been transformed when her home care provider was changed from social services to a private agency which listened to the need she expressed for greater flexibility and then provided it.

In one day centre decisions about activities, outings and holidays were made collectively.

There was a general meeting for everybody and by shows of hands people chose where they wanted to go and how many times they wanted to go where...and it was the people's own choice.

There were also examples of people working together with services to evaluate provision and to help to design strategies and policies for change. When this happened people felt valued and involved. Voluntary organisations were especially good in this respect, helping individuals and groups to organise campaigns and pressure groups to put their views forward to the statutory sector.

And a lot of it is self-help but we just need that back-up to say to somebody ' as a group we want to do this. How do we now put this into practice ? There's a lot of energy in that

People often found the voluntary sector more willing to listen and to help than other service providers.

Aids and adaptations

The irritation and inconvenience and sometimes cost, caused by the failure to listen to user and carers suggestions about the kind of equipment and the location of adaptations was apparent in all the groups. One family with a daughter in a wheel chair took matters into their own hands when the community nurse and OT recommended that the doors of their house were widened and the light switches moved at a cost of £2300.

It cost me a packet of cigarettes because I've got a friend at work who cut six inches out of the middle of the chair and welded it up again and it flew through the door. Now, they wouldn't listen to me 'Oh no, it's got to be done through the social services, through the council and it's got to be done this way' and it was as I say £2300 out of the window just because they think they know best. They won't listen to the carers but we're the people who do it 24 hours a day

Staff confirmed that provider attitudes often ignored user and carers' knowledge and experience. This, they said, was sometimes because resources were limited, sometimes because 'those who didn't shout didn't get heard', but more often because they were afraid to be honest and present all the options for discussion.

The importance of listening to user and carer views about individual service provision and of involving them in wider policy development and evaluation is evident. They are, after all, experts in their own lives and the sorts of things they need. If a charter can emphasis this and give examples of how it might be achieved, most everyone would be happier

Support for living an ordinary life

Social support

Help and support for independent living came from two main sources; family and key workers. Families provided social support in many ways; by caring and listening and talking over problems when necessary. They also often encouraged outings and visits and holidays either by making the arrangements or by joining in themselves. For those without families, key workers were sometimes the only people providing and enabling people to lead independent lives although some users said they wouldn't know what they would do without neighbours and friends.

Neighbourhood support was acknowledged to be helpful in two ways; to provide practical help and support but also to make people feel part of a community and not isolated or inferior. Some users and carers did feel isolated; sometimes because of where they lived, in rural areas or in 'problem' inner city areas; or because the demands of caring kept them from being involved in the community.

Key workers and wardens in sheltered housing provided a considerable amount of social support for older people and people with learning disabilities. The latter found their key workers an important source of help and support if they had problems which they wanted to discuss with someone. Voluntary organisation visitors and befriending schemes were also a source of social encounters for older people living alone. One scheme, provided through a community partnership initiative offered support for social activities and respite for carers of people with learning difficulties by organising outings at weekend for small groups of young adults. Carers paid the cost of the outing but the staff were paid for by the scheme.

Peer group support was also valued and found through friendships made in neighbourhoods, day centres and sheltered housing schemes.

Practical support

Practical support was provided by families especially the primary carer and to a lesser extent, by services. Carers carried heavy burdens in this respect, often doing things like nursing, lifting and physiotherapy when services could not provide help.

Staff said that some of the carers they knew carried intolerable burdens often doing things that they should not have to do because services could not stretch to help them.

Key workers also provided practical support for people with learning difficulties by taking them shopping and sometimes helping them with cooking and cleaning. However, the extent of this practical help appeared to be limited.

Neighbours sometimes offered help with gardening tasks and the wardens of sheltered housing took washing to the laundry and collected medicines.

For those clients who had greater needs for practical support to live their lives, the picture was not so rosy. Difficulties arose with home care and its incapacity to provide flexible hours or activities. These problems are discussed in more detail in section two below.

Difficulties were also experienced with 'getting around' caused by lack of transport, lack of wheelchair access to buildings, lack of aids and equipment and lack of imagination or time on the part of service providers.

Practical and social support for people to live their lives is essential to older people and to those with disabilities. We, as members of an inclusive society, could do more to offer social and practical help, these members of our society. Service providers could help also, by listening to what people say. As one participant in a staff group pointed out, research has demonstrated that if people are asked what they want, they often ask for less than what is already being provided.

Safety and Security

The extent to which people felt able to live an ordinary live depended on feeling safe and secure in their own homes and in the neighbourhoods where they lived. In the absence of these basic conditions, some disabled people of all ages were feeling under threat, frightened and vulnerable to serious abuse.

Safe neighbourhoods

In both urban and rural areas, users and carers spoke about good neighbours who were friendly and supportive. This made people feel that they belonged and were welcome in the communities they lived in. It is true that, for many people, the neighbourhood was not perceived as being particularly friendly but nor was it threatening. Thus, young people with learning disabilities who shared a house together, knew their neighbours to say "hello" to but rarely saw them during the day as they were usually at work.

However, some users told alarming stories of intimidation that they had suffered. Predictably, perhaps, these applied more often to people living in inner city areas or run down housing estates.

Well, it's pretty depressing. They're urinating in the lifts, there have been burglaries. And now they're putting doors on, you know, where you press a button – yes entry phones. The doors are too heavy but it's supposed to be for stopping mugging.

Thus, some users had had their homes burgled; some had had their property, including wheelchairs damaged and vandalised; some had been assaulted, while others had been subjected to verbal abuse and ridicule. Many more lived in fear of leaving their homes.

They seem like junkies or glue sniffers, homeless people that are drunkards and that, and they put them in.....but why do they put them next door to the old ladies?

It was clear that in some areas, efforts had been made to reduce crime through security fences and gates that restricted movement into certain residential areas. Some users disliked these measures because they made the neighbourhood feel like a prison. However, there was little evidence of any kind of measures being taken to improve policing or to regenerate communities that had deteriorated markedly according to the older people who had lived there all their lives.

Help in emergencies at home

Even in their own homes, some people felt vulnerable. This was sometimes connected with fears of intruders from outside, but more commonly with accidents that could happen when they were on their own. People were worried about falling over or being taken ill when no-one was around to help them. Not surprisingly perhaps, people living on their own valued community alarm systems that had been incorporated into their homes or that they could wear for easy access. They also appreciated having someone who would check regularly that everything was alright. In this respect, wardens of sheltered housing and key workers attached to group homes were valued sources of support. Having proper back-up to deal with breakdowns in equipment (like lifts) was considered vitally important.

Confidence in staff

Many people depended upon a range of service providers coming into their home, enabling them to lead an independent life. Unfortunately, some users and carers were feeling very vulnerable because of the unsafe practices of staff who were entering their homes. There was much criticism of shoddy workmanship on the part of staff installing aids and adaptations, which could lead to users being injured. Mention was also made of inadequate knowledge and skills among care staff.

I have a home carer as well, and I mean, she's a lovely lady and a hard worker but she's not equipped to do a bed sore as I'm not.

We've had 'em say to my wife 'How do we put the pressure sore dressings on?' Now these sisters have got qualifications as long as your arm but hands on experience, forget it.

Furthermore, concern was expressed about home care staff failing to turn up, leaving individuals bed-bound and helpless. Both users and carers who had experienced poor home care services were very critical of these home carers and of their managers who failed to act on complaints made about their service.

And when you 'phone them up – the council – they say it's nothing to do with us, that's so and so agency, see and that's it

Transport

Few people mentioned transport possibly because these services were not discussed specifically. However, the difficulties experienced in arranging and paying for transport to bring people to the focus group meetings, were sufficient to demonstrate some of the difficulties people have in getting about when they are dependent on others for moving around outside the home. The few people who did raise transport as an issue did so in relation to their disabilities. Their concerns were about the inadequacies of existing transport systems and the fact that mobility support was limited to set times for collection and dropping off. Other comments related to service cuts which had reduced staffing and petrol budgets and therefore the number of visits and outings which were possible. Transport was of particular importance to people living in rural areas where the dangers of isolation from shops and social contact were more prevalent and the difficulties of getting to appointments to see doctors were considerable.

SERVICES

The main concerns that users and carers have about health, housing and social care services are the extent to which they are able to obtain what they need, when they need it and in a manner that is consistent and reliable. They also value links being made between services that are provided by different sectors, organisations and professionals. The extent to which services are linked (or integrated) has implications for their ease of access to provision, to continuity of treatment and care and to the overall shape and balance of provision available.

Service responsiveness and flexibility

There was a good deal of praise for individual GPs, community nurses, day and home care staff, housing support workers and care home staff, who were seen as helpful to individuals, finding out what they as individuals needed, 'being there for them' to provide reassurance, to sort out problems and to obtain help for them.

I have a brilliant GP, brilliant social worker who comes every three weeks 'cause I need it and I have speech therapists and all this sort of thing. The rehab team who've really tried to work with him although he's not had a stroke and that's what they deal with. Really they've been brilliant.

Equally, there were some complaints about individual staff who were described as patronising and unhelpful – largely because they failed to really listen to what users and carers had to say.

However, the overall message here related to systems rather than to individual service providers. Much of the dissatisfaction expressed by users, carers and staff centred on the extent to which services were organised in ways that make it hard for even the most helpful staff to achieve quick and appropriate responses to individual needs and preferences. Thus, it was often the rules, regulations and eligibility criteria that governed the actions of professionals and managers that seemed to hinder responsiveness and flexibility. Put bluntly, rigidities in the service system led to many people waiting for unacceptably long periods of time for an assessment or an appointment and then receiving provision that turned out not to fit their requirements.

Inappropriate provision

There were lots of examples of people being offered provision that they really did not want, preferring to have alternatives that would make their lives easier or would reflect their own life style priorities. Thus, disabled people (young and old) and carers had been offered a commode rather than a downstairs toilet; grab rails rather than a lift; residential respite care for a disabled child rather than a family link scheme preferred by the parents; personal care but no help with cleaning, shopping or gardening. Some housing provision, that had been purpose built or specially adapted for disabled people, turned out to be unsuitable, as when the design of a newly installed shower made it impossible for a user with mobility difficulties to use it.

There were also instances of older people and of younger people with learning disability being prescribed complex combinations of medication which they had difficulties in managing. The result was that some very vulnerable people were neglecting to take their tablets, experiencing unexpected side effects and occasionally becoming quite ill. Nobody appeared to be reviewing their medication nor taking steps to tailor medication regimes (from the collection of prescriptions to the use of drugs throughout the day) in order to fit the circumstances of the individuals concerned.

Timing of services

In terms of timing, services were being provided at inappropriate times – as, for instance, where home care staff arrived late in the morning to help people out of bed and get dressed and washed, or where they arrived early in the evening to help put them to bed. In addition, some services were not being provided at certain times of the day or night – even though there was a demand for provision at those times. There were also countless complaints about the length of time people were having to wait for services. In many cases, carers seemed to be bearing the brunt of these service shortcomings.

Some people were experiencing difficulties in getting any help at night. Carers, especially but not exclusively, were concerned about the lack of night cover. Help during the night was important for some carers because they wanted relief from frequent lack of sleep caused by attending to their relatives. Wardens in sheltered accommodation also expressed concern about the lack of night cover for residents, especially for those whom they considered to be very vulnerable. For both users and carers, help at night was about being able to contact someone in an emergency, where at the very least, reassurance and advice might be given. It was recognised that many GPs are reluctant to come out to see people at night and that calls for help were likely to be met by deputising doctors, few of whom would know the particular case in question. Some people were not happy with this arrangement but they had little choice in the matter as there was nowhere else to turn if they were worried about anything out of office hours.

Waiting times were a frequent source of frustration and, at times, real hardship. Users and carers reported long waits for an assessment, for the installation of equipment or adaptations to their homes, for GP and hospital out patients appointments, for surgery such as knee or hip replacement or cataract removal, for the results of a Housing Benefit application and for allocation to special needs housing. In many cases, the waiting was no more than an annoying inconvenience but, for some, it meant continuing to live with pain and discomfort, living in overcrowded or unsuitable accommodation that restricted movement, privacy and personal dignity, feeling depressed and, in one case, attempting suicide while waiting two years in a hospital ward for more appropriate accommodation and care.

While staff often expressed the same exasperation as users did about waiting times, one or two felt it was possible for services to be provided too quickly, resulting in inappropriate use of scarce resources.

It can also work in reverse when people sometimes go home too quickly and have adaptations done that are totally unsuitable within a few weeks, and they realise that they can't live at home, or they need different adaptations to the one that's been done. What you do in this interim period I really don't know, it's difficult. But we have had massive adaptations done – only for the house to be sold within two months of the person coming home, and we're talking about £20,000 plus, which is money down the drain that could be spent to help somebody else.

This litany of common problems across all care groups and parts of the country was lightened by a few shining examples of services that users and carers valued because they had clearly responded to identified needs. These could be simple things, such as taps or door handles being fitted quickly and with a minimum of fuss once users had indicated they were having a problem. Other examples, which had presumably been less straightforward to organise, included day centres opening on week-ends and on public holidays (including Christmas Day) and of rapid assessment schemes with excellent care packages put in place following hospital discharge.

Despite these examples of good practice, it was easy to see why some people valued being given money (through direct payments) to buy services suited to their own requirements or to top up what might otherwise be provided in the way of aids and adaptations. This arrangement – which some disabled people were starting to use – was seen as preferable to having to rely on professionals who could not or would not deliver what individuals needed.

Both users and front-line staff expressed frustration with a system that prevented quick and appropriate responses. Some staff felt strongly that it was not cost-effective to have such delays in services, as crises tended to build up requiring even more expensive solutions. Furthermore, speedy installation of aids and adaptations often meant that it was not necessary to use care staff as individuals could now function well on their own. Inevitably, some users and carers took their frustrations out on individual staff, although most staff seemed to understand why that would happen. Having to bear the brunt of people's anger or irritation nevertheless had its effect on staff morale and on their subsequent attitudes and behaviour. For instance, many admitted to adapting a defensive stance, even when users and carers were asking for openness and honesty.

Service Quality

In terms of service quality, there were many examples given of shoddy work (in installing aids and adaptations); faulty equipment (community alarms); and of care staff failing to turn up on time or at all.

We 'phoned them on Saturday 'cos the other carer was leaving....but there's nobody turned up this morning and the wife 'phoned up and they said "Sorry we haven't got nobody to send round". Well, what's the good.

Some users and carers were also very critical of health and social care staff who they felt were ill-equipped to work with very ill or disabled people, either because of their patronising attitudes, or their lack of basic knowledge and skills which could lead to neglect or could endanger vulnerable people.

Concern was expressed about the difficulties in obtaining specialist medical and nursing care required by people with neurological conditions (such as MS or Parkinson's Disease) or chronic conditions like arthritis.

It's taken over at least 15 years from when I first started to become ill. I found it was very difficult to actually get the treatment that I really needed and somebody first of all to diagnose my condition and then be referred to any kind of specialist help. It's taken a long time to the stage where I am now. I'm actually getting the help I need now and that's involved, you know, seeing a specialist and having treatment from physiotherapists

In the absence of specialist help, users and carers who had lived with these diseases for many years could be quite contemptuous of doctors and nurses who had little experience in this area.

You know, I got a grovelling apology (from the hospital) and they said "Well there was nobody there who knew about Parkinson's". I said, yes there was, there were two people but you didn't even bother to ask us, you let some junior doctor take charge of this and this is what happens

Service integration

Co-ordination and continuity

One of the most serious problems for users and carers was the bewildering number of people, agencies and paperwork they had to deal with. There was praise for workers who succeeded in co-ordinating provision for them (GPs, social workers and Community Living Organisers). People also appreciated having a variety of services located on one site, such as day centres where users could access hairdressing, have a bath, bring their laundry, use chiropody or physiotherapy services and see a dentist or optician; or where care and adapted accommodation had been linked together in supported housing; or where outreach hospital services become available in local clinics and surgeries.

.....and if you want to know anything ring up so and so and they will tell you. We have got a one-stop-shop now, and you ring up....anything wrong with the house and they will put us on....so you are alright that way.

Where these connections had not been made, people found that they had to make their own way through the maze of services. This could entail successive phone calls or visiting different establishments, sometimes making long and difficulty journeys across urban boroughs or rural counties. For many people, these attempts to secure the different services required were tiring and irritating, while others experienced the whole business as maddening or felt inclined to give up. (see Communications section for more on this theme.)

At a more strategic level, there was evidence of agencies failing to work together, resulting in poor provision for vulnerable people. Examples here included disputes about health authority and local authority responsibility for paying for services for a young man with autism and confusion among users, carers and staff about where responsibility lay for funding and providing of hoists. There were also instances of discontinuity in treatment and care, where physiotherapy had been provided while in hospital but not in the community, following discharge from hospital.

Strategic planning

On the housing front, there was evidence in one area of severe shortages of adapted sheltered accommodation for people with learning and physical disabilities, alongside a reasonable or sometimes excess supply of such provision for older people. While this imbalance was known to the authorities concerned, there was no apparent sign of the responsible agencies getting together to re-shape existing provision. Difficulties in accessing rented special needs accommodation were exacerbated by confusions among users about how to apply to the many different housing organisations, each of which has its own points system. Some of these difficulties might have been eased if efforts had been made to develop an integrated lettings system. As it was, it looked as if local authorities and housing associations were competing with each other rather than collaborating to achieve a more efficient use of scarce resources.

While concerns about services crossed users and carers groups, criticisms of service inadequacy appeared to be particularly high among carers and young adults with physical or sensory disabilities. Although it was clear that some long term carers felt that things had improved in recent years. They were by no means perfect but at least they were not caring with no help whatsoever (as some had been for 5-10 years or more) Older people and young people with learning disability tended to express comparatively high levels of satisfaction with the services they were using. It is not clear whether this reflected any objective difference in service investment for those groups or more modest expectations on the part of some groups. Some combination of the two may well explain the differences.

Where services were responsive, flexible, reliable, consistent and co-ordinated, people with multiple needs were well –supported and prevented from falling through the net or left in limbo. Effective linkages, brought about by strong collaboration, resulted in provision that people regarded as both effective and efficient and what, in the end, 'good' community care was supposed to be all about.

Chart 3: Factors contributing to success in services

- willingness and ability of providers and commissioners to think creatively
- quality of staff supervision and management
- human resource issues (including recruitment, retention and training of staff)
- middle or senior management finding out about users'; and carers' experiences of services and then acting on that information
- users and carers involved in evaluating services
- range and amount of provision available to offer people

COMMUNICATION

Information

Information is seen as the key to the provision of good services by users, carers and staff. Without it people cannot know what they are entitled to or what is available to them. Lack of information restricts choice and makes it difficult to know how to get access to services.

Health care

Users and carers were particularly concerned about the lack of information they were given about their health and the medication they were prescribed. They were also concerned and often upset by the way in which this information was given or not given to them. There seemed to be a particular problem with hospital doctors and consultants. GPs often provided a better service and community nurses were also found to be helpful.

People with learning difficulties and older people were sometimes worried about the effects of medication and they did not always understand what the side effects may be. Some people had been given good information by their GPs and some had been provided with mechanisms which helped them remember when and how many pills to take. Those people who had to be given injections had them administered by district nurses who came to their homes. The lack of information about the effects of medication was also of concern to older people. One person who was diabetic said that his doctor had not explained what being diabetic meant nor what the effects of the tablets were but a district nurse visited once a week. He had read the information on the box of tablets because

It gives you more information where the doctor will not tell you. If it's something that makes you sick then the doctor should tell you... I was asking other people and they had relatives who were diabetics and I'm going through the same stages as what they were going through with their friends and family, so it gives me more heart to carry on in that way

Some users with learning disabilities said that it helped them to remember instructions about tablets and information about their illnesses to take someone else along to the consultation.

Older people and people with physical disabilities were much more concerned that doctors would not give them information about their conditions and treatments. Sentiments like ' No one tells you anything. I want to know the truth' and ' The only information I get is what I ask for' were frequently expressed.

Nobody seems to want to tell you anything.....if you ask them something you get fobbed off with an answer. Well, I don't want to be fobbed off, I want to know the truth. I want them to be as honest with me as they would be with their own family and when I ask them a question I expect it to be answered I don't expect them to turn round to the nurse and say something to them. I do object to that. I want the information. It's my body so I should have the information I need for my illness.

Carers sometimes felt they were excluded from the information about their relatives' conditions and medication which added to the burdens they already carried. This exclusion was a source of irritation and frustration to some carers because felt that they were left to carry on caring and taking responsibility 'in the dark'.

They have never, ever, even in the hospital, the doctors or anybody took me aside and explained how far her condition had gone, what they could do for her or anything of that nature, wasn't given any booklets or anything that I could have read up on. I was actually ignored, and that's one thing I felt like we should be consulted.

These problems with information about conditions, treatments and medication are widespread and not limited to people with long term care needs. All the research with users and carers of the health services shows that people want more information about their conditions. Nevertheless, these groups have particular needs and the strength of feeling and frustration they expressed should prompt swift consideration of them.

Social care

Social service information needs centred around charges, complaints procedures, assessments, carers, money and benefits. Information about all these aspects of services was felt to be difficult to get and sometimes difficult to understand. Eligibility criteria for allowances were found to be incomprehensible to most people. Staff expressed sympathy with users and carers about this aspect of services and often helped people to fill in the forms. They themselves were sometimes unclear about the criteria and did not understand why some clients received allowances and others did not.

Lack of information about charges and payments for services caused a fair amount of confusion and upset to clients. One lady who had moved from residential care into a nursing home was thoroughly confused when she received a large bill from the former. Several people were surprised when they received bills for day centres because they had not been told that charges were being increased. Similar experiences occurred with charges for home care.

Where good information was provided appreciation was expressed. Sources of this kind of information were listed as council booklets, one stop shops, voluntary organisations, help-lines and information services. On several occasions during the focus groups, one person would mention a good source of information and everyone else would ask where or how they could find it. Dissemination of information is an important issue and one which the charter should consider.

Housing

One of the main complaints about information for housing and equipment was about sources of advice, information and help. Very few people knew where they could get information about the options open to them. So, for example, one young man with serious physical disabilities who, on discharge from hospital had to be found a more suitable flat than the one he had lived in before the accident, was given no help or advice from the Council. His parents were left to sell his existing flat and find another one.

All they said (the Council) was' Well he's buying his own place'. They wash their hands of the case, they won't have no dealings with it....well it just got on top of me so much I even tried to kill myself in (hospital).

Another problem was lack of information about waiting times and assessments for aids and adaptations. Some people were told that the waiting time for an OT assessment would be a year but others were left not knowing.

We kept asking and asking and after three years they eventually acknowledged...my doctor wrote a few times as well but the letters seemed to go astray or they get neglected...after your doctor keeps *pressuring for three years they notice your letters are mounting up and then they say 'They should get to see you in about four months'*

Virtually no one had been told that they could use the value of their own home (if they owned it) against the cost of the adaptation or equipment. If that information had been given in this case, three years of the carer and user's lives would have been made easier.

On information generally, staff also referred to the importance of good and timely information for users and carers. One person said:

Information has always been the key to independence

As well as recognising the importance of information for users and carers, staff were also quite critical of themselves for failing to provide it and to share it with each other. For example, during one of the groups, someone mentioned the existence of a guide to learning disability services for GPs; no one else knew about it. Because of their lack of knowledge and information, staff said that they failed to refer users to the right or most appropriate service. One suggestion to overcome this was an A to Z of community services for specific client groups.

However, production of such guides and booklets does not mean that people will receive the information contained in them. There needs to be an effective method of dissemination planned from the outset. Services are too complacent about assuming that users and staff 'know' that this kind of help exists

Access

There are two separate issues which concern people about access; access to buildings and within buildings and access to services. The first seriously affects people with visual and hearing impairments and people using wheelchairs.

Access to and within buildings

The major problem here was with NHS buildings, (hospitals, clinics and GP surgeries), with housing and occasionally with other public buildings. All of these affected the lives of people with physical disabilities. The lack of consideration of their difficulties within the NHS and housing, sometimes with housing built for them, was particularly noticeable.

Wheelchair access is a well publicised problem but the needs of people with visual and hearing impairments are often neglected through thoughtlessness. Effective sign posting, for example, was something raised by people with learning difficulties who could not read. This problem can be resolved easily by use of picture signs which would also help those with partial sight. Lack of consideration for the needs of people with hearing impairment can be resolved by awareness of simple things like attracting attention by moving to speak directly to people rather than calling their names from a distance. This is something easily remedied.

Doctor's surgeries. There are four or five doctors working at the same time and when they're ready for the next patient they simply come on the public address system and say 'Mr Smith, room one please' Bang that's it. You've got to know your way out of the waiting room let alone know which door off the corridor it is

Lack of consideration for people using wheelchairs in new, specially built or adapted housing, is unacceptable. One person lived in such accommodation where:

You can't get out if there's a fire because the windows only open to a foot and the catch is three feet over my head to open the window wider. The oven opens into my lap and I've got five lawns to cut myself...and this was purpose build - purpose built by able-bodied people. Surely these people can get their heads together and let disabled people have a say in what they're building...

The case rests !

Access to services

Information helps people to access services and this has already been discussed (above) but there are many other barriers around getting into services. These include; telephones which are almost always engaged; being kept waiting on the telephone (expensive); gatekeepers like receptionists in doctor's surgeries and some social service personnel who appear to bar the way; filling in endless, unintelligible forms and having to give the same information to people over and over again. The frustrations in these situations are common to us all but are especially difficult for people who need to use a range of services regularly. Providers need to consider ways in which these problems can be overcome or ameliorated.

Once again it seems that complaints were much more about unhelpful systems rather than individuals. Many users and carers praised individual staff who had helped them overcome or avoid these kinds of problems.

Attitudes

One of the most distressing things about the everyday lives of these users was living with discrimination. People with learning difficulties suffered a range of unpleasant attitudes from college tutors, employers, neighbours and professionals. People who bullied them, threatened them, put them down and generally treated them badly. Their desire to be treated just like other people was pre-eminent.

People with physical disabilities suffered more in situations where people saw only their disability and not the adult, intelligent beings that they are.

Older people felt that they were of no value and often suffered from low self-esteem and being a burden to their relatives and on the services.

The attitudes of society generally are hard to change but there are some groups of professionals who should know better. Many of the comments people made in relation to attitudes were the result of experiences with professionals in the health service, particularly hospital clinicians. It was uncommon for people with learning disabilities to be spoken to directly by doctors. Usually they spoke only to the accompanying carers.

They usually talk to the staff you know, they don't talk to me. He also goes into the kitchen and talks to the staff.

I don't feel I've got a right to talk to my own doctor.

Another person pointed out that health service staff often confused learning disabilities with mental illness.

People get it mixed up with mental illness and it's completely separate...people still don't understand it. I think health still doesn't understand it which is frightening really...It's the same in social services, there are people higher up who don't understand it and get it mixed up. And whenever they talk about it they lump learning difficulties and mental health (together) and it is a completely separate thing.

One solution put forward by this group was to educate nurses and doctors about learning disabilities and how these conditions differed from mental illness and other conditions like epilepsy.

In contrast, most general practitioners and community nurses were said to be much more understanding and supportive There were also compliments for day centre staff who were sometimes seen as people who listened and treated users with consideration and respect.

Staff in the focus groups confirmed and expressed anger about discriminatory attitudes in society and of some people working in health, housing and social care.

RESOURCES

Resource issues frequently arose in discussions as users and carers talked about how they used their own money to meet costs associated with illness or disability, how they were affected by current expenditure constraints in health, housing and social services and what they felt about the way public money was being distributed.

Public and private finances

Many users and carers were paying out of their own pockets for social care (including home/day/residential and respite care), for adapted housing (including ramps and rails enabling access to their homes) and, on occasion, for health care. In the latter case, a few people had paid for private physiotherapy, counselling and psychiatry for their relatives, simply because none of these services were available through the NHS in their area - at least not without a long wait - or doctors had suggested they would have less of a wait if they opted for private treatment.

Well, I do, I employ a cleaner myself. And I get the Attendance Allowance so I pay it out of that, you see.

...they gave him shock treatment and he had fibrillations which caused his stroke which was the last thing, so I paid, I thought I must do it, I paid privately to go somewhere else.

We also paid for the hoist to be moved so it would hoist him directly into the bath and onto the bean bag and you know, we paid for it directly because they didn't have any money. I think it was about £800, something like that.

Regular income from salaries, pensions, or welfare benefits was being to used to pay for these services, but in some cases, people were drawing on savings that they had accrued before the onset of illness or disability.

Consumer expectations

There was some indication that users' and carers' expectations of services changed somewhat when they began to pay directly for services. They saw themselves as acting as consumers, with all that that means in terms of choice, control and service accountability. However, while they were having to pay for a service, some found themselves being treated by providers as if they had no say in what was being provided and when, and as if they should have been grateful for what was being offered or delivered.

Fair charges

When it came to the question of paying for services, most people felt it was reasonable for those who could afford it to be paying something towards the services in question - at least as far as housing and social care were concerned. Few were opposed in principle to the concept of charges. One older woman attending a day centre said:

Most of them pay £3 but if you have got a separate pension, it goes up. I only get £12 a week from my husband, so they make my payment £6.45. But I think it is worth it.

The exceptions here were people with learning disability and their carers who tended to be very unhappy about the recent introduction of charges for day centres and transport which had, until recently, been provided free of charge.

The main controversy about paying for services centred on the amount people were expected to pay. Some were finding it hard to find the money, especially when charges for day and domiciliary services had been substantially increased over the last year. Others clearly resented having to draw hundreds of pounds from savings, in order to pay for major alterations to bathrooms, doorways and other parts of houses or flats. Some people reported that they had decided not to go ahead with the provision being offered, because of the cost.

It was also regarded as unreasonable for disabled people to have to pay not only for themselves but also for supporters who accompanied them on outings and holidays, pushing wheelchairs and helping with personal care tasks.

So they said I could have a holiday but I would have to find a carer to take me. I would have to pay that carer, I would have to pay for the holiday for the carer. And I would also have to pay £15 a day for their expenses. Well, I thought that was a bit much.

Carers also tended to feel aggrieved about paying for respite care, particularly when that could amount to several hundred pounds for a short stay in a care home.

There were some examples of local authorities agreeing 'shared funding' packages with users which were much appreciated by the individuals concerned. In some instances, the ratio of public/private money agreed took users and carers by surprise, for they had not expected to get very much help at all.

In actual fact we did very well. I mean I've got quite a good story on it because we were told by social services that we had too much money so they couldn't fund a ceiling hoist for us, but they referred us, told us to get in touch with the Housing Department and I did this, not very hopefully, thinking we'd have to pay for it ourselves. And they came out and took details of all the vast amount of money we've got (laughing) and then came back to me and offered to pay three quarters of the cost and I nearly died! With shock! They arranged it all, got it all installed, we paid the difference and that was it and it is brilliant.

Examples like this demonstrate a 'can do' attitude in public services – something that users and carers wanted to see more of.

Pressure on resources

During the course of discussions, it was clear that many users and carers were well aware of resource difficulties affecting health, housing and social services. There were many references to the Council or the health service being 'strapped for cash'. Some of this awareness arose from media coverage of expenditure constraints, but there were also many occasions where service staff had told people that there was not enough money available to provide sufficient services for all the people who needed them.

Impact of resource constraints

In all three areas, there was evidence of people being adversely affected by cuts in services. Some mentioned cuts in social care services, such as having their home care hours reduced, being notified that their day centres would be open for fewer hours and noticing that there were now fewer supporters available to accompany people on day trips. Many others talked of problems in the NHS, with pressures on hospital beds, shorter stays in hospital and reduced numbers of staff on the wards. Valued services, like a Benefits Helpline, were reported to have been closed down.

Targeting

Staff were concerned that waiting times for adaptations (including assessment and installation) were lengthening and that tightening eligibility criteria meant that fewer people were being offered help, as priority was being given to those judged to be in most severe need.

Service users had noticed the consequences of this targeting policy. For instance, some older people, who had lived in sheltered accommodation or care homes for some years, commented that more people with quite severe disabilities were coming to live with them and that this was changing the composition of residences.

That is what they seem to be putting into the Close now. People in care....some of them can't come out of the bungalows now. And they are getting people in to do the cooking, you know, meals and things like that for them.. But we are not so bad, we can get out.

This was not necessarily a problem but clearly some people were bemused as to why it was happening and what it meant. One can only assume that nobody had ever talked to them about changes in eligibility criteria governing access to their placements.

Equitable distribution

Users and carers were aware that health, housing and social services varied according to geographical area and that the kinds of help available could be determined by where they happened to live. They disapproved of this uneven distribution of resources which, as far as they could see, did not reflect differences in need. While some appeared to be resigned to these differences, others were angry or exasperated that they could not get services that were readily available in neighbouring areas.

Means testing

Owner occupiers and people with middle incomes clearly felt they were being treated unfairly by local authorities.

We sort of have a social worker – who comes and tells us to get our own care package because we've got too much money – and they just say 'advertise yourself' so at the moment I still look after him myself all the time.

You don't mind paying for some things but her husband and my husband – they both had sort of quite high-powered careers. Through no fault of their own they've had to retire early. We've both always worked and paid into the system on the assumption that should anything happen, you know, we would be looked after. And then suddenly you're assessed and your qualify for nothing – and you get these really intrusive forms...

As mentioned earlier, some were drawing heavily on savings to meet the costs of disability (which few could have predicted or prepared for). Some believed that local authorities over-estimated their ability to pay for services. And, in one or two cases, people believed there was no point in even approaching the Council for help in either adapting or repairing their homes or in obtaining care services.

Dissatisfaction on the part of this group did not focus on means testing per se but on the ceilings that were being used to trigger charges. There was also a good deal of annoyance about professionals' perceived assumption that individuals who had previously built up savings and contributed to pension and insurance schemes could now manage without help from public resources. This was patently untrue for some users who previously had been teachers or solicitors but who had now fallen on hard times because of their illness or disability. Among some older people, there was a sense that they were being penalised at a time when they had expected help to be freely available.

While people accepted, on the whole, that queues, waiting lists and eligibility criteria were the result of agencies trying to mange demand for their services, there was some suspicion that priority was not always being given to those in most need. Some people believed that who gets what depends on who shouts loudest or having the 'right connections' (usually getting councillors to intervene on behalf of individuals).

Chart 4: Factors contributing to effective use of resources

- clarity across the different sectors about policies determining what has to be paid for and what will be provided free at the point of delivery
- openness and honesty about financial matters with users and carers by staff
- action to prevent inappropriate reliance on expensive care options
- joint commissioning and funding of services for populations and for the individual
- adequate resources

VIEWS ABOUT THE CHARTER

There was a fair amount of cynicism about what charters could achieve although most people welcomed the idea of a booklet or document if it would help them get access to services, information and help. Some people also thought that it might help to change attitudes in society. Nevertheless, peoples' experience of charters was such that they had little confidence that it would really do much to change their lives.

I'd like to say about charters that they read like fiction. They sound so wonderful and positive but when your personal experience is so diametrically opposite it just adds insult to injury to actually read them. It's like a slap in the face - you know, how can my experience be so far removed from what I'm supposed to be getting ?

Rights versus expectations

Setting aside these low expectations of charters, there were some useful discussions between participants about whether a long term care charter should contain rights or expectations. Most people felt that rights were stronger and better for them because they implied entitlement. Others had problems with the notion of expectations because they felt that they could never be met or that there was no redress if they were not met.

Well, if you're only talking about expectations I don't understand what the point of a charter is because if your expectations aren't fulfilled there doesn't appear to be anything you can do about it

One or two older people felt that it was wrong to have rights because it meant that people were demanding things

Staff also debated the issue of rights versus expectations and some felt rights should be specified whilst others were nervous about the implications of a charter which specified peoples' rights

And the fact that we can't promise anything..... creates a climate of sort of gratefulness when really it should be their right; you know they're so grateful because we're saying 'We'll try our best, we'll put a good case'. But really it is not right - it's their right.

The alternative view was put.

I think the problem when you're setting up a specific charter is that you're more or less saying to people that they do have rights and then they can become more aggressive about their rights.

Other staff thought that a document which offered national guidelines was a good idea because people could use it to take to services and say 'Here you are, this is what I can expect'.

Content

Values and principles

Several people mentioned the fact that a charter should set out some fundamental principles and values. These included **honesty**; that providers should be open and honest about what they could offer to users and carers: an underlying **philosophy** which emphasised a positive helping approach rather than a negative 'can't do' approach: the principle of **partnership** of working with clients, with other professionals and organisations; and most importantly the commitment to **user involvement** in decisions relating to their care. **Equality** and **freedom of choice** were identified as important principles as were **the right to be treated with respect** and **the right to be listened to.**

People in the groups, including staff, had many specific suggestions to make about the content of a charter but they all fell within the categories of **information, advice, service standards or processes and general issues, service standards or processes and general issues.**

- **Information** about:
  - conditions, treatments, medication
  - care after discharge from hospital
  - waiting times for hospital and GP appointments
  - repairs
  - allowances and financial information for aids and adaptations
  - disabled parking
  - entitlements in residential homes
  - a register of reliable builders
  - housing support
  - eligibility criteria
  - waiting times for assessments, aids, adaptations
  - the tasks home carers are allowed to do
  - entitlements to benefits and other sources of financial support
  - the range of options available for all services
  - complaints procedures

- **Advice** about:
  - self-help methods and health aids (e.g. walking sticks)
  - housing allocations and choices
  - allowances for aids and adaptations
  - housing support

- **Services**
  - one-stop access points for information and advice
  - regular health checks after the age of 75
  - what to expect from GP services
  - **carers** meet carers for regular up-dates on patients' health

- accept older people onto GP lists
- faster housing allocations
- purpose built housing for people with physical disabilities
- faster and better repairs services
- housing management and neighbour nuisance
- a liaison/link worker to co-ordinate all service provision for each user and carer
- regular inspection of home care providers
- training for home care providers
- ensure continuity of home care providers
- respite provision by trained nurse if necessary
- **carer** training for jobs like injections, lifting, dressings
- extended day care activities

- **General service**
  - carry out service reviews every year
  - improve collaboration/liaison between health and social care
  - local councillors to take responsibility for one aspect of services and to be informed
  - introduce an appeals procedure with teeth
  - improve efficiency of benefits offices
  - provide (replace) the Social Security help-line to help sort out benefits/allowances

- **Money / allowances**
  - provide a realistic wage for **carers**

- **Other issues**
  - introduce independent advocacy services and fund them properly
  - extend educational and work opportunities
  - provide training for work for younger disability groups
  - provide professional training for awareness of disabilities
  - provide better access to transport
  - provide work in protected environments
  - provide clear signing in public building

Format

Some useful comments were made about the way in which a long term care charter should be presented. Some people thought there should be separate charters for each of the groups and for carers. Others thought that a national charter was vital for reasons of equity. People with visual and hearing impairments suggested that the charter should be produced not only in booklet form but also in Braille, large print and video.

Several people, including staff, mentioned the importance of having an effective dissemination strategy which would not only publicise the existence of a charter but also make sure that it was available at all points of contact. Staff should also be made aware of it and have copies with them when visiting users and carers.

THE LONG TERM CARE CHARTER

The context for developing a new Charter

In our analysis of focus group discussions, three issues have emerged that the Department of Health may wish to take into account when developing the new Long Term Care Charter. First, we look at the political and social climate within which a new charter will be launched, received and implemented. Second, we consider the aspirations of people with long term illness or disability to lead an 'ordinary life' and the extent to which that contrasts with their common experience of disadvantage, discrimination and exclusion. And thirdly, we examine the need for a distinctive cultural shift in community care so that services can develop to meet modern day expectations of users and carers.

- ***The political and social climate***

  Among users, carers and front-line staff, there is a widespread perception that resource constraints have tightened across housing, health and social services in recent years. They recognise that these constraints are restricting access to services either through waiting times or through eligibility criteria that exclude those deemed to be in 'less need'. They also see these same resource constraints leading to increased service charges in means-tested provision and to increased resort to their own (or their family's) private resources in order to purchase provision that might not otherwise be made available.

  Many people seem to be resigned to this, although it has to be noted, that this widespread acceptance is tempered at times by strong emotional reactions, including irritation, anger and despair among some users and carers and among some staff who appear to be weary of having to work in services characterised by frequent shortages, steady decline or recurrent crisis. Nevertheless, there is little evidence of any widespread call for a fundamental change in community care policy, nor any expectation that the current Government will introduce any radical reform that might put an end to the difficulties being experienced in health, housing and social services.

  However, this does not mean that there is no desire to improve the current situation. On the contrary, people in the focus groups came up with lots of suggestions about what should be done to make things better. They were, at the same time, realistic about the changes that might be achieved in the current political and financial climate. It could even be said that their demands for change were quite modest, being couched in terms of 'making the best of things' and 'making better use of scarce resources'. This desire to obtain better value from current resources was linked to a view that both human and financial resources were being badly used at times.

  Alongside these policy and resource issues, there is also evidence of an emerging consumerist culture among users and carers. In a decade where great stress has been placed on market values within public services, and where people have (sometimes for the first time) paid in part or full for services received, some users and carers are starting to behave like consumers rather than as passive recipients of care. This means that most users and carers do not feel 'grateful' when they receive help from public services, and that they expect proper standards to be maintained. Some mentioned methods of redress when a 'contract' is broken. A few go further and expect to be compensated when services are less than satisfactory.

  The proposed new Charter will need to take account of a climate of opinion that is somewhat different to that that would have been evident earlier in the 1990s. It will need to avoid promising what cannot be delivered, but at the same time adopting an aspirational approach that would go some way to addressing the key concerns of users, carers and staff. It will also need to recognise that people's experience of health, housing and social services over the last few years has left them feeling rather sceptical and sometimes cynical about charters and their capacity to change anything. In this respect, it might help for the new Charter to spell out how and why it is different to its predecessors.

- ***The social exclusion of disabled people***

People with long term illness or disability clearly want to lead ordinary lives, where they have control and choice in their daily life and where they are able to take part in a range of activities in the community. Much of what we heard in the focus groups suggests that this is far from being a reality for many people, who are treated paternalistically at best and rejected and abused at worst. There is no point in repeating here the stories of social exclusion that arose in the course of focus group discussions but it is worth noting that it was by no means unusual for disabled people of all ages to experience poverty, segregation, and social isolation - all of which combined to set them apart from other people and to deny them the 'ordinary lives' that they so much wished to have. It is also worth noting that a number of users were refusing to put up with behaviour that they regarded as demeaning and discriminatory and were openly challenging services, demanding that they move from doing things to people and towards working with people.

The new Charter will need to be framed in a way that tackles head on the disadvantage and discrimination that so many people face. It will need to give a strong lead on how people should be treated as equal citizens when approaching public services and to show what action might be taken when the attitudes and behaviour of service providers falls short of what is required. It would also be helpful to include examples of service approaches or models that promote social inclusion, thus providing inspiration for the many staff who want to enable ordinary living and to acknowledge the good work that some are already engaged in.

- ***The need for cultural change in community care***

We heard a great deal from the participants in the focus groups about a system of community care that is perceived as defensive, excluding and imbued with 'can't do' attitudes. No doubt this owes much to resource constraints mentioned earlier, where eligibility criteria have been used to screen people out of the system and where managers and front-line staff have had insufficient resources to cope with increasing demands. In these circumstances, it should not be surprising that staff - by their own admission - have often acted defensively, only providing information when asked, and failing to advise potential users about places they could go for help.

However, as we have shown, users and carers want services to be presented in an honest and transparent way and for staff to adopt a 'can do' approach (which may sometimes mean "I can't help you but I know someone who can"). While they do not expect a brave new world in community care, they would like, at the very least, to know what their rights are, to have as much information as possible about services and sources of financial help across health, housing and social care sectors. They also want access to brokerage and independent advocacy to help them find their way into and through the maze of community care services. Such an approach allows for service users and providers to exercise their mutual rights and responsibilities. It also offers users and carers opportunities to participate in decisions and to make choices – a situation that would be preferable to feeling like players in a lottery where only the lucky few get through.

Considerable shifts in service culture will be required at both central and local levels, reflecting notions of active citizenship and social inclusion. From the evidence gathered here, it would seem that greater openness is unlikely to lead to unprecedented demands on resources. On the contrary, it could lead to greater understanding of resource constraints and open the way for users, carers and staff to make shared decisions about resource allocations and service use in an atmosphere of 'best can do in the circumstances'.

The new Charter is much more likely to be acceptable to a sceptical audience if it can be framed in a way that demonstrates the government's determination to bring about that cultural change. This would entail creating a charter that points the way to better public services and avoids defending the status quo. It would mean translating values into action, and creating incentives for staff to work in a way that is genuinely helpful and facilitative.

Content of the Charter

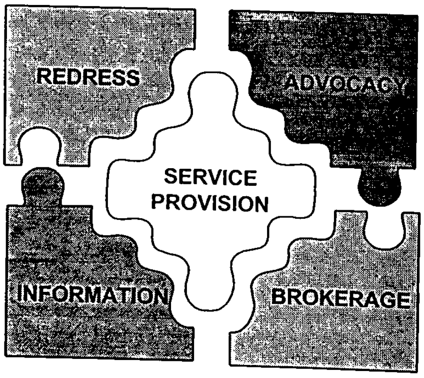
- ***A statement of values and principles***

  The Charter could begin with a short section, laying out values and principles concerning the citizenship of disabled people and the extent to which they and their carers can expect to participate in ordinary community life. This section should also emphasise the need for providers of health, housing and social services

  - to be honest and open about available provision and alternatives where these exist
  - to ensure that users and carers have maximum control and choice in their lives
  - to work in partnership with users and carers regarding their own treatment, care and support and when planning and monitoring services.
  - to promote a positive 'can do' approach among staff.

- ***A framework for better care and support***

  The main body of the Charter should focus on key dimensions of service that are crucial in determining users' and carers' experience of community care. Added together, they provide a framework which can be used to show users and carers what they can expect and to show agencies and staff what is required of them, regardless of whether they work in health, housing or social services or in the public, private or voluntary sectors. All elements of this framework are interdependent like a jigsaw where each component part has to be the right shape and size and they must all fit together to create a coherent whole (see diagram 1 below).



Elements of the framework include:

i) **Information**

Users and carers should be able to obtain a wide range of information about their health and treatment, about services and how to access them and about financial matters, such as fees and charges they may have to pay and benefits, grants and loans that are available. Inevitably, they will want to seek information that cuts across health, housing and social care sectors and that goes beyond to encompass education, employment, transport and so forth.

With the right information available at the right time, users and carers will be better able to maximise control and choice in their own lives and to exert influence over the development and delivery of services. In some instances, information is all that they may require from agencies, as some will then proceed to help themselves (through self-care or by obtaining goods and services directly).

ii) **Brokerage**

Some people with long term illness or disability will need help in accessing information, interpreting it and applying it to their own situation. Some will want advice about what to do, where to go and how to manage particular problems or dilemmas. Some will need assistance in pulling together relevant information and approaching different types of services. Users and carers should be able to contact people who can act as 'brokers', helping them to negotiate their way into and through the service system. They should also be able to access this kind of help through local provision such as one stop shops, help-lines etc.

iii) **Advocacy**

Users and carers should be able to call on the services of independent advocates in those circumstances where they are unable or lack the confidence to speak up for themselves, where they experience difficulties in obtaining the information and practical help that they require and where they wish to challenge decisions being made about service eligibility or make complaints.

iv) **Service Performance**

People will want to know what they can expect in terms of choice, reliability, flexibility and safety in services. They will want to know whether services in their area are performing or expected to perform to the same standards as elsewhere, and for this reason, it will be unsatisfactory to leave any setting or monitoring of standards or targets to the discretion of local agencies.

Furthermore, users and carers should be involved in monitoring performance as a means of keeping track of progress being made and in terms of helping them to understand the difficulties experienced by staff and service providers.

v) **Redress**

When services are found to be unsatisfactory, users and carers will need to know who is responsible and ultimately accountable for those shortcomings. They will need to know how to go about seeking redress and what action they can expect to be taken to put matters right. In this respect, we suggest that serious consideration should be given to requiring agencies to compensate in cash or kind those users or carers who experience service failures, such as care workers failing to turn up or to work the full length of time agreed, or faulty aids or installation of equipment, or dangerous practices that endanger health and well-being.

- ***Giving the Charter 'teeth'***

In all our consultations concerning the Charter, there was unanimity that it should make clear what people can expect in quite specific terms and what action can be taken when performance is less than satisfactory. There was much talk about rights and entitlements, and of setting national standards but also some recognition of the difficulties these present.

In terms of rights, we recommend that the term is used only refer to entitlements in law where challenge can be made in the courts where necessary when seeking redress. There are, of course, few such rights relating to health, housing and social services but where they exist, and are relevant to the following key concerns, they should be mentioned. A good example here would be the right to a second specialist medical opinion.

When it comes to the quality of service, users and carers identified time and time again several aspects of provision that they felt to be of crucial importance and where responsive and timely action could make a real difference. In addition to the provision of information, brokerage and advocacy earlier, key service issues included:

- specialist health care necessary for the management of chronic conditions
- the provision of personal care at home
- the provision of aids and adaptations
- availability of respite care providing carers with time off
- allocations to suitable housing and appropriate environments

The Charter could, with good effect, concentrate on these five areas of concern. The question then arises on to whether standards, targets or benchmarks should be set.

Among users, carers and staff alike, there is much support in principle for setting standards relating to the reliability, timing and flexibility of services. However, we are aware that there are real dangers in setting standards that cannot be delivered or that are inappropriate. Response times tend to fall into those categories, as when standard waiting times set for an assessment turn out to be too late for urgent cases and unnecessary for less urgent cases, or when the time set is desirable but unachievable without extra resources to manage demand. Moreover, the real test of standard setting is that service users should be able to seek redress when services fail to meet the standards set.

In our view, national standards should only be set where they can realistically be achieved over a specified period of time by the responsible agencies, and where action can be taken regarding inadequate provision. In this respect it may be more sensible to focus on targets that authorities will be expected to meet over time. Here, particular attention could be given to waiting times for aids and adaptations by specifying a time beyond which it would be unreasonable to expect users to wait for either an assessment or the provision of agreed equipment; to the frequency with which carers with heavy caring responsibilities could expect to have respite care or to period of time within which vulnerable people needing re-housing can expect to be offered an alternative housing option.

There is clear scope for adopting a bench-marking approach in the Charter, providing details of good practice provision which users and carers can use to compare performance of services in their own areas. There are also a number of service areas where more experiment and innovation is needed to achieve better solutions to problems arising. This is perhaps most evident in the area of service co-ordination and integration. In these cases, it would be premature to set standards on targets but it might be helpful to include examples of good practice that are emerging in the field. These might include:

- integrated adaptation services
- tenancy support services
- integrated housing allocation systems
- care and housing provision
- integrated health and social care teams supporting particular groups of vulnerable people.

- ***Implementing the Charter***

  Agencies and staff at local level will be responsible for implementing the national Charter. It would clearly be helpful if guidance could be produced by the centre showing staff what Government expects of them as they work with users and carers. We suggest that that should include the following requirements;

  - People (users and carers) must be involved in decisions about their care and treatment and in service planning and evaluation
  - People should be treated as partners in decisions about their treatment, care and support
  - The dissemination of information needs to be carefully planned by local providers so that people who need to use services can easily get in touch with the appropriate person or agency
  - Monitoring mechanisms should involve users and carers and include ways of documenting progress towards targets and or quality improvements
  - Complaints procedures should take a positive stance towards people making complaints and use the information collected to make service improvements
  - The process of setting standards (at local and national level) should involve people who use services
  - Ways of maximising users choice and value for money e.g. voucher systems, should be explored
  - Training of staff should include awareness, knowledge and sensitivity towards people with disabilities as well as skills required for working with people with complex and chronic conditions
  - Providers should consider how to integrate housing lettings and care and housing options.
  - Ways of sharing information and pooling resources should be explored to achieve more effective and efficient services, such as aids and adaptations
  - The suitability of housing stock and of the physical and social environment of particular neighbourhoods should be taken into account when decisions are being made about housing allocations for vulnerable people.

And, finally, as local agencies set about implementing the Charter in their areas, they will need to involve local users and carers in working with them to plan how best to do this. Consideration might be given to setting up a partnership board or committee where the different professional, managerial, user and carer stakeholders can work on developing the Charter, disseminating it locally and putting in place the arrangements that are necessary to ensure appropriate service performance. This committee would clearly need to relate to other important groups responsible for developing and implementing Health Improvement Programmes, Health Action Zones and the like. This will ensure that there is proper ownership of the Charter at local level and that there is coherence at strategic planning and operational levels.

A partnership board or its equivalent would also be an important mechanism for achieving the cultural change that users, carers and staff want to see in health, housing and social care services.

APPENDIX 1: RESEARCH METHODS

Focus Groups

The aims of the focus groups were to:

- explore user, carer and staff experiences of health, social care and housing services
- generate suggestions from each of these groups about a long term care Charter , its contents and implementation

Focus groups were chosen as the most appropriate means of gathering information because they are open-ended, provide a useful forum within which people can share views and experiences, and are a particularly effective method for 'brainstorming' and generating ideas about improvements. They also gather a range of viewpoints over a short time and the breadth of experience provides a solid base on which to build further research.

Although interactive in nature, each group was conducted with a topic guide to ensure that a similar series of topics was included in every discussion. These were all tape-recorded with the permission of those attending. Participants were assured of confidentiality and anonymity in our analysis and reporting of the data.

Fifteen focus groups were conducted during September 1998 in Shrewsbury, Knowsley and Southwark. Nine with users (older people, people with learning disabilities and people with physical disabilities), three with carers and three with front-line staff.

Sampling

Users

In order to obtain as wide a range of views and experiences as possible, users were selected according to: age, gender and experience of services. People were excluded from the groups if they had severe communication difficulties and had no supporter available to assist with communication.

A screening exercise was carried out during late August 1998. The screening took the form of an explanation of the nature, purpose and sponsor of the study and those willing to take part were then asked a short series of questions about themselves and their recent experiences of services. Quotas were assigned for each of the three main sampling factors and recruiters were instructed who to invite to the focus groups to ensure that each included people with a range of experiences. All users who answered these questions were given a letter with details of the time of the group and the local venue in which it would be held. Copies of the topic guide screening questionnaire and letters to study participants are available from the King's Fund.

As age was an important factor in people's experiences, views and priorities, groups were banded across a broad range of 18-25, 26-45, 46-64, 65-74 and 75+.

In total 120 users were included in the users focus groups. A payment of £15 was given to each user who took part in order to recompense for their time. Travel and childcare costs were also reimbursed.

Carers and staff

The same three areas were chosen for the random selection of carers and staff. Due to severe time limitations purposive sampling was not possible. Instead, voluntary organisations working with carers were approached and asked to recruit from their membership. Staff were recruited by approaching senior and middle managers responsible for commissioning or providing services in health, housing and social services, who nominated appropriate people.

Profile of users and carers attending the focus groups (total number of participants = 159

A total of 15 Focus Groups were organised in three parts of the country, namely in the County of Shropshire, the Metropolitan Borough of Knowsley and the London Borough of Southwark. 5 Focus Groups met in each of these areas, enabling the following people to meet separately in groups of 10 - 15 people:

- people with learning disability
- people with physical and sensory disabilities
- older people with a variety of health, social care and housing experiences
- carers (i.e. spouses, parents, adult children, etc. of ill or disabled people)
- front line staff such as GPs, community nurses, social workers, care staff, housing support workers, hospital consultants etc.)

The Focus Groups met during September 1998. Each met for two hours, with a facilitator, who guided discussions on the lines outlined in the topic guide.

A total of 191 people took part in focus group discussions, including

- 44 people with learning disability
- 34 young adults with physical or sensory disabilities
- 42 older people with a variety of health problems
- 39 carers
- 32 front line staff

	Learning Disability	**Physical /Sensory Disability**	**Older People**	**Carers**	**Staff**	TOTALS
Kirkby	15	11	15	8	9	**48**
Shropshire	14	13	11	15	17	**70**
Southwark	15	10	16	16	6	**63**
TOTALS	**44**	**34**	**42**	**39**	**32**	**191**

	Male	**Female**	TOTALS
Kirkby	19	37	**56**
Shropshire	23	44	**67**
Southwark	29	39	**68**
TOTALS	**71**	**120**	**191**

Users (120) had the following characteristics:

- 84 lived in their own homes (ordinary houses or flats). This included 8 individuals who lived with parents or other relatives.
- 36 lived in supported accommodation (sheltered housing, group homes or residential /nursing care homes)
- 31 owned their own homes
- 23 were in full or part time employment, or in education
- 40 were retired

Carers (39) had the following characteristics:

- 39 lived in their own homes (where they had either joint or sole ownership or tenancy)
- 25 owned their own homes
- 31 were living with the person they cared for
- 5 were in full- or part-time employment
- 3 had been caring for their relatives for less than 2 years, 6 for between 2 and 4 years, and 30 for five years or more.

Among users and carers, at least 12 were identified as belonging to black and ethic minority communities. These individuals mainly lived in inner London, but a small number lived in the Knowsley area.

The following staff (32) contributed to focus group discussions:

- 2 GPs
- 1 Consultant geriatrician
- 5 Community nurses (DN & Hs)
- 2 Occupational therapists
- 6 Social services staff (care managers and social workers)
- 6 Care staff (home, residential and day care)
- 8 Housing support staff (warden, financial counsellor, resettlement, advice, improvement)
- 1 Advocate
- 1 Befriender

Analysis

The analysis was carried out using the Framework method developed by SCPR's Qualitative Research Unit. It involves charting data from the transcripts in a synthesised form into a series of thematic matrices to allow easy comparison between and within cases. All of the data from the transcripts is systematically condensed and categorised in this way.

Copies of the topic guides and the questionnaire used for focus groups and the written evidence are available from the King's Fund.

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