

Older people's experiences of home care in England

Wendy Sykes and Carola Groom
Independent Social Research

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First published Autumn 2011

ISBN 978 1 84206 427 6

Equality and Human Rights Commission Research Report series

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Acknowledgements

We would like to thank all those who contributed to this research report; in particular the 40 participants who gave their time and effort to talk to us about their experiences. Thanks also to those friends and family members of respondents, who helped facilitate some interviews and contributed to them. We are grateful to various organisations that helped find people to take part, especially Plus Four Market Research. Staff at the Equality and Human Rights Commission provided a great deal of useful support and guidance throughout the project, in particular Liz Speed and Sue Coe who were valuable research colleagues.

Key terms and definitions

Key terms and definitions used in the inquiry were also used in the research reported on here and are set out below:

- *Older people* - people over 65 years of age
- *Home* - private domicile including supported living arrangements and extra care housing
- *Home care* – paid social care provided in the home, either funded by a public authority or privately funded
- *Social care* – includes support with personal care, preparing meals, taking medication, housework, managing money and paying bills, attending doctors' appointments, shopping, making phone calls, writing letters, keeping in touch with friends and family, equipment and adaptations such as emergency alarm systems
- *Human rights* – Are set out in the Articles of the European Convention and include not only the right to life but also a number of other important rights such as freedom from inhuman and degrading treatment.¹ Risks to human rights include:
 - Default or omission: the result of lack of understanding or systemic failure to take account of human rights issues (when commissioning services for example). There may also be unintentional effects that arise, for example, from poor standards of care
 - Intentional human rights violations: undignified or degrading treatment, abuse or neglect.

Executive summary

Introduction

A growing number of people over 65 in England need paid help and support with their everyday life. Home care is currently the main way in which such help and support are supplied by public authorities, but little attention has been given so far to examining the relationship between home care and the human rights of older people as service users.

This research was commissioned as part of a formal inquiry into older people and human rights in home care in England undertaken by the Equality and Human Rights Commission (EHRC). It is based on in-depth interviews with a cross section of 40 ordinary people receiving home care arranged mostly through their local authority but also, in a small number of cases, privately. Respondents were *not* selected on the basis of having had bad (or good) experiences of home care.

Because of the Human Rights Act, public authorities have to comply with the European Convention on Human Rights, including when commissioning, providing or monitoring home care services. The Convention protects several rights that are central to good home care, in particular: the right to respect for private and family life, which includes respect for dignity and autonomy (Article 8); and the prohibition of inhuman and degrading treatment (Article 3).

Home care has enormous potential to protect and promote the human rights of older people; for example, the right to live their lives as independently as possible, safely, with dignity and free from neglect; and this research identifies and acknowledges a whole range of different ways in which the current system supports the human rights of recipients. However, importantly, it also focuses on aspects of home care where improvements are needed in terms of how the system is both designed and delivered.

Deliberate abuse, neglect and bad treatment of older people by those supporting them are a major, and headline-grabbing, concern. But, as the findings from this research amply suggest, risks to human rights are not always, or even often, intentional and can stem from systemic weaknesses such as simple lack of understanding of human rights issues as they apply to older people, gaps in protection, failure to balance different kinds of risk and inadequacies in terms of service delivery; exacerbated by resource constraints.

Respondents were asked about their experiences of home care without direct reference to 'human rights', partly in order to avoid language they may not be familiar with or comfortable using, and to avoid pre-judging possible human rights issues. However, questions were informed throughout by an evidence framework adopted by the EHRC in its formal inquiry, based on core human rights principles, namely: dignity and security, autonomy and choice, privacy, and social and civic participation.

Experiences of home care - service delivery

The skill and professionalism of care workers was often praised by respondents, but some were upset by slapdash and hurried work, failure to tidy up and lack of respect towards them and for their home. Older people receiving home care are particularly vulnerable if care workers verbally or physically abuse them. But respondents complained more about indifference, being treated 'like a number' and being ignored.

A glaring feature in the lives of many older people was their social isolation although care workers are often unable to spend enough time with clients to begin to tackle this. Respondents placed great value on continuity of care worker, on being able to build a relationship of trust, but this was not always on offer and could be a major cause of complaint.

Timing issues in connection with care visits were a concern for most respondents. Unreliability and unpredictability – where visits sometimes did not take place at all, or care workers arrived late – caused a great deal of anxiety and had undermined people's personal autonomy, for example, being able to control their day, and take part in other valued activities. Where people need help to take medication, go to the toilet or eat, unreliability also had a serious impact. Not being told about delays adds hugely to the problem. Some respondents also commented on how care workers rushed through their duties in order to leave early.

For those who needed help to prepare for bed, the usual scheduling of this early in the evening was often contentious. Being put to bed early can be demeaning and can also mean missing evening time together with a partner, or favourite television programmes or, for some, the opportunity to go out in the evening or to come back late from an outing. It can also mean spending a lot of time lying sleepless with nothing to occupy the mind.

Respondents could find care packages overly prescriptive with little flexibility for care workers to help out in ways not written into their care plan. There are also some aspects of care that they would like help with – such as nail-cutting – that are simply not provided.

Much that causes older people stress or upset may not be seen by them as 'important enough' to complain about. Assuming that they know who to complain to and how, they are more comfortable talking to people they know face to face than pursuing more formal routes. In general, respondents had low awareness of their right to complain and others were loath to exercise those rights.

Experiences of home care – wider aspects

Respondents were not well-informed about many aspects of their home care: the broader background issues such as how the system works or – in some cases – the specifics and particulars of their own situation such as which agency provides their care, and if they contribute towards the cost of their care and how much. Information was not provided to them at a time and in a form they could fully take in. Moreover, the social isolation of many recipients of home care means they are cut off from important informal information networks.

The right to an assessment of need by the local authority did not appear to be well known. Many respondents could not remember the initial assessment of their care needs, or only vaguely understood its import at the time, because it took place during a time of crisis. Many felt that a process had simply 'happened' to them and that they had had little choice about any aspect of the outcome. Some assessments that were recalled were found intrusive, abrupt, and even offensive to personal dignity.

Reassessments were experienced sometimes as more concerned with cutting costs than with looking at whether home care met respondents' ongoing needs.

Most respondents had a care plan or folder in their home, but few consulted it readily or had a clear idea what it contained.

Some respondents had made entirely private arrangements for home care: they were generally satisfied with the flexibility and choice this gave them. There was little direct experience among respondents of personalisation mechanisms such as direct payments and personal budgets; many had no knowledge of these, others were clearly reluctant to embrace a change that might involve additional administrative burdens for them.

The general picture is of a wider home care system in which older people are not effectively involved: which they do not understand, and which does not often make the extra effort required to involve them in ways tailored to their state of health and other needs.

Concerns in relation to particular rights

Dignity and security

Clear instances of abuse by care workers were seldom mentioned to the researchers, however, a number of respondents had been subject to disrespectful treatment by individual care workers. Some had been refused a level of care they felt was important in order to protect their dignity: one example was a woman who was refused help at night to go to the toilet, being told instead to use incontinence pads for the purpose though she is not incontinent. Sometimes it was the service delivery that was found to be inadequate, for example when care workers did not turn up to provide essential help, or only one turned up for a task requiring two.

Many of the instances cited by respondents would not necessarily make the news, though their cumulative impact on individuals could be profoundly depressing and stressful. Lack of confidence in their own judgement could be a barrier to raising issues directly with care workers. Another barrier could be reluctance to alienate care workers, damage relationships with them or invite further problems.

Not only in terms of protecting dignity and security, more could be achieved through better continuity of care which can help older people to establish relationships with their care workers. The most contented respondents were those who had good, stable arrangements with care workers and whose care workers had got to know them, their homes and the way they liked things done.

In the sample, only a small number of respondents had made private arrangements and had a direct contractual relationship with a care worker. There were no apparent grounds for concern about dignity and security in these cases, and respondents often seemed better catered for than in the majority of interviews. However, one respondent had altered his will in favour of a care worker and there must be concern about the possibility of exploitation, given the absence of oversight and governance of such arrangements.

Autonomy and choice

Respondents often seemed to accept passively a lack of any real autonomy and choice as far as their home care was concerned. There was widespread resignation and lack of expectation of being consulted on key matters that affected them. There was little sense that respondents expected to have, what may be called, process rights in relation to their home care: rights to be consulted, to consent, to have access to advice and information, to have redress and appeals. The general picture, except when something was viewed as bad enough to justify a complaint, was that respondents acquiesced in a process which took a lot of decisions for them.

Most interviewees, being in poor health or frail or both, did not want to take on additional cares and responsibilities. They might welcome mechanisms and systems to improve consultation and choice, provided these did not require them to take on significant tasks of accounting, researching suppliers or carrying out status and training checks. Moreover those administering the system of home care need to understand that vulnerability may lie not just in ill-health and frailty, but in social isolation and loneliness.

Privacy

Home care is essentially intrusive because it takes place in people's homes. Respondents were aware of the need for compromise between controlling access to their home and guarding their privacy, in order to get the care they need, but they were not always happy about it. A few respondents described incidents where care workers had gone into rooms in their homes without asking permission. Some felt exposed and uncomfortable when going to the toilet or being washed; one man's wife described him looking at such times like a 'scared rabbit', and though he found communication very difficult he said himself that he is always pleased when the care workers leave. Another respondent said she was very upset by pressure put on her to sleep separately from her husband in order to make space in the bedroom for a hoist. It takes sensitivity to respect privacy while meeting fundamental care needs, and sometimes that sensitivity was found lacking from the evidence in these interviews. Inflexible care worker routines can interfere with the right to respect for a private life, and poor time-keeping by care workers can be an additional barrier.

Social and civic participation

Social and civic participation was clearly exceptionally difficult for most interviewees although a few respondents who had private care arrangements said their care workers had an important role to play in helping them to get out and about and mix with other people.

Very many of the other respondents said their health conditions or impairments made it difficult or impossible for them to participate in any activity outside of the home. They did not raise it themselves as an aspect of their lives that care workers failed to offer help with, accepting almost without question that such help was not available. Many respondents would like to browse in a shop occasionally, not just have mail order clothes or things that other people bring for them from the shops. Others have given up interests ranging from jazz concerts to going to the bookies. Many miss just sitting in the garden, or the park where they can see the world go by. When they were probed on this subject, even though they had not seen it as relevant

to a discussion of in-home care, it was clear that all were unhappy and frustrated about such severe limitations on their lives.

However the idea of a 'right' to respect for social and civic participation was not a concept that came to many people spontaneously. Rather, there seemed to be a fatalistic acceptance that, as older people, they should not expect to be able to do things the rest of society takes for granted.

Concluding comments

The areas for concern about human rights that were found in these interviews were not, on the whole, about intentional or reckless poor practice on the part of care workers or care providers. The big picture is one of a system that is essential and appreciated, but which is caught up in various imperatives: one is certainly to secure welfare and safety; another is to manage the logistics of meeting the different personal care needs of a huge number of people; a third is to distribute scarce resources according to needs ranked and prioritised fairly. Taking a human rights perspective is essential to the delivery of home care, otherwise a focus on the individual needs and requirements of older people can be lost.

1. Introduction

1.1 The report

In November 2010, the Equality and Human Rights Commission (EHRC) launched a major inquiry into the human rights of older people in receipt of home care in order to investigate if the current legislative, regulatory and quality control systems offer enough human rights protection to this vulnerable group; and to explore people's experiences of and confidence in the system to protect their human rights.

This is a report of the findings from in-depth interviews carried out in June and July 2011 with 40 people over 65 receiving home care in England. The research was commissioned by the EHRC to augment evidence being gathered as part of the formal Inquiry.

1.2 Home care in England

Local authorities have the main responsibility for the home care system in England, working in partnership with the private and voluntary sector to ensure that people who need it get the right help and support at home to enable them to carry out normal daily activities, including for example:

- Personal care – help with tasks like getting up, getting dressed, washing and bathing
- Meals – hot meals or frozen meals and some method of heating them, depending on need
- Help with house and garden – for example housework, gardening, shopping and other day-to-day tasks.²

This section provides a brief and simplified description of how the system functions or is supposed to function.

People in need of help and support at home are entitled to an assessment carried out by their local authority³ to establish what their care needs are and to determine how they might be met. Each local authority sets (and should publish) its own rules governing what services it will provide for different levels of need, and spelling out the cut-off level of need below which individuals are required to make their own arrangements for home care.⁴ Those not eligible for direct local authority assistance should, nonetheless, be offered guidance about alternatives so they can make their own arrangements, for example, they should be given the contact details of private care providers and local voluntary organisations.

Care services for those who are eligible for local authority help are provided either directly by the local authority or indirectly through agencies, local voluntary organisations and charities on behalf of the local authority. Some services can be provided free of charge for a period (usually about 6 weeks), including home services arranged to help avoid unnecessary admission to hospital or to enable people to leave hospital earlier. More usually however, recipients' financial means are taken into account to determine what proportion of the costs can be paid for by the local authority and how much they will have to contribute from their own money. The financial assessment takes into account savings and other elements including some disability-related benefits such as Attendance Allowance (AA).⁵ The charging system is discretionary and charges therefore vary between local authorities, though Government guidance to local authorities is to protect basic levels of income and individuals have the right to request a review of charging decisions.

People whose home care is paid for fully or in part by their local authority have the option to arrange personally the services they have been assessed as needing and have Direct Payments or Personal Budgets to pay for them. This means taking the home care budget allocated to them by the local authority and spending it on what they want, when they want it and with the provider they want, as long as it goes towards meeting their assessed care needs. A service user can either take their personal budget as a direct payment and organise their care themselves or through family and friends or a service provider, or leave the local authority with the responsibility to commission the services.

Each local authority is required to have a complaints procedure and to produce information about how to complain. Complaints concerning local authority assessment procedures should be made using this avenue. Problems or complaints about home care services can be addressed through informal discussions with care providers, more formally using the care provider's complaints procedure and also through the Care Quality Commission. For those whose services have been arranged by their local authority, the local authority is responsible for ensuring that the care is suitable.

1.3 Human rights and the home care system

This research explores how the home care system described in the previous section affects the human rights of home care recipients, either because of the way in which it is designed or because of how it is implemented.

The Human Rights Act 1998 makes most Articles of the European Convention on Human Rights part of UK law. The Convention, like all human rights treaties, is based on the simple idea that every human being is equally entitled to certain basic rights and freedoms. Because of the Human Rights Act, public authorities are legally obliged to respect fundamental human rights under the Convention when carrying out their powers and duties. They also have 'positive obligations' to promote and protect human rights – which includes taking active steps to prevent human rights breaches from taking place.

The Human Rights Act makes public authorities accountable for their decisions, and allows individuals who believe that their human rights have been breached to bring a case in our own courts against the public authority concerned. In this way, the Human Rights Act can help to protect vulnerable individuals against the policies and practices, actions and decisions of bodies such as government departments, hospitals and local authorities. Although Human Rights Act protection extends to residents of independent care homes whose care has been arranged by a public body, people who use private and voluntary home care agencies are not protected by the Act, even if the care is funded by the local authority.

Human rights are underpinned by five guiding principles, namely: fairness, respect, equality, dignity and autonomy. In relation to older people using home care services, the following Articles of the European Convention are likely to be most important:

- Article 8 (right to respect for private and family life) e.g. if care interferes with personal dignity or fails to address severe social isolation and lack of meaningful contact with family, this could be an unjustifiable interference with Article 8 rights
- Article 3 (prohibition of inhuman or degrading treatment) e.g. in some circumstances, a lack of care, serious neglect or intentional ill-treatment by a care provider may amount to a breach of Article 3
- Article 2 (right to life) e.g. if an older person who is highly dependent on home care services were to die as a result of care visits being stopped without warning, this could amount to a breach of Article 2.
- Article 9 (freedom of thought, conscience or religion) e.g. if home care services fail to take account of a person's religious observances, this could be an unjustifiable interference with Article 9 rights
- Article 14 (on non-discrimination in the enjoyment of other human rights) e.g. if, compared to younger disabled adults, older people receive less generous home care packages which do not support social activity, this could be a breach of Article 14 in conjunction with Article 8 (right to respect for private life).

Some human rights, such as Article 8, are qualified, rather than 'absolute'. This means that the rights can be restricted provided this is a lawful and proportionate response to one of the social needs set out in the Article itself. Essentially, this means carrying out a balancing exercise. The Human Rights Act requires public authorities to do this whenever they are considering limiting people's qualified rights. For example, in relation to Article 8, a public authority may need to balance a person's right to respect for their home against the need to tackle the risk of abuse when taking decisions about safeguarding

1.4 Scope of the research

The main aim of the research was to provide rich, robust information about older people's experiences of home care that would augment, illustrate and illuminate inquiry evidence from other sources. As well as exploring potential risks to human rights or failure to address them, the research was also concerned with good practice where the human rights of older people receiving home care are protected or enhanced.

1.5 Method

Sample structure

In-depth interviews were carried out with 40 people over 65 living in four local authority areas in England; a target of ten interviews per area. The sample areas were selected to represent a spread in terms of region, urban/rural characteristics and population mix.⁶ They included:

- A largely rural area in the East of England
- A London borough
- An urban area in the Midlands
- A largely urban area in the North West.⁷

The research aimed for a mix of respondents in terms of age, gender, care needs, type of funding and household composition, but no fixed quotas were set. Importantly, respondents were *not* selected on the basis of having had bad (or good) experiences of home care. Respondents were recruited with the help of a specialist agency using local recruiters based in each of the sample areas. Brief details of the respondent sample are provided in Table 1 below.

Table 1 Characteristics of the respondent sample

Gender	Male	13
	Female	27
Age	66-69	4
	70-79	14
	80-89	16
	90-99	6
Hours care per week	0-5	9
	6-10	12
	11-20	18
	20+	1
Household⁸	Lives alone	35
	Lives with partner	4
	Lives with other(s)	1
Care funded by⁹	Arranged/ (part) paid for by local authority	31
	Direct payment ¹⁰	2
	Self-fund	12
Ethnicity	White British	35
	Black African/Caribbean	5

Interview coverage

Interviews lasted an hour and were carried out in respondents' own homes; in a few cases, in the presence of relatives or friends. Subjects that were covered are outlined below, a copy of the full topic guide used in the interviews can be found in the appendices:

- Respondent's background and circumstances
 - home, health, regular contacts, overall help and support
- Home care services used
 - Involvement in planning
 - Care workers and quality of service provided
- Experience of assessment

- Information sought and received
- Advocacy and advice
- Any complaints and the outcome of complaints made
- Suggestions for improvement
- Examples of good practice.

Interviews did not directly broach the issue of human rights, nor was the term used in interviews. This was partly in order to avoid language that respondents might not be familiar with or that they might not be comfortable using. It was also considered important to maintain a broadly based conversation without pre-judgement as to possible human rights issues. In introducing the research more emphasis was placed simply on finding out about respondents' experiences of home care, with some mention made of wanting to know if people receiving home care felt that their rights, for example to dignity, choice and privacy were being upheld.

Caveats

Many respondents said they were glad they had taken part in the research, although interviews sometimes touched on difficult and upsetting subjects. Interviews frequently took longer than the scheduled hour because respondents were stimulated by the subject, the company and the conversation and had a lot to say once they 'warmed up'. But while the interviews yielded a great deal of rich and useful information, some account needs to be taken of factors that may have had an impact on the evidence collected. The main issues are set out below.

Health and recall

A few respondents who took part in this study had health conditions or impairments that affected the evidence they were able to supply. For example, pain or discomfort, tiredness and lack of energy sometimes interfered with their willingness and ability to take part in interviews lasting a full hour. Some people were on medication that made them feel sleepy or affected their recall of events that had happened to them, and a few respondents had health conditions that had impaired their memory or affected their ability to communicate. Many respondents said it was hard to remember things that had happened to them during periods of crisis, for example, illness or accidents that had precipitated their need for home care.

Capturing dissatisfaction

One of the most difficult parts of talking to respondents about their experiences was eliciting information about aspects of their home care that they found *unsatisfactory*. Finding out what was *not* working well often required time, patience, careful questioning and rapport building. Possible explanations for this are that respondents

did not want to be regarded as complaining, drawing attention to themselves or making a fuss. This is explored further in Chapter 3, section 3.6 (Problem management and complaints).

Gate-keepers: family and unpaid carers

Not every potential respondent was given the opportunity to take part in this research. In a few instances relatives declined the invitation without prior discussion with the person concerned. In two cases, interviews already arranged with older people were vetoed at the last minute by family members.

Relatives and others sitting in on interviews were sometimes able to fill in information respondents did not have, provide reminders and prompts, help with communication and give respondents moral support. This was probably helpful on the whole, resulting in a fuller and more accurate picture of events. However, respondents' own personal accounts of their experiences and views may sometimes have been muted, for example because they took a backseat in interviews where there was someone else there to speak for them.

1.6 Report structure

The remainder of this report is structured as follows:

- Chapter 2 describes the respondents who took part in this research - part of the population of people receiving home care in England.
- The following two chapters (3 and 4) go on to explore personal experiences of home care; what has happened to people in the system and the impact it has had on them, both positive and negative. Chapter 3 deals with service delivery, problem management and complaints and Chapter 4 with the preliminary steps towards establishing home care (for example, information and assessment). Both chapters attempt to draw out key themes with potential human rights implications.
- The final chapter reviews the key findings of the research from an explicit human rights perspective organised under the four main headings used by the EHRC in its formal inquiry: dignity and security, autonomy and choice, privacy, and social and civic participation.

2. The home care respondents

2.1 A diverse client group

Ageing is a natural process that affects everyone and the diversity evident in the general population is consequently reflected among older people, including those receiving home care. The brief pen portraits of a number of respondents presented below have been given to help illustrate this point:

Respondent A is 86 and a former prisoner of war during World War 2. He traces the depression that he regards as his main health condition to that period of his life, but he also has various other health conditions that interfere with his ability to manage alone. He keeps himself busy with various hobbies and keeping up with friends on the phone and via the internet. Many of his views about the system of home care are coloured by his political convictions. He says of his current care worker 'When you are talking about a classless society, she has got no idea'.

Respondent B is 82. A former NHS nurse and midwife, she came to Britain in the late 1950s and worked until her retirement. She is a keen traveller ('I love knowing places and mixing with people') and describes herself as a 'party woman' though she says that her health condition means she has had to limit her enthusiasm for travelling and parties. This lady has a clear understanding of the home care system and is assertive about making sure that she receives the support and the quality of service she expects. She is a very good example of someone who knows their rights and has the confidence, knowledge and skills to address any failings in the system as they apply to her.

Respondent C is 80 and divorced with two children, and was a semi-professional sportsman for a short period in his youth. He lives in sheltered accommodation and says that the warden, in collaboration with his daughter, arranged for him to have care workers. He says he did not think he needed help because he was managing everything for himself, but the warden at his sheltered accommodation volunteered that she had instigated home care because, left to his own devices, this respondent did not seem to be looking after himself very well, he was not taking his medication properly, was ill as a consequence and was showing signs of self-neglect.

Respondent D is also 80 and lives alone in sheltered accommodation in a neat and well kept home. She never married and this affects her views on

certain issues, for example of having male carers, 'I am not going to have no men in here. No way. I don't want one here, I am a spinster. I wouldn't have one in. I would feel awful.' She is gregarious and likes seeing friends as much as she can. She does what she can to make sure that she has the social contact she wants and needs. Left on her own for too long she says makes her feel very down. She has a scooter that she can use to get out independently for short local trips, but mainly she needs help to get out. She has complex health conditions and impairments that she makes light of and although she accepts that she needs home care, she works very hard to keep it to a minimum. For example, she has refused help in the evenings and in the morning gets out of bed an hour before her care worker is due so that she can be ready for them and feel properly organised and in control when they arrive.

Respondent E is 69. He used to work in a local factory until a progressive health condition that affects his joints forced him to give up work. He is divorced and lives alone. He is very stoical about his situation and has dealt with a number of trying issues to do both with his health and the care he receives by trying to adapt and learn to put up with things, rather than by fighting them or trying to change them. This is in spite of the fact that he used to help run a local social club for disabled people. He does not like to bother his children with his worries because he feels they have enough to cope with in their own lives and he does not want to be an added burden.

Respondent F is over 80 and lives with her son. She has extremely limited mobility and a number of health conditions and impairments which mean she spends most of her time at home in a hospital bed in the front room of the house. She is able to communicate, but with some difficulty and she is easily distressed and agitated. She is totally dependent on the help she receives from her care workers and from her son. This lady has a very strong personality that is clearly in evidence and robust opinions about the various care workers and other health and social care professionals she comes across. She is happiest in the company of her son or other people who she is able to chat to and 'have a laugh' with. She is very keen to get out as much as possible with her son, although the practical arrangements involved in getting her up and dressed and out are complex and laborious. He says 'She likes to go out, she always feels a lot better for it; it makes a shorter day... and when we come in we'll have a meal and she'll get her head down if she's tired'.

Everybody interviewed in this project was unique in terms of their social and economic background, personal history, interests, personality and general outlook.

They wanted different things out of their lives and different things mattered to them in terms of the kind and level of support they received. But there were also some important common themes across the sample, relevant to a human rights perspective of the home care system. These are considered in the next section and are referred to again at various points in the remainder of the report.

2.2 Common issues

Respondents comprised a group of people who were physically, emotionally or psychologically vulnerable, or all of the above. As already outlined (see section 1.5), health conditions, impairments and age-related matters could affect their cognitive abilities, their power of recall and the ease with which they communicated. With notable exceptions, they were often uncomplaining and stoical about many negative aspects of their lives such as their health conditions and the limitations these imposed. They often relied on the support of family and friends to interact with the home care system, with the attendant risk of their own voice being drowned or muted. Most notably, respondents were often virtual prisoners in their own homes and socially isolated, as described in more detail below.

Most respondents had only limited ability to leave home under their own steam, many could not manage alone. This was mainly due to health conditions and impairments but could be compounded by additional factors such as:

- Living too far from shops or other destinations they would want to visit
- Being unable to use public transport
- Stairs, uneven pavements and other physical obstacles in and around their home
- Simple lack of confidence or fear of going out alone.

For example, one respondent said she cannot climb the hill to the bus stop if she wants to go anywhere. She now worries about how much longer she will be able to manage the short flight of stairs from her front door to the street:

I worry that I am not going to be able to make the steps. How long am I going to be able to get up the steps is the thing that I worry about.
(Woman, 83, lives alone, self-funded)

One respondent who had bought a scooter to get out on his own hit a kerb the last time he used it and was so badly frightened he had not left his flat for more than four weeks prior to the interview:

I haven't been out of the house now for about four weeks. I daren't. The last time I went out on the scooter I hit the kerb and it frightened the

living daylights out of me. I managed to get indoors and (the scooter has) been there ever since and it hasn't been used. (Man, 71, lives alone, local authority funded)

Even with help, many respondents only left their homes for pre-planned trips with a very specific focus such as a visit to the doctor or session at a day centre. They seldom had the opportunity just to go out casually, look in shop windows, have a cup of tea in a cafe or generally mingle with the world, though some would dearly love to:

I would love to go to town to do some shopping. I haven't been to town for about two years... Wander round the town and have a cup of tea... I'd love that. (Woman, 85, lives alone, local authority funded)

A few respondents lived with their partners and one with her son, but the vast majority lived alone. Although some people had regular and frequent face-to-face contact for example with family, friends and volunteers from local organisations, more commonly this was not the case and some respondents said they could go for some time without seeing anyone:

When you go now, I will maybe not talk to anybody till tomorrow; maybe the whole of tomorrow nobody to talk (to)... face to face. Nobody will knock on that door, that is it, a life of isolation. (Woman, 82, lives alone, local authority funded)

The quality of social contacts was also often limited. For example, respondents were more likely to receive than to pay visits and calls were often briefer than respondents would have liked. For example, relatives who helped with a weekly shop could not always spare the time to stop for long.

Sheltered accommodation offered some respondents a welcome opportunity for social contact:

I have only got to go outside and up the hall and there is always someone knocking around. We have Saturday morning coffees and things like that. (Woman, 76, lives with partner, direct payments from the Independent Living Fund (ILF))

You've got your own place, but you've never got to go out of the building if you want to see anybody. And tomorrow morning we have a coffee morning, we have keep fit, a proper teacher... and a warden. It's all nice. (Woman, 95, lives alone, local authority funded and one self funded care worker)

But other respondents in sheltered accommodation could not leave their home without help so never saw any other residents, and there were reports of social

events (bingo nights, keep fit, coffee mornings and so on) being cut back in sheltered housing. In some cases respondents said that wardens no longer lived on site and were less likely to visit residents in person to check on their well-being. In more than one housing scheme, staff contact with residents was mainly by phone or intercom.

A small number of respondents relied heavily on the telephone and internet (email and Skype for example) to keep in contact with other people:

My eldest son bought (my laptop) for me and me printer eight years ago... I need to go on every day, but it's nice because I'm chatting to people in an email and attachments and that, photographs and things like that. (Woman, 83, lives alone, local authority funded)

However these were not realistic options for many.

Respondents almost certainly experience shrinking social networks as a result of having few opportunities to meet new people or cultivate and maintain existing relationships, and because of friends also growing older and becoming less mobile.

One respondent moved to live next door to her daughter when her husband died and although she stayed in the same area her new home was in a different part of town at least two bus rides away. A close friend who could drive used to visit her, but she died and other contacts have gradually dropped away.

Another respondent who is registered blind moved from sheltered accommodation, where she had lived for nine years, to housing providing a higher level of support and said that in the process, she had lost contact with other residents with whom she had made friends in her previous home:

The friends I have are at (name of sheltered accommodation)... but I can't go out or see anybody... getting up there is a bit awkward. (Woman, 70, lives with partner, self funded)

For all of the reasons already outlined above, many respondents said they felt cut off, isolated, bored or trapped:

Well if you're stuck between four walls of a day, every day, that is like living in a box being squeezed in. (Woman, 78, lives alone, local authority funded)

One woman said she observed, among some other residents of her sheltered accommodation, how lack of human interaction affected their intellectual and mental health:

I think the mind goes, quite honestly... I know that if I am indoors on my own for any length of time, you don't communicate so much, and slowly you become more and more introverted. (Woman, 76, lives with partner, direct payments from ILF)

Some people said they found time lay heavily on their hands. One respondent said she watched the clock and another said she found herself sleeping for much of the time:

I don't understand it, but all I seem to do is sleep. It gets boring. I get bored sitting in all the time. (Woman, 70, lives with partner, self funded)

2.3 Summary and comment

People receiving home care cannot be thought of in terms of a generic client. The lives they have led and want to lead are as different from one another as are their backgrounds, current circumstances, personality and outlook. Enabling people to continue to express their individuality and to pursue life in the way they want must be an aspiration for the home care system. At the same time, certain common characteristics in the client group affect their potential to interact personally and confidently with the home care system, and these need to be taken into account by public authorities responsible for home care.

The glaring feature in the lives of many people getting home care is their social isolation. This is highlighted later as a key area of human rights that the current system in England does not adequately address.

3. Experiences of home care: service delivery

This chapter explores the aspects of the home care system that are of greatest immediate salience for respondents: the actual services provided to them in their own home. It begins with a brief description of respondents' overall attitudes towards home care and continues with their accounts of the skill and professionalism of care workers, relationships with care workers, timing issues and the 'menu' of home care services on offer. The final section describes how respondents dealt with problems and complaints.

3.1 General attitudes to home care

For the majority of respondents, home care represents a lifeline that allows them to continue to live in their own home. They did not necessarily welcome it, because it meant they were not managing for themselves any more, but they saw it in practical terms at least as a good thing. Some respondents had been living at the same address for many years, and were evidently attached to their familiar surroundings and local networks, but above all they wanted to preserve their independence and to avoid the obvious alternative of residential care:

I know that I am being looked after basically, and the family are pleased because they know that without that care I would have to go into a care home. (Woman, 83, lives alone, local authority funded)

Being 'put into' a care home was a clear worry for some respondents, who feared loss of autonomy and control of their life. Respondents could be reluctant to identify with people in residential or nursing homes:

I don't want to go into care because I am too alert, it's just my body is getting harder (to manage). (Woman, 83, lives alone, local authority funded)

For a fortnight I went to (name of local residential home) when they done my kitchen... I don't think I could go through that again... they had people there that were a bit off-putting, and I thought 'no thanks'. (Woman, 78, lives alone, local authority funded)

For couples there may have been background concerns about being separated ('We must be together... We have been together since she was roughly 13.')

Home care, once in place, was a relief to some people who had been gradually finding it harder to cope. However, by its nature, home care is essentially intrusive and others needed time to adjust, especially if precipitated into home care by a crisis. For example, one respondent with long standing health conditions and a lot of

care needs suddenly required home care because her husband carer broke his leg. She said:

It was terribly stressful. I'd never had anything like that before. It was this intrusion into my home, I felt worse than a baby... a package that was just left there. They would come in and do this and that, and go again, and then come back. I just wanted to curl up and die. I was diminished. I wasn't me any more... A pudding, not quite a human being. My life was... taken over. (Woman, 76, lives with partner, direct payments from ILF)

Not everyone interviewed had played an active part in the decision to have home care. This, potentially, raises questions about autonomy, choice and self-determination in home care provision. For example, a male respondent said he had been persuaded into sheltered housing with home care by the pastoral committee of his local church:

They seemed to think I wasn't coping and I didn't agree; they'd been to some trouble to get me here on a trial period and so I agreed... and I'm still here. (Man, 94, lives alone, self funded)

In a few cases, respondents clearly felt that home care had been foisted on them, even if they also conceded that they needed help at home:

[Daughter] Mum didn't like that at all, she couldn't understand why (the care worker) was here... And I got loads and loads of phone calls... (She) was always on the phone to me... (Woman, 89, lives alone, local authority funded)

3.2 Skill and professionalism of care workers

Respondents wanted to see jobs well done to a high standard, and they often praised the skill and professionalism of their care workers. This was especially important to respondents whose safety and security could depend on their care worker; for example, if they were being helped with taking medication or having a bath or had a lot of complex care needs:

He does everything properly and everything is all done. They put me to bed and check my bottom because I have to wear pads of course, and then I have a rope ladder, if I want to get up in the night I have to get up with the rope ladder, and they make sure that is done. Make sure I have that chair that is in the hall (close by) because I have a lot of my control things on there to let people in... (Woman, 83, lives alone, local authority funded)

But respondents also complained about incompetent care workers:

I wasn't too happy about the way he was cooking the meals; frozen food has to be cooked at a certain time and all the details are on the packet. But he was cooking them for ten minutes regardless of what it said on the package. He didn't even look at the package... I said 'You shouldn't be doing that for ten minutes' and he said 'This'll do'. That is what he does with everything, makes it quick and saves him a couple of seconds. I asked him to wash my bed clothes one day and he was putting the whole thing in the machine, the quilt and the top. I thought he should know. So things like that get me mad. (Man, 69, lives alone, local authority funded)

Some care workers did not tidy up after themselves; low level negligence that could be upsetting and annoying for respondents. It showed lack of respect for their home or regard for their feelings if things were not left the way they liked them.¹¹

When they go and don't wash things up, and put them on the draining board, and this sort of thing. I think 'You could've done that, it wouldn't have hurt you'. (Woman, 83, lives alone, self-funded)

When my wife is doing my cleaning – arms, legs and what have you, then she will put the dirty rags somewhere. But (the care workers) most of them, will just throw them down and leave them for me and for her... In fact they should be doing it. (Man, 85, lives with partner, local authority funded)

One respondent who has had to come to terms with losing her sight recently asked a care worker to pick something up off the floor that had been dropped, and that might get in her way. The response was a curt refusal: 'That's a cleaner's job, I'm not a cleaner.'

Sometimes, respondents simply said they wanted care workers to do jobs the way they would have done them themselves. One respondent was in tears as he described how care workers had washed his trousers wrongly:

One of the care workers put my trousers in the machine and put the heater on. They should dry them on the line or something, you shouldn't put them in the heater because they shrivel up; they were creased very badly... Its things like that that upset you...I mean it's just silly things really. It wasn't just one thing, they've mounted up... (Man, 69, lives alone, local authority funded)

Care workers sometimes took liberties with respondents' homes, for example moving things about or going upstairs or into different rooms of the house without asking first, or watching the television.

[Wife] I felt like he was taking my house over; it wasn't my house... He was in every room, all over the place, and he'd sit here and watch the telly. And I said to him, you've finished now. Well I'm filling in the book, he said... (Man, 84, lives with partner, local authority funded)

There are times when you keep thinking, 'This is my house, what are they doing?'... If they suddenly need something from the bathroom upstairs for example they just dash upstairs and go and get something... But you have to let that happen (I suppose). You can't expect them to say 'Do you mind if I go upstairs?' (Man, 69, lives alone, local authority funded)

Some complained that care workers rushed through their work, getting it done as quickly as possible.

They'll come in, do what they've got to do and then off to the next client. I mean I don't mind, but it's as though they want to get all their clients finished... (Woman, 74, lives alone, local authority funded)

[Daughter] There used to be a carer who isn't there anymore, who mum used to get a bit upset about because she used to hurry you, didn't she?

[Respondent] She did, she wasn't in the house five minutes. She'd come in and say – 'Hello', and she'd have the clothes ready on her arm.

[Daughter] She was pulling your glasses off and your hearing aid out on the way to the bathroom. (Woman, 97, lives alone, local authority funded)

This could make respondents feel that they were being short-changed, that jobs were not being done thoroughly and that they were being cheated of time that they had been allocated. But they also felt that they were being 'processed' rather than treated as a person.

Some respondents mentioned care workers who were slovenly or careless in their appearance or manner, which made them feel depressed and disrespected:

Well she'd come in and she looked very untidy; she had a t-shirt on and there were all spots down it and she went into the kitchen and didn't wash her hands and she made a cup of tea and that was just cold. (Woman, 88, lives alone, self funded)

I didn't like their approach at all and they were quite scruffy as well. It looked like they were working in a factory or something; it didn't look like they were coming to assist someone. They didn't look like care workers at all, they were just scruffy. (Man, 69, lives alone, local authority funded)

One female respondent made a point about a care worker whose manner seemed inappropriate and unprofessional. This male care worker, when using a hoist to move her to the bath and toilet, made jocular and pointed reference to 'not looking', thereby making her feel very naked, undignified and defenceless:

Me in a sling with nothing else on... He was pulling me down the bed he said, 'It's all right, I'm not looking'. And I thought you can't help but look; you don't say it. And another day he was helping turn me, he said, 'It's okay I can't see anything 'cos I've got bifocals on and I can't see out of the bottom bit.' And I thought 'Do shut up'. [I felt] vulnerable... I thought it was completely inappropriate behaviour... I didn't feel in any danger... but it's just the fact of a man coming in, in your bedroom, in your nuddy, making comments. You don't need that. (Woman, 76, lives with partner, direct payments from ILF)

Another woman said she wished care workers would pay more attention to preserving her husband's dignity while washing him:

I said 'You've got to strip him off and then wash him, but while you're washing him why don't you put a towel, give him a bit of modesty and a bit of pride, and then when you've done that, wash him and get his pants on, rather than him lying there'. (Man, 84, lives with partner, local authority funded)

One man's care worker had to help him change after he soiled himself, and allegedly made no attempt to hide the disgust on her face.

3.3 Client-care worker relationship

As described earlier, for many respondents care workers were among the few people they saw on a regular basis. For people sitting alone at home for much of the time, care workers offered human contact and the chance for social interaction. It is difficult to overstate the high value that many respondents placed on the conversation, 'the laughs' and even the friendship that could develop with care workers:

(They) mean everything... (They) are a godsend. (Woman, 79, lives with partner, local authority funded)

I'd love you to meet her; she is a beautiful girl... She is the sort of woman you can really cotton on to. (Man, 76, lives alone, self funded)

We have a good laugh which I need, they do the job, but we joke and laugh at the same time. (It is important) because when you are like us, you don't go out, you don't... see anybody. They are friends. (Woman, 70, lives with partner, self funded)

I need somebody to talk to; you can't just sit in the house. I have to have somebody who I can talk to. (Woman, 85, lives alone, local authority funded)

I like people to come in and have a talk, have a laugh. (Woman, 76, lives with partner, direct payments from ILF)

She's just like a daughter, in fact people think she is my daughter when we're out. She'll tell you straight, she thinks the world of me she says, and I think the world of her. (Woman, 78, lives alone, local authority funded and one self funded care worker)

One woman thought that getting close to clients was probably discouraged but was glad her current care workers were friendly:

They're not supposed to get close to us... (but) how can you care for a person (if you are not friends). It's not something the policy wants them to be... I had one (care worker)... that you were just a number... I mean she is good in her own way, but there is that distance... But these other two... they don't keep away from you. They make you feel as if they enjoy coming to see you and that's important to me. (Woman, 83, lives alone, local authority funded)

While care workers were often praised for the personal touch in their relationship with respondents, there were also complaints about care workers who were too busy or in too much of a rush to spend time talking to clients. Tight schedules imposed on care workers by provider agencies were often blamed for this, rather than care workers themselves:

They are so inundated these care workers, whether they work for an agency or the council. They are all the time having to look at their watch, got someone else they have to fly to. (Woman, 76, lives with partner, direct payments from ILF)

In other instances individual care workers' attitudes were thought to be at fault; they were only 'in it for the money' or were uninterested in their clients:

I can't get two words out of her; it's a good morning and goodbye. (Man, 71, lives alone, local authority funded)

One respondent said his care worker talked to him about things that did not concern him, off-loading her own problems on him, for instance:

They was having a strike on the underground... She was on about the tube and everything, the buses and the lot, and I just didn't like what she

was coming out with 'cause it's got nothing to do with me. (Man, 67, lives alone, local authority funded)

There were reported cases of care workers who ignored respondents, or talked to co-workers over their heads or spent a lot of time on their mobile phone in conversation with their friends. There were a few examples in the research of respondents who had been looked after by care workers whose first language was different from their own. One respondent objected to her care workers talking to each other in their own language while they were looking after her:

I asked them to stop it because I couldn't understand what they were saying, and I think they're saying something about me... I don't like it if they talk to one another in their language, which you can't understand... They tell me they're not talking to me. If they talk to me they talk English; if they talk to one another they can talk in their language. (Woman, 75, lives alone, local authority funded)

One or two people noted that language barriers had sometimes been an issue getting in the way of conversation and social engagement:

She couldn't speak English properly so I couldn't get through to her, and I thought that was a waste of time. (Woman, 75, lives alone, local authority funded)

Continuity of care worker

Many respondents had regular care workers, individuals or teams who delivered most of their care, and this was generally an arrangement that respondents preferred, although there were a few reports of people who had got 'stuck' with care workers they did not like. Given their limited opportunities for other social contact, it is not surprising that respondents wanted to be able to get to know their care workers and build relationships with them. Aside from the purely social aspects, however, respondents appreciated care workers who were familiar with their 'ways' – their preferences and how they liked things done – and who they felt they could trust:

You get used to one don't you? They know what you want. I think it is lovely to have a regular one... If it is a stranger coming you think, 'Oh dear, I wonder who that is?' It is fair enough these days... (Woman, 85, lives alone, local authority funded)

You get to know them, and it's like a friend in some respects, and I feel that that is part of care... It's not like a relative coming in, but you don't have a stranger all the time and you feel more secure in yourself. (Woman, 78, lives alone, local authority funded)

She knows what I want and what I don't want; she has become part and parcel of me; I like her and I am sure she likes me too. If there is different care workers I can't trust any one of them... (Woman, 82, lives alone, local authority funded)

Some respondents complained about having many changes of care worker and the stress this caused them: they did not know who might walk in through the door, they could not be confident they would 'get things right', and it could mean intimate personal care being delivered by a stream of strangers:

I don't like (different) people coming to my house to give me a bath. I am not a striptease, so I can't be stripping myself to [Alison] today, [Barbara] tomorrow. You must stick to somebody. (Woman, 82, lives alone, local authority funded)

[Son] Because we get different care workers they're not familiar with the house, what needs doing and what steps to take. (Woman, 88, lives alone, local authority funded)

Because of the social vulnerability of many people receiving home care, the end of a relationship with a care worker can have a lot of impact, but this is not always handled well. A number of respondents had been very hurt or upset when care workers who they were close to stopped coming, with little warning or notice:

She didn't let me know nothing. The managers just said she left. I felt so hurt about it. I didn't know what was happening. She was a lovely lady... very nice and she did her job thoroughly. I didn't get any warning. I was hurt because I liked her. (Woman, 85, lives alone, local authority funded)

But they never told me anything. She just left and they sent somebody (else), and I said 'What is this'? I thought maybe she was sent somewhere or she was ill or anything... (Woman, 82, lives alone, local authority funded)

When her father died she had a lot of time off, and when she went back they gave her all new people, because somebody had taken over all these people so she got all new people. I didn't like it. (Man, 86, lives alone, local authority funded)

One respondent had learned on the day she was interviewed that her much loved care worker would be leaving with just one week's notice. The news affected her badly; she was very upset during the interview and very anxious about what the future would hold for her:

I feel sad... she's lovely and we've got very close. (Woman, 83, lives alone, self-funded)

3.4 Timing of visits and time keeping

The timing of care worker visits was an issue raised by almost every respondent. They wanted visits to be timed to suit their own preferred routines, rather than to dictate the shape of their day. They wanted to be able to count on care workers arriving when expected so as not to disrupt their plans, limit their opportunities to go out if they were able, or delay medication, trips to the toilet and so on. And they wanted to know that they were getting the full time from care workers that had been agreed, and that in many cases they were paying for.

In terms of the scheduling of visits, most people said they had been consulted about times, even if their preferences had not been matched exactly. However, respondents needing help going to bed often complained about being put to bed early, which they said was due to care workers being unprepared to work late but could also be due to agencies keeping costs down.

One 69 year old man is put to bed at 7.30pm which he is not happy about. Another respondent with private care workers lets them come at 9.00pm, though she would prefer 10.00pm, because 'they've got a life to lead as well'. However, she says that all the best things on television start at 9.00pm and because she goes to bed early she misses out on social time with her husband. One respondent said that she had turned down evening assistance, though it had been offered to her, because she had heard through the grapevine that care workers put clients to bed at 3.30 in the afternoon. The following respondent explained the impact on her of an early bed-time:

It is still light. I see children who don't go to bed at 9 p.m. And because I have been to bed in the day as well, I don't want to go to bed at that time... I might doze off for half an hour but then I am awake until the early hours of the morning. (Woman, 83, lives alone, local authority funded)

Care workers not arriving on time, usually late, was an issue for respondents that could make them feel stressed and worried about having been forgotten. It also had practical impacts as one lady needing help to go to the toilet explained:

You could imagine, if you could cross your legs you would... It is bad enough if you are padded all day, to be left. If you're not it is even worse! (Woman, 76, lives with partner, direct payments from ILF)

Other respondents commented:

If you don't know when the care worker is coming, maybe as soon as you dash to the shop she is here, you are not in, she goes away and you miss her. (Woman, 82, lives alone, local authority funded)

I'm epileptic and I get myself all worked up if they don't come on time (to give me my medication), if they are very late. [Son] On one occasion she didn't arrive, well we had to ring up, hadn't come at 10pm and there was absolutely no care worker available and we had to contact Social Services and ring some emergency team... (Woman, 88, lives alone, local authority funded)

One respondent said she was always very anxious that care workers would not come in time for her to be taken afterwards to a fortnightly day centre which she loves. Missing what she calls her 'happy day' would be a huge disappointment:

If they don't come I panic like mad... One day she turned up late and I had to (start to) get ready myself because the taxi was coming. I was getting my socks and my trousers on when she came. I was worried I would miss the taxi. It would be awful on my 'happy day', I would hate that. It is the highlight of my week because we have little outings. (Woman, 85, lives alone, local authority funded)

Another goes to a day centre for a bath at 10.00 a.m. on Tuesday and if the care workers do not arrive by 9.00, either he risks not being ready or his wife has to help him dress, which is very difficult for her as she has her own problems:

I have told them time and time again that we need someone here by 9.30 at the latest on a Tuesday because we go to the day centre at ten. Well, it is no good sending someone at 10 o'clock is it? (Man, 85, lives with partner, local authority funded)

On a few occasions respondents mentioned care workers arriving much earlier than expected, which could also be disruptive:

[Daughter] One of them would come in about 6 a.m. or 6.30 a.m. (instead of 8-8.30). I would've thought that would probably get Mum (who has mild dementia) more confused than normal. (Woman, 89, lives alone, local authority funded)

On other occasions care workers reportedly failed to turn up at all:

I was sitting in there waiting for my dinner and I was still waiting at 12 o'clock for her. And we never got it. I had no dinner. (Man, 85, lives with partner, local authority funded)

One person said that on a few occasions when her mother's regular care worker was away, substitute care workers had not waited long enough after ringing the bell to allow the respondent to get to the door and had gone away assuming she was not in:

Mum... is not that fast on her legs to get to the entry phone; they said they'd rung it a few times and she's not answered so she must not be there, and then they go off and she doesn't get anything. (Woman, 85, lives alone, local authority funded)

Some respondents made a point of saying that care workers did not stay as long as they were supposed to, that they skimmed on their duties or rushed through them in order to get away to other clients or for personal reasons:

They're supposed to do an hour in the morning and an hour in the evening, but she works it so quick she's gone within 10-15 minutes. (Woman, 85, lives alone, local authority funded)

Some had drawn this to the attention of care workers or agency supervisors. Two respondents described care workers who stayed the allotted time, but spent the last part of it ostentatiously staring at the clock. They were countering accusations of not staying the set time, but making the respondent's experience worse than if they had gone early.

3.5 What help is on offer

Some respondents were satisfied that the help they received was tailored to their needs. As might be expected, they included some respondents with private care arrangements:

You name it, she does it. So in actual fact I want for nothing. (Man, 76, lives alone, self funded)

But they also included local authority clients either who felt that their care plan catered for all their requirements or who had care workers they said were prepared to help them with other needs that could arise.

However, respondents sometimes complained about the home care system being overly rigid; that services prescribed for them could not be swapped for others that might be more important on a given day (a bit of shopping or cleaning instead of a bath for example). This could be very frustrating for people, knowing that a certain amount of time had been allocated to them for help and support, but that officially their care worker was not allowed to deviate from the care script they had been

given. This did not seem to make common sense to them, or be a good way of tailoring care to what they actually needed at a given time:

[Husband] They aren't supposed to [help her get out]. It isn't on the sheet. There is a care plan that is kind of a bible. (Woman, 79, lives with partner, local authority funded)

I said why can't she make it flexible? Say one day, you don't want a bath that day, and then you have a bath another day. She said no, it has to be... I said why, she's doing the same number of hours, so why does it have to be a certain job on a certain day? I can't see the difference. I mean, it was more important for (the care worker) to go out and get some shopping than it was for her to Hoover the carpet. (Man, 86, lives alone, local authority funded)

Respondents also often wanted help with things they had been told were not among the services that their care agency provided. These included help with little bits of personal care that were often very important to them like cutting nails and shaving, which they thought were off limits for health and safety reasons:

My finger nails keep growing which is a nuisance and they are reluctant to cut them; they're not allowed to in case they injure me in some way... It is the same with shaving; I have to use an electric shaver now because they won't (wet) shave me. (Man, 69, lives alone, local authority funded)

This respondent had to rely on his son to help out, which he felt uncomfortable about:

He says he doesn't mind, but he probably does. (And I mind asking him) because he is very busy and has two children of his own... and he is working full time as well... I am an extra – I try not to think of it as a burden... (Man, 69, lives alone, local authority funded)

Some respondents said that care providers had cut back on the range of services they offered, or that their local authority had switched to care providers offering a more limited (and cheaper) service. One respondent remembered a time when she would be taken out every Monday for three hours, to collect her pension, pay some bills and do some shopping, and have a drink in a café. It all came to a stop a few years ago:

A social worker came out and she said, we have to stop it all; we haven't got the funding. (Woman, 74, lives alone, local authority funded)

She now has fewer care worker visits a day that are short and limited to set tasks.

Help with getting out was seldom included in respondents' care plans and yet, as described in the previous chapter, social isolation was a major issue for almost every respondent. Many people would like help to get out more, to get into the fresh air, window shop, mix with the wider world. But this was not something they expected from home care or thought they would be allowed:

[Friend] They won't do it, because to them it's too much of a risk... I'm not saying it's black and white, that it's written down but it seems to be that there is absolutely no way on this earth that they would get him outside of that front door. (Man, 67, lives alone, local authority funded)

They're only allowed to help with certain things like with my shower and making my bed and things like that. They're not allowed to do anything outside of the flat. (Woman, 75, lives alone, local authority funded)

3.6 Problem management and complaints

Although it was evident that many respondents were unhappy with aspects of their home care, it was common for them to put up with things rather than complaining formally and proactively to a care agency, say, or the local authority. In two cases, respondents who had been very unhappy with their in-home care had soldiered on for some time, until they had been admitted to hospital and had the opportunity to talk to social services about changing to a new provider:

I asked the social worker if I could change the team, so she said yes... I didn't tell her I had trouble with the previous lot, but that was how I got out of it. (Man, 69, lives alone, local authority funded)

Another respondent complained about a care worker whose manner upset him (she took her frustrations out on him, verbally, and also did not do the tasks she was supposed to), but reluctantly and only because he felt he had no option:

That is the first time I'd complained about a worker and I didn't feel like doing anything about it, but I had no choice. (Man, 67, lives alone, local authority funded)

Some respondents were readier to complain on someone else's part than their own. One person, unable to think how he would complain on his own behalf, had complained effectively, three times, for a neighbour in his sheltered housing complex when he witnessed care workers behaving rudely and abusively:

She was effing and swearing at him, shouting at him when I walked in. I said, 'what are you doing, get out'. I rung them up and got rid of her. I got rid of three down there; three care workers from downstairs, different people. Because he was older than me... he was deaf and he was totally

blind, so he couldn't pick the phone up. I've read in the papers before now where care workers have gone wrong. He was older than me and he was blind, he couldn't see who they were. (Man, 70, lives alone, local authority funded)

On the whole, respondents seemed more likely to tell family or friends about problems they experienced which then might be taken up on their behalf. Otherwise, they preferred to talk to someone else they already knew, such as a warden or their GP.

One respondent said that he would report problems to the care provider manager who had introduced herself personally to him at the start of the contract. Another said she would tell the person from social services who conducted her six monthly assessments, and who was always careful to ask about the home care she was getting.

Some respondents were proud of not being 'complainers' and expressed disapproval of those who were; they set store by being stoical and cheerful. One respondent in a sheltered housing complex, where most residents knew each other and socialised, commented that none of them ever found anything to complain about, except *one* – and she pointed and pulled an expressive face. Comments by another person are typical:

I'm not a person that complains. Because I hate hurting people, and if I thought it was going to be a bother with their job, me causing a bother with their job, I couldn't stand that... I'm not a complainer. (Woman, 75, lives alone, local authority funded)

I don't complain because they do what they have to do; there's no reason to complain, and in life if you can't do, nobody can do your things like how you used to do it, so you have to settle for it. (Woman, 75, lives alone, local authority funded)

Not everyone seemed properly aware of their right to complain. For example, one respondent, asked what he would do if he had serious problems, said he would just have to stop having care workers on the basis that the in-home care service is a matter of 'take it or leave it':

Just say I've had enough, that's all I could do. (Man, 67, lives alone, local authority funded)

Another person, whose first experience of care workers was so poor that she asked for the service to be withdrawn, said she now thinks that she should have complained but that at the time, she did not know how to judge the service.

Others worried that they were being small-minded or petty. For example, issues such as care workers not clearing up after themselves loomed large for some respondents, but not everyone felt that it was their right to expect better:

Let's put it like this, sometimes the work they do, if you've been in the army it wouldn't have passed the Sergeant Major's inspection... She's all right... As long as she's doing the job. (Man, 86, lives alone, local authority funded)

Respondents seldom thought it was appropriate to complain about care workers not spending time talking to them, taking them out or doing other jobs that they would appreciate but were not in the care plan:

I think there is a lot she could do, but she hasn't got the time to do it. If I had the help, I would like to get out more... I would like to have somebody during the day when I'm here to talk to me. (Man, 67, lives alone, local authority funded)

You go with the flow... I mean they're only working like I used to work... They are very good... They don't only look after me, they go over there and they go into that road, go round there to that road. They've got other people to look after and by that time it's probably time for their lunch anyway. Well you can't expect them to take you out when it's their lunch time or something like that. (Woman, 82, lives alone, local authority funded)

Respondents often said that they did not want to 'upset' their care-workers, hurt their feelings or get them into trouble by making a complaint. Some respondents hesitated to ring the agency number when care workers were late, no matter how anxious they were about it, preferring instead to have the care worker's own mobile number to ring so they did not risk getting them into trouble.

One respondent said she would be anxious that care workers would be less friendly to her if she made a complaint:

The worry is they might be nasty about being told about something I don't think is right. Be horrible, don't treat you very well, be curt and standoffish. (Woman, 83, lives alone, self-funded)

Another's daughter thought there was the possibility of care workers (or the agency) taking it out on her mother in unspecified ways, if they complained:

[Daughter] We're not always here and there's so many spiteful things people can do, without actually hurting somebody. (Woman, 75, lives alone, local authority funded)

Some respondents identified practical obstacles to reporting problems or making a complaint, even if they wanted to; for example, that they would not know where to start, or that they did not know who to complain to. Some people anticipated problems and difficulties simply on the basis of past experience dealing with public bodies. For example one respondent who was blind was critical of local authority and agency telephone switchboards which, she said, rarely led to 'real' people and which could involve having to note down other telephone numbers to call – difficult for her because of her disability.

At one time I used to do all sorts of things on the phone but now I can't, I have to feel for the numbers. Everything is getting very difficult at the moment... You see when you ring up Social Services, they don't give you a certain one; you've got to have the next one that comes on the phone; I've been on that phone yesterday especially for an hour, it's like a record... When you ring up [the agency] they give you a mobile number, I can't write anything down because I can't read it back, so if they give me a mobile number it's too long for me to remember.
(Woman, 78, lives alone, local authority funded and one self funded care worker)

Much of the discussion and examples above deal with barriers to complaining. But a small number of respondents had clear ideas about what they had a right to expect and effective strategies for making sure they got it. For example, one person used her care plan to check what duties care workers said they had performed and to add her own remarks, criticisms and comments to be picked up later by the care agency. She said she had complained repeatedly to care providers for sending her care workers she did not know and for changing her care workers without warning – especially people she had formed a relationship with and 'trained' up. She had also complained about poor workers and inadequate information/communication from the agency about when to expect care workers. This respondent kept good records of the calls and complaints that she had made and their outcomes – which she was able and willing to share. The most common problems she said she had experienced in making complaints included:

- Being, in her view, 'fobbed off' – not being listened to or taken seriously (by the care provider)
- Being passed from one person to another; often going round in circles (when pursuing her complaint with the local authority):

When I was talking to them I spoke to many people on the phone. This is my diary (a record of calls made). I spoke to that one and he told me there was no reason not to change. But they never let me speak with him again; they send me to this one instead. Then I phoned G from Age

Concern, so he gave me this number. I phoned them and they transferred me back to the agency I wanted to change from, which angered me so much... So that's how they were dilly-dallying anyway. (Woman, 82, lives alone, local authority funded)

- Having to be very determined and persistent – to the point of threatening to write to her local MP - to get things changed.

3.7 Summary and comment

By offering people the opportunity to carry on living independently in their own home, rather than moving to residential care, home care helps to preserve the autonomy of many older people in the UK.

The skill and professionalism of care workers is often praised by older people, but examples were given of incompetent care workers who were a source of great stress to respondents no longer able to do certain things for themselves. They were upset by slapdash and hurried work, failure to tidy up and lack of respect for their home, but often felt they had little control or alternative but to accept what they were served.

Good relationships with care workers can offer older people receiving home care a life-line in terms of human contact, and enormously enhance their lives. But care workers cannot always afford to spend time with clients, and the chance is missed to tackle the social isolation of many older people. Older people receiving home care are particularly vulnerable should care workers ever verbally or physically abuse them. But respondents in this study complained more about indifference, being treated 'like a number' and being ignored.

Respondents placed great value on continuity of care worker. It was good for their relationship and engendered feelings of trust and security. It was also easier for respondents to feel in control of what happened in their home, if they had regular care workers who they could 'train' to do things the way they wanted. But this was not always on offer and could be a major cause of complaint.

It is important that care worker visits fit in with the rhythm of older people's lives rather than vice versa and there was evidence that care providers were sensitive to this. But bed times were often contentious; being put to bed early can be demeaning and can also mean missing prime time television, the opportunity to go out in the evening or to come back late from a day-time outing. It can also mean spending a lot of time lying sleepless with nothing to occupy the mind.

Poor time-keeping was sometimes a problem with care workers running late. This was a great cause of worry and stress for respondents that also had practical impacts. Not being told about delays adds hugely to the problem.

Respondents could find care packages overly prescriptive with little flexibility for care workers to help out with issues not written into their care plan. There are also some aspects of care that they would like help with that are off the agenda all together. Importantly, home care does not often include help with getting out of the house. This is a major area of unmet need.

Recipients of home care can be reticent about making complaints. Some people have low awareness of their rights to complain and others are loath to exercise those rights. Much that causes older people stress or upset may not be seen by them as important enough to complain about, assuming that they know who to complain to and how; they are more comfortable talking to people they know face to face than pursuing more formal routes.

Some issues, such as wanting to get out more, are not perceived by respondents to be part of the remit of home care, so respondents are unlikely to use complaints channels to express this need.

4. Experiences of home care: the wider home care system

4.1 Information and advice

Some research suggests that older people – even more than other groups – value information because it enables them to continue to make their own decisions; a key factor in older people's definition of independence.¹²

A wide range of types of information is relevant to people receiving home care. This includes, for example, information about: how the home care system is set up and supposed to work; what home care recipients have the right to expect, for instance from the local authority, care providers, care workers and national level organisations such as the Care Quality Commission; the local system and local arrangements for home care. It also includes: the basis for decisions made by the local authority or others about their personal home care arrangements; and the particulars of their personal home care arrangements, such as how much their care costs, how much they pay, what time care workers are supposed to arrive, what they are supposed to do when they come, how long they are supposed to stay, the name of their service provider and key contacts in the local authority and service provider organisation, including who to contact about worries or complaints.

Although there were some notable exceptions, respondents in this study could not be described as well-informed about many of the areas listed above. It was very unusual to come across individuals who seemed to have a good overall grasp of how the home care system works. Typically, respondents were reasonably confident about specific and highly salient aspects of their care such as how long care workers were supposed to come for and at what times, but more vague about the broader arrangements, their entitlements and how these had been worked out.

However, there were cases where respondents did not seem to know even key facts about their personal home care arrangements, such as the name of their care provider, if they were paying towards their care (or how much), what their care workers were contracted to do (rather than what they actually did), or the name of anyone in the care provider organisation or local authority with management or supervisory responsibility for their case:

I don't really know whether I am paying; am I paying for it? I can't think of the [agency] name. (Woman, 90, lives alone, local authority funded)

There was not much scope in the interviews to explore thoroughly the question of where respondents got their information about home care from and how, and what

they knew about or thought of the locally available sources and channels of information. However, some themes emerged which are explored below.

As might be expected, most respondents did not know much about the system of home care *before* they started receiving it. Exceptions included a few respondents whose partners had needed home care before they did.

Many respondents appeared to have obtained little information in the public domain for example, through websites and leaflets, though family members and others might have done some basic research on their behalf.

In interviews, respondents seldom referred to any general information about home care that they might have been given, or recognised locally produced leaflets or brochures that were sometimes shown to them. On occasions, they produced correspondence with information on specific matters such as service charges or the care worker timetable and rota for the week. The service folder provided by most care providers was rarely if ever looked at by respondents (see section 4.4) and therefore, any information it contained was not accessed.

In general, respondents tended to prefer information delivered to them personally by someone they could trust and ask questions. One respondent had learned about Direct Payments through a local council officer who came to see her and explained how it works:

I wanted it for myself because I have friends who do it and they said 'you can do it'. So I phoned the Council and said 'What if I do this and this?' One of them came to my house, she explained everything to me. She said 'You can do it. They will give you the money... But you must make sure they pay their tax, you must make sure you get their NI card.
(Woman, 82, lives alone, local authority funded)

This had helped her to decide for herself what she wanted to do about Direct Payments (she did not take it up), but these kinds of opportunities did not seem to have been available to many respondents.

Some other respondents who had had information given to them in person said it had not been presented in a way that made it easy to understand and assimilate. Staff may assume that respondents had more background information than they had:

They're very quick and they're used to it, and I wanted it spelt out slowly... Because I wasn't used to it I must have been a bit of a trial - I

don't understand this and I don't understand that. (Woman, 78, lives alone, local authority funded and one self funded care worker)

Even respondent advocates and carers often said they found it hard to find staff that could provide them with the answers they needed:

[Wife] Sometimes you feel like you're hitting your head off a brick wall; sometimes you do... I've never met anybody yet that could explain to me what I want to know... The advice is not there... Nobody will sit and explain to you; they just quote rules and regulations. (Man, 84, lives with partner, local authority funded)

Some other factors that may help to explain why respondents were often in the dark about home care or aspects of it include, for example:

- Some topics are inherently complex and hard to fathom, such as the rules used to determine contributions towards cost.
- The number of different agencies and organisations involved in arranging and providing home care made it difficult for some clients to piece together a coherent overall picture.
- Respondents had started receiving home care in a period of crisis, for example following a fall or an illness and/or a spell in hospital and did not take in the information they were given at the time.
- Some people did not 'want to be bothered' with knowing, some lacked confidence in their ability to engage with the system or felt they had few opportunities to do so. Not everyone seemed to feel that it was necessarily their business or their 'right' to know, but thought they should just accept whatever they were given.
- Some respondents had health conditions or impairments that made it more difficult for them to access, understand or interpret information. These included sensory (especially hearing and vision) and memory impairment, and also general lack of energy and feeling unwell. Some people took medication which they said made it harder for them to get to grips with information, or to remember it.

Social networks are an important source of information for most people, especially for older people, but many respondents were socially quite isolated and therefore had few opportunities to acquire information informally in this way. Where they had received information through the 'grapevine' it was not always accurate or reliable, but could be very influential. For example, one person had had negative comments about home care from a friend, one half-remembered a list of charges she had seen, which she thought were high, and one had been told that care workers put older

people to bed at 3.30pm. All three respondents (also referred to elsewhere) made important decisions about their home care based solely on this information.

4.2 Assessments

As described briefly in Chapter 1, local authorities have a statutory duty to carry out an initial assessment of need for any resident in their area who may require social care. Home assessments carried out at around the same time by the local authority are used to establish what home adaptations or aids, if any, should be provided to assist with independent living. As well as initial assessments, the ongoing needs of people who receive home care are usually reassessed at regular intervals. Anyone eligible for home care arranged by the local authority is also subjected to an assessment of financial need to determine what proportion (if any) of their home care will be paid for by the local authority and what proportion will be paid for by them.

Among respondents there was little evidence of any general awareness of the right to an assessment of need. The daughter of one respondent, who worked in social care, had asked for an assessment for her mother but did not think that other people would know about the telephone number she used. She described it as:

[Daughter] A bit of a well-kept secret. (Woman, 89, lives alone, local authority funded)

The local authority in question produces a full, informative booklet about the assessment and emergency initial in-home care service, with the telephone number featured prominently, but no one interviewed in the area mentioned the booklet, and those who were asked had no recollection of having seen it.

There were few clear-cut examples within the sample of people who had taken an individual, proactive route to getting in-home social care; who had self-diagnosed a growing inability to cope and who had approached their local authority directly for an assessment of need. Some respondents said their GP had set up the assessment. Some said their family had done so, and that they had little idea how they had gone about it. In one case, the manager of the sheltered housing complex volunteered the information that she had 'got care workers in' for a respondent who she felt was not managing well on his own.

Some respondents had care worker arrangements that were privately arranged and paid for, having never sought or been offered an initial assessment through their local authority. The reasons behind this choice, for some, are covered under 'Commissioning and procurement' below.

The interviews yielded few clear accounts of the conduct of assessments, especially initial needs assessments. Respondents often recalled the assessment of their home, for adaptations and support aids and equipment, better than they remembered any assessment of need to establish their eligibility for home care.

For some, the initial assessment had happened too long ago for them to remember the process clearly. In some cases it had taken place while they were in hospital and either because they were not well or because so many other things were being done to them at the time, they had little or no recall of what had happened. Where a partner or family member was present during an interview, the initial assessment was an event they sometimes remembered better and contributed more information about than the respondent themselves. However, some common themes emerged from the limited evidence supplied about both initial and ongoing assessments.

Respondents (and their relatives or friends) praised assessments where staff had taken their time and shown skill and sensitivity in eliciting respondents' needs and preferences:

[Wife] They were highly skilled... They came in like emergency services sort of thing, while they set up the care package, and this one young lady had done physio work and she come in and tried to help you to sit up straight... I thought the assessment was pretty thorough. I've got to admit the assessment was. (Man, 84, lives with partner, local authority funded)

[Daughter] Do you remember we all sat round here and we went through everything with that lady and we told her what you like and what you like for breakfast and all things like that, and how you like the hot cross buns? (Woman, 89, lives alone, local authority funded)

But some respondents or their representatives said that though the process seemed thorough, they did not feel there was much opportunity for the care recipient to say what they wanted: 'they' arrange everything, and tell you what 'they' are going to do.

Some respondents were also sensitive to the inherent intrusiveness of the assessment process. One lady had moved both to sheltered housing and to an in-home care package at the prompting of her daughter who was 'a worrier'. At an intermediate stage she was moved to a rehabilitation centre while the assessment continued, and she felt the visits and questions would never end; they were a reminder to her that she was losing part of her independence.

One male respondent, asked about the assessment he received after being in hospital, likened it to the research interview. He was cheerful but found answering personal questions hard work:

When I came home they come the next day and they were talking to me, similarly like you're talking to me now, asking me different questions and things like that. They asked what do I want from her and that... The questions they asked me were like (yours)! (Man, 70, lives alone, local authority funded)

A few respondents described assessments that they were not happy with. For example, one respondent's daughter said that she felt an assessment of her mother by social services was cursory and unhelpful; that the assessor had paid lip service to a process but not asked any questions that would have helped her to establish properly what help the respondent needed:

[Daughter] We had a social worker come to an assessment on Mum. She said, 'What do you need?' And we said 'That is what you are here for, that's what you've actually been asked to come and do, to actually assess if Mum needs anything else'. She said 'No, you look like you've got everything covered, call us again if you need us.' So we have no faith in the Council. (Woman, 83, lives alone, self-funded)

One respondent in hospital had been present during a heated discussion between her daughter and the assessor, which she had apparently found humiliating, about whether overnight care could be provided to assist her to the toilet. The assessor said that incontinence pads were the only viable option, although the respondent was not incontinent:

[Daughter] That's what the woman was virtually telling me, if Mummy wants to go to the toilet just piss in her pad, and that's when I terminated the interview and walked out... I wanted to hit her... No, I wasn't happy with that comment. You're taking away their dignity. (Woman, 75, lives alone, local authority funded)

Another respondent said that during a home assessment (many years ago, but vividly remembered), a local authority member of staff had been high-handed and insensitive: ordering furniture in the respondent's home to be moved without asking first, suggesting separate sleeping arrangements for the respondent and her husband ('I said, "No way, that's my husband's bed". But she just said "That's got to come out."'), and intimating that if the respondent's home (in council-owned sheltered accommodation) could not be satisfactorily arranged, she might have to be moved to a high dependency unit:

We had not been in council property before, we thought maybe the council could move us out to high dependency... I knew the high dependency unit, it's for very disabled people; nobody I could talk to there on a normal level. (Woman, 76, lives with partner, direct payments from ILF)

One person who had a re-assessment assumed his care package would be increased, as his health was deteriorating. Instead he found the assessor was asking closely about what was the minimum time required to carry out the care worker's existing tasks (and did cut his hours down, significantly).

I said to her when she come in, I think I need more time because I can't get out as much as I used to, and some jobs I can't do. She said it doesn't take an hour to give you a bath and clean the bath. Yeah, she was trying to cut the hours down all the time she was here. What she done Monday, what she done Wednesday, what she done Thursday – it was all cut down; how long does it take for the washing machine to work and all this. (Man, 86, lives alone, local authority funded)

Another said that when she complained to an assessor that care workers were rushing through their tasks and leaving early, the response was to suggest that perhaps the amount of time allocated to care worker visits could be cut down.

Some respondents complained about assessors 'policing' the care arrangements in a heavy-handed way. For example, one respondent said that during what sounded like a re-assessment visit, the assessor had seen a care worker washing dishes. This was a task the respondent's husband found difficult because it involved standing for a length of time, and he has health problems himself. He and the care worker had agreed that he would prepare the meals, and the care worker would wash up – instead of the other way around. The assessor, seeing this, stopped the care package altogether.

[Husband] She said, 'We don't provide a washing-up service', and she stopped the care workers then for a while... Well there was nothing we could do about it. [Respondent] To wash up he's got to stand and put them away. (Woman, 90, lives with partner, local authority funded)

Others said they were relieved when an intensive care package was reduced on reassessment, as long as it reflected their reduced needs. There was then a feeling of getting one's normal life back to some extent, with time to oneself or to socialise, and being self-sufficient once again.

Assessments for aids and adaptations around the home were outside the intended focus of interviews, which was to explore issues around paid social care work in the

home. However, comments about the process were often favourable, mainly because of outcomes that respondents were pleased with; respondents often wanted to 'show off' their bathrooms. for example.

In some cases, however, the process, including the follow-up, had taken a long time. One respondent, discharged from hospital with a new wheelchair that did not fit through his front or back door, was not visited by local authority staff until four months later, and then only in response to a request from him:

I contacted the social worker in April (he had been discharged from hospital in December) and she didn't know I existed. (Man, 69, lives alone, local authority funded)

He said he was still waiting, three months after contacting a social worker, for the front and back doors of his house to be adapted so that he could leave his home in his wheelchair unaided. He had not gone outside on his own since he had been discharged from hospital six months previously:

[Interviewer] Have you wondered why you haven't heard anything more about getting your door done? [Respondent] Yes I have wondered and I did phone the office, where they were doing this work for the houses from, and they gave me a number to ring and the man who answered said, 'We'll let you know'. Things can't be started because they've got other projects they're working on at the moment, and they'll get around to me when they're finished. [Interviewer] So the fact that you're actually stuck in your house – did you say that? [Respondent] No. (Man, 69, lives alone, local authority funded)

One respondent's daughter said they still had heard nothing from the local authority about a hand-rail for the steps outside her mother's house, though the assessment had been carried out six months ago:

[Daughter] She came and assessed it and filled in a form to say this needed doing with the handrail. After eight weeks I rang the Works Department and they had no record of the assessment, so they put me through to another number and I explained to the young gentleman there what had happened and he said 'We'll do an urgent referral for you'. This was (three months ago) and we still haven't heard anything, so basically we've knocked it on the head. (Woman, 83, lives alone, self-funded)

As described in Chapter 1, an initial package of care is often put in place at short notice and free of charge to meet a pressing need, for example to speed up a person's release from hospital. A few respondents had benefited from this service and knew that after the initial period they might be required to pay something

towards their home care. However, several said they were unprepared for how much they would have to contribute:

When he said £120 a week or something like that, I said that's never right in the world, I'd have no money left... I didn't realise it was going to come to so much. But anyway it has to be paid so that's it. But I object to what they're charging me, the agency. (Woman, 78, lives alone, local authority funded and one self funded care worker)

One respondent said that after a new assessment of his care needs and the initiation of a new care package, he had gone from paying a small amount towards his care to paying the full amount. He did not seem sure of the reasons for this. He was worried that his savings would run out under the new arrangement but had not spoken to anyone about it, not even his son – his main family carer:

He has enough to worry about without worrying about my finances.
(Man, 69, lives alone, local authority funded)

4.3 Commissioning and procurement

The research included a range of respondents in terms of commissioning and procurement arrangements. Most had had their home care arranged with the help of their local authority.

For those assessed as having eligible needs, home care is provided either directly by the local authority or indirectly through commercial agencies, voluntary organisations or charities commissioned to act on behalf of the local authority. Local authorities are able to give details of local care providers to people who are not eligible for or do not want local authority arranged services.

Most of the people interviewed received services that had been agreed following a local authority assessment and that were provided by an agency or agencies and paid for either in full by the local authority, or with a contribution from the recipient.

Some respondents were vague about whether or not they were paying anything towards their home care and some were vague about how much they paid. Some left such matters to be monitored by a partner or relative.

A small number of respondents had purely private arrangements, had not undergone a local authority assessment (although they might have had their home assessed for adaptations and aids), and had found, engaged and paid for their care workers without assistance or input from the local authority. Some with private arrangements

had asked for and received a list of agencies from their local authority, but not much more than that by way of guidance.

Some respondents had a mixture of home care arranged through a local authority assessment, and other paid care obtained entirely privately. One such made clear how much she prefers her private carer, who comes in the mornings and, among other things, shops and lists meal plans for the other carers to prepare and serve later.

For reasons discussed below, it was difficult to establish definitively how many respondents, if any, were receiving direct payments or had personal budget arrangements; that is to say had a budget allocated to them by the local authority to commission an individually tailored blend of services to meet their assessed needs, which they either administered themselves (direct payment) or had administered for them by the local authority (personal budget). At most it was probably only one or two.

Respondents provided little evidence of active engagement in the commissioning and procurement of home care services, apart from some of those with private arrangements. Most of those whose care was organised with the help of the local authority said they had had little say about which care provider would supply their care services. Commissioning and procurement was done on their behalf by the local authority and they were simply the recipients of care.

Some respondents seemed to find questions about choice in procurement surprising because they did not expect to have a choice. In one local authority area, for example, several respondents said they thought their agency was just 'the one the council use'. In fact the council clearly used a wide range, and several names were quoted by service users.

One man had recently been told by the local authority that his former care provider had been replaced and although he was much less happy with the services of the new agency, he felt he had little choice but to accept it, even though he was contributing towards the cost of care from his own funds.

In some instances providers had been changed, for example, because of agencies going out of business or being taken over. Respondents affected could feel they had little alternative but to put up with this and whatever consequences ensued:

When I first started it was [X agency], and then it got bought out by somebody else, and then it was bought out by somebody else and now

it's been bought out by [Y agency]. (Woman, 74, lives alone, local authority funded)

In other cases, a change of agency had taken place with the help of the local authority because the respondent was unhappy with the service they were getting. For example, one respondent had rejected her care provider because they were unable to guarantee any kind of continuity of care worker. Others had been unhappy with unreliable time-keeping and with sloppy work. However, respondents in this position were not necessarily consulted or involved in the change beyond accepting the next agency offered and seeing if it was better:

I mean, I didn't know any of them so I had to take a chance and have this one. (Woman, 78, lives alone, local authority funded and one self funded care worker)

Respondents with purely private arrangements for home care seldom seemed to have had much support from the local authority, or taken advantage of any on offer. In a few cases, they had opted for private arrangements because of poor impressions they had formed about the cost or quality of local authority-arranged services.

One person had seen a basic list of council charges for care services that she thought were expensive and was put off from making further inquiries through the local authority because she assumed she would personally have to pay in full.

Another respondent had formed a low opinion of council-arranged services based on what he had observed or found out from other residents in his sheltered accommodation. He says that 'top whack', the care workers are there for twenty minutes only and he cannot imagine what they do in the time.

Respondents with private care arrangements had sometimes opted for this route because they wanted the flexibility to say how their care worker's time was used, or they wanted to be looked after by someone they knew. One person who had been paying a contribution towards local authority-arranged home care decided that she wanted to change to a private arrangement, and 'help out' a friend who had offered her care services.

However, not everyone had actively *chosen* to 'go private'. For example, one respondent had been told by her local authority that she would have to move to private arrangements, because of changes to the council's eligibility criteria. The option of continuing with her previous agency, and long-standing cherished care

worker, as a private client was not available. She was given a printed list of local agencies that contained their contact details and Care Quality Commission star ratings (one to three stars). No further advice or help was offered. She went with the only agency to have three stars, and the only one to respond promptly to her initial message.

They'd come and told us that they were going to change because I was only having fifteen minutes care at a time. But they said you must get private care. They gave me a booklet with all the different (care provider agencies) on it. I said, if I don't want any of those, can I just keep (my old one)? No, it doesn't work like that; you have got to find private care. I did call three different ones but this one was the only one that had three stars and excellent by it and the only one that answered my phone call. (Woman, 88, lives alone, self funded)

In the event this respondent is now paying a little more for home care, but getting visits of half an hour instead of a quarter of an hour. She is also now able to decide exactly how she wants the care worker to use that time – and her old care worker now comes under a private arrangement to help with cleaning. She is happy with the new set up and, in fact, most respondents with private home care seemed happy with their arrangements.

Although there seldom appeared to be much by way of a safety net in the event, for example, of care workers falling sick or leaving suddenly without warning, most of this group of respondents did not seem unduly concerned about this. One respondent had obviously not thought about it and became very upset when the suggestion was put to him:

It is one thing I'd never thought of, but I , if anything happened to her before me; it's something to think about. I mean if I lost her I think I'd wrap up myself. (Man, 80, lives alone, self-funded)

Neither did they seem to consider themselves more vulnerable to abuse of trust or other problems, largely perhaps because they had often had a personal say in the appointment of their care worker, or had even appointed them directly without using an agency.

Personalisation

As described in Chapter 1, moves to implement personalisation of social care have the aim of giving people choice and control over what help they get, and how money is allocated to meet their needs. Under the regulations, a person in need of home care is entitled to, and should be offered, the chance to direct social services about which care provider they want and how the money that is available for their care

should be spent. Alternatively, the allocated amount should be available to them as cash to spend on meeting their needs - within certain guidelines and subject to record-keeping and accounting requirements.

It was notable, and initially surprising, how little the personalisation agenda had penetrated the perceptions of many respondents receiving home care. Questions on the topic often drew a blank. The illustrations below, where responses did reveal relevant awareness or experience, are drawn from a few interviews.

Some respondents had heard about personalisation as a trend and said they were worried about it. One was interviewed with her daughter present. Her daughter has experience of handling direct payments because her son has special needs. She has heard personalisation arrangements are being extended to older people, and feels many will not cope.

One respondent had an arrangement under which her daughter received payment from the local authority to act as her care worker, although it was only some way into the interview that she mentioned that the care worker under discussion was in fact her daughter. She was unable to elaborate much on how the arrangement worked. Her daughter produces paperwork for her to sign sometimes, and she pays half of the cost and the council the other half.

I don't know much about it, the paperwork. She manages the paperwork; I do a little, signing or whatever when they come, but she does most of the work, she uses a computer. (Woman, 70, lives with partner, local authority funded)

One man spoke at length about his frustrations with not having control over how his care worker spent her time, but said that a personal budget or direct payment – which had been suggested as an alternative – was not the answer as he would feel too vulnerable to being 'ripped off'.

Well this is something that I've heard people talk about; instead of the council providing the care worker, the council give you so much money a week and... I've had private people and I've been ripped off... You can't put yourself in a position where you rely on these people, rely on the care worker who comes here and you give her the money and you tell her what you want – you can't rely on that. (Man, 86, lives alone, local authority funded)

One woman had been told that, since she was dissatisfied with her care agency, she could commission her own care. Someone from the council came to explain it to her,

but she turned it down because of the paperwork and the responsibility for policing a worker's NI status:

One of them came to my house, she explained everything to me, she said... 'but you must make sure they pay their tax, you must take sure you get their NI card... Yes, you produce the accounts every month'. I said, 'OK, thank you very much, that is not for me'. I'm not an accountant, so I don't want it. (Woman, 82, lives alone, local authority funded)

Another respondent was a longstanding recipient of direct payment funds from the Independent Living Fund because of her health condition. She expressed clearly all the advantages the payments give her in terms of managing her own private arrangements, employing local people she knows, agreeing the times of their visits and what they do. However, crucially, she said that the governance arrangements for how she spends this money are very 'light touch', just a visit once a year to look at her bank statements. At one stage she was offered the option of moving onto local authority direct payments instead – she said she was put 'under pressure' to do so – and was very adamant in her refusal.

The council wanted me to hand over my Independent Living Fund and I said: no way! They argued with me that they could do it. I rang the Independent Living Fund and they said, 'No way, and they will not get the information out of us as to what you get'... Luckily we are both articulate and we felt very sorry for people at that time that are not so articulate, you know that couldn't perhaps get it over, what they wanted. So we remained as we are, perfectly happy. (Woman, 76, lives with partner, direct payments from ILF)

She too had heard about accounting requirements for direct payments which were much more onerous than her current regime with the Independent Living Fund.

You have to keep weekly accounts! From what they explained, a man came to tell us about it, it really was quite something that you'd got to do, like running an accountancy business. No way! I mean some people could maybe cope with it but not me. I think I'd be worried about it apart from anything else. And the time it would take. (Woman, 76, lives with partner, direct payments from ILF)

One respondent who has a lot of care needs was offered the chance to manage her own budget when she said she was unhappy with some changes that were being made to her care arrangements:

The social worker said... you would have money – I forget how much money it is – and you can do your own caring. But it's a lot of

organising... I didn't go into detail because I said, no I don't want all that worry of money... And I don't know how that would've worked. I don't know if I'd been worse off. I said, no, I'm not going down that path. I don't want a headache. I didn't want that. I don't know how it would work; I don't know anybody who does it anyway... You'll be in charge of all that yourself. I should think that'd be a headache, and I don't need a headache. I said no, leave things as they are then. (Woman, 83, lives alone, local authority funded)

4.4 Care plan

The Care Quality Commission's website explains what a care plan is:

When you first meet your care workers, they should spend time getting to know you and then agree a care plan that you are happy with. The care plan will set out your needs and how staff will meet these needs. The plan should include your social, personal and health needs and how these will be met. The care plan is a document written with your input and should be reviewed regularly to make sure your needs are being met.¹³

Most respondents, when asked, said they had a care plan. They did not always know or use the term, but they generally said that they had a 'folder' (usually described in terms of its colour, for example the 'blue folder') which had details of the services they were supposed to receive:

There is a care plan. It's a folder, a proper care plan. Yeah. It's a proper care plan, telling you exactly what you're entitled to. (Woman, 90, lives with partner, local authority funded)

Some respondents said they had been fully involved in the drawing up of their care plan, but others said not.

Most respondents were able to say what services they actually received each day, but many had not checked these against what services they were supposed to receive and had little idea if they tallied. For example, one man who had recently transferred to a new agency and had a folder he had never looked at said:

No, I haven't got a clue what the care worker is supposed to do. Nobody's told me. All I have to do now is go on the care worker's word. (Man, 71, lives alone, local authority funded)

A few people said they had used the folder to find a phone number to call if a care worker was late or failed to turn up. However, when questioned, it was apparent that respondents generally did not feel that the folder had much to do with them. They

thought of it as belonging to their care workers and the care provider agency, rather than to them personally:

I never looked at the book. It wasn't anything to do with me, that is how I felt. That was their job; part of their work was writing in. (Woman, 82, lives alone, local authority funded)

One exception was a respondent mentioned earlier in section 3.6 who inspected her folder after every visit, examined what the care worker had written in the book and added her own comments. She thought that the folder should be organised for use both by client and care worker/provider, with a column provided for clients to confirm what tasks had been performed and say whether or not they were satisfied.

A few other respondents, or their friends or relatives, made a habit of checking at least the times that had been entered for the care worker's visits. Sometimes they disputed these with the care workers, or supervisors. Some wrote their own record of the times next to them. The daughters of one respondent clearly made a point of checking all the folder daily entries in detail, partly because they felt very protective of their mother. They complained that some care workers do not write in 'the book', while others write that their mother 'looks well' when they say she clearly is not.

An incident was reported in one interview where a care worker allegedly took exception to the respondent's friend (on whom the respondent is very dependent in all practical matters) writing in the folder on his behalf:

[Friend] She basically turned around and said to him, 'Tell [friend] that he's not allowed to do this, and I'll tell my governor'. I said to [him], this is yours, this isn't hers, this is for her to fill out, but it's for you to confirm, and if she's not even giving him the opportunity to look at it, how the hell is he supposed to be able to do it? (Man, 67, lives alone, local authority funded)

4.5 Summary and comment

Respondents were not well-informed about many aspects of their home care: the broader background issues such as how the system works or – in some cases – the specifics and particulars of their own situation such as which agency provides their care, if they contribute towards the cost of their care and how much. Information sources and channels tuned to their particular needs did not seem to be much in evidence or had often failed to make their mark. The social isolation of many recipients of home care means they are cut off from informal information networks that are a very important source for older people.

The right to an assessment of need by the local authority did not appear to be well known. Initial assessments tend to be made during a time of crisis and this can affect people's ability to take in information, to contribute, and to recall and understand later what has happened to them and why. A few assessments that were recalled were found intrusive, abrupt, and even offensive to personal dignity. Some reassessments were reported as concerned with cutting costs.

Many respondents were vague about commissioning and procurement arrangements, even to the point of not knowing if they were paying contributions and how much, and who their agency was. There was often little sense of having any choice of arrangement or care provider. There was little direct experience in the sample of personalisation mechanisms such as direct payments and personal budgets; many had no knowledge of these, others were clearly reluctant to embrace a change that might involve additional administrative burdens for them. Some respondents had made entirely private arrangements for home care: they were generally satisfied with the flexibility and choice this gave them.

Most respondents had a care plan or folder in their home, but few consulted it readily or had a clear idea what it contained. It was often viewed as belonging to the care workers, for them to keep their records, rather than as a mutual agreement about the service. A few respondents and their relatives or friends used it to make their own notes; sometimes this caused friction with the care workers.

The general picture is of a home care system in which older people are not effectively engaged as full clients or partners: which they do not understand, and which does not often make the extra effort required to involve them in ways tailored to their state of health and other needs.

5. Home care and human rights

5.1 Introduction

Earlier chapters have described the experiences of home care of an ordinary sample of 40 people aged 65 or over living in England. This final chapter looks at the findings from a more explicit human rights perspective, organised under the four main headings used by the EHRC in its formal inquiry: dignity and security, autonomy and choice, privacy, and social and civic participation.

Although the interviews were carried out in order to investigate potential human rights issues for this vulnerable group of people, the subject of human rights was not raised directly with respondents. As explained in Chapter 1, this was partly in order to avoid language that respondents might not be familiar with or comfortable using. It was also considered important to maintain a broadly-based conversation without pre-judgement as to possible human rights issues.

Nonetheless, principles such as 'dignity', 'control' or 'respect' were clearly of great importance to respondents (and their carers) and were often mentioned in interviews.

Most of the risks to human rights identified in this research were *unintentional* arising from:

- Poor standards of care
- Lack of understanding of human rights issues
- Gaps in human rights protection
- Failure to balance different kinds of risk.

Much less common were risks to human rights arising from *intentionally* undignified or degrading treatment, abuse or neglect, although there were a few examples of this kind.

This report inevitably focuses on areas for concern, but it is important to note the positive impacts that home care can have on human rights for many older people. These are also highlighted throughout the remainder of this chapter.

5.2 Dignity and security

Dignity and security in the context of home care for older people implies: freedom from intentional physical abuse, freedom from unintended or careless neglect, protection from pharmaceutical or medical abuse, and protection from sexual abuse. It also covers psychological and emotional well-being: freedom from bullying and threats, freedom from disrespectful treatment, freedom from being ignored or discounted, and respect for cultural heritage and religion. Financial security and the security of possessions includes: protection from financial abuse, ensuring financial decisions are taken in a person's best interests (if someone lacks capacity), and freedom to manage personal possessions.

Dignity and security: positive

In the terms outlined above, the home care system can and does protect the dignity and security of older people on a grand scale. Care workers engaged specifically to help people with everyday activities such as getting up, bathing and getting dressed, preparing meals and taking medication provide insurance against unintended or careless neglect; guard against accidents such as falls that might occur when a frail older person takes a shower; and through regular visits, keep a watching brief on otherwise socially isolated people who could easily be overlooked or forgotten in the event of illness or accident.

Many respondents mentioned the huge psychological support they got from their relationships with their care workers, which could be among the most important in their lives:

I don't know what I'd have done without her... Sometimes I could sit and cry when she's gone. (Woman, 78, lives alone, local authority funded and one self funded care worker)

In one notable case, a care worker rescued a respondent from financial and physical abuse (through inadequate nutrition) being perpetrated by others. She noticed that he was underweight and that there was very little food in the flat; two supposed 'friends' had been taking his pension and all his savings over time, under the guise of helping him with banking and shopping. She alerted the care agency and the police and his situation was brought under control:

She knew something was going on [with those two people] because of the food that they were buying me... When she took over I was only six stone, and that's how bad it was getting. She got the ball rolling for me, so it's only thanks to [her] that I got it sorted out. (Man, 67, lives alone, local authority funded)

Dignity and security: negative

There were few clear instances reported in this research of physical, medical or financial abuse resulting from the care system itself. One respondent had witnessed another person's care workers being actively rude and bullying, and had complained on his behalf three times. Another exception was the one case where a respondent said she had been pushed by a care worker employed by a different agency from her current one. Her reaction to this event was one of shock and upset underlined by the fact that she was in her own home and vulnerable, and the perpetrator was someone who was ostensibly there to help her.

Most of the girls (from the agency) were nasty; they were rough. Rather than say sit in the chair, they'd push me back into the chair, that sort of thing and I didn't like that... It was only on one occasion; I recognised it as a push. She wasn't nice at all... I couldn't do anything about it. I can't even walk and I think they know this you see; they know you're vulnerable. (Woman, 78, lives alone, local authority funded and one self funded care worker)

While instances of gross misconduct were rare, a number of respondents had on occasion been subject to disrespectful treatment by individual care workers. In one case, care workers ignored a respondent who they were helping to wash, or talked over his head. His wife was extremely frustrated watching the care workers' behaviour.

(Wife) I've always said that's my main grudge; he's a person, talk to him. That's my main thing that I've got about it, is talking over them; also they'll laugh and joke (with him), but they're not actually conversing... are they? (Man, 84, lives with partner, local authority funded)

Another respondent had a care worker with a tendency inappropriately to vent her personal problems, 'taking it out on me'. One person said her care worker spent a lot of time on the phone to her friends as she worked. Others mentioned care workers who sat staring at the clock, or watching the respondent's television. One care worker showed disgust and impatience at a respondent's incontinence. In one case care workers talked to each other in their own language and refused to switch to English when asked. Some habitually forgot how the respondent wanted to be addressed: one respondent was referred to as 'Mr [X]' which he did not like, preferring his first name, and another was called by her first name though she resented the familiarity and had asked to be addressed by her title. One man, though he could not get to the door, hated his care workers letting themselves in without knocking or ringing and calling to him first. Most of the above examples are cited elsewhere in this report.

Some respondents complained about their personal possessions not being left as they liked them, by care workers; bathrooms and kitchens in particular being left untidy. In one case, an assessor insisted on moving furniture around against the respondent's wishes. These were all incidents that underlined for respondents their dependency on others and loss of control of their own environment.

A few respondents had been refused a level of care they felt they needed or wanted. The daughter of one respondent specifically asked for overnight care to help her mother get to the toilet; this was refused on the basis that the respondent could use pads, though she was not incontinent. A recently reported court case, in which a similar decision by another local authority was upheld, was described by Age UK among others as contravening the person's right to dignity.¹⁴

In other instances, respondents described what happened when a service was not refused but was found inadequate in practice, for example, only one care worker turning up when two are needed to lift the respondent; or sometimes care workers not turning up at all, causing significant anxiety and distress.

Respondents in general were very aware that home care services are stretched, and frequently mentioned this; not necessarily complainingly. They knew from their care workers about heavy workloads and tight timetables, and were often sympathetic to the pressures care workers are under. But in instances such as these they also felt that their feelings were simply not understood or did not count.

Dignity and security: broader picture

Dignity and security are among the most important of the human rights of older people receiving home care. This is recognised in the governance arrangements put in place by local authorities and care agencies which address, in particular, the risk of gross and criminal abuse of these rights.

But older people are still highly vulnerable to infringement of their rights to dignity and security, especially if they do not feel sure if their rights are being transgressed. Many of the instances cited above would not necessarily make the news, though their cumulative impact on individuals could be profoundly depressing and stressful. But respondents could still be uncertain that they were not just being over-sensitive or fussy and there were many barriers to them validating or expressing their concerns. For example: they were largely cut off from other people, especially others in the same situation; they did not necessarily want to burden family members; they seldom saw representatives of the care agency other than care workers themselves, and had only rare contact with local authority staff. Lack of confidence in their own

judgement could be a barrier to raising issues directly with care workers. But so also could be a reluctance to alienate care workers, damage relationships with them or invite further problems. Moreover, they were often reluctant to complain to others, for example: they worried about getting care workers into trouble or did not want to be labelled as a complainer – moaning about every little thing. Some incidents simply do not seem to older people to merit formal complaints channels, even if these are known about and easy to negotiate, but the better alternative – a private, quiet word, face-to-face with someone they know and trust – is often not an option.

In order to not just protect older people's human rights to dignity and security, but actively promote them, more could be achieved through better continuity of care workers, which could help older people to establish relationships with them. The most contented respondents were those who had good, stable arrangements with care workers and whose care workers had got to know them, their homes and the way they liked things done. Being able to trust their care worker (with their possessions and with their physical well-being) was vital to respondents, and this was easier when care workers were familiar to them.

In the sample, only a small number of respondents had made private arrangements and fewer still had a direct contractual relationship with a care worker rather than through a care agency. There were no apparent grounds for concern about dignity and security in these cases, and respondents often seemed better catered for than in the generality of interviews. However, there must be concern about the possibility of exploitation; one respondent had altered his will in favour of a care worker. He said that he gives the money he gets 'off the government' to pay for care, though he does not have a formal contract with his care worker and does not know how much time the money 'buys' him. He says:

She'd do it for nothing, but I said 'no, you can't do that'. I just give her what money I've got, and I give it to her, and I am happy and she is happy. (Man, 76, lives alone, self-funded)

5.3 Autonomy and choice

The right to self-determination is important to most people, whatever their age. This includes: the right to live as independently as possible; the right to make routine decisions (for example what to eat and what to wear); the right to be consulted about ongoing professional decisions; and the right to determine the timetable of one's day. Support that is necessary to enable people to make decisions about their care should be provided. This includes: the right to information and advice about options; the right to be offered meaningful choices and time to make decisions; the right to be offered support for personalisation of care; the right to nominate a third party to

decide, if desired; and such matters as the appropriate application of the Mental Capacity Act, which protects the rights and autonomy, as far as possible, of those whose capacity is impaired.

The scope and nature of this research did not allow for all procedural and legal aspects to be explored, but the interviews did yield a lot of material under the general heading of autonomy and choice.

Autonomy and choice: positive

Some respondents recognised that home care provides for older people in a way that has not always been available, and were grateful:

Years ago, you had to fend for yourself... In this day and age they treat the pensioners very good compared to years ago. (Woman, 90, lives alone, local authority funded)

In terms of positive impacts, home care allows people to continue to live independently, in greater comfort and safety, in their own home – offering a popular alternative to residential care, which many do not want.

Autonomy and choice: negative

The research evidence points to a number of gaps in the way the home care system responds to the rights of older people to autonomy and choice. Respondents often appeared ill-informed about all sorts of matters to do with the broader aspects of their care, and seemed to have had few opportunities effectively to exercise choice, for example about their care provider. One theme that emerged was of key decisions being made when respondents were unable to make much input, for example when they were ill or recovering in hospital prior to receiving home care, but without those decisions apparently being reviewed later to establish individuals' preferences. There was widespread evidence in the interviews of care arrangements implemented, to some degree, over respondents' heads:

The hospital arranged it and that's about all I can tell you, until the actual care worker come and then I just had to get used to it. It was hard because when I'm at home here, I've always done it myself, all of it, but now the care workers are involved and that's it; I've got to try. (Man, 67, lives alone, local authority funded)

Respondents were also often not consulted or told about ongoing professional decisions. Care agencies were switched without respondents being told, and new arrangements were brought in. Care workers were withdrawn without notice, even if they had been in place for some time and respondents had got used to them or

formed an attachment. The number of visits respondents received could be altered, apparently without notice, and so could the time of day, the duration of visits and the services provided.

Respondents were often bewildered and frustrated by the rigidity of prescribed care packages that left little room for flexibility about how care workers' time was spent during visits. Although ostensibly designed to help them live their lives independently as they would wish, they felt they had little control on a day-to-day basis to make best use of workers' time.

Early bed times were unpopular with respondents; being put to bed like a child, missing out on evening activities and television and not being able to sleep. But they felt they had few options beyond refusing bed time care. There was rarely a satisfactory alternative on offer and they felt they could not expect care workers to work in the evening (although evening shift work is common in many employment sectors).

Personalisation offers the chance of greater autonomy and choice, but appeared to some respondents to bring new, and worse, problems; the responsibilities they would be expected to shoulder if they moved to direct payments or personal budgets – directing and managing services and keeping accounts in particular. They and their relatives referred to their lack of energy and capacity to do this.

Respondents with entirely private arrangements for care workers sometimes made them with little information about what they would be eligible for if they went through the local authority. They did not appear always to be aware of any 'right' to an assessment. They exercised their right to make their own decisions, but did not make a fully informed choice.

Autonomy and choice: broader picture

Respondents often seemed to accept passively a lack of real autonomy and choice as far as their home care was concerned. There was little sense that respondents expected to have what may be called process rights in relation to their home care: rights to be consulted, to consent, to have access to advice and information, to have redress and appeals. The general picture, except when something was viewed as bad enough to justify a complaint, was that respondents acquiesced to a process which took a lot of decisions for them.

A human rights approach has to deal with what may sometimes be present as an unspoken assumption: that some older people are not able to decide what is best for

them, thereby losing the right to make their own mistakes. Family and friends as well as professionals, if they perceive that other arrangements would be 'better' or 'safer' (for example, moving the older person from an impractical home, engaging care workers to help them with everyday activities like getting dressed) can be reluctant to accept the older person's preference if it differs from theirs. Older people can also feel pressurised to agree to arrangements they did not (or would not) choose for themselves. There is a duty to secure the welfare of people who are more vulnerable, and it can conflict with rights to autonomy and self-determination – to be treated as equal human beings.

By definition, almost all of those receiving in-home care are in poor health or frail or both. Most do not want to take on additional cares and responsibility. They might welcome mechanisms and systems to improve consultation and choice, provided these did not require them to take on significant tasks of accounting, researching suppliers or carrying out status and training checks. Though it is not possible to draw detailed conclusions, the importance of some principles is clear, when considering the human rights impact of measures intended to improve older people's choice and control over the home care they receive.

- Information needs must be met, taking account of each person's physical and mental capacity at the time. Tailored information should be given personally, and where appropriate, the process of giving information and consulting the older person should be repeated when their condition changes.
- Gaps in public awareness of key information, relevant to anyone who may need in-home care, need to be addressed. Examples are the right to assessment, and what it involves; and the advisability of checks on the training and character of unregulated care workers, and information on how to obtain such checks.
- Public and private agencies and their staff should maintain older people's rights to autonomy and personal choice. The balance between these rights and the protection of those who are vulnerable is difficult, however. Vulnerability may lie not just in ill-health and frailty, but in social isolation and loneliness.
- Any new mechanisms for delivering services should not dilute governance and safety checks.

5.4 Privacy

Preserving the human right to privacy in the context of home care covers for example: doing what is possible to ensure modesty when dressing or bathing someone, and ensuring that there is privacy when someone's personal circumstances are discussed by others. Respect for personal space includes: respect for the wish to be alone, and respect for the wish to be intimate with others.

Respect for private correspondence covers private letters, other private documents and private phone calls (and where appropriate respect for private emails and other documents or files on one's computer).

Privacy: positive

Concerns about privacy issues were seldom raised by respondents, possibly suggesting good understanding of boundaries by care workers. A few specific examples are given below of incidents where respondents felt their rights to privacy were transgressed, but these were uncommon.

Privacy: negative

A few respondents described incidents where care workers had gone into rooms in their homes without asking permission. One man had been using a urine jar when a care worker had burst in on him without warning. One respondent was left lying naked and exposed while being washed by a care worker; his wife said he looked like a 'scared rabbit'. He said he is always pleased when the care workers leave. Another respondent said she was very upset by pressure put on her to sleep separately from her husband in order to make space in the bedroom for a hoist. The right to a private life can be interfered with by inflexible care worker routines, and poor time-keeping by care workers can be an additional barrier.

Privacy: broader picture

Home care is essentially intrusive because it takes place in people's homes. Respondents were aware of the need to compromise feelings about controlling access to their home, and guarding their privacy, in order to get the care they need, but they were not always happy about it.

Recipients of home care can feel their privacy has been invaded, even if care workers take care to show respect for their personal space. Intense regimes involving up to four visits a day are especially hard to ignore and may leave people feeling as though they have little private life left to them in the home and reduced opportunities to conduct a private life outside of the home. Arrangements that enable care workers to let themselves in to a client's home may be necessary, but can also feel like an invasion of privacy.

5.5 Social and civic participation

Participation covers the right to maintain relationships with family and with friends. It also covers community participation: the right to participate in community events; the right to join community groups and associations; and the right to participate in

religious or non-religious activities. Civic participation implies, for instance, the right to participate in elections.

Social and civic participation: positive

The specific issues listed above were not often raised by respondents, mainly because almost no-one expected care workers to provide help in these areas. A few respondents who had private care arrangements said their care workers had an important role to play in helping them to get out and about and mix with other people. One respondent was taken frequently to a local library and enjoyed spending time around other people, reading the paper and having coffee.

Social and civic participation: negative

There were instances where respondents' evening activities, in particular, were limited by care worker visits at inflexible times, often quite early in the evening. Some respondents were especially anxious when morning care workers were late on days when they had regular activities planned, such as visits to day centres.

When probed, very many of the respondents said their ability to participate in any activity outside of the home was nil or almost nil, because of their health and impairments. They did not raise it themselves as an aspect of their lives that care workers failed to offer help with, accepting almost without question that such help was outside the remit of home care. Some mentioned health and safety; one had a written letter saying care workers could not take clients outside. One remembered a time when she did receive such help, being taken shopping and so on, but the service had been withdrawn.

Social and civic participation: broader picture

From the interviews as a whole, it was hard to avoid the fact that two overwhelming issues cloud the everyday lives of many older people with care needs. Both of them relate to social participation.

First, many people are unable to leave their home at all, unaided. Many respondents would like to browse in a shop occasionally, not just have mail order clothes or things that other people bring for them from the shops. Others have given up interests ranging from jazz concerts to going to the bookies. Many miss just sitting in the garden, or the park where they can see the world go by. When they were probed on this subject, even though they had not seen it as relevant to a discussion of home care, it was clear that all were unhappy about or frustrated by this severe limit on their lives.

You do get fed up. I sit here, day in, day out. (Woman, 79, lives with partner, local authority funded)

However the idea of a 'right' to social and civic participation is not a concept that comes to many people spontaneously; rather there seems to be a fatalistic acceptance that older people should not expect to be able to do things the rest of society takes for granted.

The second important issue concerns the number of respondents who were lonely and isolated. For some respondents, care workers' visits are the main or only social contact they have. Care workers who are friendly, cheerful, familiar and trusted are therefore hugely valued. 'We have a laugh'. 'I think the world of her'. 'They really do care'. 'A friendly face coming in: Hello!' It was often cited as a main benefit of having care workers.

Frequent changes in care worker can break up a relationship and interfere with the formation of potentially important social bonds. Sudden changes, without warning, affected some respondents profoundly; some became visibly upset talking about the impact on them of the sudden withdrawal of a particular care worker with whom they had felt a bond of friendship and trust.

If care worker visits do not allow time for conversation or casual social interaction, people's need for companionship and social contact can be left unmet. An opportunity is also lost if care workers do not have good social skills (or in some cases, necessary language skills), or are not friendly, sensitive, or patient. The tone of interviews was markedly different where respondents did not feel personally comfortable in their relationship with their care workers. They still gave credit for a 'correct' and useful service, but the service in these cases gave no ancillary social benefit: in reducing loneliness, and supplying stimulating contact and interchange in otherwise quiet and unvaried lives.

5.6 Concluding remarks

The areas for concern about human rights that were found in these interviews were not, on the whole, about intentional or reckless bad behaviour on the part of care workers or care providers. The big picture is one of a system that is essential and appreciated, but which is caught up in various imperatives: one is certainly to secure welfare and safety; another is to manage the logistics of meeting the different personal care needs of a huge number of people; another is to distribute scarce resources according to needs ranked and prioritised fairly. In all of this a necessary focus on human rights can be lost. Local authorities and care provider agencies, and their staff, may forget or lack the time and space to ask: 'If I was in this person's

position, what would I want in terms of being consulted and informed, being told about my options, having a say about how things are done – especially in my own home, carrying out personal care?' A further question would be, 'Are we providing the help this person needs in order to protect all their rights to participate in society as an equal human being?'

In some cases the implications of such a change in emphasis would be simple to carry into effect. However, there are hard cases, where people have high levels of need, or have problems of cognition or communication for example. Some interviews have shown how care workers do make an extra effort to secure the rights of the most vulnerable people of all. Almost all interviews revealed in different ways the importance of the human aspects of the care worker/older person relationship: consistency of personnel, friendliness and respect.

6. Seven case studies

This final chapter contains seven case studies selected from the sample of ordinary people receiving home care to illustrate, in a personal context, many of the points made earlier in the report.

Case study 1

He has had partial paralysis since birth, and his problems were compounded by head injuries in an accident. He has numerous health conditions and mobility impairment with frequent falls. He cannot get out on his own. He answers questions briefly when he is able, but generally turns to his long-time friend to answer for him.

His care arrangements were put in place years ago. He has no understanding of the processes, though his assessed contributions come out of his bank account (managed for him by a relative). His friend talks about the lack of real effort by local authority or agency staff to consult him about his care:

They sort of ask him the questions, he gives them like a one-word response and then they fill in the blanks.

He needs help taking medication (which is time-critical around meals), getting washed, preparing food, and generally taking care of himself and his flat. His care workers are not seen to be very good; recently there have been three occasions in two weeks when they have not turned up at all, making him extremely anxious – he had to call his friend to come and help.

The care workers have refused to do any clothes-washing, or to shave him. When he is in the shower he has to hold on to a rail while his care worker squirts shower gel over him, because she will not touch him. He is asked how he feels about that:

I reckon it's disgusting really.

When a care worker found him needing to be changed after he had been incontinent she did not hide her disgust. His friend said:

She wasn't happy at all, and she spoke to him in such a way that it was quite disrespectful – 'Blimey, I have to do all this and you're just sitting there'... She came in and the first thing she said, 'Look at all the mess I've got to clear up'.

There seems to be no possibility of getting the service to help him get out. His main pastime used to be walking about the local area and chatting to people.

He has a care plan folder but does not feel that it belongs to him. His friend made a note in it once. The next day the care worker told him sharply to tell his friend not to do that, or she would tell her boss.

Asked what rights he thought he should have, he answered for himself:

I should be treated with respect.

[Friend] Unfortunately he falls into two categories in today's society, which is not always respected, which is the elderly and the disabled.

When asked for an example of when he feels he is treated with respect, he mentions staff at the day centre he visits, who help him when he has to go to the toilet. He finds it difficult to elaborate but agrees they make him feel okay about it. It is not necessarily the things that are done, but the subtleties of how they are done that are key to the feeling of respect.

Yeah. They're very good at the centre. There's a right way of doing it.

Case study 2

He has multiple and severe health conditions. He is, however, very alert and articulate. He cites his main health problem as depression, which he has had ever since being a prisoner of war. He spoke about this simply and movingly.

(They) came down to the camp and found us. A lot of the blokes were dead... I was blind 'cause I had heat stroke, I had malaria, I had malnutrition and I couldn't walk. When I went in the army I was ten stone and when I came out of there I was just about five... And then what they do for these chaps today, they done nothing for us.

At times the depression has been debilitating, and has affected all his relationships since. However, he has never found any totally effective treatment. He manages his mood himself, as far as he can, by keeping up his hobbies and social contacts as far as he is able, including via the internet and phone.

The discussion of his depression and its root cause did point to a contrast between the major narrative of his life – dominated by the effect of the war – and the niggling issues he has recently had to battle, generally without success, over how his care is arranged. He wants a care worker to be someone he can get on with on a personal level (as he could with a previous care worker who has now been re-allocated), and someone with whom he can agree how best her time with him should be spent, flexibly. At present he does not feel his care meets either of these requirements.

He would prefer to have less housework and more shopping. He would like to be able to ask the care worker to do things as he felt like having them done – some

days he may not feel up to having a bath, sometimes he wants help arranging things to do with his hobbies, and often he wants fresh food and milk bought. However, especially since a re-assessment which reduced his hours of help, all the care worker's time is strictly allocated to set tasks and she is not allowed to deviate from the weekly timetable.

Wednesday is the bath time, that's all she does – the bath, cleans the bath and then goes.

He was always interested in politics and brings this perspective to his personal view of the care worker 'system'.

Things are not produced for need; they're produced to make a profit. Take this home care, these agencies wouldn't take it on if they weren't making money out of it.

Case study 3

This is a highly sociable woman who lives with her husband. The two of them function as a very tight unit, sharing the same interests and outlook on life. She values the ability to stay connected within the community, to get out as much as possible and keep mentally stimulated.

Diagnosed with a progressive health condition twenty years ago, her mobility is now severely impaired. The couple first had care workers in to help with her needs in 2007, when her husband (who had managed everything himself up to then) had an accident. They have many bad memories of this time. It was necessary to have an intense regime of care workers coming in, and the sudden impact on their life and routines was a shock. Moreover, some aspects of assessment and delivery they found rigid, oppressive, insensitive and profoundly depressing. Small things included that the workers were 'not allowed to wash hair'. The bigger picture though, she expressed by saying that having care workers four times a day (while never being sure when they would turn up) – feeling that her whole life revolved around waiting to see when she would be able to go to the toilet, what they would and would not help with and so on – completely overturned her normal buoyant nature:

I'd had the carers in a fortnight. I sat in my wheelchair, and I have never said it in my life. Just said to him, 'for God's sake get better soon, because I want to die'... Inside, I wasn't me any more... A pudding, not quite a human being. My life was being taken over.

Her husband was finding it as much work as before, because of adjusting to the impact on the household, clearing up after the workers. They both felt steamrollered

by the assessment process, when the supervisor ordered their flat to be re-arranged and tried to say she would have to be moved to high dependency accommodation. As soon as they felt able, they asked for the care workers to stop coming. When, more recently, they reached the stage again of needing more help, they recruited their own care workers, using a budget made up from disability-related payments and Attendance Allowance. It is very important to her than she can control in detail what the care workers do and how they do it, that she can set the tone of the relationship. Sometimes she prefers they chat with her than rush round doing practical tasks.

She feels she has needed all her resources of resilience and understanding to negotiate the system of welfare help so far, while keeping control of her own life. She feels that many of the older people around her must be overwhelmed and swept along by systems and forms that go over their heads, that they have no hope of understanding.

Case study 4

He has considerable health issues and impairment and difficulty speaking. He was only able to give short answers to fairly simple questions. His wife clearly has the role of main carer although they do also have paid care workers coming in. She explains clearly how she wishes he was treated more sensitively sometimes, in particular that carers would make the effort to engage him in conversation, however limited, and that they would wash and dress him in ways that left him feeling not too exposed and undignified.

He has the visible after-effects of surgery which, as she says, obviously affects his feelings about personal care. She wishes the care workers would pay more attention to preserving his dignity while they are washing him. She more than once refers to his expression 'like a scared rabbit' while he is naked and being washed on the bed.

I said while you're washing him why don't you put a towel, give him a bit of modesty and a bit of pride, and then when you've done that, wash him and get his pants on, rather than (leave him) lying there; he lies there like a scared rabbit.

She and he both mention a particular care worker who is the exception, who takes care to preserve his dignity and pride.

[She] never leaves him lying – leaves his pants on, and if he's lying there she puts the duvet back over him... It's very caring because she says, it's a bit chilly in here, we'll put the duvet over you, or don't you think it's a bit hot – things like that.

In terms of making him feel at ease, she is also upset that most of the care workers do not make the (considerable) effort to engage him, and they talk over him which she does not like. He expresses some of his own feeling about having care workers, with difficulty:

I'm always glad when they've gone.

Case study 5

This respondent is a former nurse. Nearly 80 years old, she lives alone in local authority sheltered accommodation with a warden. She moved to her current home from local council housing less than a year ago. She feels it is a change for the better; her previous home was small and cramped and had no outlook. In her current home she has more room to move about and better views. She has various health conditions that seriously affect her mobility.

She is a devout Christian and an active church member. Church friends visit her, are available to talk to her on the phone and will come and collect her and take her to church. In addition she has family who visit and care workers who come in twice a day. Nonetheless, she currently spends many hours alone in bed, following another recent stay in hospital, watching television. A clock is propped on the bed next to her.

Care workers from an agency organised by the local authority come in twice a day. In the morning they help her wash, empty her commode, tidy up and give her breakfast. In the evening, the routine is shorter but similar. They give her her evening meal and empty the commode.

She says she has been trying for some time to get the number of visits put up to three a day. She says this is because she gets very hungry in the middle of the day and as a diabetic has to sustain herself with glucose drinks and snacks left next to her bed between breakfast and her evening meal at around five or six. The hospital and the social worker she is in contact with, apparently both agree that she needs a third visit, but nothing has happened so far. She says she has been waiting some time, but it was not possible to establish how long.

She is not impressed with the care workers who, she feels, are unsuited to the job they do. She says they are in it only for the money and do not have the heart for the work. They do their work quickly and with little attention to detail. They do not clean up after themselves, the kitchen is left dirty and they appear to have little pride in their work. They are often on their mobile phones while they are at work and she

describes the care worker washing her with one hand while holding her mobile with the other and talking to a friend.

She says that they do not spend the amount of time with her that they are contracted to spend. She says that in a recent meeting with a social worker, when she complained that they were taking less time than they were supposed to take, the social worker's response was to suggest that perhaps the allocated time could be cut back, since she appeared not to need it. She says the fact they are cutting corners and skimping on their work was not perceived to be an issue, and that the opportunity to save money appeared to be the most important thing. She says that this experience means that she will be careful not to complain again.

She is scornful of the care workers' attitude and lack of professionalism, and she feels standards are low and that scant attention is paid to providing quality care centred on her comfort and well-being. However, she says that generally she does not complain and she does not want to get care workers into trouble. In particular, she does not want them to lose their jobs. She also says that as a Christian she knows that God is watching and that he notices everything.

She is adamant that she knows nothing about the commissioning arrangements for her care. She says she was not party to the selection of her current care agency and she does not know who pays them. She is very resistant to being questioned in detail about her grip of the arrangements and says she has already said she knows and understands nothing. She does not look at her care plan which, she says, is more to do with the carers; in any case her eyesight is not good.

Case study 6

This lady has never had an assessment of eligible needs nor any financial assessment. However, she certainly does have multiple health conditions and has often been in hospital over recent years. She just about manages to get out on her own sometimes to the nearby doctor's, using a frame. At other times she is taken out in her wheelchair by her private care worker. She lives in a sheltered housing block (local authority). There is a support officer, but only on-site part-time. There are no social activities. She says when she first came the flat was 'full of junk'; it has also been infested with cockroaches and she now keeps traps down on the floors. She does not go to any day centre. She does have visits and some help from relatives, though her only daughter has died.

Perhaps the most remarkable thing is her matter-of-fact positivity; when talking about any of the above she insists things could be a lot worse. She enjoys her visitors but

she also likes her own company, her health is better than a year ago and the flat is in the same area where she has always lived, which means she feels settled.

A couple of years ago she felt she needed help at home. She knew that care workers could be arranged via official channels but instead she asked her friend, who had some unspecified experience (as well as numerous children and grandchildren, which was seen as a key qualification), to come in sometimes by arrangement to help with bathing, meals and sometimes take her out shopping. The hours do not seem to be precisely defined – they agree a time for the next day that suits both of them, and she pays £20 a time. She says she does not want to feel in control in the sense of being a formal boss over someone else. She has no complaints at all about her situation. Sometimes the buses make her care worker late, sometimes the care worker's grandchildren come along and play but she likes that.

Her reasons for choosing to go entirely private include the flexibility; she knows care workers arranged via the local authority would not offer this, would not take her out if that was her preference, for example. She also prefers to have someone she knows helping her with personal tasks like bathing.

Other reasons may be based on misinformation. She is sure that 'official' care workers would come at times that were totally random and unpredictable, and would not do the tasks set out in any care plan. She bases both these beliefs on what happens when community nurses visit after she comes home from hospital, compared with what is promised in terms of when they will come and what they will do. She also thinks such care workers are all charged for at a flat rate equivalent to what she is paying at the moment, because she saw a list of hourly charges once in 'a booklet' – when a therapist arranged for her to have adaptations in her flat. Without an assessment it is hard to say whether she would be charged in fact, or how much. She says no one has ever suggested a local authority social services assessment to her.

She says she has never had nor sought any proper advice on these matters. It may be that her instinct is to avoid officialdom and bureaucracy. Asked what she would do if her friend had to stop coming, she says:

I would try and cope in my own way.

Case study 7

This lady, who lives alone, has multiple health conditions and mobility impairment but has always tried to remain active and independent. Her care needs suddenly increased a year ago, when an operation led to complications which left her almost totally blind. While she was still in hospital an assessment procedure began, which involved the hospital social worker and hospital physiotherapist, a social worker at social services and staff from the various agencies. The main issue for her was only: would she be moved from hospital into residential care, or would she be able to go home? She was very clear, she wanted to go home.

Her son remembers more but even he found the assessment process confusing. There were lots of different people each asking particular factual questions, their manner often 'abrupt'. He describes it as not a 'real' assessment. However, over what he calls the 'getting to know you period', the service has developed into one that is more responsive and personal – although not without problems.

She feels her greater isolation, no longer being able to get out even to the end of her road as she used to on her own. She is bored being unable to read. At a day centre she goes to she cannot take part in many of the activities such as dominoes. She is anxious, especially about her medication being properly supervised and managed, now that she cannot see the packages or read instructions, and feels helpless when care workers are late, as often happens. After care workers failed to turn up at all on several occasions, she and her son complained and secured a change of agency, though there was no choice of agency at any stage. In fact, she has two agencies assigned to her, one specifically for evening visits. She feels annoyed by frequent changes of care worker, unsettled especially as she cannot see who it is. She also has to give each new worker instructions about her kitchen. Sometimes evening care workers come, not knowing it is supposed to be a bath night, and not having enough time to do it so she cannot have her bath. Generally, the picture is one of huge frustration at being dependent on others to get through basic daily essentials, and having no control over how, or sometimes if, things are done.

As well as two agency care folders, she has huge folders of correspondence about all aspects of her care, all of which has to be managed by her son. Financial changes and reassessments of that aspect seem to be constant. Recently she qualified for the higher rate Attendance Allowance; as a result, her charges for home care are going up. Payments for community meals, for the emergency alarm she carries, and newly introduced payments for transport to the day centre all count for her and her son as part of her overall essential package of care. Her son also deals with both agencies, and with the social worker who is monitoring the agencies.

A recent letter from one agency specified that care workers cannot take anyone out, or do shopping, and also said that if one of their care workers was employed privately by a client the agency must be paid a fee of £1000. She is acutely aware, anyway, of all the things the care workers cannot do, largely because of lack of time; especially they cannot sit and chat as she would like, and certainly they cannot read to her.

For all her criticisms and feistiness, she appreciates the company of the care workers three times a day.

I can't get out... I can't read and I can't see to do anything, only just sit here... I'm glad of them coming in. I'm glad of the company, although it's only for half an hour. You're not lonely like, you know someone's coming in. If they could only stop a bit longer... cause you like a little talk. But they have no time they say, got a lot to do. So off they go.

Appendix Topic guide

This document provides a rough template for each interview. It sets out key topics to be covered and suggests key questions and possible probes. In practice interviews may develop very differently according to what respondents have to say on different subjects.

1. Introduction

- Thank respondent for agreeing to take part. Show them copy of respondent letter and information sheet and make sure they have read them.
- Provide a brief recap based on the following:

The Equality and Human Rights Commission is interested in whether people getting care services at home feel that their rights, for example to dignity, choice and privacy are being looked after.

We are carrying out interviews with about 40 people over 65, living in England, who receive care and support at home, not counting any they get from their family or friends, to find out what their experiences are.

Our findings will go into a published report along with other information that the Commission is collecting. We may use anonymous examples from our interviews in the report, including yours, but none of your personal information that could identify you will be shared with anyone outside the research team.

With your permission, I would like to record the interview because it saves time making notes as we go along, and gives an accurate record of what we cover.

For about the next hour, we are going to have an informal conversation during which we will talk about the care service you get. I am interested in anything you have to say about it - especially about how you feel about it and how it affects you personally. There are no right or wrong answers, and I am interested in things you feel positive about as well as things that may be more negative.

Check if respondent has any questions and that **consent form** has been signed.

2. Background (5 minutes max)

I would like to start by asking you to tell me a bit about yourself, so I can understand something about your circumstances....

KEY QUESTION	POSSIBLE PROBES
Can I ask if you live alone or with someone else?	If with someone else, probe for details of relationship. If someone other than a partner/spouse, probe for how long the current arrangement has been in place, and further details of household support network and family life as appropriate.
Who (apart from people you live with) do you have <u>regular</u> contact with?	Who do you see regularly – daily, weekly, monthly, less often but regularly? What about contacts by phone or other (e.g. internet)- how satisfactory is it to have contacts this way, what are the problems? Do you get out at all? Where to and how often? Do you rely on other people to get out? Which other people? In your day to day life, who are the most important people in both practical and emotional terms? What roles do they play? How isolated or cut off do you feel your home is (from family and friends, facilities, services and amenities)? Does this limit what you can participate in – and if so what examples? What forms of transport are available to you that you can use?
Can I ask about your home?	How long have you lived here? Do you own or rent or have some other arrangement? What do you like most about your home and where you live? What do you like least?
Briefly, how would you describe your overall state of health?	How do you regard your own state of health? Do you have any particular health conditions or impairments and how, if at all, is your ability to do everyday tasks affected? Do you feel your general state of health is getting, better, worse or staying the same? Do you worry about your health? What do you worry about?

3. Service delivery and quality (20 minutes)

I would now like to ask you a bit about any care, help and support that you get with everyday living.....

KEY QUESTION	POSSIBLE PROBES
What help and support do you currently get from social services or other organisations and from family and friends?	Probe for help and support they currently get from all sources, formal and informal. Establish how long they have been getting <u>formal/paid</u> services, what they have formal help with and who provides it.
Can I ask you how often care workers come to your home and at what time of day?	How often does a care worker come in? Is it the same person or different people? If different, is it a team that you know well? If not, how does that affect you? Do you have the chance to get to know them? Do care workers come when they are supposed to come? If they are unpredictable, what effect does it have on your day to day life? If they are delayed for any reason or can't come, do they let you know? What kind of reasons do they give, if any? For how long do they come each time? Do they stay as long as they are supposed to? Is there enough time for them to do what you want them to do, the way you would like it done?
And what about the	What do the care workers actually do? As far as you know, does

<p>jobs that the care workers do?</p>	<p>the care worker do what they are <u>supposed</u> to do? Do they do it well? Do they seem to have the right skills and training for the job? What do you <u>like</u> about the way the care workers do their jobs? And what do you <u>not</u> like? Does anything worry or bother you about the way care services are carried out? Do they ask you how you want things done, and leave things as you would like? Is there anything care workers do that you wish they didn't do? Is there anything you would like the care workers to do that they won't do? Probe as appropriate. Is there anything that irritates/worries you at all, even if you do not think it can be helped and do not wish to complain? Throughout probe for impact on respondent.</p>
<p>How do you feel when the care workers are here?</p>	<p>How easy do you find it to communicate with the care workers? Probe answers in depth. What are the impacts if any of poor communication? Do you feel at ease when they are there? How do you address each other? Are you happy with it? What kind of relationship do you feel you have with the care workers? Is it an 'equal' one, or do you defer to the care workers or vice versa? Probe impact. Is there anything about the home care you receive that makes you feel comfortable or uncomfortable? What and why? When care workers are helping with personal care (washing, dressing) how do they talk to you? Do they explain what they are going to do, ask how you want it done? How would you feel about telling the care workers about anything that you don't like or would like done in a different way? Do the care workers ever make you feel rushed? Do the care workers help and encourage you to do more, to get out if you can and do things for yourself at home? Do you ever feel things are just done to you, or do you feel the care workers are doing things with and for you? Do you feel able to talk through their needs and any worries or complaints with the care workers? What about the care agency or social services?</p>
<p>What do you value most about the care service you get?</p>	<p>How does the care service improve your life, if at all? Is there anything about the care you get that you think is particularly good and that perhaps other people would like to benefit from? What do they think makes (or would make) a good home care service?</p>
<p>Is there anything you would change about the home care you get?</p>	<p>What would you change and why? From the jobs the care workers do, to the way they do them to your relationship with the care workers. Throughout probe for the impact on their lives of any aspects that they mention they would like to change. Are there any ways in which you feel that the care you get has <u>limited</u> or changed your life in ways you regret or are not that happy about?</p>
<p>What, if anything, have you had to change about how you live, because of having care workers coming in?</p>	<p>Do you feel that there are new 'rules' now that you have to stick to? What are they? What is the reason for them? What has the impact on you been?</p>
<p>Overall, how far does the home care you get seem to take account of your personal needs and wishes?</p>	<p>Is the focus as much on you and your needs and wishes as you would like?</p>

Information and assessments (5 minutes)

Thinking back to when you first started getting home care.....

KEY QUESTION	POSSIBLE PROBES
When was that?	What year was it? What events led up to it? What happened? How did you know/find out that care was available? Did you get any information? Where from and was it useful? (Probe eg for issues around information that is on the internet, its accessibility and quality. Information from GPs – quality and helpfulness?) Did you go through any voluntary sector organisations for information – if so what was satisfactory or not?
Were your care needs assessed by the local council?	What happened? What was the process? How did it go? Did you have an intensive re-enablement and assessment package, from the local authority, following hospitalisation for example? What was your experience of that - and also of when it finished, how that was handled? If assessment was not after a crisis, how did you find out what to do? Was the local authority helpful? How long did you have to wait? What was the impact on you? Were you given clear information about entitlement to assessment – and about eligibility for a funded care package? What was the impact of all the information (or lack of it) on you? How good do you feel the assessment process itself was in terms of helping you to convey your needs? How relevant were the questions they were asked? What did you think of the social worker/occupational therapist who carried out the assessment? Did they put you at your ease and listen to what you had to say? Did you understand what questions you were being asked and why?
What was the outcome of the assessment?	What was the outcome of the assessment? How did you find out about the outcome? How did you feel about it? Has your case been reviewed since the first assessment? How does your care package compare with what you thought about the assessment – does it cover all the areas you said you needed help with?
Who organises and pays for the care you currently get?	Is it organised and paid for by the Local authority, do you get Direct Payment or a Personal Budget from the council to organise and pay for care themselves, or is the care you get self-funded (including paid for by a family member, friend or other). Was there anything you found hard to understand about these matters? Was there anything that you felt was unfair, or that put undue pressure on you? Was there anything that was particularly welcome? What is the impact on you, of how care is managed and paid for?

4. Commissioning and procurement (8 minutes)

KEY QUESTION	POSSIBLE PROBES
Were you able to choose who provides your care services?	How did you end up with the particular provider/agency that you did? Was there enough opportunity (or not) for you to be involved in making a choice? What information and advice was available to help with this choice and with other matters of managing your care (training for PAs, security checks?) – how helpful was this? Have there been any changes of agency/provider? How did the changes come about and how did you feel about them? What was the impact? Have you wanted a change of agency but not been

	able to get one? What has been the impact on you?
<u>Direct Payment /Personal Budgets and self-funders:</u> Do you think that the cost of the care services you get is reasonable?	Do you know what the cost is? Do you understand how it is calculated? How would you know if it seemed high or low or about right? What would you compare it with? How easy do you feel it would be for you to 'shop around' or do some 'market research' to see what different agencies/providers offer and what they charge? What about the other aspects of personal choice, with your own budget (direct payments, personal budgets and self-funders) – what are your good/bad experiences? Is the personal budget (if you have one) enough for your needs? Is part of it paid over for someone else to manage the contract for you? Is the remainder sufficient for your care needs? Do you pay for part of your care yourself, to top up your personal budget or as an assessed contribution to care part paid for by the authority? Does your contribution seem reasonable? What is the impact on you of the cost of your care service?
<u>Direct payment/Personal Budgets:</u> Do you personally organise payment for the care services you get?	How far do you feel you understand how Direct Payment/Personal Budget is supposed to work? Is there anything you are particularly unclear/confused about? Probe if yes. Were you given any advice on how to manage it, or any literature? And were you offered any help with finding or recruiting an agency, or vetting and training an individual? Do you feel happy that the people you will have as care workers under this system are supervised, monitored and checked for your safety? What is the impact on you of the council not delivering care services, but instead another agency doing so? Do you personally arrange for the payments, or do you get help? From whom? If you have someone helping you manage your Direct Payment/Personal Budget was any training/help available to that person? What do you have to provide by way of invoices or other information to the council to show what you have spent their care budget on? Who does that? By giving people a budget and money to spend, Direct Payments are supposed to give older people more choice and control over which services they get and who provides them. How far do you feel that you have had choice and control over the home care you get? Probe answers in full. Have you heard of/been in touch with an Independent Living Adviser, worker from the Voluntary and Community Sector (VCS)?
<u>Direct payment/Personal Budgets:</u> How did you find out about the possibility of being given a budget by the Council to find and pay for your home care services?	Who told you about it? How was it presented? Why did you decide to go for a personally controlled budget rather than letting the council organise and pay for your home care? Did you feel you could choose <u>not</u> to take charge of your own budget if you wanted to?
<u>Do you (or your family) pay for all your in-home care yourself?</u>	At what stage did you decide to self-fund? If you were made aware you would not be eligible for funded care, how did this happen? Were you still encouraged and informed about help from the local authority - e.g. with assessment of your needs, or finding a care agency, or training and vetting someone? What is the impact on you of funding your own care, not just the financial impact? What are the benefits? (e.g. regarding privacy of your business, choice and priorities in what services you want) What are any problems, and worries you have? (e.g. around impaired

	capacity over time, difficulties of organising own care, lack of safeguards and redress)
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5. Care Plan (5 minutes)

KEY QUESTION	POSSIBLE PROBES
Do you know if you have a care plan?	If yes, do you know roughly what is in it or not? How involved (if at all) do you feel you were in drawing it up? What is the effect of having a care plan, on you? Can you say what the benefits are, in terms of making your needs and wishes central to what happens to you? Would you like to change anything about it and – if so – do you know how to go about getting it changed? How feasible do you think it would be for you to get any aspect of your care plan changed?

6. Advocacy, advice, information, complaints (5 minutes)

KEY QUESTION	POSSIBLE PROBES
Do you feel able to judge if the care you receive is below average?	How, if at all, do you evaluate the care you get? What, if anything, do you measure it against?
What do you/would you do if you have/had problems with your home care service?	Can you give any examples of where problems have occurred? With what impact on you? If you wanted to talk to someone about problems you were having with the care service, who would you go to? How would you go about it? If you have experience of a complaints or consultation procedure, please describe it. Was it a paper form or questionnaire – if so how did this meet your needs, or what problems did it present? Do you know about a special telephone line for anyone to get help or advice, or to express concern about home care? What information do you recall about it? Have you used it? How would you feel about using it? Is it possible to speak to someone face to face about these issues? If you wanted the service to stop, or to be stepped up or changed in some way, what would you do? Do you feel able to express their feelings and wishes to anyone in authority about the home care you get? Do you feel you are/would be listened to? Would you be/are you worried about complaining? Why?

7. Final section (10 minutes)

Everyone agrees that it is important that people receiving care at home are well treated and that their dignity and privacy is properly respected. They also agree that it is important that people getting care still feel they can make decisions for themselves, keep control of their own affairs, and maintain their relationships with the people that are important to them.

KEY QUESTION	POSSIBLE PROBES
Some people have said they have been treated badly when they are receiving care services.	Have you ever felt badly treated in any way – how? Probe as appropriate. What effect did/does this have on you? What – if anything - did you do about it? Why? What

What are your views about bad treatment?	happened?
Dignity and privacy are important when people are receiving home care. What sorts of things in your view have an effect on dignity and privacy?	Can you provide examples? What about you, has your dignity and/or privacy been undermined by care workers coming to your home? Probe as appropriate In general do you feel that you are treated sensitively and respectfully?
Some people can feel they are having <i>control</i> of their own lives taken away when care workers come into their home, do you feel that has happened to you?	Can you provide examples? Probe as appropriate? What effect did it have on you? What – if anything - did you do about it?
It is important that people with care needs can still keep their relationships going with family and friends, get out and about and participate as much as possible in the life of the community. Do you feel that having care workers has helped you to keep your relationships and activities going or has it had the opposite effect?	Can you provide examples (good and/or bad)? Probe as appropriate. What – if anything – do you feel you can do about it? Probe for e.g. effect of rural location, distance from family, etc. – is anything offered to help with that? What would you like, that would help you keep up social relationships and participation in activities etc?

Thinking about the home care service you currently get, do you think that your rights in the matter are considered, as you would like them to be? What makes you say that?

Lastly, can I ask how confident you feel that your rights as an older person receiving care at home are being protected? That is to say that there are enough checks in the system to make sure that you are given choices and are not treated badly or with loss of dignity, privacy or your right to maintain relationships and participate in wider society. Probe fully.

CLOSING COMMENTS AND THANKS

Endnotes

¹ All are underpinned by key principles such as dignity, autonomy and respect. These rights - and the principles behind them - are at the core of what good care should mean at a day-to-day level. They can be about such ordinary everyday things as eating a meal when you are hungry rather than when a service wants to provide it, having a bath in privacy and comfort and maintaining contact with children or grandchildren.

² These services tend to be offered only on a limited basis by local authorities and people requiring them may have to employ someone privately or see if there are services available run by local voluntary organisations.

³ Usually the social services or adult care department of the local council.

⁴ Over 80 per cent of local authorities currently restrict eligibility for home care services to those with either 'substantial' or 'critical' need (78 per cent substantial and a further 4 per cent critical).

⁵ Some older people are able to claim social security benefits to help meet the cost of any extra care and support they need at home. Attendance Allowance (AA) is for people over 65 who because of a health condition or impairment need help with personal care or supervision.

⁶ Socio-demographics such as income, social class and ethnic minority populations.

⁷ For practical reasons, the 40 achieved interviews were spread less evenly than originally planned; the four areas generated 9, 14, 9 and 8 interviews respectively.

⁸ A significant number of respondents lived in accommodation with a warden or with additional support workers present at least during the day. Purpose built sheltered housing can offer an alternative to care homes for people whose home is no longer suitable for them and whose needs will not be met simply by downsizing to a smaller or more manageable property. Sheltered housing is built with the needs of older residents in mind and developments are available that offer different levels of support to residents while allowing them to continue to live more independently than they would in a care home. It is available both through the local authority and for those who are self-funding.

⁹ Sums to more than 40 because a few respondents had a mixture of arrangements.

¹⁰ Includes one respondent who received direct payments from the Independent Living Fund (ILF).

¹¹ These criticisms were also sometimes applied to domiciliary health care workers; one respondent said that the nurse who helped her at home to manage her diabetes frequently left used needles lying around her flat.

¹² Gilroy, R. (2005). 'Meeting the information needs of older people: a challenge for local governance'. *Local Government Studies* 31 (1): 39-51

¹³

<http://www.cqc.org.uk/usingcareservices/adviceaboutdifferenttypesofcare/socialcare/agreecareplan.cfm> (accessed 13th September 2011)

¹⁴ <http://www.ageuk.org.uk/latest-press/archive/age-uk-intervene-in-landmark-care-case/> (accessed 16th November 2011)

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This research was commissioned as part of a formal inquiry into older people and human rights in home care in England. It is based on in-depth interviews with a cross section of 40 older people receiving home care arranged mostly through their local authority but also, in a small number of cases, privately. As well as exploring potential risks to human rights or failure to address them, the research was also concerned with good practice and the positive impact that home care can have on human rights for many older people.